

Positive Action 2008: Conference summary report and agenda for action

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Foreword

On the 1 March 2008 nearly 100 people living with HIV (plwh) gathered together in London for the Positive Action 2008 conference.¹ This conference was the culmination of the hard work and inspiration of a lot of people over a long period of time. The origin of the event was the first ever national conference of plwh, Changing Tomorrow, held in 2004.

Building on the success of this event, the UK Coalition of People Living with HIV and AIDS (UKC) held a series of focus groups across the UK in 2007 to identify key HIV related concerns on which to base a second national conference. Following the closure of UKC a small steering group lead by Positively Women, supported organising the Positive Action 2008 conference.² The National AIDS Trust (NAT) produced a report based on the outcomes of the regional meetings, 'Key Issues for People Living with HIV' and the content of Positive Action 2008 was based on these findings.³

The aims of the Positive Action 2008 conference were to:

- Create a forum for dialogue on key issues of local concern to plwh
- Develop community leadership for increased influence and action
- Create opportunities to form sustainable networks for plwh.

With workshops on criminal prosecutions, influencing services, stigma and discrimination, education, employment and creating sustainable networks, a lot was covered during the day.

Each workshop was asked to agree an Agenda for Action, priority steps for people to take forward in the future, either individually or collectively.

There was also the opportunity to attend an optional lunchtime session where individuals could ask Simon Collins from i-Base questions about the latest developments in treatment.⁴

This report aims to summarise the key points from the discussions and ends with the identified agenda for action. The contents of the report and the identified agenda for action reflect the views of attendees on the day and are not recommendations developed by NAT or the conference steering group.

On the day Positively Women staff and volunteers played a leading role in ensuring everything went smoothly. The lively discussions were lead by able presenters and workshop chairs. NAT staff and volunteers worked with conference attendees to develop a record of the day, summarised in this report.

All of this would not have been possible without the support of the Department of Health, the Elton John AIDS Foundation and Gilead Sciences Ltd. We'd also like to thank the Terrence Higgins Trust for providing the venue for the conference free of charge.

We hope you find this report a useful summary of the Positive Action 2008 conference and look forward to working with you in the future to take forward the agenda for action.



Deborah Jack
Chief Executive
National AIDS Trust



Elisabeth Crafer
Director
Positively Women

¹ There were 94 conference attendees: 56 male, 44 female. Of these 38 were white British and 62 were Black African.

² The steering group was made up of representatives from Diverse, George House Trust, HIV Scotland, i-Base, Long term Survivors Group, NAT, NCB, Positive East, Positively Women, Poz-fem UK, and the Terrence Higgins Trust.

³ *From a positive perspective: key issues for people living with HIV in the UK*, the National AIDS Trust, January 2008.

⁴ For more information about i-base see: www.i-base.info

Introduction

The conference began with an introduction from the conference chairs Susan Clydesdale Cotter (chair of Positively Women), Andrew Little and Elinah Mugwagwa (George House Trust). The speakers emphasised that Positive Action 2008 was a conference of plwh from across the whole of the UK, welcoming the fact that there were attendees representing people from nearly every region. They underlined the importance of identifying actions to take forward; the event was just the beginning of future action by both plwh and the organisations that support them, to make a difference.

Plenary update on criminal prosecutions

The introduction was followed by a short criminal prosecutions update from Matthew Weait, Senior Lecturer in Law and Legal Studies at Birkbeck University. It is worth noting the this update and the following workshop discussions took place before the publication of the Crown Prosecution Service's new guidance to prosecutors to explain how it deals with cases involving the intentional or reckless sexual transmission of an infection.⁵

Matthew outlined how, as the law stands, someone is criminally liable if they *intentionally transmit* HIV, or if they *recklessly transmit* HIV to another person without the informed *consent* of the other person to the risk of transmission. The maximum sentence for reckless transmission is five years (for each transmission) and for intentional transmission the maximum sentence is life. The words above in *italics* have specific meanings which Matthew explained:

Intention

In the eyes of the law, someone transmits HIV intentionally if (1) it is their purpose to transmit the virus or (2) transmission is virtually certain and they foresee that that transmission is virtually certain. Intention to transmit is very difficult to prove and although some people in the UK have been charged with transmitting HIV intentionally, no one has been convicted.

Recklessness

In the eyes of the law, someone transmits HIV recklessly if (1) they are aware of the risk of transmitting the virus (2) they take that risk and (3) the risk taken is unjustifiable.

Someone is "aware of the risk" if they are aware that they might be HIV positive or if they know for sure that they are. It is likely now that the courts will only accept that someone is "aware of the risk" if they have actually been told that they are HIV positive or if they have presented with HIV-related symptoms and refused a test. It is likely to be very difficult for someone to claim that it was justifiable to take the risk of transmitting HIV.

Consent

A person consents to the risk of being infected with HIV only if they make a willing and informed consent to the risk. The courts take the view that consent can be given only if somebody who is HIV positive discloses their HIV status, or where the complainant was made aware of that person's HIV positive status indirectly.

Proving Transmission

Matthew also stressed the need to prove transmission; in England and Wales there is no criminal liability simply for exposing somebody to the risk of transmission. A crime occurs only if transmission actually happens. Proving that person X transmitted HIV to person Y is quite difficult and requires phylogenetic analysis. For more details and discussion on criminal prosecutions see the workshop summary on this topic.

⁵ For further information on this see: www.nat.org.uk

Workshop summaries

During the day there were three opportunities for attendees to attend workshops on six topics: criminal prosecutions; influencing services; stigma and discrimination; education; employment; and creating sustainable networks. In some incidences workshops on a particular topic were repeated to ensure people had the chance to attend.

This summary report provides a synthesis of the main discussions on each topic rather than a write up of each individual workshop.

Criminal prosecutions

Two workshops were held on criminal prosecutions; the same presentations were given at each workshop. The workshops were chaired by Roy Kilpatrick, HIV Scotland, and Angelina Namiba, Positively Women.

Presentations

The sessions began with a presentation from Yusef Azad, Director of Policy and Campaigns at NAT. A summary of his slides is given below.

The policy response to prosecution

Most organisations in the HIV sector oppose prosecution for reckless HIV transmission but attempts to change the law have not been successful and it is clear that the Government are resistant to decriminalising any activities. Achieving change is a long and difficult process. In the meantime it is important to minimise the harm to plwh.

The Crown Prosecution Service (CPS) has consulted on consistent guidelines for prosecutors in England and Wales (recently published). Authorities need to be clear and consistent in how they approach these cases. They need to have an accurate understanding of the CPS guidelines and ensure they operate in a fair and open way.

NAT are planning to work with Association of Chief Police Officers (ACPO) on guidelines for police investigation and discussing cases with media. Further guidance on this area is also needed for clinicians, lawyers, plwh and organisations supporting them. NAT and the Terrence Higgins Trust (THT) are working together to develop this

Implications for people living with HIV

To be sure of avoiding future prosecution for the transmission of HIV, plwh should use a condom and/or disclose their status before sex with a significant risk of HIV transmission. There is no 'list' as to what sexual behaviours are considered to involve significant risk (it is not clear whether oral sex would be classified as risky). If a condom breaks and someone has not disclosed, it is recommended that they advise their partner to access Post Exposure Prophylaxis (PEP) as soon as possible. If someone attempts to prosecute you for reckless transmission then:

- ⌘ REMEMBER - you may well not be the person responsible for the other person's HIV positive status. Do not plead guilty immediately
- ⌘ REMEMBER - there is specialist support out there to help you. Ring THT Direct or your local organisation for information about where to get expert legal advice

Yusef's presentation was followed by a second presentation given by Matthew Weait, Senior Lecturer in Law and Legal Studies at Birkbeck University, based on notes prepared by Edwin Bernard (editor of *AIDS Treatment Update*). The presentation looked at the importance of evidence in the prosecution of the transmission of HIV. A summary of the main points covered by Matthew is given below.

Scientific Evidence

In early cases no scientific evidence was used, however in more recent cases, phylogenetic analysis (comparing bloods) has had an important role. This technique was designed to track different strains of HIV moving across the population not to identify the route of transmission between individuals. In 2006, virologist Dr Anna Maria Geretti of London's Royal Free Hospital testified that although the two people's viruses were genetically similar, phylogenetic analysis was unable to rule out the possibility that a third party with genetically similar virus may have been responsible. As the complainant had engaged in high-risk sexual behaviour with other people before testing HIV positive it was possible that he had been infected by an unknown third party. The defendant was therefore acquitted. NAM and NAT have published a document *HIV Forensics* providing more information about the limitations of this type of evidence.⁶

Pleading 'guilty'

There is a lot of pressure for someone accused of reckless transmission to plead 'guilty' – reasons given for doing so include avoiding a trial and getting a reduced sentence if convicted.

Since 2006, there have been three cases where the person charged has admitted to passing on the infection and in each case the person has been given a lengthy jail sentence. However, in cases where the defendant has not pleaded guilty, there have been three instances where the court has recognised the importance of scientific evidence and the defendant has been cleared of all charges.

It is important that if you are accused of reckless HIV transmission you should seek professional help straight away. Even if you feel guilty remember that a recent study found that between 60-70% of the time the person thought to have infected someone newly diagnosed with HIV could not have done so.⁷

Points to consider if you are thinking of accusing someone of infecting you with HIV

If considering taking someone to court for infecting you with HIV, you need to consider:

- ✂ The CPS will only take someone to court if there is evidence that a jury is more likely to convict
- ✂ Your sexual history will be 'on trial' too
- ✂ All your previous partners are likely to be investigated and have to give blood for an HIV test to rule them out as having infected you and they are likely to become aware of your status

The chance of a successful prosecution is not high – particularly where you have had multiple partners and/or are not in a monogamous relationship.

Matthew concluded his presentation by signposting attendees to Edwin Bernard's blog on this topic, which can be found at: <http://criminalhivtransmission.blogspot.com>

Discussion

Education and the media

There was discussion about the importance of educating legal professionals. People supported NAT's proposals to produce information for lawyers and ensure HIV is properly covered in the Benchbook for Judges. There was also concern about how the police deal with these cases, particularly in relation to the media. The need for NAT, THT and other organisations to work with the police to improve practices was stressed.

Disclosure

Concern was expressed that the courts seem to think that disclosure was always easy. People felt it is important to consider the defendant's state of mind; were they genuinely afraid of abuse/harm

⁶ *HIV Forensics*, NAT/NAM Feb 2007 <http://www.nat.org.uk/document/230>

⁷ Quoted in O'Connor C. Law and disorder, *Positive Nation* (126) October 2006.

if they disclosed their status. There also needs to be greater clarity about what disclosure means in different communities.

Undetectable viral load

Participants discussed whether undetectable viral load could be used as a defence, particularly in the light of recent guidance from the Swiss AIDS Federation for plwh in sero-discordant relationships. It was confirmed that this currently would not be recognised in an English Court.

Responsibility and confidentiality

The question was raised as to whether it is the responsibility of an organisation to take legal action if they know someone with HIV is behaving recklessly. There is no legal obligation to do this. For someone to be prosecuted there must be a complainant who has been infected and is willing to press charges. A similar question was raised in relation to health professionals. Doctor and health adviser have no criminal liability, though there are specific issues for GPs to consider.⁸ There is guidance on the BHIVA website for clinicians about this issue.⁹

Compensation and identity protection

There was a discussion about whether people found not guilty would have access to some form of redress/compensation. The public announcement of someone's HIV status is not something which can be taken back and may have very serious consequences.

NAT are currently arguing that prior to conviction the defendant's identity should be protected. At the moment there is no compensation for those who are acquitted. However, in the light of the recent CPS guidelines there is hope that in the future a prosecution will not be brought if there is insufficient evidence.

Providing support

The need for organisations supporting plwh to give clear guidance to people around the use of condoms was stressed. Confusion on this issue was unhelpful. Services need to know how to support people.

PEP and the need for improved access was highlighted. It was suggested that those who are HIV positive could have a starter kit to access easily if a condom breaks.

Hepatitis C

The issue of prosecution for Hepatitis C transmission was raised. There was general agreement that like HIV, it will be very difficult to prove that one person has undisputedly passed the infection to another. The consequences of the prosecution for the transmission for Hepatitis C for people who are HIV positive and use sero-sorting to select sexual partners was highlighted.

Both workshops identified points from their discussions to add to the Positive Action 2008's Agenda for Action. These are listed below.

Agenda for action

National organisations

- ⌘ Provide clear guidance for all health professionals and work with BHIVA to ensure their guidelines are updated to reflect new CPS guidance

⁸ Reference was made to the Gillick case which established that a doctor could not be considered to be aiding and abetting the crime of underage sex by providing contraception to a young person who was able to make decisions about their own sexual health (*Gillick v West Norfolk and Wisbech Area Health Authority* [1985] 3 All ER 402 (HL)). The only possible exception to this would be in the case of a GP where both parties were under his/her care. They would have a fundamental "duty of care" to their patient and would have to balance the need to prevent serious harm against their obligation of confidentiality. In such rare cases it would be likely that the GP would persuade them to disclose.

⁹ See: <http://www.bhiva.org/>

- ⌘ Provide information and support to local organisations so that they know what to do if a case occurs in their area
- ⌘ Develop greater clarity around Hepatitis C transmission and what this might mean for plwh
- ⌘ Educate the CPS about the difficulties of disclosing in different communities
- ⌘ Educate the police about HIV and the CPS guidelines and provide further guidelines on the police speaking to the media about cases
- ⌘ Ensure guidance for plwh emphasises the importance of not pleading guilty and makes it clear where they can get expert legal advice
- ⌘ Ensure the media do not continue to stigmatise those involved in HIV prosecutions
- ⌘ Decide how much effort should be put into continued campaigning for a change in law

Local action (individuals and organisations)

- ⌘ Ask your local PCT what they are doing to prevent the need for criminal prosecutions and push for greater services and support for plwh in disclosing their status and practicing safer sex
- ⌘ Campaign for easy access to PEP in your local area
- ⌘ Ensure local clinical services respect confidentiality of plwh and are in no sense encouraging the newly diagnosed to consider litigation
- ⌘ Make sure local police are aware of CPS guidelines and have a good level of understanding of the realities of HIV
- ⌘ Make sure local organisations supporting plwh have a clear protocol in place for dealing with prosecution queries, police investigations etc
- ⌘ Work with local organisations to ensure that they are equipped to support plwh who are the subject of an accusation
- ⌘ If a case does occur locally, engage with the local media to prevent stigmatising coverage (see NAT/NUJ Guidelines on reporting on HIV)¹⁰

¹⁰ *Guidelines for reporting HIV*, NAT and the National Union of Journalists, April 2007

Influencing services

“Think, ‘this is MY CARE’ and get involved”

There were two workshops on influencing services. The morning workshop was chaired by Jack Summerside with contributions from Chris Woolls (CARA) and Julie Reynolds (Positively Women). The afternoon session was chaired by Danny West (RYL Training Consultancy) with presentations from Garry Brough (Bloomsbury Patients Network), Memory Sachikonye (Positively Women) and Paul Ward (THT).

Presentations

Garry gave an overview of his experience setting up the Bloomsbury Clinic’s user group. The process began in 1991 and initially it was difficult to get people interested. A survey had found that 97% of patients were unhappy with general pharmacy so they used this as the ‘hook’ to get the group going. The group had many achievements, for example succeeding in getting an in-house pharmacy for the clinic despite the fact that the trust had resisted clinician calls for one previously. In 2004, the first paid patient representative post (paid for by Primary Care Trust (PCT)) was appointed. The main purpose of this role is peer support especially during patients’ first visit; the process ensures the new patient meets someone living with HIV as well as medical staff. They have now started to link with other service user forums in London hospitals to influence services on a London-wide and national basis.

Memory built on Garry’s presentation, outlining her experience of several different user groups. She highlighted the importance of being visible, feeling empowered and influencing services for others. You need to think, ‘this is MY CARE’ and get involved; don’t be afraid to ask questions. She suggested that plwh should look out for patient involvement groups, get to know their HIV service commissioners and get involved with local support groups.

Paul’s presentation aimed to ‘demystify’ the NHS and outline the opportunities to get involved. He outlined the different opportunities in each country. For example in England there is a statutory requirement for a Patient Advisory and Liaison Service to exist in every NHS Trust.¹¹ In Scotland there are Public Partnership Forums which have been set up to consult with patients and the public. In Wales Patient Panels have been established to ensure people have a voice in the care they receive.

Discussion

Why bother?!

The question of why it is important for plwh to influence services was discussed in both groups. Attendees highlighted the importance of plwh taking an active role because of their unique understanding of the HIV-related needs.

There was a discussion about how to encourage young people to become involved in patient activism. The need to find a ‘hook’ to get them involved and inspire them was stressed. The importance of involving plwh from different communities was also underlined.

Opportunities to influence services

The opportunities to influence services were discussed. The shifting balance of power from Central Government to Local Government was highlighted. This means there is more opportunity for plwh’s voices to be heard. Some felt lobbying should be left to those organisations that are set up to do it (e.g. NAT or THT). Others suggested looking at organisations dealing with other issues for models of best practice. The importance of using statistics to make your case was underlined; if you can say 80% of people support your campaign, you add legitimacy.

¹¹ See: <http://www.pals.nhs.uk/>

Barriers to influencing services

People felt that plwh need to have a greater understanding of Local Government structures and 'jargon' before they can confront local service commissioners. For example, there were real concerns about the lack of transparency in commissioning but as a lay person it is not always easy to engage with decision making bodies. People were not sure how to find out who to contact, and felt there were no obvious routes of communication. Differences between both the four nations in the UK and local regions make it difficult to share models of practice. People stressed the 'lack of enabling mechanisms' and the need for guidance and the development of a 'how to kit' in accessible language. Existing guidance is too long and complex; simplicity should be the key to any future resources.

Some plwh have particular concerns due to their migration status and are worried about 'rocking the boat'. People also mentioned competing priorities, as like everyone else they have other commitments such as children and careers.

Success stories

Despite these barriers, several attendees had positive stories to tell. For example, the OASIS in London got a year's reprieve when a service user suggested a letter-writing campaign to save the service. This highlights the effectiveness of direct action. THT's E-campaigning was highlighted as another good example.¹² Positively Women's model of user involvement was also praised; service users decide what the issues are and how to address them, using the specific skills and talents of volunteers. Some attendees would like to see a 'Positively Men' group set up building on the success of this model. The wider success of HIV sector lobbying was highlighted, with the example given of the continuation of the AIDS Support Grant. These successes should be celebrated.

Determination is also required as it can take years to make changes; in one area it took 15 years to get a service-user group set up in a clinic. However, they did ultimately succeed so it is important to keep the pressure up.

People also highlighted the potential to get financial support for providing user involvement. For example the Bloomsbury Patients Network got external funding to start, proved themselves, and is now funded by the PCT. The need to get organised first, and then apply for funding was underlined.

Agenda for Action

National organisations

- ⌘ Create a web-based resource mapping out UK HIV Services
- ⌘ Share good practice; don't reinvent the wheel! Network and share skills/knowledge across regions
- ⌘ Ensure services feedback to their service users about what choices have been made and why
- ⌘ Look at ways of increasing the number of plwh working for those organisations that support them
- ⌘ Provide simple resources on how to be an activist including: a 'jargon busting' tool; example letters; guidance on how to get in touch with local services; and routes in to lobby local and central decision making bodies

¹² See: <http://www.tht.org.uk/>

Local action (local organisations and individuals)

- ⌘ Demand greater transparency and accountability from organisations supporting plwh and other service providers; ask how monies and grants to support plwh are spent
- ⌘ When you decide to lobby on an issue, act collectively as there is strength in numbers
- ⌘ Use existing, proven models to bring about change
- ⌘ Identify your local allies, within and outside the NHS (e.g. media)

Stigma and discrimination

"I've never experienced stigma or discrimination in the 17 or 18 years I've been living with HIV...but I still stigmatise myself"

"The worst thing about my HIV status is the stigma"

The workshop on stigma and discrimination was chaired by Fiona Pettitt (Pozfem) with contributions from Michael Carter (NAM), and Catherine Dodds (SIGMA).

Presentations

Michael's presentation looked at NAM's recent review of its booklet *HIV and You*, originally published in 2006 as part of the Department of Health's stigma strategy.¹³ The review involved input from plwh through a series of workshops. People felt the original booklet targeted people who were already quite accepting of their HIV status. For example, some people felt that even putting "HIV" in the booklet's title meant that by picking it up somebody would be forced to disclose their HIV status. Other people disliked the section on "stigmatising yourself" which seemed to force acceptance on them. The revised booklet will be re-issued shortly as a resource to help plwh to deal with stigma.

Catherine's presentation looked more widely at how stigma operates in society. There is a traditional view of stigma which relies on representations of "villains" and "victims" but Catherine challenged the view that only individual people and their attitudes stigmatise. Instead, social systems which reinforce power imbalances also contribute to stigma. This is a "structural model" of stigma.

HIV does not exist in a vacuum: it is strongly associated with fear of others, issues of blame and it is used as a tool to make people feel that they do not belong. Sexism, homophobia, racism and xenophobia all reinforce stigma associated with HIV. Press reporting, employment discrimination and asylum legislation also contribute to stigma. However, high quality HIV services, the Disability Discrimination Act 2005 (DDA2005) and positive press associations provide a starting point for change.

This structural model of stigma suggests that stigma associated with HIV will not go away unless these other root causes are addressed. This in turn requires change at the structural and political level.

Discussion

Personal experiences

People discussed their own personal experiences of stigma and discrimination. These varied enormously, with some finding the stigma and discrimination around the status the most difficult thing to deal with. Others felt that they did not experience stigma from others but from within themselves. People had had negative employment experiences. Some felt that disclosing their HIV status at work had put them under enormous pressure to 'not go off sick'. A number of people were more concerned with the impact of stigma and discrimination on their families than on themselves.

There were several ideas for what should be done to challenge stigma and discrimination. Specific actions for companies, organisations supporting plwh, Government and public figures were identified; these are detailed in the agenda for action below.

Disclosure

There was a lot of discussion about disclosure and openness as a way of tackling stigma. Some people are very open about their HIV status in all parts of their life. One person described disclosure as requiring a form of "risk-assessment" first and another said that after years of being

¹³ *HIV and You*, National AIDS Map, 2006.

very open about his HIV status he now tended to keep it quiet. Several people expressed concern about the impact of disclosure on their families.

Who's responsibility?

Identifying an agenda for action generated a great deal of discussion. There was a lot of debate about plwh's role in tackling stigma and discrimination. Some people felt that it's up to grass roots movements to challenge stigma and achieve change. Comparisons were drawn with the LGBT movement which relied on individuals making brave decisions and being open about who they are.

Others felt very strongly that it is not fair to put the burden of tackling stigma and discrimination on plwh when they already have so much to deal with: "HIV encroaches on your life enough. Having constantly to challenge stigma and discrimination is too exhausting". Similarly: "Our lives are not just about HIV and cannot be reduced to anecdotes for the purposes of campaigning".

Agenda for Action

National organisations

- ⌘ Encourage companies to link HIV to their corporate social responsibility programmes and act as champions (as Nike does for sport)
- ⌘ National organisations supporting plwh should make alliances with other organisations dealing with long term conditions to challenge stigma and achieve change, as they did around the DDA 2005
- ⌘ Influence Government to do more to educate people about HIV

Local action (local organisations and individuals)

- ⌘ Local/regional organisations working with plwh should empower individuals to challenge stigma and discrimination
- ⌘ Plwh should be as open as they feel able to be about their HIV status
- ⌘ Public figures living with HIV especially should be open about their status

HIV and education

There were two workshops held on HIV and education. The workshops were chaired by Angelina Namiba (Positively Women) and Katherine Sladden (NAT) with contributions from Damian Kelly (George House Trust), Katherine (as above), Angelina (as above) and Imaad James (NCB and Children with AIDS Charity).

Presentations

Damian highlighted the lack of education about HIV across the board, particularly over the last ten years and how this links into discrimination. He also raised his concern about the lack of awareness of the reality of living with HIV, with many believing people could 'just take one pill a day and be fine for life.'

Katherine spoke about the work NAT is doing on education. This includes providing a resource for schools on how to include HIV across the curriculum (and not restrict HIV to sex and relationships education).¹⁴ NAT has also been working to challenge discriminatory and inaccurate reporting in the media, producing guidance for journalists on how to speak about HIV.¹⁵ She encouraged plwh to take part in challenging the media by writing to the editor and complaining when stories were discriminatory or inaccurate. NAT has formed a group called Press Gang which provides support and advice on how to engage with the media and informs members of stories they may want to challenge. Katherine was also happy to help advise on how to place positive stories in the press and can be contacted on press@nat.org.uk.

In the second workshop Angelina outlined Positively Women's approach to education. They work with healthcare providers, the media, students and schools. They use training sessions, consultation responses, seats on advisory groups and a quarterly magazine to get their messages across. They want to make sure that people from all communities have a basic awareness around HIV. Angelina concluded by noting how sad it is that over twenty years on from the discovery of HIV we still need to discuss the issue of education. She referenced the results from NAT's MORI/IPSO poll which underline the importance of revisiting HIV education for the public.¹⁶

Imaad James (NCB and Children with AIDS Charity) shared his experience of going into schools and talking to groups of young people about HIV and sex. He teaches boys aged between 13 – 15. He stressed the need to ensure young people feel that you understand their lives and where they are coming from. It is important to make them feel relaxed and safe but also establish ground rules for the discussion.

Speaking as an HIV positive person is very effective. When you disclose your status young people begin to take the issue more seriously. The more honest you are the more they respect you and are willing to listen. There is great value in having an external person coming in to talk to a group; they are far more responsive than when speaking to a teacher. Imaad stressed the need to encourage more plwh to do this.

Discussion

Reaching out to young people through HIV positive speakers

In both groups, there was a focus on educating young people, and the need to consider how HIV education is approached in schools. Several people felt it would be important to develop an HIV positive speakers programme. One delegate emphasised that before plwh can be 'pushed into the classroom' they need training and support. You cannot presume that just because someone is HIV positive that they know all there is to know about HIV. They may not have the right knowledge or skills so there is a need for a basic training course for those that are interested in this.

¹⁴ *HIV in Schools*, NAT, October 2007

¹⁵ *Guidelines for reporting HIV*, NAT and the National Union of Journalists, April 2007

¹⁶ *Public attitudes towards HIV 2007*, NAT, January 2008

There was some debate about whether it was the responsibility of plwh to educate young people; is this not the responsibility of Government and Local Authorities? There is so much to manage when you are HIV positive that many people will not have the time or energy to commit to this. However, others felt that plwh were in a unique position to educate others and that getting into schools was a fantastic opportunity to make a difference.

Faith schools

The difficulty of accessing faith schools was raised. The need to ensure your message fits into each particular school environment was underlined; it maybe necessary to water down messages for some faith based schools. The feeling was it is better to get into schools and talk about HIV in some form than not get in at all. Stigma and discrimination in religion were also discussed. The need to influence the religious leadership was stressed and the work AHPN has been doing on faith leaders was mentioned.¹⁷

Sex and relationship education on the curriculum

The need to lobby to make sex and relationship education a part of the core curriculum was stressed by some. The appointment of a Minister for Children was a positive step and plwh should lobby this minister about this issue. As children seem to be having sex earlier it was felt it was particularly important to start education earlier.

The importance of educating the educators was also raised; many of those teaching about HIV aren't trained properly. There was a suggestion that schools were willing to talk about HIV in Africa but not about HIV in the UK.

Local action

Some had become frustrated with national politics and felt it was better to try to make an impact at a local level. There are 33,000 schools in the UK and many more plwh so if everyone went to one school the community of plwh could make a huge difference. The discussions should not just be about sex as HIV is so much more than this; you can approach it as a longterm condition a disability etc. WAD is a good hook for getting into schools.

The value of lobbying school governors was discussed. There is also potential to lobby the person responsible for Personal, Social and Health Education (PSHE). People also raised the possibility of speaking to Head Teachers about this, though one delegate had found it difficult to access head teachers; Section 28 did a lot of damage and schools can be reluctant to engage on sex related issues.

Education needs of HIV positive young people

The importance of meeting the sex education needs of children and young plwh was stressed. Regular sex education lessons will take the starting point that HIV is a serious illness that pupils should protect themselves against. How does this work if you are a young person who already has HIV?

Role of parents

The importance of parents in sex education was raised, if parents cannot talk about sex how can the teachers? The Speakeasy programme run by the Family Planning Association (FPA) for parents to help them discuss sex with their children was mentioned as a way of helping parents be open.¹⁸

Role of national charities

The role of national charities in HIV prevention was raised. Many in the room felt that national charities were failing in their duty to educate as they targeted specific communities and not the general population. There was a worry that this may result in rising diagnoses amongst white heterosexuals. The need for a co-ordinated message about HIV was identified and the possibility

¹⁷ See: <http://www.ahpn.org/>

¹⁸ See: <http://www.fpa.org.uk/>

of a national conference to create a unified approach on public education in the sector was discussed.

Education for wider communities

The need for education within communities was mentioned; education is not just an issue for young people. Lack of knowledge in the gay community was raised. It was questioned whether there was so much HIV information that people had become blasé about the risks. The conflicting prevention message of 'don't get HIV' and the anti-stigma message of 'people with HIV are living long, fulfilling lives' further complicates matters.

Healthcare settings

The need for education in healthcare settings was stressed with several people giving examples of discrimination. The importance of challenging medical professionals who discriminate was underlined. Someone should start collecting examples of where discrimination has occurred. The anti-discrimination legislation is there so people need to take action.

The media

Tackling stigma in the media was discussed. Journalists often want very specific people in their stories that maybe unrepresentative of plwh as a whole. The Stephen Fry documentary, 'HIV and me', was discussed. There was a range of views from those that felt it had portrayed people as victims to those that welcomed the programme, though overall most people felt negative about it. Some stressed that organisations have a duty of care to protect people and should not put individuals forward for case studies if they feel the journalist's agenda was not in the best interest of the individual.

Employers

HIV education for employers was raised. The need to explain the reality of living to HIV to employers was underlined. For example, explaining what taking HIV medications actually means, how it might impact on working life, and how employers could be flexible to support individuals.

Agenda for action

National organisations

- ⌘ Create guidelines on how to campaign to get HIV education into schools. These should include: the current curriculum obligations; legal obligations; who to speak to (schools, Local Authorities, governors); and the educational resources that are already available
- ⌘ Ensure school nurses are given HIV education
- ⌘ Ensure teachers, governors and Local Authorities are aware of their responsibilities under the DDA 2005
- ⌘ Work with teachers' unions and signpost them to resources
- ⌘ Encourage parents to talk to their children about sex – for example make them aware of the FPA's Speakeasy resources¹⁹
- ⌘ Educate HIV positive people so they have a good understanding of basic HIV facts and the skills to go into schools and teach
- ⌘ Provide the media with alternative stories about the reality of living with HIV
- ⌘ Educate healthcare professionals, particularly GPs

¹⁹ See: <http://www.fpa.org.uk/>

- ⌘ Collect examples of discrimination in healthcare and challenge professional bodies on what they are doing about these examples of discrimination (use the Patient Liaison Service)²⁰
- ⌘ Create a healthcare 'what-to-do' guide to build the confidence of plwh to challenge discriminating behaviour in healthcare services²¹
- ⌘ Educate small businesses about HIV and their responsibilities as employers²²
- ⌘ Ensure people with expertise in London, share their experience with those in the regions, so people everywhere are empowered to act
- ⌘ Disseminate policy work and provide training / support so that resources are effectively used by plwh

Local action (local organisations and individuals)

- ⌘ Challenge myths about HIV in the media, either through NAT's Press Gang or independently²³
- ⌘ Challenge discrimination in healthcare settings
- ⌘ Provide the media with alternative stories about the reality of living with HIV
- ⌘ Lobby at a local level for better HIV education in schools
- ⌘ Use resources (such as NAT's *HIV in Schools* pack or NCB's *Teaching and Learning about HIV: A resource for Key Stages 1 to 4*) to go into schools and encourage teaching on HIV²⁴

²⁰ See: <http://www.pals.nhs.uk/>

²¹ This may be particularly necessary for some African communities who fear their services may be taken away.

²² See *You Can't Always Tell- A Guide to 'Unseen' Disabilities for Small Businesses*, NAT, 2006

²³ For more information on Press Gang, see: <http://www.nat.org.uk/Public-Perceptions-of-HIV/HIV-and-the-Media>

²⁴ *Teaching and Learning about HIV: A resource for Key Stages 1 to 4*, Simon Blake and Paula Power, NCB, 2003

HIV and Employment

There were two workshops on employment. The workshops were chaired by Danny West and John Stevens with contributions from Luke Mallett and Colin Armstead (George House Trust).

Presentations

Luke Mallett gave an overview of HIV and employment. He considered why returning to work has become such a big issue. He explored push factors such as changes to the Disability Living Allowance. He highlighted the need for Government and employment agencies to recognise that returning to work is a graduated process.

Luke considered the consequences of the end of Ensuring Positive Futures. Ensuring HIV positive people have the skills and confidence to return to work is vital. It is essential that providing skills and confidence to return to work are integral to employment initiatives.

Since 2005 HIV positive people are protected from the point of diagnosis by the DDA 2005. There are some concerns that employees don't know their rights and employers don't know their responsibilities under the Act.

Disclosure and concerns around stigma and discrimination are very important issues. Fear of stigma is often a barrier to plwh feeling confident disclosing their status. This in turn can impact on a person's protection under DDA

Luke raised the issue of whether there is a need for HIV specific policies that recognise the unique and different ways that HIV impacts on the workplace and a person's employability.

Luke noted the many positive reasons why employers should consider employing plwh. HIV is associated with less non-disability related absence, increased loyalty to the job and employer, cultural diversity of the workforce and a relatively untapped skills market.

Colin gave an overview of some of the issues he wished attendees to consider in the discussion: the difference between choosing to and being forced in to returning to work; the implications of the Government's review of the Disability Living Allowance; barriers for plwh who want to go back into employment; how voluntary organisations can help; the support plwh need when in work; the role of trade unions and employers' knowledge of the DDA2005.

Discussion

Returning to work

The many difficulties in returning to work were discussed by both groups. Key concerns were around a lack of confidence after being out of work for long periods of time, lack of skills (e.g. IT skills) and nervousness about how colleagues will respond if they discover your status. There was also fear about how to explain long periods of unemployment on your CV. People had concerns about health questionnaires and whether they should disclose their status during the application process or after they had been offered a position.

The benefit of volunteering as part of the returning to work process was highlighted. This can often turn into paid employment and many organisations that support plwh employ HIV positive staff.

Should you disclose?

There was some discussion about the responsibility of plwh to disclose their status to an employer. There is no legal duty to disclose; however non disclosure means people cannot access the protections offered to them by the DDA 2005. Concerns were raised about how plwh can find out and prove if they failed to secure a post due to their status. The tribunal process can provide opportunities to press employers to reveal notes of their employment process.

Employers' duties

Some felt that the Government was putting the emphasis on plwh and disabled people to go back to work, rather than encouraging employers to take on those with disabilities. There was recognition that there are some exemplary employers. However, these tend to be the exception rather than rule. There is also a need for a wider discussion of what employers' duties are under the DDA 2005, for example what should be considered a 'reasonable adjustment'.

Treatment

People looked at treatment issues and the workplace. There were concerns about the negative impact of taking time off to attend medical appointments. This has the potential to draw unwanted attention to plwh, may give rise to difficult questions from colleagues and potential discrimination. People had concerns that if they invoked the DDA 2005 to access their rights they would be labelled a 'trouble maker'.

People also felt that managing their condition would make it difficult for them to take up a senior role because of the amount of time spent attending medical appointments.

Trade unions

The role that trade unions could have in supporting plwh in the workplace was discussed. Although some have already produced support materials there may be more they could do. Plwh need to consider how they could work to influence the unions on this issue.

Agenda for Action

National organisations

- ⌘ Provide DDA 2005 rights awareness training courses for both plwh and employers, supported by further sources of information²⁵
- ⌘ Develop skills training and information for people seeking to return to work and ensure it is made available across the UK, filling the gap left by Ensuring Positive Futures
- ⌘ Encourage employers to develop effective HIV awareness training including advice for managers about how to support people with disabilities re-entering the workplace
- ⌘ Best practice standards with case studies for employers on employing plwh to be developed and widely disseminated
- ⌘ Ensuring employment programmes such as Work Directions and Pathways, have the skills and knowledge to support plwh
- ⌘ Influence the Government to introduce a 'soft entry approach' to allow benefits to taper off as employment hours increase (rather than cutting benefits as soon as someone starts working 16 hours a week or more)
- ⌘ Develop advice/guidance on filling in health questionnaires
- ⌘ Create a list of the top 100 companies to work for if you are HIV positive
- ⌘ Provision of positive role models and case studies for plwh
- ⌘ Engage with the media on the issue of discrimination in employment
- ⌘ Produce draft HIV human resources policies for employers
- ⌘ Begin a national debate on what reasonable adjustments are
- ⌘ Inform employers about the potential benefits of employing plwh

²⁵ For existing resources see: <http://www.nat.org.uk/Discrimination%2C-the-Law-and-Human-Rights/Employment>

Local action (local organisations and individuals)

- ⌘ Local organisations need to provide advocacy services for employed plwh to challenge stigma and discrimination in the workplace
- ⌘ Plwh need to find out about their rights under the DDA and speak out when they experience discrimination
- ⌘ Local organisation to provide advice and training to employers and plwh filling the gap left by Ensuring Positive Futures.
- ⌘ Local organisations need to provide opportunities for plwh to gain work experience through volunteering
- ⌘ Plwh should utilise resources and information from the Ensuring Positive Futures (EPF) website (still running), NAT and TUC websites, Positively Women's magazine and toolkits
- ⌘ Employed plwh should join their employer's disability network / group to ensure the needs of plwh are understood and recognised
- ⌘ Employed plwh could set up networks and act as mentors for others considering entering/re-entering employment

Creating sustainable networks

There were three workshops looking at creating sustainable networks. The workshops were chaired by Julie Reynolds (Positively Women), Jack Summersides and Alice Mugabo (Positively Women) with contributions from Silvia Petretti (Positively Women), Joyce Lyamulya, Mavis Makhaza (Women and Asylum Seekers Together) Edith Kaggwa and Beatrice Nabulya (Africans Getting Involved).

Presentations

Silvia Petretti and Joyce Lyamulya gave an overview of 'Pozfem', the national voice of women living with HIV.

Pozfem was formed in 2004 after the Changing Tomorrow conference. It is the only national network of women living with HIV. It provides a support network for women, particularly those that might be geographically isolated or in prison. It keeps women informed of HIV health and psycho-social issues. It works to improve policy makers and service providers' understanding of female HIV-related concerns.

In the second workshop Mavis Makhaza of 'Women Asylum Seekers Together' gave an overview of the organisation. This small network campaigns on behalf of, and supports, people fighting deportation. The work is focussed in the Manchester area and despite limited resources and few formal structures it achieves significant success through personal contact and high local visibility.

In the third workshop Edith Kaggwa and Beatrice Nabulya gave a brief overview of 'Africans Getting Involved'. The network was established in 2004, an outcome of the Changing Tomorrow conference. It came out of the need to address the specific concerns of the African population in the UK living with HIV (e.g. concerns such as immigration and access to treatment). 'Africans Getting Involved' aims to address the gap between grass root communities and policy makers, ensuring Africans living with HIV have the opportunity to influence Government policy. Their achievements include: responding to consultations; presenting at conferences; speaking at hospitals; and lobbying on immigration issues.

Discussion

Why set up a network?

All three groups highlighted the need to share good practice and build on existing networks' successes. There was some discussion about the role of networks; HIV services in the UK are already very good but if they are going to continue to improve plwh need to come together to lobby on key issues. Funding cuts to HIV provision services mean it is important to keep up the momentum if further cuts are to be avoided. People also felt that networks were a useful way of sharing problems/finding solutions, sharing knowledge and meeting new people.

One group or many?

There was some debate about the value of having separate groups for different communities. Some felt that segregation between different groups of plwh was counterproductive and there should be a more inclusive approach. Others felt that some people, for example women or Africans, face particular forms of discrimination and have specific concerns unique to them which justify the existence of separate groups. One delegate gave the example of a Welsh internet network which has been set up to discuss problems specific to Wales.

There was overall consensus on the need for a UK wide organisation open to everyone living with HIV to replace UKC. There was some discussion about how, after the folding of UKC, a financially viable organisation could be set up.

Scarce resources were seen to be the main barrier to setting up sustainable networks. People thought that networks were more sustainable when they have clear aims and objectives to hold the group together.

Shared agenda for action

- ⌘ Build a UK HIV website which provides an accessible forum for all the things plwh want to discuss.
- ⌘ Hold (biannual) conferences of plwh to create the opportunity to share concerns and identify actions.
- ⌘ Continue to learn from other networks who do this well.
- ⌘ Use the list of emails gathered during the conference to develop a UK network.
- ⌘ Create a national “social” event with UK-wide participation.

Optional treatment update

The programme included a lunchtime treatment update from Simon Collins (HIV i-Base). This was a question and answer session which gave people the opportunity to raise current issues of concern.

Issues raised during the session included:

- ⌘ The impact of new drugs on lipodystrophy
- ⌘ The availability of one-a-day drugs in the UK
- ⌘ The effect of treatment on bone density
- ⌘ Whether there is a link between muscle loss and HIV treatment
- ⌘ How are treatments costed and whether costs will come down over time
- ⌘ Latest information on the risks and benefits of treatment interruptions, and whether these are still possible for some people

Simon also gave an update on the recent CROI conference held in Boston in February 2008. Feedback included:

- ⌘ Latest results from the CASTLE study supporting the use of atazanavir/r as first therapy.
- ⌘ Information from the D:A:D study, particularly the report of the increased risk of heart attack from current or recent use of abacavir and/or ddI. This study has important implications for people using this widely prescribed HIV drug in their combination who have high underlying risk of heart disease.
- ⌘ An update on tesamorelin, a promising treatment to reduce central fat accumulation (lipodystrophy). It has a much safer side effect profile than Human Growth Hormone, but is also likely to need maintenance treatment, at an as yet undetermined maintenance dose, to stop the fat returning after the initial treatment.
- ⌘ The case report of a patient with leukemia who was treated with stem-cell transplant from a donor who was resistant to HIV infection and who has been able to stop taking HIV drugs for eight months without having a rebound in viral load. Perhaps a first case of clearing HIV?
- ⌘ New detailed research trying to identify exactly how infection takes place, with implications for prevention and treatment.

Details of these studies are included in a non-technical report of 25 studies from the conference that was distributed as part of this workshop. This is available online at www.i-Base.info

Elton John AIDS Foundation update and conclusion

The conference closed with a short presentation from Babs Evans (UK Grants Manager) from the Elton John AIDS Foundation, outlining the aims of the organisation and future priorities. For more information about the Foundation visit: <http://www.ejaf.org/>.

Susan Clydesdale Cotter, Andrew Little and Elinah Mugwagwa thanked everyone for their contributions and the staff and volunteers from Positively Women for organising the day. They closed the event by stressing the importance of taking forward the actions identified during the day to improve the lives of plwh across the UK.

Agenda for Action

Each workshop identified key actions to be taken forward after the conference. These actions are listed by topic after the summary of each workshop theme in the report. The actions from each topic have been brought together here to create one list for easy reference.

National organisations

Criminal prosecutions

- ⌘ Provide clear guidance for all health professionals and work with BHIVA to ensure their guidelines are updated to reflect new CPS guidance
- ⌘ Provide information and support to local organisations so that they know what to do if a case occurs in their area
- ⌘ Develop greater clarity around Hepatitis C transmission and what this might mean for plwh
- ⌘ Educate the CPS about the difficulties of disclosing in different communities
- ⌘ Educate the police about HIV and the CPS guidelines and provide further guidelines on the police speaking to the media about cases
- ⌘ Ensure guidance for plwh emphasises the importance of not pleading guilty and makes it clear where they can get expert legal advice
- ⌘ Ensure the media do not continue to stigmatise those involved in HIV prosecutions
- ⌘ Decide how much effort should be put into continued campaigning for a change in law

Influencing services

- ⌘ Create a web-based resource mapping out UK HIV Services
- ⌘ Share good practice; don't reinvent the wheel! Network and share skills/knowledge across regions
- ⌘ Ensure services feedback to their service users about what choices have been made and why
- ⌘ Look at ways of increasing the number of plwh working for those organisations that support them
- ⌘ Provide simple resources on how to be an activist including: a 'jargon busting' tool; example letters; guidance on how to get in touch with local services; and routes in to lobby local and central decision making bodies

Stigma and discrimination

- ⌘ Encourage companies to link HIV to their corporate social responsibility programmes and act as champions (as Nike does for sport)

- ⌘ National organisations supporting plwh should make alliances with other organisations dealing with long term conditions to challenge stigma and achieve change, as they did around the DDA 2005
- ⌘ Influence Government to do more to educate people about HIV

HIV and education

- ⌘ Create guidelines on how to campaign to get HIV education into schools. These should include: the current curriculum obligations; legal obligations; who to speak to (schools, Local Authorities, governors); and the educational resources that are already available
- ⌘ Ensure school nurses are given HIV education
- ⌘ Ensure teachers, governors and Local Authorities are aware of their responsibilities under the DDA 2005
- ⌘ Work with teachers' unions and signpost them to resources
- ⌘ Encourage parents to talk to their children about sex – for example make them aware of the FPA's Speakeasy resources²⁶
- ⌘ Educate HIV positive people so they have a good understanding of basic HIV facts and the skills to go into schools and teach
- ⌘ Provide the media with alternative stories about the reality of living with HIV
- ⌘ Educate healthcare professionals, particularly GPs
- ⌘ Collect examples of discrimination in healthcare and challenge professional bodies on what they are doing about these examples of discrimination
- ⌘ Create a healthcare 'what-to-do' guide to build the confidence of plwh to challenge discriminating behaviour in healthcare services²⁷
- ⌘ Educate small businesses about HIV and their responsibilities as employers²⁸
- ⌘ Ensure people with expertise in London, share their experience with those in the regions, so people everywhere are empowered to act
- ⌘ Disseminate policy work and provide training / support so that resources are effectively used by plwh

HIV and employment

- ⌘ Provide DDA 2005 rights awareness training courses for both plwh and employers, supported by further sources of information²⁹
- ⌘ Develop skills training and information for people seeking to return to work and ensure it is made available across the UK filling the gap left by Ensuring Positive Futures

²⁶ See: <http://www.fpa.org.uk/>

²⁷ This may be particularly necessary for some African communities who fear their services may be taken away.

²⁸ See *You Can't Always Tell- A Guide to 'Unseen' Disabilities for Small Businesses*, NAT, 2006

²⁹ For existing resources see: <http://www.nat.org.uk/Discrimination%2C-the-Law-and-Human-Rights/Employment>

- ✂ Encourage employers to develop effective HIV awareness training including advice for managers about how to support people with disabilities re-entering the workplace
- ✂ Best practice standards with case studies for employers on employing plwh to be developed and widely disseminated
- ✂ Ensuring employment programmes such as Work Directions and Pathways, have the skills and knowledge to support plwh
- ✂ Influence the Government to introduce a 'soft entry approach' to allow benefits to taper off as employment hours increase (rather than cutting benefits as soon as someone starts working 16 hours a week or more)
- ✂ Develop advice/guidance on filling in health questionnaires
- ✂ Create a list of the top 100 companies to work for if you are HIV positive
- ✂ Provision of positive role models and case studies for plwh
- ✂ Engage with the media on the issue of discrimination in employment
- ✂ Produce draft HIV human resources policies for employers
- ✂ Begin a national debate on what reasonable adjustments are
- ✂ Inform employers about the potential benefits of employing plwh

Local action (individuals and organisations)

Criminal prosecutions

- ✂ Ask your local PCT what they are doing to prevent the need for criminal prosecutions and push for greater services and support for plwh in disclosing their status and practicing safer sex
- ✂ Campaign for easy access to PEP in your local area
- ✂ Ensure local clinical services respect confidentiality of plwh and are in no sense encouraging the newly diagnosed to consider litigation
- ✂ Make sure local police are aware of CPS guidelines and have a good level of understanding of the realities of HIV
- ✂ Make sure local organisations supporting plwh have a clear protocol in place for dealing with prosecution queries, police investigations etc
- ✂ Work with local organisations to ensure that they are equipped to support plwh who are the subject of an accusation
- ✂ If a case does occur locally, engage with the local media to prevent stigmatising coverage (see NAT/NUJ Guidelines on reporting on HIV)³⁰

Influencing services

- ✂ Demand greater transparency and accountability from organisations supporting plwh and other service providers; ask how monies and grants to support plwh are spent

³⁰ *Guidelines for reporting HIV*, NAT and the National Union of Journalists, April 2007

- ✂ When you decide to lobby on an issue, act collectively as there is strength in numbers
- ✂ Use existing, proven models to bring about change
- ✂ Identify your local allies, within and outside the NHS (e.g. media)

Stigma and discrimination

- ✂ Local/regional organisations working with plwh should empower individuals to challenge stigma and discrimination
- ✂ Plwh should be as open as they feel able to be about their HIV status
- ✂ Public figures living with HIV especially should be open about their status

HIV and education

- ✂ Challenge myths about HIV in the media, either through NAT's Press Gang or independently³¹
- ✂ Challenge discrimination in healthcare settings
- ✂ Provide the media with alternative stories about the reality of living with HIV
- ✂ Lobby at a local level for better HIV education in schools
- ✂ Use resources (such as NAT's *HIV in Schools* pack or NCB's *Teaching and Learning about HIV: A resource for Key Stages 1 to 4*) to go into schools and encourage teaching on HIV

HIV and employment

- ✂ Local organisations need to provide advocacy services for employed plwh to challenge stigma and discrimination in the workplace
- ✂ Plwh need to find out about their rights under the DDA and speak out when they experience discrimination
- ✂ Local organisation to provide advice and training to employers and plwh filling the gap left by Ensuring Positive Futures.
- ✂ Local organisations need to provide opportunities for plwh to gain work experience through volunteering
- ✂ Plwh should utilise resources and information from the Ensuring Positive Futures (EPF) website (still running), NAT and TUC websites, Positively Women's magazine and toolkits
- ✂ Employed plwh should join their employer's disability network / group to ensure the needs of plwh are understood and recognised
- ✂ Employed plwh could set up networks and act as mentors for others considering entering/re-entering employment

³¹ For more information on Press Gang, see: <http://www.nat.org.uk/Public-Perceptions-of-HIV/HIV-and-the-Media>

Shared agenda for action

- ⌘ Build a UK HIV website which provides an accessible forum for all the things plwh want to discuss.
- ⌘ Hold (biannual) conferences of plwh to create the opportunity to share concerns and identify actions.
- ⌘ Continue to learn from other networks who do this well.
- ⌘ Use the list of emails gathered during the conference to develop a UK network.
- ⌘ Create a national “social” event with UK-wide participation.



**Conference Programme - 1 March
Lighthouse West London 111-117 Lancaster Road W11 1QT**

| | | | |
|------------------|------------------------------------------------------------------------------------------------------------------------------------------------|----------------------------------------------------------------------------------------------------------------------------------------------------------|--------------------------------------------------------------------------------------------------------------------------------------------------------|
| 9.30 - 10.00 | Registration / coffee | | |
| 10.00 - 10.15 | Introductions, objectives and agenda for the day Housekeeping details Co-chairs: Susan Clydesdale Cotter, Andrew Little, Elinah Mugwagwa | | |
| 10.15 - 10.30 | PLENARY | | |
| | <i>Update on criminal prosecutions</i> - Matthew Weait | | |
| 10.30 - 11.45 | WORKSHOP <i>Criminal Prosecutions</i> Chair: Angelina Namiba Facilitator/Speakers: Matthew Weait Yusef Azad | WORKSHOP <i>Influencing Services</i> Chair: Danny West Facilitator/Speakers: Gary Brough Memory Sachikonye Paul Ward | WORKSHOP <i>Stigma & Discrimination</i> Chair: Fiona Pettitt Facilitator/Speakers: Michael Carter Catherine Dodds |
| 11.45 - 12.00 | COMFORT BREAK /ROOM CHANGE | | |
| 12.00 - 13.15 | WORKSHOP <i>HIV & Education</i> Chair: Chris Woolls Facilitator/Speakers: Damian Kelly Katherine Sladden | WORKSHOP <i>Criminal Prosecutions</i> Chair: Roy Kilpatrick Facilitator/Speakers: Yusef Azad Matthew Weait | WORKSHOP <i>HIV & Employment</i> Chair :John Stevens Facilitator/Speakers: Colin Armstead |
| 13.15 - 14.15 | LUNCH | | |
| | Optional plenary: <i>Treatment Information:</i> Simon Collins | | |
| 14.15 - 15.30 | WORKSHOP <i>HIV & Employment</i> | WORKSHOP <i>Influencing Services</i> | WORKSHOP <i>HIV & Education</i> |

| | | | |
|------------------|-----------------------------------------------------------------------------------------------------------------------------------------------------------|---------------------------------------------------------------------------------------------------------------------------------------|-------------------------------------------------------------------------------------------------------------------------------------------|
| | Chair :Danny West Facilitator/Speakers: Luke Mallett | Chair: Jack Summerside Facilitator/Speakers: Chris Woolls | Chair: Katherine Sladden Facilitator/Speakers: Angelina Namiba Imaad James |
| 15.30 - 15.45 | TEA / COFFEE BREAK | | |
| 15.45 - 16.30 | WORKSHOP <i>Creating Sustainable Networks</i> Chair :Julie Reynolds Facilitator/Speakers: Silvia Petretti Joyce Lyamulya | WORKSHOP <i>Creating Sustainable Networks</i> Chair: Alice Mugabo Facilitator/Speakers Beatrice Nabulya | WORKSHOP <i>Creating Sustainable Networks</i> Chair: Jack Summerside Facilitator/Speakers: Mavis Makhaza |
| 16.30 - 16.45 | SUMMARY, THANKS, NEXT STEPS Co-chairs: Susan Clydesdale Cotter, Andrew Little, Elinah Mugwagwa Babs Evans EJAF | | |
| 16.45 - 18.00 | Optional networking with wine and snacks | | |

Positive Action 2008 Supported by:

The Department of Health

The Elton John AIDS Foundation

An unrestricted educational grant from Gilead Sciences Ltd

Attendees were asked to rate each conference session from 1 to 5 with 1 as very poor and 5 as excellent. Overall 55 people completed the evaluation form and the results are shown below (the number of people that responded to each question is given in brackets after the session title). For workshop feedback, the average rating from respondents is given (the average numerical rating from 1-5 is given in brackets).

Morning session

Criminal prosecutions (15 respondents)

| | |
|---------------------------|---------------|
| Content of discussion | Good (4.1) |
| Opportunity to contribute | Good (3.8) |
| Agenda for action created | Average (3.5) |

Influencing services (17 respondents)

| | |
|---------------------------|------------|
| Content of discussion | Good (4.3) |
| Opportunity to contribute | Good (4.1) |
| Agenda for action created | Good (3.9) |

Stigma and discrimination (15 respondents)

| | |
|---------------------------|------------|
| Content of discussion | Good (4.4) |
| Opportunity to contribute | Good (4.3) |
| Agenda for action created | Good (3.7) |

Pre lunch session

HIV and education (18 respondents)

| | |
|---------------------------|------------|
| Content of discussion | Good (4.1) |
| Opportunity to contribute | Good (4.1) |
| Agenda for action created | Good (3.9) |

Criminal prosecutions (10 respondents)

| | |
|---------------------------|-----------------|
| Content of discussion | Excellent (4.8) |
| Opportunity to contribute | Good (4.3) |

| | |
|---------------------------|------------|
| Agenda for action created | Good (4.2) |
|---------------------------|------------|

HIV and employment (15 respondents)

| | |
|---------------------------|------------|
| Content of discussion | Good (4.2) |
| Opportunity to contribute | Good (3.9) |
| Agenda for action created | Good (3.6) |

Afternoon session

HIV and employment (9 respondents)

| | |
|---------------------------|-----------------|
| Content of discussion | Excellent (4.6) |
| Opportunity to contribute | Excellent (5) |
| Agenda for action created | Excellent (4.6) |

Influencing services (11 respondents)

| | |
|---------------------------|------------|
| Content of discussion | Good (3.9) |
| Opportunity to contribute | Good (3.9) |
| Agenda for action created | Good (3.9) |

HIV and education (14 respondents)

| | |
|---------------------------|------------|
| Content of discussion | Good (4.2) |
| Opportunity to contribute | Good (4.2) |
| Agenda for action created | Good (4.3) |

Creating sustainable networks (42 respondents)

| | |
|---------------------------|------------|
| Content of discussion | Good (3.8) |
| Opportunity to contribute | Good (3.8) |
| Agenda for action created | Good (4) |

Update sessions

Update on situation regarding criminal prosecutions (29 respondents)

| | |
|--------------------|-----------------|
| Content of update | Good (4.4) |
| Speaker's delivery | Excellent (4.6) |

Treatment update (16 respondents)

| | |
|--------------------|------------|
| Content of update | Good (4.4) |
| Speaker's delivery | Good (4.4) |

Organisation of the day (43 respondents)

| | |
|--------------------------------|------------|
| Communication before the event | Good (3.8) |
| Registration on the day | Good (4.4) |
| Format of the day | Good (4.3) |
| Venue | Good (4.4) |
| Catering | Good (4.3) |

Examples of attendees' responses when asked 'How could today have been improved?' are given below:

- "None!"
- "Less whingers and more practical let's do something about it people"
- "Excellent day"
- "Get more people regionally involved"
- "More time for HIV positive people to talk..."
- "Time for more talk should be over. It's time for action, action now!"
- "More time for more questions"
- "Could have been a two day workshop" (echoed by several respondents)
- "Better information earlier!"
- "One room too small and confusion over room allocation"
- "Excellent conference - I learnt a lot and have made useful contacts"
- "Very well run under difficult circumstances. Thanks and well done"
- "Better planning of some workshops"
- "For a one day conference I'm not sure how you could improve"
- "This was the most informative day I have experienced for many years"
- "Why wasn't the conference staged outside of London?"

Getting involved

Attendees were asked to answer the following questions, 'Prior to today, how do you feel you have been able to influence: your local HIV organisation; local healthcare services; other local services; and national policy and decision making.' The results, in percentage, are displayed in the table below.

(52 respondents)

| | | | | | |
|--|------------|------------|---------------------|-------------|-------------------|
| | Don't know | Not at all | To a limited extent | Quite a lot | To a large degree |
|--|------------|------------|---------------------|-------------|-------------------|

| | | | | | |
|-------------------------------------|----|-----|-----|-----|-----|
| Your local HIV organisation(s) | | 12% | 23% | 42% | 23% |
| Local healthcare services | 6% | 22% | 39% | 21% | 12% |
| Other local services | 8% | 21% | 33% | 24% | 14% |
| National policy and decision making | 6% | 29% | 39% | 18% | 8% |

Examples of the type of actions attendees cited when asked ‘What actions have you signed up to undertake today?’ are given below:

- “Lobbying and networking”
- “Complain through PALS”
- “Get involved in local healthcare planning and PI structures”
- “Create a national network for all people living with HIV”
- “To be active in organisation network”
- “To get involved and get noticed”
- “To feedback information to local organisations”
- “To personally involve myself in the disability influencing group at home”
- “To be part of plwh e-networks”
- “Stand up for my rights”
- “Develop leadership”
- “Organise a big social for all HIV positive people – lobby and campaign”
- “Work with other disability organisations”
- “Sustainable networks across Scotland and UK”
- “Training of Pozfem on DDA”
- ”Promoting of Positive Futures resources on PW magazine”

Attendees were asked to answer the following questions, ‘Do you think your level of involvement will increase as a result of the conference in the following: your local HIV organisation; local healthcare services; other local services; and national policy and decision making.’ The results, in percentage, are displayed in the table below.

(51 respondents)

| | Yes | No | Don't know |
|-------------------------------------|-----|-----|------------|
| Your local HIV organisation(s) | 80% | 6% | 14% |
| Local healthcare services | 65% | 10% | 25% |
| Other local services | 62% | 4% | 34% |
| National policy and decision making | 63% | 6% | 31% |

Appendix three: Report of conference representatives' meeting at the Spring BHIVA Conference

Representatives of the Positive Action 2008 Conference of plwh met with BHIVA representatives at the Spring BHIVA Conference on 23rd April 2008 in Belfast.

The following issues were raised:

- The direction BHIVA is taking in relation to social and political issues affecting the health and wellbeing of plwh
- Support from BHIVA for setting up a network of plwh and developing a dialogue with the existing UK network of women living with HIV, Poz-fem UK. Community networks do not have the strength of the expert groups on HIV, and there would be a mutual benefit in improving this dialogue
- The effect that the move to shared care is having on the treatment and care of plwh
- Criminal prosecution and guidelines for clinicians in the light of the new CPS guidelines

Proposal:

The group has requested that the Autumn BHIVA conference includes time for exploring the benefits of strengthening a dialogue with a representative network of plwh and the ways in which this can be achieved.

Appendix four

Relevant resources

The list below details relevant resources referred to during the conference.

From a positive perspective: key issues for people living with HIV in the UK, NAT, January 2008

<http://www.nat.org.uk/document/400>

Guidelines for reporting HIV, NAT and the National Union of Journalists, April 2007

<http://www.nat.org.uk/document/267>

HIV and Recruitment, NAT, 2007

<http://www.nat.org.uk/document/233>

HIV Forensics, NAT/NAM February 2007

<http://www.nat.org.uk/document/230>

HIV in Schools, NAT, October 2007

<http://worldaidsday.org/schools1.asp>

Public attitudes towards HIV 2007, NAT, January 2008

<http://www.nat.org.uk/document/405>

Speakeasy: talking with your children about growing up, the Family Planning Association, 2008

(http://www.fpa.org.uk/products/sex_and_relationships_education_publications/detail.cfm?contentid=847)

Teaching and Learning about HIV: A resource for Key Stages 1 to 4, Simon Blake and Paula Power, NCB, 2003

http://www.ncb.org.uk/dotpdf/open_access_2/2007_ncb_publications.pdf

You Can't Always Tell- A Guide to 'Unseen' Disabilities for Small Businesses, NAT, 2007

<http://www.nat.org.uk/document/292>