

Case Study 1

Getting equal and free HIV treatment for undocumented migrants in England

What was the issue?

Migrants with HIV were being deterred from testing for HIV and accessing treatment, leading to deaths and onward transmissions.

The [National Health Service](#) (NHS) provides health services free to every resident in England “at the point of need”. However, some groups, including undocumented migrants and overstayers, were historically excluded from most healthcare services. Free treatment for them was available for other serious infectious diseases, including TB and other STIs, but HIV was excluded.

Until 2004, undocumented migrants with HIV were often given antiretroviral treatment under a rule which allowed free treatment for people residing in the country for more than 12 months. However, in 2004, due to anti-immigrant fears about “treatment tourism” the regulation wording was changed to “*lawful* residence” and hospitals were instructed to pursue payments from others. This affected a substantial number of people with HIV in the UK.

Why was change needed?

Political and managerial pressures caused a breakdown in existing informal clinic arrangements for treating undocumented migrants quietly. Some migrants with HIV stopped accessing treatment, while others (including even some who were entitled) were refused treatment by Payments Officers who often didn't understand the regulations. Others saw no point in testing for HIV (which was free) if they could not get treatment. Some, distressed by huge bills, walked out of treatment until they collapsed with late stage HIV, or failed to access free TB treatment because they could not pay for their HIV treatment. Some hospitals employed bailiffs to try and recover costs from people who were already destitute and even homeless. The system was increasingly chaotic, with people trapped in a cycle of sickness: expensive emergency in-patient treatment, temporary remission and sickness again. Several people known to support agencies (and thus probably others too) died as a direct result of this policy.

How could access be improved?

NHS regulations needed to be changed in Parliament to allow free treatment to everyone living in the country. This would ensure better health for all, reduce care costs and reduce onward transmission of HIV.

What were the barriers to change?

Several barriers operated to impede open access. Before 2004, many clinicians felt that the informal system was working sufficiently and no change was needed. This perception changed as the situation worsened. There were high levels of hostile media coverage about “treatment tourists” taking advantage of free NHS services, with HIV often named due to the stigma and perceived high cost of treatment. Successive Health Ministers made evidence-free claims about the cost to

the NHS of treatment for migrants and many sympathetic politicians were reluctant to support what was seen as a politically unpopular issue.

How long did change take and who made it happen?

The campaign took almost a decade to reach its main aim of abolishing HIV treatment charges. Although earlier concern had been expressed by NGOs, including research in 2003 by [Terrence Higgins Trust](#) (THT) and [George House Trust](#) (GHT) which challenged the growing myth of HIV treatment tourism, it was the 2004 change in regulations which galvanised campaigners both in the HIV sector and in the wider migrant health sector. This led to a wide coalition group called the Entitlement Group, of which the [National AIDS Trust](#) (NAT) and THT were founder members. Within the HIV sector, many other organisations and clinics were involved in providing evidence of the harms caused by restricted access.

Regulations attached to the [Health and Social Care Act of June 2012](#) finally abolished NHS charging for HIV care in England, though not the charges for other health conditions affecting people with HIV such as pregnancy, cancers or side effects. The campaign for these issues continues as part of the wider rights programme of HIV policy.

How was change made?

Because this was a campaign to change a piece of Government legislation which had widespread support from the public and the media, it took a long time and a lot of people to create a chain of change, snowballing supporters by gathering evidence, identifying expert witnesses, making broad alliances and tactical lobbying. In the end, research advances in HIV treatment were the tipping point.

Gathering evidence: The THT/GHT research of 2003 reviewed 60 existing client records to show how and when undocumented migrants with HIV were diagnosed. This relatively easy, cost-free exercise was able to show that most people had been in the country for several years before testing, contradicting the claim that they came to the UK for free HIV treatment. Many were only diagnosed when seriously, and expensively, ill. In 2008 a more rigorous and extensive report from the NAT, [“The Myth of HIV Treatment Tourism,”](#) comprehensively demolished the arguments for charging, using new data from [Public Health England](#) (PHE), the Government’s own public health body. The report is still on their website and is a good example of evidence-based argument for change. NAT and PHE collaborated on work to show the lifetime cost of HIV and relative high costs of inpatient care for late diagnosis. Throughout the campaign supportive NGOs and hospitals gathered case studies showing the damage caused to individual and public health by the policy. People with HIV who had regularised their immigration status were supported to speak publicly about their experiences. Clinic staff provided strong evidence anonymously about what they saw going wrong with the system in their hospitals and the [British Association for Sexual Health & HIV](#) organised a survey of their membership about harms caused. All of this went into submissions to politicians and the NHS and stories to the media.

Making internal and external alliances: Within the HIV sector, there was a strong commitment throughout to involve doctors, nurses, researchers and public health. Talks and debates were held at sector conferences. Although clinical associations were initially reluctant to engage, their members experiences of the detrimental impact, alongside treatment advances and changes in elected officers, changed their stance to the extent that [British HIV Association](#) (BHIVA) in particular was a key ally in the final push for change.

Externally, the Entitlement Group (see previously) was the planning focus for a wider campaign but over the decade other allies included a growing number of politicians, particularly backbench Members of Parliament on the Health Select Committee, who understood the evidence and were prepared to risk unpopularity in the media.

Challenging myths with simple facts: Throughout the campaign, politicians and media commentators were prone to repeating popular myths about HIV “treatment tourism”. These began to be countered, over time, with brief factual responses to demolish them.

“People with HIV will flood in if we give them free treatment.”
Why haven't they flooded in to Scotland next door, where they can already get it?

“People only come here because they have HIV and want our high quality services.”
Why are most of them not diagnosed for three years or more after entry?

Campaigners were able to use these to challenge what were often seen as “common sense” assumptions.

Making financial as well as humanitarian arguments: Campaigners often assume that people will care about humanity and human rights but often pragmatic arguments can make as much or more impact. People have often been told that treatment is expensive, so explaining that not treating people leads to higher costs, both in more expensive late stage treatment and in higher levels of onward transmission, had a real impact. Politicians, in particular, find cost savings arguments persuasive.

Seizing the moment (1) new scientific advances: “The real game changer in all of this was the proof of treatment as prevention” (Yusef Azad, NAT). Clear scientific proof that treating people with HIV drastically reduced onward transmission brought many people on board with the campaign. It gave a strong argument for including HIV in the list of infectious diseases always treated free on public health grounds and also for increasing testing campaigns for those most at risk, including African migrants.

Seizing the moment (2) finding the right politicians: Although previous Public Health Ministers had not been helpful, in 2010 the new Coalition Government appointed a former nurse, Anne Milton in that role. She not only understood the issues but, equally important, was prepared to stand up to other Government departments who saw the issue purely in terms of illegality. “It's your job to deport people, but it's my job to preserve public health while they're here” she told them. Similarly Lord Fowler, who had been the Minister for Health during the early days of the AIDS crisis and was highly respected, led the [2011 Lords Committee on HIV](#) which made a recommendation of free treatment for all.

Seizing the moment (3) keeping on track: Over the course of the decade, a number of small concessions were made by the authorities about how payments would be pursued, treatment of pregnant women and so on. Further attempts were also made to restrict healthcare access e.g. through charging for primary care (local General Practice doctors). In each case, campaigners responded to the issue and, where appropriate, supported the wider migrant groups alliance – the case against GP charging was partly won by use of NAT's arguments about HIV and TB failing to

be diagnosed if charging was brought in – but none of this altered the main ongoing focus of the campaign.

Using Government mechanisms and structures: From early on, campaigners supported the [Health Select Committee](#) (a Parliamentary scrutiny group) to review the evidence on charging for HIV treatment. This included a full Commons Health Committee report on “[New Developments in HIV and Sexual Health](#)” in 2004-5 at which NAT, THT and others gave oral evidence on charging. NAT also gave evidence to the Joint Committee on Human Rights for asylum seekers on the issue. Campaigners used the UK's international commitment to the principle of universal free treatment to highlight the contradiction of charging within the UK, leading to one being told he had been vetoed to speak at a Department for International Development event on HIV “*because you will keep showing the home team up by mentioning charging*”. The Lords Select Committee on HIV, led by Lord Fowler in 2011, was crucial in making clear, evidence based recommendations to a Minister who was finally prepared to listen. A clause about free treatment was inserted into an earlier Health Bill in 2010 but withdrawn on the Minister's promise of an enquiry. The issue was finally won through regulations attached to the [2012 Health and Social Care Bill](#), drafted in line with a previous amendment from activists and clinicians.

Educating and identifying supportive legislators: It was helpful that NAT's Policy Director was a former Parliamentary Clerk with an expert understanding of Parliamentary mechanisms which is vital to effect any legislative change. Both NAT and THT were politically active in briefing and lobbying Parliamentarians and in mobilising networks of campaigners to target MPs. Members of the House of Lords were particularly helpful as they are not subject to elections and therefore less easily swayed by public or media opinion. While some MPs of African or migrant origin were supportive, others were reluctant to be identified with the issue.

Challenging the media: As evidence emerged over the course of the campaign, people began challenging myths and factual inaccuracies in the media. [The Press Gang](#), a group of NAT volunteers monitoring media coverage of HIV issues, wrote letters and emails correcting stories. Although, as a Governmental body, Public Health England could not directly argue for political change, the two factual reports they produced on [Migration](#) and [HIV](#) in this time provided extremely helpful and well respected data for the case for change.

Patience: “*Just banging on about it year after year eventually worked*” (Yusef Azad, NAT). Policy change can be a very long game; ten years from people starting to gather evidence to the final change in the law is not exceptionally long in these terms. Keeping the message alive through policy handouts, training, attending political conferences and events can slowly move an issue from the fringe to the mainstream and make it seem less controversial.

After years of this being a hotly contested issue that politicians feared would give them a bad press, when the legislation was finally changed there was hardly any fuss. Subsequent attempts by far-right politicians to use the issue have seen them widely condemned, including by some in their own party. If the issue had been forced at an earlier stage, before treatment as prevention was established and before the Government Minister herself understood the facts, it is likely that not only would campaigners have lost the fight then but that it could have made change more difficult later.

Are there any ongoing issues?

Although the case for free HIV treatment for all was won, people with HIV who are not entitled otherwise to free health services are still being charged for other conditions which either arise from or interact with their HIV; this continues to be problematic. Additionally, the Government continues to make attempts to introduce charging into primary care, which would likely reduce diagnoses amongst migrants. Some politicians continue to use HIV stigma as an amplifier for anti-immigrant rhetoric and thus it is important to keep the case for free treatment alive, the evidence updated and to monitor the media and politicians for ongoing factual inaccuracies about HIV and/or migration and undocumented migrants.

Links

NAT report: <http://www.nat.org.uk/media/Files/Publications/Oc-2008-The-Myth-of-HIV-Health-Tourism.pdf>

NAT presentation, IAS 2014: <http://pag.aids2014.org/EPPosterHandler.axd?aid=9043>

BHIVA statement: <http://www.bhiva.org/Migrant-access-to-HIV-care.aspx>

THT resource sheet on current rules: https://www.tht.org.uk/~/_media/Files/Will-I-have-to-pay.ashx

Research paper on impact: <https://hal.archives-ouvertes.fr/hal-00590597/document>

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