



London Enriched

A response by the National AIDS Trust

The National AIDS Trust is the UK's leading independent policy and campaigning charity on HIV. The National AIDS Trust develops policies and campaigns to halt the spread of HIV and improve the quality of life of people affected by HIV, both in the UK and internationally.

HIV-positive refugees and asylum seekers are some of the most vulnerable people living with HIV in London. Migrants living with HIV often come from countries with high rates of infection. In addition, the process of migration, including high risk of poverty and poor access to safer sex education and healthcare, can contribute to the risk of becoming infected.¹ More needs to be done to ensure the best possible support for the health and well-being of refugees and asylum seekers, and particularly, those living with HIV.

Yet, promoting Londoners' health means, crucially, also tackling the determinants of health. These are the underlying factors like poverty, employment, housing, education, and stigma and discrimination which affect people's long-term chances of staying well. Health can be undermined by poor living conditions, below standard levels of support and a sense of powerlessness as applicants try to negotiate the complex asylum process.

The National AIDS Trust welcomes the Mayor's consultation on a draft strategy for refugee integration in London and its emphasis on addressing the health inequalities many refugees and asylum seekers face. This strategic plan presents an important opportunity for the Mayor to support the well-being of HIV-positive refugees and asylum seekers living in London, not only for their sake, but for the benefit of all Londoners.

This response is structured around the five areas for action in the *Health* section of the consultation document and one area for action in the *Refugee children and young people* section. Specifically, these include:

1. 7A – Refugees and the Mayor's Health Inequalities Strategy
2. 7B – Refugee participation
3. 7C – Evidence
4. 7D – Rights, entitlement and access to services
5. 7E – Mental health
6. 9B – Be healthy

Each is discussed, in turn, below.

¹ National AIDS Trust and Crusaïd (2006) *HIV and Poverty*, www.nat.org.uk/document/207.

7A – Refugees and the Mayor’s Health Inequalities Strategy

Migration itself is an increasingly diverse and fluid phenomenon. It is not all one way, nor always permanent. People come and go, travel on visas, return to visit relatives, often for extended periods, reside in London or elsewhere in the UK for months or years before returning to their country of origin, or are removed either voluntarily or by enforcement should their asylum application be refused.

Such complexity and fluidity pose significant health challenges both in London and the UK as a whole. Some are identified in the recent helpful report from the Health Protection Agency *Migrant Health*.² It is therefore increasingly and urgently important that the strategies guiding the health and well-being of refugees and asylum seekers in London are consistent and joined up.

Recommendations: The National AIDS Trust agrees with the proposals for action as outlined in the Mayor’s draft strategy and welcomes its particular focus on HIV. The National AIDS Trust recommends, as priority, that the Mayor’s strategy:

- **Complement other London strategies for which the Mayor is responsible including the Mayor’s Health Inequalities Strategy (currently under development).**
- **Explicitly address the needs and experience of London’s migrant communities in relation to HIV and barriers to accessing sexual health information and services.**
- **Include a monitoring element to evaluate how the strategies are being applied to improve health and social care provision for refugees in London.**

7B – Refugee participation

Merely receiving services is not integration. Becoming integrated in London life means refugees and asylum seekers, particularly those living with HIV, must have the opportunity to actively help to shape it. The National AIDS Trust believes that a key step towards integration and wider participation is ensuring the city’s refugees play an active and effective part in the making of its decisions.

Recommendations: The National AIDS Trust agrees with the proposals for action as outlined in the Mayor’s draft strategy and recommends, as priority, that:

- **Public engagement in forming health and social care policy in London should include refugees and asylum seekers and we endorse the Mayor’s proposals for action to ensure this occurs.**
- **Refugee participation in processes of consultation on health and social care policies at local and city-wide level should be encouraged and promoted by the Mayor. This should be done through available channels including refugee representatives and**

² Health Protection Agency (2006) *Migrant Health: Infectious Diseases in Non-UK Born Populations in England, Wales and Northern Ireland*, http://www.hpa.org.uk/publications/2006/migrant_health/migrant_health.pdf.

other key support services and stakeholders working with migrants, particularly those living with HIV.

7C – Evidence

Research suggests that HIV prevalence from certain communities may be higher than in the general population of the UK, although there is no accurate way of knowing how many migrants are living with HIV in London or the UK as a whole.³

However, the Health Protection Agency found that there has been a large increase in the number of individuals diagnosed with HIV in England, Wales and Northern Ireland. Many of these diagnoses were in black and minority ethnic (BME) adults, among whom an estimated 3.6 per cent of black Africans and 0.3 per cent of black Caribbeans are living with HIV in the UK.⁴ This correlates respectively to 46 and 3.7 times the estimated prevalence of diagnosed HIV infection in white heterosexuals (0.08 per cent). As the number of BME heterosexuals living with HIV in the UK grows, the likelihood increases of expanding heterosexual HIV transmission. In addition, late diagnosis was more common in BME communities. Two in five (40 per cent) HIV-infected BME adults were diagnosed late and they were seven times more likely to die within a year of their HIV diagnosis than those with higher CD4 counts (3 per cent compared to 0.4 per cent).⁵

Thus, there is an urgent need to ensure the HIV-related needs of refugees and asylum seekers are met. These statistics also demonstrate the need for the HIV risk in migrants to be considered earlier and that this should form an important element of strategic plans to help address the health inequalities faced by refugees and asylum seekers.

Recommendations: The National AIDS Trust agrees with the proposals for action as outlined in the Mayor’s draft strategy and recommends, as priority, that the Mayor’s final strategy:

- **Emphasise the importance of identifying ‘gaps’ in existing information on health and, specifically, HIV.**
- **Expand the current evidence base to develop knowledge and thereby improve the support available to refugees and asylum seekers living with HIV.** This should include mapping the number of refugees and asylum seekers living with HIV in London and their migration status, those registered with General Practitioners and those accessing health services.
- **Engage refugees and asylum seekers, particularly those living with HIV, to provide evidence and input into the gathering of evidence.**

³ Extrapolation from HIV prevalence data in applicant countries is problematic because it assumes that HIV prevalence among migrants is the same as for the total population. This may not in fact be the case and migrants may be more or less vulnerable to HIV for a variety of reasons. However, it is still a reasonable assumption that HIV prevalence among migrants will be higher than in the general population in the UK. Due to a lack of official data, Gazzard, *et al* estimated the number of asylum seekers living with HIV in order to calculate treatment costs. Despite limitations, using immigration and HIV prevalence data for 2003-04 they estimated there would be 899 asylum seekers living with HIV from the top ten application countries (2005) www.ukcoalition.org/migration/HIV-Treat_With_Respect1.pdf.

⁴ Health Protection Agency (2006) *A complex picture: HIV & sexually transmitted infections in the United Kingdom 2006*.

⁵ *Ibid*.

7D – Rights, entitlement and access to services

Charging refused asylum seekers and individuals with uncertain or undocumented residency status for HIV treatment and care continues to be a critical issue. The National AIDS Trust believes that the *NHS (Charges to Overseas Visitors) Regulations 1989* are a danger to both individual and public health and are preventing vulnerable people living in the UK, including pregnant women, from accessing vital treatment. To charge the, often, destitute for their care is deterring vulnerable people from continuing to access the vital treatment they need with possibly fatal results and serious consequences for public health. There is increasing evidence that these regulations are causing harm⁶, and the National AIDS Trust believes they are not only inhumane, a danger to public health and a breach of human rights, but are discriminatory and increase avoidable and unnecessary costs to the NHS.

Recommendations: The National AIDS Trust agrees with the proposals for action as outlined by the Mayor's draft strategy and welcomes its particular focus on campaigning to promote a better understanding of access to HIV services. The National AIDS Trust recommends, as priority, that the Mayor's strategy:

- **Aims to ensure better understanding of entitlements and access to sexual health and HIV services by refugees and asylum seekers and those working with them, including clinicians, officials, and voluntary sector services staff.**
- **Emphasises the importance of providing training for London health services staff at all levels on refugee rights and service entitlements.**
- **Supports the provision of informational resources on entitlements and access to sexual health and HIV services for refugees and asylum seekers in key languages via health services staff and voluntary sector organisations.⁷**
- **Promotes better understanding of the major sexual health risks facing refugees and asylum seekers in London, including HIV, through the provision of campaigns that target refugees and asylum seekers, voluntary sector organisations and support services.** These should communicate sexual health- and HIV-prevention promotion messages in key languages through not only printed and online materials, but also by word of mouth via community networks. This is particularly important as English is a second language for many migrants and some prefer receiving sexual health- and HIV-related information through participatory discussion forums.⁸
- **Engages with local Primary Care Trusts (PCTs) and London's Strategic Health Authorities to encourage the Department of Health, Home Office Border and Immigration Agency and other key stakeholders to work more closely and provide guidance that states that debt for NHS treatment can be written off if a PCT has**

⁶ National AIDS Trust (2007), *Accessing HIV treatment and care in the UK: Cases related to charging*, www.nat.org.uk/document/336.

⁷ One such resource is *Will I have to pay?* developed by the National AIDS Trust and Terrence Higgins Trust (2007) www.nat.org.uk/document/253.

⁸ Winnie Ssanyu Sserum and HIV i-Base (2007) *Assessing the treatment information needs of Africans living with HIV*.

taken reasonable steps to secure payment but there is no realistic prospect of success. Those refused asylum seekers previously in receipt of Home Office Border and Immigration Agency benefits and/or initial accommodation have already been assessed as destitute and thus are wholly unable to pay such NHS bills. Home Office Border and Immigration Agency officials should be ready to inform local PCTs, if approached, not only that an asylum claim has been refused but that the individual has been previously assessed as destitute and would therefore be unable to pay bills for NHS treatment and care. Such bills should then be automatically written off by the PCT.

7E – Mental health

Any aspect of life can affect mental health. An HIV diagnosis typically has an immediate impact; distress, shock and anger are common. Although most people overcome these initial reactions, the uncertainty of living with HIV sustains a heightened level of anxiety. For many people living with HIV, particularly those with prior mental health problems, this can lead to depression and other mental illness.⁹

The impact on mental well-being of physical suffering can be profound. Acute and/or chronic illness and treatment side effects take their toll, both directly and through their secondary effects such as loss of self-image due to changes in physical appearance. The social impact of HIV can also be distressing, particularly if people experience rejection and discrimination following disclosure of their status or alternatively choose to not disclose within otherwise close relationships.¹⁰ People living with HIV may be coping with relationship breakdown, isolation and loneliness.¹¹ Those who continue to live with partners or families may still have to manage the burdens of care giving, for adults or for children, on top of their own needs.¹²

However, evidence shows that mental health organisations in London are having mixed success in providing services that are accessible and responsive to the local population. There is a great deal of variation in the amount of public money that is spent on mental health services relative to need and some areas are greatly under-resourced. In addition, there are wide variations in the access certain communities, including refugees and asylum seekers, have to translation services.¹³

In addition, HIV-related stigma and discrimination are persistent problems for those who have been diagnosed and contribute to reduced health, particularly mental health, for those most vulnerable to infection including refugees and asylum seekers.^{14 15} HIV-related stigma and discrimination also threaten the effectiveness of prevention and care programmes by discouraging individuals from coming forward for testing and from

⁹ Catalan (1999) provides a detailed description of the factors that contribute to the psychological problems of people living with HIV.

¹⁰ Doyal and Anderson (2003) *My heart is loaded*, <http://www.tht.org.uk/informationresources/publications/policyreports/myheart584.pdf>.

¹¹ Doyal, Anderson and Apenteng (2005) *I want to survive, I want to win, I want tomorrow*, <http://www.tht.org.uk/informationresources/publications/policyreports/iwanttosurvive.pdf>.

¹² Wright (2000) describes the impacts of adult care giving on mental health, drawing particularly attention to the added stresses for people with HIV when caring for partners who are themselves ill because of HIV. Chinouya-Mudari and O'Brien (1999) describe the caring responsibilities thrust on children in African refugee families.

¹³ Foster (2003) *Availability of mental health in London*, http://www.london.gov.uk/mayor/health/mentalhealth_availability/mentalhealth_main.pdf.

¹⁴ UNAIDS (2005) *HIV-related Stigma, Discrimination and Human Rights Violations Case studies of successful programmes*.

¹⁵ Sigma Research (2004) *Outsider Status: Stigma and Discrimination Experienced by Gay Men and African People with HIV*.

seeking information on how to protect themselves and others, as well as increasing late diagnosis which lessens the effectiveness of treatment.

Recommendations: The National AIDS Trust agrees with the proposals for action as outlined in the Mayor's draft strategy and recommends, as priority, that the final strategy:

- **Support a more comprehensive approach to developing mental health services to help overcome the *ad hoc* service delivery which currently exists and reduce the wide variation in services between London boroughs.**
- **Research and identify available mental health services across London, and increase accessibility to those services by, for example, supporting the development of a comprehensive language support strategy in London to enable refugees and asylum seekers to better access mental health services.**
- **Include a specific proposal for action on tackling and monitoring progress on reducing stigma and discrimination, particularly related to HIV. This may be done by:**
 - **Collating current and commissioning further research on anti-HIV stigma and discrimination, and on proven ways of addressing them in London.**
 - **Developing and supporting, with other key London stakeholders, a holistic approach to the interconnected prejudices and human rights issues around HIV – including xenophobia, racism, sexism, homophobia and discriminatory attitudes to refugees and asylum seekers.**
 - **Supporting human rights-based processes to monitor progress in tackling anti-HIV stigma and discrimination.¹⁶**
 - **Integrating an anti-stigma perspective into all of the Mayor's strategies and activities.**
 - **Positioning the Mayor as a champion of evidence-based anti-stigma work as a key long-term intervention, in particular using his political influence with other officials and stakeholders.**

9B – Be healthy

Refugee children and young people face a number of different issues from most of their non-refugee peers. These problems may be worsened by poor access to healthcare, partly because refugee families may not know how to access services for children and young people, including HIV care.

¹⁶ Such an approach should include: (1) disaggregated data to identify the needs of those most vulnerable to HIV and AIDS prejudice and to assess the impact of efforts to reduce stigma and discrimination, (2) measurable progress over time through baseline surveys, setting benchmarks and the use of indicators to assess whether those targets have been met, (3) qualitative data in the form of the experiences of people living with HIV and AIDS to measure impact, and (4) HIV policy and planning processes to ensure they include meaningfully all vulnerable groups.

Recommendation: The National AIDS Trust agrees with the proposals for action as outlined in the Mayor's draft strategy and recommends, as priority, that the final strategy:

- **Identify and seek to address barriers to young refugees' access to appropriate services as to better promote physical, mental and sexual health.** For example, the Department of Health and Home Office are currently reviewing NHS charging as a whole and the National AIDS Trust understands that compulsory charging in primary care settings is being actively considered by the Government review board.¹⁷ Should this happen, the impact on children's health and rights would be catastrophic. This measure would make it next to impossible for tens of thousands of children, including many refugees and asylum seekers, to access primary healthcare, inevitably resulting for some in serious illness or death. It would also add a significant barrier to accessing maternity care, thus contributing to maternal and infant mortality. The review board is expected to make its recommendations by the end of 2007, followed by a brief consultation period. **In line with his obligation to promote equality, the Mayor should respond to the consultation.**

Conclusion

Being well, physically and mentally, will clearly make a huge difference to HIV-positive refugees' and asylum seekers' prospects of meeting the other challenges they may face, such as finding a home, getting qualifications and a decent job, building their social life, and stigma and discrimination. The Mayor's strategic leadership on the integration of refugees and asylum seekers presents an important opportunity to not only tackle health inequalities, and particularly those related to HIV, but invest in London for the benefit of all its residents.

The circumstances that bring refugees and asylum seekers to London are often painful and tragic, but in the 21st century, as throughout history, their arrival offers London huge potential benefits. Given the right opportunities and support, refugees can strengthen London's economy and enhance its social, cultural and civic life.

**National AIDS Trust
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¹⁷ Government Response (2006) *Joint Committee on Human Rights Tenth Report: Treatment of Asylum Seekers.*