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Migration and HIV

Issues facing mobile populations accessing HIV treatment in Europe and the UK

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This presentation

1. **Background** on HIV and mobile populations
2. **Focus on** specific factors: access, stigma, and lived experience
3. **Suggest recommendations** for policy, healthcare, and research

Background

Terminology

- **Migrants**: people who move not because of a direct threat of persecution or death, but mainly to improve their lives by finding work, for education, family reunion, or other reasons. Unlike refugees (who cannot safely return home), migrants face no such impediment to return. If return home they will continue to receive the protection of their government (UNHCR).
- **Undocumented migrants** live in a country illegally (with no residence status). The hardest to reach community in public health.
- **Refugees**: people fleeing armed conflict or persecution, and protected under international law. (UNHCR)
- **Asylum seekers**: people (usually refugees) seeking asylum and whose request for sanctuary [in a receiving country] has yet to be processed. (UNHCR)
- For the NHS, an **overseas visitor** is not ordinarily resident in the UK and subject to 'visa control'. This does **not** include EEA nationals or someone with indefinite leave to remain. Overseas visitors from outside the EEA (or from the EEA but not resident in the UK at the time they seek hospital treatment) may be charged. (NAT 2016)

HIV and mobile populations (Europe)

- In the EU, migrants from high endemic countries are **disproportionately affected** by HIV. (Eurostat, 2013)
- Nearly **four out of ten people with HIV** in the European Economic Area (EU + Iceland and Norway) is a migrant.
- Between 2007 and 2012, 60,446 out of 156,817 new cases of HIV **(38%)** were in people who were not native to the country where they were diagnosed.
- Nearly all HIV-positive migrants are **concentrated in the richer countries** of western Europe, with only 5% of diagnoses in central Europe and 1% in eastern Europe being migrants.

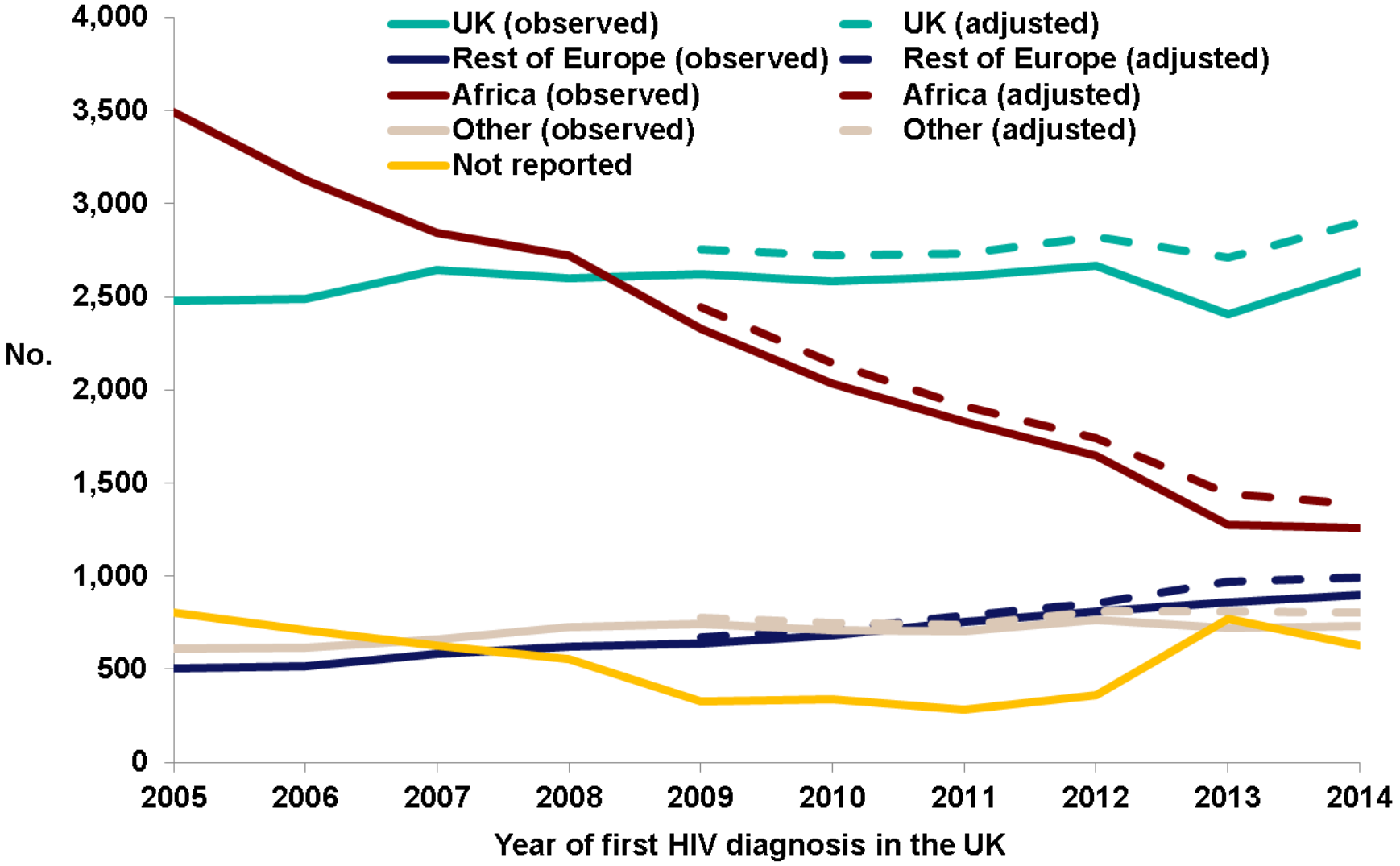
HIV and mobile populations (UK)

- 57% of newly diagnosed people are **born abroad**.
- Evidence suggests significant proportion of HIV acquisition in this group occurs **after arrival in the UK.** (Deblonde *et al*, 2015)
- 20% of newly diagnosed people are **born in Africa** (this has decreased from 34% in 2010).
- 15% are born in the **rest of Europe**.
- 24% **MSM** and 41% **heterosexual diagnoses** are acquired outside of UK.
- 19 of 29 **children diagnosed with HIV** in the UK in 2014 were born outside of the UK.

[Source: NAT and Public Health England]

Public Health England

Number of people newly diagnosed with HIV by world region of birth: United Kingdom, 2005 - 2014



Values are adjusted for missing country of birth where stated

Asylum seekers are particularly vulnerable

- May have **been triggered** by detention, torture, rape, sexual assault, and harassment, or they may have been exposed to high-risk situations for HIV.
- In the UK the **experience of being an asylum seeker** may involve poor living conditions, malnutrition, lack of protection and depression, all leaving them vulnerable to sexual exploitation.
- **Female asylum seekers** are the most seriously affected.
- Following the recommendations of the European Union Agency for Fundamental Rights, **ensuring access to HIV-care for all sub-populations**, including undocumented migrants, would **fulfill the human rights** of those populations and strengthen the control of HIV incidence among those not currently able to access HIV care. (Deblonde *et al*, 2015)

Our challenge…

- Migrants and refugees **do not pose an additional health security threat to the host communities**. Screening can be an effective public health instrument but should be non-discriminatory, non-stigmatising and carried out to the benefit of the individual and the public; it should also be linked to access to treatment, care and support. **It should ultimately serve the true needs of the refugees and other migrants.** (WHO Europe, 2015)
- Many migrants living with HIV in the UK **already encounter difficulties accessing treatment, care and support**. Undocumented migrants in particular find it difficult to register with a local GP and are often required to prove their identity (and don't understand NHS entitlement rules or how to apply for treatment). (NAT, 2015)
- **In focus:** asylum seekers require information and support when seeking access; they may **go to the wrong place** (for example specialised hospital care instead of a local GP) which can lead to incurring charges [and subsequent lack of access].

Focus: access, stigma, and lived experience

Access to services in Europe

- A significant number of EU/EEA countries do not provide antiretroviral treatment to **undocumented migrants**. (Deblonde *et al*, 2015)
- Migrants are **confronted with multiple risk factors** that shape patterns of HIV susceptibility and vulnerability, which simultaneously affect HIV transmission. **Undocumented migrants incur additional risks** for contracting HIV due to limited access to adequate health care services, protection and justice, alongside insecure housing and employment conditions. (Deblonde *et al*, 2015)
- The quality of **mental health and perinatal services** for refugees and asylum seekers differs markedly across the region. (WHO Europe, 2015)

Access to services in Europe

- Impact of **austerity** in some countries (such as Greece and Spain) has excluded universal access for migrants. (NAM, 2015)
- The UK has **relatively good provision of care**, but "scores badly on its harsh treatment of the relatively small number of migrants with serious health problems who are forcibly removed." (NAM, 2015)
- One small (but interesting) study suggests **higher mortality of migrants** in countries with restrictive immigration policies and social climate due to long-term stress and poor healthcare. (Ikraz *et al*, 2015)

TRANSFORMING THE UK'S RESPONSE TO HIV

NAT

Some NHS services are ALWAYS free

- HIV and sexual health services
- Primary Care*
- Treatment for communicable diseases
- Treatment provided in A&E*

*until further Government announcements

Who is chargeable in the context of immigration?

- Those 'ordinarily resident' in the UK should not be charged for using any NHS services
    - UK nationals, EEA nationals and people with indefinite leave to remain
- Those subject to visa control **cannot** be considered ordinarily resident for NHS access purposes
    - But can get care if they pay the surcharge

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Who has to pay? (2014)

No charge

- UK nationals
- EEA nationals
- ILR
- Non-EEA nationals who have paid the health surcharge

Subject to visitors charges

- Unpaid/expired health surcharge
- Undocumented migrants
- Refused asylum seekers with no Home Office support
- Visitor visas
- Visa overstayers
- UK/EEA nationals not ordinarily resident

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Exemptions

- Refugees and Asylum seekers
- Refused asylum seekers receiving Home office support
- Children looked after by a Local Authority
- Victims of human trafficking
- Prisoners
- Those in immigration detention
- Reciprocal agreements with other nations
- Compulsory treatment under court order/ detained in NHS hospital/ deprived of liberty

Who has to pay?

How NHS overseas visitor charges apply to migrants and asylum seekers in England

The National Health Service (NHS) is free to anyone who is 'ordinarily resident'[1]. Those who are not ordinarily resident in the UK can be charged for using some NHS services.

There are exemptions from NHS charges for specific types of treatment and also specific groups of people. In addition, there are rules to make sure that no one is denied life-saving and urgent treatment (but some patients will still be asked to pay for this treatment).

This is a factsheet about the NHS in England. However, HIV and sexual health testing, treatment and care is available free of charge from the NHS throughout the UK, regardless of immigration status[2].

Types of treatment which are always free

NHS overseas visitors charges apply to most secondary care (hospital services) – but some NHS services are always free:

- HIV and sexual health services are freely available to all, regardless of immigration or residency status. This includes testing, seeing a doctor and any medicine you may need for your HIV or other sexually transmitted infection.
- Primary care services (e.g. seeing a GP doctor or nurse) in England are not subject to NHS overseas visitor charging rules. The Government has talked about introducing charging in primary care but this has **not** been implemented. This means primary care is free to all.
- Treatment for other communicable diseases, including TB, is freely available, regardless of immigration or residency status.
- Treatment provided in A&E (accident and emergency) is free. This doesn't include any treat ment as an inpatient (e.g. if you get admitted to hospital overnight or are sent for surgery straight from A&E) – only the treatment you got directly in A&E is exempt from charges.

Understanding who is 'ordinarily resident'

People who are 'ordinarily resident' in the UK should not be charged for using any NHS services. Under the Immigration Act 2014, anyone who is subject to visa control **cannot** be considered ordinarily resident for the purposes of NHS access. This means that **only** UK nationals, EEA nationals and people with indefinite leave to remain (ILR, sometimes called 'permanent residence') can be considered ordinarily resident.

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[1] Most people who use the NHS are asked to pay a small 'prescription charge' for any medication they need, as well as to contribute to the cost of NHS dental care.

[2] In Scotland and Northern Ireland, HIV is exempt from charges under the law; in Wales this happens in practice. Information on charging in Scotland: http://www.show.scot.nhs.uk/overseas_visitors.php ; Wales: http://gov.wales/topics/health/publications/health/guidance/implementing/?lang=en ; Northern Ireland: http://www.nidirect.gov.uk/living-in-northern-ireland/health. UK wide guide to charges: https://www.citizensadvice.org.uk/healthcare/help-with-health-costs/nhs-charges-for-people-from-abroad/

Country examples

Mobile populations and HIV





Country examples: Portugal

The biggest barrier facing migrant population **relates to culture**. They live together in a community and most of the time it is hard to get privacy for going to the hospital, to secure the confidentiality. There are also problems understanding the language [of healthcare].

Country examples: Spain

- The origin of the immigrants coming into hospital and the community is mostly **South America** (e.g. Venezuela, Brazil, or Columbia), with smaller numbers from Eastern Europe and Asia.
- Access to HIV treatment for non-residents can be difficult – it depends on the 'autonomous community' (region), Generally, foreigners living with HIV who are **resident** in Spain can receive care and treatment.
- Depending on the country of origin, **stigma** is strongest against women, MSM, and TG.
- **Religion** also determines and accompanies these patients who cannot share their situation. There is also social isolation, loneliness, and employment problems.
- **Drug use** enables them to 'escape' from their problems.

Country examples: Finland

- Public health care in Finland is residence-based. You need to be seen as living permanently here (irrespective of the person's nationality). This creates problems because **Finland is very strict about being permanent**, and residence status is not easy [to acquire].
- In theory, without this you have to pay the **full amount of treatment which runs quickly into thousands of euros**. So, in practice it is impossible for most patients. However, at our clinic **we try to find a way around this** and so far we have not left anybody without treatment.
- Asylum seekers have **access to acute treatment only** but this includes all HIV treatment and medication. **We start treatment** even if he/she doesn't have confirmation they will be able to remain (a process that can take months or years).
- On the whole, patients are motivated and come to our clinic willingly - it may be the **only place where they can speak openly about their status**. This is especially true for migrants and asylum seekers. **HIV stigma** can be very strong in her/his culture. You can be killed or jailed in your own country. **It's difficult to trust anybody**.
- They **really need help with 'the system**' which is often complicated to understand. They feel uncertain, fearful, and lonely.
- **Sometimes they tell us** about abuse, exploitation, and poverty. They can have religious beliefs – that God takes care of health, and medication is poison. Some believe in the power of traditional medicine.
- If they cannot stay in Finland and need medication, but the home country has no medication available, **the clinic might write a letter about their health status** to advocate for the person to stay. Sometimes we just [have to] let them go. It depends on the situation in their home country.

Country examples: Belgium

- Stigma and discrimination in healthcare settings continue to **have a pernicious effect** on the health-seeking behaviour of [migrants] living with HIV in Belgium.
- There seems **limited HIV knowledge**. Lack of awareness among healthcare providers is a major cause of stigma.
- Stigma and discrimination in healthcare settings are exacerbated by **institutional labelling** that hinders efforts [for support] and HIV prevention.
- **Consequences** include**:**
  - Emotional **stress**
  - **Inconsistent** health care seeking behaviour
  - **Non-disclosure** to non-HIV healthcare providers

[Source: Arrey *et al*, 2016]

Country Examples: UK

Stigma Index: Migrants and HIV

- **Deprivation** was a key theme. Most participants reported that they were unemployed. A fifth reported that they had experienced **episodes of food insufficiency** in the past year.
- **Control of information about a positive diagnosis** is critically managed. More than half the participants reported that they had personally disclosed to family members. Ten percent reported a **breach in confidence** where members of their families had been informed about their HIV status without consent.
- **Felt stigma was common**. Over half of the participants reported feeling ashamed living with HIV. This **increased anxieties** about personal safety, particularly amongst men. **Male participants were three times more fearful** than women of being insulted, physically harassed, and/or assaulted
- **Personal strategies** for safeguarding against the negative impact of stigma included avoiding social gatherings, friends, intimacy, clinical and social care settings.
- Most participants were **unaware of policies and declarations** that protected them as persons living with HIV. Although some participants believed that their human rights had been violated, they were unlikely to seek legal redress.

[Source: Chinoyou *et al*, 2014]

Stressors for migrants in the UK

- **Pre-migratory** – difficulties in the home country prior to leaving.
- **Post migratory** – fears of being sent home, problems accessing healthcare, separation from the family, difficult interviews with immigration officials, detention, and unemployment.
- These stressors are **compounding**, and **in addition** to the stress of living with HIV, and a differing understanding of how the UK health system works.
- Contrary to populist media narratives there is **no evidence of health tourism.** Data suggest an average of 5 years between arrival in the UK and HIV diagnosis (Health Protection Agency, 2012).

Resilience

Responses to stressors

- Reported by Orton (2012)
  - There are differing levels of **resilience** in asylum seekers living with HIV as they confront stressors.
  - **Primary stressors**, such as leaving behind social support, HIV stigma, and being 'trapped' in the asylum system (where they are unable to influence the outcome of their case) leads to tapping into personal resources such as drawing on a personal faith, seeking support from HIV care providers, and 'staying busy'.
  - Asylum seekers living with HIV in the UK show **immense resilience**. However, their isolation means they are **often unable to deal with their treatment in the asylum system**, with negative consequences for their perceived health and wellbeing.
  - HIV voluntary service providers, and NHS staff, **can make a difference by taking a holistic approach** to the care of those with health conditions and complex social care needs. But they will **be limited by the structures within which they work.**

Treatment vacuum?

Study: Immigration Removal Centres (NAT, 2013)

- **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.
- 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.

Recommendations

The challenge…

*Emphasis should be **placed on human rights** and non-discrimination in meeting the health needs of refugees and migrants.*

***Health system capacity** may need strengthening, especially in the frontline Member States, to provide migrant-sensitive health care.*

***Sustainable models of health care financing** to cover migrant health needs should be identified. In this respect, migrant health needs should be included in local, regional, and global funding mechanisms. (WHO Europe, 2015)*

Recommendations

1. Policy

- Universal primary care systems are vital for individual and public health. **Ensuring asylum seekers gain access should be a prime aim of government policy.** Health systems should be culturally adept and appreciative of the lived experience of illness and disease. (Hodgson, 2014)
- Adjustment of **health care provision** to improve service utilisation, for example longer appointment times, transport provision. (WHO Europe, 2015)
- Develop a **model for offering HIV testing for mobile populations** (for example in asylum centres), and ensure consistency of information (with roadmaps for accessing the system) for **all** migrants.
- **For dispersal**, ensure guidelines are applied: 'Dispersal process for asylum seekers living with HIV' (NAT, 2014), and evaluate the impact on people living with HIV.
- How will 'austerity' impact on the lives of migrants and asylum seekers and the asylum support allowance? We **should advocate for health policies** protecting the rights of mobile populations to treatment and care.

Recommendations

2. Healthcare

- Mobile populations are **especially vulnerable** to HIV, social, and personal threats. Orthodox public health interventions and healthcare should apply as everywhere else. In 'hot spots' (such as IRCs) and elsewhere in the system we should **maintain unbroken access to ARV** for an HIV positive detainee who arrives with medication.
- The **experience of stigma is universal** – as argued previously (by me!) stigma is rooted in mechanisms shared by all cultures and communities. How can we address this?
- Mobile populations face particular **stressors**, and adapt through **resilience**. For migrants, perhaps the worst thing is **being alone** – away from their country, extended family, and culture. **Ensuring access to competent health care** will ameliorate at least one of their concerns.

Recommendations

3. Research priorities

- Improving the collection of quality of data, prioritising the mapping of **good practices** and encouraging research to underpin the development of **minimum standards in health and social care of mobile populations**.
- We need to establish what the **long term impact of mobility** on a person's health and wellbeing in the context of HIV actually is.
- This includes **specific groups** (migrants from within Europe, those from outside Europe, and asylum seekers) and from **key populations** (MSM, sex workers, drug users, and adolescents).
- We need further data on **promoting and evaluating peer education models** to access hard-to-reach communities.

Final thought…

Asylum seekers living with HIV in the UK show immense resilience. However, ***their isolation means they are often unable to deal with their treatment in the asylum system****, with negative consequences for their perceived health and wellbeing.* (Orton 2012)

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