

**All Party Parliamentary Group on AIDS and
All Party Parliamentary Group on Refugees, Migrants and HIV**

**Submission by MSSVD and AGUM on behalf of Genitourinary Medicine
Specialists**

MSSVD and AGUM, the specialist societies for GU Medicine, welcome the opportunity to give verbal and written evidence relating to the special needs of refugees and migrants with HIV. Our submission will focus upon **Healthcare and Treatment** issues.

1. Entitlement to NHS treatment

- 1.1 Maintaining open access services for patients who have or are at risk of sexually transmitted infections (including HIV) has been a fundamental principle of GU Medicine clinics since their inception in 1917. This approach minimises barriers to care, affords prompt treatment, and reduces onward transmission.
- 1.2 The regulations about entitlement to NHS treatment are complex. Overseas visitors, students, asylum seekers and immigrants frequently access our services. Some of these categories are entitled to NHS care. Clinicians rightly want to treat all individuals based on their clinical need and according to evidence-based national guidelines. It is an inappropriate use of scarce clinician time to require that they discriminate between individuals and to expect that they should argue both clinical and legal eligibility for treatment.
- 1.3 Most Trusts do not have robust mechanisms for assessing the eligibility for treatment of outpatient clinic attenders, especially in GU Medicine clinics where strict confidentiality is essential. Some Trusts 'police' inpatient care more carefully than others. Recently, individual Trusts have introduced policies attempting to select individuals who may access care or have presented some patients with bills after the event when there is no likelihood of payment. Some Trusts have pursued this policy not just for HIV patients but also for patients seeking non-HIV STI care. There are inequalities in care provision and disproportionate care burdens between clinics that inevitably result from the disparate approaches of Trusts.
- 1.4 Tensions inevitably arise when clinicians are told by managers that they cannot provide further care for patients who are already receiving treatment. Stopping anti-retroviral treatments abruptly can have serious consequences for the health of the individual as well as pose an increased risk to public health with the development of drug resistant virus strains. Arguing individual cases is an unnecessary distraction for clinicians.
- 1.5 There are obvious contradictions between policy and practice that place physicians in difficult positions. There is a National policy to offer all pregnant women an HIV test via ante-natal screening. There have been reports of some trusts subsequently failing to provide treatments to prevent onward transmission of HIV from mother to child because of unclear immigration status of mothers.
- 1.6 There needs to be clarity about entitlement to NHS treatment. It is preferable that potential patients be informed outside the care setting and before the initial consultation whether they will receive free treatment or have to pay in advance. Clinicians should not have to get involved in policing any tightening of regulations.

1.7 GU Medicine has always had a very strong public health role in the control of sexually transmissible diseases. The full management of HIV positive patients necessarily requires a multi-disciplinary approach, with a focus on secondary prevention strategies for a newly diagnosed HIV positive patient. These include partner notification and an offer of HIV testing to partners. It is of concern that any policy which further prevents individuals' access to services (such as the subsequent lack of access to therapy) may have a damaging effect on the control of the UK HIV epidemic.

1.8 Whilst respecting the philosophy of local priority setting by PCTs, maintaining equal access to high quality HIV and STI care throughout the UK remains of paramount importance.

2. Diagnosis and Management

2.1 Migrants with HIV tend to be diagnosed with advanced disease and frequently have multiple pathologies, including tuberculosis and viral hepatitis, which present serious public health risks. They then require complex management, with a multi-disciplinary team.

As well as the established HIV specialist services (which may or may not be provided by GU specialists) an increasing number of GU services are required to provide expert in-patient advice and care for sick patients.

2.2 An influx of HIV positive patients has a disproportionate effect upon small centres, especially those served by a single-handed consultant, as these have little flexibility of manpower or resource.

2.3 A rapid upsurge in HIV workload will adversely affect access for clients seeking screening/treatment for other STIs. Thus HIV-related delay favours onward transmission of STIs and exacerbates the current severe pressures on GU Medicine services; this is unacceptable as delays may be catastrophic for public health.

3. Communication and Cultural Issues

3.1 There are problems of communication with those whose first language is not English. Many clinics have a shortage of suitable interpreters, and cannot readily access those who have had training in confidentiality. Resorting to the use of family members and friends is completely inappropriate.

English speaking asylum seekers and migrants may be unused to the biomedical descriptions of bodies and disease. They require more consultation time because of the complex technical language often required to explain the natural history of HIV and how treatments work. An understanding of the issues is essential to ensure adherence to treatment regimens.

3.2 Inevitably consultations with these patients take longer and this adversely influences other clinical work, especially getting patients through the clinic in a timely fashion.

3.3 Tensions between migrant and indigenous patients attending clinics may occur. In clinics with poor waiting facilities, socially inappropriate interactions may erupt as waiting times get longer and tempers become frayed.

3.4 There are a variety of cultural issues that need to be additionally considered in patient management. These include special difficulties in disclosure of status to partners and carers, and concerns about being seen by other community members accessing an HIV service. These concerns may inhibit regular clinic attendance, the uptake of interventions to prevent mother-to-child transmission by antiretroviral treatment and avoidance of breast-feeding.

4. Treatment with ART and Adherence

4.1 Optimal response to treatment requires strict adherence to prescribed drug regimes. This is dependent upon developing good professional relationships, support, and close monitoring of patients. In general, the experience of clinicians is that most migrant populations follow clinical advice, sometimes better than the indigenous population. However, if patients are relocated quickly and without liaison with the relevant health care providers, especially shortly after treatment initiation, adherence can be jeopardised.

5. Dispersal

5.1 Dispersal often happens at short notice that does not allow arrangements for onward care. Receiving clinicians may have a rapid influx of new HIV patients for whom there are no medical records available. Trying to access information from previous clinics and hospital admissions then requires time consuming telephone calls and faxes. There may be unnecessary duplication of investigations and treatment delay.

5.2 When individuals move away from their initial diagnosing centre, sometimes soon after anti-TB and/or anti-HIV treatment has been commenced, breaks in therapy may occur which promote the development of drug resistance and subsequent treatment failure, with the potential for serious adverse patient and public health outcomes.

5.3 The unpredictability of location and housing causes major psychological difficulties to many individuals that temporarily outweigh concerns about physical health. This further threatens their health seeking behaviour and adherence to treatments.

5.4 Some individuals who need to report to immigration centres on a regular basis have had difficulties attending outpatient appointments regularly. When admitted to hospital they are not able to attend immigration at the right time/date, which leads to additional administrative burdens upon health care service providers.

5.5 There are problems organising social support and care. This is exacerbated by the reduction in local authority AIDS support grants and lack of ring fenced money for HIV care.

6. Surveillance

6.1 The routine surveillance data collected does not readily distinguish between asylum seekers, migrants, students, and visitors. As a result, it is difficult or impossible to be precise about the specific contribution of these different groups to the recent rapid upsurge in new HIV diagnoses. More detail is needed to avoid unjustified stigmatisation of asylum seekers, as well as to improve service planning to meet the respective care needs of these patient groups and their families.

6.2 The complexity of individual clinics' workload is not easily discerned from surveillance data. A newly diagnosed, healthy HIV positive gay man identified via a routine STI check up may be less complex than a newly identified HIV positive pregnant woman, whose native tongue is not English. Developing data systems that reflect additional clinical workloads would improve service planning and resource allocation.

7. Resources

7.1 Current predictions of HIV numbers are likely to be a serious underestimate given the large impact of cases in migrant workers and asylum seekers.

7.2 There is insufficient flexibility in present funding arrangements to adapt to rapid changes in caseload.

7.3 The annual number of new HIV cases has doubled in the past three years. At an average per patient annual treatment and care cost of £15000, the additional funding required for new HIV patients in 2002 is over £100 million. The annual incremental cost is likely to continue at this level or rise over the next three years. It is not apparent to us that PCTs have been or will be provided with this additional funding within their general allocations to meet this ever increasing need. There is little evidence that PCTs have an awareness of the scope of this problem in their locality.

7.4 Treatment and care funding of HIV is now devolved to PCTs, and is often the responsibility of inexperienced lead sexual health and HIV commissioners. Few clinics and PCTs have either adequate financial reserves or plans to meet a rapid influx of new positive patients. There is a real risk of large budgetary deficits being incurred within some Trusts, leading to increased tensions between clinicians and managers, and attempts to ration HIV and STI care by patient post-code.

7.5 We welcome the DH HIV and Sexual Health strategy and the development of the National standards for HIV services that go some way to focus on the need to standardise HIV services. However the lack of a NSF for HIV and Sexual Health leads to problems of prioritising resources for HIV/ Sexual Health at PCT level.

7.6 A central budgetary mechanism allowing for responsive funding to ensure that funding truly follows these patients in real time would be desirable.

8. HIV Infected Healthcare Workers

8.1 The well- intentioned initiative of seeking healthcare workers from abroad to relieve the chronic staff shortages within the NHS has contributed to problems faced by GUM/HIV specialists. There will continue to be cases of healthcare workers identified as HIV positive. The NHS needs to continue to develop policies and approaches which are supportive to these individuals, recognising the increased workload and resources required.

8.2 In some instances where HIV infection has been detected after the health worker has been involved in exposure-prone procedures, time consuming, resource intensive look back procedures have been necessary.

8.3 Without additional resource being provided for these activities, there are inevitable additional adverse consequences upon existing services that result from staff involvement as well as understandably heightened public concern about the safety of care. Primary Care and acute Trusts should not be expected to find additional funding for these from within their baseline budgets.

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