Cynulliad Cenedlaethol Cymru
Y Pwyllgor Iechyd a Gwasanaethau Cymdeithasol

The National Assembly for Wales
The Health and Social Services Committee

Dydd Mercher, 11 Hydref 2006
Wednesday, 11 October 2006

Cynnwys
Contents

Cofnodir y trafodion hyn yn yr iaith y llefarwyd hwy ynddi yn y pwyllgor. Yn ogystal, cynhwysir cyfieithiad Saesneg o gyfraniadau yn y Gymraeg.

These proceedings are reported in the language in which they were spoken in the committee. In addition, an English translation of Welsh speeches is included.

Aelodau Cynulliad yn bresennol: Rhodri Glyn Thomas (Cadeirydd), Brian Gibbons (y Gweinidog dros Iechyd a Gwasanaethau Cymdeithasol), Helen Mary Jones, Jonathan Morgan, Lynne Neagle, Jenny Randerson.

Swyddogion yn bresennol: Irene Allen, Y Gangen Iechyd Plant; Claire Bond, Y Gangen Iechyd Plant; Phil Chick, Cyfarwyddwr Iechyd Meddwl, Llywodraeth Cynulliad Cymru; Dr Tony Jewell, Prif Swyddog Meddygol; Peter Jones, Cwnsler Gwasanaeth Seneddol y Cynulliad; Ann Lloyd, Cyfarwyddwr, Adran Iechyd a Gwasanaethau Cymdeithasol; Kathryn Potter, Gwasanaeth Ymchwil yr Aelodau.

Eraill yn bresennol: Will Bee, Cyfarwyddwr, Y Comisiwn Hawliau Anabledd; Simon Dean, Comisiwn Iechyd Cymru; Dr Andrew Fowell, Cadeirydd, Grwp Cyfeirio Arbenigol; David Groves, Swyddog Polisi Iechyd a Gwasanaethau Cymdeithasol; Dr Jane Hanson, Cyfarwyddwr, Grwp Cydlynu Gwasanaethau Canser; Laura Jerram, Rheolwr Datblygu Gwaith; Jeff Stamatakis, Cadeirydd, CaNISC; Dr Gwyn Thomas, Cyfarwyddwr, Hysbysu Gofal Iechyd.

Gwasanaeth Pwyllgor: Jane Westlake, Clerc; Sara Mansour, Dirprwy Glerc.

Assembly Members in attendance: Rhodri Glyn Thomas (Chair), Brian Gibbons (the Minister for Health and Social Services), Helen Mary Jones, Jonathan Morgan, Lynne Neagle, Jenny Randerson.

Officials in attendance: Irene Allen, Children's Health Branch; Claire Bond, Children's Health Branch; Phil Chick, Director of Mental Health, Welsh Assembly Government; Dr Tony Jewell, Chief Medical Officer; Peter Jones, Counsel to the Assembly Parliamentary Service; Ann Lloyd, Director, Department for Health and Social Services; Kathryn Potter, Members' Research Service.

Others in attendance: Will Bee, Director, Disability Rights Commission; Simon Dean, Health Commission Wales; Dr Andrew Fowell, Chair, Expert Reference Group; David Groves, Health and Social Services Policy Officer; Dr Jane Hanson, Director, Cancer Services Co-ordinating Group; Laura Jerram, Practice Development Manager; Jeff Stamatakis, Chair, CaNISC; Dr Gwyn Thomas, Director, Informing Healthcare.

Committee Service: Jane Westlake, Clerk; Sara Mansour, Deputy Clerk.

Dechreuodd y cyfarfod am 9.31 a.m.
The meeting began at 9.31 a.m.

Cyflwyniad, Ymddiheuriadau, Dirprwyon a Datgan Buddiannau
Introduction, Apologies, Substitutions and Declarations of Interest

[1] **Rhodri Glyn Thomas:** Bore da a chroeso cynnes i'r cyfarfod hwn o'r Pwyllgor Iechyd a Gwasanaethau Cymdeithasol. Gobeithiaf fod pawb sydd angen yr offer cyfieithu bellach yn gallu clywed y sain yn glir.

Rhodri Glyn Thomas: Good morning and welcome to this meeting of the Health and Social Services Committee. I hope that all of you who require translation equipment can now hear the sound clearly.

[2] Yr ydym wedi derbyn ymddiheuriadau gan Karen Sinclair a John Griffiths. Atgoffaf aelodau'r pwyllgor, a'r bobl sydd wedi dod i

We have received apologies from Karen Sinclair and John Griffiths. I remind committee members, and the people who

roi tystiolaeth y bore yma, y dylent aros nes bod y golau coch yn dangos yn glir ar y microffonau cyn llefaru oherwydd y mae pob sylw yn cael ei gofnodi ac os nad yw'n mynd drwy'r offer technegol, mae'n bosibl y collir rhai o'r geiriau agoriadol. Gofynnaf hefyd i bawb yn yr oriel gyhoeddus ac o amgylch y bwrdd hwn ddiffodd unrhyw offer technegol sydd ganddynt, gan gynnwys ffonau symudol a BlackBerrys. Nid yw gadael yr offer mewn cyflwr 'distaw' yn ddigonol oherwydd mae hyd yn oed ei adael yn y cyflwr hwnnw yn gallu effeithio ar y system sain.	have come to give evidence this morning, that they should wait until the red light shows on the microphones before speaking because every comment is reported, and if your words do not go through the technical equipment, it is possible that some opening words will be lost. I also ask everyone in the public gallery and around this table to switch off any technical equipment that they may have, including mobile phones and BlackBerrys. Leaving them on 'silent' is not enough because even leaving them on that setting can affect the sound system.
[3] Yn ogystal â darparu'r cyfieithiad, mae'r system sain yn chwyddo'r sain, felly os yw pobl yn ei chael hi'n anodd clywed, mae'r system yn ddefnyddiol. Os bydd angen i ni adael yr ystafell hon neu'r oriel ar fyrder, am unrhyw reswm, dilynwch gyfarwyddiadau'r tywysyddion, os gwelwch yn dda.	As well as providing the translation, the sound system also amplifies sound, so if people have hearing difficulties, the system is useful. If we are required to leave this room or the gallery in a hurry, for any reason, please follow the ushers' instructions.

9.32 a.m.

Adolygu'r Gwasanaethau Canser—Tystiolaeth Lafar
Review of Cancer Services—Oral Evidence

[4] **Rhodri Glyn Thomas:** Symudwn ymlaen yn awr at ein hadolygiad o wasanaethau canser. Byddwn yn derbyn tystiolaeth lafar y bore yma ac mae pawb sydd yma eisoes wedi cyflwyno eu tystiolaeth ar bapur. Fe'ch sicrhaf fod yr Aelodau wedi darllen eich tystiolaeth ac felly bwriadaf symud yn syth at gwestiynau ar y dystiolaeth yr ydych wedi ei chyflwyno. Croeso cynnes iawn i'r pedwar ohonoch: Jeff Stamatakis, Simon Dean, Dr Jane Hanson a Dr Gwyn Thomas. Yr ydym yn ddiolchgar eich bod wedi cytuno i ddod i'r cyfarfod. Gall aelodau'r pwyllgor gyfeirio cwestiwn yn benodol at un ohonoch neu, os yw'r cwestiwn yn benagored, mae croeso i chi i gyd ymateb, ond gofynnaf i chi fod mor gryno ag sy'n bosibl. Mae gennym ychydig dros awr a hanner ar gyfer y sesiwn hon, felly mae gennym ddigon o amser. Dechreuwn gyda Jenny Randerson.	**Rhodri Glyn Thomas:** We will now move on to our review of cancer services. We are to receive oral evidence this morning and everyone who is here has already presented written evidence. I assure you that the Members have read your evidence and therefore I intend to move straight on to questions on the evidence that you have provided. I warmly welcome the four of you: Jeff Stamatakis, Simon Dean, Dr Jane Hanson and Dr Gwyn Thomas. We are grateful that you have agreed to come to this meeting. Committee members may direct a question at one of you or, if the question is open-ended, you are all welcome to respond, but I ask you to be as brief as possible. We have a little over an hour and a half for this session, therefore, we have plenty of time. We will start with Jenny Randerson.

[5] **Jenny Randerson:** On information technology, you make a powerful case for improving IT and, in this day and age, I suppose that one expects that. Given the experience in England of having very expensive IT systems and IT systems that have been abject failures, how do you think that this will be afforded within current budgets and how could you guarantee that it would be successful? In addition to that, I would particularly like to address the cross-border issues, because many patients receive cancer treatment across the border in

England. You could have perfectly compatible systems in Wales that were not compatible with those in England.

[6] I visited a GP surgery recently, and it was stressed to me that GPs' IT need to be able to talk to everyone else's. They said that, as a hope, that was pie in the sky because all GPs have different systems and they cannot talk to each other and cannot talk to the hospitals properly. I can see massive practical difficulties.

[7] **Mr Stamatakis:** I will start, if I may. On the national perspective, Gwyn will have a lot more to say than me. We are here to talk about cancer and where we are with Cancer Network Information System Cymru at present. You are absolutely right to point out that there are difficulties across the border. The approach in Wales, which Gwyn will speak a bit more about, will be incremental. CaNISC is an IT system that looks at a single disease. The reason that cancer should be at the forefront of IT is because patients are treated on two or three different sites, and it is an act of faith relying on paper records travelling with patients. So, from the patient's perspective, the quality of care depends on communication between clinicians—and all healthcare workers—on different sites. We have taken cancer and developed this.

[8] Will it work? Well, does it work? CaNISC at present is used by eight of the 12 acute trusts in Wales to look, for example, at standard of care, which are the service and financial framework targets, and all of those eight trusts have reported on time. CaNISC has never failed to deliver the end-of-the-month returns. There have been a couple of glitches, but we have sorted them. Two of the other four trusts are, as we speak, moving to CaNISC to do their SAFF reporting, but I cannot speak for the other two. So, 10 out of the 12 trusts in Wales are using CaNISC and it is working.

[9] In terms of providing clinical information, the Assembly is keen that, in Wales, we take part in the Healthcare Commission's audits for cancer, so that we can benchmark Welsh trusts and Welsh performance against what is happening in England. We have just submitted the data to the Healthcare Commission's lung cancer audit, and the cancer registry in Wales tells us that we should register about 1,800 patients with lung cancer in Welsh trusts a year. We sent in data on 1,600 patients to the Healthcare Commission audit this year, which is 89 per cent. In England, there are about 10,000 or 11,000 submissions from a possible 30,000. We are doing the same with other audits that I could talk about.

[10] So, CaNISC has been developed slowly and it has been very clinically based. There is a huge input from clinicians—and Dr Hanson might talk later about the clinician input to all aspects of cancer care in Wales through the cancer services co-ordinating group. So, there is a major clinical input to the data sets and the process, which is one reason why things are so successful in Wales. I think that that provides answers from the CaNISC point of view, unless there is anything else. If not, I am sure that Gwyn would like to come in.

[11] **Dr Thomas:** From the national perspective, I think that the best indicator of whether we can succeed comes from what Jeff has said, because there are significant differences in the approach that we are taking in the programme in Wales. I do not have time to go into them all, but there are three basic elements. One is that it is going to be incremental. We are not buying a single, all-Wales computer system; we are phasing this by talking to clinicians and patients and agreeing that they should contribute to the design of the systems. That is something else that is the experience with IT programmes everywhere, not just in England. If you do not involve the end users, there is an enormous resistance to implementing systems. I hope that you got the flavour from the paper that I produced that we spent the last year engaging with stakeholders and getting their commitment to the approach that we are taking.

[12] The third element is that it is important that people have some choice in the systems

that go in, because that is another way in which to reinforce commitment. We are not going to give free choice for any and every system that is potentially available—those systems will have to comply with certain technical standards, and suppliers will have to demonstrate that their systems work before we accept and install them.

9.40 a.m.

[13] On your point about GP systems talking to each other, in Wales, I think that only three GP systems suppliers cover something like 80 per cent or 90 per cent of all GP practices. So, there are only three suppliers that we have to work with. Once we get those systems to talk to each other, we will have got most of the coverage of Wales anyway.

[14] You mentioned the point about GP systems talking to hospital systems. In some local areas, some trusts are already doing that. For example, they are transferring pathology results to GP systems. So, the technical feasibility is not in question. The issue is usually one of scale, and I think that Wales has a big advantage there, because we are quite small compared with England. The issue is one of priority, and I think that our discussion today on cancer illustrates that, if you start with a clinical priority and put in an IT system that supports the clinicians, you increase your chances of success immeasurably.

[15] **Rhodri Glyn Thomas:** Diolch. A oes cyfraniadau eraill?

Rhodri Glyn Thomas: Thank you. Are there any other contributions?

[16] **Jenny Randerson:** What about cross-border issues?

[17] **Dr Thomas:** We are engaging with the national programme in England on three fronts. One is that we are talking to them about agreed technical standards. On one level, this is just calling a test result the same thing in Wales as in England, so that information can move across from one to the other. That area is far wider than England and Wales; we are already beginning to engage with Europe, as the European Commission wants to introduce an emergency care record for patients travelling across Europe. So, there is also a European standards dimension to this.

[18] Currently, we receive a series of existing national services from England, and they are broadly called demographic services, which contain names and addresses. NHS numbers are also issued to people. We will continue to receive services from the existing providers until the English programme has delivered new services and put those in place. We have begun to negotiate with them how much that will cost and what our requirements will be, and I think that we have a tenable position on how we migrate from previous services going forward to future ones.

[19] The third issue is just one of access. I also hope that you will see from this paper that we are tackling the issue of putting in a patient record by taking the information from GP systems, rather than creating new systems and ripping out old ones. So, we already have the information in GP systems in England and Wales. Once we have got the systems in Wales to talk to each other, we will begin to work directly with the systems suppliers to make sure that that happens across the boundary into England.

[20] **Mr Stamatakis:** To add a comment on primary care, with the cancer record, there are a couple of Cardiff general practices that have access to the CaNISC system through Velindre NHS Trust, and also through palliative care in the voluntary sector. There are quite a number of non-NHS institutions in private and palliative care that have access to the cancer record through Velindre. So, these are small numbers, but the real limiting factors are cost and training issues. Technically, it is happening.

[21] **Rhodri Glyn Thomas:** A oes rhywun am ddilyn pwynt Jenny?

Rhodri Glyn Thomas: Does anyone wish to follow up the point that Jenny raised?

[22] **Jonathan Morgan:** Jeff, can I just deal with the issue of who accesses information and what can be accessed? You said that there are a couple of GP practices in Cardiff that can access the CaNISC system. In terms of desirability, would you like to see that rolled out throughout GP surgeries and pharmacies in Wales? I know that there have been concerns from pharmacists about access to information, particularly over the weekends and out of hours and that sort of thing.

[23] In terms of 'Informing Healthcare', this is an immensely complicated area, because, in essence, you are trying to draw together many different systems and ways of storing, recording and using information. I am concerned about compatibility, not just with other parts of the UK, but also between professionals within Wales. I would be very keen to see how that will develop. What level of resources has been put in to develop the strategy? I cannot imagine for a second that it will be cheap. Are we devoting sufficient resources to meet the targets of this very ambitious strategy?

[24] **Dr Thomas:** To deal with the point on resources first, you will see reference in this paper to an international conference that we organised a few weeks ago. One of the messages that people who attended from those six countries conveyed was that every country in the world finds it difficult to come up with a sustained investment to support IT projects. So, if we start from the premise that there will never be enough money—and sometimes you can have too much money—and shift the debate to a discussion about clinical priorities and how we can deliver programmes like this to achieve benefit, as opposed to just putting systems in place, I think that we will then get a sensible investment profile, which demonstrates benefit as it goes along rather than promising jam tomorrow. Of the resources that we have applied for—and this programme has had around £20 million or so per year for the past three years—around three quarters have been spent on local organisations, doing readiness activities, getting the paper records sorted out, and putting new people in place locally. I think that that is absolutely appropriate, to prepare the ground before we move on to doing something very complicated. It is very complex trying to knit all of these things together.

[25] So, our approach is saying that it is a phased programme. The phases should be determined by the healthcare priorities that we have to deal with. The business case—the justification for the investment—should be that the information technology should be integrated into the investment in changing healthcare, and not marginalised as some programme about computers and cables.

[26] **Mr Stamatakis:** We just have to remember that we are doing all of this for the patient. To exclude primary care from the electronic health record does not serve the requirements of the patient. So, access from primary care has to be a long-term objective and, as Gwyn and I said, things are being dealt incrementally at present. In the long term, I would hope that all primary care providers could access it, but also there is no reason why patients should not access their own records, given the appropriate security and so forth. That could be discussed.

[27] In respect of pharmacies, the electronic record is no different from the paper record, in that all healthcare professionals access the paper record. Patients' notes are on the ward, and so a pharmacist will go to a ward and look at a patient's notes to see their drugs, allergies and reactions and so forth. So, access to notes should not be limited to clinicians only; it should be for all healthcare workers involved in managing the patient. That raises issues of communication with the public and explaining why it is being done, asking, 'Would you like your healthcare professional staff to have full information about you or not?'—or however these questions are phrased. It is a mistake to consider the electronic record as different in any

way from the paper record—other than that it is better. There is no reason why a pharmacist outside hospital should not access a patient's record, with permission. It is all about permissions and access, which I can see us working on.

[28] **Rhodri Glyn Thomas:** I know that we are looking at papers 1a and 1b, but you are welcome to join the discussion, Simon Dean and Dr Jane Hanson, if you so wish. We would be very happy to hear your comments, but we will be coming to your papers slightly later.

[29] **Helen Mary Jones:** First, I want to explore the phased approach some more. I can see that there is a lot of sense in it in many ways. I was particularly pleased by what you said about getting the people who will be using the IT to be key in designing it. The perception is that what went wrong over the border was that no-one actually stopped to ask a nurse, doctor or patient what the record might be needed for. So, it is very good that we have learned from that. Are there any risks in taking the phased approach, or are other organisations buying other systems—whether they are GP practices or trusts?

9.50 a.m.

[30] I would also welcome your comments about the 10 out of 12 trusts—that seems like two trusts too few to me, and I am curious as to why that is so. This comes back to my point on phasing. Is there a risk that those trusts are making investments in other systems that you may be able to make compatible, but there would be a certain amount of time and effort lost in doing that? May I have a response to that, Chair? I also have a couple of other specific issues arising from the papers that I would like addressed.

[31] **Rhodri Glyn Thomas:** We will take that specific question first of all.

[32] **Dr Thomas:** Programmes such as this are always a trade-off of risks, as I am sure that you appreciate. The major risk that we face in breaking it down into a phased approach is ensuring that it all fits together when you roll it up again. We are managing that risk by producing what you will see referred to in this paper as a national technical architecture, which is a bit of IT-speak, so apologies for that. Essentially, it is a blueprint for how all of these systems will fit together in future. Given the size of Wales, we are moving away from each trust, for example, having its own patient administration system, and more towards national services, such as a national scheduling system and a national radiology system.

[33] We have done a lot of work over the past six to nine months or so, going around each trust—we must have made about three or four visits to every trust—in order to get them to understand the destination that we want to arrive at in terms of national services, and for each trust to agree to set up its own migration plan to get us from where we are now to where we want to be. We have agreed to do that in common, together, so that there will not be a gold rush for procuring local systems, because they will have to have passed one major hurdle, which is whether they fit with the national strategy. If I believe that they do not, then I will not support the purchase of those systems.

[34] However, we do not want to be a programme that stops all activity until all of this wonderful new technology is in place, which is why CaNISC is such a good example of a system that, in some cases and some respects, as someone said, is ahead of what we are trying to do. We will build on that; we will not stop CaNISC, although it is not currently the strategic solution. The strategic solution is an individual health record for all patients. We will keep working in tandem, and learn from what is happening in the development of CaNISC, not only from a technology point of view, but from a clinical design point of view and an implementation point of view, and do this as a partnership as we move forward.

[35] **Mr Stamatakis:** I will just endorse what Gwyn said. There has been a change in the

service from the fortress trust mentality of some years ago. People know that 'common by default' is the option now. Everyone is tight for money and no-one will throw money at a system that does not integrate with the national product. In Wales, we have to make use of our biggest advantage, which is that we are small and that people talk to each other. With regard to CaNISC, because I am a retired clinician, I will go to talk to clinicians—I know most of the surgeons in Wales personally. This approach of having contact with trusts, from me and from the people in 'Informing Healthcare', is how the system will roll out in Wales.

[36] The biggest risk for me, not being an IT person, is uptake by the clinical fraternity, that is, getting doctors and nurses to use the system and to collect information. Implementation is a big hurdle, but, again, because of our size and our contacts, I think that it is surmountable. Two trusts do not use CaNISC at the moment. One is Cardiff and Vale NHS Trust. It is a huge trust, and it will have to comment on this, but my perception is that it is a process issue now, and that is being addressed. The other trust that is not using CaNISC is Gwent Healthcare NHS Trust, which has its own systems, but, again, it has realised that it will have to move to CaNISC eventually. It may be that it will do that next year. That is all that I have to say.

[37] **Jenny Randerson:** May I just ask how long it will be before Cardiff and Vale NHS Trust moves to using CaNISC?

[38] **Mr Stamatakis:** That is a difficult question. I do not know. We are offering support—

[39] **Jenny Randerson:** So, it will not be as soon as next year?

[40] **Mr Stamatakis:** I would hope so. I would be very disappointed if it is not in place by next year.

[41] **Helen Mary Jones:** The paper mentions that palliative care is not included in the CaNISC system. That is a big problem, which is potentially worse for palliative care provided in the community and for those providing those services on a community basis. It says in the paper that it is a matter of resources, not a technical issue. Do you have any plans to include palliative care in future? It seems to me to be a big gap.

[42] **Mr Stamatakis:** It is an embarrassment to me that palliative care is not included in CaNISC, but you may be aware that CaNISC was funded for its first three years by the new opportunities fund. The amount of money was limited and palliative care was not included. To include it in CaNISC now would require starting from the ground up. There is not even a national England and Wales or anywhere data set on what to collect for palliative care. Dr Fowell is probably more up to speed than I am on this, but the UK Council for Palliative Care's data set goes back to 1996 and is used to record contacts, not for contracting purposes, but for activity. Many of the trusts in Wales use CaNISC. I do not want to cause confusion, but CaNISC and a system called ISCO are exactly the same. In Velindre NHS Trust, the system is known as ISCO for historic reasons; it is where it was developed. Outside of Velindre, the system is known as CaNISC. The ISCO system has taken 15 years to develop and that is the IT infrastructure upon which CaNISC runs. Through ISCO and, therefore, through CaNISC, a lot of palliative care instituted in Wales uses the system, but only to log patients and patient contacts. There is nothing about quality, type of care or outcomes. However, if someone gave us the money, we would start on it tomorrow.

[43] **Helen Mary Jones:** Would you suggest that we recommend that?

[44] **Mr Stamatakis:** Palliative care is such an important part of cancer care that patients are being disadvantaged, particularly in the community, where access to hospital notes and

records is so difficult.

[45] **Rhodri Glyn Thomas:** I am loath to ask committee members whether they agree with that recommendation, because we are dwindling in number.

[46] **Helen Mary Jones:** Those of us who are here agree with it. Perhaps we could note it for discussion in future. I am particularly struck by the fact that it is not even clear what ought to be recorded. In other contexts, we have talked about how you ensure that palliative care is provided consistently and we have talked about how you can involve the voluntary sector in that, and we might want to explore that further, because it is not about how you have the system to collect data, but what data you are collecting and for what purpose. So, we might want to come back to that.

[47] **Rhodri Glyn Thomas:** I am happy to note that recommendation. It is useful, as we go along, if recommendations are made, and there is a consensus on them, that we note them and come back to them at a later date. Jeff, did you want to come back before Helen asks another question?

[48] **Mr Stamatakis:** No, thank you.

[49] **Helen Mary Jones:** Forgive me for not being able to pick out exactly where this reference was made, but, in reading through the papers, I came across a reference to collecting genetic information in relation to cancer, and that that ought to be done. I have concerns about that because we have been clear, in the discussion so far, and in the paper, that the main purpose of collecting data is to benefit patients and to ensure that their care pathways are correct and so on. Having genetic information about a patient is clearly important for the clinicians involved, so that they know if there are genetic factors to the cancer, but people have fears and concerns about the implications of genetic testing in medicine and about what is done with that information. Do you have any comments on that?

[50] **Mr Stamatakis:** CaNISC does not collect genetic information, but we intend that CaNISC will be a source of cancer information for the Wales Cancer Bank. However, for that information to be made available to the cancer bank, patients and relatives are counselled very clearly and asked to sign explicit consent forms to allow information about their cancer to be shared with the Wales Cancer Bank. So, CaNISC is helping with the genetic aspect of cancer care in that way, but we do not collect specific genetic information. That is not in the record.

10.00 a.m.

[51] **Helen Mary Jones:** To be clear, any use of a patient's information over and above what is necessary for that patient's clinical care can only be made with that patient's consent?

[52] **Mr Stamatakis:** Absolutely. The Healthcare Commission audits are covered under section 60, so we do not obtain explicit consent from patients to take part in the Healthcare Commission audit. The data that go to the Healthcare Commission are not identifiable, so, in a way, that is not relevant. However, explicit consent is required for information to go to the cancer bank. I am sure that the same is true for the clinical trials network.

[53] **Rhodri Glyn Thomas:** I think that Andy wants to come in on this point.

[54] **Dr Fowell:** It is not on this specific point, but Jeff mentioned funding and that the first three years of the project were funded through the new opportunities fund. Can you assure us that funding for the future is now secure and that we can now see this project continuing to go forward in a stable way, because it has been a bit wobbly at times? I think that where we are at is fantastic, but it would be great to think that we can get to where we

want to be.

[55] **Mr Stamatakis:** I have an empty wallet, but the gentleman on my right is moneybags. Gwyn, do you want to respond to that?

[56] **Mr Thomas:** The cancer project is strategically very important to the 'Informing Healthcare' programme. One of the first decisions that we have to make is how we can turn it into something that is industrial strength. It has been developed with voluntary money, it is fit for purpose as it is and its potential is enormous. However, we now need to take a step up and look at the strategic development of CaNISC, as opposed to just putting more money into it and doing things in the same way.

[57] The other challenge that the 'Informing Healthcare' programme faces is that, up to now, we have spent three quarters of our budget on local organisations. We now have a road-tested implementable plan and that expenditure has to shift to much more of a collective national spend. We have to strike a balance between keeping projects like CaNISC going, because they are important, and learning from them, and, at the same time, putting in basic infrastructure. We talked earlier about people getting access to the patient record. To allow that, you have to put in a security model and an authentication system, so that if someone says, 'I want access', we know that that person is the right patient, doctor or pharmacist. So we now have to invest in infrastructure at the same time. Although I cannot give you a cast-iron guarantee—who can nowadays?—we are not going to let the CaNISC system stop for want of decisions about switching investment within the 'Informing Healthcare' programme.

[58] **Rhodri Glyn Thomas:** Are there any further questions on papers 1a and 1b? If not, we will move on to paper 1c. Gwyn and Jeff, you are welcome to stay with us if you wish and to contribute towards further discussions. However, if you need to leave, then you are free to do so.

[59] **Helen Mary Jones:** On the first page of the paper, you talk about the lists. You say that the lists are subject to ongoing discussion between Health Commission Wales and the local health boards. Why? I would also be interested to know how much those discussions cost, given that each discussion presumably involves staff time. More importantly, what do you recommend should be done, as far as possible—there will always be some grey areas, I am sure—to put an end to those discussions? My perception is that they are probably not a good use of your time or that of the LHB. More importantly, they are certainly not good for the patients, who are left not knowing who they ought to be arguing with to get their care commissioned.

[60] **Mr Dean:** Cancer is a complex area and the lists are complicated by definition. The resource-mapping issues were also complex, so we just have to accept that complexity is a fact of life in the system. I remember the last time that I attended the committee—it was in February, I believe—I was asked whether I thought structural change was the answer to many of these issues; my response was that there are boundaries everywhere in the system, and our job is to work across those boundaries. The same is true here. We can use the network models to drive those debates, but there are anomalies, which cause practical difficulties, although not huge practical difficulties. My colleagues spend some time on this, but it does not dominate the cancer agenda.

[61] Therefore, we need to use the cancer networks and the commissioning groups to ensure that we respond appropriately to issues as they arise. In parallel, there is the work on reviewing commissioning arrangements, generally, which will provide a platform for addressing some of these issues in the longer term. Therefore, it is a difficulty, but not a major difficulty.

[62] **Helen Mary Jones:** You are right to say that there are always boundaries. However, are there too many boundaries in Wales, or have we got that right?

[63] **Mr Dean:** That is probably a question to address to others. My job is to work within the system as it exists. I have worked in the health service for 24 years, in all sorts of variations of organisational configurations, and there are always boundary issues that have to be addressed. The question of whether there are too many boundaries in Wales should probably be addressed to others.

[64] **Rhodri Glyn Thomas:** It was worth a try, but that is not a question for Simon to answer.

[65] **Helen Mary Jones:** I would submit that someone who works within the system is probably in a better position to know whether or not there are too many boundaries. I accept that it may be difficult for Mr Dean to answer the question publicly, but I believe that it was a relevant question to ask.

[66] **Rhodri Glyn Thomas:** It was worth your raising the issue, but Simon has clearly said that he is working within the system, and it is not a matter for him to decide on the system itself, or on the structures of the system.

[67] **Helen Mary Jones:** Chair, if we are going to—

[68] **Rhodri Glyn Thomas:** That is my view on that point, so we will not pursue that particular question.

[69] **Helen Mary Jones:** But this is important for the rest of the review. Is there any point in having people here to give evidence if they are not able to answer the crucial questions, as we believe them to be?

[70] **Rhodri Glyn Thomas:** I will not pursue that question. It is not appropriate to ask someone working within the system whether or not he or she agrees with that system. It is perfectly fair for Simon to say that he does not want to respond to that question. Is there another question?

[71] **Helen Mary Jones:** There are several, but I am not sure whether there is any point in putting them.

[72] **Jonathan Morgan:** Simon, whether or not you feel that the system that we have is appropriate or inappropriate, in terms of your 24 years of experience working in the health service—and now heading up an organisation that is one of the substantial commissioners of various services—can you see any pitfalls in the way that the commissioning currently operates? You have already alluded to the fact that there are grey areas and that there are disputes between the list of responsibilities that you have, the list that the local health boards have, and somewhere in between we get these discussions, as you put it. Therefore, you have recognised that there are pitfalls in the current commissioning arrangements.

[73] Now, some people around this table—me being one of them—would argue that we should commission cancer services at an all-Wales level, and remove local health boards from commissioning those cancer services that they are currently empowered to commission. What could be done to improve the current commissioning arrangements? You mentioned the cancer networks. Sadly, many clinicians in Wales are baffled as to what cancer networks are there to do; they believe that the system is bureaucratic and convoluted. There is a difference of opinion between those who work from a—if I can use the term—‘bureaucratic’ perspective of commissioning services at an official level, and those who are trying to deliver clinical

services. There is a difference of view, which we are going to try to resolve. Therefore, in your experience, what should we be looking at to cure some of the problems that exist?

[74] **Mr Dean:** I will venture a comment that perhaps also addresses part of the last question that I was asked. We need to think carefully about what we mean when we say ‘cancer services’. We had a discussion a few moments ago, for example, about palliative care. Where in the system is palliative care provided, and by whom? Therefore, we have some aspects of cancer care that are provided at primary-care level, and then we have extremely rare interventions that are provided for handfuls of patients a year. There is a whole spectrum between those two extremes. We must get practical arrangements—I will not, if I may, address the question about organisational arrangements—in place and get the right people working together at the right levels to get the right results for patients. In services like palliative care, there are different groupings that need to work together. In cases where we are talking about very rare clinical procedures, there is again, perhaps, a different focus. So, we must see commissioning strength at all levels.

10.10 a.m.

[75] Key in this will be the mechanisms by which people get together and, crucially, what they do when they meet around those tables. I recognise that getting people together does not necessarily mean success, it may mean talking—that is not a comment about the cancer networks or any others. I expect the networks to be focused, to have an agenda, a work programme and a purpose, and to hold themselves to account on the delivery of that purpose, and, indeed, that others hold them to account. So, I can see ways of getting people to work together effectively at different levels that reflect the organisational structure that exists in Wales.

[76] **Jenny Randerson:** These ongoing discussions, three years after the establishment of the current system, seem, to a layman, pretty amazing. It strikes me that there are echoes here of the perpetual discussions between local authorities, social services departments and the NHS on continuing care. Given that you say that there will always be boundaries—and we have a lot of boundaries—do you think that there is a role for an independent adjudicator, possibly even the Minister, who, after all, set up the system, although not personally? Should he be saying, ‘Okay, this is a treatment that someone should fund and the LHB and Health Commission Wales cannot decide who’? Brachytherapy is possibly an example of something that has fallen foul of this issue of financing. Therefore, this independent adjudicator or even the Minister would be able to say, ‘Okay, it is your job’. Someone needs to do it, and they should not spend hours of people’s time on the decision.

[77] I want to raise the issue of brachytherapy, because it is in the paper at two points. It is an amazing issue from the outside—

[78] **Rhodri Glyn Thomas:** Jenny, before you go on—

[79] **Jenny Randerson:** It is an example of commissioning.

[80] **Rhodri Glyn Thomas:** Do you want to discuss the general points of commissioning and we will take brachytherapy as a specific point afterwards?

[81] **Jenny Randerson:** All right.

[82] **Rhodri Glyn Thomas:** Simon, will you deal with the general points on commissioning in terms of Health Commission Wales and LHBs? Helen will speak first and then perhaps we will deal with that general point.

[83] **Helen Mary Jones:** I want to pursue the issue of the networks. I was struck, Mr Dean, by what you said about how we do not want this to be a question of people sitting around, that there needs to be a clear agenda and that people need to work together. Certainly, it has been put to us that there is, at the very least, no universal agreement that the networks are working as they are; I am being polite. Do you have any specific recommendations as to how to make the networks more effective? If they are the way to go, rather than national commissioning—it will be a matter for us as a committee to decide with regard to what we recommend to the Government—what could be done to make the networks more effective? My experience is that of someone who, in the olden days, used to work in partnership and found it to be a blinking nightmare. Does it work if you do not pool budgets? I have never known a partnership to really work unless budgets are pooled, because there are always tensions. What can make the cancer networks work, and should we be looking at encouraging pooled budgets to make this work?

[84] **Mr Dean:** There were a couple of comments there. On what could be done to make the cancer networks work, my view is that the cancer networks derive their authority from the bodies that constitute them, and it is therefore important that those bodies hold the networks to account. So, if I have my staff going to a network meeting—any network, or any meeting; I am not talking specifically about cancer—I want to know why they are going, what the purpose is and what they expect to get out of it. If the response is, ‘Well, we are not quite sure why we are going, or what we expect to get out of it’, then I would question the purpose of the meeting. It would then be for me to talk to the other organisations sponsoring that network and ask them what we are trying to achieve, whether we have an effective mechanism in place and, if not, how we make it effective or substitute it with a different way of getting the business done. It is about ownership, and there is a danger that networks, speaking generally, can become free floating, and it is incumbent on all of us who participate in the networks to ensure that they are not free-floating. I stress that I am not saying that that is the case with the cancer networks, but that is a danger that I have seen elsewhere, where they become fora within which people exchange views but which do not necessarily have a clear purpose, outcome or work programme. I think that the way to drive any collaborative venture is to make sure that it has a clear purpose and that people have signed up to it.

[85] In terms of pooled budgets, my view is that, on the face of it, they are the answer, but in practice, they do not necessarily prove to be the answer. I can attest from experience that the debate rapidly shifts from the pooled budget to how much each party contributes to the pooled budget. So, you can still end up with difficult financial dynamics; they just take a different form. Again, for me, it is about having a shared agenda and purpose, and agreements up front about what we are trying to achieve. If we are going into a partnership of any sort with any party that is not committed to the achievement of a clear objective at the start, then the partnership has been set up on the wrong basis.

[86] There are ways in which these things can work, but we need, collectively, to hold them to account. That is part of the way in which my organisation should be held to account—it is a matter of asking how we are contributing to the networks and whether we are playing our part and collaborating effectively with colleagues. That does not mean that we will always agree on every single point, because that, clearly, would not be realistic, but I am quite prepared, and would expect for us to be held to account on how we contribute to the process.

[87] **Rhodri Glyn Thomas:** The difficulty is that people feel that, unless there are pooled budgets, decisions are often taken on a financial basis rather than a clinical basis, and that the patient is not always getting the best clinical provision. I take your point that the argument can turn on who is contributing what to the pooled budget, but if you have a pooled budget, you are in a situation in which it is, presumably, easier to take the clinical decision without any financial implications for that decision.

[88] **Mr Dean:** It would be easier to take the clinical decisions that are affordable within the pooled budget. The difficulty comes when the pooled or conjoined budgets are insufficient to address all the possibilities. That is the issue facing us. Many treatments cost substantial sums of money; many of them are additive, and we and other commissioning organisations have to make choices, some of which are driven by the availability of resources. That is inescapable. The question then becomes one of the basis on which we make those choices and how we approach the choices about things that are actually quite dissimilar. If you look at HCW's commissioning remit—please stop me if this is a little bit too broad—we commission services that range from those that immediately save lives through the management of pain and disability, through elective procedures to screening well populations. So, we commission a huge range of dissimilar services, and, within that portfolio, we have to make choices, a part of which, clearly, will be about resource issues. It is a difficult issue, and we have to acknowledge that pooling a budget, of itself, would not necessarily be the answer. It might help with some of the dynamics of the partnership, but it would not necessarily make the decisions any easier at the end of the debate.

[89] **Rhodri Glyn Thomas:** Does anybody want to pursue the general point before we move to brachytherapy? Jenny?

[90] **Jenny Randerson:** I will start with a preliminary question. Am I right that LHBs commission the usual treatment, which we have been used to, for prostate cancer?

10.20 a.m.

[91] **Mr Dean:** Yes.

[92] **Jenny Randerson:** In that case, I am using brachytherapy, because you use it in your paper, as an example of how the frustrations of the system mystify the public, and even us, on many occasions. Why is Health Commission Wales involved in the commissioning of brachytherapy, which is hardly a new treatment? It might be new in Wales, but half the men in America with prostate cancer are now treated with brachytherapy. We went to a centre in France where it is used all the time. Why is Health Commission Wales involved in this? This is the lesson to be heeded by other treatments. Why is it not possible, within the system, for Health Commission Wales, which currently does not have the money—and I understand budget constraints entirely—to commission this treatment? Why can you not say to LHBs, 'Okay, we will share the cost of the treatment for those patients for whom it has been identified as a suitable treatment; you put in the normal amount that you would spend and we will top it up'?

[93] **Mr Dean:** That is precisely the discussion that I am planning to have with LHB colleagues.

[94] **Jenny Randerson:** Why does it take so long?

[95] **Mr Dean:** It takes so long because we have had to get to this point. I do not know whether the committee would find it helpful if I just gave a brief resume of the brachytherapy story; that might help with the discussion. Low-dose brachytherapy, as you rightly said, is a treatment for prostate cancer. It is not the only one; there are other high-quality, evidence-based treatments—prostatectomy and wide-beam radiotherapy being two of them—that are commissioned by LHBs. We are responsible for low-dose brachytherapy because it is a specialised technique. It is a feature of many of the care programmes, not just in Wales, but in England, that the specialised end of the care pathway forms part of the responsibility of the specialised commissioner, rather than the commissioners who do the majority of the commissioning work. So, a boundary is introduced into the care pathway there.

[96] The issue for us with brachytherapy is that we did a lot of work with the surgeons on this and the estimate was that about 56 men in Wales would be suitable, and would opt, for this treatment each year. Based on the costs that we would have paid to our English providers—the treatment is not available in Wales—that would have cost about £80,000 a year. We identified £80,000 within our commissioning plan for this year, and I think that you appreciate our overall financial position. It then turned out, when we were negotiating with the English providers, that the price went up from about £1,500 per case to between £5,000 and £5,500 per case. I think that the reason for that increase was that the English providers had costed the treatment at the standard urological price and had subsequently realised that they may have costed it at the wrong level. We were faced with a potential bill of somewhere between £280,000 and £300,000 to treat the 56 men who were expected to present as being suitable for that treatment.

[97] We took the view that because alternative evidence-based, high-quality, good-outcome treatments were available, and because of the other choices that we had to make within our commissioning portfolio, we could not commission that service, to that level, this year. We then had to decide to what level to commission the service. The decision that I took was that, at that stage, we had 11 patients on waiting lists who had an expectation of receiving brachytherapy treatment, and we had to honour that commitment. I then decided that we could not accept any more patients onto the waiting list because it would be quite difficult to manage the process of accepting some, but not all.

[98] Subsequently, we discovered that there are a further five patients on the waiting list of an English provider who had not been declared to us, so we will be spending around the £80,000 that was initially allocated. I have met with the clinicians, and with people from Velindre NHS Trust who are developing a business case to provide this service in Wales. The difficulty with that business case at present is that the average cost in year 1 is just under £11,000 per patient. In year 2, it drops to somewhere around £8,000 and, in year 3, it becomes about £6,000, but that it because of the build-up of patient numbers as the service is established. So, I have asked the trust to re-cost that business case and to see whether it can develop a more affordable business case for a service in Wales. So, that is one avenue.

[99] The second action that I have agreed to take is precisely the one that Ms Randerson mentioned, which is to talk to the LHBs, because these patients are being treated and are consuming NHS resources in Wales—money is being spent on prostatectomies and wide-beam radiotherapy—and we are constructing a paper with Jim Barber from Velindre NHS Trust to take to the LHBs to have the debate with them about whether we can shift resource from the LHBs to us to fund this treatment.

[100] **Helen Mary Jones:** Thank you for setting that out, Mr Dean, because it makes the brachytherapy case clear for people, but it is also a useful example of what seem to be perfectly rational decisions taken by organisations at every step of the way that are absolutely incomprehensible if you are the patient and your clinician thinks that this is the right treatment for you and you agree. It highlights commissioning weaknesses. How did it happen that the English providers were originally quoting on a different basis for what they were being asked for? Did they not understand what they were being asked for or did the commissioning process not make it clear what was being asked for? Those are the sorts of questions in terms of commissioning capacity that we really need to understand, particularly when we are talking about a therapy that, as Jenny Randerson has said, is new to Wales but is not a new, untried drug that has just come onto the market or whatever, for which you are still experimenting with the dosage and so you might originally think that it will cost this much, but then you might find that you need more and that it will cost that much. So, I would be interested in an explanation of what happened in that bit of the process.

[101] You are, at this stage, having the discussions with the LHBs. I am exploring this as an example. For the purposes of today, this is not about the brachytherapy issue so much as the points in the system at which things from the patient's point of view, and probably that of the clinician, seem strange. I think that we established before that the overall cost of the treatment in England is comparable with the cost that the LHBs would pay for the more traditional kinds of services that are provided locally. I am sure that you can understand that this is very difficult for patients to understand. This is NHS money, and money that Dr Gibbons, as our Minister, has decided is going to be spent, and it is difficult for a patient to understand that, effectively, he cannot have that treatment because, from his point of view, the money is in the wrong bit of the NHS that he pays his taxes for. Could you explain why the English providers under-quoted in the first place?

[102] More generally, do you have any suggestions about how these sorts of decisions could be made in a more streamlined way in future, given that the Chair is preventing me from asking you whether you think that the system is sensible—and I can see why he is preventing me from doing that, but I will persist in doing it—

[103] **Rhodri Glyn Thomas:** You used a bit of subtlety when you asked that question.

[104] **Helen Mary Jones:** Given that the structures are as they are, would there be ways in which these kinds of decisions could be made in a more streamlined and efficient way, from the patient's and the clinician's point of view?

[105] **Jenny Randerson:** That goes back to my question about the arbiter, which was not really answered. Is there a way out of this farcical situation?

10.30 a.m.

[106] **Rhodri Glyn Thomas:** I think that this is also an extremely important question. As well as the issue of streamlining the process, there is an issue of communication, because we have had correspondence on a very different issue in a different field of medicine, and that was a situation in which the communication was not happening. I am not being critical, but it just was not happening within the system. Am I right in my understanding that Health Commission Wales does not discuss the treatment with patients, because quite often what happens is that you are talking to clinicians, and clinicians are talking to patients, and the message does not always get back to the patient? Patients are left in a situation, as Helen said, whereby they know that what is being suggested is the best treatment for them, but, for some reason, they are unable to get access to that treatment and that message is not always clearly communicated to them. So, as well as looking at that, can you also look at the communication element?

[107] **Mr Dean:** I have noted six points that I hope will cover the ground. Please remind me if I miss any. Why do the English providers get it wrong? The short answer is that the English system is moving to payment by results, so they have changed their whole way of doing business, and it is a big upheaval in constructing tariff prices for things that they have not priced at that level before. I think that it is simply a feature of the change to the payment-by-results system. You see that the English tariff prices are moving around as things settle down, so I do not think that there is anything sinister on the English side. I do not think that it is caused by a breakdown in the commissioning relationship; it is simply a costing issue resulting from the introduction of payment by results.

[108] I would also make the point that brachytherapy is not available throughout England—there are some primary care trusts that are not commissioning it. So, it is a well-tested technique, but it is not universally available in the UK.

[109] I want to reiterate the point about choices; I will broaden it out slightly and then I will come back to the specifics. We have to make choices about what we do with Welsh taxpayers' money across the whole range of our responsibilities. As we make those choices, we have to consider the options that are available in any particular service area. Where there are high-quality, evidence-based current treatments, that will bring a perspective to the choice if the choice is between funding for that treatment and funding for treatments for which there is no alternative. So, that becomes a part of the wider choices debate, but I understand why, at an individual patient level, that is difficult to communicate and is not a welcomed message.

[110] I will move on to communications and then come back to my other two points. We should be working exclusively through contracts with providers. We should be commissioning NHS trusts and the independent sector in England and Wales to provide us with volumes of service that they then manage. We do that for most of our portfolio, apart from the bit that we call the individual patient commissioning process. Within that process, we receive about 2,000 referrals a year. That has doubled in each year of HCW's existence. In my view, the figure is far too high. We should not be dealing with individual patients because we are making decisions about individual patients without a context. We are unable to engage the clinicians in the choices, and I think that that is what we have to do. We have to engage the clinical community in a choice. To take brachytherapy as an example, if brachytherapy is a treatment of choice for prostate cancer, what choices are the clinicians going to help us to make within the resource that we can make available for the commissioning of cancer services? That becomes the issue of debate, because we cannot manage a system wherein we simply add things on all the time. There has to be substitution, and we have to be able to move resources around. I think that that is an entirely legitimate debate to have, and I think that clinicians have a responsibility to engage with us in that debate. We must then have the management framework that allows that debate to happen. I come back to the networks, because I think that is the vehicle that we should be using, because that is the vehicle for the people with the money, pooled or otherwise, can come together, can take that overview of the service as a whole, and can engage in that debate about choices—because it will come down to choices. It always does, to some extent. So, I think that we can use the networks as a vehicle for having that debate.

[111] We talked earlier about the role of the networks. I do not think that an independent arbiter would be a good idea, as that gives people an opt-out. If you have an independent arbiter, it allows people not to reach a decision. I think that arbitration, generally, is a very bad thing. I think that it is a sign of failure. I do not want to go to arbitration on any matter, because, if I do, it suggests to me that I have not done my job properly. That does not mean that I have come up with an answer that everyone likes, but I think that, if you have a court of higher authority, there is a danger that the people who should be reaching the decisions find it more difficult to do so, for whatever reason. So, my personal view is that an arbiter would hinder rather than help.

[112] In terms of communication with individual patients, we work through the referring clinician, which I think is the right thing to do. I think that it is right for the commissioner to work through the referrers, preferably within a contractual framework rather than within an individual patient framework. It is important that we engage with clinicians on the choices, and on the communication of those choices to patients. It is also appropriate that we are held to account by individual patients or their representatives seeking information about why decisions were made, asking for those decisions to be reviewed. We have a mechanism in place that allows for those decisions to be reviewed. However, it should be on the grounds of exceptionality. I am very keen that we move towards making clear statements of our commissioning policies so that, in every service area, what we are commissioning and the criteria against which we are commissioning are clear, because that provides the framework. People say, 'I do not like that commissioning policy; I would prefer it if it were something different', but it provides clarity in the system. It will also help us to manage innovation. I

take the point that low-dose brachytherapy is not a new technique per se, but it is a new technique in Wales. We have to manage the introduction of change and, within that, we have to look at how we can free up resources already in the system to resource that change.

[113] That was a long answer, but I hope that I covered the points that were raised.

[114] **Rhodri Glyn Thomas:** I know that we have further questions. Presumably, they are on this.

[115] **Jonathan Morgan:** I have a very quick question on this. Effectively, you said that the problem was down to the way in which the tariffs changed in England; they pushed the prices up so that we could not afford it. If that happens with one type of service, I assume that it could happen with any other service that you wish to commission in England. Are there any other problems at present that we should be aware of?

[116] **Rhodri Glyn Thomas:** I will also take Jenny and Helen's questions, because we need to move on to Dr Hanson's paper. If they are on this issue, we will take those questions now.

[117] **Jenny Randerson:** I just wanted to come back to the point about choices. I think that we all understand the concept of choices: if an expensive new cancer drug comes on the market and it is commissioned, it means that there is less money for other treatments. In this particular case, it appears that you had £80,000, the local health boards had the regular money, and, if you added the two together—I have just done a quick sum—you could almost certainly have managed to treat all 56 of those people who would be entitled, eligible, or appropriate for the treatment this year. It is the lack of co-ordination between the two that is the problem in this case. It may not have been the problem in lots of other cases but, in this case, as Helen Mary said, it is a case of the money being in the wrong bit of the NHS, or in two different bits of the NHS, and they could not get together. You are beginning to get together at this very late stage, but I am concerned that you are just getting a paper together. This issue has rumbled on for months, and clearly the discussions have not even started if you are just getting the paper together.

[118] **Helen Mary Jones:** Following on from Jenny Randerson's point, I think that the point about substitution is very important, because the resources will never be infinite. We all know that, and there will always be choices to make. Would it be accurate to say that, in the case of brachytherapy treatment, there is a pretty direct substitute? If the person does not receive brachytherapy, he will be receiving surgery and the more traditional radiation treatment.

10.40 a.m.

[119] In that case, it seems to me that it is a question of where you work out the substitution, because it is not substituted from your budget but from someone else's. I want to be clear that I understand that correctly.

[120] My other point is on communication, which picks up on Rhodri Glyn Thomas's point. I think that you are right in that you should be working through clinicians and that, ideally, that should be on a contractual basis as far as possible and not on an individual basis. As a Member, I have come across cases where the clinician thinks that your decision is wrong, and that then means that the patient is vulnerable, as you have the clinician saying, 'I want to be able to give you this treatment, Mrs Jones, but Health Commission Wales will not let me'. I cannot see how that could be avoided, but do you have any comments on that?

[121] There will be occasions when a clinician is recommending a particular treatment that

you are not prepared to fund for whatever reason, whether it is affordability or it is to do with NICE guidance. Some of those decisions will be proper, but if they are communicated to the patient only through a clinician who is hostile to that decision, it can be a difficult situation for a patient to be in, even when you are right. Someone will always believe the doctor with whom they have a day-to-day relationship over someone whom they see as a bureaucrat in an office somewhere. Are there better ways of dealing with those situations when you and a clinician go head to head and the patient is caught in the crossfire? Is there a way of communicating those decisions? I do not know. I can see that that is a difficult situation and so do you have any suggestions as to how that might be overcome?

[122] **Mr Dean:** It is totally inappropriate for patients to be caught in the crossfire, to borrow your phrase. I think that we, as managers, and clinicians, as clinicians, have an ethical responsibility to manage our business appropriately. We need to make our decisions and be accountable for our decisions. Clinicians need to influence those decisions, but they need to live within the context that exists. It would be totally unacceptable for clinicians to wind patients up, for want of a better phrase.

[123] **Helen Mary Jones:** But you know that they do. We have corresponded on cases where it appears, from your point of view, that that is what has happened. Do you have any suggestions as to how that could be dealt with?

[124] **Mr Dean:** To use brachytherapy as an example, on the day that I made the decision to suspend commissioning brachytherapy, I wrote to all consultants and outlined the position, asking them not to offer brachytherapy as an NHS treatment option for patients. I think that that was an entirely appropriate line to take. I have to say that one or two clinicians have suggested otherwise, but I do not believe that I was wrong; that was entirely right.

[125] You can offer as a choice only those things that are available; you cannot choose between things that are not available to you. So, the right route for clinicians or others to express that they may not agree with a treatment not being available is through a dialogue with the commissioners, and not with individual patients. I am not suggesting that in the case of brachytherapy; I am talking more generally. It is entirely proper for clinicians to ask me to explain why we have come to a particular policy position, but it is they who need to do that, because that debate needs to happen outwith any discussion about individual patients. It is entirely inappropriate to place patients in that position, as I can imagine it must be incredibly confusing when you have your clinical advocate, the expert, telling you one thing, and the system is saying something different. We have to find a professional, calm and ethical way of managing that debate.

[126] In the Assembly, there is some work going on with regard to developing an ethical framework for commissioning, which I welcome. That, for me, is hugely important. On what basis do we make these decisions? We are not comparing apples and pears; we are comparing hugely dissimilar things that have hugely dissimilar benefits and costs, and cost/benefit ratios. All commissioners, not just in Wales, are incredibly exposed on these things.

[127] If you take most issues in isolation, there will be a clear answer, but it is the sum of all those things that you would like to do, and the process and the basis on which you make the choices that are important. It is an ethical issue for clinicians and managers, and that work is hugely important. However, we need that debate to take place separately from any debate or argument about the needs of an individual patient. We have to manage that in a different way, cognisant of the fact that we must not inadvertently allow the patient to become caught up in an inappropriate debate. So, that was the ethical issue.

[128] The question of substitution and LHBs is interesting. It might be idle to speculate on what the outcome might have been had all the commissioning been in the same place. Would

the decision on low-dose brachytherapy have been different? I do not know; I cannot answer that. However, if the choice were within my power, given the other choices that I have to make across the range of other service areas, I am not sure whether I would necessarily have come to a different position on low-dose brachytherapy this year. I might have done, but I might not, because I would still face the overall choice that I have to make across a diverse range of services, many of which could present similar cases that are highly worthy of consideration. So, it is a difficult one to speculate on, but that might be where I go.

[129] Have I picked up all the questions asked?

[130] **Rhodri Glyn Thomas:** I think that you have.

[131] **Jonathan Morgan:** There was a question on the fact that it was the changing tariff situation in England that resulted in not being able to commission brachytherapy services. If the tariff situation had been changing to such an extent that it was pushing costs up, were there any other services that you could commission in England that also face the same difficulty? If so, brachytherapy may not be the only service in England that could pose such a difficulty for us in certain services.

[132] **Mr Dean:** It is certainly true that we will face choices across a range of service areas, many of which are expressed through the referrals to England, because it is usually the referrals to English centres that come through the individual patient routes—not exclusively so, but it does tend to be those. We commit most of our money through contracts with Welsh providers. We spend around £70 million a year in England, so many of the individual requests are those directed to English centres. I want a debate with Welsh clinicians on how we can use resources in Wales to develop those services in Wales for access reasons, to further develop sub-specialties locally, and also to have a debate about choices. So, if we have referrals to an English centre for a neurosurgical procedure, for example, that would be at full cost in England as opposed to the marginal cost that I would expect to negotiate in Wales. That is a new technique.

[133] I am interested in having a debate with the neurosurgeons about where that stands in their view of commissioning for the specialty as a whole, because they have to engage with us on those choices. It is also an opportunity to develop those sorts of sub-specialties in Wales. We are currently setting up arrangements that better regulate the flow of patients out of Wales by creating gate-keeping arrangements in the tertiary centres in Wales and asking clinicians about the opportunities for treating patients more locally. That will help, but it is a slightly long answer to your question. The short answer is, yes, there will be other pressures across a range of service areas. I would not want to pick out one or two specifics, but we face a challenging financial position. We will drive hard on efficiency and negotiate hard on prices with all of our providers, but we will still have to make choices about what we commission and when we commission it. That will be a feature of our commissioning for the immediate future.

[134] **Rhodri Glyn Thomas:** Thank you, Simon. It has been a long session, but it was always going to be the case that there were going to be a number of questions about the commissioning process of HCW.

10.49 a.m.

Adolygu'r Gwasanaethau Canser: Tystiolaeth Lafar (Grŵp Cydlynu Gwasanaethau Canser)
Review of Cancer Services: Oral Evidence (Cancer Services Co-ordinating Group)

[135] **Rhodri Glyn Thomas:** I invite questions on paper 1d to Jane Hanson.

[136] **Jenny Randerson:** In your paper, you refer to reviewing the membership of the steering groups to ensure appropriate clinical multi-professional representation. Perhaps you could flesh that out a bit and explain to us what groups you feel have not been adequately represented in the groups so far.

[137] **Dr Hanson:** If you came to a meeting of the cancer services co-ordinating group, the people whom you would meet would be individuals who represent the core multi-disciplinary team on the ground—traditionally, the surgeon, radiologist, clinical nurse specialist and others whom patients would meet. Those specialties are represented on the all-Wales groups. We are also trying to build up patient representatives on those groups. We have had one patient or carer on those groups, and we are trying to work towards having two, so there is also a patient input. The reference was about reviewing the current groups, not because we need more—apart from one or two to take us through the additional NICE service guidance that has come out more recently—but, essentially, to ensure that the groups reflect the multi-disciplinary team, that the right specialties are included, and, in terms of succession planning, to ensure that we have new people coming through onto the groups. So, we were trying to look at comprehensive coverage of the multi-disciplinary teams and ensuring that the right people were included.

[138] Once the cancer networks were set up, we automatically allocated three places on each of the groups for the network lead clinicians for that cancer site. So, it was about ensuring that that was all working and coming through. It was about comprehensive coverage within each group. We are currently in the process of setting up a sarcoma group, which is probably one of the last ones that we will put forward. That is to take forward NICE service guidance on sarcoma, which was issued earlier this year.

[139] **Jenny Randerson:** The therapists believe that they have been under-represented and that the NHS is missing a trick in terms of ensuring that treatment includes not only the immediate acute phase but also helps people to live well with cancer and adapt to a new situation and so on. They believe that if this was done at the right time and in appropriate quantity, depth and so on, then it would save money in the long run.

[140] **Dr Hanson:** You are right, and that was partly why, when this was penned, I was concerned about how we included the allied health professionals and the wide scope. With regard to the existing groups, where there is key allied health professional input—for example, in the case of head and neck cancers, in which speech and language therapists are involved—those professionals are now on those groups. So, such key professionals are on the tumour site groups. However, to try to ensure that we tap into this wider potential, we have set up the nursing and allied health professional cancer advisory group. Part of the remit is for it to be a forum for them to get together and begin to work through what is appropriate and how they can be used more and dovetail in. You are right, you tend to think of doctors, nurses, specialist nurses and dieticians in relation to upper gastro-intestinal cancer, but do you think of the physiotherapists and the others who are important, but who are more in the general supportive field? The nursing and allied health professionals group is a new group, which has been running for about a year. The focus has been pretty much on training, but we will be developing that with them shortly. For next year, I know that the group has in mind a showcase conference to get information across to a wider audience about their roles.

[141] **Jonathan Morgan:** I would like to make an observation on the section on radiotherapy and chemotherapy—it also ties in with the information provided in Simon's report. What observations have been made by clinicians about the state of radiotherapy, and how we are able to manage the demand for radiotherapy services, bearing in mind that it says

in Simon’s report that, in south-east Wales, we have 3.55 linear accelerators per million of population, where the average is four, and the recommendation is five? In the Health Commission Wales report, there is plenty of information about the plans that are being developed—there is a south-east Wales strategic plan, an all-Wales capital investment plan, and some other plan relating to south-east Wales, so plenty of plans are being considered. However, what is the clinical view about the situation relating to radiotherapy, and particularly about raising the number of linear accelerators beyond the national average of four?

[142] **Dr Hanson:** I will wind the clock back to 2001, when the Assembly asked the cancer services co-ordinating group to advise on a national strategic forward plan. We did that, and submitted it around Christmas 2002. It covered, or aimed to cover, the breadth of cancer services. There were two main parts to that. One was radiotherapy and developing radiotherapy services, and the other was implementing NICE service guidance. We have subsequently been asked to look at updating that strategic plan. When I discussed that with the individual groups—all those listed in the boxes in the chart that I gave you—the feedback that I had strongly was that we needed to pull up radiotherapy again, and take the issue forward. There had been investment back in 2002, and just before that, in terms of radiotherapy services. However, there was a general acknowledgment across the UK and Europe that radiotherapy planning had not been at the forefront of the agenda, and it needed to catch up.

[143] As you can see, in one of the boxes we now have the radiotherapy and chemotherapy advisory group—that is one of the new ones. We submitted a forward plan for radiotherapy to take us to 2016, I believe, which went to the Assembly this year, and that is going forward. The concern across the three radiotherapy centres was that we need to have a clear route map for how we will take this forward. It is predictable—linear accelerators have a lifespan, and you know that they will be renewed. The new plan—and perhaps I would say this—is a much improved version of the one that we submitted in 2002. In it, we have been able to take account of similar work going on in Scotland, and England will also publish a plan later on this autumn, I believe. We have been able to do more than just asking, ‘For the population, how many linear accelerators do you need per million?’, and have been able to begin to look at what the capacity and the demand is, and to look at the efficiency that we would expect from linear accelerators, so that we know that they are being utilised fully, and we look at the skills mix to wrap around that.

[144] Therefore, that is there. That is the national plan that has been submitted to the Assembly. Outside of that, and this is where it possibly gets rather confusing, there has been additional work between the south Wales networks about taking this forward beforehand. That sometimes gets confused with the national advisory plan that is coming, if that helps.

[145] **Helen Mary Jones:** You say in your paper, in looking to the future, that there is a need to ensure transparency and adequate clinical representation. You said a bit about clinical representation. Could you tell us some more about what the transparency issues are, and what plans there are to address those issues?

[146] **Dr Hanson:** We have already mentioned communication in response to questions. Part of the issue for any national group is ensuring that we communicate what we are doing, and make that available. Therefore, in terms of meetings and agendas, and so that anyone can tap in to find out what we have been discussing, those papers are now available on our HOWIS website. Even though we have our network lead clinicians at the meetings, and we video-conference all over the place—or try to—there is an issue around whether people at the multidisciplinary-team level know what is going on. If there is a decision or a consensus about something, which has been thrashed out at the all-Wales level, how do we communicate that? Therefore, it is about that level and trying to ensure that people can have an input. This

is part of the role of the three network lead clinicians, so that when we discuss matters at an all-Wales level and get clinical consensus, if there is a debateable point, the three network lead clinicians can take that back and communicate it around the network. Recently, I was challenged about how we make sure that this happens and we have thought about various ways of e-mailing all multi-disciplinary teams the minutes of meetings and so on. So we are looking at how we can improve the communication back and forth.

11.00 a.m.

[147] **Helen Mary Jones:** That is very helpful. It is a huge challenge, is it not, to get people the amount of information that they can use and need, and to strike a balance between that and giving them perhaps so much information that they would never read it? I know how difficult that is. The purpose of the committee review is for us to make recommendations to the Government about the future of cancer services in Wales. If you could ask us to make one particular recommendation about the decision-making processes—and if it is not appropriate for you to answer this, then that is fine—would there be something on the clinical side that could be done better, and more efficiently, or that would strengthen and support the work that you are trying to do, or is it a question of carrying on with what we are doing, but doing it better?

[148] **Dr Hanson:** From the cancer services co-ordinating group's point of view—and I try to get to all the meetings of the clinical groups—the work that is in train and the current strategy to build radiotherapy, which we have just mentioned, and to implement NICE guidance, should be completed and supported. That is the strategy that we have been working to and it encompasses the national cancer standards. So the cancer standards are not something different, they encompass NICE service guidance and so on. If the groups were here, I think that they would say that we need to focus on completing that piece of work. We have been working on it since 2002, supported by various service and financial framework targets along the way. That needs to be done. We must get it done—there is an urgency to do that, certainly in terms of Wales being able to remain at the forefront and to be able to recruit new consultants to vibrant cancer teams. We need to do that.

[149] **Helen Mary Jones:** That was really helpful. You said that the work needs to be 'completed and supported'. Are there specific things that need to be done to support the work, that, perhaps, you need more of? I am interested in where that support needs to come from and whether there are issues about needing more of it or needing it to be better.

[150] **Dr Hanson:** In a way, it backs into the previous discussion about having solid commissioning and seeing it progress. I know that a lot of work is being done at the moment in the Assembly in terms of improving the commissioning framework. Anything like that would be of real benefit to pushing the whole process forward.

[151] **Rhodri Glyn Thomas:** I see that there are no further questions on paper 1d. Thank you all for your evidence in responding to questions. It has been an interesting and useful session in terms of collecting evidence and information.

[152] Jonathan Morgan has asked to raise a few issues on paper 4, which was to be noted, on horizon scanning for new drugs and treatment, and I am happy to accommodate that request.

[153] **Jonathan Morgan:** I had a quick question on the process that has been undertaken in terms of horizon scanning, and the level of consultation—if any—that has taken place with the private sector and with those in the pharmaceutical sector. I appreciate that horizon scanning, particularly in terms of recognising when new drugs and therapies are likely to come on stream, may put particular financial pressures on commissioning. I am pleased to see

that the group has recommended that it will be able to appraise up to 32 new cancer, cardiac and high-cost drugs, instead of eight. That is certainly a step in the right direction, so I congratulate it on that, but what level of consultation has there been with the private sector? Is it engaged, because, obviously, they are the ones with the information?

[154] **Brian Gibbons:** You are quite right in that we need to engage with individual pharmaceutical companies as well as collectively with Association of the British Pharmaceutical Industry members. They are key partners in doing this, although, from speaking to officials who have worked on this paper, the horizon that they are working to is fairly far off in the future. That is going to be the main source of information, but not to the exclusion of the pharmaceutical industry. The ABPI is involved as a partner in this as we speak—it is not going to be something that has to be new for the dialogue to take place. There is also the Wales industry group, which is linked to the ABPI, but that would not be quite as relevant as the ABPI in this particular instance.

[155] Certainly, from the impression that I had, I was not quite aware as to how far the horizon scanning is going, and much of it is going on for drugs that probably will not be coming down the line for another four or five years, even in a way that we would recognise them. I think that Jane might be able to say a little more about that.

[156] **Dr Hanson:** In terms of new cancer drugs, colleagues and I are working very hard with the cancer networks to finalise a proposal for submission to the Assembly for consideration that will be trying to create a front door, if you like, for cancer drugs and implementing new cancer drugs, so that we will have clinical advice. It would support the AWMSG processes, and that is something that we really need to take forward. What the cancer networks bring is a discussion with the commissioners, because they involve the commissioners, and we felt that rather than actually doing it even at a regional level, we should do that at an all-Wales level, with the three networks working together. So, watch this space, really. That is the intention; that we will submit the proposal to deal with the new cancer drugs in that way at the all-Wales level.

[157] **Jenny Randerson:** The paper includes information about early information on new drugs, cost estimates and so on and the appraisal process, including better co-ordination of appraisal resources with the Scottish Medicines Consortium and NICE, and that also follows on from the resolution passed in Plenary, I assume. However, I cannot see anywhere else in the paper where the links with Scotland are drawn out. I realise that this is a paper on cancer services, but today, if it is accurate—which it may not be, as it was on the news—what we heard about the Alzheimer drugs emphasised that, in Scotland, you can get these drugs for mild Alzheimer's, but not in England and Wales. Where will this liaison with Scotland be, and how are we going to avoid contradictory decisions?

[158] **Rhodri Glyn Thomas:** Before you answer the question, Minister, it would be useful for the committee—I am glad to see that you are prepared to respond orally—to have a note on the situation with Alzheimer treatments in Wales and the implications of this decision, if the information is correct on the BBC. We would like a note on that, but please respond to Jenny's points orally.

[159] **Brian Gibbons:** Ann will be able to fill in the details, but there are bilaterals with Scotland, and the all-Wales medical strategy group's approach will be to look at what NICE is going to do over the next 18 months, possibly two years, and see the drugs that it will study. It has even been suggested to us that, because of the new rapid assessments that NICE will do, this new arrangement might even be overcome by the incoming tide. Assuming that that will not take place, we will look at what NICE is going to do and also have bilaterals with Scotland, looking at what it is going to do. We will look at what our priorities are, and then try to share out the drugs that will be looked at between us and Scotland. There is a difference

between us and Scotland, because the Scottish Medicines Consortium's assessment process is more or less the end of the road, whereas we are subject to NICE. When NICE comes up with definitive guidance, that is the gold standard.

11.10 a.m.

[160] Going back to what Simon was saying, it is inevitable that, when you are in a situation in which the efficacy or cost-effectiveness of various treatments is debatable, you will have a difference of opinion around the edges. You will not have that difference of opinion where there is a clear-cut view one way or the other. This reflects the difficulty with Alzheimer's drugs, in that it has always been a marginal judgment as to how efficacious they are. That, in itself, is a tragedy, because if the drugs were efficacious, they would make a dramatic difference to people's lives and to the health service. However, we get these differences not because Scotland and NICE are poles apart, but because there is a very real debate to take place in an area where the benefits are probably disappointingly small. Scotland may have just taken a slightly different view to NICE. I do not think that it is a black-and-white situation in the way that it is often portrayed, as if people were being denied a treatment that is absolutely, unequivocally and proven to be of benefit to them. In something like this, the balance is narrowly drawn.

[161] **Rhodri Glyn Thomas:** Ann, do you have anything to add to that?

[162] **Ms Lloyd:** I will just add something on the process. What will we decide that we are going to ask the all-Wales medicines strategy group to evaluate on behalf of Wales? The group will be alerted to the impending arrival of new drugs, far in the future—even beyond the five-year stage, if we can do that—by using the Welsh medicines information centre, the national horizon scanning centre and the clinical trials networks. All those groups will have different perspectives and they will come up with a very long list, which the strategy group will then discuss with NICE and the Scottish Medicines Consortium. Therefore, there will be no duplication of effort and the body of evidence that will have been collected will be similarly evaluated. It is of no use to have totally different evaluation systems being applied across a number of bodies. That is how it is going to do it and we will be starting our first-year trial now.

[163] **Rhodri Glyn Thomas:** Thank you. I am glad that we were able to raise that issue; Jenny Randerson was very creative in bringing the latest news about Alzheimer's treatment to the table.

[164] **Brian Gibbons:** On Alzheimer's treatment, the information is probably on the NICE website—it was due to be there this morning. NICE is producing further guidance on the management of Alzheimer's in the next month to six weeks. In making a judgment on this—again, going back to the point that Simon made—cost effectiveness is one of the bases on which a decision is made. NICE is developing treatment protocols—I am not party to them, only to the fact that it is developing them—and the overall package will also have to be taken in that context.

[165] **Rhodri Glyn Thomas:** Given the timescale, perhaps you could refer to it in your next Minister's report.

[166] **Brian Gibbons:** If it is out, I will, but I doubt that it will be out.

[167] **Rhodri Glyn Thomas:** We just want an update on the situation; it would be useful.

[168] **Brian Gibbons:** I suspect that it will be closer to December when we can do that, but we will certainly do it when we can.

[169] **Rhodri Glyn Thomas:** Thank you. We will reconvene at 11.30 a.m.

Gohiriwyd y cyfarfod rhwng 11.14 a.m. a 11.34 a.m.
The meeting adjourned between 11.14 a.m. and 11.34 a.m.

[170] **Rhodri Glyn Thomas:** Croeso yn ôl i'r cyfarfod hwn o'r pwyllgor.

Rhodri Glyn Thomas: Welcome back to this committee meeting.

[171] [COMMITTEE MEMBERS: 'There is no translation.']

[172] **Rhodri Glyn Thomas:** Ymddiheuriadau; dechreuais funud yn gynnar, ond yr oedd y toriad ychydig yn gynnar hefyd.

Rhodri Glyn Thomas: Apologies; I started a minute early, but we also broke a few minutes early.

[173] **Jonathan Morgan:** That is your fault, Chair.

[174] **Rhodri Glyn Thomas:** Mae'n braf cael fy meirniadu am fod o flaen amser, yn hytrach nag ar ôl amser, fel sy'n digwydd fel rheol.

Rhodri Glyn Thomas: It is nice to be criticised for being ahead of time, rather than for being behind time, as is usually the case.

11.35 a.m.

Adroddiad y Comisiwn Hawliau Anabledd ar Anghydraddoldebau Iechyd

Report of Disability Rights Commission into Health Inequalities

[175] **Rhodri Glyn Thomas:** Yr ydym yn falch iawn o gael Will Bee, sef cyfarwyddwr y Comisiwn Hawliau Anabledd, Laura Jerram a David Groves yma. Yr wyf wedi esbonio iddynt bod aelodau'r pwyllgor wedi darllen yr adroddiad. Mae cyfle yn awr i Aelodau godi unrhyw gwestiynau neu wneud sylwadau a gall Will, Laura a David benderfynu pwy fydd yn ymateb i ba gwestiwn. Mae Phil Chick hefyd yma, a bydd yn ymateb i gwestiynau priodol.

Rhodri Glyn Thomas: We are very pleased to have Will Bee, the director of the Disability Rights Commission, Laura Jerram and David Groves here. I have explained to them that committee members have read the report. There is now an opportunity for Members to raise any questions or to make any comments and Will, Laura and David can decide who will respond to which question. Phil Chick is also here and he will respond to relevant points.

[176] **Helen Mary Jones:** I welcome you all and I welcome the report. It is a very useful piece of work. Sadly, it did not contain many surprises for any of us, but it does give an evidence base for things that we may like to ask the Assembly Government to do.

[177] I know that this is an England and Wales report and what we have is the all-Wales bit, but did you find, in the work, substantial differences between England and Wales? Are there things that we are doing better that perhaps other places should learn from or are there things that we are not doing as well that could be learned from?

[178] I want to ask specifically about some of the recommendations, Chair; do you want me to do that now or shall we just deal with the general point?

[179] **Rhodri Glyn Thomas:** Let us have the general response first and then I will come back to you.

[180] **Ms Jerram:** I will take that, if I may. Yes, there are definitely learning points across the two countries, although the experiences of people with learning disabilities and those with mental health problems are perhaps broadly the same in that the barriers that they face are very similar across the two countries. However, the countries' approaches to solving those problems are slightly different and there are some things that we are really pleased to say that Wales is doing very well. One of those is making changes to the GP contract to incentivise certain things, including the introduction of annual health checks for people with learning disabilities, a new annual health review for people with mental health problems, and incentives for making surgeries more accessible for disabled people. So, we are very pleased that there has been a handle on the GP contract in that sense. Those things are not happening in England, so we are really leading the way, which is really good.

[181] However, there are also learning points the other way. One thing that exists in England and does not seem to exist here quite so prominently is the health action plan for people with learning disabilities; one of the smaller points within one of the report's recommendations is to consider whether those would be useful here. So, that is an example, but there are differences of approach.

[182] **Helen Mary Jones:** If I have a criticism of the report, it is that some of the recommendations are very broad. I can see advantages in that, but I can also see potential disadvantages. Recommendation 1 is about action and leadership and it says,

[183] 'All professionals and organisations with a role in the provision of primary care health services to people with learning disabilities or mental health problems must act now to tackle the inequalities in physical health'

[184] I would be looking to know what they need to do—perhaps this could come as part of a process where you work with this committee or with the Welsh Assembly Government. They obviously need to act, because the evidence that is set out in the report shows that the situation is not acceptable.

[185] There are other examples. Recommendation 3 says that urgent and positive action is needed to ensure that people with learning disabilities and/or mental health problems have advice about physical health. However, we need to know from you, or from someone, what specifically needs to be done, because there is a recommendation in the covering paper, that I hope that other Members would support, that we come back to this in six months' time and see how the Government and other appropriate bodies have responded to this. I know that we have a very crowded agenda but we should do it if it is at all possible. In doing that, it would help me to know a bit more about what you and the commission feel regarding who needs to do what.

11.40 a.m.

[186] We need to do something about the situation regarding people making decisions in primary care, but it would help me to know more about what specific action is being taken. I suppose that with a report such as this, you present it to the Government and we will look for action planning and things out of that, but in terms of the discussion today, I would be interested to know more about the specifics. Connected to that, you also mention in the report that there are some very good innovative local projects in Wales, and some of the answers to what specifically needs to be done might lie in some of those projects. So, can you mention examples of things that are being done right in some areas that could be rolled out in other parts of Wales?

[187] **Mr Bee:** If we could split the answer to that, our approach to this general formal

investigation was very much to work with the medical profession and the NHS in Wales, and not to see it as a confrontational exercise with which to hold people up and beat them with it. We wanted it to be a collaborative process with an emphasis on recommendations that will achieve change. I think that we have been very effective in achieving that, and I have been pleased with the degree of collaboration that we have had from Assembly officers and the positive meetings that we have had with the Minister to discuss progress. However, that also means trusting the Assembly, to some extent, to know exactly what levers to pull. The Assembly is the expert, or so one would hope. We cannot profess to know the details of the administration of health and exactly how to do it. We have set out some quite broad and robust recommendations, we hope, but we have not gone down to the minutiae of action planning, which is what we hope will come forward in the responses from the Welsh Assembly Government. Can you highlight some examples, David?

[188] **Mr Groves:** I wanted to emphasise within the report the areas that the Assembly can influence. They are around things such as the need for an overarching health and equalities strategy, so that disability equality across the board takes its place within 'Designed for Life', within an overarching health and equality structure and strategy, and also within health, social care and wellbeing strategies. The first tranche of those, although focusing clearly on learning disability and mental health, did not focus on the physical health needs of people with learning disabilities and mental health problems. There is a clear need for the next round of health, social care and wellbeing strategies to embrace the physical health needs of those particular groups and disabled people in general. So, when the guidance is rewritten, it is important that that is broadened.

[189] One of the other issues that is possibly relevant, and which we highlight within the recommendations, is the need for a clear and transparent pathway that can transform local successful initiatives into national policy. So, there is a need for the process to convert inequalities in health fund examples or education and training advocacy grant examples into national schemes.

[190] **Ms Jerram:** I will add that we have some more detail to this report. This is a summary for Wales, and it is very much a summary of what was a huge piece of work. One of the papers that you may be particularly interested in, if you want that detail, is the inquiry panel report, which is a 200-page document that can show some pathways to some of these outcomes, and suggested pathways, with a lot more detail as to who does what, and which health bodies need to do what. As Will said, they are suggestions; we cannot profess to know the detail, but it is there for you.

[191] The other thing to say is that we have local examples. We are aware of the fact that Powys has done a lot of work on mental health and the links between mental health and physical health. It has a number of projects that involve the voluntary sector and people with mental health problems, including the Healthy Friendships project, which provides advocacy for people with mental health problems—it provides befrienders who can go with people to health appointments. That seems to be a very good idea. We know that one local health board in Wales explored the use of commissioning to in-reach into nursing homes and residential homes, and having a GP and a pharmacist visiting together to health check and improve the access to primary care for people living in those settings. So, those examples are cited throughout the report. As David said, we are very keen that there is more use of these good, innovative projects in Wales, so that there are systematic transparent ways of turning a local project into a national successful project.

[192] **Helen Mary Jones:** There are a few points that I might want to raise further on in the discussion with the Minister.

[193] **Jonathan Morgan:** To start with recommendation 2 on planning and commissioning,

I was very interested in what you said on page 9, I think, about the fact that the Government should produce new guidance on health, social care and wellbeing strategies. Much of what the Government can do is in issuing guidance and publishing strategies relating to primary care and the care that can be commissioned via local health boards. This is a very interesting way of getting things done. However, many services are provided through local authorities. I am not asking you to comment on the particular example that I will use—although please feel free to do so, if you so wish—but there is a debate in Cardiff at present about the provision of services that are developed through the local authority and how moneys are identified to pay for those services. Some people feel that a significant number of adults with learning disabilities will be affected as a result of the decisions that could be taken. When I look at the planning and commissioning, it strikes me that there are so many different fragmented services. While you may have a strategy to improve the health and wellbeing of that category of individual, you are reliant on so many different people taking so many different decisions for so many different budgets. It is difficult to see how you can judge the impact of those strategies.

[194] I was particularly taken with recommendation 3, because, in referring to empowering users—a key area that we looked at when we did the review of mental health services—it sums up the problem in the quote by someone, who says:

[195] ‘I have had an assessment, but not allowed info about this and not allowed to see my care plan’.

[196] This really sums up some of the difficulties that we have in convincing people within the clinical sector to take people seriously when discussing their care plans. What specific, urgent and positive action do you think needs to be taken to get this across to clinicians in the field?

[197] My final comments and question relate to recommendation 7 and the experience that people have of their GP practices. In a number of meetings that I have had in the past few months, it has struck me that many people, at the first instance, see their GP as a first port of call. Sadly, for many people, as I think you have alluded to in the report, the trust in the GP practice can fall simply because of their experiences. How do we raise, or how should we be raising, awareness specifically among GPs and GP practices of some of the difficulties and barriers faced by those individuals with learning disabilities in particular? Also, how do we raise the levels of expertise? Many months ago, we discussed the pilot project in Barry, which was developing GP specialist services. The project in Barry was on orthopaedic services, but some people have suggested to me that perhaps we ought to be asking local health boards to develop expertise in these sorts of areas, in addition, perhaps, to mental health care, among a core number of GPs within each LHB area so that you have people leading on this sort of issue. As a result of that, over time, we could see increased awareness among GPs. Perhaps people’s confidence may be raised as a result of that.

11.50 a.m.

[198] **Ms Jerram:** I will take those in reverse order, if I may. On the last point about GP awareness, we are very pleased to be involved in a project that is being led by the Royal College of General Practitioners, with disability organisations, to promote a development and training plan for all GPs across Wales. We will be involved in that, which will start soon and will provide training on disability equality. There is a difficult balance with training and awareness as to whether to ensure that everyone has an understanding of these barriers and the needs of these groups, because everyone knows someone in their area who should be able to use their local services just like everyone else can. That is important, but we also recognise the importance of some of the expert networks that exist in Wales, and where there are pockets of expertise, we need to find ways of spreading that information.

[199] We want to make it easier for disabled people to register with a GP, and for there to be clearer opportunities for that to take place. Where there is a problem in a relationship with a GP, which results in the breakdown of that relationship, there should be some right of appeal and some independent system set up, particularly, perhaps, when there is a disability-related reason or a discrimination-related reason, which I think is linked to that issue.

[200] On empowerment and care planning, you will see that we have made some recommendations to embed these issues within existing care planning and a unified assessment process. However, you are right; unless service users are then empowered to use their care plan, we are in trouble. We do not want this to just be a bureaucratic exercise, so we need to be working together with disability organisations and disabled people to find out how to empower people in that process, and the use of advocates and all of those things will help. The nitty-gritty information or the detail can be found in some other reports in terms of what service users have told us, but we agree that that powerful relationship—the relationship between the professional and the service user—can be quite unequal, particularly in terms of these groups.

[201] On judging the impact of commissioned services, one of our big problems is that there seems to be an absence of monitoring in terms of these health inequalities and a lack of data being collected. We have now collected a body of data, using the data that were available on patient records, and we need to see a strategy that measures over time whether people are living longer and whether they are surviving from certain conditions, and that might help us to determine whether or not some things are working. There are also other measures of success, in terms of how many people have had a health check and how many GPs are taking up the opportunity to make their services more accessible for their extra payment. There are some things that we can monitor and, in any commissioning process, you do not want to be putting money into something that is not showing some kind of outcome. So, we need to be careful there. I do not know if that helps.

[202] **Mr Groves:** Just to add to that, the initiative around training for staff in primary care, which committee members might be aware of, is called Equip.

[203] **Brian Gibbons:** When was the field work done for the report? I could not find reference to it. The particular example in relation to the person not seeing the care plan is completely against the whole principles of the care programme approach, which we have been trying to drive forward. I do not know whether you have an idea as to when the field work and the evidence was collected.

[204] **Ms Jerram:** That would have been a response to our questionnaire phase—when we sent out questionnaires to disabled people across England and Wales. We have used the Wales responses for those quotes. We had a good turnaround on those questionnaires, and you may remember that 35 per cent of the questionnaires that came back were from Wales, which is good. That would have been at the beginning of the investigation, almost two years ago now. We would hope that some improvements have been made since then.

[205] **Mr Groves:** The questionnaire phase ended in March 2005, so that was in the early days, but we did have a good response from Wales.

[206] **Jenny Randerson:** I wanted to raise the issue of links with the prison service, because there is a high level of learning disabilities and mental health problems among prisoners. GPs have told me how frustrating it is for them that people do not get their medical record when they come out of prison. I visited Cardiff prison's health wing over the summer, and the same story came out there of problems with continuity despite what they are trying to do. Providing records is intrinsic to improving the level of service. There are issues between

the local authorities and the health service, but there are massive issues between the prison service—which is not devolved—and the health service in Wales. Have you looked at this in any way and come up with any potential solutions, or are you were aware of any work being done in the Home Office to try to facilitate that continuity of care?

[207] **Ms Jerram:** We looked at prisons in the early stages to decide how much time we would spend on that area, and I am afraid that we have not done as much work as you may like. However, we have included in the report the need for in-reach into a range of residential and secure settings, and prisons fall into that recommendation. Furthermore, the health checks of people who are about to go into, or are moving between, services and institutions are very important, as is access to GPs at those points. So, we have had concerns that people's health has deteriorated, in some cases, after entering secure psychiatric units, and there needs to be a way of measuring and of providing better healthcare for people in those settings.

[208] On prisons, we found some research of a UK-wide nature and I am sure that we can try to locate that and provide you with that in writing after the meeting.

[209] **Mr Groves:** Within our recommendations, we highlight the necessity of the right of registration when people move from prison back into the community setting.

[210] **Mr Chick:** It would be helpful to raise the fact that we launched the prison mental health pathway for Wales yesterday, which considers the assessment process for people who are entering prison and recognises their specific needs in terms of their physical healthcare, but, more importantly, their mental health needs. That is embryonic in the sense that it is beginning a process. However, there was a great consensus yesterday that this will improve the quality of healthcare provided very much, both in terms of primary healthcare and in the focus on secondary care through the prison in-reach services that we have developed in all Welsh prisons.

[211] Furthermore, this new pathway will also improve the outreach so that we do not lose the opportunity to reach people who may have undergone a detox while they were in prison, and who are dealing with the physical implications of substance misuse. After treating someone while they were in the prison environment, it will also allow us to link them back to community mental health services when they are discharged. Importantly, what is clear about our prisoners is that their physical healthcare on admission is poor, as they often come from socially excluded groups. There is a recognition that mind and body need to be taken care of when they are in prison. We also need to ensure that we maximise the opportunity to plug those people back into community services upon their discharge from prison.

[212] **Lynne Neagle:** On the research on bowel cancer, you refer in the paper to what you describe as, 'alarming data' showing that people with schizophrenia are almost twice as likely to get bowel cancer. Could you say a bit more about that, particularly whether you have drawn any conclusions as to why? You refer later to the need to encourage exercise and diet, but is it just that people with schizophrenia are more likely to have poorer diets and so on, or have you drawn any conclusions about any other possible causes for that higher risk factor?

12.00 p.m.

[213] **Ms Jerram:** Yes, we are concerned about that finding. It is a brand-new finding internationally, and we are waiting for this to be peer reviewed. So, until we have had it peer reviewed, we recommend that the Government just knows that this is here. As soon as it is peer reviewed, we will want the new national bowel cancer screening programme to take these findings on board. Our research does not give us answers on why this is happening and it would be wrong of me, particularly as someone who is not in the medical profession, to say why that might be. Further research is needed to discover the reasons. We do not know

whether it is linked to the medication that people are on. The analysis also found that, after adjustments—for smoking, obesity, deprivation and use of commonly prescribed medication—patients with schizophrenia had a 42 per cent increased risk of breast cancer. So, that came with the same piece of research. Obviously, we have lots of statistical data, only some of which we could summarise in that short report for Wales. However, there are individual research reports, which are all available on our website and which we are hoping the right people in the Assembly, those responsible for health promotion and research, will be using.

[214] **Rhodri Glyn Davies:** Gwn fod Helen eisiau dod yn ôl gyda chwestiynau i'r Gweinidog, ond parhawn â chwestiynau a sylwadau ar adroddiad y comisiwn cyn dod at y pwyntiau hynny. Gwelaf nad oes cwestiynau na sylwadau eraill am adroddiad y comisiwn, felly diolchaf yn fawr ichi am ddod. Mae croeso i chi aros; yr wyf yn siŵr y byddai diddordeb gennych yn y cwestiynau y bydd Helen yn eu gofyn i'r Gweinidog. Atgoffaf bawb fod cyfarfod wedi'i drefnu yn ystafelloedd 22 a 23 yn nhŷ Crucywel, y drws nesaf. Mae croeso ichi ddod i'r sesiwn honno, a fydd yn dechrau yn union ar ôl y cyfarfod hwn, i drafod yr adroddiad a hawliau pobl ag anabledd. Mae'r Gweinidog yma, felly mae'n briodol i Helen Mary fanteisio ar y cyfle i ofyn cwestiynau iddo.

Rhodri Glyn Davies: I know that Helen wants to come back with questions to the Minister, but we will continue with questions and comments on the commission's report before coming to those points. I see that there are no questions or comments for the commission, so I thank you very much for attending. You are welcome to stay; I am sure that you would find Helen's questions to the Minister interesting. I remind everyone that a meeting has been arranged in rooms 22 and 23 in Crickhowell house, next door. You are welcome to attend that session, which will start directly after this meeting, to discuss the report and the rights of people with a disability. The Minister is here, so it is appropriate for Helen Mary to take advantage of this opportunity to ask questions.

[215] **Helen Mary Jones:** It is clear from what the commission has said that work is going on to address the issues that this raises. It is a formal investigation and it is serious stuff. It is the sort of stuff where, if people do not do it, they can end up in court. We have been talking about it as though it was a general research report, but it is not. I remember when you began the investigation why you decided, as a commission, that you needed to do that. So, the status of this is quite serious and it is clear from what you have already said that the Government is responding to that.

[216] The Minister may not be able to answer in full today, but perhaps we could have a written report on this. I know that we will not have time to discuss it in committee. Is an action plan being developed specifically to respond to each of these recommendations point by point? I know that I may be told that there is general work on disability equality going on throughout the division, but we need something to pull that together, such as an action plan that responds to these recommendations and that says what the Assembly Government will do—where it is for the Assembly Government to act, of course, because some of these recommendations are not specifically for the Government, though the Government may take the lead on them.

[217] Within that, I would be interested to know what work has been done to make sure that people understand what all this means; for example, the social model of disability that the Assembly Government has formally adopted—and I could give loads of examples, but I will not. By that, I mean commissioners of services, as well as the front-line clinicians who are dealing with patients on a day-to-day basis. Have you ensured that the training that you commission for clinicians, whether nurse training or medical training, addresses the social model of disability? It is asking people for a big mindset shift. Will knows, because he has dragged me kicking and screaming along this road. I have felt that I have had to shift how I think about these issues. For people who are used to dealing with people as patients, it is easy

to slip back from that model. It is important that we do not think that everyone understands what it means, simply because we have formally adopted it. I certainly think that I am still learning about that.

[218] Therefore, what is being done to develop understanding and to turn the social model into what informs policy in practice? In addition, how are these issues being picked up in Government policy making more broadly? For example, on the plans around managing chronic conditions, are we ensuring that we are building into those plans the specific needs of people with learning disabilities and mental health issues, to enable them and the clinicians who work with them to address their physical illnesses?

[219] I could mention many specifics, Chair. However, could we, as a committee, have some sort of written response from the Government, setting out how it will address these recommendations, and what it will do to try to influence areas where it is not for the Government to address—such as the issues that Jenny Randerson raised about prisons—so that we can come back in a few months' time, and do something meaningful by way of monitoring? It may be that the Government is not minded to accept all these recommendations, because it does not have to. If the Government has decided not to accept any of them, I would be interested to know which ones, and why.

[220] **Rhodri Glyn Thomas:** Yr wyf yn ddiolchgar fod y Gweinidog yma, a'i fod yn barod i ymateb ar lafar. Buasai papur i'w nodi i'r pwyllgor yn ddefnyddiol yn y dyfodol, pan fydd y Gweinidog mewn sefyllfa i roi ateb mwy cynhwysfawr.

Rhodri Glyn Thomas: I am grateful that the Minister is here, and that he is willing to respond orally. A paper to note for the committee would be useful for the future, when the Minister is in a position to give a more comprehensive answer.

[221] Ar bwynt Helen Mary, bwriadaf ddychwelyd i'r mater hwn ymhen tua chwe mis—buasai hynny'n mynd â ni bron â bod at y toriad cyn yr etholiad. Fodd bynnag, bwriadaf sicrhau bod cyfle i chi ddod yn ôl ymhen chwe mis—fwy na thebyg ym mis Mawrth nesaf—i ni weld pa le yn union yr ydym wedi ei gyrraedd ar y mater hwn, cyn diwedd yr ail Gynulliad.

On Helen Mary's point, I intend to come back to this matter in about six months' time—that would take us, more or less, up to purdah, the recess before the election. However, I intend to ensure that there is time for you to come back in six months' time—probably next March—so that we can see where we are on this matter before the end of the second Assembly.

[222] **The Minister for Health and Social Services (Brian Gibbons):** On that last point, the question on when the fieldwork was done is interesting, and it gives us a good baseline from which to start. Many of the initiatives that are pertinent to how we respond to this were probably not in place at that time; for example, even the care programme approach was not really in place, in the Welsh context. Therefore, even if we take such things as the CPA, as regards how we respond with service delivery, the whole approach that has been adopted in the national service framework underpins the social model, hopefully, particularly for people with mental illness.

[223] We are also doing other work, through, for example, Create in Swansea, Cam Ymlaen in Llandudno, the Objective 1 programme through Want 2 Work, the Department for Work and Pensions, Pathways to Work, and so on. Our free bus travel scheme also includes people with a disability. A range of Assembly policies complements the narrow health model, and those policies are not even in my portfolio in many instances, so there is a fair bit of joined-up Government going on there.

[224] However, we need to create a sense of value, or purpose, for all these services. Giving people a full service does not stop at health, and it certainly does not stop with doctors and

nurses, tablets and injections, and so on. That is far too narrow. Apart from people's rights as citizens, therapeutically, if we take a narrow medical model, the outcomes for people will be that much worse as well. Therefore, even within a narrow medical model, that demands a wider social model to deliver benefit. Yesterday, we launched the action plan for mental health promotion in Wales, and that is another example of our commitment to drive this wider agenda forwards.

12.10 a.m.

[225] We can issue the documents, and it is up to us to work with other people then to drive that agenda forwards. For example, on the health, social care, and wellbeing plans, which are being revised at present, the guidance will go out over the winter, to allow organisations to reformulate their health, social care, and wellbeing plans. One of the key parts of those plans is the two statutory organisations that are obliged to be partners in their creation, one of which are the health people, but local government also has a statutory duty. So, again, this underpins the social model of care for the particular area of work that we are dealing with.

[226] Even though we have a good baseline from which to start, I am not sure whether or not six to 12 months will really answer this question. I would be nervous if people were to draw definitive conclusions. Even if we revisited it in six months and said, 'Nothing much seems to have happened', I would urge caution in drawing too much from that. We need to take a much longer-term view. I do not have any evidence, but, anecdotally, I would think that we are looking at two or three years to draw some sort of conclusion as to whether or not we genuinely are making progress. There are a number of encouraging things, which have been mentioned: the directed enhanced services for people with severe mental health problems and the directed enhanced services for people with learning disabilities. The directed enhanced services are, to a certain extent, optional. It is up to practices whether they opt in or out. The local health board must try to provide them, however, so that, in every area, there will be directed enhanced services to deliver this. However, even in the quality outcome framework, one of the indicators for all GPs who are engaged with this is that health promotion must be offered. So, there are three or four fairly significant financial incentives that are offered to practitioners to deliver this agenda, but a culture change is needed. The work with the Royal College of General Practitioners is an important part of that, and that is why we need a slightly longer timeframe to see the benefits.

[227] Prisons health services, with the exception of those at Parc Prison, are commissioned by local health boards, so, hopefully, the revised health, social care and wellbeing strategies will pick up on a fair bit of health in prisons. Laura is right on the findings on bowel cancer and even breast cancer. They are new findings and we need to look at other research and to have those particular findings verified through further research, before we go down the road of fully committing to that. However, they are interesting findings, and it will be interesting to see where that takes us. Health Commission Wales, as the commissioning organisation for bowel screening, will also need to take this on board, but, because these are, as you said, preliminary findings, I would not like to say whether or not it would be reasonable for Health Commission Wales to specifically include people with a learning disability or schizophrenia in a screening programme at this stage. We would need to take professional advice on that. My impression is that it might be something that would need to be confirmed by further evidence before we specifically targeted people with schizophrenia for screening in the way that has been suggested. It is for us to take professional advice on that. It is not that we are excluding it; that is just an initial impression in reaction to the suggestion or proposal.

[228] **Rhodri Glyn Thomas:** Yr wyf yn derbyn pwynt y Gweinidog, sef ein bod yn edrych ar newidiadau tymor hir a sylfaenol yma, ac ei fod yn newid diwylliannol yn

Rhodri Glyn Thomas: I accept the point that the Minister makes, that we are looking at long-term and fundamental changes here, and that it is a change of culture as much as ogystal ag unrhyw beth arall. Mae'n bwysig ein bod fel pwyllgor yn cadw mewn cysylltiad gyda'r comisiwn ac yn cael ein diweddaru ynglŷn â datblygiadau, ond nid ydym yn disgwyl y byddwn yn cwblhau'r gwaith hwn ym mis Mawrth. Fodd bynnag, mae'r broses o gadw mewn cysylltiad a chynnal y deialog yn bwysig.

anything else. It is important that we, as a committee, keep in contact with the commission and are updated on developments, but we do not expect that we will be able to complete this work in March. However, the process of keeping in contact and maintaining dialogue is important.

[229] **Brian Gibbons:** One thing that I meant to say was that there was an interesting piece in one of the appendices in *British Medical Journal* looking at medical education—not nursing education, but medical education—and it was fairly critical of the amount in the curriculum on disability awareness. Some universities are doing very well, but you cannot over-generalise on that. I have given that document to my officials so that we can look at what is happening in the medical curriculum here in Wales as well. Part of the culture of change has to happen in the medical schools.

[230] **Helen Mary Jones:** I would like to respond briefly to what the Minister said, Chair, as I know that we have to move on. I do not think that anybody thinks for a minute that you can solve these problems within six months, Minister, but this is a formal investigation, and I am sure that you will be developing an action plan that will set out how that is addressed. I would have thought that after six months, we would have that action plan and that we should be able to have some targets in that—'targets' is always a dangerous word when you are talking about health and social care, but there should be clear measures so that you will be able to show the commission, and, therefore, us as a committee, what steps are being taken. We are talking about changing the whole culture of delivering the service, so this is huge. Also, as you rightly pointed out, there are some things that, since the beginning of this investigation, have already changed. In your response, presumably, you will be setting out the steps that have already been taken to deal with some of the things that came out of evidence two years ago. Nobody expects you to solve the problems within six months: if you could do that, we would be sending you to Iraq to sort the problems out there. However, as a committee, we have a responsibility to monitor what the Minister is doing in response to what is, I stress, a formal investigation. This is the sort of thing that equality bodies do when they are really worried, and not responding to it is actionable. That is what I was asking for within that timeframe, Minister: a clear action plan that looks at each one of these recommendations, what you have already done, what you are going to do, and what other bodies need to do, and how you can influence or direct, where appropriate, those bodies to do them. On what you said about the responsibility of local government, that is, of course, different, as you can direct local health boards but you cannot direct local government, although you can give guidance. It is about those sorts of things and this comes back to my original point that the recommendations are very broad, and I need to know how I will know whether that something has happened or not, or that steps towards making it happen are in place or not.

[231] **Brian Gibbons:** We are happy to do that.

[232] **Rhodri Glyn Thomas:** Fe allwn ni roi sicrwydd ichi, fel comisiwn, y byddwn yn cadw mewn cysylltiad â'r Gweinidog ar y mater hwn, ac edrych ar y datblygiadau. Deuwn yn ôl at hyn ymhen chwe mis i weld pa gynnydd sydd wedi ei wneud. Mae hynny'n bwysig oherwydd bod natur y pwyllgorau yn newid wedi etholiad 2007, ac efallai na fydd yr un mor rhwydd inni gadw cysylltiad â'r holl fudiadau iechyd a

Rhodri Glyn Thomas: We can assure you, as a commission, that we will keep in touch with the Minister on this matter, and keep an eye on the developments. We will come back to this in six months' time to see what progress has been made. That is important as the nature of committees will change after the 2007 elections, and we will perhaps not be as free to keep in touch with all the health and social services organisations under the new regime, gwasanaethau cymdeithasol dan y system newydd, lle bydd llawer mwy o graffu ar ddeddfwriaeth o'r rheidrwydd. Felly, byddwn yn eich gwahodd yn ôl cyn diwedd y Cynulliad hwn.

where the emphasis will be, of necessity, on greater scrutiny of legislation. Therefore, we will invite you back before the end of this Assembly.

[233] Diolch yn fawr am yr adroddiad ac am roi cyfle inni edrych ar yr argymhellion.

Thank you very much for the report and for the opportunity to look at recommendations.

12.19 p.m.

Is-ddeddfwriaeth: Rheoliadau Cynllun Cychwyn Iach (Disgrifiad o Fwyd Cychwyn Iach) (Cymru) 2006
Secondary Legislation: The Healthy Start Scheme (Description of Healthy Start Food) (Wales) Regulations 2006

[234] **Rhodri Glyn Thomas:** Nid oes gwelliannau wedi eu cyflwyno, ond cyflwynwyd pum pwynt am eglurhad. Os oes pwyntiau sy'n wahanol i'r pump hyn, mae'n bosibl y bydd rhaid inni ofyn am nodyn ar hynny oherwydd, gyda deddfwriaeth, mae'n bwysig rhoi rhybudd blaenorol, yn hytrach na'n bod yn gofyn i rywun i wneud dyfarniad yn y fan a'r lle. Nid yw hynny'n ffordd briodol o ymwneud â deddfwriaeth. Fodd bynnag, gallwn nodi unrhyw bwyntiau eraill a gofyn am eglurhad pellach.

Rhodri Glyn Thomas: No amendments have been put forward, but there are five points for clarification. If there are any points other than these five, we may need to ask for a note on that because it is important that forewarning is given with legislation, instead of us just asking someone to give us a judgment here and now. That is not an appropriate way of dealing with legislation. However, we can note any other points and ask for a further explanation.

12.20 p.m.

[235] Mae Helen Mary Jones wedi cyflwyno pedwar pwynt. A yw Helen yn dymuno—

Helen Mary Jones has presented four points. Does Helen wish to—

[236] **Helen Mary Jones:** Cawn ateb y Gweinidog. Mae'r pwyntiau ym mhapurau pawb.

Helen Mary Jones: We can have the Minister's answer. The points are included in everyone's papers.

[237] **Brian Gibbons:** The first point was in relation to the value of the tokens. The tokens did not have a monetary value per se. They were essentially part of a barter system—you presented your token and you got the goods or the item without a monetary exchange. In that sense, there was no monetary value to the food tokens, just value in what you got in return for them.

[238] On breastfeeding, you generally get the forms to apply for this scheme through maternity services. When you turn up at a maternity clinic, this is one of the batch of forms that you fill in to become eligible for the scheme, if you meet the benefits criteria or if you are under 18 years of age. The midwives are involved in promoting breastfeeding, so that is built into the system. Another important incentive is going to change, because the overdependence on milk in the original scheme sent out a mixed message to people—'We believe in breast feeding, but here is a wheelbarrow-load of formula milk'. The make-up of what is available under the new healthy start scheme sends out the right signals, and the milk element has been

reduced is in line with that. There has not been a significant change in the budget: it is still £9 million.

[239] **Ms Lloyd:** We have not spent that much for a number of years.

[240] **Brian Gibbons:** I think that, in fact, it was originally a good bit higher. I think that I remember a figure of £12 million or something three or four years ago, but do not quote me on that.

[241] **Rhodri Glyn Thomas:** It is not up to me whether Helen Mary wants to quote you or not.

[242] **Helen Mary Jones:** He just gets nervous when he sees me writing things down.

[243] **Brian Gibbons:** Yes, that is right.

[244] The anticipated take-up of the scheme is in the context that it has been difficult to get full engagement with it. Offering a wider variety of choices to people may make a difference, and there have been concerns that any baby that would manage to consume all the milk that was being offered—

[245] **Helen Mary Jones:** It would drown probably.

[246] **Brian Gibbons:** Yes, you would be drowning them in milk, which is a reason why the scheme had to change to a more balanced and healthy diet. I do not know whether Helen has any other questions on that.

[247] **Helen Mary Jones:** I have a supplementary question on the point about uptake, and perhaps a note would be appropriate, if the Minister cannot give an answer now. I would like to explore what businesses are being targeted as outlets for the scheme. I know that you are targeting the main multiples, but we know that, in the most deprived communities, it is going to be difficult for people to get to those shops—they use their small corner shop on their estate. With a wider variety of goods available, what can be done to ensure that the outlets are ones that people can get to and use? I have concerns about that.

[248] **Brian Gibbons:** When I saw this regulation that was precisely the view that I took as well. At the moment, you get a lot of these items from the milk round, but also from chemists, pharmacists and welfare clinics. This scheme is opened up to a much wider range of organisations. We are not totally masters of our own destiny in this because we are, essentially, administering a Department of Health scheme and it is primarily responsible. However, our press colleagues are working with the Department of Health to try to ensure that when the scheme is launched, other possible providers will be alerted to it and it will become more widely available. There is no reason, for example, why even farmers' markets or food co-operatives could not do this, as long as they can meet the criteria in terms of fresh fruit—you do not have to supply everything either; as long as you can provide some of the elements of this, you are eligible for the scheme. So, I fully agree that people in many of the more disadvantaged communities—because, other than those under 18 years of age, those are people who are on benefits and low incomes—will be the recipients. So, it is important that issues of access are addressed.

[249] **Helen Mary Jones:** This is probably stating the blindingly obvious, and you are probably doing it anyway, but one way that you and the department might deal with that is by talking to organisations like Spar and Londis, which are umbrella organisations—they kind of are businesses and they are not businesses. That might be a way of getting into some of those smaller shops in areas where you have a large concentration of potentially underprivileged

children and mothers.

[250] **Brian Gibbons:** I agree, and we also need individual proprietors.

[251] **Helen Mary Jones:** Yes.

[252] **Brian Gibbons:** As I say, we have seen the publicity yet, so we do not quite know what the Department of Health is planning, but I agree that, once we have a view of what it is doing—particularly because of our situation here in Wales—we need to see whether or not we should do something a little more proactive to promote it among the smaller retail outlets in disadvantaged communities.

[253] **Jenny Randerson:** I was concerned, Minister, to see that the upper age limit for eligibility for the vouchers was being reduced from five to four. That seems to be a retrograde step. I would like to know why that is and whether we would have legally had the freedom—I understand that the legislative situation is complex—to stick with the five-year-old upper limit? I realise that this is, in some ways, a joint scheme, but could we have had separate eligibility criteria?

[254] **Brian Gibbons:** No. My understanding is that we were tied into the Department of Health scheme and even the commencement Order, if I am correct, is dictated by the Department of Health rather than by us in this instance. We disputed that with it, but it was an argument over principle rather than practicalities in the sense that it is a good idea that we try to get it up and running in November and that is what the Department of Health has done. There was no point arguing the toss with it. We agreed that we should go down this road, so let us get on with it rather than get involved in the constitutional argument with the Department of Health.

[255] We can vary what is available for the vouchers. For example, fruit juice is not included at present and one of the reasons for that is that a lot of stuff that is branded as being natural fruit juice is nothing like it. Equally, certain types of vegetables and fruit would be included if we could be sure that they would not include things like chips and so forth, or stuff that requires deep frying or something like that. So, there are options for us to vary what will be included in the scheme, but, until those issues are clarified, we are proceeding on the basis of what has been agreed with the Department of Health. The rationale was to try to concentrate our efforts on where we felt the need was greatest—in other words, the younger children—and to expand the scheme to include all under-18s. The scheme is largely, as I said to Helen Mary, the same sum of money, but it is a case of how that is distributed. So, it was an effort to distribute it to focus it on the earlier years and then to bring in the under-18s, regardless of the means test, which was not the case before.

[256] **Jenny Randerson:** I suspected that it was a case of the money, but, given that—

[257] **Brian Gibbons:** It is not essentially the money. This was based on a review that was done about six or seven years ago on how the scheme was working, and the primary reason for changing this scheme was not the money; it was due to an overdependence on milk. A wider variety of provision of fruit and vegetables, and so forth, would make sense. So, the primary driver was the quality of the project—it was not the money. Once that decision was made, it was meant to be cost-neutral.

12.30 p.m.

[258] **Jenny Randerson:** I fully accept that the new scheme is much better than the old scheme, which was out of date—it was well-intentioned in its time, but is now inappropriate. I gather that the amount of formula milk available was about twice as much as a child should

have at that age, and so on. Given that it is a much better scheme, I am sure that you would agree, Minister, that if you could continue it up to the age of five it would be better than stopping it at the age of four. You said that it should be done within this sum of money; given that the money, according to what you said earlier, has been under-spent, it is a great pity that we are not able to continue the scheme up to the age of five. I understand the point that it is better to get it up and running than to spend ages arguing about the complexities of the situation. However, you may think in the future about trying to get permission from the UK Government for us to do something for ourselves, and expand it to the age of five. We have special needs in Wales—we have an intensity of need that is not seen anywhere else. It was said on television this morning that eating problems are greater in Wales than they are in the rest of UK.

[259] **Brian Gibbons:** One of the factors is that it used to be quite common for children to start school at the age of five; now, they start aged four, or three in most parts. When Flying Start kicks in, children will be in some sort of childcare/education system even under the age of three. I do not know for certain, but I am sure that the age of five was historically taken as a time when children would be starting school and getting free school meals, and so forth. It is one of the historical legacies in this scheme. How far back does the scheme go?

[260] **Ms Allen:** It goes back to the 1940s.

[261] **Jenny Randerson:** Yes; I remember going with my grandma to collect the wonderful concentrated orange juice.

[262] **Rhodri Glyn Thomas:** O fynd yn ôl i ddyddiau ysgol Jenny Randerson yr ydym mewn perygl o grwydro ymhell oddi wrth y pwyntiau o eglurhad ar ddeddfwriaeth. Mae gan Lynne Neagle bwynt i'w ychwanegu, ond pwynt i'w nodi yw hwnnw, o bosibl, gan na fu rhagrybudd.

Rhodri Glyn Thomas: We run the risk of deviating considerably from the points of explanation on legislation if we go back to Jenny Randerson's schooldays. Lynne Neagle has a point to add, but it is possibly a point to note, as no advance warning was given.

[263] **Lynne Neagle:** I agree about the age issue, because you are talking abut anyone over the age of three not being in the programme. Although I recognise what the Minister said about children starting school, there are still many people who do not take up nursery entitlement and so on. Health-visitor provision is all geared towards children up to the age of five, and the dietary advice that is given in terms of switching to low fat foods is given to children from the age of five. So, we need to think about that.

[264] I wanted to ask about the amounts of money and how they have been arrived at. A sum of £2.80 for a child aged three and under is not huge—it is half the amount of money for a child aged one and under. Is that because of the additional cost of formula? How were those amounts arrived at, because you will not get much milk and fruit and vegetables for a toddler for £2.80?

[265] **Brian Gibbons:** I do not know about that. I know that in the food co-op in the upper Afan valley you can get a hell of a lot of fruit and veg for £2.80. I do not know whether Irene or Claire can explain why—

[266] **Ms Bond:** Up to the age of one, children get double vouchers, worth £5.60.

[267] **Lynne Neagle:** What was the thinking behind the two amounts, and why was it double for one-year-olds and half for the slightly older children?

[268] **Ms Allen:** Again, in the first year it is also to the benefit of the mother. So, there are

double vouchers going in, but I do not know how the actual monetary value is arrived at. We can look at that and give you a note from the research undertaken by the Department of Health. However, a pilot project was undertaken in Devon and Cornwall and the feedback from that was excellent—the uptake was much increased and the value of the voucher was also assessed. We can give you some feedback on that.

[269] **Rhodri Glyn Thomas:** Diolch yn fawr. Ni chredaf bod modd inni gael mwy o eglurhad; credaf ein bod wedi cael mwy o eglurhad nag y gallem ei ddisgwyl ar y pwyntiau hynny. Diolch i chi ac i'r swyddogion.	**Rhodri Glyn Thomas:** Thank you. I do not think that we could have any more clarification; I think that we have had more clarification than we could have expected on those points. Thank you to you and to the officials.

Papurau i'w Nodi
Papers to Note

[270] **Rhodri Glyn Thomas:** Mae dau bapur i'w nodi, sef papur 4, yr ydym eisoes wedi'i drafod, a chofnodion y cyfarfod diwethaf. Diolch.	**Rhodri Glyn Thomas:** There are two papers to note, namely paper 4, which we have already discussed, and the minutes of the last meeting. Thank you.

Daeth y cyfarfod i ben am 12.35 p.m.
The meeting ended at 12.35 p.m.