

Eligibility for free HIV treatment and care

NAT argues that the Government must reverse its policy of charging certain people living in the UK for HIV treatment and care.

DEPARTMENT OF HEALTH: PROPOSALS TO EXCLUDE OVERSEAS VISITORS FROM ELIGIBILITY TO FREE NHS PRIMARY MEDICAL SERVICES
A CONSULTATION

THE NATIONAL AIDS TRUST RESPONSE TO THE DEPARTMENT OF HEALTH CONSULTATION



Summary

The National AIDS Trust argues that the charges recently introduced in hospitals, denying free HIV treatment and care to certain very vulnerable groups, will

- deter many from HIV testing
- lead to an increase in the numbers of HIV positive people undiagnosed in the UK
- increase the number of HIV infections
- increase the number of TB infections
- increase the number of transmissions of HIV from mother to child.

Both the charges already introduced in hospitals and those now proposed for primary care

- are not justified by evidence
- are not accompanied by a public health impact assessment
- run counter to good clinical practice
- will impose improper and undue administrative burdens on NHS staff.

In addition, the charges proposed for primary care will

- deny those with emergency conditions the required initial assessment of need in the GP setting
- remove a key opportunity to identify the need for an HIV test.

HIV treatment and care should be exempt from hospital charges, as is already the case for STIs and other infectious diseases with significant public health impacts. The charges proposed for primary care should not be introduced.

1. Introduction

- 1.1 The National AIDS Trust (NAT) is the UK's leading HIV and AIDS policy development and campaigning organisation. NAT works in the UK and internationally for policies that will prevent HIV transmission, improve access to treatment, challenge HIV stigma and discrimination, and secure the political leadership to effectively fight AIDS.
- 1.2 **NAT believes that the introduction of charges for primary care services as proposed in the consultation document will be extremely harmful both to individuals with HIV and to public health in general. We argue in this paper not only that the proposed primary care charges should not be introduced but also that HIV should be exempted from the secondary care charges which were introduced on 1 April this year.**
- 1.3 The consultation paper includes a number of questions, inviting responses from consultees. We have decided not to answer the questions specifically since this paper sets out a broader and fundamental set of arguments against the whole of the new charging system.
- 1.4 We concentrate in this response on the consequences of the proposed charges for HIV treatment and care in the UK. We also focus on those groups who as a result of the 1st April secondary care charges and those now proposed for primary care are most seriously affected, namely failed asylum seekers, visa overstayers and illegal immigrants ['the affected groups'].

2. The profile of those affected

- 2.1 **Our concern is a result of the fact that there is in all probability a higher prevalence of HIV in the affected groups, and those who are HIV positive are almost without exception not in a position to afford to pay for HIV treatment and care. The effect of the changes is simply to deny them the treatment they need.**
- 2.2 The Government has not provided any analysis of the make-up or health of the groups most significantly affected by the changes in charging. Given that up to half of current asylum applicants are from Africa, where there is much higher HIV prevalence, it is highly probable that HIV prevalence will also be higher amongst these affected groups. Ante-natal screening reveals HIV prevalence amongst women giving birth in England and Scotland in 2002 as 0.14% but with the highest prevalence being amongst women of sub-Saharan African origin at 2.47%.
- 2.3 There is also little doubt that the affected groups are amongst the most socially and economically marginalised and impoverished in the country. Payment of charges will not be an option for the vast majority, particularly as many will probably not have a legal right to work and, if employed, be engaged in low-paid activity.
- 2.4 Amongst those denied treatment will also be some failed asylum seekers who the Government accepts cannot for the present return to their country of origin. It is unjust that the Government accepts such persons must at least temporarily reside in the UK but denies them the life-saving treatment they need.
- 2.5 It is important also to understand that **the impact of these charges will be to exclude many people who in fact are entitled to free NHS treatment.** Voluntary organisations have many examples of people being denied treatment improperly and a recent letter to The Guardian from 10 doctors states that "Some healthcare providers have already misunderstood and anticipated changes and there have been cases of 'non-failed' asylum seekers being refused hospital, GP or dental care to which they were entitled".¹ Evidence collected by the Refugee Council on the impact of Section 55 of the Nationality, Immigration and Asylum Act 2002 also

¹ The Guardian Monday August 9 2004

suggests that those entitled to state support have been improperly denied it.²

- 2.6 Not only will there be improper refusal of care. There will also be a deterrent effect on those from certain ethnic minority communities accessing NHS care even when they are entitled to it. They may wrongly assume that they are excluded by the regulations. In addition, the intrusive questioning over residency status is something many people find unsettling, traumatic or discriminatory even when they have a right of residence. The likelihood is many will not access NHS services as readily and promptly as they should as communities feel discriminated against and pressurised.

² 'Section 55 – one year on: The real impact of denying support to destitute asylum seekers' The Refugee Council

3. Some Fundamental Principles

- 3.1 Central to NAT's argument is a principled view of the National Health Service – both whom it is for and how it should be run.

The NHS is for those who live in the UK.

- 3.2 This is not just the opinion of NAT. We quote from the Minister's foreword to the consultation document where he states that the NHS "is there to provide free treatment for those who live here and not for those who don't". Similarly, his foreword to the Guidance on the new Hospital Charging Regulations insists that NHS resources are "used to meet the health care needs of people who live in the UK". Put differently, the Minister objects in both documents to NHS treatment for those with "no substantive connection with the UK".
- 3.3 Taken literally, we do not object to these definitions of eligibility. Our problem is with the classification of groups of people as "overseas visitors" who are not simply passing through but who have been resident for significant periods of time and have every intention to continue this residence unless they are deported. They are not visiting. They live here, in significant numbers. They have substantive connections with this country, albeit not legally sanctioned.
- 3.4 If the NHS is to fulfil Beveridge's original ambition to banish from this country the 'giant of disease', it must continue to provide care based on need to those who actually live here, not just to those whom the Government wants to live here. From a public health perspective, legality of residence is irrelevant – it is the fact of residence which is important. The position prior to 1st April this year was the correct one, where those who could demonstrate 12 months residency in the UK were eligible for free NHS treatment.

Decisions about the NHS must be taken on the basis of need with the aim of optimising public health.

- 3.5 NAT does not take a view on the Government's immigration policy nor in general on the rights of particular persons to reside in this country beyond the international treaty obligations and human rights principles with which the UK must comply.

- 3.6 We do, however, stress that it is unacceptable for health policy to become a tool for or adjunct to immigration policy. The reason is straightforward. The harm to public health. To deny free health care to people who effectively, if illegally, live here is to use the health system punitively rather than on the basis of need. The actual public health outcome will not be either to deter new migrants nor encourage those illegally here to leave. It will be to create a pool of poor, marginalised, exploited and increasingly sick people, with adverse social consequences both for themselves and for those amongst whom they live and work.
- 3.7 It is also wholly wrong for the NHS to become a surveillance system for the immigration services. We have evidence of mothers being apprehended and deported immediately after giving birth in hospital. The result will be that mothers of uncertain residential status, or those who perhaps wrongly fear they might be apprehended, will opt for home births without medical attention, with all the attendant risks for both mother and child (including in the case of HIV-positive mothers, mother-to-child transmission). This effect of people opting out of NHS care through fear is already taking place. At a recent meeting one refugee organisation spoke of two cases known to them of people being run over but refusing to be taken by ambulance to hospital as a result of fear of the authorities.
- 3.8 The immigration services should of course undertake their statutory duties but the very different social objectives of the NHS require some 'chinese walls' for both services to operate as they should.
- 3.9 **There is no evidence that the Department of Health has undertaken a public health impact assessment of the new charges, either those introduced in hospitals or those proposed for GPs. This is an extraordinary omission, particularly in relation to serious infectious diseases such as HIV. Until such a thorough and scientific public health impact assessment is completed, it would be highly irresponsible for the proposed charging scheme to go ahead.**
- 3.10 In particular, there has been no discussion as to how the charges will affect the aims, objectives and targets set out in the National Strategy for Sexual Health and HIV. Almost every aspect of that strategy, such as the target of reducing newly acquired HIV infections by 25% or the programme for

increasing the offer and uptake of testing for HIV, will be adversely affected by these charges.

- 3.11 Section 4 of this paper goes on to outline the good reasons for fearing an increase in HIV and TB infections in the UK as a result of these changes.

Decisions about the NHS must uphold the highest standards of clinical care

- 3.12 The charging system being introduced is entirely inappropriate for a life-threatening and chronic condition such as HIV. It is proposed that HIV-related illnesses be treated free of charge in A&E as and when they become emergency conditions but that clinicians refuse to provide the anti-retroviral treatment which would avert such illnesses occurring.
- 3.13 **To wait until someone is critically ill before treatment when the situation could be readily and cost-effectively averted by an earlier intervention is unethical.** This is not treatment based on clinical need. It cannot be good clinical practice to watch a patient attend A&E with increasing frequency and morbidity until they die, treating only the immediate condition, when treatment is available which would save and prolong that person's life.³

Decisions about the NHS should be evidence-based.

- 3.14 At the heart of objections to these proposals is a failure by the Department of Health to provide any convincing evidence that there is a serious problem to be addressed, or of the economic benefits of the proposed charging regime.
- 3.15 There is no estimate offered of the numbers currently accessing NHS services free of charge who have been excluded by the 1st April changes and the charges proposed in the current consultation. There is no analysis offered of their health needs, treatment currently accessed or the costs to the NHS.

Health tourism

³ see British Medical Journal 2004; 329; 346-349 (7 August) Pollard and Savulescu

- 3.16 More specifically, these changes have been a response in part to media discussion of 'health tourism'. Neither in the consultation over the changes to hospital charges nor in the current consultation is there any attempt to provide evidence of the extent of health tourism, its costs to the NHS, or areas of the country or specialties particularly affected.
- 3.17 With regard to HIV, evidence currently available to NAT, researched by Terrence Higgins Trust and George House Trust amongst recent migrants using HIV services, shows that "by far the most common reason given for testing was the onset of symptomatic HIV, with ... 58% ... testing when they had become actively unwell".⁴ If they had come to the country to access services, it is unlikely they would have waited until they were severely unwell before seeking testing or treatment.
- 3.18 **The evidence to date on HIV and these vulnerable groups suggests there is no systematic, widespread or cynical HIV-related health tourism.**

Costing the changes

- 3.19 Even if there is no intentional abuse of the system, the argument is made that the changes to the charging regime will save the NHS significant funds which can be spent instead on those legally resident. But again, no attempt at costing is offered.
- 3.20 NAT's view is that it is likely to be as or more expensive for the NHS to treat patients free of charge for HIV-related illness in A&E departments as it is to provide ART.
- 3.21 Research in Switzerland (Sendi et al. 1999), which the authors felt was easily applicable to other developed countries, found that not only was there a cost benefit to treating HIV-positive individuals with ART rather than in accident and emergency settings, but also the contribution to society that healthy HIV-positive people could make added to the economic benefit.
- 3.22 Even without an analysis of these wider social costs, discussions between NAT and clinicians suggest that whilst

⁴ 'Recent migrants using HIV services in England' Terrence Higgins Trust and George House Trust 2003

ART costs somewhere in the region of £800 a month, a hospital bed costs on average £500 a day.

3.23 Without ART HIV-positive individuals will get seriously and repeatedly ill, presenting with ever increasing frequency at A&E departments. ART reduces the number of inpatient days for people with HIV at all stages of HIV infection. It would only take two fewer days in a hospital bed to pay for a month of ART. Thus it may well be the case that the withdrawal of ART is a false economy and that costs in terms of bed use in A&E mean there are no savings or even additional costs.

3.24 **The absence of any costing of these charges with regard to HIV is a serious omission and it is regrettable that the 1st April changes were introduced without analysis of the HIV-related cost implications. It is likely that the new charges will result in a greater cost burden to the NHS.**

4. The Impact on Public Health

A deterrent to testing

4.1 HIV testing remains free under current and proposed arrangements. This of course is welcome. But the denial of HIV treatment and care will have a profound impact on the willingness of people in the affected groups to test. The link between availability of treatment and willingness to test is now generally understood. DFID in its recently published HIV Treatment and Care Policy states:

“There is now an international consensus that treatment and care are essential parts of an effective and comprehensive response to AIDS. As well as the direct benefits for people receiving it, access to treatment and care can help prevention efforts and programme designed to minimise the impact of AIDS. Availability of ART in particular gives people a reason to seek testing, and it might reduce the level of transmission in a population.”

Recent data from Taiwan suggests that the government policy there of providing HIV-positive people with free ART reduced the rate of HIV transmission by 53%.⁵

4.2 **The offer of testing without treatment flies in the face of the Government’s own stated policy on the close relationship between treatment availability and testing take-up.**

4.3 Testing is often a traumatic process and a positive result brings many stresses and challenges into an individual’s life. With no treatment on offer it is hard to believe there will be any incentive to test. With HIV positive individuals in these groups remaining untested and undiagnosed, there is an obviously harmful effect on their own health as needed treatment is unnecessarily delayed. Only at later stages of infection when they fall seriously ill and end up in hospital will HIV be diagnosed, by which time the impact of anti-retroviral treatment is likely to be significantly reduced.⁶ With a third of HIV positive people in the UK unaware of their status the Government should be making every effort to encourage testing in vulnerable populations. These charges have the opposite effect.

⁵ Journal of Infectious Diseases August 15 2004, Chi-Tai Fang, Jung-Der Wang

⁶ BHIVA Guidelines 3.3.1.1 Individuals with CD4 counts <200 cells/mm³

- 4.4 A further deterrent to testing is the impact of the new system on the principle of confidentiality. If henceforth at GUM clinics patients cannot receive HIV treatment in an entirely anonymous fashion but have to provide proof of eligibility, there are concerns this will deter even from the initial free test those fearful of admitting they have no legal right of residence.
- 4.5 **Undiagnosed individuals will not be equipped to make informed decisions about their sexual behaviour nor counselled on taking precautions against transmission to sexual partners. The result is likely to be an increase in transmission of HIV and considerable harm to public health.**
- 4.6 **Whether diagnosed or not, the refusal to provide ART will mean that individuals will remain much more highly infectious than they would otherwise be. Such high infectivity, joined with an absence of ongoing counselling and considerable personal fear and trauma, is likely to result in an increase in onward transmission of the virus.**

The danger to mothers and babies

- 4.7 There is an additional danger arising from this legislation for HIV-positive women who are pregnant. In order to reduce chances of vertical transmission of HIV from mother to child it is advised that the woman has an elective caesarean and/or be given the drug AZT during pregnancy and birth. If a pregnant woman is unable to afford any of these options, the likelihood of transmission is high – the rate of transmission in an untreated population of breast-fed infants is 25-35%. The use of AZT reduces the transmission rate to below 1%.
- 4.8 **Without ante-natal HIV treatment, we will see an increase in the avoidable infection of newborn infants. We expect such infants to receive treatment under the provisions of the Children's Act, regardless of the mother's eligibility. But the mother will not receive treatment, will become increasingly ill and unable to care for the baby. The end result in some cases will be orphaned children.**
- 4.9 This is also another cost implication for health and social services which has not been taken into account. It appears

that the Government has simply not considered the full implications of its new charging regime and the unacceptable human costs.

The impact on TB infection rates

- 4.10 TB cases have increased by nearly 20% in England and Wales over the last two years, with London, now a 'TB Hotspot', accounting for nearly half of all UK cases at around 3,000 a year.
- 4.11 TB is one of the infectious diseases exempt from the introduced and proposed NHS charges, and this exemption is welcome. But failing to treat HIV fatally undermines public health measures designed to address the growing TB infection rates in this country. HIV and TB together "form a lethal combination, each speeding the other's progress".⁷
- 4.12 Those who are HIV positive and infected with TB are many times more likely to become sick with TB than those who are HIV-negative. The World Bank have estimated that 25% of HIV-negative persons dying of tuberculosis in the coming years would not have been infected with the bacillus in the absence of the HIV epidemic. Each of these new infections represents a further cost to the health sector.⁸
- 4.13 **To fail to treat HIV, and thus, as explained, to risk increased HIV transmission in the general population, is also to increase TB infection rates in the UK.**

The implications of extending charges to primary care

- 4.14 The extension of the charging regime to primary care is in the view of NAT extremely harmful to the fight against HIV in the UK. It is also unworkable in a system which still aims to treat emergency and other serious conditions free of charge.
- 4.15 GPs remain a vital first port of call for those concerned about their health. GPs can often diagnose serious conditions on the basis of apparently minor symptoms, or at least identify the need for further investigation and tests. **Those HIV-positive individuals unable to access primary care because of charges will have early indications of possible HIV infection undetected. This will only exacerbate the delays in diagnosis, and consequent harm to public**

⁷ WHO Tuberculosis factsheet

⁸ Quoted in the UNAIDS Report on the Global HIV/AIDS Epidemic June 2000

health, which we have already stated to be a crucial failing of the new charging system.

- 4.16 Emergency care will still be provided free of charge in the A&E department of hospitals. There is also free treatment for TB, STIs (apart from HIV), and other diseases which come under existing public health regulations. But such provision depends crucially on an initial assessment of need ordinarily provided by the GP. **Having to pay for an initial assessment by a GP undermines completely the aim of then providing free treatment for emergency conditions and diseases with serious public health implications.**

The impact on NHS administration

- 4.17 We have serious doubts that the charging system can be implemented in a non-discriminatory and efficient way. It will be difficult to enforce these complex regulations in a way which does not make undue assumptions about some of those accessing services. This will make healthcare workers vulnerable to accusations of racism. The training necessary for all staff to ensure this does not happen will be costly and time-consuming and is not justified in our view by the claimed benefits of the system. We already have evidence that the hospital charging scheme results in contradictory and delayed decision-making.⁹

⁹ see forthcoming report 'HIV, stigma and discrimination: developing the evidence base' NAT/Sigma Research, to be published September 2004

5. Conclusion – charging for HIV treatment

- 5.1 Our focus has been the potentially disastrous consequences of the new charging system for those living with HIV and for public health more generally. Our priority is ensuring that those actually resident in the UK receive free NHS treatment and care for HIV.
- 5.2 Whilst we consider the system of charging for hospital care introduced on 1st April 2004 to be contrary to the purpose of the NHS and immensely harmful to groups already marginalized, stigmatised and suffering from poor health, we are aware that prospects for repeal are slim in the immediate future.
- 5.3 **We recommend the immediate inclusion of HIV treatment and care in the list of diseases exempt from charges.** There is no reason from a public health perspective why HIV is excluded from this exempt list. It is comparably infectious to many of the diseases included and has more serious implications for both morbidity and mortality than most STIs. We can only presume that cost considerations are behind the omission to exempt HIV but for reasons given earlier we believe this is a false economy. The current anomalous position of HIV only adds to the stigmatising of the disease.
- 5.4 Such exemption will not be enough, however, to address the problems identified with extending the new charging system to primary care. **Above all else, the importance in any system for an initial assessment of need free of charge means that the proposed charges for primary care should not be introduced.**

National AIDS Trust 13 August 2004