



**Cynulliad Cenedlaethol Cymru
The National Assembly for Wales**

**Y Pwyllgor Iechyd, Lles a Llywodraeth Leol
The Health, Wellbeing and Local Government
Committee**

**Dydd Mercher, 30 Ebrill 2008
Wednesday, 30 April 2008**

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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'r pwylgor yn bresennol
Committee members in attendance

Lorraine Barrett	Llafur
	Labour
Irene James	Llafur
	Labour
Helen Mary Jones	Plaid Cymru
	The Party of Wales
David Lloyd	Plaid Cymru
	The Party of Wales
Nick Ramsay	Ceidwadwyr Cymreig
	Welsh Conservatives
Jenny Randerson	Democratiaid Rhyddfrydol Cymru
	Welsh Liberal Democrats

Eraill yn bresennol
Others in attendance

Carol Lamyman Jones	Cyfarwyddwr, Bwrdd y Cynghorau Iechyd Cymuned Director, Board of Community Health Councils
Naomi Phillips	Swyddog Materion Cyhoeddus, Cymdeithas Dyneiddwyr Prydain Public Affairs Officer, British Humanist Association
Greg Pycroft	Y Gymdeithas Seciwlar Genedlaethol National Secular Society

Swyddogion Gwasanaeth Seneddol y Cynulliad yn bresennol
Assembly Parliamentary Service officials in attendance

Stephen Boyce	Gwasanaeth Ymchwil yr Aelodau Members' Research Service
Carolyn Eason	Gwasanaeth Ymchwil yr Aelodau Members' Research Service
Steve George	Clerc Clerk
Joanest Jackson	Cynghorydd Cyfreithiol Legal Advisor
Catherine Lewis	Dirprwy Glorc Deputy Clerk

*Dechreuodd y cyfarfod am 9 a.m.
The meeting began at 9 a.m.*

Ethol Cadeirydd Dros Dro
Election of Temporary Chair

[1] **Mr George:** I declare the meeting of the Health, Wellbeing and Local Government Committee open. The first item on the agenda is the election of a Chair under Standing Order No. 10.19, in the absence of Jonathan Morgan. I invite nominations for the appointment of a temporary committee Chair.

[2] **Helen Mary Jones:** Yr wyf yn **Helen Mary Jones:** I nominate Nick enwebu Nick Ramsay.

[3] **Mr George:** I see that there are no other nominations, so I declare Nick Ramsay appointed and invite him to take the chair.

*Penodwyd Nick Ramsay yn gadeirydd dros dro.
Nick Ramsay was appointed temporary chair.*

9.01 a.m.

Cyflwyniad, Ymddiheuriadau a Dirprwyon Introduction, Apologies and Substitutions

[4] **Nick Ramsay:** I welcome members of the public gallery and remind people of the availability of headsets for simultaneous translation and sound amplification. The ushers will assist with any problems. Translation is available on channel 1 while channel 0 is the floor language. I ask everyone, including those in the public gallery, to ensure that all mobile phones, BlackBerrys and pagers are switched off. I advise everybody, in the event of an emergency, to follow the advice of the ushers.

[5] Apologies have been received from Jonathan Morgan, Ann Jones and Val Lloyd. There are no substitutions.

[6] I invite Members to make any declarations of interest under Standing Order No. 3.16. I see that there are none.

9.02 a.m.

Ymchwiliad Pwyllgor i Bapur Ymgynghori Llywodraeth Cynulliad Cymru 'Cynigion i Newid Strwythur y GIG yng Nghymru'—Tystiolaeth gan Fwrdd y Cyngorau Iechyd Cymuned Committee Inquiry into Welsh Assembly Government Consultation Paper 'Proposals to Change the Structure of the NHS in Wales'—Evidence from the Board of Community Health Councils

[7] **Nick Ramsay:** I welcome Carol Lamyman Jones, director of the Board of Community Health Councils in Wales. Thank you for agreeing to attend.

[8] Is there still a problem with the computer that controls the microphones or has that been rectified?

[9] **Mr George:** There is still a problem, so it would help if you could press the button on your microphones before you speak.

[10] **Nick Ramsay:** Please be mindful of the need to turn your microphones on and off throughout the session.

[11] This is the second oral evidence session of the committee's scrutiny inquiry. Thank you for attending, Carol Lamyman Jones. Rather than allow you to make a presentation, we will launch straight into asking questions, if that is okay with you. I will ask the first question.

[12] The Assembly Government proposes to abolish the internal market in the NHS in

Wales and to move from a commissioning to a planning model. How effective has the internal market been in Wales and what might you gain by its abolition?

[13] **Ms Jones:** [Inaudible.]

[14] Local health boards are ineffective as they stand. The idea of abolishing them is welcomed by the majority of CHCs in Wales.

[15] **David Lloyd:** Welcome to the committee. On abolishing the internal market and moving from a system of commissioning to a system of planning the health service, the consultation document proposes to remove responsibility for commissioning secondary healthcare from local health boards and for resource allocation to be undertaken by a new national board. Would a national approach offer a more effective means of securing health services in Wales in your opinion?

[16] **Ms Layman:** I think that it would. Again, although it is still early, the consensus of opinion is that the idea of one board would be effective in terms of economies of scale and in the procurement of services. Obviously, the choice of chief executive for such a board would be crucial, but a job at that level would attract the cream from Wales or from wherever. Indeed, I think that there is a general feeling that the special health authority option would be the most favoured for its independence. In fact, I have quite a long list of answers that you are welcome to have on the detail. However, if appointed, the board should consist of representatives of all NHS trusts in Wales. Also, I feel that there has to be an independent voice, which is why it is important that the Board of Community Health Councils in Wales is involved in that planning, with involvement of the Wales Council for Voluntary Action as well to ensure that volunteer organisations are on board. Obviously, you need to look at other organisations with links to the NHS, such as the Care and Social Services Inspectorate Wales and the local authorities. A lot of time and effort has to be put into considering this as we are still early on in the consultation.

[17] I will expand a little on the matter by adding that, although we were not aware of the consultation early on, I met, for the first time, the Minister for Health and Social Services on 10 March, prior to coming in to my present role. I have been in post for six weeks, although I have been involved with community health councils for much longer than that. It was felt that there is a need for localism in terms of community health councils and to assist with this—obviously, this is not our consultation, but we are there to assist in the dissemination of the information to the public, and we have already started to do that.

[18] In terms of the consultation document, we have summarised it and produced a very simplified document that we have disseminated far and wide to all localities in Wales so that when it comes to public, local and technical events, particularly the letter that Mrs Ann Lloyd is organisation, the detail of which we heard this Monday, we will be well prepared to gather information about public consensus.

[19] **Lorraine Barrett:** The consultation document states that formal planning activity will be based on three levels: national, health community, and local authority. How effective do you believe this arrangement will be, particularly in meeting healthcare needs at a local level? Do you think that local health boards work more effectively with their boundaries aligned to the trust areas rather than to local authority area?

[20] **Ms Layman:** It is a difficult one, but the first question—I am sorry, but can you repeat the first element of it?

[21] **Lorraine Barrett:** I am sorry; perhaps I should not have put them together. Formal planning activity will be based on three levels: national; health community; and local

authority. How effective do you think this arrangement will be, particularly for local health needs?

[22] **Ms Layman:** I have been made aware that consultation seminars are being held by local authorities—we have been informed of that. I assume that, on the national level, the technical events, which are primarily for the chief executives of trusts, local health boards, the board of community health councils and the WCVA, will deal with the more strategic issues. Then, of course, in all CHCs, we are attempting to ensure that we are there to inform the public, as I said earlier, and to ensure that they can ask specific questions about their own local health needs, particularly in terms of the issues of transferring community services from trusts to LHBs, because that is important.

[23] In our response to the public, when people ask what is happening, they need to know what is evident in their locality and, invariably, that only happens when they are in need of services, so it is important that we get involved early on to explain clearly, in a jargon-free way, what is going on. The second question was about local health boards—

9.10 a.m.

[24] **Lorraine Barrett:** Yes, it was about the boundaries of local health boards being aligned with those of local authorities.

[25] **Ms Lamyman Jones:** It makes sense, at this early stage, that there is coterminosity—it enables them to offer that greater vision, if you like. I mentioned economies of scale, and as I say, these are early days, but we are hopeful that disseminating that information now will be a constructive step—there is nothing worse than the public perceiving a fait accompli, and that it is unable to offer any alternatives. It is also important that we speak to the people who need to comment, and not just the agreed bodies who would normally participate. That is fundamental—that people know exactly what is going on, in order for it all to be clear, open and transparent.

[26] **Jenny Randerson:** Do you think that local health boards would work more effectively if boundaries were aligned with those of the trusts than with those of local authorities, as at present?

[27] **Ms Lamyman Jones:** To be honest, I think that the jury is out on local health boards. In some areas, where they are more local, if you like, or on a smaller scale, there is a better working relationship with NHS trusts. It is only through real partnership working that there can be any cohesion, and that is essential. Obviously, it pops into one's head that, eventually there will be coterminosity in terms of local authorities, LHBs and trusts, and that might be the future. However, at the current time, it is important that people are made aware of who does what—I am sorry to repeat it, but it is true. Not everyone knows what a local health board does, so it is down to us to explain how it will affect Joe Bloggs on the street. Ultimately, people want to know if they will be able to receive their services on time, delivered in an equitable fashion, with clarity as to who is doing what.

[28] **Jenny Randerson:** If the number of LHBs is reduced from 22 to eight, what effect will that have on the relationship between LHBs and local authorities?

[29] **Ms Lamyman Jones:** I have not had much one-to-one contact with local authorities recently, in terms of their perception of what is going on. That will become more apparent when we hold the explanatory technical events. However, there is a need for greater understanding, and greater clarity—particularly around the shift to community services, which is my special concern. We need to know whether local health boards are sufficiently experienced to deal with community services. I am sorry if I am digressing, but I think that it

is important. There is a lot of confusion today. In certain areas in Wales, there has been an overspend on LHBs, and some specific services, namely, prescribing, and continuing care. So, in terms of looking at the new structure, we need a named clinician or nurse with responsibility for that shift to community services. That is most important, and in terms of the local authorities, we need greater clarity concerning that, and the effect that it will have in terms of boundaries and the co-location with local health boards. I think that that will become more apparent once we have understood what strategic overview Mrs Ann Lloyd has in terms of her technical events.

[30] **Helen Mary Jones:** Y syniad gwreiddiol dros gael byrddau iechyd lleol ac awdurdodau lleol gyda ffiniau cyffredin oedd iddynt gydweithio'n agos ar faterion yn ymwneud â'r gymdeithas, er enghraifft gofal parhaus, a phethau felly. A oes gennych, fel cynghorau iechyd cymunedol, syniad ynglŷn â pha mor effeithiol y bu hynny? Y syniad y tu ôl i hynny oedd y byddai cael ffiniau cyffredin yn gwella cydweithrediad.

[31] **Ms Lamyman Jones:** Nid wyf yn credu bod cydweithio rhwng y byrddau iechyd lleol a'r ymddiriedolaethau iechyd wedi bod yn llwyddiannus—nid yw wedi bod yn llwyddiannus yn yr ardaloedd lle'r wyf wedi bod yn gweithio. Credaf bod gofyn cael cydweithio sy'n gwbl addas i'r gwaith mae'r cyrff i fod i'w gyflawni. Hyd nes y byddant yn cael eu hariannu mewn ffordd effeithiol, nid wyf yn meddwl y bydd hynny'n digwydd. Efallai bod modd edrych ymlaen a datblygu rhywbeth sy'n mynd i fod yn effeithiol yn yr hir dymor.

[32] **Nick Ramsay:** Do you think that the reduction in the number of local health boards will, ultimately, be detrimental to local accountability? I know that you have covered a large part of that.

[33] **Ms Lamyman Jones:** Sorry, I have jumped a little.

[34] **Nick Ramsay:** You spoke about the coterminosity issue, and of increasing that coterminosity, but do you think that it will be difficult to retain those local links that many people have grown to think to be quite important?

[35] **Ms Lamyman Jones:** No, I do not think so, but there needs to be greater clarity in the definition of what can and cannot be managed on a large scale in terms of LHBs. In terms of clarity of what they do—I am sorry, I know that I am singing from our CHC hymn sheet here—it is important that we play a fundamental role. The Minister has intimated, albeit verbally, that she sees a role for the localism element of all CHCs in Wales in delivering that. As I say, the jury is out in terms of local health boards, per se, but it is sensible in terms of the coterminosity issue. It currently appears that there is consensus that no great problem is perceived in reducing the number of LHBs from 22 to eight.

[36] **Helen Mary Jones:** Mae dogfen y **Helen Mary Jones:** The Government's

Llywodraeth yn tynnu sylw at gryfderau a gwendidau'r gynrychiolaeth bresennol ar y byrddau iechyd lleol. Dywed, ar un llaw, ei bod yn bositif bod cymaint o randdeiliaid a phobl sydd â diddordeb yn cael eu cynnwys, ond, ar y llaw arall, bod hynny'n cael effaith ar eu gallu i wneud penderfyniadau mewn ffordd sy'n atebol. A oes gennych, fel mudiadau, syniadau ynglŷn a pha mor effeithiol yw'r gynrychiolaeth bresennol ar y byrddau iechyd lleol?

[37] **Ms Lamyman Jones:** Ni allaf siarad ynghylch y trefniadau ledled Cymru, ond gallaf siarad am y sefyllfa yn sir Gaerfyrddin, lle'r oeddwn yn gweithio cyn dod i'r swydd hon. Yr wyf yn meddwl bod y byrddau iechyd lleol yn cynnwys pobl broffesiynol sy'n gallu cyfrannu cryn dipyn i'r trafodaethau, ond tuedda'r lefel uwch i fwrw ymlaen â'i waith yn hytrach na gwrando, efallai, ar yr hyn sydd gan y bobl broffesiynol i'w ddweud. Dyna sydd wedi'i ddweud wrthyf, felly credaf bod rhaid—beth bynnag y bydd y bwrdd rheoli newydd yn ei gynnwys—cael cynrychiolaeth deg o bobl sy'n gallu cyflawni'r hyn sydd ei angen.

9.20 a.m.

[38] **Helen Mary Jones:** Ymhellach i hynny, wrth edrych at y dyfodol, a ydych chi fel cynghorau iechyd cymuned wedi ystyried sut y dylem sicrhau bod llais y claf yn cael ei glywed yn y byrddau iechyd lleol newydd?

[39] **Ms Lamyman Jones:** Fel y soniais yn gynharach, mae'n bwysig bod y sector gwirfoddol yn chwarae rhan annatod ar y byrddau hynny, yn ogystal â bwrdd y cynghorau iechyd cymuned—hynny yw, rhywun fel fi, sy'n gyfarwyddwr, sy'n gallu ychwanegu at y sgwrs a sicrhau bod llais y claf yn ganolog i bopeth sy'n cael ei drefnu. Wrth gwrs, mae cyrff eraill hefyd. Fodd bynnag, mae'n rhaid edrych ar hyn yn awr, yn hytrach na fel rhywbeth ychwanegol. Mae'n rhaid sicrhau bod llais y claf, yn enwedig, yn ganolog i bopeth sy'n cael ei drefnu.

[40] **Helen Mary Jones:** A ydych yn awgrymu felly y dylem ni fel pwylgor, wrth ymateb i ddogfen y Llywodraeth, ddweud wrth y Llywodraeth ei bod yn bwysig ei bod

document mentions the strengths and the weaknesses of the present representation on local health boards. On the one hand, it says that it is positive that there are so many stakeholders and interested people involved, but, on the other hand, it says that that also has an effect on their capacity to take decisions in an accountable way. Do you, as organisations, have any views about the effectiveness of current representation on local health boards?

Ms Lamyman Jones: I cannot speak about the arrangements in all parts of Wales, but I can speak about the situation in Carmarthenshire, where I worked before taking up my present post. I think that the local health boards include professional people who can contribute much to the discussions, but those on a higher level tend to carry on with their work rather than listen, perhaps, to what the professionals have to say. That is what has been said to me, so I think that we need to look—whatever the new management board will look like—to have a fair representation of people who can do what is needed.

Helen Mary Jones: Further to that, looking to the future, have you as community health councils considered how we should ensure that the patient's voice is heard in the new local health boards?

Ms Lamyman Jones: As I mentioned earlier, it is important that the voluntary sector plays a central role on the board, as well as the board of the community health councils—namely, someone like me who is a director who can add to the debate and ensure that the patient's voice is central to everything that is arranged. Of course, there are other bodies too. However, this must be looked at now, rather than considered as an add-on. We must ensure that the patient's voice, especially, is at the centre of everything that is arranged.

Helen Mary Jones: Are you suggesting therefore that we as a committee, in responding to the Government's document, should tell the Government that it is

yn sicrhau o'r dechrau bod llais y claf yn gryf?

[41] **Ms Lamyman Jones:** Ydwyf; dylai llais y claf fod yn gryf ac yn ganolog i bopeth sy'n cael ei drefnu. Dyna pam yr ydym ni fel corff wedi sicrhau ein bod wedi dosbarthu'r wybodaeth cyn i'r Cynulliad wneud hynny, gan fod aros am y gwahanol ddogfennau yn cymryd amser, ac mae'r wythnosau yn mynd heibio. Yr ydym yn edrych ar 25 Mehefin i wneud penderfyniad. Dyna pam yr wyf yn hynod falch fod pob cyngor iechyd cymuned wedi cydio yn hyn, ac wedi trefnu cymryd rhan yn y gwahanol gyfarfodydd, ac wedi trefnu cyfarfodydd annibynnol, fel eu bod yn gwneud eu gorau i gael cynifer o bobl â phosibl i ymgymryd â'r gwaith, ac i wrando a chynnig trafodaeth.

[42] **Lorraine Barrett:** The consultation document suggests two possible approaches to defining the role of the NHS trust boards. One would be where the trust boards scrutinise the trust from the viewpoint of communities and service users, and the other option would be a greater emphasis on providing direction and control of the services. Could you say something about your views on each of these approaches?

[43] **Ms Lamyman Jones:** In terms of direction, I believe that the consensus, again—and I can only give you what we have received as of today—is that, if a special health authority board has the authority, not only for funding, but for the day-to-day overarching responsibility, that is the favoured option. That would allow NHS trusts to get on and do what they are meant to do, namely providing services to the public. Ensuring the independence of this board would be preferable to all the other options that have been made. Does that answer your question?

[44] **Lorraine Barrett:** Yes.

[45] **Nick Ramsay:** Jenny Randerson has the next questions.

[46] **Jenny Randerson:** Do you believe that NHS trust boards should be made more directly accountable to their local communities than at present, and, if so, how?

[47] **Ms Lamyman Jones:** When you say directly accountable to their local communities, what aspect are you referring to?

[48] **Jenny Randerson:** One of the criticisms of NHS trust boards has been that decision making has been opaque, and has not been communicated with the communities that they serve. They will be even bigger in the future, so there will be a greater tendency for them to be very distant from their communities. The big criticism has been that they have not consulted meaningfully on proposed changes to the services that they are planning to provide. It has been said that they are too autonomous. The Minister's paper proposed that the NHS board should deal with the Government aspect of this. However, it does not deal with accountability to local communities. I am suggesting that you might consider how they could resolve the difficulties that I have outlined.

[49] **Ms Lamyman Jones:** Absolutely. You are quite right, but that is not always

important from the beginning that the patient has a strong voice?

Ms Lamyman Jones: Yes; the patient's voice should be strong and central to everything that is arranged. That is why we as an organisation have ensured that we have disseminated the information more rapidly than the Assembly has done, because waiting for the various documents takes time, and the weeks fly by. We are looking at 25 June for making a decision. That is why I am extremely glad that every community health council has taken this up, and has arranged participation in the various meetings, and has arranged independent meetings, so that they do their best to get as many people as possible to participate in the work, and to listen and to offer debate.

reflected. In some cases—though not in every case—the lack of openness and transparency is down to the media and their reaction in wanting bad news stories. Having said that—and, again, I speak from experience—there is a tendency to want to hone in on the negatives and not always to seek out the positives. I agree with you that there is a need for trusts to become more accountable. I am sorry, I know that I am sounding our trumpet once again, but there is a real case for community health councils to be a part of that and to take a more strategic role in terms of consultation. Some criticism has been levied against local health boards in the past—whatever one might think of that—for not consulting adequately with the public. The same could, perhaps, be said of NHS trusts. There is a need to get to the person on the street. Not everyone is able to attend a meeting between 9 a.m. and 12 p.m., or between 2 p.m. and 5 p.m., so, as the statutory health watchdog working in the best interests of the public in terms of NHS provision, we feel that we need to be out there disseminating the information in a clear way and at times that are suitable to the public.

[50] We all know how busy people's lives are. What do the majority of people do at the weekend? They all have to shop. Therefore, we need to move away from holding stuffy meetings—I am sorry, I am not referring to a particular aspect of any meeting—where you tend to see the same individuals. They are the people who want to have their voices heard, but we need to reach the groups from whom we seldom hear, such as single parents, and black and minority ethnic groups. I apologise if I am digressing, but, as the new director of the board of CHCs, I want to make community health councils and all other organisations more representative of the communities that they serve. That is vital. At the moment, we are not really encapsulating everyone's views. Trusts need to be more accountable, and they need to get their message across, but we also need to have a clear message from the media so that they give the facts and the truth and do not always bombard newspapers and the other media with the negatives.

[51] **Jenny Randerson:** How would you change the NHS trust boards and their make-up to make them more representative of local communities?

[52] **Ms Lamyman Jones:** I have probably touched upon this. I would ensure that, on those boards, there would be individuals who are not necessarily, for example, retired consultants—I am not being derogatory about any of the professionals—because we need greater representation on boards so that the voice of the public can truly be heard. It is not always the loudest voice that is important; we tend to have groups that are not always armed with the correct knowledge.

9.30 a.m.

[53] So, we need to have individuals who have the ability to look at the information that is given to them and make the most appropriate decision, given the funding that is on the table at that time. I would look for a wide variety of individuals to be represented on those boards, from the voluntary groups, CHCs and anyone who truly wants to make a difference and to be part and parcel of that developmental change for the better.

[54] **Helen Mary Jones:** Yn gryno, hoffwn ddilyn trywydd y syniad o atebolrwydd lleol. Un math o atebolrwydd cwbl uniongyrchol yw atebolrwydd democraidd, wrth gwrs. A ydych fel mudiad yn rhagweld posibilrwydd o ran rhoi llais cryfach i aelodau etholedig lleol, fel sydd gennych ar fyrrda'u'r heddlu neu'r gwasanaeth tân, er enghraifft?

Helen Mary Jones: Briefly, I would like to follow up the idea of local accountability. One type of totally direct accountability is democratic accountability, of course. Do you as an organisation foresee any possibility of giving a stronger voice to locally elected members, as is the case with police boards or fire service boards, for instance?

[55] **Ms Lamyman Jones:** Credaf ei fod yn bwysig, oherwydd yr aelodau lleol sy'n gwybod beth yw union broblemau, anawsterau a gofynion eu hardal hwy. Felly, mae'n bwysig bod yr aelodau lleol yn cael llais ar y byrddau hynny, ac yn cyflawni'r hyn y maent i fod i'w gyflawni.

[56] **Jenny Randerson:** The proposals include an option to move responsibility for providing community health services from NHS trusts to local health boards. What would you see as the advantages and disadvantages of that?

[57] **Ms Lamyman Jones:** I have consulted as widely as possible on this, and the feeling that I am getting—and please accept my apologies if I touched on this earlier—is that there are negative aspects to this; in fact, no positives have been raised with me. The perceived threat of doing this lies in the inexperience of LHBs at having that responsibility. Continuing care is a major problem and delayed transfers of care are another, as is, perhaps, confusion among the public. The feeling among those whom I have liaised with is that there needs to be an individual with the responsibility for overseeing this if the transition is to work, so that there is a seamless service from in-patient care to community care and vice versa, and a smooth transition between primary and community, out-patient and in-patient care.

[58] There is also a need to get the buy-in of GPs—and I am sorry that Dr Dai is not here to hear this—because CHCs find increasingly that a lot of the out-of-hours issues, such as the surge in attendance at out-of-hours services, is caused by people's inability to access a GP within a specific period. So, we need to look carefully at that. There is also a feeling that local health boards do not have the experience, and so what is the threat to community hospitals, for instance? That subject needs to be discussed in far greater detail.

[59] **Lorraine Barrett:** I am looking at the role of community health councils, patients and the communities that you serve. The consultation paper states that the role of community health councils needs to be enhanced to reflect the needs of local communities. Do you have any ideas about how that might be achieved?

[60] **Ms Lamyman Jones:** I do, indeed. Part and parcel of my role in directing and managing the board is to offer support to individual CHCs. We currently need to ensure a greater variety of voices from members of the public, and the Welsh Assembly Government's appointments branch is assisting us with that, although we are also doing it at a local level. Perhaps we need to walk away from the perception of the CHC member as a retired professional who has time on his or her hands, and to ask other members of the public to participate. They will see the consultation advertised in the newspaper, and can see the details on our website, but we want to reach people who are not currently part of our local CHCs.

[61] We do not necessarily have to have more council members, although that would be great; we want to have virtual groups. For instance, I met with an equalities specialist who has just been seconded to the Welsh Assembly Government, who is looking at the Gypsy cohorts around Wales. We need to get to them and find out their opinions, and get information to them about how they can access services. We know that too few women from the Gypsy community who are expecting a child are obtaining services or being seen by a doctor regularly, for whatever reason. Regardless of whether that is their own doing, we need to ensure that they get the information in a timely way.

[62] I am there to develop the CHCs, to strengthen them, and to ensure that more people at grass-roots level can participate and give their views. Even if they do not want to attend a formal meeting, they should be able to give us their opinions via a virtual group or whatever.

That is what I aim to do, because I think that it is important. Particularly with all this reorganisation going ahead—and I will be quiet in a minute—we must be there to get the views of the public. It is important.

[63] **Nick Ramsay:** We do not want you to be quiet; we want you speak.

[64] **Ms Lamyman Jones:** Sorry, that was verbal you-know-what.

[65] **Nick Ramsay:** Lorraine, you have a supplementary.

[66] **Lorraine Barrett:** I am pleased to hear what you say, because we had evidence from Ann Lloyd last week about patient groups that need to be represented in more formal structures. You have already talked about a virtual system, and I am thinking about websites, and that kind of thing. With patient groups, you can get individuals who dominate the group, and so there needs to be a way to reach out to more people. You started to touch on that, and I wonder whether you have any further ideas about what kind of structures might be effective in dealing with the various patient groups, because there are different categories of conditions that need different approaches.

[67] **Ms Lamyman Jones:** Absolutely. I am sorry to keep harking back to Carmarthenshire, but a lot of work has been going on there. There is a lot of support for stroke services, and the community health council in that area was fundamental in helping to establish a diagnostic service at Prince Philip Hospital in Llanelli. Getting to the people who use these kinds of services, perhaps via Diabetes UK and the various support groups, is important. There is not necessarily a need for those people to become a formal part of community health councils, but we do need to go to them to inform them of what we are trying to achieve, to get a consensus from them, and to include their voice as part of our overall voice.

[68] **Irene James:** How would a reduction in the number of LHBs and a change to their functions affect the complaints advocacy and inspection duties of CHCs?

[69] **Ms Lamyman Jones:** We are looking at that. My fundamental message to the Minister for Health and Social Services was that, in light of all the proposed changes, we did not want to see a change in community health councils. I cannot put her on the spot, but I believe that she appreciates the local aspect of CHCs. Currently, in Pembrokeshire, Ceredigion and Carmarthenshire, for instance, we have one advocate serving those three counties. Increasingly, with the introduction of the newly revised redress scheme, it is important to put more funding into advocacy services, and we hope to be able to inform the Minister about that, to strengthen our role there. We deal with approximately 13,000 formal inquiries a year, which is important. That is an awful lot of people who are being helped through the NHS complaints service. Without that, particularly in light of the new reorganisation, the public would need to know that help was at hand, and I think that we are best placed to provide that. Therefore, I do not think that there will be a huge change there, apart from the fact that we may need more advocates in the near future to ensure that all the LHB areas are covered adequately by the service that we are providing.

9.40 a.m.

[70] **Irene James:** How are community health councils seeking the views of patients and local communities on the proposed reforms? You have mentioned what you want to do, but are local CHCs actively consulting local people, or are you waiting for them to approach you with their views?

[71] **Ms Lamyman Jones:** No, we are approaching them. The initial information about

the consultation was made public on 2 April, and, because the document is quite lengthy and contains quite a lot of jargon—and I am not being derogatory about it, but although you and I might be aware of what is meant by the different terms, the person on the street might not be—we reduced it. We have a bilingual information officer who has reduced that document to one page, and that has been produced bilingually. It has been put on our website and disseminated via our formal councils, local groups and virtual groups. In advance of the public and technical events that are to be held by the Welsh Assembly Government, we have started work. Each CHC has its own strategy as to how to reach individuals. What I did not want to happen was for us to be into the fifth, sixth or seventh week of the consultation, waiting for events to happen, without having got the core information out to the public. That is what we are doing. Should you wish to have copies of that document, you would be more than welcome to; I could send them to you electronically, if so.

[72] **Nick Ramsay:** It would be very helpful, Carol, if you could provide that. We like a lessening of jargon in this committee.

[73] **Ms Lamyan Jones:** It is important because although a document summarises the key areas, however good it is, the only thing the person on the street wants to know is, ‘What will happen when I get my hip operation; who will take charge of that?’. Those are the fundamental issues that they want to know about. What we have included on each sheet is where people can go to look for help and additional information. They are also invited to contact me or the chief officer in each CHC area. We are more than happy to go to speak to individual groups, as well.

[74] **Helen Mary Jones:** Yr ydym wedi cael dystiolaeth gan Gonffederasiwn GIG Cymru sy'n awgrymu y gallai'r aildrefnusy'n digwydd ar hyn o bryd fod yn gam cyntaf tuag at newidiadau ehangach a fyddai'n arwain at un corff yn darparu gwasanaethau iechyd a gofal cymdeithasol. A oes gennych farn ynghylch a fyddai hynny'n syniad da?

[75] **Ms Lamyan Jones:** Credaf y byddai'n syniad da. Ar hyn o bryd, mae gan gynghorau iechyd cymunedol hawl statudol i fynd i mewn i gartrefi'r henoed, ac, a minnau'n berson sy'n edrych o safbwyt y claf, teimlaf ei fod yn angenrheidiol i ni gael mynd i sôn wrth y gwasanaethau cymdeithasol am yr hyn sy'n mynd ymlaen hefyd. Ar hyn o bryd, nid yw'r hawl honno gennym. Byddai'n beth hynod o dda pe bawn yn gallu uno'r ddau wasanaeth ac edrych ar sut y gallem ni, fel corff statudol sy'n edrych ar wasanaethau a lles unigolion, wneud hynny.

[76] **Nick Ramsay:** I think that that completes the questions, unless Members have anything further to add. I see that they do not. Thank you. It has been a very useful session today. It is quite clear to us that the community health councils are thinking very hard not just about the reorganisation of the health boards, but about the whole way in which that is communicated to the public. Consultation will clearly be an important part of the whole process.

[77] **Ms Lamyman Jones:** Before I finish, may I just thank you for this opportunity?

[78] Diolch yn fawr am y cyfle i ddod Thank you very much for the opportunity to come here today.

[79] If it would be helpful, I will send you the document, and I will also send you my brief notes because I was not able to refer to everything, and if you wish to use that information, you are welcome to do so.

[80] **Nick Ramsay:** Thank you.

9.45 a.m.

Papur Cwmpasu ar Ymchwiliadau Pwyllgor y Dyfodol
Scoping Paper on Future Committee Inquiries

[81] **Nick Ramsay:** There is no paper for this item, but the Members' research service's scoping paper has been circulated to Members. At the committee's meeting on 16 April, we asked for advice on possible options for the committee's next full inquiry, following the conclusion of the inquiry into presumed consent. Following that, we now have several specific areas listed. Ann Jones has indicated that she would be interested in an inquiry on equal pay. Do any other Members have ideas that they would like the committee to discuss?

[82] **Helen Mary Jones:** It is difficult to do this without Ann here, but I disagree with having an inquiry on equal pay. I think that equal pay has been done to death. We know what the problem is, namely that local authorities have known for 30 years that they needed to comply with the law, but they did not do it. It is no mystery as to why they did not do it; they did not do it because their unions colluded with them in discriminating against women in the workforce. I have put that quite harshly but, joking apart, the previous equality committees have done a lot of work on this issue, and I am not sure what we have to add to that. We know what has gone wrong and we know where we are, and the only thing that we can do is to keep an eye on what the Government is doing to support local authorities to get out of the hole that they have wilfully got themselves into. We could do that in our scrutiny sessions with the Minister for Social Justice and Local Government. We should keep an eye on it, but I am much more interested in some of the bigger questions about structures and functions. We were talking during that last evidence session about whether the local authorities are the right bodies to provide complex social services. I have my views on that, but it would be good to have some hard evidence. So, as I say, it is difficult to do this without Ann being here to contribute to the discussion, but I know why Ann is concerned about equal pay from an old trade unionist point of view. Her concerns and point of view on it are the same as mine, but I am not sure what this committee can add to what has already been done in terms of having an in-depth look at what is wrong.

[83] On the positive side, looking at structures and scrutiny would be useful, because—and I do not want to refer to events going on outside this building tomorrow—on the doorstep, members of the public have been asking me about how decisions are made at local government level and whom they should ask if they are not happy with something. So, looking at structures and scrutiny would be my priority.

[84] **Nick Ramsay:** I share your reservations about the equal pay issue, but it was something that Ann raised. As you say, it is difficult to discuss it without her being here, but I have noted what you said.

[85] **Helen Mary Jones:** We will see what other Members think.

[86] **Lorraine Barrett:** [Inaudible.]

[87] **Nick Ramsay:** I apologise to Members for the current problems with the microphones, but please make the best of it. The microphones appear to have died. Is anyone else's microphone working apart from mine? I see that they are now working.

[88] **Lorraine Barrett:** As an even older trade unionist than Ann, I will not get into an argument about Helen's comments about unions colluding, but I agree with her that we do not need an inquiry into this issue. It is an issue for the Committee on Equality of Opportunity as well as for us. When the Minister comes before us, that will be an opportunity for us to ask for a specific report or an update on where we are with this, because it is in train at the moment. I think that an inquiry into possible structures and organisational matters would be more appropriate in local government.

9.50 a.m.

[89] **David Lloyd:** I take on board the comments and I agree with Helen and Lorraine. I also take on board the comments about structures, but if we are going to produce a distinct piece of work, then we need to home in on the aspect of the structures that concerns us. An aspect that concerns me is local service boards. I am not convinced that they can or will work or can deliver anything that is expected of them. So, in terms of this committee doing a distinctive piece of work in a relatively short timeframe, we can zone in on that. Everyone keeps talking about local service boards and so on, but we need to drill down to exactly what they are required to do. That would be a useful piece of work to do on the general structure situation.

[90] **Jenny Randerson:** I agree with Dai that local service boards would be a useful place to start and could lead us into further work on structures. I am also keen on the idea of looking at scrutiny in local government, because I agree with Helen Mary that scrutiny is dealt with differently in different parts of Wales—it is sometimes quite rigorous and challenging for the executive on the local council, but in other local authorities, it is lip service at best. I have always felt that scrutiny was the big weakness of the cabinet system in local government and I have not seen anything to change my mind.

[91] **Lorraine Barrett:** I support Jenny on that. The old local government committee that Ann Jones chaired undertook an inquiry into the cabinet system, the old committees and scrutiny. So, there is work in the archives that may be a useful starting point. We could look at the recommendations that we made and at what has happened, if anything, with those recommendations. Much of it was about training for scrutiny members in local authorities. Perhaps we could use that when looking at local service boards in conjunction with the changes coming about in the health service. We could also apply that to what was raised last week on the mix of responsibilities between health and local authorities, particularly with regard to social services. That may come out in the whole package, but I think that we can all agree on the type of issues that we can start to consider.

[92] **Nick Ramsay:** I am getting a feeling from the committee that we do not want to look at equal pay but at local service boards and the scrutiny aspect of local government. Local service boards are at the top of the list. I think that it would be helpful for us to look at that. As Dai Lloyd said, many questions have been asked about the effectiveness of local service boards and getting some answers on their effectiveness would be a good thing.

[93] **Mr George:** Would Members want to take those two aspects together or would you

like to take them in sequence? It may well be possible to undertake a short scrutiny session on local service boards and the current position on those before the summer recess. However, a more far-reaching inquiry about scrutiny structures could take longer, so there is a scheduling issue there.

[94] **Jenny Randerson:** Lorraine said that work had already been done on scrutiny and we do not want to repeat work, but I am aware that that work was done some years ago and things will have moved on and changed. I suggest that we first look at local service boards and undertake a shorter piece of work on scrutiny, building on the work that the previous committee did and the outcomes of that and consider whether there has been any progress since then.

9.55 a.m.

[95] **Helen Mary Jones:** I will support that, Chair, but only if we do not lose sight of the fact that we need to look at the long-term, bigger structural issues. My personal view is that the elephant in the sitting room of Welsh public life is the structure of our local government, as some of our counties are plenty big enough to do what they do—arguably, some are too big, geographically—while others are so small that it is difficult for them to find the resources to deliver. It is hard to talk about that, because you do not want to criticise individual authorities, as many of them do a good job in spite of their size, but somebody has to ask that question and take some objective evidence on the matter. When we talked about it some months ago, this committee felt that fairly soon after the local government elections would be the time to start asking those big questions. So, I am not saying ‘no’ to scrutiny. My view is that if you start with local service boards, that will lead to the bigger questions, because local service boards are often put forward as the answer to all the problems of non-joined-up decision making and so on. So, if we find out how well that works, it may give us the questions that we need to ask about some of the bigger, structural stuff, but let us not lose sight of that.

[96] **Jenny Randerson:** Sorry to contribute yet again, Chair, but I strongly recommend that we follow Helen’s suggestion. Those two pieces of work are relatively short, and they will give us the grounding and the basic knowledge that we need because, after all, when we mention local government structures, we are told, ‘Well, we have just had the Beecham review and we have a set of proposals on partnership working based on the local services boards, and we have to see whether they work’. We can see from the first two pieces of work whether scrutiny is working and whether local service boards are working, and that will lead, naturally, on to the bigger picture. I see no harm at all in our doing three pieces of work on local government in quick succession, because we have paid scant regard to it up to now, regrettably, although for very good reasons.

[97] **Nick Ramsay:** What we are hearing is that local service boards are at the top of the agenda of what the committee would like to consider. The best way ahead is to ask the clerk to produce a more detailed scoping paper on the terms of reference, the timings, and the witnesses that we could call with regard to a local service board inquiry, and then we can see how that could follow on to a larger look at local government per se, once the local elections are out of the way. Does that fit committee’s view? I see that it does.

9.58 a.m.

Ymchwiliad Pwyllgor i Ganiatâd Tybiedig i Roi Organau—Tystiolaeth gan y Gymdeithas Seciwlar Genedlaethol

Committee Inquiry into Presumed Consent for Organ Donation—Evidence from the National Secular Society

[98] **Nick Ramsay:** For this item, we will take evidence from the National Secular Society. I welcome Greg Pycroft. Thank you for agreeing to attend this session. It is a first for this committee to call a witness from a non-faith group, and I think that I am right in saying that it is a first for the Assembly as a whole. We will launch straight into the questions, the first of which is from me—if I can find it.

[99] On the subject of personal decisions, you say in paragraph 1 of your written memorandum that,

[100] ‘donation of organs by consenting adult individuals either while they are living or after death is entirely a matter for personal decision.’

[101] To what extent do you think that the introduction of presumed consent for organ donation, particularly the hard system of consent, benefits personal choice?

[102] **Mr Pycroft:** The National Secular Society’s position is that it is very important that the individual has the opportunity to give his or her organs. In a system of presumed consent, the presumption is that the majority of the population wish to give their organs, based on and backed up by the evidence of various surveys. In terms of personal choice, we see that the system of presumed consent supports the personal choice that the public currently has.

10.00 a.m.

[103] The National Secular Society has chosen the hard system of consent, otherwise known as the strong system of consent, due to the possibility that relatives, who may not necessarily share the faith of the person donating the organs, may intervene somehow and ensure that the donation does not go ahead. The strong system better satisfies that presumption and enables an individual to go ahead with organ donation.

[104] **Lorraine Barrett:** I do not think that I am required to do so, but I declare an interest as a member of the NSS. You say in paragraph 3 of your memorandum that the NSS is concerned about minimising the reasons for failure to donate or blocking donations that are based on misperceptions of religion. Can you explain what those misperceptions of religion that lead to objections to donation are?

[105] **Mr Pycroft:** They are quite broad and are based on the misunderstanding of scripture. As we state later on in our memorandum, the main faiths in Britain have signed up to the campaign to promote organ donation as it is at the moment. So, the support from religious groups and organisations for organ donation is there. The problem is individual misunderstanding of scripture or a more cultural misunderstanding of the way in which the body is treated after death, which may lead to consent being refused by relatives. That seems to be quite a tragic circumstance, particularly if the individuals concerned wanted to donate their organs after they died.

[106] **Lorraine Barrett:** You mentioned surveys earlier. Has any work been done by the NSS on the level of that misunderstanding? Do you have any evidence that shows that that is a big part of the reason for preventing donation?

[107] **Mr Pycroft:** Unfortunately, we do not; it is not necessarily the National Secular Society’s remit, per se, so we welcome the opportunity to give the organisation’s opinions in this regard. Many of the figures that you find in the memorandum are based on the organ donation taskforce’s report, which was published earlier this year. The figure of a refusal rate

of 40 per cent among relatives comes from that paper. The taskforce has not broken down the reasons why relatives do not give consent, but I understand that it has reconvened to look at the issue of presumed consent. I would think that there is some scope to perhaps carry out research on this issue.

[108] **Irene James:** You have covered part of what I was going to ask you. However, ‘misconception’ is a strange term to use. Would it not be better to say that people interpret religious laws in different ways? Do you not think that it is important to respect that interpretation? I am thinking of the Buddhist Council of Wales, which has stated that each tradition differs in its views on body organ donation and that individual responses come down to that and vary according to that.

[109] **Mr Pycroft:** I guess, to a degree, that individuals have different opinions, and we have every respect for that. However, we have certain objections when that opinion is imposed on another person. In terms of presumed consent, we would expect a registered system to allow someone to opt out of presumed consent, which would respect the individual’s right to object to organ donation. However, under the current system, there is no system of opt-out; you have to opt in to the system. So, despite the imperfections of the current system, there is no way of affirming your opposition to organ donation if you wish to opt out of it. Having an opt-out system and presumed consent enables the individual who has different reasons for opting out to have an opportunity to do so, and that would respect the different religious attitudes that exist.

[110] **Helen Mary Jones:** Your memorandum comes down very strongly in favour of the hard or the strong option, and you say that that should be adopted so that donors’ wishes would be respected. Could you elaborate on your reasons on reaching this recommendation in light of the fact that most other organisations who have given us evidence, including the medical professionals, prefer the soft option?

[111] **Mr Pycroft:** Yes, I noticed that the British Medical Association supports the weak or the soft system of consent, and I respect that decision. We feel that the strong or hard system gives a safeguard in that it ensures that the individual’s decision to donate organs is respected. However, we would not necessarily expect any system to immediately enable the harvesting of organs from an individual; we think that there is a perfect opportunity here for hospital staff or the medical profession, for champions of organ donations who are civilians in normal life, who may have experienced organ donations. There is an opportunity here for them to champion the system of organ donation with relatives. The hard system is not necessarily a system whereby the relatives’ views are completely removed from the system; we would expect an ongoing conversation between relatives and the medical profession to champion the decision of the deceased, but, despite that, we feel that the views of the deceased must be respected. In a system of presumed consent, unless the person has opted out, donation should go ahead.

[112] **Helen Mary Jones:** Just to be clear about this, what you are saying is that there should be a dialogue with the patient’s relatives or loved ones, but that, ultimately, if it comes down to the patient’s wishes versus the loved ones’ wishes, the patient’s wishes should be paramount. However, in a system of hard consent, with a person who has not expressed their wishes one way or another, a ‘no view’, if you like, would then take precedence over the patient’s relatives’ wishes. Given the emphasis that you put on individual choice, what about the choice of the relatives? In a situation where a patient is carrying a card, because he or she has made a positive choice, I can understand the position, but if you are in a position of hard consent, where everyone is presumed to have consented whether they have consented or not, if you have not had a clear individual expression by the person who has deceased, what about the individual’s wishes and the clear individual expressions of the wishes of those who remain?

[113] **Mr Pycroft:** That ethical question is a sound one. I see the system preceding the donation as being paramount, as does the National Secular Society. That is a system that would not be too dissimilar from what we have at the moment, where there is public education and information.

10.10 a.m.

[114] The donor has, hopefully, made an informed decision not to opt out of the system, and the presumption therefore would be that that person, because he or she has not opted out, would want the donation to go ahead. That is under a system of presumed consent; it is quite different to the present system. However, it creates a wider opportunity for donations to take place in the future. If that is one of the outcomes that we want from this, that is a valid way of going forward.

[115] **Lorraine Barrett:** Thanks, Greg. What you have just been discussing with Helen goes to the crux of the issue. We all know that people do not read everything that comes through the letter box; they do not take much notice because they do not believe that it will affect them—we all think that. As you said, you need to build the organisation up, and it will take a long time before we get to that situation. Have you therefore given any thought to how we might reach out, to ensure that the majority of people know that they would have to make that considered decision to opt out?

[116] The other ethical side—and this came up in an earlier meeting that we had with an organisation—is that, even if someone opts out, relatives could still intervene, even under a hard option, if they felt strongly enough about it. I am concerned about that—will people have to make a will to ensure that their wishes are followed? What is the best way of reaching out to everyone, to ensure that everyone is as informed as they can be?

[117] **Mr Pycroft:** We have to accept that there will not be a situation where everything is perfect—it certainly is not at present, given the relatively low level of donation in this country, compared with Spain, say. Twice as many people, relatively, are donating organs in Spain than in this country. Bearing that in mind, we need to create a system that, although not perfect, is better than the one that we currently have. It is a tricky one, because, as you say, even in a hard system of consent, there is the possibility that relatives will try to intervene. However, if that is the case, I would still say that the individual donor's wishes, in a presumed system of consent, would mean that the donation would go ahead, even if there is contrary evidence. It is difficult to think of this issue hypothetically, bearing in mind that we will not necessarily reach a perfect system, and there are going to be difficult decisions ahead. However, if the presumption is that the donor has given consent, I believe that that presumption should be carried through.

[118] **Lorraine Barrett:** One suggestion that we had was that there should be a question on the electoral registration form; that might be one way of telling people, 'This is your chance to opt out if you want to'. Do you believe that that might be a way forward?

[119] **Mr Pycroft:** The electoral roll is probably one of the better regulated public databases, and it is a trusted system, compared with other Government databases, which are perhaps not as trusted. Therefore, as long as the choice was kept confidential and private, that would probably be the kind of database on which you could expect to register your opt-out in a system of presumed consent.

[120] **Irene James:** We heard evidence last week from an organisation called Patient Concern, which described the hard option of presumed consent as having no place outside a fascist state where individual liberty counts for nothing. What are your thoughts on that view?

[121] **Mr Pycroft:** I disagree with that. There is an argument that presumed consent is no consent. I disagree with that view, as does the National Secular Society. There would be four aspects to a system of presumed consent. The first is the fact that individuals are aware of the issues taking place around them; that is, a system of education and information that surrounds individuals. They would be aware of that question being posed and the significance of opting out or remaining silent. So, there is the education and the information that society and Government is there to provide. Secondly, there should be an easily recognisable system of recording your objections. You would not get that in a fascist state, nor would you get that in some authoritarian states. So, you are looking at a system such as that which we have just discussed with regard to the electoral roll, where there are accessible opportunities to opt out. The third is that a reasonable time period is provided in which such a decision can be made. It would have to be rolled out, or there would have to be a certain period of time before a system of presumed consent came into effect. So, it would not necessarily be an arbitrary decision by Government. Finally, there would be no significant detrimental consequences of choosing to opt out. That, again, goes back to the confidential system of recording objections. If you decided to opt out, you would not be judged for it, because everything would be kept quite quiet. With those safeguards in place, a system of presumed consent can operate. It would be an informed system, with safeguards to protect people who are presumed to have given their consent, but also to protect those people who have chosen to opt out for religious and other reasons.

[122] **Irene James:** Thank you. I will not give you my personal opinion on much of what you said, but do you recognise that the use of this hard option could put medical professionals in a very difficult position when they are dealing with bereaved families?

[123] **Mr Pycroft:** Yes, but I do not necessarily see that as being the sole reason why it should not go ahead. I see an opportunity to introduce improved bereavement training and improved counselling into hospitals and, perhaps, even an opportunity to introduce champions for organ donation who may have already experienced organ transplants or who may be related to someone who has experienced organ transplants. One of the great things about the current debate is that it opens up so many different opportunities. We can take some comfort that there is discussion and that this is not being imposed upon us arbitrarily.

[124] **Jenny Randerson:** Can we go back to the issue of the hard option? As you have said, it will not be a perfect system—life does not work like that; there are always problems with databases and so on. Therefore, such a system could lead to an individual's organs being removed against their wishes, simply because they had not got around to registering their dissent. Does that not contradict your fundamental view that donation is a personal decision rather than the decision of one's relatives and so on?

10.20 a.m.

[125] **Mr Pycroft:** Were there not a system under which there was a large amount of education, were the implications of opting out or remaining silent not put forward, were there not an easily accessible means of recording objections and consideration of those other points that I put across, I would have serious reservations about a system of hard consent. The issue of personal choice and an individual's wishes and consent would become much more of a moot point in that you would not quite know what the person wanted. It would not work. You would just be relying on the consent of relatives and, as we have said, there is a distinct possibility that people may object for religious reasons. We have those reservations. However, if the system that I have just set out existed, while not perfect, it would go a long way towards rectifying many of the problems that currently exist. We would like to see a system in society in which the pool of people who wish to donate their organs is greatly increased.

[126] The soft option could be seen as the more politically acceptable option, but if we are going to try to rectify this issue of there being a lack of organs—and, as our figures show, in 2006-07, 1,000 people died waiting for organ transplants—we must look at making what could be seen as difficult decisions, based on presuming that the majority of people wish to donate organs.

[127] **Lorraine Barrett:** Have you made any assessment of public reaction to the hard system of presumed consent?

[128] **Mr Pycroft:** The National Secular Society has not, although we hope that the organ donation taskforce's investigation into presumed consent will look into the public's reaction to soft and hard consent.

[129] **Lorraine Barrett:** Patient Concern's written evidence to the committee last week said that:

[130] ‘Presumed consent may seem to be in the interest of a small minority of patients but it is an insult to the rest of us’.

[131] What is your reaction to that statement? Before you say anything, I would like to flag up a piece that was in the *South Wales Echo* yesterday about a father of two who flew 7,000 miles to buy a kidney from a live donor in the Philippines. He was that desperate. He may be one of a small minority. Luckily, he got his second kidney transplant on the NHS in south Wales. He had not been able to buy a kidney from a live donor, thankfully. Anyway, I wonder what you think about the statement that it is in the interest of a small minority but an insult to the rest of us.

[132] **Mr Pycroft:** I would have to disagree strongly with that. In either the current system of consent or a system of presumed consent, there is still the presumption that people are giving their organs in an altruistic way and that there is not some sort of system of harvesting and retaining organs for some reason. It is a difficult procedure that people depend upon. We need to look seriously at this and make some difficult decisions if we are to increase organ donation in this country. Other countries are making those decisions as we speak, and when you look at countries like Spain—which has improved its figures significantly—you wonder whether we are doing something wrong or failing to do something that is being done there and which we should learn from.

[133] **Helen Mary Jones:** Your evidence refers to concerns that relatives may prevent donations because of their religious beliefs. However, there may be other reasons for loved ones to object to a donation. What weight do you believe should be given to objections that are not based on religious belief?

[134] **Mr Pycroft:** In a hard system of consent, we would hope that individuals would have spoken to their relatives, or at least made their wishes clear to them, so that there is no confusion at the end of the day. If the events that led up to that person dying were particularly traumatic—a car accident, for example—and the person was not able to give their opinion, that could be seen to be a grey area. However, because the opportunity is open for relatives to object on religious grounds, more thought would need to be given to protecting the interests of the individual concerned. That issue exists at the moment. We need to think about how to protect the interests of the individual.

[135] The problem with this is that it seems awfully callous at times, because you are talking about people who are bereaved, and it is a horrible time in their lives. You would not want to experience that yourself, but this issue needs a lot of thought, because a hard system

of consent provides protection for individuals who have opted out of their family's religion, and decided not to follow it. Those safeguards would be in place. Other issues would hopefully have been discussed in the period that led up to the person either opting out or remaining in the presumed system. It is a difficult question, admittedly.

[136] **Helen Mary Jones:** I am not quite sure how the discussion is more likely to take place under hard presumed consent than it is in the current situation. However, we will leave that, and I will move on to a further issue that is important. Your written evidence states that black and minority ethnic groups are particularly affected by a combination of high need, low donor rates, and misconceptions about donations. Could you elaborate on those misconceptions, and any evidence that you have to suggest that black and ethnic minority groups may be more affected than other groups, for example, religious groups?

[137] **Mr Pycroft:** There can be misconceptions based on an individual's or a small group's interpretation of scripture. So, you are looking at considering an individual's decision on whether a body needs to be buried within 24 hours of death occurring. That may prohibit donations from taking place. However, as we have said, the leaders of all major faiths practised in the UK, including the Islamic, Hindu and Sikh faiths, recognise that we need more organ donations from the black and minority ethnic community. We need an increase in the number of life-saving transplants, and we have the support of the faith leaders for that.

10.30 a.m.

[138] Unfortunately, it seems that the messages have not yet reached the communities that practise these faiths. Perhaps an improved level of education within those faiths might improve donation rates. At the moment, we have reached a stage at which organ donation does have the support of all faiths, so it is very difficult to consider those reasons as being religious if religious leaders already support organ donation. That is why we consider it more as a misconception or a misunderstanding of their religious objections. We need to overcome that, working with the religious faiths and their communities.

[139] **Nick Ramsay:** Thank you, Greg Pycroft, for attending today's session. You have certainly given us some things to think about and it has been interesting to hear the view of the National Secular Society, which is in quite marked contrast to that of other witnesses that we have called, so thank you.

[140] **Mr Pycroft:** Thank you very much.

10.31 a.m.

**Ymchwiliad Pwyllgor i Ganiatâd Tybiedig i Roi Organau—Tystiolaeth gan
Gymdeithas Dyneiddwyr Prydain
Committee Inquiry into Presumed Consent for Organ Donation—Evidence from
the British Humanist Association**

[141] **Nick Ramsay:** We will now take evidence from the British Humanist Association. Naomi Phillips is the public affairs officer for the association. The association has produced a memorandum of evidence for the inquiry, which has been circulated to committee members as paper 3. Sorry, Naomi, I will give you time to sit down. As indicated, you will not make a formal presentation, so we will go straight on to questions. There has been a problem with the microphones today, so, before you answer, if you could hit the button in the middle to switch the mic on, and again afterwards to switch it off, it would help the translators and the Record staff no end.

[142] I will kick off with the first question. Your memorandum sets out some of the association's main aims. Could you elaborate on how many people in the UK and Wales are members or supporters of the BHA and also the importance of your association's perspective on presumed consent?

[143] **Ms Phillips:** At the moment, we have around 8,000 members and more supporters. I am afraid that I do not know the exact figures for how many members we have in Wales. We look at a number of ethical issues as part of our work, and we consult with our members regularly on those issues. Many of our members are eminent authorities in fields such as science and ethics; we have a humanist philosophers' group, for example. Presumed consent to organ donation is certainly an important aspect of that work. We gave evidence recently to a House of Lords inquiry on a similar subject. We briefed and consulted our members in Wales specifically in the run-up to this inquiry, and we encouraged them to take part in your online consultation. We got a good response to that.

[144] **Irene James:** Paragraph 3 of your memorandum states that,

[145] 'Most of us would not object to our body parts and organs being donated and used for good ends'.

[146] How should people be able to object, and what ethical issues are there around objecting?

[147] **Ms Phillips:** We take the position, based on the evidence that there is, that most people support organ donation after death. Our position is that we have a moral responsibility to donate our organs after death because of the benefit to the wider community, in that donation helps to save people's lives and to improve the lives of people who desperately need those organs. We would support a soft system of presumed consent. We support presumed consent absolutely, but we want to give people the ability to opt out, because it is important to respect individuals' wishes. However, we expect that only a small minority of people would choose to opt out. It would have to be bolstered by a very good public information system, and people would have to talk about these things and know the issues. For us, it is really important that people make decisions based on rational evidence and on objective information. That information should be available and talked about, so that people are able to make those decisions without this being imposed on them. We would not expect very many people to opt out, but it is important that people have the right to do so.

[148] **Irene James:** Also in paragraph 3, you state that,

[149] 'policy actions at both state and European levels are needed in order to increase the number of organ transplants and so save lives'.

[150] Could you elaborate on what policy actions you think are necessary to increase the number of transplants?

[151] **Ms Phillips:** These things do not happen in isolation, and there is an increased market for organs that goes across borders. The best thing for Wales, the UK and Europe more generally would be a general policy across Europe, and perhaps the European Parliament could issue a directive encouraging member states to introduce systems of presumed consent, so that it became more common across the board. In the UK and in Wales, that would vastly increase the availability of organs, and there would be much less desire to traffic organs in from other, perhaps less developed countries, which is increasingly causing problems. There can be a lot of coercion in those instances, and there is no consent to donate organs.

[152] **Nick Ramsay:** We hear a lot about the increase in organ trafficking. Does your

association have any specific evidence of that, which leads you to those concerns?

[153] **Ms Phillips:** No, we do not have our own evidence of it, but the recent House of Lords inquiry looked at the European evidence on trafficking, which was available from the European Commission.

[154] **Lorraine Barrett:** I do not think that Naomi was here at the beginning of the meeting to hear your comments, Chair, so I would just like to reiterate that this is an historic first for the British Humanist Association and the National Secular Society, giving evidence to the National Assembly. I should say, for the Record, that I am a member of the BHA.

[155] Paragraph 5 in your memorandum states that you,

[156] ‘oppose general policy being made on the basis of religious dogma or superstition’.

[157] However, you then say,

[158] ‘we recognise that provision must be made to accommodate the personal wishes of individuals based on such considerations’.

[159] Could you explain what provision you think should be made to accommodate those religious wishes, and to what extent the religious views of relatives should be taken into consideration?

10.40 a.m.

[160] **Ms Phillips:** We advocate a secular style of governance, and think that the state should be neutral on matters of religion or belief, so that religious or even non-religious beliefs are not given privilege over others in policy making. So, we certainly do not think that a Christian—or humanist—perspective should take precedence over rational and evidence-based policy making. Religious or non-religious views are important to the individual and to relatives, but people can object to organ donation for a number of other, equally important reasons, and those reasons should be seen as being equally valid. A religious objection is no more valid than a strongly held cultural conviction, for example.

[161] Given that the majority of people are in favour of organ donation, many people who are religious also do not object to organ donation. We advocate a soft system of consent, which means that people’s decision to opt out because of religious or other convictions should be respected, provided they were well informed and made their decision based on rational and objective information and evidence.

[162] On the relatives left behind, as humanists, we try to support the happiness and wellbeing of living human beings, which is very important. We do not believe in an afterlife, and so the most important people to us are those who are living. Organ donation can be difficult for the bereaved relatives, and we think that their views should be taken into account under certain circumstances; they may object for religious or other reasons, or they may simply not have known what the individual wanted. We certainly think that that should be taken into account. We think that the soft system of consent would lessen the objections to organ donation, because the current system allows you to ask relatives what the individual would have wanted, but the soft system allows you to say, ‘Look, this is the system and this person has not chosen to opt out; do you know whether they had any strong personal objections?’. That would make it easier for relatives, and it is a better system for helping relatives to make those kinds of decisions once someone has died, but it also means that, if someone still had strong objections, they could be heard.

[163] **Lorraine Barrett:** You say in paragraph 6 of your paper that,

[164] ‘there must be appropriate safeguards in place to protect the wishes of the deceased individual’.

[165] What sort of safeguards would you envisage?

[166] **Ms Phillips:** I would suggest something along the lines of what I have just mentioned. At the moment, there really are not many safeguards. Even if your name is on the donor register, it is likely that your relatives will still be asked to consent. Many people do not talk about these things; it is not something that is often discussed around the dinner table. Relatives often do not know what people would have wanted and, at a time of bereavement, do not want to do anything that the person may not have wanted. So, I think that having a system of presumed consent would safeguard people’s wishes more, because it would be less likely for relatives to object. If you are already in the system and you actively have to opt out of it, it sends a much stronger signal that that is really not something that you wish to happen to you after you die.

[167] **Lorraine Barrett:** Some witnesses have voiced concerns that some people may not choose to opt out because of social or peer pressure. What are your thoughts regarding that, particularly in the light of the comment in your paper that,

[168] ‘most humanists would consider that we have a moral responsibility to allow our organs to be used for transplantation’?

[169] **Ms Phillips:** We consider it to be a moral responsibility because transplantation is of benefit to wider society. Although we take the position that the individual is the most important unit, we also recognise that, in that sense, we are also social beings and members of families, and that is important. We believe that human beings should work for the social good.

[170] On peer pressure and so on, that is difficult. Generally, we know that most people want this and we know that those who do not would have strong objections and possibly would not be easily persuaded. Again, you could not introduce a system of presumed consent without a huge accompanying public information campaign, which should reach everyone in society, including the hard to reach and the vulnerable. There may be occasions when that would happen, but there are ways of introducing the system to minimise that.

[171] **Nick Ramsay:** You say in paragraph 8 of your memorandum that the current opt-in system of donation has contributed to the present shortage of organs. Do you have evidence for that? Do you think that other factors have contributed to the shortage of organs and could you identify what those might be?

[172] **Ms Phillips:** This is not evidence that our organisation has produced, but it is research undertaken in the run-up to this inquiry. We know that in systems that you have to opt out of, there are high rates of organ donation. This is a huge thing because, as I said before, people do not talk about it—it is not something that is in the public domain. Many people have just not thought about it. However, if there were a system of presumed consent, people would think about it and consider it, and I think that only a small minority of people would opt out. There are, of course, other reasons—the rates of organ donation after death in countries vary hugely—but it is difficult to say what those reasons are. There will be religious, cultural and social reasons. It could also be down to the fact that there is not a good welfare state in a given country. There will also be pragmatic reasons because there is simply not the capacity to enforce such a system. However, I believe that the opt-in system has contributed greatly to that shortage.

[173] **Nick Ramsay:** Do you think that there is potential for better advertising of the current donor system and do you think that that would increase the take-up of organ transplants or strengthen the availability of organs?

[174] **Ms Phillips:** Yes, any good advertising campaign would do that. It must include objective information on the benefits of donating organs and why people should encourage their relatives to sign up to organ donation and to carry a card. It should inform people why they should talk to their friends and relatives about their views on this and whether or not they have signed up to the register. I think that that would increase the numbers, but it would not be enough because of the action of having to opt into the current donor system.

[175] **David Lloyd:** In your evidence, you say that presumed consent:

[176] ‘Would be likely to vastly increase the number and availability of organs suitable for transplantation, would decrease the trafficking in organs and human beings’.

[177] I happen to agree with you strongly on that, but we have received evidence in this committee from other sources to suggest that while presumed consent may help, its effect is likely to be marginal compared with that of other factors. How do you respond to that?

10.50 a.m.

[178] **Ms Phillips:** This is not our research, but we have produced evidence on the basis of our own research on this. If it were based on a system of presumed consent in Wales only, for example, I could understand that. In terms of numbers, it would probably have a minimal effect. However, if it were UK wide, that would really make a difference. If it were Europe-wide, that would make a huge difference, because the number of available organs would be vastly increased and that must reduce the desire or the need to traffic organs from elsewhere.

[179] **David Lloyd:** Moving on, you also say that a system of presumed consent would be,

[180] ‘better able to protect the wishes of someone who had not opted-out, even if the relatives themselves have strong views against organ transplantation’.

[181] Can you expand on your reasons for that view?

[182] **Ms Phillips:** Sure. As I said before, under the current system, after someone has died, the relatives are asked, ‘Do you know what they would have wanted?’’. That makes the situation difficult for them. In a perfect system, accompanied by good education and so on, if someone has opted out, there is a clear message that they absolutely do not want to participate. If they have not opted out, then there is good reason to think that they want to stay in that system. It makes it easier for relatives because, if you can say to someone, ‘Look, this person did not choose to opt out while they were alive’, it makes a person’s wishes much clearer for the relatives after their death.

[183] **Nick Ramsay:** Thank you, Naomi. The last question is from me.

[184] In paragraph 11 of your memorandum, you say that you,

[185] ‘support the British Medical Association’s “soft” system of “presumed consent”’.

[186] It has been explained to the committee that, under the BMA’s proposals, organs would only rarely be taken when relatives have objected—that is a key aspect of the ‘soft’ system. Given that, what practical difference to you think presumed consent could make in

the long run?

[187] **Ms Phillips:** It would make a huge difference. It would change the whole idea of organ donation, which is not spoken about at the moment. It would change how we as citizens view the issue. It is incredibly important to us as a society to maximise the wellbeing of those who are living. To have a system of presumed consent would change hugely how we as citizens view these things, how the Government views these things and how we as society look at this. To have that in the public consciousness with the right perspective, I would consider, is a good and important thing that is for the benefit of all. Not only is it very likely to increase the number of organs for donation, but how we as society view the issue would be very different, and that would have a huge impact.

[188] **Lorraine Barrett:** I was just thinking of something that the National Secular Society touched on and I wondered whether you have any views on it. When we think of faith groups and religious groups, the perception is that they are against organ donation. Do you find in your work that that is not quite the case, and that quite a lot of faith groups and religious organisations are not averse to organ donation?

[189] **Ms Phillips:** I cannot speak for religious groups or religious individuals. The fact that the vast majority of people in the UK support this suggests that the majority of people who would consider themselves religious or who have some religious affiliation would support organ donation. To my knowledge, there are not any necessarily religious objections to this. Also, when a church leader says something, you can bet that many people who are affiliated to that church do not think exactly the same thing. That is why it is important to take the individual focus, because individuals have differing views, and whether you consider yourself religious, humanist, Christian, or whatever, it is likely that your views will be different to those of other people. So, the individual focus is important, and it is important not to make generalisations by saying, 'Christians think this, or Jewish people think this', because it is unlikely to be the case.

[190] **Nick Ramsay:** The National Secular Society, while supporting a hard system of presumed consent, pointed out that there could be incidences where someone could, after not opting-out of the system, change their mind and express that to relatives shortly before they die. I assume that, in supporting the soft system of consent, you would consider involving the relatives to be paramount in avoiding those types of dilemmas.

[191] **Ms Phillips:** Yes, I would agree with that, because although the relatives would have limited options, they would be able to make their objections afterwards.

[192] **Nick Ramsay:** Thank you, Naomi Phillips, for giving the views of the British Humanist Association. Once again, it was an interesting session, and as Lorraine Barrett said earlier, it is a first for this committee and for the Assembly to hear the views of non-faith groups. They are much appreciated and will be considered in the committee's deliberations in coming to a final conclusion on this subject. Thank you for attending.

[193] There are two papers to note, namely written evidence from the Buddhist Council of Wales and written evidence from the Bahá'í Council for Wales. Having looked through the papers, it seems to me that they are saying that they are not coming out one way or the other, and that it is an issue to be left to individuals.

[194] **Lorraine Barrett:** I am pleased to note these papers. Interestingly, the letter from the Bahá'í Council for Wales says that there is nothing in the teachings of its faith that could forbid a Bahá'í to bequeath his eyes to another person or to a hospital. On the contrary, it says that it seems a noble thing to do. I think that that is interesting and quite telling. I just wanted to get that on the record.

[195] **Nick Ramsay:** I also picked up on the word ‘noble’, which I thought had an impact. Do Members wish to add anything on this issue? I see that they do not. To close, the next meeting of the committee will not be here or even in the committee room next door; it will be in Merthyr Tydfil where we will take evidence from the Welsh Kidney Patients Association as part of the ongoing inquiry into presumed consent. There will be an open-mike session for members of the public should they wish to contribute.

[196] Finally, I have been passed a note that says that the Royal College of General Practitioners is launching an event at 12.00 p.m., hosted by Jeff Cuthbert. Committee members who wish to support that event are welcome to attend. Thank you for attending the meeting.

*Daeth y cyfarfod i ben am 10.58 a.m.
The meeting ended at 10.58 a.m.*