DH Department of Health

REVIEW OF ACCESS TO THE NHS FOR FOREIGN NATIONALS

February 2010

Consultation Response Form

We would prefer this form to be returned to us electronically as an email attachment. The email address for responses or queries is **overseasvisitorsconsultation@dh.gsi.gov.uk**. You can provide a covering letter by email if you wish.

Postal responses can be sent to:

NHS Overseas Visitors Policy Team
Department of Health
Room 4W04 Quarry House
Quarry Hill
Leeds LS2 7UE

Email responses to the consultation will receive an acknowledgement of receipt. Postal responses will not receive an acknowledgement.

The consultation closes on Wednesday 30 June 2010.

YOUR CONTACT DETAILS

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Freedom of Information

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Information provided in response to this consultation, including personal information, may be published or disclosed in accordance with the access to information regimes. The relevant legislation in this context is the Freedom of Information Act 2000 (FOIA) and the Data Protection Act 1998 (DPA).

If you want the information that you provide to be treated as confidential, please be aware that, under the FOIA, there is a statutory Code of Practice with which public authorities must comply and which deals amongst other things, with obligations of confidence. In view of this, it would be helpful if you could explain to us why you regard the information you have provided as confidential. If we receive a request for disclosure of the information we will take full account of your explanation, but we cannot give an assurance that confidentiality can be maintained in all circumstances. An automatic confidentiality disclaimer generated by your IT system will not, of itself, be regarded as binding on the Department.

The Department will process your personal data in accordance with the DPA and in most circumstances this will mean that your personal data will not be disclosed to third parties. However, the information you send us may need to be passed on to colleagues within the UK Health Departments and/or published in a summary of responses to this consultation.

I do not wish my response to be passed to other UK Health Departments (please mark with an 'x').

☐

I do not wish my response to be published in a summary of responses

☐

About You

Please delete as appropriate. I am responding:

- on behalf of an organisation

If you are responding as a professional, please supply the following details:

Area of work:

NHS	
Social Care	
Private Health	
Third Sector	
Regulatory Body	
Professional Body	
Education	
Trade Union	
Local Authority	
Trade Body	
Other (Please give details)	
Independent Contractor to NHS [	
Manufacturer	
Supplier	
Other (where relevant)	

If you are responding on behalf of an organisation, please indicate which type of organisation you represent:

NHS	
Social Care	
Private Health/Independent Sector	
Third Sector	X
Regulatory Body	
Professional Body	
Education	
Trade Union	
Local Authority	
Trade Body	
Other (Please give details)	

In which of the following areas do you live: (please tick one box only)	
North East	
North West	
West Midlands	
South East	
London	
Humberside/Yorkshire	
East Midlands	
East of England	
South West	
No answer	

Please provide us with some information about yourself. This will help us to determine whether we have captured the views of everyone. All the information you provide will be kept completely confidential. No identifiable information about you, will be passed to on to any other bodies, members of the public or press.

1. What is your sex? *(Tick one box only)*

Male ☐ Female ☐

2. Which age group do you belong to? *(Tick one box only)*

- 0-15 yrs ☐
- 16-24 yrs ☐
- 25-34 yrs ☐
- 35-44 yrs ☐
- 45-54 yrs ☐
- 55-64 yrs ☐
- 65-74 yrs ☐
- 75-84 yrs ☐
- 85 yrs and over ☐

3a. Do you have a disability as defined by the Disability Discrimination Act (DDA)? *(Tick one box only)*

Yes ☐ No ☐

The Disability Discrimination Act (DDA) defines a person with a disability as "someone who has a physical or mental impairment that has a substantial and long-term adverse effect on his or her ability to carry out normal day to day activities".

b. If yes, please tick all which apply

- Partial or total loss of hearing ☐
- Partial or total loss of vision ☐
- Speech impediment or impairment ☐
- Other communication difficulty ☐
- Mobility impairment or difficulty moving around ☐
- Learning difficulty or learning disability ☐
- Mental health condition or disorder ☐
- Severe physical disfigurement ☐
- A longstanding illness or disease ☐
- Other medical condition or impairment (please specify)

____

4. What is your ethnic group? *(Tick one box only)*

A White
- British ☐
- Irish ☐
- Any other White Background, please write below

____

B Mixed
- White and Black Caribbean ☐
- White and Black African ☐
- White and Asian ☐
- Any other Mixed Background, please write below

____

C Asian or Asian British
- Indian ☐
- Pakistani ☐
- Bangladeshi ☐
- Any other Asian Background, please write below

____

D Black or Black British
- Caribbean ☐
- African ☐
- Any other Black Background, please write below

____

E Chinese or other ethnic group
- Chinese ☐
- Any other, please write below

____

5. What is your religion or belief? *(Tick one box only)*

- Christian ☐
- Buddhist ☐
- Hindu ☐
- Jewish ☐
- Muslim ☐
- Sikh ☐
- None ☐
- Other (please write below)

____

6. Which of the following best describes your sexual orientation? *(Tick one box only)*

Only answer this question if you are aged 16 years or over.

- Heterosexual/Straight ☐
- Lesbian/Gay ☐
- Bisexual ☐
- Other ☐
- Prefer not to answer ☐

REVIEW OF ACCESS TO THE NHS FOR FOREIGN NATIONALS

Consultation Questions

Please mark your answers with an “x” as necessary.

Chapter 2: The Charging Regulations and Guidance

Q1- Do you agree that the draft new consolidated Regulations provide a clearer, accurate and more succinct reflection of the existing Regulations?

Yes	No
X	

Comments

The draft new consolidated regulations include some important clarifications.

We particularly welcome the clarification that primary care services (primary medical services, primary dental services and primary ophthalmic services) are not included in the list of potentially chargeable "relevant services". However, we have not as yet been able to identify a legal definition of these primary care services (what is excluded and what excluded). Given the extensive reconfiguration of NHS services, we request that further clarification be included in the Guidance to avoid confusion as to what constitute primary care services.

We also welcome the confirmation that anyone who has a pending application for humanitarian protection will be exempt from charges. There has been, until now, some confusion about whether about individuals who have a claim under Article 3 of the European Convention on Human Rights for humanitarian protection are considered entitled to free secondary care. As those with an Article 3 claim are considered by UKBA and Local Authorities to be in the category of 'asylum seekers' for benefits purposes (section 94(1) Immigration and Asylum Act 1999), it is appropriate that the new draft Regulations and the Guidance [4.50] confirm that they are entitled to the same exemptions as other asylum seekers.

Q2- Do you agree that the consolidated Regulations do not imply any material change in policy?

Yes	No
	X

Comments

We have concerns over the new explanation of 'the easement clause' on continuation of existing courses of treatment in cases where an individual becomes chargeable during the course of treatment.

Under the current Guidance, if an individual's asylum claim is finally rejected and they become liable to charges, they will still not be charged for any treatment they were already receiving prior to the decision:

"If the claim is finally rejected (including appeals) before the patient has been in the UK for 12 months, they cannot be charged for a course of treatment they were receiving at the time

their status was determined. That remains free of charge until completed." [Current Guidance 6.24]

However, this is not included in the new Guidance, which only refers to the scenario in which the individual has fulfilled the 12 month lawful stay in the UK.

Furthermore, in the consultation document itself at footnote 10 [page 10] there is a mis-statement of the current position when compared with the current Guidance quoted above.

It is immensely important that this text on the easement clause is reinstated in the new Guidance in relation to asylum seekers. Not only is it unethical to change the basis of the provision of a course of treatment mid-way through its provision, there is an immense risk of individuals abandoning the treatment before its conclusion. This not only means the treatment may be ineffective and the person will become very ill. For HIV, and other relevant conditions, it can also result in the development of drug-resistant virus strains which cause great harm to public health.

The cumulative impact of such treatment interruptions is an increase of the 'pool' of infectiousness in society. It also creates a disincentive for asylum seekers to test and seek treatment for HIV if they may not be able to access essential treatment for the duration of their stay in the UK.

Q3- Does the new draft guidance clearly and comprehensively explain how the consolidated regulations should be interpreted and applied?

Yes	No
	X

Comments

There is much helpful material in the draft of the Guidance which more clearly explains how the consolidated Regulations should be applied. We have answered 'no' to the question because there are still some specific and important improvements which should be made. We address below the risk of inferior treatment and the way this will breach human rights and ethical guidelines.

The risk of inferior treatment

As recognised by the Joint Committee on Human Rights (JCHR), in its report on the *Treatment of Asylum Seekers*,[1] restrictions on refused asylum seekers' access to free healthcare from the NHS violates their right to the highest attainable standard of health as guaranteed by Articles 2 and 12 of the International Covenant on Economic Social and Cultural Rights (ratified by the UK in 1976). The JCHR noted further that in cases where the state denies healthcare to an individual which is available to the population, and in doing so puts his/her life at risk, issues may arise under Article 2 of the European Convention on Human Rights and Fundamental Freedoms.

We are concerned that the new draft Guidance conflicts with the obligation noted above, by requiring clinicians to consider providing healthcare to refused asylum seekers and others which is of a lesser standard than that offered to the population at large.

The draft Guidance states,

> "while it should not become the major factor, and where it is medically safe to do so, *the financial consequences should play a role in the choice of treatment provided to chargeable overseas visitors who cannot pay* or the limits imposed on their treatment, to the same extent that these considerations are taken into account for ordinarily resident NHS patients."
> [3.32, emphasis added]

[1] JCHR. 2007. The Treatment of Asylum Seekers. HL Paper 81-1. 30 March 2007.

It also states in a later paragraph that,

"The clinician can [after the Overseas Visitors Manager (OVM) has confirmed that they are dealing with a chargeable overseas visitor] consider what limits can safely be applied to that patient's treatment, thereby preventing the patient incurring a potentially unnecessarily large bill, or the relevant NHS body suffering a loss if debt recovery is not successful, which would mean less resources available for other patient services." [5.4]

Clinicians are already under a professional obligation to choose the most reasonable cost-effective treatment for all patients- including those with entitlement to NHS services- when deciding on a course of treatment. As such, the statements quoted above are at best redundant, or may otherwise suggest that the new Guidance will become the basis of a two-tiered system of treatment. Such a two-tiered system, in which those without entitlement to the NHS or who are unable to pay for treatment receive a lower standard of care, would contravene the obligations referred to above.

Moreover, delivering care based on a patient's immigration status or ability to pay would conflict with the ethical obligations of clinicians, and could leave them liable to charges of negligence. The clinician's role is to provide appropriate treatment for their patients within protocols and guidelines (including those of NICE). To base decisions about treatment on cost could expose clinicians to charges of negligence or failure in their duty as doctor.

It should also be noted that the decision to provide inferior treatment on cost grounds may lead to poorer outcomes for patients. In the case of HIV, which requires clinicians to make extremely precise dosage decisions in prescribing treatment, drawing from a wide range of possible medications, there is a risk that two-tier system could lead to compromises of cost over expected efficacy.

For these reasons, **these statements should be removed from the final version of the Guidance**.

Q4- Does Chapter 3 of the new Guidance document fully and clearly explain the NHS's obligations and requisite processes to ensure the provision of immediately necessary and urgent treatment to chargeable patients who are unable to pay prior to the treatment needing to be provided?

Yes	**No**
	X

Comments

Overall, Chapter 3 clearly sets out the NHS's obligations and requisite processes for immediately necessary and urgent treatment. However, we have some specific comments on this section of the Guidance.

HIV as 'immediately necessary' treatment

We welcome the fact that the Government is currently undertaking a separate review of the case for exempting HIV treatment from NHS charges. NAT, along with the rest of the HIV sector, believe that HIV treatment should be exempted on the same public health grounds as apply to every other infectious disease and sexually transmitted infection. Should the new Regulations be agreed and this charging Guidance published in advance of the HIV charging review coming to such a conclusion, **we recommend that HIV, like maternity services, be singled out by the DH as always 'immediately necessary'**. The British HIV Association (BHIVA) has made clear to the DH that it considers HIV treatment to be 'immediately necessary'.[2] This should be reflected in the Guidance. The two reasons given for the singling out of maternity services - significant risk of life-threatening illness and the risk of harm to others - apply equally to HIV.

[2] In a letter to Dawn Primarolo, Minister of State for Public Health, dated 7 October 2008.
http://www.nat.org.uk/Media%20library/Files/Policy/2010/BHIVA%20letter%20to%20Primarolo.pdf

Maternity Treatment

We welcome the clear definition of maternity treatment as immediately necessary, in section 3.7, and the obligation on OVMs and clinicians to specifically inform patients that their maternity care will not be withheld, regardless of their ability to pay. This is particularly important for ensuring pregnant women living with HIV receive the treatment they need to prevent transmission of HIV to their child.

Ensuring continuation in care of those who need immediately necessary treatment

The Guidance rightly emphasises that the provisions around immediately necessary treatment are necessary for human rights obligations to be met. There is welcome content in the Guidance which makes clear that for an individual's human rights under Article 2 and other ECHR Articles to be met not only must the policy be right (treatment must be immediately given) but the charging process must support the individual to exercise his or her rights.

Thus the Guidance emphasises that no administrative staff should obstruct anyone accessing a clinician, so that the clinician may make the assessment of whether treatment is immediately necessary, urgent or non-urgent [3.25]. The Guidance also states that in the case of 'immediately necessary' treatment it should be made clear to the patient that treatment will not be withheld or delayed if they do not pay in advance [3.22] and that the patient '"should not be discouraged from receiving [the treatment], even if they indicate that they are unable to pay" [3.23]. It is stated that timing of presentation of any bill should bear in mind the importance of not discouraging someone from accessing this care.

This is very helpful. However, further guidance on billing needs to be provided so that this human rights obligation not to deter people from accessing life-saving treatment and care is upheld in practice. In the case of HIV, once treatment is begun it will continue for the rest of that person's life. For these patients, discussion of charges and presentation of a bill will by necessarily always take place when that person is receiving 'immediately necessary' treatment.

It is recommended in the Guidance that a debt recovery agency be used [3.39]. Our experience has invariably been that approaches for recovery of NHS debt from such agencies have been experienced as threatening, heavy-handed and a deterrent to continue to access treatment. Their use for those accessing immediately necessary treatment is inappropriate and could be considered to undermine the individual's rights.

Similarly, more guidance should be given on processes for the writing off of debt for those unable to pay. Not only is pursuing such un-payable debt a waste of money, it also deters those in need of immediately necessary treatment from accessing their care. As noted in the draft Guidance, a large proportion of people in this situation are refused asylum seekers previously assessed by the UKBA as destitute for the purposes of receiving UKBA subsistence and accommodation support. Identifying the debt as un-payable should be a quick and easy thing to do.

We therefore recommend that the Guidance state -

- **That the charging process for 'immediately necessary' treatment should be one that positively encourages people to continue to access the relevant treatment for as long as clinically necessary**
- **That debt recovery agencies should not be used to recover debt from those accessing 'immediately necessary' treatment**
- **That debt recovery agencies should never be used to recover a debt until it has been established that it would, given the patient's circumstances, be cost effective to pursue the debt**
- **That those accessing 'immediately necessary' treatment, when informed that charges might apply [3.21], should also be informed that ability to pay is taken into account in the charging process and there are possibilities of paying by instalment and of debt write-off in certain circumstances**
- **That determination of a patient's circumstances and the cost-effectiveness or otherwise of pursuing a debt should be undertaken by the OVM prior to**

[3] JCHR. 2007. The Treatment of Asylum Seekers. HL Paper 81-1. 30 March 2007.

commencing recovery of a debt, to minimise unnecessary costs to the NHS and distress to the patient.

Model Request for Advice from Doctors/Dentists (Appendix 2)

Under the new Guidance, the form, which records the opinion of a clinician as to whether treatment was 'immediately necessary' or 'urgent' should be signed jointly by the OVM and the clinician. As such, the clinician becomes legally responsible in the decision. In signing they may also open themselves to accusations of unethical behaviour, as discussed in Question 3.

We recommend that clinicians not be asked to sign what is an administrative form. The opinion of clinicians on the urgency of treatment for any individual patient should continue to be documented as at present.

However, if clinicians will be required to sign such forms, there needs to be an adjustment to the text of the form to bring it in line with the definition of 'immediately necessary' treatment. The form should read (new text marked in bold):

- I intend to give treatment which is immediately necessary to save the patient's life **or to prevent a condition from becoming life-threatening or prevent serious damage from occurring.**
- I intend to give urgent treatment which is not immediately necessary to save the patient's life but cannot wait until the patient returns home.
- The patient has presented with symptoms which require further investigation to establish whether treatment is immediately necessary or urgent.

Posters

Finally, the draft Guidance makes reference to posters which state that if a patient is unclear about his/her eligibility for NHS Treatment, the receptionist should be approached for further information. These posters should not be used. Frontline staff are not expert in charging decisions. The JCHR noted that a major barrier to access to healthcare for those entitled included frontline staff's incorrect assessments of entitlement by frontline staff.[3] The recommendation that receptionists should be approached for further information for those unsure about their entitlement to NHS services should be removed or replaced with information about members of staff who have the appropriate skills and knowledge to assist patients in making this determination.

Chapter 3: Proposals for Change to the Charging Regulations.

Q5- Do you agree with the proposal to exempt Section 4 and Section 95 failed asylum seekers from charges for NHS hospital treatment?

Yes	No
X	

Comments

We strongly support the proposal to exempt Section 4 and Section 95 refused asylum seekers from charges for NHS hospital treatment.

To be eligible for Section 95 or Section 4 support a refused asylum seeker must be found to be destitute. While on the support, they live on as little as £5 a day. Many struggle to meet their basic nutritional and health needs.[4] The vast majority will not be allowed to look for

[4] Lisa Doyle. 2008. *More Token Gestures*. Refugee Council.

work (asylum seekers may only apply for permission to work after 12 months). These extremely vulnerable individuals have no ability to pay thousands of pounds for HIV treatment. Moreover, recipients of Section 4 support receive their payments in vouchers or via a pre-paid card, meaning they have no access to cash at all.

Without this exemption from charges, refused asylum seekers in receipt of Section 95 or Section 4 support may be deterred from accessing essential HIV treatment, with severe consequences for both individual and public health.[5]

We wish to state our belief that all those living in the UK, irrespective of residency status, should be able to access free NHS treatment and care. We consider this to be an essential aspect of their right to health. As a first step, **the Government should implement the recommendation of the Joint Committee on Human Rights report on the Treatment of Asylum Seekers, that all refused asylum seekers should be able to continue to access free NHS care until they leave the UK**.

Q6- Do you agree with the proposal that any unaccompanied non-resident Children should be exempted from NHS treatment charges?

Yes	**No**
X	

Comments

This proposal will help ensure that unaccompanied non-resident children access the HIV treatment they need.

However, we are concerned that there are still children who are not exempt from charges for their HIV treatment, if they are accompanied by parents or guardians who can be held responsible for their treatment charges. For families who cannot afford to pay, these charges may present a barrier to children receiving essential HIV treatment.

We recommend that NHS secondary care for children of chargeable parents or guardians should be free of charge (at a minimum, for 'immediately necessary' or 'urgent' treatment).

Q7- Do you agree that UK residents may be absent from the UK for up to six months in a year before potentially being liable for charges for NHS treatment under the Charging Regulations?

Yes	**No**

Comments

No comment.

[5] For a number of cases related to charging see: www.nat.org.uk/Media%20library/Files/PDF%20documents/NAT-Access-to-treatment-and-care-cases.pdf.

Q8- In respect of the proposals referred to in Questions 5-7 are you able to provide any additional data that may inform the calculations of costs and benefits?

Yes X	No

Comments

We wish to note the cost benefits to the NHS of exempting HIV treatment from charging, which are of course also relevant to the exemption from charging of those on Section 4 or Section 95 support.

Providing universal and free HIV treatment will save the NHS money in the long term. People not entitled to NHS treatment (or who believe wrongly that they are not entitled) are in the main from the African community in the UK. In the UK, black Africans with HIV are diagnosed disproportionately later, often when seriously unwell. Data from Canada shows that HIV-related hospital care costs 15 times more for late presenters than for those diagnosed and treated in a timely fashion.[6]

Costs of intensive care and even ordinary inpatient treatment are far higher than ordinary HIV treatment. Currently, London hospitals estimate that a week's stay in an Intensive Care Unit (ICU) is between £14,250 and £25,000. A major Midlands hospital estimates 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. The cost of first line HIV treatment in London is now £5,485 per annum. Given that someone not using 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.

This is confirmed by a case of a newly diagnosed HIV positive patient whose ARV treatment was delayed by the hospital because she was not eligible for free treatment on the NHS and was unable to pay.[7] This delay in care caused her condition to rapidly deteriorate, and to be admitted into the hospital's ICU where she was treated for a variety of complications, 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.

Timely treatment not only improves individual health and reduces healthcare costs, it also reduces onward transmission. Successful HIV treatment reduces viral load to an undetectable level which, in turn, reduces the risk of onward transmission of HIV to a very low level. Given that each onward transmission of HIV costs the NHS between £202,957 and £362,422 over a lifetime, this is a significant cost saving.[8]

Charging for HIV treatment also interferes with other areas of public health. People co-infected with HIV and TB (which is not uncommon among African migrants to the UK) have particular difficulties. TB treatment is free to all on public health grounds, but the UK HIV sector cite examples of patients who have left TB treatment after being billed for HIV treatment. The British Association for Sexual Health and HIV (BASHH) has noted cases of people not using HIV treatment due to cost who then went on to contract TB and extensive (and expensive) complications.

The work of NAT (National AIDS Trust) on *The Myth of HIV Tourism* should also be noted. It rebuts claims that free NHS treatment is or has even been the primary reason for travel to the UK for a significant number of migrants.[9]

[6] Krentz et al (2008) “Cost of medical care for HIV-infected patients within a regional population from 1997 to 2006” *HIV Medicine* 9:9 721-730.
[7] Fowler et al (2006) “HIV, HAART and overseas visitors” *Sexually Transmitted Infections*, http://sti.bmj.com.
[8] Devine et al (2009) “Estimating costs of HIV treatment in the UK” *Proceedings of the Health Protection 2009 conference.*
[9] NAT. 2008. 'The myth of HIV tourism'. Available from www.nat.org.uk

In summary, charging for HIV treatment has no impact on the numbers of people living with HIV in the UK; secures hardly any income to the NHS for treatment, which is provided as 'immediately necessary' regardless of payment; and results in more costly treatments (due to interrupted treatment and the development of drug resistance) and increased onwards transmission in the long term.

Chapter 4: Tackling NHS Debt and Misuse

Q9- Do you agree with the proposal to require an overseas visitor receiving chargeable NHS treatment to provide personal information to aid subsequent recovery of charges?

Yes	No

Comments

No comment.

Q10- Do you agree with the proposal that NHS organisations must provide information relating to outstanding debt for NHS treatment to the Department of Health or to an appointed agency?

Yes	No
	X

Comments

The proposal to provide information on outstanding debt to the DH or an appointed agency seems to be for the purpose of passing that information on to UKBA, which we strongly oppose. We therefore disagree with the proposal to send personal information on outstanding debt to the DH.

Despite the statement in the consultation document [p20] that data collected would not include any clinical information, we remain concerned that sharing information about NHS debts may in practice occasionally result in the disclosure of a patient's HIV status without their permission. This would clearly be a breach of the patient's right to confidentiality.

Rather than collecting of individual information for the purpose of pursuing debts, we believe that the Guidance should instead identify a common dataset of information around chargeable overseas visitors to be collected by PCTs (and other charging health authorities) and stored in an anonymised form. Debate on the issue of personal NHS debts has to date been hampered by inconsistent and incomplete data at the PCT level, which has only encouraged speculation and prejudice. It would be useful to know the health conditions for which people are being charged for treatment; whether individuals are tourists, for example, or refused asylum seekers; the extent of debt repayment and debt write-off; the proportion of treatment charged which was immediately necessary; and when patients interrupt or fail to complete courses of charged-for treatment. Common collection of such anonymised data would allow collation of statistics by the DH when necessary to assess how the charging system is working and its impacts.

Q11- What safeguards on the protection of personal information are needed beyond those described?

Comments

No comment.

Q12- Do you agree that the NHS Counter Fraud Service should transfer the data from the Department of Health's appointed agency to the UK Border Agency to support recovery and implement any agreed immigration sanctions under rules approved by parliament?

Yes	**No**
	X

Comments

The transfer of data from the DH's appointed agency to the UKBA is an unacceptable breach of the confidentiality of migrants accessing the NHS. We strongly oppose it. We are particularly concerned that this practice would create a further disincentive to access essential HIV care.

It is already the case that HIV treatment charges deter many of those with HIV from getting tested and accessing treatment in good time. A quotation from a recent research study is typical, '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]'.[10] Delayed diagnosis and treatment result in serious ill-health and more onward HIV transmission.

Linking immigration sanctions to unpaid NHS debt will make this situation even worse. In the case of immediately necessary treatment such as that for HIV, it should be noted that the vast majority of chargeable patients do not visit the UK with the aim of accessing such care - they are here already and become ill. Knowledge that accessing essential NHS care will result in an unpayable bill, and that such an unpaid bill will fatally undermine a current or future attempt to stay or enter the UK, will simply end in migrants not seeking the testing and treatment they need. The result will, as stated above, be serious and in some cases fatal consequences for individuals and - in the case of infectious disease - greater onward transmission, harming public health.

We believe that for a disability such as HIV where the treatment is immediately necessary, an immigration refusal on the basis of an unpayable bill could constitute disability discrimination.

Even if the clinical condition were omitted from the information sent to UKBA, we have no doubt that the proposed system would also reinforce the erroneous but commonly held belief that HIV status was communicated to UKBA and that immigration decisions took HIV status into account. Such beliefs contribute significantly to the high rates of late diagnosis in African communities which pose such a challenge to public health.

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[10] Thomas F, et al. *"If I cannot access services, then there is no reason for me to test": the impacts of health service charges on HIV testing and treatment amongst migrants in England.* AIDS Care 22: 526-531, 2010.

Data-sharing between the NHS and UKBA will undermine the trust that patients have in the NHS, and in their doctors.

There is also a risk that immigration sanctions could negatively impact on someone trying to flee their country in fear and therefore, it would put the UK at risk of breaching its human rights obligations.

Rights of review/appeal

Experience in the HIV sector has been that NHS treatment charges are in a significant number of cases misunderstood and misapplied even by those with responsibility to enforce them. They are equally misunderstood by migrants, whether chargeable or not. There is nothing in the new proposals to suggest this situation will change. Furthermore, whilst Guidance can provide pointers as to what constitutes 'ordinarily resident' status, consideration of whether the House of Lords definition applies must be made on a case-by--case basis, taking into account the specific circumstances of the individual.

In this context of complex decision-making, inconsistently and often incorrectly applied across the country, it is wrong that there is no appropriate process of review and appeal of decisions, beyond the generic NHS complaints procedure. Were such charging decisions also to have an impact on immigration rights, we have no doubt that the lack of such an appeal process would constitute a denial of fundamental human rights and due process. Immigration sanctions based on such charging decisions would be frequently challenged. This has a cost implication which has not been addressed by the DH or UKBA. But it also raises doubts as to whether in practice details of the individual's condition can possibly be kept from UKBA. Any appropriate review of the merits of a decision will inevitably have to involve the nature of the condition (was it exempt? immediately necessary?) and quite possibly the relevant and identified clinician.

Q13- Do you agree that the Secretary of State Directions to the NHS Business Services Authority should be amended to enable the NHS Counter Fraud Service to lawfully carry out the data transfer process?

Yes	**No**
	X

Comments

We disagree with the proposal to transfer data between the NHS and UKBA, for the reasons set out in answer to question 12.

Chapter 5: Health Insurance for Overseas Visitors

Q14- Do you support the principle that a requirement for chargeable overseas visitors to have health insurance should be introduced to cover the costs of any NHS treatment they may require during their stay?

Yes	No
	X

Comments

In the case of HIV, the proposal to make compulsory health insurance a condition of entry will not have the desired impact of reducing the development of NHS debts by chargeable overseas visitors. It will have, however, a range of negative and discriminatory impacts for chargeable overseas visitors living with HIV.

Foreign nationals who are chargeable for their HIV treatment in the UK include, amongst others, refused asylum seekers, visa overstayers and those without documentation. They are among the most vulnerable in our society, with the least resources, and are those who are least likely to have health insurance. They would be unlikely to access insurance that would cover their HIV condition, but would still need to seek HIV treatment from the NHS for which they will be chargeable. Requiring visitors to the UK to have health insurance will not alter this situation.

No one who left their home country to seek asylum in the UK would be expected to arrange health insurance before leaving. As such, this proposal will not cover the costs of refused asylum seekers who need to seek HIV treatment while still in the UK. The same is almost certainly the case for those who have entered the UK unlawfully.

For those who enter the UK on a visa, there may be issues of availability of appropriate insurance in their home country. Insurance companies may refuse to offer insurance to those living with HIV, or the insurance plans that are offered may be prohibitively expensive. Insurance requirements may also mean in effect a requirement for all visa applicants to have an HIV test. This will create a de facto restriction on travel to the UK for people living with HIV. At a time when most countries are finally removing HIV testing at borders and travel restrictions, the UK will be effectively re-instating such practices for migrants from a range of countries who do not have reciprocal agreements for healthcare with the UK.

The proposal is therefore likely to disproportionately affect some of the most disadvantaged foreign nationals. As it also will have a particular impact upon those with HIV, it could also be considered discriminatory under the Equality Act 2010, which provides protection against discrimination from the point of HIV diagnosis.

Q15- What issues may arise from a system of either strongly recommended or mandatory health insurance for chargeable overseas visitors? How might these be overcome?

Comments

We are concerned that many overseas visitors who are chargeable for HIV treatment would face significant barriers to accessing health insurance before entering the UK (*see response to question 14*).

Q16- Do you support the principle that some overseas visitors who are currently exempted from charges should instead fund their treatment costs through health insurance?

Yes	No
	X

Comments

In respect of HIV treatment, all overseas visitors should be exempt from NHS charges - see 'Further Comments'. Difficulties around accessing health insurance for people living with HIV have been outlined in response to question 14.

Q17- What practical issues may arise if particular categories of overseas visitors or temporary residents were required to cover or insure their own healthcare costs rather than be entitled to free NHS treatment? How might these be overcome?

Comments

As noted in the response to question 14, there are a range of practical issues which would arise if people living with HIV were required to have health insurance. These are:

- **It is highly unlikely that asylum seekers would obtain health insurance before entering the UK**
- **It is highly unlikely that undocumented migrants and current visa overstayers would have health insurance**
- **Visa applicants may not be able to access health insurance if they HIV**
- **Visa applicants may not be able to afford health insurance, especially if there is an HIV-related premium or higher rate to pay**

This may amount to disability discrimination.

In the case of HIV, the most cost-effective way to ensure essential treatment is available without discriminating against the most disadvantaged, is to make HIV treatment exempt from charges for all foreign nationals actually living in the UK.

Please feel free to submit any further comments on these draft regulations below.

Further comments

We wish to make further comments on two aspects of the consultation:

- **The theory of 'health tourism' informing the new draft Regulations and Guidance**
- **The possibility of exempting HIV treatment from NHS charges**

Defining 'health tourism'

There is a worrying failure in the consultation document to define health tourism properly, and this compromises much of the policy analysis in the document. The consultation document speaks of the risk "that some visitors to the UK deliberately access healthcare without paying" and describes this as health tourism. A better definition would be that "the term 'health tourism' refers in particular to the claim that foreign nationals are leaving their home country with the main and express purpose of receiving free healthcare in the UK."

In the case of HIV, the vast majority of those miscategorised as 'health tourists' (or described as 'abusing' the system) are simply people who become ill whilst in the UK and who do not currently have lawful or settled residency status. There has been no plan to abuse, exploit or defraud the NHS. Thus the assumptions around deterring migrants' entry to the UK are incorrect, as are the estimates of the amount of money which would be recovered under the proposed system, which simply ignore the fact that most of those charged can pay nothing.

Neither the DH nor UKBA present any evidence on the proportion of chargeable patients who are actually 'health tourists' - we think it very probable our experience in HIV is typical, in other words a small minority.

There is then a small but real issue around people visiting the UK on a one-off or regular 'tourist' basis to access free NHS care. This needs to be addressed. But not by entrenching further the health inequalities of already vulnerable people living in the UK.

Exempting HIV treatment from NHS charges

We wish to comment on the position taken in the consultation document in relation to the case for excluding HIV treatment charges on public health grounds (chapter 3). Treatment for other sexually transmitted infections (STIs) and infectious diseases is exempt from NHS charges. This is because of the immense public health importance and benefit of treating the condition. The same principles should be applied to HIV.

We are aware of and welcome the separate, specific review into charging for HIV treatment. In advance of the outcome of this review, however, we wish to outline briefly the evidence in favour of exempting HIV treatment from the list of chargeable relevant services provided by the NHS, and refute misleading statements made in the consultation document.

<u>The benefits of treatment</u>

The consultation document states that:

Unlike other sexually transmitted diseases… individual treatment for HIV is life-long and does not offer a cure. The risk of infection to others remains and so that case to make HIV treatment exempt from charges on public health grounds is less strong…. [p15]

It is true that HIV infection is not curable. However, research has demonstrated the significant impact of effective ARV treatment on onward transmission. Studies of HIV transmission in HIV-discordant couples show almost no examples of HIV transmission where the infected partner has a persistently suppressed viral load on treatment.[11] Evidence from population-based studies show that expanding access to ARVs to people with HIV, and thereby

[11] Castilla et al (2005) "Effectiveness of highly active antiretroviral therapy in reducing heterosexual transmission of HIV" *AIDS*, 40(1): 96-101.

decreasing the mean viral load in the HIV-infected segment of the population, results in decreased rates of HIV transmission and incidence of new infections.[12]

Given that HIV treatment is life-long, it is surely even more important from a public health perspective that onwards transmission is reduced. Universal access to free HIV treatment would greatly reduce the risk of HIV transmission throughout the population.

The myth of HIV health tourism

The consultation document also states that:

…A charging exemption could attract visitors specifically seeking treatment, increasing NHS costs and demands on available capacity [p15]*….*

This statement reflects an assumption which is behind many of the proposals made in this consultation, that NHS resources are frequently and significantly compromised by the practice of 'health tourism'. The consultation document acknowledges that there is no quantifiable evidence that the phenomenon exists on any significant scale; instead anecdotal reports are relied upon.

In respect of HIV, NAT (National AIDS Trust) has analysed Health Protection Agency (HPA) data to find no support for claims of HIV-related 'health tourism'.[13] On average, migrants are in the UK for almost five years before they even have an HIV diagnosis (and this was true when in practice there was no charging for HIV treatment). This is in stark contrast to the claim that migrants arrive with the intent to access antiretroviral (ARV) treatment. Even in the case of sub-Saharan African countries with high HIV prevalence, the evidence is that the HIV prevalence amongst migrants is invariably lower than in their country of origin. Were HIV treatment a 'pull factor' for migration to the UK, we would expect HIV infection to be disproportionately high amongst migrants to the UK compared with those staying in their country of origin.

The conclusions NAT have drawn from HPA data have been confirmed by surveys by Terrance Higgins Trust and George House Trust[14] and by the Home Office's own research on motivations for migration and destination choice.[15]

Given the complete lack of quantitative evidence for the phenomenon of 'health tourism', we question the language of 'misuse' to describe access to NHS services which incur treatment charges. Chargeable patients with HIV in the vast majority of cases are not health tourists, have a human right to such immediately necessary treatment, and would pay charges had they the means to do so. It is wrong to use the language of 'abusing the system' to describe vulnerable people in these circumstances.

Disincentive to leave?

We also have serious concerns about the statement in the consultation document that:

…The need for continuing treatment may also be a disincentive to return for those with no further permission to remain. [p15]

HIV treatment is invariably considered by clinicians to be 'immediately necessary' treatment and so is provided irrespective charges and ability to pay. There is no evidence the current charge encourages anyone to leave the UK. In the vast majority of cases the person is destitute and the bill should in any event be written off. This argument does not apply.

We do not accept the arguments against the exclusion of HIV from treatment charges provided in the consultation document. HIV treatment should be free to all, regardless of residency status, to protect both individual and public health.

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[12] Fang et al (2004) "Decreased HIV transmission after a policy of providing free access to highly active antiretroviral therapy in Taiwan" *Journal of Infectious Diseases* 190(5): 879-85; Montaner et al (2008) "Longitudinal plasma HIV RNA level and HIV incidence among injection drug users" Abstract LBPE1160, Paper presented at XVII International AIDS Conference, Mexico City.
[13] NAT (2008) 'The Myth of HIV Health Tourism', www.nat.org.uk.
[14] THT and George House Trust (2003) *Recent Migrants Using HIV Services in England*, www.tht.org.uk.
[15] Home Office (2002) *Understanding the decision-making of asylum seekers*, www.homeoffice.gov.uk.