



Access to HIV treatment: The need to amend charging regulations

Reasons why the National Health Service (Charges of Overseas Visitors) Regulations 2011 should be amended to exempt HIV treatment from charges.

For public health:

New evidence shows that effective HIV treatment results in a 96% reduction in onwards transmission. Ensuring that everyone who needs treatment receives it is the key to tackling the UK HIV epidemic.

Charges deter people from testing for HIV and from accessing the treatment they need in good time, making them more likely to need more expensive treatment in future and increasing the likelihood that they will pass on HIV to others in the community.

Charging for HIV treatment also deters people from seeking treatment for communicable illnesses (such as TB) for which treatment is free.

To safeguard NHS resources:

Ending charging for HIV treatment will actually save the NHS money by: preventing new HIV infections; identifying HIV early when it can be effectively treated; and reducing the need for hospitalisation and other costly care when people with HIV become seriously ill.

Charging for HIV does not currently recoup what the NHS has spent on treatment. Those charged are almost all destitute and unable to pay these bills. In fact, the NHS is currently incurring the cost of pursuing unpayable debt without any return.

Because there is no such things as HIV 'health tourism':

There is no evidence to support claims of HIV 'health tourism', or to suggest that ending charging would lead to this phenomenon.

For further information contact:

Laura Dunkeyson, Senior Policy and Parliamentary Officer, NAT

laura.dunkeyson@nat.org.uk ; 020 7814 6767

NAT (National AIDS Trust) is the UK's leading charity dedicated to transforming society's response to HIV. We provide fresh thinking, expertise and practical resources. We champion the rights of people living with HIV and campaign for change.

What is the current situation?

Most people in England living with HIV have free access to secondary care under the NHS. However, certain types of migrant are charged for secondary care, including life-saving HIV treatment.

This includes refused asylum seekers, visa overstayers and undocumented migrants. Many of these migrants are destitute and are unable to pay for essentials, let alone HIV treatment.

There are some healthcare settings and some conditions exempt from NHS charges in all circumstances on public health grounds. These include treatment for TB and for all sexually transmitted infections (STIs) except for HIV. The Government has rightly taken the view that charging people with a communicable disease will undermine efforts to prevent the spread of infection. HIV is the only serious communicable disease and only STI for which treatment is not provided free of charge, irrespective of residency status. This is inconsistent, confusing and undermines efforts to prevent further infections.

The National Health Service (Charges of Overseas Visitors) Regulations 2011 specifically exclude HIV from the free treatment available for all other STIs:

“6. No charge may be made or recovered in respect of any relevant services provided to an overseas visitor for....

(e) treatment for sexually transmitted infections, but in the case of services which relate to infection with Human Immunodeficiency Virus, only to the extent that they consist of a diagnostic test for evidence of infection with the Virus and counselling associated with that test or its result.

This was also the case with the previous 1989 Regulations.

Public health harms arising from HIV treatment charges

Charges deter people from testing for HIV and from accessing the treatment they need in good time, making them more likely to need more expensive treatment in future and increasing the likelihood that they will pass on HIV to others in the community.

“So if I cannot access HIV services, then there is no reason for me to test - if I test and know I'm HIV positive, I know it will be very difficult to access [treatment]”.

- Study participant, Thomas F et al *AIDS Care* 22: 526-531, 2010.

It is the case that even where the individual is chargeable for HIV treatment, the treatment is usually provided because clinicians consider HIV treatment to be 'immediately necessary' to save or preserve life. But the prospect of bills for many thousands of pounds, wholly unpayable and often aggressively pursued by debt collecting agencies, means that some people disappear from care. A far greater number hearing about such charges, prefer not to think about the possibility they might have HIV and are thus deterred from testing and accessing treatment in the first place.

Case study

Julia* is a pregnant woman who, following an antenatal screen, received a letter informing her that her residency status means she will not be provided free treatment for HIV and would have to pay for the drugs she needed. Julia disappeared from care, unable to afford the charges and to prevent transmission of HIV to her unborn child. The fate of Julia and her child is unknown. (**name changed*)

Black African migrant communities are most seriously affected by the public health consequences of charging for HIV treatment. Approaching one in twenty people within the British African community has HIV. It is a serious concentrated epidemic and the Government's HIV policy over the last decade or more has aimed to address HIV-related needs in this community, including testing, prevention and treatment needs.

It is estimated by the Health Protection Agency that about 29% of African men in the UK and 22% of African women who are HIV positive do not yet know it, as they have not been tested.¹ Additionally, the highest proportion of late diagnoses of HIV in the UK is found amongst Africans (66% of Africans diagnosed in 2009 were diagnosed late, after the point at which they should have begun HIV medication). Someone diagnosed late is likely to have had HIV for at least five years before they were tested.

Late diagnosis is very strongly associated with risk of serious ill-health, even when on treatment, and indeed early death. Any policy which deters individuals from testing will result in increased morbidity and mortality. Furthermore, research suggests that more than half of new HIV infections are passed on by people who are undiagnosed.² So a policy which encourages people to go untested results in an increase in HIV transmissions, particularly (though not exclusively) within the African community.

The preventive benefit of ensuring people with HIV are diagnosed early and access anti-retroviral therapy (ART) has been demonstrated in a number of important scientific studies, most recently with a demonstrated 96% reduction in HIV transmission.³ Charging policy must catch up with what we now know about the centrality of treatment access to prevention efforts. Aiming to deter anyone with HIV from accessing HIV care is utterly counter-productive, simply encouraging further HIV infections.

Charging for HIV treatment also deters people from seeking treatment for communicable illnesses for which treatment is free.

People co-infected with HIV and TB (which is not uncommon among African migrants to the UK) have particular difficulties.⁴ The UK has one of the highest rates of TB in Western Europe with concerning levels of treatment non-completion and of TB drug-resistance.⁵ TB treatment is free to all on public health grounds, but there are known examples of patients who have abandoned TB treatment early after being billed for HIV treatment. They risk developing drug-resistant TB, which is a serious public

¹ Health Protection Agency data

² Marks, G, Crepaz N, Janssen RS. 'Estimating sexual transmission of HIV from persons aware and unaware that they are infected with the virus in the USA. *AIDS*. 2006 Jun 26;20(10):1447-50

³ See http://www.nejm.org/doi/full/10.1056/NEJMoa1105243?query=featured_home& and HTPN press release at

http://www.htpn.org/web%20documents/PressReleases/HPTN052PressReleaseFINAL5_12_118am.pdf

⁴ <http://bhiva.org/documents/Guidelines/Treatment%20Guidelines/Current/TreatmentGuidelines2009.pdf>

⁵ 'Tuberculosis in the UK: Report on tuberculosis surveillance in the UK 2010' HPA

http://www.hpa.org.uk/web/HPAwebFile/HPAweb_C/1287143594275

health risk in the UK. In addition, untreated HIV itself increases risks of TB transmission.⁶ In failing to tackle effectively the HIV epidemic in England, we are also undermining our response to TB.

Case study

Martin* had HIV and TB, a relatively common co-infection for African people. He was told that, whilst his TB treatment is free, he will be charged for the HIV treatment he needed. Martin, unable to pay for his HIV treatment, left the hospital before the end of his course of TB treatment, risking developing multi-drug resistant TB (which is transmissible) and returning to the community still able to transmit TB. He was not seen at the hospital again. (*name changed)

Increased costs to the NHS arising from HIV treatment charges

Ending charging for HIV treatment will actually save the NHS money by: preventing new HIV infections; identifying HIV early when it can be effectively treated; and reducing the need for hospitalisation and other costly care when people with HIV become seriously ill.

How can making HIV treatment free for everyone living here actually save the NHS money? As demonstrated above, reducing undiagnosed HIV in African communities and increasing the proportion of people with HIV on effective ART will reduce the number of HIV transmissions occurring in the UK. Preventing new HIV infections saves money. Modelling by the Health Protection Agency shows that preventing one onward transmission of HIV saves between £280,000 and £360,000 in treatment costs across a lifetime.⁷ Using statistics from 2008 as an example, the HPA noted that preventing UK transmissions diagnosed in one year alone would have saved £1.1 billion in future HIV-related costs.

Furthermore, people diagnosed late or not accessing treatment become seriously ill and will often require expensive in-patient care. In 2010 London hospitals estimated that a week's stay in an Intensive Care Unit (ICU) was between £14,250 and £25,000. A major Midlands hospital estimated the cost of a week in ICU, before any treatments or other medical interventions, at £8,750 and a week in an ordinary ward at £3,850 before any treatments or other medical interventions. One year of routine HIV treatment and care is estimated to cost between £10,000 and £16,000. Given that someone not on HIV treatment will, once ill, have repeated admissions to hospital, it is clear that it is much cheaper to treat early, rather than at a later stage of infection.

Charging for HIV does not currently recoup what the NHS has spent on treatment. Those charged are almost all destitute and unable to pay these bills. In fact, the NHS is currently incurring the cost of pursuing unpayable debt without any return.

There is no precise figure on the number of HIV positive migrants in England not entitled to free NHS care. On the basis of a very robust study of HIV positive clinic attendees in East London, NAT has calculated in relation to African migrants that it probably falls within a range of between 670 (with 190 of them undiagnosed) and 1,000 (with 280 of them undiagnosed).

⁶ UNAIDS states, 'HIV activates dormant TB in persons, who then develop active disease and have the potential to spread the TB bacillus to others'.

⁷ HPA. (2010). HIV in the United Kingdom: 2009 Report.

Case study

The economic argument is illustrated in a 2006 paper examining the case of a newly diagnosed HIV positive patient whose antiretroviral treatment (ART) was delayed by the hospital because she was not eligible for free treatment on the NHS and was unable to pay. This delay in care caused her condition to rapidly deteriorate, and she was admitted into the hospital's ICU where she was treated for a variety of complications. She subsequently started receiving ARV treatment and had a long convalescent period. She was discharged 3 months after admission. An analysis shows the cost of admission to ICU was £20,043 and that of the convalescent period was £8,307. The total cost, including the initial admission, the ICU treatment and the convalescent period was £32,392. Should she have been discharged initially with ARV treatment the cost would have totalled £4,042, a saving of £28,350. (These figures were correct in 2006, and although the exact figures will now be different the cost comparison still stands.)

Fowler et al (2006) "HIV, HAART and overseas visitors" Sexually Transmitted Infections, <http://sti.bmj.com>.

Bearing in mind that those diagnosed will for the most part be accessing treatment, albeit often facing unpayable bills, the only additional cost to the NHS from exempting HIV from charges will be hopefully the earlier testing and entry into care of the 280 (or fewer) migrants undiagnosed. In the context of the NHS budget this is a small number. But in any event this group will be diagnosed eventually when they become very ill even were charges to remain in place - but it would be with all the excess costs of dealing with someone at that late stage of infection and the additional onward transmissions which have occurred prior to their diagnosis.

The myth of HIV 'health tourism'

There is no evidence to support claims of HIV 'health tourism', or to suggest that ending charging would lead to this phenomenon.

A common argument against revising the charging regulations is that it will encourage HIV 'health tourism'. NAT produced a report on the myth of HIV health tourism in 2008, demonstrating that claims of HIV health tourism to the UK are wholly unfounded.⁸ For example, data from the Health Protection Agency shows that the average time between a migrant arriving in the UK and an HIV diagnosis was almost five years⁹. Government reports suggest that asylum seekers have no detailed knowledge of the UK's asylum policies, welfare benefits or entitlement to treatment prior to arriving in the UK.¹⁰

HIV charges are not applied, to varying degrees, in Scotland, Wales or Northern Ireland. Were health tourism a real phenomenon we would expect to see a movement of HIV positive migrants from England to other nations in the UK to access free treatment. There is no evidence of such a pattern since charges were introduced in England. If individuals do not move from London to Edinburgh to access free HIV treatment it is difficult to believe they moved from, say, Harare to London for this reason

In addition, since 2004 (when charges for HIV treatment began to be implemented in practice in England) there has been a thirteen-fold increase in access to ART in low- and middle-income countries round the world, with sub-Saharan Africa seeing the greatest increase in the absolute

⁸ NAT (2008) *The Myth of HIV Health Tourism*, www.nat.org.uk

⁹ Personal correspondence between NAT and HPA. Year of arrival is completed by clinicians for just over half of people who acquired their infection abroad.

¹⁰ Barton J (2004) Challenging the myth of 'treatment tourism': Is access to medical treatment for HIV a pull factor in migration to the UK?, www.uel.ac.uk/ssmcs/research/fmsc/papers/Barton.pdf

numbers of people receiving treatment. ART coverage of all those who need it now stands at 37% in the region and continues to increase.¹¹ It is most likely that those able to purchase a flight to the UK are those able to access ART in their own country.

Having HIV does not in and of itself prevent removal from this country if a person is in breach of immigration rules, as was established at the European Court of Human Rights in the case of N.¹² So there is no reason for someone who knows they have HIV to migrate to the UK believing that their HIV positive status will secure settled residence and ongoing access to treatment. Nor would encouraging people without lawful residency status to get tested and access treatment have any impact on immigration processes, including removal where appropriate.

Conclusion

HIV is the only STI and the only serious communicable disease for which treatment is not provided free of charge, irrespective of residency status. England is alone in charging for HIV treatment. Scotland, Wales and Northern Ireland have chosen, either in policy or practice, not to charge for HIV treatment for the reasons set out above.

HIV clinical bodies and voluntary sector organisations all oppose charging for HIV treatment. When the issue has been investigated by parliamentary committees, such as the recent House of Lords Select Committee on HIV and AIDS in the UK, the Health Select Committee and the Joint Committee on Human Rights (JCHR)¹³, the committee recommendations have been to end charging for HIV treatment on public health and human rights grounds.

Charging for HIV treatment has serious public health implications, exacerbates the destitution of those migrants affected and does not make sense financially. Additionally, there is no evidence to support the frequently raised concern of HIV health tourism as a justification for continuing to charge. NAT believes that revising the charging regulations will reduce long term costs, reduce transmission of HIV and prevent many premature deaths in the UK.

NAT September 2011

¹¹ 'Towards universal access: Scaling up priority HIV/AIDS interventions in the health sector Progress report 2010' WHO 2010

¹² N was from Uganda and was HIV positive on arrival in the UK. N was ill with AIDS-related illnesses including a form of cancer. Her condition had however stabilised as a result of ART. Her life expectancy in the UK was around 10 years, but only two years if returned to Uganda because of difficulty in obtaining suitable medical treatment there. It was determined that these circumstances were not exceptional enough to establish a breach of the human rights convention.

¹³ Select Committee on HIV and AIDS in the UK session 2010-12, HL Paper 188. Health Committee Session 2004-2005, HC 252; JCHR Session 2006-07. HL Paper 81