

The growing challenge

A strategic review of HIV social care, support and information services across the UK

This briefing contains a short summary of research commissioned by the AIDS Funders Forum and undertaken by Sigma Research. The aim of the research was to review the commissioning and provision of social care, support and information for people with diagnosed HIV across the UK. The research will inform future grant making strategies of AIDS Funders Forum members. It should also inform the commissioning and provision of services for people with diagnosed HIV.

This report appears 10 years after the widespread introduction of anti-retroviral therapies. Availability of effective HIV treatment has transformed the UK epidemic, producing a dramatic reduction in mortality and, for many people with diagnosed HIV, an increase in health and well-being. Yet, in spite of medical advances, many commissioned services continue to follow a historical pattern. There remains a lack of needs-based planning, levels of knowledge and expertise among commissioners seem to be diminishing and there is limited strategic vision.

1. HIV IN THE UK

- The number of people living with diagnosed HIV in the UK has grown by 6,500 to 7,000 in each of the last 3 years (2003-2005). By the end of 2005, the total number of people living with diagnosed HIV in the UK was over 47,000. There may have been a recent decline in the rate of growth of numbers of people with diagnosed HIV but prevalence continues to increase by more than 10% every year.
- With the introduction of anti-retroviral treatment, the number of people with HIV dying every year radically declined ten years ago and has remained stable ever since (at about 500 deaths per year).
- Prevalence of diagnosed HIV infection is highest in England, then Scotland, Wales and Northern Ireland. Half of people with diagnosed HIV in the UK today live in London.
- In the UK, HIV disproportionately affects men rather than women and adults rather than children.
- There has been a recent decline in the number of people moving to the UK with HIV. In the UK overall, 51% of people living with diagnosed HIV are White, 43% are Black and 6% are of other ethnicities. Among the Black people with diagnosed HIV resident in the UK, 89% are African, 7% are Caribbean and 4% are from other Black groups.
- There has been no decline among the number of domestic HIV infections in the UK, suggesting

the number of people living in the UK who acquire HIV (sexually) continues to grow. About 80% of all domestically acquired HIV infections occur as a consequence of sex between men.

2. OBSTACLES TO THE PROVISION OF SERVICES

2.1 *HIV is not a political priority, either nationally or locally*

- There are no government targets against which NHS or Local Authority performance with respect to HIV prevention or social care, support and information for people with HIV is measured. As a result, local targets concerning HIV are rare.
- Charitable HIV organisations are concerned about the lack of priority given to HIV in national and local policy. They report widespread indifference towards HIV from Local Authority, NHS and some charitable funders. The search for funding is a constant pressure on organisations and in many cases has a serious impact on their service delivery and long-term viability.

2.2 *The NHS is (always) in crisis*

- NHS HIV commissioners occupy a range of job roles, have a range of backgrounds and skills and are rarely HIV specialists. Many have multiple other priorities and roles, few have received any formal training and many receive no ongoing support. Expertise in service development is not a common skill among commissioners.

- The end of ring-fenced HIV funding is having an effect as the NHS undergoes another restructuring. PCT deficits figure prominently in commissioning decisions – often more prominently than need. Many NHS commissioners feel their role is to save money and monitor and remove existing contracts rather than commission new services.
- HIV social care, support and information services are often seen as secondary to treatment and care budgets. They are constantly under threat and their survival often depends on the negotiating power of commissioners. However, large-scale decreases in the funding of HIV social care, support and information services were not proven.
- Many charities feel it is increasingly difficult to establish and maintain contracts with Local Authorities and Primary Care Trusts. The mainstreaming of HIV figures prominently in these difficulties as does the limited priority attached to social care, support and information for people with HIV.

2.3 Local Authorities are mainstreaming services

- Mainstreaming of Local Authority services threatens to disrupt continuity of HIV social care. In particular, Social Services are increasingly unable to serve the complex and acute needs of the growing population of asylum seekers with HIV. This is putting undue pressure on charities to fill ever-widening gaps in service provision.

3. CHANGES IN SERVICE PROVISION

- Charitable providers have a great deal of expertise in the planning and provision of services – many innovate in response to changing need and changing patterns of HIV infection. However, the lack of a national HIV social care, support and information strategy makes prioritising need problematic. The overriding impression is of a high volume of aims and needs (and target groups) with no way of prioritising among them. Often one group (or service) cannot gain without another losing.
- Approximately half of charities described cuts in HIV social care, support and information services in the last 3 years but three quarters described introducing new services in the same period. The description of services cut and services started suggests that changing patterns of HIV infection and associated need are less important than the changing political and funding environment (including NHS funding shortfalls, Local Authority mainstreaming and political pressures).

- Looking across all organisations in the UK, very similar services are being cut and launched, and these changes are not usually a consequence of changing need. There are many disparate factors driving innovation but funding, political and NHS and Local Authority priorities are key. The wish lists of service providers suggest there is no consensus about the ideal mix of HIV social care, support and information services for people with HIV, nor the key target groups and needs.
- Needs-led commissioning against strategic aims and objectives is very rare as is tendering of service contracts. The most common reason for funding a service is historical precedent and funding tends to roll forward year-on-year.

4. IMPROVING HIV SERVICES

- The majority of respondents did not think all people with HIV were equally well served by the current configuration of HIV social care, support and information services. Migrants, asylum seekers and ethnic minorities emerged as the groups around which most respondents expressed concern (over one third felt they were under-served and felt that should be targeted for funding by members of the AIDS Funders Forum).
- The majority of respondents thought members of the AIDS Funders Forum should prioritise specific needs of people with HIV when considering future funding especially needs around social care and support, financial security, education, training and employment, housing need, health care needs, legal and welfare benefits.

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This research was funded by the AIDS Funders Forum, a consortium of grant-making charities including Crusaid, The Derek Butler Trust, The Elton John AIDS Foundation, MAC AIDS Fund, The Monument Trust, and The Peter Moores Foundation.

Our sincerest thanks to the 394 people who completed the online survey describing their experience of commissioning or providing services to people with HIV. Our thanks to all those that agreed to follow-up telephone interviews and especially those 18 whose views are represented in the main report. Without the willingness of all those experts to share their experiences so honestly with us, this research would not have been possible.