



COUNTERPOINT POLICY ALLIANCE



SECURING OUR FUTURE

Maintaining and developing a robust HIV Charity Sector enabling smart solutions and innovative answers to the challenge of HIV through and beyond the current economic challenges

**A Collaboration of
NPL, Positive East and Positively UK**

January 2011

1. Introduction

Securing the Future is a project initiated by the Counterpoint Policy Alliance, a collaboration of Naz Project London (NPL), Positive East and Positively UK. These three partners are a group of small to medium sized service delivery charities, close to their communities. The Alliance's Mission is 'To amplify the voice of people living with HIV, through seeking and applying evidence, and bridging the gap with public policy makers.'

Securing our Future is as a creative response to the financial challenges being faced by HIV-related health and social care users and providers. It is intended to provide innovative answers and smart solutions to help sustain a robust and vibrant HIV charity sector during and beyond the current financial challenges.

NPL is the longest established and largest Black and Minority Ethnic (BME) charity in London addressing the sexual health and HIV/AIDS needs of its communities. NPL provides sexual health promotion and STI/HIV prevention services; culturally sensitive care and support to BME people living with HIV; as well as national training and consultancy services and educational resources.

Positive East works to prevent the transmission of HIV and supports people living with HIV to gain and sustain their health, wellbeing and independence. It delivers HIV prevention, sexual health trainer, peer mentoring and counselling services across London; HIV testing services in East London and Islington; and both primary and secondary HIV prevention work with individuals and communities across East London.

Positively UK is a national charity that champions the rights of people living with HIV and related health conditions. It provides specialist and peer support, advocacy and information; campaigns against discrimination; promotes positive attitudes and equitable access to health; and strives to increase the involvement, voice and visibility of people living with HIV.

The three partners of the Counterpoint Policy Alliance would like to thank everyone who participated in the **Securing our Future** project. Key among these are Kay Orton from the Department of Health who provided funding for this small project, and Derek Bodell who facilitated our stakeholder event and helped us pull together initial summaries and information updates. And, of course, a very special thanks to the 31 HIV organisations and over 125 people living with HIV who participated in our focus groups and surveys.

2. Background

As the number of people living with HIV increases, the challenge of responding effectively to their needs is significant. It includes a greater degree of complexity of support and wellbeing needs, continuing levels of HIV late testing, the ongoing issue of addressing HIV prevention needs, and ending HIV related stigma and discrimination.

The HIV charity sector plays a central role in developing and delivering innovative responses that contribute to addressing these challenges. It is therefore essential that the sector remains robust and vibrant. These key abilities are at risk in the context of the current financial challenges. Charities have to face the certainty of lesser funding in the foreseeable future while continuing the role of addressing the needs of people living with HIV.

Near the end of the previous government, the Cabinet Office responded to the financial threat especially to frontline services for vulnerable and disadvantaged people by creating 'The Hardship Fund'. The Charity Commission and the Association of Chief Executive of Voluntary Organisations both called for new levels of partnership working in the sector in order to help address the impacts of the economic downturn.

With the formation of the new coalition government, there have been further developments in the sector and its financial circumstances. These include:

- Reorganisation of the NHS, including GP-led commissioning and local authority responsibility for Public Health
- Drastic reductions in statutory services as a result of economic constraints
- Abolition of the ring fence for the AIDS Support Grant
- Very challenging fundraising environment
- Closures and reductions in charity sector services
- Reduction in welfare provision
- Increased costs for housing, transport and food
- Increased unemployment
- Initiation of the Transition Fund by the Cabinet Office and the Financial Assistance Fund by the Department of Health

These developments are played out in the concerns and issues raised during this project's stakeholder meeting, focus groups and survey responses. The signs are clear that the time to develop a new way of working is now. The HIV charity sector needs to grasp the opportunity to review how it's works and provides services.

3. Project design

The Securing Our Future project set out to achieve the following two objectives:

- Identify key issues and areas of focus to ensure a viable response to the challenges of HIV

- Highlight the role of national and local government, NHS and charities to ensure a robust and vibrant HIV charity sector, to enable the charity sector to play our full part in developing and delivering the response

To achieve these objectives, the three partner organisations of the Counterpoint Policy Alliance undertook the following:

- Online survey of people living with HIV
- Online survey of charities working with people living with HIV
- Three service user focus groups
- Externally chaired stakeholder event for individual and organizational service providers

4. Summary of Findings

Outlined below are the key issues that emerged from the individual and organisational surveys, user focus groups and stakeholder event.

Individual Survey:

The individual survey involved input from 122 service users from across London, 92% of whom were people living with HIV. The majority of the respondents were Black African, Caribbean or Mixed (52%), heterosexual (53%), male (53%), and the largest group was in the 25-44 year age band.

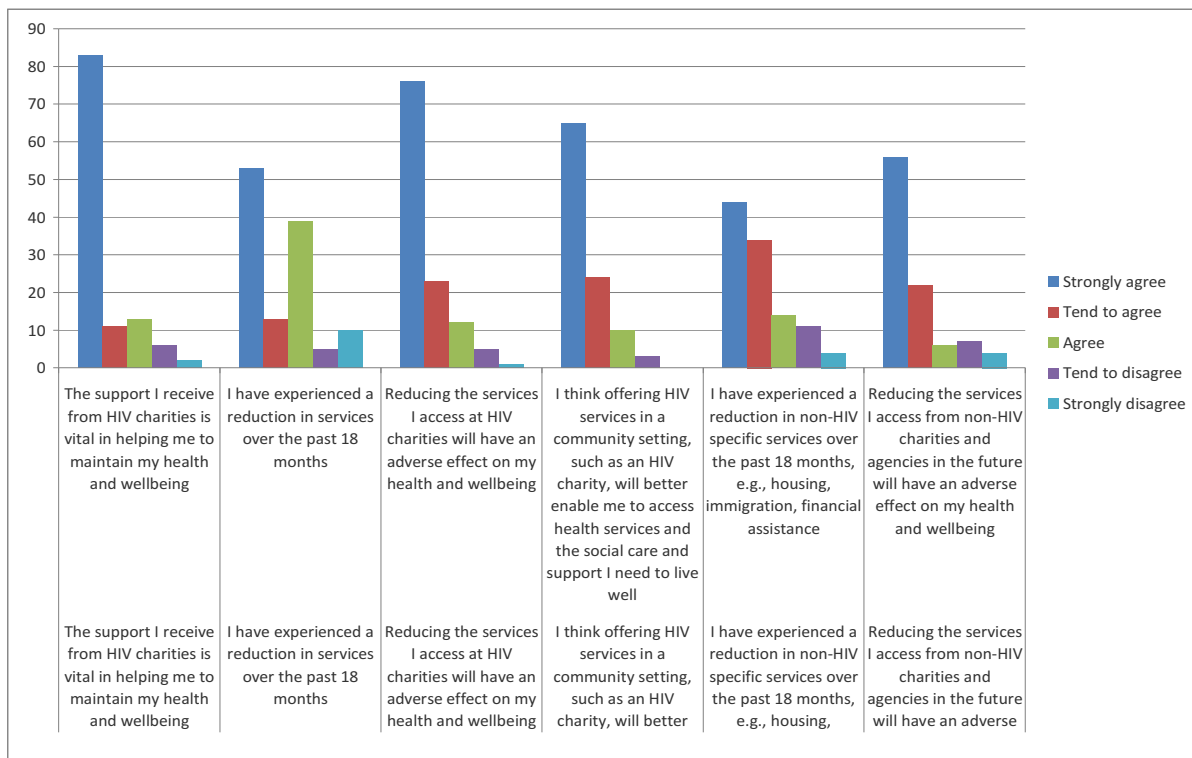


Figure 1: Summary of individual responses to survey questions

The survey illustrates how an HIV diagnosis is a significant challenge to achieving and maintaining health and wellbeing. It highlights the vital role that HIV support organisations play in overcoming these challenges. Clearly there is strong consensus for maintaining support services provided by HIV charities, and that the reduction of such services would have an adverse effect on the health and wellbeing of people living with HIV.

Organisational Survey:

The organisational survey was conducted in Spring and Summer of 2010. A total of 31 HIV service provider charities participated in the survey.

The overall indication from the survey was of a steady increasing negative impact on the HIV charity sector as a result of the financial downturn. On the other hand, people living with HIV were already beginning to experience strong impacts on their personal lives, e.g., as a result of dwindling social services, or increasing costs of living (SEE **Figure 2** below). Based on the experience of the three Counterpoint Policy Alliance partners, this situation has aggravated since mid 2010. HIV charities now face severe financial pressures, with reductions in NHS commissioned contracts and fundraising opportunities leading to diminished financial reserves and a bleak outlook for service provision. The individual lives of people living with HIV have become more difficult as HIV support services begin to be cut.

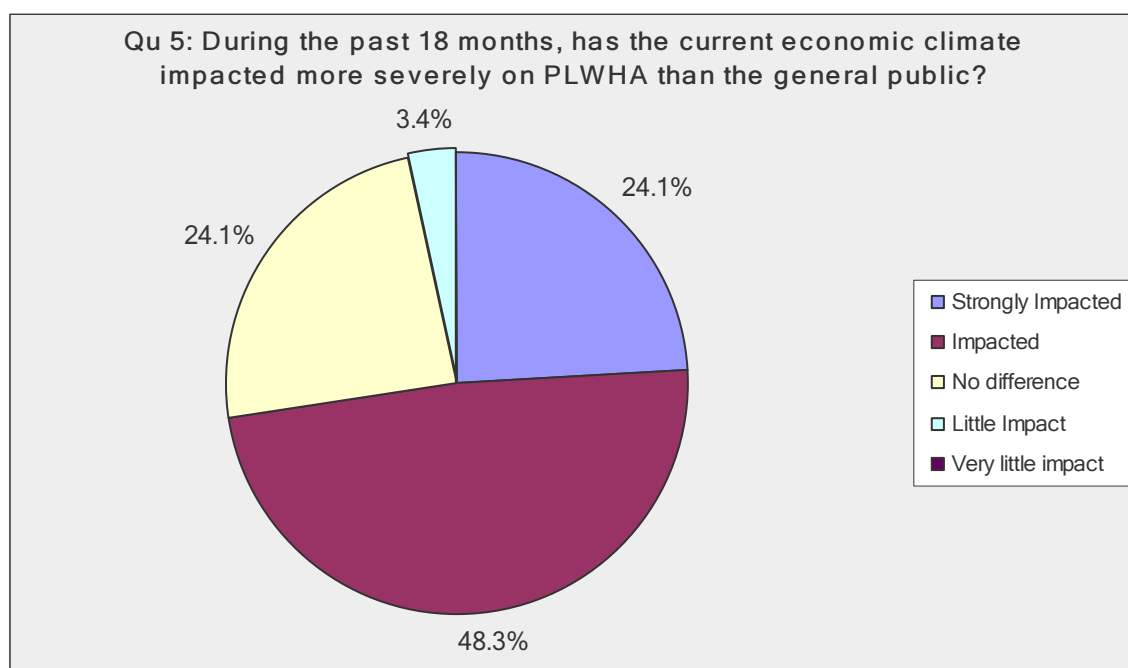


Figure 2: Impact of current economic climate on people living with HIV

Focus Groups:

A total of 35 people took part in the focus groups. The groups highlighted several key points:

- the range of services that people needed and were accessing, e.g., information and redirection to other services including legal and welfare advice; counselling; information on treatment regimes; support and training for people seeking a return to work including areas such as computer skills plus the provision of alternative therapies
- indications that PCTs are examining costs and excluding non-residents from some local service
- non-HIV specific services have noticeably declined, e.g., services for homeless women
- concerns about moves that would limit access to and support from voluntary organisations which might result in a greater reliance on more expensive hospital-based services while not offering the same level and quality of provision particularly in the areas of confidentiality and trust
- health promotion appears to have reduced in many PCTs
- community based services provided by charities were responsive to changing need, accessible and could offer support and services to wider family, partners and friends
- women were concerned about wider HIV support needs that included the family, e.g., disclosure of parental HIV status to children
- mental health impacts of an HIV diagnosis, and potential impact of a loss or reduction in access to mental health and psychological services
- some providers were changing what they could or would offer and there were signs it was becoming confusing

A service user noted: *“Speaking to another person with HIV has helped me most in keeping well in mind and body.”* Another service user observed: *“You can’t share everything with your colleagues or your family but with a counsellor I can pour it all out.”*

All of the groups reported that participants saw the decline in access to services as a risk to their well being and their management of their HIV diagnosis. In terms of the priorities for the future, the focus groups identified **peer-based personal support** (one-to-one, mentoring and support groups), and **mental health counselling**. These findings echo the experience of the Counterpoint Policy Alliance partners on the role information, advice, advocacy and support services play in the lives of people living with HIV.

Stakeholder event:

This event was chaired by Derek Bodell, Joint Vice Chair of the Independent Advisory Group on Sexual Health; he began the event by presenting an overview of the impact of the recession on the HIV sector. A series of panellists then provided various perspectives on the topic. Ben Kerningham (Deputy CEO, NCVO) shared learning from the wider voluntary sector. Paul Ward (Deputy CEO, THT), provided insights from a large HIV charity. Ijeoma Ajibade (Economic Business Policy, GLA) explored a London-wide perspective. Matthew Williams (Executive, Monument Trust) provided a funder's perspective. And Vandna Gohil (Director, Voice4Change) shared the perspective of BME voluntary sector.

The panel discussion was followed by three separate discussion groups. Various proposals emerged from these groups. Highlights were:

- Plan for various scenarios in reduced funding for the sector
- Get clearer about your business case: why am I in business?
- More demonstration of impact
- Ensure user feedback and involvement provide the lead on service restructuring
- Consider how to use the opportunity of PCT mergers
- Be clear in demonstrating why the needs of people living with HIV are important, and why the case for HIV is different that other long-term conditions
- Have a long term vision beyond recession-related crisis management
- Be clear about principles of collaboration

5. Steps toward securing the future

The project aims were to identify key issues and areas of focus to ensure a viable response to the challenges of HIV; to highlight the role of national and local government, NHS and charities in ensuring a robust and vibrant HIV charity sector; and to enable the charity sector to play our full part in developing and delivering the response.

The concerns and issues raised by the surveys, focus groups and stakeholder meeting, and identified as being of importance to people living with HIV, have been exacerbated by most of the recent developments noted above (page 2). These include a steady but persistent reduction in the services available, and access to peer support, advice and up to date information.

The challenge of the moment is to ensure that access to HIV specialist support and advice continues to be available. The Counterpoint Policy Alliance is concerned that in these difficult financial times and with the rapid re-organisation of the health service, key frontline services will be lost. The user survey and focus groups evidence how HIV support organisations play a central role in the care pathways for people living with HIV. Their services prevent the escalation of need, maximise the impact of clinical interventions, bridge the gap between health and social care, and support effective discharge planning. In crude economic terms, HIV support organisations reduce and eliminate demand in the health and social care system.

Clearly, one way in which the impacts of reduced services or closures can be minimised is by HIV charities working more closely together, reorganising when and how services are offered and/or reconfigured. Additionally, with the appointment of Lord Fowler to Chair the ad hoc Committee on HIV, a new platform has emerged where the issues raised in this project can be highlighted. The Committee will consider

- whether public education has been effective and how it might be improved

- the importance of early diagnosis (currently about 27 per cent of those with HIV do not know that they are infected)
- what improvements can be made in HIV testing
- evidence of HIV discrimination.

Leadership from the HIV charity sector

This project has explored how the actions of government, the NHS and HIV charities interact. At the moment that interaction is volatile and seems potentially toxic,. However, it is vital to focus on opportunities and the ability of the HIV sector to respond to change in a fast and positive manner.

As a result of all the feedback received from the surveys, focus groups and stakeholders, the Counterpoint Policy Alliance identifies eight key action points or recommendations for the HIV charity sector:

- 1. Maximise the role of people living with HIV working as peers to address their needs and change perceptions about HIV***
- 2. Ensure the sustainability especially of peer-based personal support services (one-to-one, mentoring and support groups), and mental health counselling for people living with HIV and their families.***
- 3. Facilitate a process among people living with HIV to build a shared vision of what the HIV charity sector would look like in 2016 (5 years time)***
- 4. Increase innovative sharing and use of peer volunteers across HIV charities***
- 5. Build a unified and strong advocacy voice across HIV charities***
- 6. Initiate a mentoring programme where larger HIV charities are available to assist smaller ones as/if needed, e.g., to understand the changing economic and social environment, and analytical skills to accurately identify what the implications are for the organisation and how best to respond***
- 7. Encourage more partnerships among HIV charities that share back office and service delivery functions***

8. Explore merger options among HIV charities that avoid homogenisation, and maintain community relationships as well as the ability to target and tailor for specific needs and sub-populations.

We are moving into an era of radical revamping of the NHS and how health and social care services are provided. It is vital that we maximise opportunities to ensure that the needs, views and experiences of people and communities affected by HIV are at the centre of public policy and development in London. In order to achieve this and take forward the above eight recommendations, there will need to be increasing levels of collaboration across the HIV charity sector. The Counterpoint Policy Alliance looks forward to playing an active part in such heightened collaboration.

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NOTE: For electronic copies of all graphs pertaining to the organisational or individual surveys, please email one of the three partners of the Counterpoint Policy Alliance.