

George House Trust's 25th Anniversary
National HIV Social Care Conference



Conference Report



george house trust

still life with HIV



Foreword

The George House Trust national HIV social care conference, ***Still Living with HIV: Building Together for Tomorrow*** took place on Tuesday 20th April 2010 at the Manchester Central Convention Centre in the heart of Manchester city centre. The conference formed part of George House Trust's silver jubilee celebrations and provided an excellent opportunity to celebrate all that has been achieved by the HIV sector in the last 25 years and to reflect on all that still remains to be done and the oncoming challenges that will need to be met. The main aim of the conference was to bring the sector together to discuss the main issues, share good practice and work together to plan for the future to ensure that as a sector we can not only survive but grow in these oncoming difficult times, and that we can continue to meet the changing needs of people living with HIV.

George House Trust was delighted to welcome delegates to its first conference since 2004. Over 60 organisations were represented at the event with attendees from the voluntary, statutory and clinical sectors throughout the UK. Chief Executives from the Terrence Higgins Trust, Black Health Agency, Positively Women, African HIV Policy Network, Positive Action and the Lesbian and Gay Foundation all joined George House Trust for this landmark event. We were also pleased that commissioners and policy makers from both central and local government came along to contribute to and listen to the debates. They were joined by senior medical consultants, clinical psychologists and HIV Social Workers. The diversity of the people attending the event meant that the debates and discussions were well-balanced, and took on board a full range of differing views.

It's now 25 years since George House Trust was set up as Manchester AIDSline in July 1985. A great deal has changed and improved in the last quarter of a century: knowledge and information about HIV, the social and medical care available to positive people, the advent of anti-retroviral treatment, and the rights of people living with HIV. However, there is still much that remains to be done and the range of keynote topics and workshops on the day reflected this and afforded delegates and speakers a chance to explore the issues, challenges and opportunities that exist for the sector in our next 25 years.

George House Trust would like to thank everyone who attended the event, contributed to the discussions, and made the conference such an inspiring and productive day. We would like to thank Councillor Paul Fairweather for opening the conference, Dr Ed Wilkins, Ford Hickson and Dr Ade Adeagbo for their thought-provoking keynote speeches, and all our excellent workshop speakers and chairs from the twelve workshop sessions. We would also like to thank our distinguished panel speakers Adela Mugabo, Elisabeth Crafer and Sir Nick Partridge, and the panel Chair Gus Cairns. Finally we would like to thank our staff, trustees and volunteers who worked so hard before, during and after the conference.

The challenge now for all that attended and for the sector as a whole is to take forward some of the inspiring ideas from the day and to continue to work together in the years to come to further our legacy of innovative and relevant services with positive people at the heart of all that we do.



Rosie Robinson
Chief Executive, George House Trust

Keynote Speakers

Rosie Robinson, Chief Executive, George House Trust

Rosie looked at key issues and achievements in the last 25 years including the commitment of the LGBT community to supporting services and fighting stigma and discrimination. She highlighted that although gay men remain at the forefront of the epidemic, the epidemiology of service users has noticeably changed with a rise in the number of service users that are heterosexual, and in older people aged 50 years plus. Rosie applauded the partnerships with other organisations that have emerged and which continue to be so vital to the future of the sector. She also celebrated the fact that people living with HIV have been so instrumental in shaping services.

Rosie went on to highlight some of the harsh realities we still face: that access to anti-retrovirals is by no means universal, the impact of the brutal UK immigration system on HIV positive asylum seekers and refugees, the political uncertainties and expected funding cuts, and the ongoing challenge of tackling HIV-related stigma and discrimination. She concluded by urging the sector to:

- make the ideas in the new HIV social care framework happen
- reduce the number of people who disappear from clinics
- secure the AIDS Support Grant
- challenge stigma
- develop positive prevention
- support large numbers of older people with HIV, and
- enable people to move from benefits to work

Dr. Ed Wilkins, Clinical Director of Infectious Diseases, North Manchester General Hospital.

Dr. Wilkins talked about his belief that HIV/AIDS will move more into the primary care arena. He started with a brief chronology of the HIV/AIDS epidemic and talked about his personal history working in HIV since the first AIDS case was diagnosed.

Dr Wilkins went on to talk about the challenges in funding, and focused on three main issues: all money has been channel into drugs, there is less money available, there are more people than ever now living with HIV in the UK. An estimated 77, 400 people were living with HIV in 2007, and of the 7734 new cases that year, 32% of people living with HIV were diagnosed late with all the inherent health and treatment complications associated with this.

Dr Wilkins talked further about the epidemiology of the HIV positive population in the UK to highlight the challenges, and opportunities, this posed. The majority of those diagnosed late are heterosexual women; how do we encourage testing in this group? HIV is no longer a young person's disease; the combined impact of an ageing population and the uncharted territory of long term ARV use. A key question is how can we prepare for this? Manchester has the highest HIV prevalence in the North West, and the highest outside of London.

Dr Wilkins highlighted that the key is to treat people immediately and helping people to live longer. People living with HIV aged 35 in a developed country (and on treatment) will live for another 37 years. They also have access to clinical support, financial assistance and advanced legal information. However, we must continue to protect voiceless and marginalised groups, such as children and asylum seekers.

Dr. Ade Adeagbo Chief Executive, African Policy Network

The main focus of Ade's presentation was HIV and the challenges for African communities new to the UK. He looked at the journey so far, the progress that has been made in the reduction in transmissions and death. However, HIV continues to represent a major global challenge and in African communities there is still a lot of stigma, particularly surrounding men who have sex with men (MSM) and mental health/emotional well-being.

He talked about the needs of HIV positive people in African communities, focussing particularly on financial issues, as many people are struggling with employment (either due to their health or asylum status). He also highlighted social inequalities; African Women are more likely to be HIV positive because of gender inequalities and empowerment issues.

To integrate services, Ade believes commissioning is key; especially as NHS management is in a period of transition. He went on to outline the main challenges ahead, including:

- The 'post code' lottery in terms of commissioning
- A new generation of 'hard to reach' and seldom heard
- More 'passion projects' less for Community Based Organisations (CBO)
- Multi-morbidity – additional health issues that may complicate / exacerbate those stemming from HIV
- Need to work alongside Primary Care Trusts (PCT)
- Preventative agenda needs more energy from all involved if it is to be successful with African communities

Ford Hickson, Senior Researcher, SIGMA Research

Ford talked about his contribution to Positive Prevention for All and highlighted that HIV prevention that focuses on the economic benefits will save money but that our core aim has to be saving lives.

Ford outlined his view that people living with HIV's right to have sexual relationships. Ford's research specifically explores the sexual relationships of Men who have Sex with Men (MSM). Sex can be a major obstacle for a person living with HIV due to the impact of treatment, issues around disclosure, and concerns about infecting sexual partners.

Ford was instrumental in the production of CHAPS' 'Making It Count' Report. This reports looks at the risks taken by Men who have Sex with Men, testing, and how people can make the best choices for themselves and their partners. He also talked about the 'Swiss Statement' and the need to question whether undetectable means non-transmissible.

Ford focussed on three main issues that need to be considered, when looking at the sexual relationships of HIV positive MSM:

1. Sharing STI/HIV status with sexual partners. This can be dependent on the partners' status. Disclosure opens up the possibility of experiencing rejection.
2. Full exploration of the levels of risk involved in having regular partners and open relationships as people do not fall neatly into 'risk' and 'risk free' categories.
3. The best sex comes from being informed and confident enough to make the right choices

Workshops

A1 Consistency in Health Messages

Speakers Colin Armstead, George House Trust and Dr Ashish Sukthakar, Manchester Royal Infirmary

Chair Gordon Mundie, Terrence Higgins Trust

Medical care and social care services are the two key sources of support and information around the management of health and transmission risk for HIV positive people. This workshop explored the inconsistencies in messages and information given by medical and social care services, in terms of sex, treatments and life expectancy and the impact of conflicting messages on people living with HIV. The workshop highlighted that good relationships and communication between medical care and social care services are key in ensuring consistent health messages.

A2 HIV Social Care Framework

Speakers Peter Keogh, National Centre for Social Research and Peter Weatherburn, Sigma Research

Chair Tommy McIlravey, Sahir House

This workshop looked at the HIV Social Care Framework and explored how organisations can adopt the framework and move it forward in their region.

A3 Women and HIV

Speaker Elizabeth Crafer, Positively Women

Chair Priscilla Nkwenti, Black Health Agency

This workshop explored what an ideal service for women should look like and the realities of making it happen. Participants looked at how HIV maximises gender differences, therefore reinforcing the inequalities between men and women. Concerns were raised that organisations may fall foul of meeting the needs of those who are more vocal. All service users need to feel valued and empowered and feel they can challenge aspects of the service that they are dissatisfied with.

A4 'Lost to Clinics' and the Path Ahead

Speaker Chris Morley, George House Trust

This workshop looked at the rate of people dropping out of clinical care and explored possible reasons why. A presentations of facts, figures and evidence was followed by a debate around how we can work together to find and work with people, who are not accessing clinical care.

A5 Practical Support for Immigration

Speakers Daniel Murphy, George House Trust and Hermione McEwen, Greater Manchester Immigration Aid Unit

Chair Denise McDowell, Greater Manchester Immigration Aid Unit

The discussions in this workshop focussed on how to support positive people with immigration issues; in terms of legal and practical support. Attendees looked at case studies and best practice.

L1 AIDS Support Grant

Speaker Eleanor Briggs, National AIDS Trust

In this lunchtime session, Eleanor shared the key findings from NAT's review of the AIDS Support Grant; looking at how it is currently spent and the likely future of local authority spending, following the removal of ring fenced funding. Participants discussed how the sector can work together to secure future funding.

L2 Double the Impact

Speakers Colin Armstead and Lynda Shentall, George House Trust

This lunchtime session explored the impact on HIV positive staff of working in the sector. Participants explored what the issues were for them personally, how they each coped with the impact of these, what support was available for them currently and what else could be done to offer support.

B1 Positive People Challenging Stigma

Speakers Maurice Hebert, National AIDS Trust and Kath Morgan, George House Trust

Chair Councillor Paul Fairweather

In challenging HIV stigma, positive people themselves are the most powerful weapon. However, disclosure of status, as seen in the George House Trust Positive Speakers Programme and National AIDS Trust's Press Gang, has to remain within the HIV positive person's control. Public disclosure in these ways can have incredible benefits, if proper support is provided and the level of involvement and exposure is constantly re-evaluated by the person living with HIV. Disclosure should always be through individual choice and not through pressure or the expectations of others. Due to these underpinning ethics, both programmes have been highly successful in terms of challenging stigma and personal development for participants.

B2 Promoting Positive Prevention

Speakers Colin Armstead, George House Trust and Tim Molloy, Gay Men Fighting AIDS

This workshop explored work with or led by people living with HIV to assist in preventing the onward transmission of the virus. Best practice around positive prevention work with gay and bisexual men from George House Trust's newly diagnosed and residential weekends and GMFA's online campaigns was shared.

B3 Ageing Population: Older Survivors

Speakers Gus Cairns, NAM and Garry Brough, Terrence Higgins Trust

Chair Babs Evans, Elton John AIDS Foundation

This workshop looked at the issues of the ageing population and long term HIV survivors and the needs of the growing number of people, who will soon fit into both categories. The epidemiology of 'older' people living with HIV was explored, along with the biological impact of old age, living with HIV for a long time, and long-term use of ARV's. The views of HIV positive people, aged over 50, were shared through the results of Terrence Higgins Trust's 50plus research.

B4 Benefits to Work Transformers

Speakers Sue Murphy and Rebecca Byekwaso, Positive East

Chair Eleanor Briggs, National AIDS Trust

Good practice from Positive East's employment support projects was shared in this session and volunteering as a pathway back into work was explored.

B5 Summary of (British HIV Association) BHIVA's themes

Speakers Professor Jane Anderson, Homerton Hospital and Silvia Petretti, Positively Women

Chair Lynda Shentall, George House Trust

The upcoming British HIV Association / British Association of Sexual Health and HIV Spring Conference themes of relevance to those working in HIV social care were explored. There was a particular focus on community representation, the use of BHIVA guidelines by General Practitioners, Primary Care, spending and HIV, and the absence of a working group on mental health and HIV.

Panel Debate

Chair: Gus Cairns, **National AIDS Manual**

Panel members: Adela Mugabo, George House Trust

Sir Nick Partridge, Terrence Higgins Trust

Elizabeth Crafer, Positively Women

The panel gave their perspectives on the following questions:

What were the key issues that stood out at today's conference?

- How people living with HIV can combat stigma
- The draconian UK immigration system and support. For example, the voucher system, destitution and poverty
- Important to focus on social care – exploring the scale of need
- Issues around self-confidence, sex and mental health. The conference provided a better picture of what we are up against, particularly in light of the forthcoming General Election
- Ideas of how to work together in the future
- Where we need to channel resources in the next few years
- How do we cope with inequalities and complexities; for example 50% of people living with HIV are unemployed
- HIV has moved into the ageing population – what is the role of the voluntary sector in addressing these changing needs?
- There needs to be greater energy in campaigns – there may be a loss of activism because we of our successes in effecting change

What will you tell people about HIV today?

- We need a clear message and a national message – some of the available information about transmission is unclear.
- Stigma and discrimination and the impact it has on disclosure
- Highlight gender inequalities as a major factor in the increase in HIV prevalence

Views from the floor

- Campaigning for an end to HIV stigma and discrimination has to be carefully thought out and put together so there is not an 'othering' of people living with HIV
- There is a concern that young people (18 – 21 years old) have been neglected. What messages can we give them?
- Focus on giving people accurate up-to-date information. When we have information we need to share it
- Concerns about government spending and available funds for HIV
- Disclosing HIV status is powerful in relation to ending stigma and discrimination

Feedback

"Extremely important to have conferences such as this for people working within the HIV field that focuses on the very real social issues. EXCELLENT."

"Many thanks, I have had a very interesting and thought provoking day."

"Would have been good to have been able to access more of the workshops. Very impressed with the work of GHT and its representatives."

"Good opportunity to mix with others working in this area. The enthusiasm, from attendees was positive."

"Good piece of work and 1st step for more work to a better future."

"Hopefully this can be repeated to add momentum to our messages."

"Great for networking"

"I am slightly concerned about the discussion regarding people being out and free and easy about their status. I appreciate that the two speakers have had good experiences which are encouraging to hear. Sadly this isn't representative of most positive's experience. Sadly I've heard far too many stories and most recently for discrimination and stigma that positive's have experienced from general public and professionals. Possibly due to rurality perhaps vs city culture and experience. I would really appreciate this comment being added to your conclusion document."

"Many thanks for putting on this day especially in the light of such a difficult financial period."

"Well organised, friendly GHT staff, very interesting with content and atmosphere."

"Excellent summary of HIV in the UK and 25 years, healthy mix of social care, 3rd sector and health overview from communities infected."

"Most enjoyable conference attended for years. Well done."

"A speaker from social care might have been interesting. Their absence says a lot probably!"

"Felt that the day more re-iterated what we already know rather than gave additional information/ideas."

"Really enjoyed the whole day, just wish I had been able to go to more seminars."