

Welsh Assembly Government Written Response to the Equality of Opportunity Committee's Inquiry into Discrimination against People Living with HIV by Healthcare Professionals and Providers.

June 2010

I welcome this report. Equality and human rights are fundamental values of the NHS in Wales and discrimination against people with HIV is not only unacceptable but is illegal. I am committed to wiping out this type of discrimination wherever it exists in our health service.

Many of the recommendations contained in the report fit well with our current policy direction and I am pleased to be able to accept the majority of them.

One of the key issues that has arisen as part of this Inquiry is the lack of 'formal' evidence available about discriminatory practices. The survey from AIDS Trust Cymru for the Inquiry and more recently the report from the HIV Stigma Index, 'Give Stigma the Index Finger'¹ indicate that some people living with HIV in Wales have experienced different forms of discrimination within the health service. On the other hand, the Inquiry has not uncovered any 'formal' complaints to the NHS on this subject.

I recognise that it is often the stigma associated with HIV that prevents people from speaking out when they have experienced discrimination. I want people with HIV to feel able to report and challenge discriminatory behaviour where it is experienced so that it can be investigated and appropriate action taken.

The findings from the Inquiry suggest that there are different forms of discrimination. It appears that some of the practices that are perceived as discriminatory emerge from a lack of understanding about HIV and the use of universal precautions. It is estimated that one third of people in the UK with HIV are undiagnosed. It is essential that healthcare professionals work within current guidelines to strike a balance between preventing the spread of undiagnosed HIV and other blood borne viruses, and ensuring that patients known to have HIV are not subject to unnecessary additional precautions which would be discriminatory.

I will soon be launching the Sexual Health and Wellbeing Action Plan for Wales. This outlines the Welsh Assembly Government's commitment to continue to improve sexual health in Wales, reduce sexual health inequalities and develop more open discussion about sex, sexuality and sexual health. As part of this Action Plan I have highlighted the need for a renewed focus on HIV prevention and treatment. I am committed to continuing a programme of HIV prevention in Wales, supporting the All Wales HIV Network, and improving the healthcare for people with HIV/AIDS through implementation of 'Providing for the needs of people living with HIV/AIDs in Wales: National

¹ www.ippf.org/NR/rdonlyres/.../0/InitialFindingsStigmaIndex.pdf

Care Pathways and Service Specification for testing, diagnosis, treatment and supportive care’.

As part of the Action Plan work has commenced on reviewing and strengthening the All Wales HIV Network. Management of the Network has been taken over by Public Health Wales with Positive Participation Groups continuing to be led by local HIV charities. HIV network members agreed that the renewed goal for Positive Participation Groups is ‘full and equitable partnership so that policy and practice can be influenced by experience and evidence’. Local Positive Participation Groups meetings have traditionally been attended by local HIV service providers and they provide an ideal forum for feedback to local health boards about the care provided. Part of the role and responsibility of local Positive Participation Groups will be to report back experiences of stigma and discrimination to the wider group. A new website for the All Wales HIV Network is due to be launched at the end of July and an additional confidential internet forum for HIV positive members of the Network is being developed.

The Network is undertaking a needs assessment of people living with HIV in Wales. Part of this assessment will look at experiences of stigma and discrimination. Most people living with HIV are not necessarily in touch with the HIV voluntary sector and it is important that their views are also represented. This assessment will attempt to reach a wide range of people living with HIV. A report is due at the end of July.

Recently the Constitutional Affairs Committee, during its consideration of the Health Protection (Part 2A Orders) (Wales) Regulations 2010, recommended that the Government may wish to consider the impact of these regulations, in relation to issues around stigmatisation of those with HIV or other STIs. The Health Protection (Part 2A Orders) (Wales) Regulations 2010 are made under the amended Public Health (Control of Disease Act) 1984. This Act gives powers to a Justice of the Peace (JP) to make Part 2A Orders imposing restrictions or requirements on people to protect against an infection or contamination that presents or could present significant harm to human health. The regulations supplement the Act by setting out the evidence that must apply before a JP can make an order and providing safeguards to protect anyone who may be subject to an order.

Under the legislation, the JP order making powers are subject to strict criteria and evidential requirements which mean that one cannot be made unless it is necessary to do so and there is no alternative to achieve the desired health protection outcome. The powers are not in place to increase discrimination or stigma experienced by any one particular group.

All orders placing restrictions or requirements on people are restricted to a maximum of 28 days and can be varied or revoked. The regulations require that any orders are reported to Welsh Ministers so that they may be scrutinised and published. This reporting and monitoring of Part 2A orders will ensure that if there is evidence of orders being used inappropriately against any one group of people, action can be taken.

Whilst it is important to protect the public from the risk of infection or contamination, it is as important to protect individual's rights, and not increase discrimination or stigmatisation experienced by one group of people. The regulations provide effective safeguards to protect people, regardless of their circumstances, against any potential misuse of these powers.

I have set out below my response to the Report's individual recommendations.

Detailed Responses to the report's recommendations are set out below:

Evidence base for Discrimination

1. The Committee welcomes the initiatives introduced by some local health boards to improve the experiences of patients, particularly the patient and public involvement groups set up by Abertawe Bro Morgannwg University LHB and recommends that the Welsh Assembly Government encourage other local health boards to consider implementing similar initiatives

Response: Accept

Involving patients in the development of health services is key to improving the experience of patients in the NHS and I commend the approach taken by Abertawe Bro Morgannwg University Local Health Board.

As mentioned in the introduction to this report, the All Wales HIV Network supports local Positive Participation Groups. Part of the remit of these groups is to provide a platform for service providers and HIV positive people to work together to improve services in their locality. Indeed, in some areas there has been regular attendance from local health service providers at these meetings which have led to improvements in service provision.

I will write to local health boards to ask them to consider what arrangements they have in place to work with HIV positive people to improve their services. I will use this opportunity to highlight the All Wales HIV Network and Positive Participation Groups.

Financial Implications: None. Funding for Positive Participation Groups is within existing budgets.

Complaints

2. The Committee believes that AIDS and HIV charities are in the prime position to advise patients on their legal rights including any rights they have under the Disability Discrimination Act 1995 or future legislation. We recommend that they build upon this role to act as advocates for any patients who wish to pursue legal action as a result of experiencing discrimination and believe that the Equality and Human Rights Commission should actively use their powers and expertise to support the charities.

Response: Accept

I agree that HIV and AIDS charities have an important role to play in assisting patients who experience discrimination and act as advocates for them where a legal challenge to discrimination is taken forward. However, it is also important that all patients feel able to raise a concern about their healthcare and have it dealt with appropriately and promptly by the NHS organisation concerned, without feeling that they have to have recourse to legal action. I have recently consulted on a set of draft regulations (the draft NHS (Concerns, Complaints and Redress) (Wales) regulations 2010) which will underpin new arrangements for the handling of concerns about the NHS in Wales. These regulations, which I intend to lay before the Assembly after the summer recess, require NHS bodies to make provision for the specific needs of people raising concerns, and to ensure that people have proper information about the process. It is also open to any patient to ask for assistance from the Community Health Council Complaints Advocacy Services should they wish to raise a concern about their healthcare.

Financial Implications: None. This is within the existing remit of the charities and the Equality and Human Rights Commission.

3. We believe that the evidence base for cases of discrimination could be boosted by charities alerting local health boards informally of any instances so that they are aware and can keep a record.

Response: Reject

I agree that we need to boost the evidence base for cases of HIV related discrimination. However, there are a number of potential legal issues which make me unable to accept this recommendation. First, there is concern about the effectiveness of any such records given the informality of the proposed process. Any allegations that were brought to the attention of local health boards in this way would not have been investigated and the account of the complainant would not have been tested. Local health boards could therefore be recording an act of discrimination which, if it had been subject to an investigation, may not have been proven.

Second, complainants may not be happy for their concerns to be passed onto local health boards in this way and may only be prepared to speak to the charities in confidence.

Third, whilst it is proposed that local health boards would only keep an informal record of allegations of discrimination, they would need to consider how they would handle a serious complaint received in this way. If they wished to investigate, this may require the cooperation of the complainant, which the complainant may not wish to do.

Fourth, in the event that local health boards did not to investigate complaints that were brought to their attention under this process, that could be unfair on the alleged perpetrators of the discrimination. They may never be informed that these complaints had been made against them or given any opportunity to defend themselves and clear their name.

Finally, this type of material could also be covered by the Data Protection Act 1998, which requires various conditions to be met before it can be retained or processed, including a requirement to ensure the information is accurate. The local health boards could therefore be in breach of data protection principles if this information was retained without being verified.

I believe that it is proven cases of discrimination that will build the evidence base. If a patient experiences discrimination they should be encouraged and supported to take forward complaints through the NHS complaints procedure and/or through the relevant professional body for investigation. As I have outlined in my response to recommendation 2, I will be laying down draft regulations to the Assembly that require NHS bodies to make provision for the specific needs of people raising concerns, and to ensure that people have proper information about the process. This includes them being supported through Community Health Council Complaints Advocacy Services as well as HIV charities. Additionally, the All Wales HIV Network's local Positive Participation Groups provide an existing platform for HIV positive people to raise issues with local health boards and to work together to improve services in their locality. I will ask the HIV Network and Community Health Councils to ensure good links are in place between Community Health Councils and Positive Participation Groups.

Financial Implications: None. Any additional funding will be met within existing budgets.

Lack of Information, Experience and Skills

4. The Committee recommends that the Welsh Assembly Government put arrangements in place with local health boards to allow all GP and dental practices to be able to contact a HIV specialist by email or telephone to discuss treatment prior to issuing a prescription. This would ensure that patients receive appropriate medication without having to consult their specialist.

Response: Accept

I agree that a patient's non-HIV related primary care needs should be met by primary care practitioners and not by being referred to their HIV specialist. This will provide a more acceptable service to patients and increase efficiency by reducing unnecessary consultations with HIV Specialists.

Communication between primary care and specialist services is the key to resolving this issue. Where some medication is being provided by a specialist

clinic and other routine medications provided through primary care there is a risk that one prescriber may not be aware of changes being made by the other clinician. There is therefore a concern that potential drug interactions might be missed. With detailed and timely communication these issues can be resolved but there are often delays in communication.

There are a number of ways this situation can be improved and electronic communication has a big part to play in resolving these issues. Expert prescribing advice should also be available from local health board pharmacy teams or through consultation with colleagues in specialist clinics as suggested in the recommendation.

Within this context it is also important to acknowledge the role that people with HIV play in challenging poor practice themselves. The Stigma Index Report found that 45 per cent of people surveyed had challenged, confronted or educated someone who had been stigmatising them. In Wales, the Terrence Higgins Trust delivers the Expert Patient Programme specifically for people with HIV. Part of this programme looks at how the patient can work with their healthcare providers. An 'expert patient' may be well placed to challenge what they perceive as inappropriate or unnecessary practice.

I will ask local health boards to consider arrangements that can best support primary care practitioners in the care of HIV positive people

Financial Implications: None. Any costs will be drawn from existing budgets.

Training

5. The Committee recommends that local health boards use the experience of HIV specialist consultants and nurses to provide in-house training on the advancements within HIV care for other medical staff

Response: Accept

In line with the example of good practice provided to the Inquiry by Betsi Cadwaladr Local Health Board, I will ask all local health boards to consider implementing in-house training on HIV care for other medical staff.

Additionally, I will ask them to consider how HIV is covered in basic equality training and training associated with the Disability Discrimination Act (2005).

Financial Implications: None. Any additional costs will be drawn from existing training budgets.

Awareness of Cross-contamination Procedures

6. The Committee recommends that the Welsh Assembly Government carry out an exercise to increase the awareness of universal cross-contamination procedures, including displaying information posters in GP surgeries and hospital waiting and consulting rooms.

Response: Accept in principle

A range of information material on universal/standard infection control precautions aimed primarily at NHS staff, produced at local and national level by bodies such as Local Health Boards and the Royal College of Nursing, already exists. In addition, Public Health Wales have developed a number of infection control model policies, including for Occupational Exposure Management (including “sharps” injuries), and the Management of Blood and Bodily Fluids, which are available on the Public Health Wales website. A model policy on transmission-based precaution policies/procedures is in development.

The Welsh Assembly Government and Public Health Wales will explore the possibility of adapting the range of existing materials for use by the public.

Financial Implications: None. Any additional costs will be drawn from existing programme budgets.

Public Awareness

7. The Committee recommends that the Welsh Assembly Government works with the Department for Health to run a nationwide campaign to educate all sectors of society of the facts of HIV in order to erase the memories of outdated campaigns.

Response: Reject

I agree that there needs to be better understanding of the facts associated with HIV. However, I do not believe that there is evidence to suggest that a nationwide campaign would be an effective way of achieving this. HIV/AIDS-related stigma is not a straightforward phenomenon as attitudes towards the epidemic and those affected can vary massively. Reactions to HIV/AIDS will vary between individuals and groups of people. Religion, gender, sexuality, age and levels of HIV/AIDS education can all affect how somebody feels about the disease. A single nationwide campaign is unlikely to address all of these issues.

A multi-faceted approach is required that promotes HIV awareness across different settings, amongst different cultural groups and across ages.

Effective sex and relationships education (SRE) in schools plays an important part in ensuring that young people know the facts about HIV. As part of the forthcoming Sexual Health and Wellbeing Action Plan updated SRE guidance for schools is being developed. The updated guidance renews the Welsh

Assembly Government's commitment for schools to teach about sexually transmitted infections including HIV/AIDS.

It is well established that the stigma associated with HIV can often prevent people from coming forward for testing. The Welsh Assembly Government funds an All Wales HIV Prevention Programme. Part of the work in recent years has included working with African communities where the stigma associated with HIV, particularly for women can be high. Work has been taken forward with community groups and organisations to promote greater understanding of HIV and the benefits of HIV testing. Community based approaches using point of care testing have been developed in Wales to make the testing environment more acceptable.

There is recognition that there needs to be a strengthening of HIV related work in more general sexual health work. Public Health Wales are currently exploring how their local public health teams can be more involved in the delivery of HIV prevention work. The All Wales HIV Network feeds into the All Wales Sexual Health Network. It is envisaged the Sexual Health Network will include a greater focus on HIV. Membership of the Sexual Health Network is wide and it affords opportunities to raise the issue of HIV and discrimination among a wider audience including, education, the youth sector, health visitors, and school nurses.

The All Wales Sexual Health Network will be carrying out a review of sexual health information and resources available in Wales. As part of this review they will consider what is available with regards to HIV/AIDS.

Financial Implications: None. To be taken forward within existing programme budgets.

8. The Committee heard that Body Positive Cheshire and North Wales had already worked with community and voluntary groups to develop their own understanding of HIV. We believe that this is vital to increasing public awareness and that this role should be expanded further. We understand that the charities face difficult financial pressures and would recommend that the Welsh Assembly Government consider introducing specific funding grants for this purpose.

Response: Reject

I commend the work that Body Positive Cheshire and North Wales has taken forward with community and voluntary groups to develop their own understanding about HIV. However, I feel that the opportunity already exists through the All Wales HIV Network's Positive Participation Groups to work more widely with the local community. These groups are led by local HIV charities and in North Wales this role is undertaken by Body Positive. Positive Participation Groups have already worked effectively with local service providers including health and social care and in some areas the police. As

mentioned in the introduction of this paper, the review of the All Wales HIV Network includes the strengthening of these groups.

I will ask the All Wales HIV Network to consider how local Patient Participation Groups can work more closely with community and voluntary groups.

Financial Implications: None. To be taken forward within existing budgets.

Stigma

9. The Committee recommends that the Welsh Assembly Government encourage local health boards to identify options for routinely offering HIV screening, such as through antenatal screening, and roll out a scheme throughout Wales.

Response: Accept in principle

In October 2007 the Chief Medical Officer (CMO) and Chief Nursing Officer (CNO) wrote to all doctors and nurses in Wales about improving the detection and diagnosis of HIV in non-HIV specialties including primary care.² This letter highlights best practice about offering and recommending HIV testing in all healthcare settings. It encourages doctors and nurses to be alert to the circumstances in which it is appropriate to offer and recommend an HIV test.

In 2008, UK National HIV Testing Guidelines³ were published jointly by the British HIV Association, British Association for Sexual Health and HIV and the British Infection Society. These guidelines are intended to facilitate an increase in HIV testing in all healthcare settings as recommended in the CMO letter. Misconceptions remain regarding HIV testing that hinder increased testing. In particular, many clinicians believe that lengthy pre-test counselling is required prior to testing. These guidelines provide the information needed to enable any clinician to perform a HIV test within good clinical practice and encourage 'normalisation' of HIV testing.

As a follow up to their 2007 letter, I will ask the CMO and CNO to write to local health boards drawing attention to the UK National HIV Testing Guidelines and asking what action is being taken to implement these.

Financial Implications: None – any additional costs will be met within existing budgets.

Healthcare Professionals with HIV

² <http://wales.gov.uk/topics/health/ocmo/publications/cmo/2007/hiv/?lang=en>

³ <http://www.bhiva.org/HIVTesting2008.aspx>

10. The Committee recommends that as part of its review the Welsh Assembly Government considers whether the guidance issued by the Department of Health in 2005 could be updated, specifically addressing whether the rule of immediately withdrawing dentists who are HIV positive is proportionate.

Response: Accept

The four UK Chief Dental Officers have endorsed a tripartite working group involving the UK Advisory Panel on AIDS, the Expert Advisory Group on AIDS and the Advisory Group on Hepatitis who are currently carrying out a review of current policy on blood borne virus infected healthcare workers. The review will involve a comprehensive analysis of all relevant evidence and is anticipated to be completed by the end of the year. Any revision of current guidance needs to be based on the best evidence.

Financial Implications: None. This work is being taken forward within existing budgets.

Edwina Hart, Minister for Health and Social Services.