

Institution: City University London
Unit of Assessment: 3 Allied Health Professions, Dentistry, Nursing and Pharmacy
Title of case study: Unemployment, poverty and discrimination among people living with HIV in the UK
<p>1. Summary of the impact</p> <p>Research conducted by Professor Jonathan Elford of City University London among people living with HIV in East London has had significant impact in the UK as a whole. The National AIDS Trust (NAT) used key findings from the research on employment, immigration and poverty in its submissions to the House of Commons. This led to:</p> <ul style="list-style-type: none"> • A change in the law through the Equality Act 2010 on pre-employment screening for people with HIV; it is now prohibited to ask people about health and disability, including HIV, on pre-employment screening questionnaires before the offer of a job has been made and employers can no longer ask applicants to complete health questionnaires prior to interview. • The removal of charges for hospital treatment for people with HIV who do not have leave to remain in the UK; since 1 October 2012 treatment and care are now freely available in England for anyone diagnosed with HIV. • The retention of a specific funding line for HIV social care in the Comprehensive Review for 2011–2015; as a consequence local councils in England are able to commission and fund social care for people living with HIV.
<p>2. Underpinning research</p> <p>The two groups most affected by HIV in the UK are men who have sex with men (MSM) and black African heterosexual men and women. They account for more than 80% of the 74,000 people currently receiving HIV treatment and care in the UK. Research into the experience of these groups was undertaken at City University London. The Principal Investigator was Professor J. Elford (October 2001 to date), working with Dr C. Bukutu, Research Fellow (2003-2005), F. Ibrahim, Research Fellow (2005-2007) and Professor J. Anderson (Co-investigator), Homerton University NHS Foundation Trust Hospital and Honorary Senior Lecturer, City University London (2003–2006).</p> <p>People diagnosed with HIV infection attending HIV treatment clinics in East London in 2004–2005 were invited to participate in the study (the East London Project). The research was funded by St Bartholomew's and The Royal London Charitable Foundation (see section 3). Patients with a limited command of English were ineligible for the study as were those who were too ill or too distressed to complete a questionnaire. During the study period, 2,680 patients with HIV attended the outpatient clinics in the six participating hospitals; 2,299 of these were eligible for the study and 1,687 completed a confidential questionnaire (response rate 73%). The sample included 758 MSM (646 described their ethnicity as white, while 112 said they belonged to an ethnic minority) and 704 black African heterosexual women and men. The research focused on the respondents' social and economic circumstances, disclosure of HIV infection and HIV-related discrimination, paying particular attention to HIV among people from African communities as well as MSM.</p> <p>The research found that black African heterosexual men and women living with HIV consistently reported more difficulties than any other group in relation to employment, income, housing and residency status.</p> <p><i>Employment:</i> Unemployment was high among people living with HIV; fewer than half the respondents</p>

were employed at the time of the survey. Black African heterosexual men and women were less likely to be employed than MSM.

Social and economic hardship: Nearly half the black African heterosexual men and women, one-quarter of the ethnic minority MSM and 10% of the white MSM did not have enough money to cover their basic needs. The research provided further evidence that HIV in the UK is associated with poverty, especially among migrant and ethnic minority populations.

Discrimination: Nearly one-third of people living with HIV surveyed in the East London clinics in 2004–2005 reported being discriminated against because of their infection. Half of those reporting HIV-related discrimination said this had involved a healthcare worker, including their dentist or general practitioner.

Disclosure: Only one in five respondents had disclosed their HIV status to their employer. There were striking differences, by ethnicity, in the extent to which people with HIV disclosed their infection. Black African heterosexual men and women were less likely to have told people about their HIV infection than MSM.

3. References to the research

1. Elford, J., Ibrahim, F., Bukutu, C., & Anderson, J. (2008). Over fifty and living with HIV in London. *Sexually Transmitted Infections*, 84, 468–472 [10.1136/sti.2008.031187](https://doi.org/10.1136/sti.2008.031187)
2. Ibrahim, F., Anderson, J., Bukutu, C., & Elford, J. (2008) Social and economic hardship among people living with HIV in London. *HIV Medicine*, 9, 616–624 [10.1111/j.1468-1293.2008.00605.x](https://doi.org/10.1111/j.1468-1293.2008.00605.x)
3. Elford, J., Ibrahim, F., Bukutu, C., & Anderson, J. (2008). Uptake of antiretroviral treatment among people living with HIV in London: ethnicity, gender and sexual orientation. *Sexually Transmitted Infections*, 84, 176–178 [10.1136/sti.2007.029249](https://doi.org/10.1136/sti.2007.029249)
4. Elford, J., Ibrahim, F., Bukutu, C., & Anderson, J. (2008). Disclosure of HIV status: the role of ethnicity among people living with HIV. *Journal of AIDS*, 47, 514–521 [10.1097/QAI.0b013e318162aff5](https://doi.org/10.1097/QAI.0b013e318162aff5)
5. Elford, J., Ibrahim, F., Bukutu, C., & Anderson, J. (2008). HIV-related discrimination reported by people living with HIV in London. *AIDS and Behavior*, 12, 255–264 [10.1007/s10461-007-9344-2](https://doi.org/10.1007/s10461-007-9344-2)
6. Elford, J., Ibrahim, F., Bukutu, C., & Anderson, J. (2007). Sexual behaviour of people living with HIV in London: implications for HIV transmission. *AIDS*, 21(Suppl. 1), S63–S70 [10.1097/01.aids.0000255087.62223.ff](https://doi.org/10.1097/01.aids.0000255087.62223.ff)

These journals are all highly regarded in their field and apply a rigorous peer-review process.

Grant title: Patients with HIV infection in East London: A Clinical, Epidemiological and Socio-Economic Assessment. Sponsors: (1) St Bartholomew's and The Royal London Charitable Foundation, Research Advisory Board, Project Number: JRB XMNS. October 2003 – September 2005. This was a competitive bid to the Charitable Foundation that was subject to extensive peer review. The value of the grant was £77,000; (2) City University London. October 2005 – June 2007. City provided 'top-up' funding of £52,000 from its Research Sustainability Fund.

4. Details of the impact

The National AIDS Trust (NAT) is the UK's leading charity dedicated to transforming society's response to HIV. NAT 'provides fresh thinking, expert advice and practical resources, champions the rights of people living with HIV and campaigns for change'. The research team worked closely with NAT when designing the study and shared results with them at an early stage. The research findings from the East London Project on employment, poverty and HIV-related discrimination have

been used by NAT in its reports and practical guides and for lobbying Government, the public and the private sector, with significant outcomes for people living with HIV.

Pre-employment screening for HIV

In November 2008 NAT submitted written evidence to the Work and Pensions Committee in the House of Commons when it was reviewing the proposed Equality Bill. NAT was subsequently invited to give oral evidence in January 2009. The NAT submission focused on pre-employment screening for HIV and cited the research on employment among people living with HIV, conducted as part of the East London project². The Work and Pensions Committee recommended that pre-employment screening be prohibited. NAT cited the East London data during advocacy for an amendment to the Equality Bill both in its submission to Government and in the notes for a Peer who was to speak to the issue in debate⁷. As a result of submissions from NAT and two other organisations, an amendment was agreed and the law was changed; it is now prohibited to ask people about health and disability, including HIV, on pre-employment screening questionnaires before the offer of a job has been made. This legislation came into effect in Great Britain on 1 October 2010. Since the introduction of the Equality Act in 2010, employers can no longer ask applicants to complete health questionnaires prior to interview. This legislation protects people with HIV from potential discrimination on the grounds of their infection.

Working with HIV

As a consequence of the East London Project's findings on HIV and employment, the NAT asked Professor Elford to assist them in conducting further research examining the employment experiences of people living with HIV in Britain. In August 2009 NAT published a report based on this research called *Working with HIV*⁸. Professor Elford was a co-author of this report, which builds on the findings from the East London Project, and supervised the NAT researcher who worked on the project⁹. *Working with HIV* makes specific recommendations concerning the employment rights of people living with HIV in the UK. The report was timely in the light of welfare reform and the focus on encouraging people living with HIV to remain in the workforce. This report has fed into two further guides that form part of NAT's online resources for employers and employees^{10,11}. It is important that employers have a better understanding of the employment issues for people living with HIV so they can recruit staff from diverse backgrounds.

HIV treatment and care

NAT used data on immigration collected as part of the East London Project when making the case for access to free treatment for people with HIV infection, regardless of their residency status. The data demonstrated that the number of people who were not legally resident in England who were likely to seek HIV treatment and care was very small. NAT's paper, drawing on the East London data, was part of the formal submission of NAT with the Terrence Higgins Trust (THT) and African HIV Policy Network to the Department of Health's (DH) internal review on NHS charging for HIV treatment¹². The DH officials expressed particular appreciation for this information since there had been no previous indication of relevant numbers. The estimates (with explicit reference to the East London Project) were also cited in the NAT briefing for MPs and Peers that accompanied the Parliamentary debates on this issue during the passage of the Health and Social Care Bill in 2011 and 2012. As a result of this briefing, all charges were abolished from 1 October 2012 and HIV treatment and care are now freely available in England for anyone diagnosed with HIV, with significant benefits for patients as well as healthcare providers.

HIV social care and HIV-related discrimination

NAT used data on social and economic hardship collected as part of the East London Project² to undertake work around poverty, benefits and social care for people living with HIV. East London data were cited in NAT's report *The AIDS Support Grant: Making a difference?*¹³. This report was successfully used to advocate for the retention of a specific funding line for HIV social care in the

Comprehensive Review for 2011–2015. As a consequence local councils in England are able to commission and fund social care for people living with HIV. The data from the East London project were also cited in the NAT/THT report *Poverty and HIV 2006–2009*¹⁴.

This research undertaken in East London by City University London has had a significant impact in the domains of health and welfare, social policy, public policy and services, enhancing the equality of people living with HIV in the UK.

5. Sources to corroborate the impact

7. www.publications.parliament.uk/pa/cm200809/cmselect/cmworpen/158/158we04.htm#n4.

8. National AIDS Trust (2009). *Working with HIV*. London: NAT. www.nat.org.uk/Media%20library/Files/Policy/Our%20thinking/Employment%20summary%20report%20-%20FINAL%20August%202009.pdf.

9. Douglas, N. (2009). *I just get on with it: a study of the employment experiences of gay and bisexual men and black African men and women living with HIV in the UK*. London: NAT. www.nat.org.uk/Media%20library/Files/Policy/2009/Final%20full%20report%20for%20website%20August%202009.pdf.

10. National AIDS Trust (2010). *HIV@work. Advice for employees living with HIV*. www.nat.org.uk/Media%20library/Files/Policy/2010/5180-NAT-A5-HIV-Work-Employees.pdf.

11. National AIDS Trust (2012). *HIV and recruitment. Advice for employers*. www.nat.org.uk/media/Files/Policy/2012/Jul_2012_HIV_and_recruitment_Advice_for_employers.pdf.

12. National AIDS Trust (2012). *Access to HIV treatment: The need to amend charging regulations*. London: NAT.

13. National AIDS Trust (2009). *The AIDS Support Grant: making a difference?* www.nat.org.uk/media/Files/Publications/July-2009-The-AIDS-Support-Grant-making-a-difference.pdf.

14. National AIDS Trust and Terrence Higgins Trust (2010). *Poverty and HIV 2006–2009*. www.nat.org.uk/media/Files/Information%20and%20resources%20-%20publications/Poverty%20and%20HIV%202006-2009.pdf.

Further information to corroborate claims can be provided by:

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