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Executive summary

Plus One is a large qualitative research study that explored the needs and experiences of sixty black African people living in England who were in relationships where one person had diagnosed HIV and the other did not. These relationships are often called 'sero-discordant'. The main findings of the study are described in detail in four focussed reports, listed above. This executive summary describes the background and methods to the study before providing an overview of key findings and programme-level recommendations that will be relevant for anyone working to improve the sexual health and well-being of black African people in England.

BACKGROUND TO THE STUDY

The number of black African people living with diagnosed HIV in the UK currently stands at approximately 28,000 and it is estimated a further 9,000 are HIV infected but not aware of it¹. The governments, charities and other organisations working to reduce the incidence of HIV among the black African population in England require an understanding of what the HIV prevention needs of the population are and how these might best be met. They also require an understanding of the health and social care needs of people with diagnosed HIV so that interventions can be developed to help them lead healthy and fulfilling lives.

Much of the HIV social research among black African people previously conducted in England has been survey-based^{2,3} and has focussed on describing sexual risk behaviour and indicators of prevention knowledge. While this provides essential information about population-level HIV prevention need, surveys are not able to capture the detail of complicated needs or experiences, such as those of people who are living with, or directly affected by, HIV. Qualitative research involving face-to-face interaction, such as interviews with people from the target population, is a means of achieving this and forms the basis of the research described in these reports.

The National African HIV Prevention Programme (NAHIP) is delivered by a range of HIV prevention organisations united by a strategic planning framework, '*The knowledge, the Will and the Power*' (KWP)⁴. This framework describes the priority groups for HIV prevention among the black African population in England. These are (in order):

- (1) People with HIV;
- (2) People in sexual relationships with people with HIV;
- (3) People with multiple sexual partners;
- (4) People who have sex with people with multiple sexual partners; and
- (5) People who are or will be sexually active.

This research project aims to better understand the experiences, HIV prevention needs, and health and social care needs of people in the first two priority groups: those with HIV and those in sexual relationships with people with HIV.

METHODS AND SAMPLE

This research study utilised a community-participatory approach⁵ based on the inclusion of HIV prevention and service provision agencies in the design, data collection, and implementation of the research. Collaborations to disseminate and apply the research findings are ongoing. The starting point of exploring the needs and experiences of people in sero-discordant relationships was drawn from the KWP strategic planning framework; however, the focus of the interviews was determined by the NAHIP partners. The agencies identified issues commonly presented by people in sero-discordant relationships, hoping that further exploration of these through research would help to improve service provision for this target group.

While a small number of the interviews were conducted by permanent staff from Sigma Research at the London School of Hygiene & Tropical Medicine (LSHTM), the vast majority were conducted by a team of black African people who were recruited from HIV community-based organisations and were often existing staff or volunteers of these organisations. This provided them with an opportunity to learn new skills for their own personal development, as well as helping to increase the research capacity within the black African HIV sector more generally. These individuals received extensive training about conducting research on sensitive topics and were supported throughout the process of interviewing by the project leader. Wherever possible, participants were given the choice of having a male or female interviewer.

All NAHIP partners were given the opportunity to feedback on earlier drafts of these briefing papers and will be given the

chance to feed into the development of more detailed intervention planning arising from these findings.

The research project included interviews with 60 people who had experience of being in a relationship where one person had HIV and the other did not. In order to be eligible to take part they had to:

- be over 18 years of age;
- be in a relationship where one person had diagnosed HIV and the other did not **OR** have been in such a relationship in the previous year;
- describe themselves as black African (or similar African ethnicity), or be in a sero-discordant relationship (as above) with someone who is.

It was not a requirement that both partners in a relationship took part, but some did so and were interviewed separately. This sampling approach allowed us to speak to people who had experience of being in a sero-discordant relationship that had ended as well as those that were ongoing. It was often the case that the HIV negative or untested partners of people with diagnosed HIV were not willing to take part. Despite the best efforts of the collaborating agencies, only 16 such people were interviewed (as shown in Table 1 below). While individuals in *relationships* with people who have diagnosed HIV do not represent all sexual partners of people who have HIV (i.e. some sexual contact may be casual or infrequent), those in sero-discordant relationships may be at greatest risk of exposure to HIV and represent a coherent target group for interventions.

Participants were recruited by a number of HIV charities and

NAHIP partners. We gratefully acknowledge their help and support at www.kwp.org.uk/planning/plusone. Interviews took place either in the offices of the collaborating agencies or in private rooms at municipal facilities. Participants' confidentiality was assured and all were reimbursed expenses of £20. The interviews generally lasted around one hour and explored issues surrounding HIV status disclosure (or lack thereof); the broad impact of HIV on the relationship; sexual behaviour and means of managing transmission risk; and people or services that provided support. Ethical approval for the study was granted by the Faculty of Humanities and Social Sciences Research Ethics Committee at the University of Portsmouth, which is where the lead researchers were based at the time the study started.

SUMMARY OF KEY FINDINGS

The HIV prevention, care and support needs of the people we interviewed were complex. We interviewed a broad range of people including: a majority who were HIV positive but some who at their last test were negative; some who had been recently diagnosed with HIV and others who had been living with it for many years; a few had entered into a sero-discordant relationship recently and some who had been in one for a long time; some were older or younger and they lived in many different parts of the country. Some appeared relatively settled in their sero-discordant relationships whereas others were facing significant challenges at the time of interview. A few had, for a variety of reasons, found the pressures of maintaining their relationship too great and had recently separated from their partners. The key findings of the study are explored in reports 2-5 but a brief summary of their contents is provided below.

TABLE 1: PARTICIPANT DEMOGRAPHIC CHARACTERISTICS

AGE Average (mean) age Age range	40 22-58	GENDER Male Female	21 39	RELATIONSHIP STATUS Currently in SD [†] relationship No longer in SD relationship	52 8
COUNTRY OF ORIGIN Zimbabwe Uganda Nigeria Zambia Other African nations European nation	20 9 7 6 17* 1	AREA OF RESIDENCE London Leeds/Bradford Nottingham Huddersfield Bristol Wakefield Luton	27 20 4 4 2 2 1	HIV STATUS Diagnosed positive female Diagnosed positive male Negative or untested male Negative or untested female	32 12 9 7
EDUCATION Primary/elementary Secondary/high school University/college Other	4 26 29 1	TIME IN RELATIONSHIP Average (median) Range	3 yrs 1 month- 12 yrs	TIME IN THE UK Average (mean) Range	11.3 yrs 2-55 yrs
ETHNICITY Black African Black African British Mixed African Arab White European Other	54 3 1 1 1	EMPLOYMENT STATUS Full-time employment Part-time employment Voluntary work only Education or training Carer/homemaker Casual/cash in hand Not in employment, education or training	11 8 10 5 3 1 22	IMMIGRATION STATUS Indefinite leave to remain Asylum seeker British nationality Compassionate/exceptional leave to remain Student Citizen of other EU country Visitor Don't know Other	18 16 11 3 3 1 1 2 5

† = Serodiscordant. * Other African nations include: Malawi, Kenya, Democratic Republic of Congo, Sierra Leone, South Africa, Somalia, Liberia, Angola and Rwanda.

HIV DIAGNOSIS & DISCLOSURE

Receiving the news of an HIV diagnosis (whether their own or their partner's) was extremely difficult for all participants. Inaccurate beliefs that HIV always results in serious ill-health and untimely death dominated most initial responses. Many of those we interviewed, particularly those who had been diagnosed within the previous few years, were still adjusting to HIV being a part of everyday life. Participants with diagnosed HIV had faced the decision of whether, how and when to disclose their status to their partner. This decision was informed by their feelings for that particular individual, their hopes for the future and, most importantly, their fears about how the partner might react to the news. Sometimes participants with diagnosed HIV did not feel sufficiently empowered to disclose and thus found themselves in unhappy relationships and burdened by keeping their HIV status a secret.

Those who did disclose their positive status were often met with hostile responses, verbal assault or complete rejection by their partners. Concerns about whether they too might have become infected dominated the response by partners as did fears of negative association within local African communities. There were some partners who were supportive from the outset, but even they held significant concerns about the prognosis of their diagnosed partner and whether there was any possibility of conceiving children.

MANAGING THE RELATIONSHIP

Time, support and information helped many of those in longer-term relationships adapt to HIV. However, this experience was not universal, and some were still in acute need at the time of interview. Some were struggling to cope with HIV on a personal level, were experiencing serious problems within their relationship, or described a relationship that had ended because of HIV. Some relationships floundered in the early days following disclosure, with one or both partners seemingly unable to

discuss or find resolution to their worries or concerns, while others sought advice or support to better understand the consequences of their situation. Disempowerment was evident within many of the relationships we explored. It was often related to fears of abandonment by the negative or untested partner, but there was also significant evidence of the unequal status of female partners within heterosexual relationships.

Both partners needed time to come to terms with HIV as a part of their lives and what this meant for them on a daily basis. Those relationships where people appeared most content or settled were most often those where both partners were well-informed about the nature of HIV and where both had openly and honestly discussed their worries and concerns about HIV and their relationship. However, many also stressed a desire for HIV not to cast a shadow over everything they did or to become a 'third person' in their relationship. Concerns relating to HIV added to other everyday stressors, especially for those with an unsettled immigration status.

SEX AND RISK

Having an HIV diagnosis, or being the partner of someone who has been diagnosed, had immediate and profound effects on sexual expression, at least in the short term. Some described ways in which they were able to overcome their initially debilitating fears about HIV transmission within the relationship and now were enjoying a full and happy sex life with their partner. However, this was not the experience of the majority. Key issues that prevented a healthy sex life included difficulties with condom use, and profound lack of awareness of other harm reduction measures that might help to alleviate anxieties about transmission during recreational sex or during sex with the aim of conception. Around a third of participants had never heard of post-exposure prophylaxis (PEP) and a further third had heard the name but were uncertain as to its meaning or how it might be accessed. Many had heard of the concept of treatment as prevention (i.e. a suppressed viral load rendering the person with

KEY THEMES

A number of themes that seem integral to the everyday lives of most of the people we interviewed span all four reports. These themes were more or less central to each participant but their salience varied depending on individual circumstances.

Uncertainty: A great many participants, both with diagnosed HIV and without, remained uncertain about their ability to safely conceive children, what transmission risks were associated with oral sex or vaginal sex with condoms, and what protection from infection an undetectable viral load may offer. On a broader level, many were uncertain about their future and about the long-term viability of their relationship.

Stigma: HIV stigma influenced how participants with HIV felt about themselves at the point of their diagnosis, how their partners reacted to their disclosure, what support they could access from friends or family, as well as how safe they

felt in their community. Such stigma contributed to a real sense of isolation for a significant number of participants.

Disempowerment: Informed by a fear of rejection or abandonment, the power to negotiate a safe and satisfying relationship was lacking for many of the participants with diagnosed HIV. A significant number of women too (both with and without diagnosed HIV) seemingly occupied a position of limited power within their relationships, which made it difficult for them to attain happiness.

Resilience: Despite often facing stigma or rejection from those around them, there were still those individuals and couples who had accepted and integrated HIV into their everyday lives and who seemed happy in their relationships. While in the minority, there were those who described how facing such adversity had, in the long run, brought them closer together and more confident as individuals.

HIV less infectious) but were either uncomfortable or suspicious of it, feeling that it lacked the certainty that condoms or abstinence could provide. A lack of confidence, or a lack of power within the relationship, meant that a significant number of participants, particularly women, were not able to negotiate sex that they were comfortable with.

EXTERNAL INFLUENCES ON THE RELATIONSHIP

Community-level stigma related to HIV was a major concern for most of those taking part. It negatively influenced the social support that people with HIV and their partners were willing and able to access from traditional sources, such as family or friends. Many had not disclosed their own or their partner's HIV status to children they cared for, which meant keeping a difficult secret in the family home and adding unseen pressure on the relationship. Those who had experienced rejection tended to lose self-confidence, and as a result were often profoundly isolated. While in a few instances, friends, family or faith leaders were supportive, it was common to be reliant on professional support services to

help cope with everyday life. Support groups at local HIV charities in particular offered an opportunity to be open and honest about the nature of HIV in their relationships and to share experiences and gain advice from people in similar circumstances.

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RECOMMENDATIONS

Each report provides detailed recommendations based upon the findings discussed and a summary is provided here. The recommendations should be considered within the context of *The Knowledge, the Will and the Power (KWP)*: the strategic planning framework for HIV prevention among black African people in England. The KWP website (www.kwp.org.uk) provides concise descriptions of potential intervention aims and interventions themselves.

1. Culturally appropriate oral and written information regarding prognosis should be clearly provided to black Africans when they are informed of their positive HIV status. Similar information should be provided to their partners, children and other family members if the individual with diagnosed HIV chooses.
2. One-to-one therapeutic support should be provided for people living with diagnosed HIV, and their partners, who are particularly struggling to come to terms with HIV as part of their everyday lives.
3. Individuals with diagnosed HIV should be supported and empowered to disclose their status to their partners should they wish to do so.
4. Provide safer conception advice to all people with diagnosed HIV and their partners while also working to ensure that safer conception options are accessible.
5. Promote and provide an array of male and female condoms for both risk reduction and sexual pleasure and provide counselling and support to address any problems with condom use.
6. Provide information, advice and support about harm reduction tactics beyond condom use, including: reducing facilitative factors during sex (such as other STIs), having non-penetrative sex, considering viral load and infectiousness, and knowing how and when to access PEP.
7. Devise strategies to highlight people in sero-discordant relationships where both partners are happy, settled and in control, and who are willing to act as role models in their communities. Facilitate spaces in which people black Africans in sero-discordant relationships can meet other couples in the same circumstances to share experiences.
8. Empower African women with the knowledge, skills and resources to negotiate the relationships, and sex, they want.
9. Offer confidence building activities for people living with diagnosed HIV to help ensure they can negotiate relationships and sex they are happy with.
10. Continue and extend efforts to curb community level HIV stigma in England with a focus on explaining HIV prognosis when on anti-retroviral therapy.

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