

SHAPING ATTITUDES
CHALLENGING INJUSTICE
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HIV care in Immigration Removal Centres



KEY MESSAGES

- NAT (National AIDS Trust) and the British HIV Association (BHIVA) have previously published best practice advice on the treatment and care of HIV in Immigration Removal Centres (IRC).
- NAT, with the support of BHIVA and Offender Health (now Public Health England Directorate of Health and Justice), surveyed Immigration Removal Centres (IRC) and HIV clinics local to these IRCs about the treatment and care of HIV positive detainees during 2011/12.
- All 10 main IRCs responded to the survey (short-term holding facilities were not included). Seven HIV clinics responded. These clinics are local to nine of the 10 IRCs. However, two of the IRCs reported that their HIV positive detainees continued in the care of their existing clinic.
- Between 1 July 2011 and 30 June 2012, healthcare teams in IRCs saw 95 cases of detainees with diagnosed HIV. As there is movement between IRCs, this represents fewer than 95 individual detainees. Based on the number of transferred patients reported by IRCs, NAT estimates that there were between 60 and 70 individual patients. 67% of the reported cases were in the three largest IRCs (Harmondsworth, Yarl's Wood and Colnbrook).
- The quality of information provided by the IRCs varied greatly, with the most significant gaps in data from the IRC which treated the largest single cohort of HIV positive detainees (Harmondsworth, which saw 34 HIV positive detainees).
- Around 10% of patients arrived at the IRC without a supply of their antiretroviral medication. Of this group, only one patient received a supply of the necessary medication within 24 hours, as recommended in the NAT/BHIVA advice.
- There were at least four (and possibly as many as 12) cases of treatment interruption (not including additional interruptions associated with arrival at the IRC) during this time-period. IRC healthcare teams, HIV clinicians and voluntary sector organisations disagree about how many of the detainees missed doses of ART while in detention.

- Patients from some IRCs are still attending HIV clinics in handcuffs and accompanied by more than one security escort. In at least one location these restraints are kept on and security escorts are present during consultations.
- In around 53% of cases the patient was removed from the UK, meaning that in nearly half of cases the patient continued to need HIV care services from the NHS after leaving the IRC. On leaving the IRC around 32% of patients were returned to the community and 7% were transferred to another IRC.
- Five IRCs reported that HIV positive detainees who were removed from the UK left with a three month supply of ART. Others reported that patients left with less than three months' worth, ranging between 11 and 80 days' supply.
- HIV clinics treating patients from IRCs were in most cases notified of upcoming removals of their patients, but were not routinely notified or consulted about patient release to the community or transfer to another IRC. This means that patients were not provided with a letter from their treating clinician to facilitate continuity of care.
- There is significant variation in how IRC healthcare teams approach HIV treatment and care, even where two IRCs are co-located and share the same local HIV clinic.



RECOMMENDATIONS

The NAT/BHIVA best practice advice has had an impact, but as it does not hold the status of official NHS or Home Office guidance, it is up to individual healthcare teams to decide how much of the advice to implement.

In order to address the remaining gap between clinical recommendations and current practice, healthcare teams in IRCs need to be given stronger, authoritative unambiguous guidance on the provision of HIV treatment and care. NAT recommends that NHS England develop within a national service specification clear requirements for HIV testing, treatment and care within immigration detention, including information on preparing patients for removal, release or transfer.

NAT recommends that any such NHS England service specification take into account the specific recommendations for service improvement which we have made in response to the findings of this research:

- IRC healthcare teams should be required to have a formal, written protocol with the local clinic which treats HIV positive detainees. This should include a commitment from the IRC healthcare team to contact the clinic immediately that they become aware that a detainee needs ART access, and a commitment from the clinic to provide ART within 24 hours of this request.
- IRC healthcare teams should be required to have a formal, written protocol on HIV testing, in line with existing clinical and public health guidelines produced by BHIVA/BASHH/BIS and NICE.
- When a patient is transferred between IRCs, the healthcare team at the sending IRC should be required to send medical records within 24 hours of the transfer.
- Clinics who are aware that a patient has been taken into immigration detention should promptly forward medical records to the new treating clinician. However in many cases it will be necessary for IRC healthcare teams to notify the clinic of their patient's whereabouts and to ask for the transfer to be made.
- HIV positive detainees should be allowed to hold their ART medication, unless contra-indicated by an individual risk assessment.
- While detainees should hold their medication where possible, IRC healthcare teams still have a responsibility to provide support with adherence to all detainees who are taking ART, including making regular checks on their physical and mental health and wellbeing.
- The clinical protocol between IRC healthcare teams and local clinics should include a reciprocal agreement to notify the other party about any treatment interruption experienced by a patient.

- Attendance at HIV clinical appointments must always be considered a priority for transport bookings.
- Detainees who are attending HIV clinic appointments should not routinely be restrained and the presence of security escorts should be proportionate and based on an individual risk assessment. Patients should never be handcuffed during consultations and tests and should not be accompanied into the consulting room by security escorts.
- Detainees living with HIV should be screened and treated for psychological health needs in line with the agreed Standards for psychological support for adults living with HIV.
- All people living with HIV who are being removed from the UK should be provided with at least a three months' supply of ART to support unbroken access to medication and continuity of care.
- All people living with HIV who are being released to the community should be provided with an adequate supply of ART to support unbroken access to medication and continuity of care.
- All people living with HIV who are being removed from the UK or released to the community should be provided with a letter from their treating clinician to support unbroken access to medication and continuity of care.
- IRC healthcare teams should be required to notify clinical care teams of any planned release, removal or transfer of a patient as part of a pre release/removal/transfer checklist. It should not be possible for a detainee to leave the IRC without these preparations having been made.
- IRC healthcare teams should be provided with clear guidance on assessing whether an HIV positive detainee is 'fit to fly', including a requirement to ask the clinical opinion of their HIV consultant or specialist nurse.
- All providers of healthcare in IRCs must be required to keep a basic set of records about the treatment of detainees, kept in a retrievable format for seven years from the time that the patient leaves the IRC. This should include information on testing (if applicable), ART prescriptions and access, medical appointments made and kept, and preparations for release, transfer or removal.

In addition, NAT recommends that:

- As Yarl's Wood is the second largest IRC and the only IRC to house a significant number of woman detainees, it is vital that the local HIV clinic and other relevant healthcare services make available to NHS England accessible, accurate and disaggregateable data on its patients from the IRC.
- NHS England should satisfy itself that there are no gaps in continuity of care for those people living with HIV who leave detention and return to community in the UK.

INTRODUCTION

People who are held in prison and other detention settings, including immigration removal centres (IRCs), are entitled to the same range and quality of healthcare service as the NHS provides to the general community. However, there are specific challenges associated with providing effective healthcare in detention settings.

These challenges are especially pronounced when considering the needs of people living with HIV in immigration detention. Antiretroviral treatment (ART) is highly effective at suppressing viral load, but only when adhered to perfectly (more than 95% of the time, or no more than one missed dose of per month of a once-daily treatment). HIV is a complex and highly specialised area of medicine, and patients must have 3-6 monthly consultations with an HIV consultant or specialist nurse to monitor their health and response to treatment.

Following anecdotal reports that people living with HIV were not receiving the quality of care they needed while in immigration detention, NAT surveyed IRC healthcare teams in 2005 about the HIV treatment and care they were providing. The survey revealed a number of gaps and pressure points in IRC healthcare processes which were leading to treatment interruption and poor continuity of care for people living with HIV who were taken into immigration detention and/or removed from the UK.

To address these problems, in 2009 NAT and the British HIV Association (BHIVA) published Detention, Removal and People Living with HIV – Advice for healthcare and voluntary sector professionals (hereafter 'NAT/BHIVA advice'). This best-practice advice for those providing HIV services to immigration detainees is built around the principles of maintaining continuity of care and supporting effective ART adherence throughout detention and removal (or release to the community).

The advice contains detailed information about how to meet the needs of people living with HIV in immigration detention, but some of the key recommendations include:

- Maintain unbroken access to antiretroviral medication for an HIV positive detainee who arrives with his or her ART. In most cases, patients should be allowed to hold their own ART to limit the risk treatment delay and interruption.
- Have an arrangement in place between the IRC and the local HIV clinic to obtain ART within 24 hours if it is found that an HIV positive detainee has arrived without his or her ART.
- Offer HIV testing where clinically indicated or requested by the detainee, including appropriate post-test counselling, baseline assessment and onwards referral.
- Make arrangements in advance for any transfer of an HIV positive detainee out of the IRC either to another IRC or into the community, in consultation with the HIV clinic currently treating them.
- Ensure that any HIV positive detainee is medically stable and fit to travel before removal.
- Ensure that any HIV positive detainee who is to be removed from the UK has a supply of three months'

ART before removal, a letter from their treating clinician, and information about HIV services in their destination country.

- Detainees who are to be released into the community should also have an adequate supply of ART and letter from their treating clinician.

Since the release of the NAT/BHIVA advice, the care of detainees living with HIV has been reported on by the charities Medical Justice (Detained and denied, 2011) and the African Health Policy Network (I'd rather be in prison, 2012). Both reports indicated that interruptions to treatment and care were still occurring in IRCs. There have also been a number of court cases where immigration removal decisions have been challenged because HIV positive detainees have not receive adequate clinical care or preparation for removal from the UK.



ABOUT THE SURVEYS

During 2012/2013, NAT surveyed IRCs and their local HIV clinics about their treatment and care of detainees living with HIV for the year 2011-12. The survey followed the typical journey of a detainee through reception, detention and release/removal. The questions addressed the same areas of treatment and care which are outlined in the NAT/BHIVA advice.

Immigration removal centres

NAT (National AIDS Trust) asked all IRCs to respond to a 12 month “look back” survey of HIV care in their centre between July 2011 and June 2012 (see Appendix A).

The following IRCs responded to the survey (this list comprises all of the 10 main IRCs):

- Brook House
- Campsfield House
- Colnbrook
- Dover
- Dungavel
- Harmondsworth
- Haslar
- Morton Hall
- Tinsley House
- Yarl's Wood

Short-term holding centres were not surveyed.

When responding to the survey questions, IRCs were asked to give the absolute numbers of patients where possible, or an estimated proportion where not. For this reason some of the percentages given below are approximate. There was variation in the amount of data provided by IRCs: some could respond to each question while others reported that key data was ‘unretrievable’ or ‘not known’.

Clinics

Detainees who are living with diagnosed HIV will typically be in the care of an HIV clinic located near to the IRC (although some will continue to be in the care of an HIV clinic they were already attending in the community). HIV clinics local to the immigration removal centres were surveyed about this group of patients, over the same period covered by the IRC survey (see Appendix B). This survey was sent jointly from NAT and BHIVA (British HIV Association).

The following clinics responded to the survey:

- Crawley Sexual Health Clinic (treats patients from Brook and Tinsley House)
- GU Clinic, Oxford-Radcliffe Hospital (local to Campsfield, but reported that patients from the IRC had continued to see their existing clinic.)
- Tudor Wing Sexual Health Centre (treats patients from Colnbrook and Harmondsworth)

- The Gate Clinic (treats patients from Dover)
- Area Infection Unit, Monklands (local to Dungavel, but reported that patients from the IRC had continued to see their existing clinic)
- GU, St Mary's Portsmouth (treats patients from Haslar).
- Lindon House Clinic (local to Morton Hall).

Despite repeat approaches from NAT and extended deadlines, responses were not received from:

- GU Clinic, Bedford Hospital (local to Yarl's Wood)

Therefore, the clinic findings come from five clinics, reporting on patients from seven IRCs.

Additional case study evidence

As an additional source of evidence to triangulate the findings from the two surveys, NAT contacted Medical Justice about their caseload over the same time period. Medical Justice is a charity which arranges for doctors to provide independent medical advice to detainees. Their doctors saw 27 detainees with diagnosed HIV across the detention estate between July 2011 and June 2012.

Comparing the responses from IRCs and clinics

Overall, the data from IRCs and clinic is in agreement about the number of HIV patients seen and where they were treated. In four locations, the IRC and clinic identified the same number of patients from the IRC attending the local clinic. Crawley Sexual Health Clinic (Brook/Tinsley House) and the Lindon Clinic (Morton Hall) each reported one more referral to their services from the IRC than the centres had reported. There was a significant discrepancy at Heathrow, where the clinic reported seeing 14 fewer patients from Harmondsworth than the IRC had reported referring to them.

There was greater variation between IRC and clinic reports about the quality of care experienced by detainees living with HIV. For example, Brook and Tinsley House reported no treatment interruptions in any of their patients, while the Crawley Sexual Health Clinic (Brook/Tinsley House) said that interruption happened in 'most' cases.

Treatment interruption and other measures of quality of care will be discussed in greater detail below, however it is also worth noting that case study evidence from Medical Justice similarly included a much higher rate of interruption than that reported by the IRCs. It would of course be expected that this caseload would have a higher proportion of medical problems than the overall cohort of HIV positive detainees. But although Medical Justice only saw 27 of the 95 patients covered by the survey, they reported 12 cases of treatment interruption – this compares to a total of four cases reported by the IRCs.

FINDINGS

In the write-up of the findings, the responses from the IRCs will form the basis for the discussion, augmented by relevant findings from the clinic survey. The reasons for this decision are: all IRCs responded to the survey, whereas all relevant clinics did not; at some IRCs, patients were sent to their original clinic, which was not surveyed; and two of the clinics saw patients from more than one IRC, where these are co-located. Responses from clinics will be included as commentary on these primary findings, especially where the data is apparently contradictory.

Profile of patients

95 cases of detainees with HIV were identified in the 10 IRCs during the 12 month period. As there is movement between IRCs, this represents fewer than 95 individual detainees. Based on the number of transferred patients reported by IRCs, NAT estimates that there were between 60 and 70 individual patients moving through the detention estate during this time period. 67% of the reported cases were in the three largest IRCs (Harmondsworth, Yarl's Wood and Colnbrook). 67% were in the three largest IRCs.

There was a wide range of nationalities represented from Africa (62 cases) Asia (12), the Caribbean (7), Europe (4) and the Americas (4). The ratio of male to female patients was approximately 75:25. All the female patients were from Yarl's Wood (19) and Dungavel (2), where there were no clinic survey responses, so there are no clinic reports available about this group. No pregnancies were reported by any IRC or clinic. There were no children living with HIV reported by the IRCs or clinics.

In the three largest IRCs, the median times spent in detention were 21, 48 and 294 days. Across the estate, detention duration ranged between 1 day and 605 days. This indicates that the vast majority of patients with HIV were in detention for long enough to expect the healthcare teams to implement best practice around their treatment and care, as outlined in the NAT/BHIVA advice booklet.

Recommendation

As Yarl's Wood is the second largest IRC and the only IRC to house a significant number of woman detainees, it is vital that the local HIV clinic and other relevant healthcare services make available to NHS England accessible, accurate and disaggregateable data on its patients from the IRC.

Case study: Relying on an informal agreement for prompt ART access

The following report was made by an HIV clinical nurse specialist who was the informal contact for all urgent ART requests. It illustrates the risks in relying on an informal arrangement, rather than the formal protocol recommended in the NAT/BHIVA advice:

"He arrived at IRC on 17/3/12 and I was contacted at 1700hrs (Saturday out of working hours on work mobile) I advised IRC to ask patient to ask NOK [next of kin] to bring in ARVs. I telephoned IRC on 18/3/12 and they stated patient had refused to ask his NOK as unaware of HIV diagnosis. I contacted treatment centre on Monday 19th March and spoke to the CNS [clinical nurse specialist at original clinic] patient named. Patient not known at this centre, further telephone calls to IRC and Centre, patient used an alias. CNS sent supply to IRC which arrived 21/3/12. 6 days without treatment."

FINDINGS: RECEPTION

Urgent access to ART on arrival

In approximately 10% of cases the patient arrived at the IRC without a supply of their antiretroviral medication. Of this group, only one patient was reported to have received a supply of the necessary medication within 24 hours, as recommended in the NAT/BHIVA advice.

The NAT/BHIVA advice makes clear that a protocol should be in place between the IRC and their local clinic to ensure this prompt access to ART. Eight of the IRCs reported that they had a protocol for the management of newly-arrived patients with HIV (in two cases, the IRC stated they used the NAT/BHIVA advice as their protocol).

Two clinics described the processes they had in place with IRCs to ensure prompt access to ART. The Gate Clinic (Dover), which saw five patients in 2011/12, had an informal 'unwritten agreement' hinging on the role of the HIV clinical nurse specialist (CNS). The CNS received direct requests for ART from the IRC. The detailed comments provided by this CNS in response to the survey indicated that while the three patients who had urgently needed ART on arrival did receive their treatment, there were delays longer than 24 hours. In two cases the delay was caused by an initial delay in the IRC making the request for ART. In at least one case it was connected to the request being made 'out of hours'.

The other process described was a formal protocol, between the Tudor Wing Clinic and the two IRCs at Hillingdon, who reporting seeing 27 of the total 44 HIV positive detainees resident in the two IRCs – 20 from Harmondsworth and 7 from Colnbrook. The clinic noted that a further 13 patients were referred but were either released, removed or transferred before reporting for care, leaving four patients completely unaccounted for. The remaining patients may similarly have left the IRCs, even prior to referral. However, it is worth noting that the data sent from Harmondsworth was generally much poorer than from other IRCs. Harmondsworth and Colnbrook each has their own referral form which is faxed to the clinic. Under the protocol, all received faxes are reviewed and ART dispensed on the same day (including bank holidays). The IRC healthcare teams also have the direct numbers for the clinic administrator and HIV nursing team. Any request for HIV medication would be dealt with urgently, and scripts are written for patients even before they can be seen in clinic or the results of HIV confirmatory tests available.

The third clinic (Crawley), which sees patients from the Brook and Tinsley House IRCs, reported that there is not a protocol in place with the IRCs (though the responses they made to other questions suggests that this was not due to lack of engagement from the clinic.) Lindon House (Morton Hall) reported that two of their five patients had arrived at the IRC with very little ART and urgently needed to access a supply. However, there was not a formal protocol in place to guarantee this.

Recommendation

As Yarl's Wood is the second largest IRC and the only IRC to house a significant number of woman detainees, it is vital that the local HIV clinic and other relevant healthcare services make available to NHS England accessible, accurate and disaggregatable data on its patients from the IRC.

Offering tests to new arrivals

Around 5% of patients were diagnosed in the IRC. Seven of the IRCs reported they had a protocol for HIV testing. In one case this protocol was to not routinely offer tests. Another reported that they used NICE testing guidance for their protocol.

Recommendation

IRC healthcare teams should be required to have a formal, written protocol on HIV testing, in line with existing clinical and public health guidelines produced by BHIVA/ BASHH/BIS and NICE.

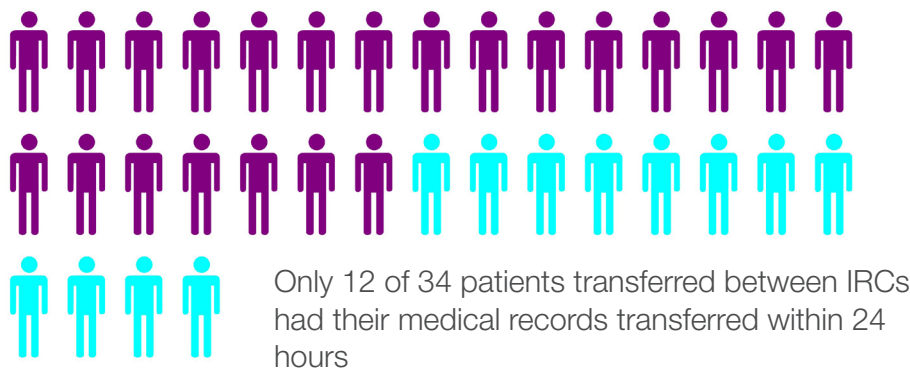
Receiving patients from another IRC

Of the 34 patients who were reported to have been transferred into the responding IRC from another IRC, only 12 had their medical records transferred within 24 hours as recommended by the NAT/BHIVA best practice advice.

No IRC healthcare team reported any cases of missed ART doses due to transfer from another IRC. The clinics did not report any treatment interruptions caused by transfer (however it is important to note that it was not always clear to clinics why interruptions had occurred).

Recommendation

When a patient is transferred between IRCs, the healthcare team at the sending IRC should be required to send medical records within 24 hours of the transfer.



Transfer of medical records between clinics

Where patients from IRCs are in the care of local clinics (not their existing clinic in the community), the NAT/BHIVA advice makes clear that timely transfer of medical records is essential. The local clinics treating detainees were asked how many such records were received within five working days. This information was not routinely collected by all the clinics, although there were five reports of records received within five days, and three cases of records received outside of this timeframe. Crawley Sexual Health Clinic (Brook/Tinsely House) said that they did not receive any forwarded records. Tudor Wing was not able to provide data on specific timeframes but reported that in most cases they did eventually receive a summary record, though the level of detail varied amongst sending clinics.

Recommendation

Clinics who are aware that a patient has been taken into immigration detention should promptly forward medical records to the new treating clinician. However in many cases it will be necessary for IRC healthcare teams to notify the clinic of their patient's whereabouts and to ask for the transfer to be made.



FINDINGS: TREATMENT AND CARE

Access to medication

Most IRCs reported that patients were able to hold their own medication, as is recommended in the NAT/BHIVA advice. There were only three cases reported where the detainee had been given their medication dose by dose. The survey did not ask the reason for this approach, but it may have been following an individual risk assessment.

Tudor Wing Clinic (Harmondsworth/Colnbrook) and The Gate Clinic (Dover) reported that they instruct IRC healthcare teams to allow patients to hold their medication themselves to reduce the likelihood of treatment interruption.

Recommendation

HIV positive detainees should be allowed to hold their ART medication, unless contra-indicated by an individual risk assessment.

Treatment interruption while in detention

Based on the IRC reports, at least four patients missed doses of ART while in detention (in addition to those missed due to arriving at the IRC without ART). This was between one and two doses, depending on the case. Yarl's Wood stated they could not report how many patients had missed doses, due to their policy of allowing patients to hold their own medication. This suggests that they would only be aware of treatment interruption in cases where the patient had completely run out of their medication, and that the healthcare team is not regularly checking how detainees with HIV are managing their treatment. Harmondsworth reported there were cases of interruption, but that they were not able to provide any details.

Although the clinic reports represent only six IRCs (excluding one of the largest, Yarl's Wood), their responses indicate that more than four patients experienced interruption. Tudor Wing saw three interruptions, The Gate Clinic (Dover) saw two, Lindon House (Morton Hall) one, and the Crawley Sexual Health Clinic (Brook/Tinsley House) said that "patients [are] often left in the IRC until they have no/ very few tablets, then [the IRC healthcare team] contact the clinic urgently. In some cases patients were left to run out of ARTs without the clinic being contacted". The reporting clinician also stated that "most patients experience treatment interruption. This leads to failure of treatment for some of them". The four clinics said that they would notify the IRC healthcare team about any such interruptions. As noted above, Medical Justice reported seeing 12 cases of treatment interruption during the time-period reported.

Recommendation

While detainees should hold their medication where possible, IRC healthcare teams still have a responsibility to provide support with adherence to all detainees who are taking ART, including making regular checks on their physical and mental health and wellbeing.

Recommendation

The clinical protocol between IRC healthcare teams and local clinics should include a reciprocal agreement to notify the other party about any treatment interruption experienced by a patient.

Attendance at clinic appointments

IRC responses indicated that at least five patients missed medical appointments while in detention. Reasons given were: an emergency in the centre; patient refusal to attend; cancellation of the appointment by the hospital; and transport failures. However, Tudor Wing Clinic alone recorded 18 'did not attends' (DNAs) from Harmondsworth and Colnbrook IRCs and stated that there is a "very high DNA rate for scheduled appointments" from the IRCs. Crawley Sexual Health Clinic stated that missing appointments was "the norm" for patients from Brook and Tinsley IRCs. Lindon House (Morton Hall) had two patients who failed to attend. In one case, no reason was given but the clinic subsequently learned that the patient had been removed from the UK. In the other case, the IRC told the clinic that the patient had refused to leave their room.

Four IRCs specified that medical appointments would be considered a priority for transport bookings. Another stated that if the patient needed access to ART this would be considered a priority for booking transport.

Recommendation

Attendance at HIV clinical appointments must always be considered a priority for transport bookings.

Use of restraints at clinic appointments

Healthcare teams were also asked about the protocols they used on transporting patients to medical appointments. The NAT/BHIVA advice makes it clear that patients should not be handcuffed or restrained in any way while seeing their clinician, and should not be accompanied by a security guard into the consulting room. Tudor Wing Clinic reported that Home Office recommendations also support this advice. However, Dover and Haslar IRCs stated that patients are routinely handcuffed when attending medical appointments (it was not clear whether these were removed during the consultation, as outlined in the NAT/BHIVA best practice). Brook House, Colnbrook, Tinsley House and Yarl's Wood said that restraints would be used based on a risk assessment which their security provider would conduct. Colnbrook did note that the handcuffs would be removed for the consultation and the patient would be able to see the clinician privately.

When asked about restraints, Crawley Sexual Health Clinic (Brook/Tinsley House), Tudor Wing Clinic (Harmondsworth/Colnbrook), Lindon House (Morton Hall) and The Gate Clinic (Dover) reported that use of handcuffs was very common, as was patients being accompanied by sometimes more than one security officer during their clinic visit. All made efforts to have handcuffs removed and security officers excluded from the consulting room when the patient was with the clinician. The Gate Clinic had succeeded in this point. Crawley Sexual Health Clinic said that they were asked by security staff to conduct all consultations and tests with the patient in restraints (despite being on the fifth floor of the hospital building). Lindon House said they usually used a 'long chain' so that security guards would allow patients to see the consultant in private. Tudor Wing Clinic saw 20 patients arrive in restraints from Harmondsworth (they were kept in these restraints while in the waiting room), whereas patients from Colnbrook were not restrained but were escorted into the clinic by security guards. Clinicians at the Tudor Clinic stated that they would refuse to see any patients who was in restraints or accompanied into the consulting room by a security officer.

Recommendation

Detainees who are attending HIV clinic appointments should not routinely be restrained and the presence of security escorts should be proportionate and based on an individual risk assessment. Patients should never be handcuffed during consultations and tests and should not be accompanied into the consulting room by security escorts.

Other care issues

The Tudor Wing Clinic expressed particular concern with the mental health care provided by the IRCs, stating that in both Harmondsworth and Colnbrook there is "no real support for patients with mild, moderate or severe mental health illness. It has proved difficult even to get a formal assessment of patients with symptoms suggesting mental health issues, and we have also had difficulty passing on concerns and getting assessments for patients expressing suicidal ideation."

Supporting the psychological wellbeing of detainees is an important goal in its own right. It is also crucial for ensuring the physical health of people living with HIV, as poor mental health is associated with poorer adherence and therefore treatment outcomes.



The reporting clinician from the Crawley Sexual Health Clinic (Brook/Tinsley House) also expressed serious concern for his patients' wellbeing while in the IRCs:

“We observed that detainees' rights of normal medical care are abused and neglected in these centres (IRCs). We observed inhumane treatment and humiliation. This is a widespread observation by our colleagues in similar clinics. Urgent action needs to be done. They do not acknowledge BHIVA guidelines and national standards.”

Recommendation

Detainees living with HIV should be screened and treated for psychological health needs in line with the agreed Standards for psychological support for adults living with HIV.

Case study: Comparing Colnbrook and Harmondsworth IRCs

Although Colnbrook and Harmondsworth IRCs are co-located in Hillingdon and both send patients to the Tudor Wing Clinic, the clinic reported significant differences in clinical attendance from patients at the two IRCs. They noted that healthcare is provided by two different providers at each IRC, and that at Harmondsworth there had been significant change in provision over a short period of time (which the consultant believed had destabilised healthcare provision).

The reporting clinician stated that “there has been no continuity of staff working in the medical centre, and records seem to be very poorly kept, with no computer data-base. There have also been several significant drug errors during this time period, with patients' medications being lost, or given to another patient. Overall Harmondsworth compares very poorly to Colnbrook, with clear differences in how patients are treated, the overall care they receive, over-officious security, and a poor professional working relationship with the medical team at the Tudor Centre”.

From Harmondsworth, 15 patients missed one or more appointments and four patients attended all that were scheduled. From Colnbrook, three patients missed one or more appointments and four patients attended all of their scheduled appointments. The reasons for missed appointments included: not enough security staff available to transfer patients; only one patient being allowed out from the IRC at any time; IRC staff being unable to find the patient in the IRC; and the patient being transferred, released or deported without notifying the clinic.

The clinic reported that it was “very difficult and time consuming trying to get through to the health centre at Harmondsworth to chase up DNAs and reschedule appointments. [It is] far harder to sort out security to bring patients to clinic at Harmondsworth than it is for Colnbrook.”

FINDINGS: REMOVAL OR RELEASE

In around 53% of cases the patient was removed from the UK, meaning that in nearly half of cases the patient continued to need HIV care services from the NHS after leaving the IRC. On leaving the IRC around 32% of patients were returned to the community and 7% were transferred to another IRC.

Only at Harmondsworth did removals significantly outnumber release or transfer (25 of 34 HIV positive detainees were removed from the UK).

Recommendation

NHS England should satisfy itself that there are no gaps in continuity of care for those people living with HIV who leave detention and return to community in the UK.

Provision of ART

There were significant gaps in the data provided by IRCs about preparation for patients who were removed, released or transferred. The limited information that was provided does show that IRCs are not following NAT/BHIVA advice to always provide at least a three month supply of ART to patients with HIV who are either being removed or released to the community.

Five IRCs (Brook House, Campsfield, Colnbrook, Dover, Tinsley House) reported that all patients with HIV who were removed from the UK left with at least a three month supply. From IRC reports, at least six patients left with less than three months' worth, ranging between 11 and 80 days' supply. Harmondsworth said that it could not provide any information about how much ART was provided to the 25 HIV positive detainees who were removed from the UK. This gap in the data means we cannot test the suggestion previously made by IRC healthcare staff that given the proximity of Harmondsworth to Heathrow Airport, the local PCT would refuse to accept the cost burden of ART for detainees who were being removed. (This assertion is not supported by the evidence provided by the local clinic, who seemed very willing to prepare patients for onwards travel).

Preparation for removal was a key area where responses to the clinic survey helped fill in gaps in the data. The Tudor Wing Clinic reported that of the patients they saw, eight patients left with three months' ART, two patients left with just over two months' ART supply, one patient had just less than two months, and a further two patients had around one month of treatment. This accounts for 15 of the 17 patients which the Tudor Wing Centre knew had been removed from the UK during this time period. This group of 17 represents just over half of the total 30 people living with HIV who were removed from either Harmondsworth (25 patients) or Colnbrook (5 patients) during this period. Tudor Wing Centre noted that while they were 'usually informed' about upcoming removals, they rarely were notified if a patient was going to be transferred or released into the community.

Crawley Sexual Health Clinic stated that they were not contacted by Brook or Tinsley House about

the removal or transfer of any patients. The reporting clinician was only aware of one patient who was removed from the UK, whereas there were five removals from Brook and Tinsley House during this period. It is possible that some of these detainees were still attending their existing clinic and may have been provided ART by clinicians there.

Lindon House (Morton Hall) reported that of the three patients they saw removed, none had the three months' supply. One held 30 days' worth, and the other two less than this. The clinic noted that this was because they did not have warning of imminent removals.

There were also gaps in the information provided by IRCs around the amount of ART normally provided to detainees who were being released to the community. The NAT/BHIVA advice states that patients should be given "adequate medication" in preparation for leaving. One IRC (Colnbrook) stated that the patient would leave with however much ART they currently held. A similar approach seems to be adopted by other IRCs, with the amount of ART held by released detainees ranging from 15 to 92 days. Only Lindon House had any data about people who had been released, and could report one case of a patient who did leave with three months' medication. In general, the clinics reported little or no notice that a patient was going to be released.

Recommendations

All people living with HIV who are being removed from the UK should be provided with at least a three months' supply of ART to support unbroken access to medication and continuity of care.

All people living with HIV who are being released to the community should be provided with an adequate supply of ART to support unbroken access to medication and continuity of care.

Case study: The Gate Clinic (Dover) – patient removal

The reporting clinician said: "On two occasions I was telephoned once the patient had been moved. On the other [three] occasions I phoned them to find out the whereabouts. Often the staff don't know, they say he had a[n] RD, which may [either] be a release date or a flight out."

Clinical notes and 'fit to fly' assessments

IRCs reported that the majority of patients who were removed from the UK left with a letter from their treating clinician. Only two patients released to the community were reported to have been given letters for onwards referral. In one case the healthcare team stated that patients were "returned to own addresses [and] advised to liaise with own GUM clinics".

A range of practices were outlined around the provision of 'fit to fly' letters. Some are routinely prepared in house (e.g. by a medical officer), others are sought from the GP or HIV clinic local to the IRC.

The clinics did not provide much data on these points, beyond what has already been noted about the lack of notification of patient transfer and release. The Tudor Wing Centre indicated that it had provided letters for patients who were being removed, but not for those who were being released.

Recommendations

All people living with HIV who are being removed from the UK or released to the community should be provided with a letter from their treating clinician to support unbroken access to medication and continuity of care.

IRC healthcare teams should be required to notify clinical care teams of any planned release, removal or transfer of a patient as part of a pre release/removal/transfer checklist. It should not be possible for a detainee to leave the IRC without these preparations having been made.

IRC healthcare teams should be provided with clear guidance on assessing whether an HIV positive detainee is 'fit to fly', including a requirement to ask the clinical opinion of their HIV consultant or specialist nurse.

Record keeping by IRCs

As noted in several sections above, not all IRC healthcare teams were able to provide data on some of the basic questions about treatment and care of HIV positive detainees. This was especially pronounced at Harmondsworth, who stated that the data was 'not retrievable' for several key questions including preparation for removal and release.

Recommendation

All providers of healthcare in IRCs must be required to keep a basic set of records about the treatment of detainees, kept in a retrievable format for seven years from the time that the patient leaves the IRC. This should include information on testing (if applicable), ART prescriptions and access, medical appointments made and kept, and preparations for release, transfer or removal.

Case study: The Tudor Wing Clinic – clinical preparation for removal

The reporting clinician said: “[We had one] patient deported despite a letter requesting that he be kept in the country until his HIV treatment could be changed; he was on an inappropriate regimen, with the risk of significant drug interactions. A treatment history from his original clinic was needed before appropriate changes could be made to his regime. He left with less than one month of medications, no letter, and no information about treatment centres in his destination country. The agreement we have with both IRCs is that a patient is to be kept if a doctor’s letter has been sent stating that their medical condition is not stable. However when this letter was sent for this patient it was ignored.”



CONCLUSION

People living with HIV who are detained in IRCs continue to have their treatment and care interrupted.

The NAT/BHIVA best practice advice has had an impact and some healthcare teams have implemented elements of best practice in areas including:

- Allowing patients to hold their own medication where possible
- Establishing HIV testing protocols
- Prioritising medical appointments within transport protocols.

While there is some good practice, the following elements of accepted best practice for HIV care in IRCs are not being consistently met across the estate:

- Access to antiretroviral treatment within 24 hours of arrival
- Provision of at least 3 months' ART prior to being removed
- Prompt transfer of medical notes when patients are transferred between IRCs
- Notifying treating clinicians prior to patients being transferred or released to the community.
- Letter from treating clinician provided to those released to the community, to facilitate onwards treatment and care.

However, it is certainly not the case that all IRCs are failing on all these counts. Looking at the responses in the round, it appears that several IRC healthcare teams are providing care which is broadly in line with the NAT/BHIVA standards. But the gaps which do exist tend to be found in the larger IRCs, which are seeing a greater number of patients. It is not clear whether the volume of patients is a key contributing factor to this difference in quality of care. However, the case study of Colnbrook and Harmondsworth shows that there can be significant variation in quality of care between centres which share a location and a clinic. The evidence provided by the Tudor Wing Clinic clearly illustrated that patient experience may depend on which private company was providing the healthcare in the centre, as much as on other factors.

The inability of some IRCs to provide data in response to questions about the preparation of patients with HIV for removal, release and transfer is of particular concern. Harmondsworth, one of the largest IRCs, who treated around a third of the 95 patients identified, was unable to provide any data from the previous 12 months about how people living with HIV were prepared to leave their centre. This raises serious questions about the accountability of healthcare teams in the detention estate.

A full list of our recommendations is on pages 4 and 5 of this report.

APPENDIX A

HIV care in detention – Survey for IRC healthcare teams

Please send your responses to sarah.radcliffe@nat.org.uk by 7 November 2012

Please respond to all questions, using additional sheets if needed.

Please provide answers to the following questions, with reference to your centre's healthcare records from 1 July 2011 to 30 June 2012.

1. How many HIV positive people stayed for any period in your centre over this twelve-month period?

The remainder of this survey will ask about this group of HIV positive patients.

A. Characteristics of patients

2. Please list all the nationalities represented amongst your HIV positive patients, and the number of patients from each nation.

3. How many of these patients were

Male:

Female:

Number of patients for whom the above information is not known:

4. How many of these patients were pregnant while in your centre?

5. How many of these patients were children (under the age of 18)?

6. How long did these patients stay in the centre? Please provide the minimum, maximum and median stay for this group of patients;

OR

simply list the duration for each patient, if known.

B. Reception

7. Does your centre have a clinical protocol for the management of the newly-arrived patients with HIV, to ensure access to antiretroviral treatment?

If yes, please give details.

8. Of the total number of HIV positive patients at your centre, state the number* who:
Were diagnosed while in the centre:
Disclosed their HIV positive during routine healthcare screening held within 24 hours of arrival:
Disclosed their HIV positive status at some other point:
Number of patients for whom the above information is not known:
*where the number has not been recorded, please state the approximate proportion and state that this is approximate: e.g. 'approx 20%'
9. How many HIV positive patients arriving in your centre did not need access to antiretroviral medication (i.e. not as yet clinically recommended in their case)?
10. Of HIV positive patients who do need antiretroviral medication, how many arrived at your centre:
With antiretroviral treatment:
Without antiretroviral treatment:
Number of patients for whom the above information is not known:
11. Of the patients who need antiretroviral medication but arrived without it, how many were given access to the medication they needed:
Within 24 hours of their HIV status becoming known:
More than 24 hours but less than 48 hours after their HIV status became known:
More than 48 hours after their HIV status became known:
Number of patients for whom the above information is not known:
12. Did you receive any HIV positive patients who had been transferred from another Immigration Removal Centre?
Number of patients transferred into your centre:
Number of cases where the sending centre forwarded the patient's medical records within 24 hours of the transfer:
Number of patients where you were aware of an interruption to access to antiretroviral medication as a result of transfer (and number of doses missed):
Number of patients for whom the above information is not known:
13. Does your centre have a protocol or guidelines for offering HIV tests to detainees? If so, please give details.

C. Detention

14. How many patients who were taking ARVs:

Held these themselves:

Were given these dose by dose:

Number of patients for whom the above information is not known:

If you have a protocol or guidance for when patients will be allowed to hold their own ARVs, please give details:

15. Are you aware of any occasions on which a patient missed a dose of ARVs?

Number of patients who missed at least one dose:

Number of doses missed for each patient (please state number per occasion, separated by a comma, if there was more than one occasion on which patients missed ARVs):

16. How many HIV positive patients attended appointments with?

The local HIV clinic:

Their existing clinic:

17. Are you aware of any occasions on which patients missed medical appointments?

Number of patients who missed at least one appointment:

Number of occasions for each patient:

Reason/s for missed appointments:

18. Does your centre have a protocol or guidance on transporting patients to medical appointments?

If so, please detail what this covers (e.g. how to book and prioritise transport, use of handcuffs and restraints, etc).

D. Removal, release or transfer

19. How many HIV positive patients left your centre in order to be*:

Removed from the UK:

Released to the community:

Transferred to another IRC:

No information provided by UKBA about their destination:

Number of patients for whom the above information is not known:

*Based on what you were told by UKBA prior to the patient leaving

20. Of patients who were leaving to be removed from the UK, how many left with:

At least a three month's supply of ARVs:

A supply of ARVs of less than three months (please specify number of days of medication held by each applicable patient, separated by commas):

A letter from their clinician with relevant treatment information:

Information about HIV services at destination:

Confirmation from a clinician that they were 'fit to fly':

Number of patients for whom the above information is not known:

21. Of patients who were leaving to be released to the community how many left with:

A supply of ARVs (please specify number of days held for each patient):

A letter from their clinician with relevant treatment information:

Advanced contact made with a receiving clinician about their ongoing care:

Number of patients for whom the above information is not known:

22. Does your centre have a medical protocol or guidance around preparing patients with HIV to leave for removal, release or transfer? If so, please provide details.

23. Any additional comments or information.

Thank you, this is the end of the survey.

Please email your responses to sarah.radcliffe@nat.org.uk by 5pm, 7 November 2012

APPENDIX B

HIV care in detention – survey for clinics local to IRCs

Please respond to all questions, using additional sheets if needed, by 30 June 2013.

For more information, or an electronic copy of the form, email sarah.radcliffe@nat.org.uk

Please provide answers to the following questions, with reference to any HIV positive patients you had who were resident in the immigration removal centre, between 1 July 2011 and 30 June 2012.

Please give as much detail

as possible to each question, whilst keeping patients anonymous.

1. How many HIV positive patients from the IRC were in your care during this 12 month period?

The remainder of this questionnaire will ask about this patient group.

2. Please list all the nationalities represented amongst your HIV positive patients, and the number of patients from each nation.

3. How many of these patients were

a) Male:

b) Female:

4. How many of these patients were pregnant?

5. How many of these patients were children (under the age of 18)?

6. How many of these patients had been diagnosed with HIV during their stay in the IRC?

7. On how many occasions was your clinic contacted for urgent access to antiretroviral treatment for a patient resident in the IRC?

Please provide as much detail as possible about each case- in particular, if you are aware that the patient missed any doses while waiting for access.

8. Does your clinic have an agreed protocol with the IRC for urgent access to antiretroviral treatment?

If so please provide details.

9. For patients who had previously been treated in another clinic, in how many cases did medical notes arrive:
- a) Within 5 working days
 - b) After 5 working days
 - c) No notes were transferred for the patient
 - d) No patients were transferred in.

10. Have you treated any patients from the IRC who were restrained (e.g. in handcuffs) when they arrived at the clinic and/or during their consultation?

Please provide as much detail as possible about each such case. In particular it would be helpful to know if patients who are brought in handcuffs have these removed for the duration of the consultation.

11. How many patients from the IRC have missed scheduled appointments at your clinic?

Please provide as much detail as possible about each such case, including any reasons you were given for missing the appointment.

12. Had any of the patients experienced a treatment interruption whilst resident in the IRC?

Please provide as much detail as possible about each such case, including any information they gave about the cause of the treatment interruption (e.g. lack of access to medication, time spent in 'segregation', adherence problems).

13. Would you contact the IRC healthcare team if you find that a patient has experience treatment interruption?

Please detail any relevant protocol or practice and any cases where you did this in the 12 month period covered.

14. To your knowledge, in the last 12 months how many HIV positive patients in your care left the IRC in order to:

- a) be removed from the UK:
- b) be released to the community:
- c) be transferred to another IRC:
- d) no information provided about their destination/ lost to follow-up

15. Of patients who were leaving to be removed from the UK, how many did you provide with:

- a) At least a three month's supply of ARVs:

b) Less than three month's supply of ARVs (please specify number of days given to each patient, separated by commas):

b) A letter for their future clinician with relevant treatment information:

16. Of patients who were leaving to be released to the community how many did you provide with:

a) A supply of ARVs (please specify number of days given to each patient, separated by commas):

b) A letter for their future clinician with relevant treatment information:

17. Of patients who were leaving to be transferred to another IRC, in how many cases did the IRC healthcare team notify your clinic prior to transfer?

Please provide as much detail as possible about the notification process and what information was given and sought.

18. Please provide any other information about your care of this patient group which you feel may be relevant.

Thank you, this is the end of the survey.

Please submit responses by 30 June 2013 to:

Sarah Radcliffe

NAT

New City Cloisters

196 Old Street

London EC1V 9FR

Or fill in the online form at <https://www.surveymonkey.com/s/IRCHIVCare>

NAT 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.



SHAPING ATTITUDES CHALLENGING INJUSTICE CHANGING LIVES

Our vision:

Our vision is a world in which people living with HIV are treated as equal citizens with respect, dignity and justice, are diagnosed early and receive the highest standards of care, and in which everyone knows how, and is able, to protect themselves and others from HIV infection.

Our strategic goals:

All our work is focused on achieving five strategic goals:

- effective HIV prevention in order to halt the spread of HIV
- early diagnosis of HIV through ethical, accessible and appropriate testing
- equitable access to treatment, care and support for people living with HIV
- enhanced understanding of the facts about HIV and living with HIV in the UK
- eradication of HIV-related stigma and discrimination.

WWW.NAT.ORG.UK

www.lifewithHIV.org.uk – a resource for HIV positive people

www.HIVaware.org.uk – what everyone should know about HIV

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