

# Anti-HIV treatments information

NAM, the National AIDS Trust, Sigma Research and the African HIV Policy Network have conducted research into the treatment information needs of African people with HIV living in England. This briefing is a summary about treatments education needs of African people with HIV. It is intended for people providing HIV treatment information in the corporate, statutory or non-governmental sectors. Other briefings address other needs of this population (Briefing Sheet 2) and policy lessons from this research (Briefing Sheet 3).

With 435 participants, Project *Nasah* is the largest UK research project among African people with HIV. The sample represented over six per cent of all those African people living with HIV in England at the time of the study. In addition, our sample was remarkably similar to what we know about the national profile of (black) African people with diagnosed HIV.

Treatments information plays a key role in extending the quality and length of people's lives. People with HIV who adhere to their anti-HIV drugs tend to live longer and healthier lives. The British HIV Association *Adherence Guidelines* state:

"Patients who understand the rationale for anti-HIV therapy and the role of adherence in the development of drug resistance and treatment failure report higher adherence levels than those without this information. Reinforcing information provided verbally with written information to take home, and by checking that information delivered has been heard correctly is likely to be beneficial as patients commonly misunderstand their health care providers' instructions."

Clearly, it is important for people with HIV to have access to information on how to maximise the effectiveness of their medical treatment and care. Project *Nasah* found that compared with other people with HIV, Africans are eight times more likely to report a need for more information or knowledge of anti-HIV treatments (see Briefing Sheet 2).

Project *Nasah* also found:

- The majority (91%) wanted to know more about anti-HIV treatments.
- Nearly half (46%) of those taking treatments were not sure if they knew enough about their current treatment regime.

- Almost a third (30%) were uncertain of the relationship between drug resistance and treatment failure.

Access to HIV treatments information is significantly poorer for African people than for the rest of the population of people with HIV.

- **All agencies providing any type of information to people with HIV need to focus on reaching Africans resident in England as a priority.**

## TREATMENT INFORMATION NEEDS

Project *Nasah* found the majority of African people with HIV knew the most basic facts about anti-HIV treatments, but many could benefit from a more secure footing for their knowledge. It also found the vast majority were happy with the written materials that they had received.

However, the following *Nasah* data might influence how we meet information needs:

1. African people with HIV are likely to have had HIV for a longer period at diagnosis;
2. Two thirds (68%) will have been diagnosed less than four years;
3. A third (38%) will have been diagnosed with HIV as hospital in-patients;
4. Over half (55%) have been ill due to HIV;
5. Most (79%) will have taken anti-HIV treatments.

The above indicate that:

- **at HIV-diagnosis, African people have an immediate need for information concerning suppression of the virus, how resistance develops and how to adhere to therapy.**

Other issues relate to the findings that those diagnosed for less time had lower levels of formal education (which might mean a greater challenge in understanding medical information), and were the least likely to have a job. These findings and the fact that many African people will not necessarily have English as one of their preferred languages indicates that:

- **There should be a range of information resources and presentations that address different levels of education and literacy.**

## **INFORMATION FORMAT**

Most African people with HIV were broadly satisfied with the written materials they had seen. Attending presentations from medical staff and other people with HIV were also important sources of anti-HIV treatments information. There was also high demand for seminars and workshops. Respondents also identified newsletters and leaflets as important means of continued learning.

- **The range of interventions through which anti-HIV treatments information is currently delivered were broadly acceptable and appropriate to African people with HIV.**

## **ENSURING INFORMATION REACHES AFRICAN PEOPLE WITH HIV**

The role of the HIV doctor and other HIV clinic staff as fundamental sources of treatment information was a crucial finding. Other core findings suggest a high proportion of African people with HIV read printed information and talked about treatments with staff at HIV and African organisations, and with other people with HIV at support groups and elsewhere. Providing written information during such interactions is an excellent way of consolidating learning.

- **Rather than rely on one form of communication, we need to use as many methods as possible to reach as diverse a range of people with HIV as possible.**

Given the high levels of HIV diagnoses on hospital wards and in GP's surgeries, non-specialist NHS clinical staff need to understand something about HIV management. As a minimum they need to understand where to refer their patients.

- **There must continue to be an improvement in collaboration between the clinical and voluntary sectors in coordinating information provision.**

It is difficult to reach people who are not part of established communities, such as those who have recently arrived in England. Poverty, poor housing, unemployment, dispersal, language difficulties and the resulting isolation can make it hard for some African people with HIV to access appropriate services.

## **TARGET AND TAILORING INTERVENTIONS**

Project *Nasah* suggests agencies do not necessarily need to provide treatments information exclusively for African people with HIV – the core issues apply to all people with HIV. However, cultural competence remains an important issue. If treatments information is intended for all people with HIV, then it has to be made equally accessible and acceptable to all. In the case of written interventions, for example, this will mean ensuring the text is as simple as possible (as some people will not have English as a first language), that images represent all targets for the information; that design is not dominated by a specifically gay (or African) iconography *etc.* For seminars and presentations this will mean considering when the event is held; where it is held (does it have creche facilities?); and who the speakers are *etc.*

You can download copies of the three briefings and the original research report from:

[www.aidsmap.com/publications/reports/nasah.pdf](http://www.aidsmap.com/publications/reports/nasah.pdf)  
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Project *Nasah* was funded by Camden & Islington Health Authority; the London NHS HIV Consortium; Gilead; GlaxoSmithKline; Bristol-Myers Squibb; Boehringer Ingelheim; & East Surrey Health Authority.

# The needs of African people with HIV

Sigma Research, The National AIDS Trust, NAM and the African HIV Policy Network have conducted research into the treatment information needs of African people with HIV living in England. This briefing sheet addresses the social and economic needs of African people with HIV. It is intended for people providing HIV services in the statutory and non-governmental sectors. Other briefings address the anti- HIV treatment information needs of this population (Briefing Sheet 1) and policy and research implications of the research (Briefing Sheet 3)

With 435 participants, Project *Nasah* is the largest UK research project among African people with HIV. The sample represented over six percent of all those African people living with HIV in England at the time of the study. In addition, our sample was remarkably similar to what we know about the national profile of (black) African people with diagnosed HIV.

Poverty dominates the lives of Africans living with HIV in England. The burden of poverty is greatest for those who are denied the right to work and welfare because of their immigration status. A majority of Africans with HIV are also coping with poor housing and living conditions. Experience of discrimination is common. These problems contribute to anxiety, depression and low self-confidence.

The table below describes the proportion of respondents in the *Nasah* survey who had experienced problems in the previous twelve months. They were asked about 19 different areas of need. A comparison to Sigma Research's national survey of people with HIV (*What do you need?*) highlights the huge disparities in need between African and white British people living with HIV.

Table 1: Problems experienced by Africans living with HIV in England

<i>Problems experienced in the last 12 months</i>	<i>% Africans with HIV</i>	<i>Difference from White British</i>
Money – getting enough to live on	77	<b>10 x greater</b>
Anxiety and depression	71	no difference
Sleeping	57	no difference
Self-confidence	56	no difference
Immigration status	55	comparison not possible
Housing and living conditions	54	<b>7 x greater</b>
Relationships	51	2 x greater
Access to skills, training and job opportunities	48	1½ x greater
Household chores and self-care	42	no difference
Mobility	41	2 x greater
Sex	40	no difference
Discrimination	38	<b>3 x greater</b>
Looking after children (of those living with children)	38	no difference
Eating and drinking	37	no difference
Friendships	35	1½ x greater
Taking HIV treatments regularly (of those that do)	36	no difference
Knowledge of HIV treatments	27	<b>8 x greater</b>
Dealing with health professionals	28	no difference
Drugs and alcohol	7	no difference

## MENTAL HEALTH PROBLEMS ARE COMMON

Project *Nasah* demonstrates that many Africans living with HIV suffer from anxiety, depression and loss of self-confidence. These common mental health needs are often linked to problems with relationships, friendships and sex – problems which are intensified by the stigmatisation of HIV within African communities, and the racism and stigmatisation of immigrants in wider society.

- **Community organisations should focus on building support networks for African people with HIV who experience rejection and isolation because of HIV infection.**

## BUT POVERTY IS THE BIGGEST PROBLEM

The greatest challenges faced by African people living with HIV are very practical. Poverty is an overwhelming problem in this population, with 77 per cent of Africans experiencing difficulties getting enough money to live on – ten times the rate among white British people living with HIV. Similarly, over half of African people living with HIV have problems with their housing and living conditions, seven times the level among white British people with HIV.

African people resident in England have relatively high educational attainment: 36 per cent of the *Nasah* respondents had a university degree or higher, compared to 23 per cent of the *What do you need?* respondents. The strikingly high rates of poverty and housing need are clearly a reflection of the social and institutional discrimination African people face in England. The greatest of these are created by the immigration service: over half of Africans living with HIV have outstanding immigration problems which can deny them rights to welfare, work and education. This can leave people in desperate circumstances. The high rates of reported discrimination indicate the wider problems which Africans face in trying to sustain day-to-day life in England.

- **Poverty can make all other health and social care needs harder to meet.**

Almost two in five Africans with HIV are struggling to care for children (53% are living with children). Similar numbers have problems with mobility and with coping with household chores and self-care.

## ADDRESSING INEQUALITY IS A PRIORITY

These results demonstrate that although Africans living with HIV have far more needs than White British people living with HIV, they get much less support to deal with them. Any commissioner or provider with a concern for the health and well-being of African people living with HIV must address these fundamental social and economic problems as a matter of urgency.

- **Basic practical and economic support for African people living with HIV should be a commissioning priority.**

## DIFFERENCES AMONG AFRICANS LIVING WITH HIV

Within the population of Africans living with HIV, there are some differences across the needs described in Table 1. In particular, the respondents who had recently arrived in the UK were the most needy, experiencing more problems with money, anxiety and depression, immigration, housing, access to training and jobs, and their ability to eat and drink.

- **Providers should aim to address the particular vulnerability of African people with HIV that have been resident in the UK for the shortest time (especially those resident here for less than two years).**

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# Policy & research implications

The National AIDS Trust, NAM, Sigma Research and the African HIV Policy Network have conducted research into the treatment information needs of African people with HIV living in England. This briefing is a summary about the policy and research implications of the research for providers of services to African people with HIV. Other briefings address the treatment information needs (Briefing Sheet 1) and other needs (Briefing Sheet 2) of this population.

With 435 participants Project *Nasah* is the largest UK research project among African people with HIV. The sample represented over six per cent of all those African people living with HIV in England at the time of the study. In addition, our sample was remarkably similar to what we know about the national profile of (black) African people with diagnosed HIV.

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## STIGMA AND DISCRIMINATION

Project *Nasah* tells us a little about African peoples' experience of HIV-related stigma and discrimination in the UK. In the last year over a third (38%) of African people with HIV in England had experienced problems in relation to discrimination. In addition, disclosure of HIV status presents significant problems for a number of African people with HIV. Problems with disclosure of HIV status were often connected to the feelings of shame or taboo from having an HIV-positive diagnosis. Disclosure to parents was a problem for many, with less than half having told either their mother (41%) or father (30%) about their HIV diagnosis. Almost two thirds (64%) had told none of their children about their HIV status, and telling GPs was a problem for a quarter (23%) of the sample. African people with HIV were more likely to tell their partner about their HIV status (85%) and some of their friends (84%).

## THE DISPERSAL SYSTEM

Project *Nasah* was limited in its ability to track the needs of asylum seekers who had been dispersed under the Home Office policy. Our expectation was that these people will have even greater levels of need than those described in Briefing Sheet 2. They were assumed to be more likely to be isolated, and less likely to have come across HIV services that meet their needs both in terms of HIV specialist skills and cultural competency. The majority of HIV specialist services and African community organisations are in London, or in other major cities like Manchester.

These problems of isolation and lack of links to good quality services not only deprive people of the services they deserve, but it also means that they become 'hard to reach', and therefore hard to involve in needs assessments and other research. This then further marginalises them since their needs and experiences are not reflected in formal accounts of individual and community need. African asylum seekers with HIV need most from services and almost certainly get least.

The All Party Parliamentary Group on AIDS' report on *Migration and HIV: improving lives in Britain* (July 2003, [www.appg-aids.org.uk](http://www.appg-aids.org.uk)) highlights many of the significant HIV-related problems created by the dispersal system. These problems in turn raise many new research questions.

## RAISING SOCIAL RESEARCH QUESTIONS

Project *Nasah* was one survey across a sub-population of people with HIV. It was not an in-depth study and identified many questions requiring more investigation. For example, *Nasah* shows that many African people with HIV had problems with relationships (51%) and sex (40%). We need to understand these problems a lot better in order to ease the pressures and problems that HIV brings, to provide better quality services and inform HIV health promotion. Three quarters (71%) had problems with anxiety and depression. We need to know much more about the mental health of African people with HIV – not just that there are problems, but what these problems are and how our services can become more competent in meeting people's needs to manage anxiety and depression in their everyday lives.

For those working in HIV organisations the pressing need for information and evidence is no surprise. Around the UK, organisations are changing in an attempt to better meet the needs of African individuals with HIV and the communities they live in.

We still know very little about African people living with HIV in England. Problems with stigma, discrimination, disclosure of status, sex and relationships, as well as mental health are all examples of critically important factors about which this research effort says little. Knowing these are problem areas, we now need to ask how and when we will address them. We must learn more. Because of this research, there is now a body of trained researchers with access to African communities in England (especially in London). This asset is probably the most important single positive outcome of the Project *Nasah* research process.

These are just some examples of how social research can raise new questions. As well as giving service planners and community-based organisations general assessments of need across a population, surveys can point to areas that require more enquiry and more in-depth understanding.

Project *Nasah* provides our first substantial national picture of the high levels of need among African people with HIV living in England. Needs in relation to

HIV treatments and treatment information were established (see Briefing Sheet 1), as well as a range of other needs to do with managing day-to-day lives (Briefing Sheet 2). The findings from *Nasah* should help HIV-specific and other services develop in a way that best meets the needs of Africans living with HIV. These findings should also inform the process of shaping and / or changing organisational priorities.

## **PARTICIPATORY METHODOLOGY**

Project *Nasah* was a research process led by a partnership between researchers, service providers and advocacy organisations – Sigma Research, NAM, the African HIV Policy Network and the National AIDS Trust. We used a methodology that recruited, trained and employed 26 African community members to carry out the research. Hence, recruiting people to participate in the survey was done by community members in community settings. The research partners also saw the *Nasah* project as an opportunity to develop the research skills of 26 African community members. As many more research questions are raised by this research we will need many more community members to drive and shape HIV social research into the future. We will also require funders of research to invest in understanding African communities affected by HIV. Such investment has been woefully inadequate to date.

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