

Cynulliad Cenedlaethol Cymru The National Assembly for Wales

Y Pwyllgor Cyfle Cyfartal The Committee on Equality of Opportunity

> Dydd Mawrth, 3 Tachwedd 2009 Tuesday, 3 November 2009

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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 pwyllgor yn bresennol Committee members in attendance

Eleanor Burnham Democratiaid Rhyddfrydol Cymru

Welsh Liberal Democrats

Ann Jones Llafur (Cadeirydd y Pwyllgor)

Labour (Committee Chair)

Jonathan Morgan Ceidwadwyr Cymreig

Welsh Conservatives

Janet Ryder Plaid Cymru

The Party of Wales

Joyce Watson Llafur

Labour

Eraill yn bresennol Others in attendance

Dr Tony Calland Cadeirydd Pwyllgor Moeseg Feddygol Cymdeithas Feddygol

Prydain

Chair of the British Medical Association Medical Ethics

Committee

Stuart Geddes Cyfarwyddwr, Cymdeithas Ddeintyddol Prydain Cymru

Director, British Dental Association Wales

Dr Richard Lewis Ysgrifennydd, Cymdeithas Feddygol Prydain yng Nghymru

Secretary, British Medical Association Wales

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

Catherine Hunt Dirprwy Glerc

Deputy Clerk

Helen Roberts Cynghorydd Cyfreithiol

Legal Adviser

Bethan Webber Clerc

Clerk

Dechreuodd y cyfarfod am 9.30 a.m. The meeting began at 9.30 a.m.

Cyflwyniad, Ymddiheuriadau a Dirprwyon Introduction, Apologies and Substitutions

[1] Ann Jones: Good morning and welcome to the Committee on Equality of Opportunity. I will announce the usual housekeeping rules. Will Members please switch off their mobile phones, pagers or anything else that is likely to interfere with the broadcasting of this committee? I remind Members that we operate in both English and Welsh and that translation is available via the headsets, on channel 1. If you have problems with hearing, channel 0 can be used for amplification of sound. We are not expecting a fire alarm test, so if you hear an alarm, please take instructions from the ushers, who will direct everyone to the nearest safe exit and the assembly point. Other than that, as I always say, you can follow me, because I will be one of the first out of the building.

[2] Do Members have any declarations of interest to make? I see that they do not. We have received no apologies; Janet Ryder will join us later from another meeting.

9.31 a.m.

Ymchwiliad i Wahaniaethu yn Erbyn Pobl sy'n byw gyda HIV gan Weithwyr Gofal Iechyd Proffesiynol a Darparwyr Gofal Iechyd—Tystiolaeth gan Gymdeithas Feddygol Prydain

Inquiry into Discrimination against People Living with HIV by Healthcare Professionals and Providers—Evidence from the British Medical Association

- [3] Ann Jones: I am delighted to have with us Dr Tony Calland, chair of the British Medical Association medical ethics committee, and Dr Richard Lewis, Secretary of BMA Wales. You are both very welcome. Thank you for your paper. We have a set of questions, but is there anything that you would like to add to your paper now?
- [4] **Dr Lewis:** We are happy to go straight to questions.
- [5] Ann Jones: That is great; thank you both. I will start. Your paper points out that evidence of discrimination against people living with HIV is largely anecdotal and you acknowledge the challenge in providing precise figures, as patients living with HIV may be reluctant to report their concerns. On the basis of the evidence that is currently available, to what extent do you accept that discrimination against people living with HIV by some—not all—doctors across Wales is a problem?
- Dr Calland: We agree that there probably is a problem with some doctors, but it is probably generated out of ignorance rather than personal prejudice. When there was first publicity about HIV, there were a number of connotations around infectivity, which was probably over-exaggerated, in terms of the infectivity of the actual virus compared with other viruses like hepatitis B or hepatitis C, which are probably more infectious. Therefore, that publicity generated a misapprehension that people with HIV posed a huge risk. In some quarters, that impression still remains, and doctors are not as aware of HIV, perhaps, as they should be. I was a general practitioner in Wales for over 30 years, and my practice had no patients with HIV—I practiced in the Wye valley, which had a very low incidence of drug abuse and whose population was mainly elderly. It was not a problem, so we did not run across it very often, and if you do not run across it, you do not necessarily recognise it with the frequency or consistency that you might do if you were working in a deprived area of Cardiff, with a high drug-abusing population.
- [7] **Jonathan Morgan:** I will just move on from that on the same theme, I suppose. You say in your paper that there have been, on occasion, cases where people living with HIV presented to their GP with a minor illness or condition, only to be referred to the specialist HIV consultants. The issue there, of course, is what could the Assembly Government do, perhaps working with the BMA and others, to improve that situation, so that GPs have more confidence to deal with patients who are living with HIV, but may well see them for a minor condition instead of referring them to someone else?
- [8] **Dr Calland:** There are some real difficulties around this. Any doctor must only practice within the sphere of their own expertise and experience. For instance, if I had had a patient with HIV in my practice, having explained what I have just explained, and they developed an unusual set of symptoms that may well be a simple transient infection, or may be the beginning of a problem secondary to the HIV, one would be quite keen to ensure that you did the right thing by the patient. That might mean referral for that patient, because, if you do not have a huge amount of experience of a condition, the right thing to do is to refer

the patient on. I understand that the patient may feel it to be inappropriate, but it is only inappropriate after they have been and everything has been sorted out. You can only do it in retrospect, and I would say that, when faced with such matters as a GP, you err on the side of caution for your patients. It would be wrong, and very difficult, to put pressure on general practitioners to extend the limits of their expertise just to make a point about stigmatisation, which is not necessarily the point in this particular case.

- [9] **Dr Lewis:** It is also important to point out that that is not necessarily the case only for patients with HIV/AIDS; it covers all patients with a particular condition that you, as a GP, might not have experience of. Just as in life generally, each of us has mixed experiences with regard to background, and for us that includes the clinical jobs worked in hospitals and so on. There are different levels of experience, so whereas the threshold for referring certain patient groups may be lower for one doctor, it may be higher for a colleague with greater experience. Tony alluded to the low number of HIV/AIDS patients in Wales, and that is the key to the amount of experience to which many GPs are exposed, so, broadly, they have a lower threshold for referring, as they err on the side of safety.
- [10] **Jonathan Morgan:** I suppose, Chair, that the issue for us is whether GPs who encounter patients who have HIV but who have come to see their doctors for some other problem are proportionately more likely to refer them because of the HIV than they are patients who have a minor condition in addition to some other illness that is life-limiting. It is a matter of whether a GP is more confident in dealing with a patient who is living with cancer, perhaps, but who is suffering from an additional, minor ailment, than in dealing with a patient who has HIV but is suffering from a different ailment. That is the difficult issue to break down in any statistical way.
- [11] In terms of providing help and support in these circumstances, is it feasible for GPs to get advice from consultants or pharmacists who have particular expertise in this field over the telephone during a consultation?
- [12] **Dr Calland:** That is difficult. You gave the example of a patient who has cancer, but, to be perfectly honest, if your patient has a history of breast cancer, for example, and then develops some new symptom, such as a headache, you would certainly think more carefully about how you handled the issue of the headache than you would for a patient with no significant previous medical history. It is difficult to single out HIV as a particular issue; it is a complex condition that can present or re-present in a variety of ways, and you have to ensure that you get the diagnosis right so that you treat the right thing. As a GP, you have to refer these patients as you would those with any other serious and complex condition. From that point of view, I do not think that GPs necessarily refer patients with HIV more frequently than they would any other condition.
- [13] In terms of getting advice, GPs can always ring up consultants. In the old days, when I was first in practice, one could ring a consultant in a hospital at the end of surgery, get an answer and proceed appropriately. These days, because consultants are extremely busy, as are GPs, that kind of dialogue has, sadly, in many ways been lost, and it is one of the big problems that the new arrangements of local health boards may seek to address so that one team, rather than two sections of the health service, can work together. That is very valuable, and it saves a lot of time and a lot of unnecessary toing and froing for patients.

9.40 a.m.

[14] In relation to pharmacists, I am a little more hesitant to suggest that GPs would get a great deal of expert advice on HIV from pharmacists. It is a complex condition, and pharmacists may know a lot about the medication, but when it comes to the disease process, that is more of a medical issue.

- [15] **Jonathan Morgan:** Your paper also talks about the prevention of cross-contamination. How confident are you that doctors in all settings employ universal cross-contamination prevention measures, rather than employ special measures to deal with patients who are known to be HIV positive?
- [16] **Dr Calland:** Again, it is about the history of this, because a number of well-publicised infections popped up at about the same time with new variants of CJD and HIV. Cross-contamination procedures were brought in, were heightened and made more sophisticated on the back of these types of infections. I hope that the medical profession would treat any patient the same, because you do not know whether they have a potentially significant infectious illness. You put on gloves when you take blood, you use the same cross-infection measures and you ensure that your equipment is properly sterilised, and so on. Therefore, I do not think that there is a specific issue on HIV. If things are working properly, the patient should not feel any more isolated than anyone else, because good proper medical practice will necessitate the use of proper cross-infection control measures for everyone.
- [17] **Jonathan Morgan:** That leads me to my next question, which is about how patients with HIV perceive the way in which they are being dealt with. Your paper suggests that some people with HIV might think that they are being subjected to over-the-top precautionary measures, when universal measures are just being employed. To what extent can that be verified? Again, I suppose that it would be very difficult statistically to know what proportion of patients who are seen by the medical profession feel that way without being able to test that in any way, shape or form. I doubt whether there is a requirement to do so, but in relation to good practice, do you know of situations where doctors explain to patients why these precautionary measures are being taken—that they are being taken on the grounds of crosscontamination and not just on the grounds of being over-the-top because of the nature of the patient's condition?
- [18] **Dr Calland:** If I were being absolutely honest, I do not think that doctors necessarily explain why they take cross-contamination measures. We assume—perhaps incorrectly—that patients understand why we wear gloves, why equipment is sterilised, and so on. If there are people who do not understand that or think that it is being done only for them, then that is an area where we have not majored on. I think that you have to assume a certain level of understanding among the population; otherwise, one gets into completely ridiculous levels of explaining the blindingly obvious.
- [19] **Dr Lewis:** In response to part of that question, we suggest in our evidence that a lot of the comments were anecdotal, and while it may be difficult, the comments warrant a more evidence-based study, and we would be more than happy to work with organisations in Wales that represent patients with HIV and AIDS to facilitate such a further study and to assist with implementing or raising awareness of any concerns that came out of any such evidence-based study.
- [20] **Jonathan Morgan:** If I may give you an example, which was put to us by AIDS Trust Cymru—and I have no reason to believe that what it is telling us is not accurate—it is reported that some people have been placed in the side rooms of hospital wards with biohazard infection signs outside the rooms and barrier nursing used. Again, these are anecdotal examples and it is not scientific in the sense of having a body of evidence that can be statistically tested, but we would welcome any moves by the BMA to work with other organisations to see what could be done to help to inform doctors of more sensitive ways to deal with these cases.
- [21] **Dr Lewis:** It is not only about doctors; it applies to all health professionals and the way in which our health services in Wales are managed. Many procedures and protocols will

be implemented because of guidance and policies in hospital trusts or general practices. Clearer guidance is needed on not employing any discriminatory practice with regard to patients in Wales because, as Tony covered well earlier, we must assume that all patients and all of us have the same potential for infectivity, whether it be of HIV, AIDS or hepatitis C, so everyone should be treated equally in that sense and no-one should feel that they are being treated differently. However, we need to look beyond doctors' attitudes, to attitudes and policies in the health service as a whole in Wales.

- [22] **Janet Ryder:** My apologies for being late, Chair, I had a meeting that ran over. Therefore, I am not too sure what has already been discussed. In the evidence that we have taken to date, it has not been all doom and gloom, particularly in north Wales, where some of the voluntary sector organisations have highlighted some areas of really good practice where GPs are doing well. Their surgeries have a good treatment system and the practices are geared up to treat people living with HIV and AIDS. What can be done to ensure that those examples of good practice are, first of all, highlighted and then how do you go about cascading that knowledge and that practice into other GPs' practices?
- [23] **Dr Calland:** What I said earlier was about how common this particular illness is in various parts of Wales. As I said, I practiced in the Wye valley, between Monmouth and Chepstow, which is not a hotbed of HIV infection. There were very few drug users among my patients and it was mainly an elderly, rural population. Therefore, my experience of HIV was relatively small. If you are practising in certain parts of Wales that are what you might call drug hot spots, you may have much more experience of it. The more experience that you need to have, the more that you will go as a doctor to find out about it. We could certainly raise the overall awareness of HIV, and I was talking to Richard earlier this morning about how the initial symptoms of an HIV infection are particularly difficult to diagnose unless you have your antennae twiddling around all the time. Out of several hundred people who will come to you with a cold, cough or a sore throat or whatever, to pick out the one person who has an initial presentation of HIV is pretty difficult unless you ask some penetrating questions that you would not ask everyone walking through the door with a cough and a cold. So, where you have a higher incidence of HIV, you will find that doctors make themselves aware of what they need to know.

9.50 a.m.

- [24] The risk is where you have a low incidence of HIV and where you have patients who present in that area who have it. It is difficult to know how you will overcome that rather than having a specific target of everyone in Wales having to learn about HIV, which—to be perfectly honest—could create a separate stigmatisation that you suddenly have to educate people about this terrible illness. Do you do it for diabetes and schizophrenia? Where do you stop? It would be valid to do that for each of the particular conditions.
- [25] In a long-winded answer to your question—and I apologies for that—it is difficult to raise awareness across the board about a particular illness without having a national focus on that illness. It is almost counterproductive in some ways. It may be the case that you have to rely on doctors to become more expert where there is a higher incidence because they have to address it more often. I think that the professionalism of individual doctors is usually such that they will want to know more; they will want to feel more confident and they will want to get the information and the training that they need when the need arises. I certainly know more about various rural diseases, such as orf, than colleagues who work in Birmingham.
- [26] **Janet Ryder:** Thank you for that full answer. There are two issues here. There is the issue of how doctors raise their awareness in diagnosing the problem in the first place. The issue that we are looking at here is not so much the diagnosis but the treatment that those people receive when they go into a doctor's surgery. Therefore it is more a case of customer

awareness, if you like, than front-line diagnosis. The burden does not just fall on the doctor; the burden must fall, presumably, on the whole practice—on the nurses, the reception staff and on the ethos within that. Do you think that the same thing applies in that you would only raise awareness of how to overcome those customer relation issues—if I can call them that—in these hot spot areas?

- [27] **Dr Calland:** No. Let us take MRSA as an example. Patients who are known to have MRSA are often dealt with in a separate room in the surgery. If they come in for an operative procedure, change of dressings and so forth, the practice has to think very carefully about where it puts that patient to do those dressings when you also have patients without MRSA coming into the surgery. You need to have a general awareness of the procedures for treating infections of which HIV is obviously one. The example of having a patient put in a room with flashing lights and biohazard signs all over it was probably pretty extreme. However, you could argue that people with MRSA, E. coli or any particularly nasty infection should also go in there. That is for the protection of other patients, themselves as a patient, and the medical staff and to raise awareness. There is a balance to be struck between the benefits to and the rights of an individual, and the proper and reasonable protection of the public and the medical staff.
- [28] **Ann Jones:** Did you have another question to ask, Eleanor?
- [29] **Eleanor Burnham:** Yes. What do you believe that you know about patients these days? In past times, a GP would have visited people's homes and perhaps made a better diagnosis. I am being very careful how I say this. I used to work in social services dealing with elderly and disabled people, and a home visit to someone was always wonderful because it opened your eyes to all sorts of issues, which you would not have known about were they sat in your surgery. You have even less time now to deal with a patient. Do you think that perhaps we should be looking at that angle, apart from reassessing and perhaps raising more awareness generally, because you cannot possibly know about people when they are just sitting in front of you. As a GP, you might not be conversant with certain people, because they may never come in to see you.
- [30] **Dr Calland:** How long do we have?
- [31] **Ann Jones:** You have a couple of minutes on this question, because we have several more.
- [32] **Dr Calland:** Home visits are extremely helpful, and you are preaching to the converted. I am an old, has-been GP now, and there has been a huge change over my career. There has been a loss of information-gathering ability, because we do not go into patients' homes. The fragmentation of primary care into all kinds of different facilities, be they walk-in centres or whatever, also detracts from that overall, holistic knowledge of the patient. I do not know what else I can say on that.
- [33] **Dr Lewis:** It is helpful, but, particularly with HIV and AIDS, you can make assertions, which may or may not be accurate, in terms of visiting people in their homes. However, you can certainly pick up certain information.
- [34] To go back to Janet's question, I think—if I read your question correctly—that there is a need to raise awareness of the way in which health professionals treat all patients in terms of dignity and so on, that goes beyond the clinical diagnosis and the technical details of making that diagnosis or management. So, there is always a need to raise awareness with regard to how we, in your words, provide customer service, look after people and treat people with dignity and confidentiality. All of those things should apply equally to all our patients, irrespective of whether they have HIV, AIDS or any other condition.

- [35] **Ann Jones:** Do you want to move on, Janet?
- [36] **Janet Ryder:** To flip this whole thing over, there are also situations where doctors have HIV and there is an issue as to how they are treated by their own profession, their employers and by the patients whom they minister to. Are you aware of how big a problem that might be in Wales? Do you perceive that there is discrimination against those doctors? If so, what can be done to counter it?
- [37] **Dr Lewis:** I am not aware of any doctor cases that have been presented to the BMA or any that we have supported, although I noticed in the press recently that there have been concerns over a doctor who was working in England. His patients were reviewed once he had the diagnosis of HIV. They were all contacted, notified and so on. Your question is valid, because if we are suggesting that HIV and AIDS patients should be treated no differently from anyone else in terms of their risks, if we are employing appropriate cross-infection procedures, doctors should also be treated no differently from anyone else. However, there is a wider population and there are specific risks that would have to be mitigated in certain high-risk surgical procedures and so on, but that risk is conversely true with regard to doctors managing patients in that situation. I do not think that they should be treated any less favourably than the patients that they see.
- [38] **Janet Ryder:** Presumably your association would be the body to deal with this issue if it arose.
- [39] **Dr Lewis:** If a doctor is inappropriately dealt with by his or her employer and is a BMA member, it is likely that he or she would come to the BMA. If it is related to a clinical matter, the doctor could go to one of the medical defence organisations. In a Welsh context, however, I am confident in saying that we have had no doctors approach the BMA with regard to that specific issue.

10.00 a.m.

- [40] **Joyce Watson:** Good morning, and thank you for your paper. I would like to go back to training and education, just so that we get things on the record. Your paper states that a number of components are necessary to combat discrimination in the healthcare setting, including awareness raising among individual practitioners; you have talked a little about that this morning. You also say that it is important to ensure that adequate supplies of information and equipment are available, and that policies for reducing stigma and discrimination are in place. Can you tell us more about the kind of actions that should be taken?
- [41] **Dr Calland:** Again, for the reasons I explained earlier, if we are looking at stigmatisation then we should look at infectious disease across the piece rather than HIV in isolation, because it is important for doctors to be aware of the effect of stigmatisation on the patient, and see things from the patient's perspective. That is not specifically related to HIV—it could be related to obesity, which certainly creates a lot of stigmatisation, or people who smoke, and alcoholics. In their different ways, they are all judged by the public, and particularly the press, because there is a social element to those types of illness: why are they alcoholics? Why do they not just stop drinking? Why does someone not stop smoking? Why is someone so fat? Generally, the public is pretty unaware of the effect of stigmatisation, but even in the medical profession, we do not get stigmatisation training, as it were. You just have to try to understand it through your interaction with patients, and the way that you relate to them. You might have a kind of epiphany where you realise that that patient is deeply bothered because of their illness, much more than you had thought, because they are obese, or whatever. In fact, it can have a catastrophic intellectual effect on the patient, so we need to emphasise that kind of training at all levels, but particularly at medical school. Medical school

is difficult because you are learning an enormous amount of stuff in a short time, and certainly, when I was a student, we did not have any training about how patients might feel about being called alcoholic, or whatever. It is only subsequently, as you start to get into practice, that you work out that labelling people is dangerous. You have to start at the beginning, and help the patient to gradually come to terms with their problem through a process of repeated emphasis and osmosis.

- [42] **Ann Jones:** Janet, I think that you want to come in here.
- [43] **Janet Ryder:** Briefly, we recently had Dr Andrew Dearden in to the cross-party group on autism to give evidence about the treatment that people with Asperger's and autism receive from their GPs. One of the things that he pointed out was that, as autism is a new diagnosis, there is an age-gap among GPs as to the training they have had. Even if they have been trained relatively recently, this kind of thing does not really register; as you have just pointed out, the syllabus for medical students is crowded. Dr Dearden highlighted the annual retraining units that doctors must attend, and the number of hours that are spent on retraining. Do those units provide retraining on AIDS, and if so, does that cover just the medical diagnosis, or the all-round treatment of AIDS patients, and how that fits into a medical setting?
- [44] **Dr Lewis:** There are many resources available for training and information on AIDS. I think that the Royal College of General Practitioners has highlighted the importance of training that GPs can access on HIV and AIDS. To go back to a point raised earlier, we have to accept that, relatively, there is a small number of presentations in a Welsh context of HIV and AIDS and autism, although they may have had a high profile in terms of the recent committee exposure. It is a matter of striking a balance with the number of courses you can go on, given the range of conditions that you may rarely see in some parts of Wales. Most health professionals will address the need to look at and access those courses irrespective of where they are, and there is a myriad available, depending on the range of clinical presentations. Tony has mentioned a couple of times that, if you are living in an area with a high incidence of drug abuse, your awareness of transmittable diseases, whether HIV or others, will be high, and you may well want to access those courses.
- [45] The background to your question is that most courses, whether they are on HIV/AIDS, diabetes, hypertension or obesity, will have a core component on treating patients with dignity and the appropriate way to manage patients, with respect to confidentiality, consent and all the ethical and moral issues more broadly. That is taught in the undergraduate curriculum; it is not specifically attached to any disease, but students are taught about ethics and morals with regard to how you have a clinical relationship with the patient, irrespective of the condition.
- [46] **Joyce Watson:** I want to get down to the specifics of this. You have talked about general training. Would you identify any particular groups of medical practitioners that would benefit from additional training?
- [47] **Dr Calland:** I would more or less be reiterating what we have said already. Accepting the fact that you cannot know everything about everything, you have to strike a balance and become as expert as you can be in the things that you meet commonly. By definition, general practitioners know a little about a lot rather than a lot about a little. As I said, practising medicine in the countryside, I had to know about things such as orf, Weil's disease and so on. If you practise in inner-city Birmingham, you probably do not see too many cases of orf. You develop the expertise that you need, so, from a general practitioner's point of view, the training is practice-based, by which I do not mean that the training happens in the practice, but that the training depends on the kind of practice you work in. With regard to specialty, if you are an infectious disease consultant, you will know an awful lot about the

details of it and you would have had appropriate training.

- [48] I am not saying that everything is right; I am not being complacent, but, again, it comes back to the issue of balances. This is about what you can balance and how much time you can give to this. The treatments for common diseases, such as heart disease, diabetes in particular, hypertension and so on, are very complex. With regard to general practitioners, proportionately, it is far more important that we understand diabetes than some other less common illness. So, I cannot really give you an answer to that question. Perhaps Richard can.
- [49] **Dr Lewis:** I cannot, but I can give you another example to make the difference. All GPs will be familiar with malaria, although it is not endemic in the UK, but it is part of our training and we would have a basic knowledge of that.

10.10 a.m.

- [50] One of the key issues with regard to general practice is that we try to identify the condition and keep a patient safe, while not necessarily being able to manage that condition. While I would not expect to go on an annual malaria training course, because of the rarity by which malaria presents itself, I would expect to have a baseline knowledge so that I would be able to suspect it if someone came to my surgery with the relevant symptoms and had recently been abroad, for instance, and then refer them to a specialist. With regard to some of the anecdotal evidence, the threshold by which we refer depends on individual experience. For example, if I had been a malaria specialist before going into general practice and I identified someone with malaria, then it would be possible for me to manage the patient within a practice setting. So, it depends on the individual. It is impossible to train everyone in every condition to the standard at which it could be managed within general practice. The nature of general practice is not such that it works in that way.
- [51] **Ann Jones:** How easy is it for someone who has HIV or who has the potential to cross-infect, such as people who are heavy users of drugs, to get on a doctor's list when they move into an area?
- [52] **Dr Calland:** I would absolutely hope that it would be completely straightforward; if it was not, because of their infectious disease, it would be extremely inappropriate of the practice.
- [53] **Ann Jones:** So, you have no indication that there are practices that operate a policy of not taking on, for example, drug users who may then contract HIV. Is that right?
- [54] **Dr Calland:** They would be looking at a very quick route to the General Medical Council if they were operating such a policy.
- [55] **Ann Jones:** Okay, thank you.
- [56] **Eleanor Burnham:** I am going to ask my question in Welsh; I believe that the translation can be heard on channel 1 of your headset.
- [57] Pa sefydliadau y dylid eu cynnwys yn y gwaith o gydgysylltu a chynnal ymgyrch mor gynhwysfawr? A fyddai cyrff addysg a hyfforddi, Llywodraeth Cymru a sefydliadau'r sector gwirfoddol, er enghraifft, ymhlith y rhain?

Which organisations should be involved in the co-ordination and delivery of such a comprehensive campaign? Would these include, for example, education and training bodies, the Welsh Government and voluntary sector organisations?

[58] **Dr Lewis:** We would expect all the professional organisations in Wales to be

involved in any awareness raising-voluntary sector organisations would be involved obviously, as you mentioned. Local authorities and social care are components that we have not yet mentioned, but they are particularly important in supporting and being aware of campaigns. So, the campaign would be cross-professional, not just within general practice, and would also include the royal colleges that are represented in Wales, particularly the Royal College of General Practitioners.

- [59] rhoi i Gymdeithas Feddygol Prydain mewn ymgyrch mor gynhwysfawr?
 - Eleanor Burnham: Pa rôl y dylid ei Eleanor Burnham: What role should the British Medical Association play in such a comprehensive campaign?
- **Dr Lewis:** I mentioned that we have not met with any of the voluntarily organisations that represent patients with HIV and AIDS in Wales, although we regularly meet with a range of other voluntary organisations to do joint work. We would very much welcome an approach from those organisations in Wales, and I intend, following this meeting, to contact those organisations so that we can have a joint meeting to listen to their concerns and to work on any initiatives. It would be helpful, as I mentioned earlier, to have an evidence-based study of HIV and AIDS patients in Wales so that, rather than having anecdotal evidence, we have more structured evidence with regard to the concerns that those patients may raise. We would be happy to work with those organisations on whatever was appropriate, following that evidence-based study.
- Eleanor Burnham: The concern that the Chair mentioned previous to my question could be looked at on the basis of evidence.
- **Dr Lewis:** Yes. It is difficult with anecdotal evidence, because invariably, irrespective of who you are and what condition you have in Wales, you will encounter problems with health or social care services, with politicians or anyone else in Wales.
- [63] **Ann Jones:** Perish the thought.
- Dr Lewis: It would be helpful if we had broader evidence to suggest what sort of issues need to be addressed. We would be happy to work with organisations to support raising those issues with our members.
- [65] Eleanor Burnham: So, in effect, our project here has been worth while, even with that in mind.
- **Dr Lewis:** Very much so. [66]
- Eleanor Burnham: Good. There is anecdotal evidence, and we, as Assembly Members, come across all kinds of issues. The Chair rightly pointed out that one of the major issues, which does not just relate to people who use drugs, is that if you live in a rural area, what choice do you have if your GP does not want to take you on?
- [68] **Ann Jones:** Janet, you have one last question before we wrap this up.
- Janet Ryder: In giving your evidence you have both linked HIV and AIDS patients with drug users. I know why you are linking them, but why make that one connection specifically? People can, unfortunately, contract this in a number of ways. If it is the case that such a link has been made, has that unwittingly coloured any of the programmes that you run? You were talking about doctors being given specific training if they are in an area where there is a tradition of high drug use. However, presumably people can contract HIV in a number of ways, and therefore they can present in several different areas.

- [70] **Dr Calland:** We are getting into one area that creates prejudice, which is that of sexual behaviour. I was talking earlier about how general practitioners have to try to recognise the one case of initial HIV infection among the myriad of coughs and sneezes, and so on. To do that, and to raise your suspicion, you would have to have some further knowledge. I intimated that you would have to ask further questions. You do not normally ask about the sexual habits of every patient who comes in with a sore throat, and you might get a rather strange reputation if you did. You may well know that the patient is a drug abuser, or a haemophiliac, but you may not know about their sexual preferences, and to find out you would have to ask. That is a more difficult question to ask, and you may not have that information in the medical record. There is a difficulty in that regard, and, as I said, it links in to some of the stigmatisation and people's views about homosexuality, promiscuity or sexual behaviour generally. I did not mention it because I was trying to steer a careful path through it all. Doctors do not look at HIV as only a drug abuse issue; where they know about the sexual behaviour of their patients, they may well have a higher suspicion of HIV infection, or of hepatitis and other infections.
- [71] **Ann Jones:** We always open Pandora's box right at the end. Eleanor has the last question.
- [72] **Eleanor Burnham:** There is evidence that, perhaps some time ago, the procedures in relation to the supply of blood for blood transfusions were not as clean as they should be, and many haemophiliacs contracted HIV. Are we now certain that all the necessary procedures are in place so that no more people contract it? You say that it is to do with sexual behaviour, but we understand that many people contracted HIV because of laxity in procedures relating to blood.

10.20 a.m.

- [73] **Dr Calland:** I do not think that it was laxity; I think that it was ignorance. I can answer the question generally and then not answer the question—not answer the question because I am not competent to give you a scientific answer. In general, nothing in medicine is ever absolutely clear.
- [74] **Ann Jones:** Okay, thank you very much. The aim of this committee is not necessarily to look at how people contracted HIV in the first place, but to ensure that they are not discriminated against.
- [75] I thank you both for your evidence this morning. You will get a copy of the transcript. I apologise for the noise from the committee next door. I think that they have a video link, which always increases the volume. We will have to ask for soundproofing if that is going to continue. I thank you both for coming this morning.

10.21 a.m.

Ymchwiliad i Wahaniaethu yn erbyn Pobl sy'n Byw gyda HIV gan Weithwyr Gofal Iechyd Proffesiynol a Darparwyr Gofal Iechyd—Tystiolaeth gan Gymdeithas Ddeintyddol Prydain Cymru Inquiry into Discrimination against People Living with HIV by Healthcare Professionals and Providers—Evidence from the British Dental Association Wales

[76] **Ann Jones:** We are staying with our inquiry into discrimination against those suffering from HIV. We are pleased to welcome Stuart Geddes, the director in Wales of the British Dental Association. We thank you for coming this morning and for your

comprehensive papers. Is it all right with you if we move straight into questions, or have you prepared opening remarks?

- [77] **Mr Geddes:** No, I have not.
- [78] **Ann Jones:** You state in your paper that discrimination against people on the grounds of their being HIV positive is entirely unacceptable, and you have provided some in-depth papers relating to guidance and policy documents. To what extent do you accept that discrimination against people living with HIV by dentists is a problem in Wales?
- [79] **Mr Geddes:** I have no evidence of that. As part of my homework before I came to talk to you, I enquired of the organisation that I thought was perhaps the most appropriate, which is the Terence Higgins Trust in Cardiff. I specifically asked questions about incidents of discrimination against its clients and it was unable to provide me with any evidence that it was a problem in Wales. That said, the organisation based in London has recently undertaken some research. It has given examples in its paper; I think that I have given you a reference to that. It has found examples where people living with HIV and AIDS have been discriminated against, but they are old references; they are not recent. The world has moved on an awful lot. Dentistry was very much at the forefront of looking after this particular group of patients and I would be disappointed if any of my colleagues discriminated against those patients.
- [80] **Ann Jones:** Okay, thank you.
- [81] **Janet Ryder:** I would like to follow that up. The last time we took evidence from AIDS Trust Cymru, it said that
- [82] 'People are telephoning to try to find space on a dentist's list, but when they disclose their HIV status there is suddenly no space.'
- [83] AIDS Trust Cymru's written report indicates that one person was told that the sterilisation equipment was not capable of dealing with HIV. That seems to contradict what you have just told us. The evidence to this committee to date has given examples where people have found it difficult to access NHS dentists. AIDS Trust Cymru told us that people have been turned away, having been on the list, after disclosing that they are HIV positive. Are you still satisfied that you are not aware that that is the case in Wales?
- [84] **Mr Geddes:** That is interesting evidence that I did not determine for myself. I would be keen to talk to that organisation and to find out exactly where this is going on. To say that the sterilisation procedures in the practice are not capable of dealing with those patients could be summed up in a word that begins with a 'b' and ends with an 's' because it is completely and totally untrue. The modern standards of cross-infection control in a practice are such that we treat everyone as though they have the Black Death and every lurgy going. That is absolutely at the forefront of our provision. Cross-infection control in a dental practice is probably better than it would be in many hospitals. It is really good. I am very disappointed to hear that comment. I think that that particular practice is laying itself open to some serious questions being asked of it.
- [85] **Janet Ryder:** So, you are currently satisfied that that is not the case at the moment in Wales. Will you carry out further inquiries into that issue with dental practices?
- [86] **Mr Geddes:** I might like to talk to that organisation about it.
- [87] **Janet Ryder:** You mentioned the sterilisation and protection processes that are in place, but we have also received evidence that, in some cases, dentists are not wearing only one pair of gloves or even two pairs, but three pairs to protect themselves.

- [88] **Mr Geddes:** That is just silly. Could I return to the point about patients not being able to get onto a dental list? That is a problem for everyone in Wales and not simply for people who have a lurgy deemed to have been a problem in the past. That is a general issue of NHS availability and is all down to contracting with local health boards. Some local health boards simply do not have enough of these mystical units to contract with dentists to provide the care necessary in that particular area.
- [89] **Janet Ryder:** To take you back to the sterilisation issue and the use of gloves as a barrier, there are general principles here that would be applied to every patient regardless.
- [90] **Mr Geddes:** Yes.
- [91] **Janet Ryder:** So, no discrimination would be shown and no further preventative measures would be taken against patients who declared that they had HIV, TB or variant CJD.
- [92] **Mr Geddes:** There certainly should not be. To address the examples that you just gave, TB is an increasing problem in general medicine and dentistry, particularly in Wales, given that the immigrant populations are quite prone to developing TB. However, the biggest risks are posed by some of the 'hepatitises'—if that is the correct plural—particularly hepatitis C, D and E, which are fatal. If you contract those diseases, you will die. We want to protect ourselves and our staff as well as ensuring that we are not the method by which the disease is transmitted to someone else.
- [93] **Joyce Watson:** Some of the evidence that we have received appears to claim that dentists are offering the last dental appointment of the day to their infected patients. Have you got any evidence that that happens?
- [94] **Mr Geddes:** It used to happen, but there is no reason for that to happen now. Those patients could be treated in a normal clinic. The cross-infection control measures in place would be applied equally to you as to anyone else. As I said, we would treat you as though you had the Black Death or the lurgy.
- [95] **Joyce Watson:** You also point out that, in some cases, a dentist might refer a person to an HIV specialist if they felt that there were problems beyond their area of expertise. You say that that is not discrimination, simply patient care.
- [96] **Mr Geddes:** There are particular conditions that manifest themselves in the mouth, one of which has the displeasing name of hairy leukoplakia, which are white patches in the mouth that look hairy. Those impact on the oral tissues making it difficult to treat them. However, those conditions need to be treated with specialist drugs that would not be prescribable through a normal dental practice. So, in those circumstances, one would refer the patient to an appropriate specialist, and we have an oral medicine unit in Cardiff that would deal with those and the patients would receive the appropriate care there. They may choose to have all their dental care within the dental school rather than go back to the practitioner, but that would be the patient's choice.

10.30 a.m.

- [97] **Joyce Watson:** Following on from that, and accepting that, what we are trying to get at is how to get the patient to feel that that sort of referral was in their best interest rather than just a discriminatory process. There seems to be a mismatch between what is advised as the best care for the patient and what the patient perceives to be discrimination.
- [98] Mr Geddes: Do you not think that patients living with HIV and AIDS are now well

educated about their own conditions and how they may develop? That said, under the modern regime, they would receive anti-viral and other drugs, which have progressed a great deal. The incidence of the disease moving on—although that still happens—does not happen at the pace at which it used to happen when AIDS was first identified back in the early 1990s. I hope that this is a matter of patient education, and not of educating the professionals who treat and look after them.

- [99] **Joyce Watson:** This is the last question from me. I will flip this and turn it on its head. Can you tell us more about the discrimination against dentists who might be living with HIV and the form that that discrimination might take?
- [100] **Mr Geddes:** If a dental practitioner declares, and they have a duty to do so, they will be stopped from working immediately. Their careers are at an end.
- [101] **Joyce Watson:** Is there anything that can be done to address that?
- [102] **Mr Geddes:** In this case, it is the Department of Health that makes the rules. We need to persuade it to look beyond the borders of this country to Europe and other areas, and possibly to read the Beijing declaration, which says that dentists who are appropriately treated can treat patients and continue with their lifestyle and their work. We need to stop this old-fashioned, unhelpful attitude in this country. It is a UK problem.
- [103] **Eleanor Burnham:** May I clarify something? Did I hear you correctly? If a dentist in the UK has HIV and has declared it, he or she is not allowed to work?
- [104] **Mr Geddes:** Yes, they are stopped from working immediately.
- [105] **Eleanor Burnham:** Why does that not apply to other medical professions?
- [106] **Mr Geddes:** Originally, it was to do with what dentistry is. Everything that a dentist does is described as an exposure-prone procedure. Are my medical colleagues still here? No, I think that they have gone. Doctors do not do anything but sit and prescribe. I could not say that when they were here. [Laughter.]
- [107] **Eleanor Burnham:** Surgical intervention is the issue, therefore.
- [108] **Mr Geddes:** Anything that a dentist does is classed as exposure prone, so there is a perceived, but in fact non-existent, risk to the patient.
- [109] **Ann Jones:** I hope that they are not waiting outside for you now.
- [110] **Mr Geddes:** I will go out the back way. [Laughter.]
- [111] **Jonathan Morgan:** Good morning, Stuart. One difficulty of doing a review such as this is in trying to distinguish the evidence that is quantifiable and qualitative and that which is, in a sense, purely anecdotal. In some written evidence, we have had a lot of anecdotal evidence that some people with HIV feel discriminated against for a variety of reasons. Working on the basis that some people do feel that they have been discriminated against in a dental setting, what can be done through training, education and awareness raising to help dentists to overcome those perceptions, and to get to a position of the patients not feeling as though they are being discriminated against? Can anything be done through training and awareness raising?
- [112] **Mr Geddes:** I was talking to someone from the University of Birmingham about this just last weekend. Dental students today, as part of the ethics course, have a lot of discussion

about the sort of things that may affect their patients, which may raise alarm bells or fears. It is important that they treat their patients with respect and confidentiality, and that they continue in that way, but it is equally important that they train their staff to behave in a similar manner.

- [113] On ongoing training, the General Dental Council already has in place a programme of continuing professional development. We will shortly be looking at reaccreditation, and we already have to sign a five-year ticket to say that we have completed the necessary postgraduate education. There are a number of core subjects in those courses, one of which is ethics. Therefore, I would expect all dentists to have a reminder of their ethical obligations over a course of five years at least. In fact, we are running a course in Cardiff from February on confidentiality and ethics, which will reinstate the ethical obligations to the older members of the profession who are perhaps not quite as up to date on these things as they could be.
- [114] **Joyce Watson:** I will ask a question that I am sure is going through many people's minds. We hear evidence of the shortage of NHS dentists and all the rest of it, but, with the British Dental Association, are you talking about all people involved in the provision of dental care, so people who practise privately as well as those attached to the NHS?
- [115] **Mr Geddes:** We are a professional organisation representing all dentists in the UK. We do not represent dental care professionals—the dental nurses, therapists and hygienists—but we work closely with their organisation and provide them with certain services. We would also offer them the same opportunities to attend our courses as part of our education opportunities for dental practitioners. For example, in south Wales last spring, we ran a large course focusing on cross-infection procedures, such as sterilisation, and that audience was two thirds practice staff and one third dentists.
- [116] **Joyce Watson:** I will follow on in that vein, because we are trying to get all the evidence from all the people involved in dental health care. Is there another organisation that we need to speak to apart from yours, which represents the people involved in dental health care, who may not be dentists?
- [117] **Mr Geddes:** There is an association that represents therapists and hygienists and there is an organisation for dental nurses. I could pass their addresses onto you.
- [118] **Ann Jones:** That would be helpful, thank you.
- [119] **Janet Ryder:** You talked about retraining for dentists. Doctors must undertake between 30 and 50 hours a year of retraining as part of their assessment. Is there the same requirement for dentists and, if it is not stipulated, are there courses available? Just as GPs have a whole menu of courses to choose from, I presume that dentists do as well, so are there courses available on the treatment of patients?
- [120] **Mr Geddes:** I can answer by saying 'yes' on every count. We have to do 50 hours a year. There are core courses that include cross-infection control and ethics, and, in the main, they are provided by the postgraduate department in Wales, although we also provide supplementary courses, which, in my view, are better. There is also always a focus on the core courses at the annual conference, so there are plenty of learning opportunities for dentists and their staff.
- [121] **Ann Jones:** Jonathan, we can go on to your other question now.
- [122] **Jonathan Morgan:** It is all right, Chair, because my question on the retraining has been covered. Stuart touched on particular groups that may need retraining. For example, to put it delicately, a difference in age may be a factor, as the older generation might require a

bit more retraining than the younger generation, who may be slightly more tuned in to these sorts of issues?

10.40 a.m.

- [123] **Mr Geddes:** It is not so much retraining; it is the renewal of their knowledge and highlighting or raising the profile.
- [124] **Jonathan Morgan:** Stuart put it more delicately than I did.
- **Ann Jones:** Okay. So you are happy with that then, Jonathan. Thank you. [125]
- [126] **Eleanor Burnham:** I will ask my question in Welsh. The translation is on channel 1.
- [127] Mae'r cwestiwn yn debyg i'r hyn a I asked a similar question to the medics sefydliadau a ddylai gael eu cynnwys yn y gwaith o gydgysylltu a chynnal ymgyrch i sicrhau bod modd i bob deintydd ddarparu triniaeth ddeintyddol i bobl sydd â HIV, heb wahaniaethu yn eu herbyn?

ofynnais i'r meddygon yn gynharach. Pa earlier. Which organisations should be included in the work of co-ordinating and delivering a campaign of ensuring that all dentists are able provide to discriminatory dental treatment to people living with HIV?

- [128] Mr Geddes: That is interesting. As most dentists in Wales work as NHS contractors, I would have thought that the local health boards could be in a position to provide some helpful advice. The postgraduate department has a resource and we have a resource. The General Dental Council will issue formal reminders occasionally, as it does in its documents of standards in practice. I would be very happy to work with organisations representing those patient groups. If they approached us, we would be very happy to work with them.
- [129] Eleanor Burnham: Fy nghwestiwn Eleanor Burnham: What role would the British Dental Association have in such a olaf yw pa rôl fyddai gan Gymdeithas Ddeintyddol Prydain mewn ymgyrch mor comprehensive campaign? gynhwysfawr?
- [130] I am making the point that you are NHS contracted.
- [131] **Mr Geddes:** The BDA is not, but the dentists would be.
- [132] **Eleanor Burnham:** Yes, I mean the dentists, sorry.
- [133] **Mr Geddes:** It would be a matter of whether an approach was made to us and we could then highlight that through our in-house journals and local mailings. A publicity mechanism is available to use in the profession and we have a very good network for getting at dentists and their staff. I am sure that we could do that, but, specifically, I am not sure what you are getting at.
- [134] **Eleanor Burnham:** Just that if you are going to raise awareness and have a campaign to ensure that all dentists are able to provide non-discriminatory dental treatment to people who are living with HIV, what role would the BDA have to ensure that—
- [135] **Mr Geddes:** This is already in our advice leaflets and notes. It is something that dentists should be doing anyway. Even their NHS contract says that they should not discriminate against patients on any grounds whatsoever. That is in their core NHS contract.
- [136] **Eleanor Burnham:** That is the comprehensive answer; thank you.

- [137] **Ann Jones:** Are there any further questions? I see that there are none. Thank you for your evidence. We have come to the end of our questions; if there is anything that you would like to add, now is your opportunity do to so.
- [138] **Mr Geddes:** I gave you quite a big pile of papers, which would probably make good bedtime reading for you.
- [139] **Eleanor Burnham:** It was most comprehensive; I was up all night reading it.
- [140] **Ann Jones:** I did not get that far, but most of us now could probably ask a dentist if we could train as their receptionist. All the information that you have provided is spot-on in terms of where dentists are going. Thank you for your evidence today.
- [141] In closing today's meeting, I remind Members that, apart from the excellent evidence presented by the BDA, there are a number of papers to note. Our next meeting is on 17 November, at which we will continue to take evidence for this inquiry.
- [142] **Eleanor Burnham:** Will that be at 9.30 a.m. again?
- [143] **Ann Jones:** Hopefully, yes.
- [144] **Eleanor Burnham:** Will you let us know in plenty of time?
- [145] **Ann Jones:** We will.
- [146] **Jonathan Morgan:** There is a point, Chair, that we will have to consider. Obviously, we will take further evidence, and in addition to the anecdotal evidence that we have referred to this morning, we may well find more concrete evidence. My concern at this stage is that, unless we get evidence beyond the anecdotal, it becomes difficult to make firm recommendations, because—although I am not saying that they are not relevant, because they obviously are, and what organisations hear from patients is evidence of a sort—it is difficult to quantify, and from a qualitative perspective, it is difficult for us as a committee to base our work on anything that is not absolutely firm. I am sure that we will get further evidence, but at this stage, I have a concern about the nature of some of the evidence that we are getting.
- [147] **Janet Ryder:** I support what Jonathan said. Reading some of the evidence from Dr Olwen Williams at the NHS trust in north Wales, the cases that she mentions are over five years old now. It may be that this is anecdotal, and that it is people's perceptions that are being affected, but we need to back this up with some firm, current evidence.
- [148] **Ann Jones:** One way forward might be to make that kind of statement in our report—that we have only received anecdotal evidence, and so if there is firmer evidence to come forward, we would be grateful for that. We have had evidence from the Aids Trust Cymru and Body Positive, so we might go back to ask them to firm up their evidence. It is difficult, is it not? People do not want to be identified, but if we referred to a 'Mr X' or 'Ms Y' from a certain region, that might be the way forward.
- [149] **Janet Ryder:** All of the evidence is anecdotal, and we need to change that. We can avoid giving names or identifying specific cases, but we need to say that these are the issues that have been reported, and there is firm evidence on that.
- [150] **Ann Jones:** Yes, we might also recommend a further investigation to try to find firmer evidence.

- [151] **Joyce Watson:** I absolutely agree that we should go back to witnesses and ask for firmer evidence. One pertinent question for Aids Trust Cymru might be whether it has had occasion to take up a case on behalf of someone. If that has happened anywhere, then that would take us beyond the anecdotal.
- [152] **Ann Jones:** You would like to think that, with some of the evidence about cases that are five years old, procedures will now have changed—I do not know.
- [153] **Janet Ryder:** That was the basis of the evidence from north Wales, was it not?
- [154] **Ann Jones:** That is right—there had been changes there.
- [155] **Eleanor Burnham:** We should also be speaking to Betsi Cadwaladr University Local Health Board in north Wales—
- [156] **Ann Jones:** Olwen Williams has provided a paper.
- [157] **Janet Ryder:** The same consultant is in charge of it.
- [158] **Ann Jones:** Yes, there was written evidence from the north Wales trust, from Olwen Williams, who is the lead on this.
- [159] **Ms Webber:** Olwen Williams is coming in on 17 November.
- [160] **Ann Jones:** Thank you.
- [161] I will now bring the meeting to a close.

Daeth y cyfarfod i ben am 10.48 a.m. The meeting ended at 10.48 a.m.