HIV SOCIAL RESEARCH AND AFRICAN COMMUNITIES IN THE UK: BUILDING THE EVIDENCE BASE
SUSIE MCLEAN, SENIOR POLICY OFFICER, NATIONAL AIDS TRUST

The impact of HIV on African communities living in the UK is profound. Behind those startling figures of rapid rises in heterosexual transmission of HIV in the UK lie many individuals, families and communities struggling with new infections, illness, death, stigma and separation from family and home.

These experiences of hardship and struggle resonate for those of us who were involved in earlier phases of the HIV epidemic. Stigma, prejudice, illness, death, loss – these are themes common to HIV in many places and times. But the particular interaction of these experiences with so many other social factors – migration, different languages, racism, different social and family norms, poverty, asylum, separation from family, different gender norms – make the picture of HIV for African communities a complex one.

There is a set of circumstances which makes living with HIV as an African in the UK unique.

For those of us working in HIV, understanding this picture is not easy. The National AIDS Trust (NAT) worked in partnership with the African HIV Policy Network (AHPN) to lead policy development in this area last year, resulting in the soon to be published HIV Prevention and African Communities Living in England – A Framework for Action. The AHPN are developing a similar piece of work on the social care needs of Africans with HIV living in England. What we learnt through that work, and what many Africans working in HIV already know, is that the term ‘African’ means so much and yet so little. Yes, it’s a signifier often for many of the problems listed above – difference, migration, social exclusion, racism – but so many cultures and societies and experiences and norms exist under that title, that the main task required of many of us is fundamentally to learn much more.

What do we need to know?

As many of us struggle either to make our services more relevant to African communities, or to establish and develop African-led HIV organisations, what we need to guide our work is greater insight – insight into the many factors that shape behaviour in communities that are markedly different from gay men’s communities.

Some key questions are: What are some of the patterns of socialising and sexual mixing? What is the significance of national or tribal associations? What communities are well established in the UK, and what communities are new? How does religion shape peoples’ understandings of HIV? What are the implications for a wife and mother from a traditional cultural background of disclosing to her husband that she is HIV positive? How do you tell your children that you’re sick with an HIV related illness? What are the social implications of not breast-feeding? How do you encourage your partner to find a clinic that can test you for HIV? How to prioritise health over financial difficulties? How will young people find out about HIV? What is the impact of migration on health? Are beliefs about masculinity and traditional gender roles getting in the way of behaviour change? Are asylum seekers getting access to information and condoms?
So many questions, so much unknown. It is in this context that much of the HIV work targeting African communities is conducted in this country. We have the precious expertise that lies in African community organisations about community norms, practices and belief systems. And we have a growing expertise across the sector about what works in HIV prevention. But what we don’t have is the insight and knowledge about culture, community and behaviour that comes from a national programme of social research into the UK’s African communities.

At present a number of small studies have guided our work. They have been enormously useful in beginning to understand need, and targeting work more appropriately. But the vast sum of what we don’t know can be overwhelming.

Priorities

The National African HIV Prevention Framework, soon to be published by the Department of Health, outlines some of the key priority areas for HIV social research in African communities:

- Epidemiology and monitoring – much remains unknown about the epidemiological and demographic features of the African HIV epidemic, and this becomes more urgent as the dispersal system forces many new and vulnerable people out of London.

- Sexual behaviour – there is a critical need for a better understanding of the sexual behaviours and attitudes of Africans with or at risk of HIV, in the context of cultural practices and beliefs, relationships, gender disparity, and economic status.

- Gender specific research – there is an urgent need for more understanding of attitudes, beliefs and practices surrounding breastfeeding, pregnancy and termination, experiences of antenatal testing, male approaches to condom use, experiences and behaviours of African men, sexual negotiation and masculinity.

- Specific sub-populations – more information is needed on asylum seekers and visitors, Africans who inject drugs, African men who have sex with men and African sex workers.

- Health services and prevention interventions – patterns of service use by African communities, evaluation of HIV prevention interventions, the development of research tools to reflect African community experience.

This list is by no means exhaustive. It comes from a national policy approach to HIV prevention, and we can expect that many more items would be added to this list were we to approach it from the perspective of clinical care or community support.

The African HIV Research Forum

The overall size of the above list, and the enormous need to get some of this work funded and undertaken, has prompted the establishment of the African HIV Research Forum. The African HIV Research Forum was established last year to try to raise the profile of the need for a nationally coordinated programme of HIV research for African communities, and to support those who are trying to get African HIV research in the UK off the ground. The Forum is a collection of professionals working in the field who come together regularly to share information about any progress in this area, to plan ways of getting more work funded, and to organise occasional seminars to promote work that is currently being conducted. The second seminar will be held on 26 April.

The African HIV Research Forum is an unfunded group. There are no staff, nor is any meaningful budget attached to it, but we do believe that there is value in highlighting the urgent need for investment in, and coordination of, a national programme of HIV social research for African communities. The Forum is beginning to question the value of programmes of work in HIV prevention or care that are being commissioned almost ‘blind’ to the needs, beliefs, behaviours and practices of the target audience. The African HIV Research Forum asserts that the national programme of HIV social research guiding HIV prevention for gay men is urgently required for African communities, and is starting to question why the big research funders are slow to invest in work focusing on African communities.

There is an emerging dialogue among members of the African HIV Research Forum regarding the need to develop research tools to reflect African community experience. New and innovative methodologies are being tried and tested in particular settings, and the Forum is keen to support these new approaches, as the task of researching vulnerable or marginalised communities is a difficult one.

So ideally, not only can the Forum suggest to research funders or commissioners what the priority areas are, but also it can begin to suggest methodologies to engage ‘hard-to-reach’ populations and that work in ways that can support communities rather than draw expertise away from communities.

The African HIV Research Forum is co-chaired by Dr Ade Fakoya and Dr Kevin Fenton, and will be launching its website by May 2002. The web address will be available through the Useful Links page on the NHPIS website. For further information about the Forum, or about the seminar on 26 April, please contact Kevin Fenton at kfenton@gum.ucl.ac.uk or Ade Fakoya at ade.fakoya@newhamhealth.nhs.uk
ONGOING RESEARCH

Study of Newly Acquired HIV Infection among Africans in London (SONHIA)
October 2003 to September 2005

HIV/AIDS among Britain’s African communities is a major public health concern, in part because of their delayed presentation, poor uptake of health services, and the resultant negative impact on mortality, morbidity, psycho-social wellbeing and economic cost to the health service. Many opportunities for earlier diagnosis and treatment among Africans are missed, onward disease transmission is facilitated, and healthcare services are burdened by the intensive healthcare requirements of advanced HIV disease.

The aim of the project is to describe the health beliefs, health care utilisation and presentation patterns of newly diagnosed HIV positive Africans in London in order to inform the development of culturally appropriate HIV prevention interventions. It will try to assess the impact of missed opportunities on onward HIV transmission among and by this group within the UK. The study population will be all newly diagnosed HIV positive African patients attending seven London HIV treatment centres. The project consists of two inter-linked components implemented over two years: an interview-based qualitative study among a selected sample employing in-depth interviewing techniques; and a cross-sectional questionnaire-based quantitative study. The health implications of this study lie in its potential to inform HIV prevention strategies and policies aimed at reducing adverse health outcomes and health inequalities.

Funding: Wellcome Research Training Fellowship in Health Services Research

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The Experiences of Women Receiving an HIV Positive Result through HIV Antenatal Screening
December 2001 to July 2002

In 1999 national targets were set in England for the universal offer and recommendation of HIV screening during antenatal care. The rationale is to identify all HIV infected women and offer treatment which may prevent transmission from mother to baby. Making the test routine was seen as normalising it, therefore increasing its acceptability. Although many studies have reported on the increased uptake of screening in London, little attention has been given to women’s experience of the procedure, particularly those who received a positive result.

Most women testing positive are from the African continent and this group may have additional burdens of stigma, which to date have not been investigated. As these women have to confront the issues of being both pregnant and HIV positive, it is essential that their perceptions and views are included in a research agenda. By focusing on women identified as HIV positive through antenatal HIV screening in the London area, this study will capture critical data about their experiences, which can inform practitioners about how best to manage the screening process and improve uptake rates outside of London.

The key research questions that are to be investigated include:

- Has universal screening reduced the perception of stigma for those identified as being HIV positive?
- What did the women who were diagnosed HIV positive find helpful and unhelpful about the screening process?
- On receipt of a positive result, were the women referred to an appropriate support agency?

This is a qualitative piece of research that aims to capture the experiences of women identified as being HIV positive through antenatal screening. The study will be conducted by Thames Valley University and Terrence Higgins Trust Lighthouse (THTL).

A critical review of the literature will be undertaken to identify articles relating to antenatal screening, including HIV. Relevant databases will be accessed including Medline, CINAHL, Psychlit and MIDIRS. A report summarising the findings will inform the next stage of the project.

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NATSAL (The National Survey of Sexual Attitudes and Lifestyles) Ethnic Minority Boost: Exploring Ethnicity in the Second National Survey of Sexual Attitudes and Lifestyles
Ends December 2002

Sexual behaviour is a major determinant of sexual and reproductive health. The second National Survey of Sexual Attitudes and Lifestyles (Natsal 2000) was carried out in 1999-2001 to provide population estimates of behaviour patterns and to compare them with estimates from 1990-1991. Natsal 2000 was a probability sample survey of 11,161 men and women aged 16-44 resident in Britain, using computer-assisted interviews.

A second sample, for an ethnic minority boost, was also undertaken to increase the numbers of Black African, Black Caribbean, Indian and Pakistani respondents in the sample. These groups...
were selected for inclusion because they were sufficiently prevalent to be screened cost-effectively and because they are of public health concern with regard to STI epidemiology. In total, interviews were completed with an additional 949 respondents in the ethnic minority boost sample, which significantly exceeded the research team’s original target of 735 achieved interviews.

Preliminary results of the main Natsal 2000 study have already been published (see The Lancet v.358 (9296), 1st December 2001 – www.thelancet.com) and provide updated estimates of sexual behaviour patterns. Observed increases in the reporting of risky sexual behaviours are consistent with changing cohabitation patterns and the rising incidence of sexually transmitted infections.

Further analysis exploring ethnic variations in sexual behaviour and attitudes is currently under way.

Funding: Grant from the Medical Research Council with funds from the Department of Health

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Eosinophilia Study: the Prevalence and Causes of Eosinophilia in HIV-1 Infected Africans Attending a District General Hospital Ends December 2003

Eosinophilia, a condition in which a type of white blood cell is abnormally raised, may be found in a wide variety of medical conditions and may have a broad differential diagnosis. Common causes include allergic diseases, parasitic infections, and drug reactions.

Exposure to a wide range of parasitic infections is likely within individuals who have originated from or spent long periods in Africa. Intestinal parasites, schistosomiasis and filarial infections are all chronic infections that persist without treatment. Previous studies have reported eosinophilia in patients with HIV/AIDS, often associated with a high prevalence of specific cutaneous diagnoses. Whether it is beneficial or cost effective to screen for these conditions and investigate eosinophilia in Africans with HIV is not known. It may be important to screen for untreated parasitic infections within African populations as it may have relevance to the long term sequelae of these infections and it is possible that these infections may themselves increase the risk of progression by increasing viral load. A fall in viral load on treatment of helminthic infections alone has recently been reported in individuals with HIV infection.

This project is therefore designed to determine the burden of eosinophilia and its determinants among sub-Saharan African patients attending a large London HIV clinical service. The study also aims to determine and document individuals’ responses to specific therapy for eosinophilia and in so doing, inform the development of appropriate and acceptable clinical intervention strategies for diagnosing and managing these patients.

Funding: MSSVD Clinical Development Fund

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Sexual Health Promotion Needs of HIV Positive Africans in Lambeth, Southwark & Lewisham (LSL) January 2002 to June 2002

This project is being conducted by Health First, a specialist health promotion agency for the Southeast London boroughs of Lambeth, Southwark and Lewisham (LSL). It will assess the sexual health needs of HIV positive African adults in LSL, examine the health promotion and service delivery offered to this group, and recommend improvements.

The target group will be surveyed using a simple self-completion questionnaire to assess needs and identify gaps in the service. A series of semi-structured interviews will be conducted to gain in-depth information on the social and emotional issues that affect sexual behaviour and the perception of sexual health. Focus groups will be conducted to pilot the questionnaire and to formulate the interviews. In a later phase of the project, focus groups will be conducted to develop recommendations based on the results of the research.

The research is being conducted by the project coordinator at Health First, together with a freelance researcher. Other support, such as transcribers, translators and administrators will be sought on a freelance basis. A multi-disciplinary Steering Group will be set up to oversee the project. Other staff members of Health First will be available for supporting this project, and are expected to play key roles.

The findings of the research will be published in a report which will be disseminated to stakeholders in LSL, in particular partner agencies such as community-based African organisations, sexual health service providers and primary care providers.

Funding: LSL Health Authority

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**HIV Positive Women from Africa: Health and Social Care Needs and Experiences in London**  
*March 2001 to June 2002*

The aims of the study are to document the circumstances of HIV positive women from African backgrounds living in London, to explore their experiences of health and social care and to analyse the policy implications of these findings for the future delivery of primary and secondary care for this group of patients.

This is the first ethnographic study of HIV positive African women living in London. It consisted of in-depth interviews with a random sample of 62 women from 11 different countries receiving care in four London hospitals. All had been in the UK and aware of their diagnosis for at least six months. The interviews were based on a narrative approach, which asked the women to talk about their HIV status in the broader context of their life history. Particular attention was paid to the nature of their daily lives as migrants who are also HIV positive. The group came from a wide range of socio-economic and educational backgrounds and the majority had dependent children. Analysis, which is still ongoing, has identified a variety of themes. These include limitations due to poverty, management of a chronic life threatening medical condition, fears of stigmatisation and discrimination, maintenance of social and family relationships within the African community both in the UK and in Africa, immigration and legal concerns, and complex issues concerning children and childbearing. A variety of support mechanisms and coping strategies used by women to surmount many of their daily difficulties has emerged.

It is hoped that this study and its policy implications will inform the future delivery of primary and secondary care for this group of patients.

**Funding: Private Patients Plan Healthcare Trust, Mid Career Break Programme**

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**The Padare Project**  
*January 2002 to August 2002*

Padare is a Shona (Zimbabwean language) word that refers to a place where intimate issues are discussed such as sexual health and gender issues. The aims of the Padare research project are to examine the sexual attitudes and practices of HIV positive Africans who access services in the London Borough of Camden and Islington. Results from the study will inform the development of practice, theory and methodology for engaging HIV positive Africans in designing and developing research tools and interventions that reflect their experiences and meet their needs.

The research employs both qualitative and quantitative methods in a synergistic way. Qualitative methods that place an emphasis on the views from HIV positive Africans are used to inform questionnaire design. Key research questions are focused on the perceived and behavioural risk of onward transmission, understanding of viral load, disclosure, perceptions and women's behaviour with respect to vertical transmission. The research is grounded in process evaluation.

The research aims to recruit a minimum of 200 HIV positive African respondents who access services in clinical settings, or from local authority or community-based agencies.

The results of this research will be published in August 2002.

**Funding: Camden and Islington Health Authority (NHS Trust)**

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**The Pachedu-Zenzele Action Research and Intervention**  
*October 2001 to April 2002*

The Pachedu-Zenzele Project is a community-based, peer-led action research intervention. The words Pachedu-Zenzele are derived from two Zimbabwean languages, Shona and Ndebele, and the phrase means ‘Togetherness – let’s do it ourselves’. The name is intended to capture the spirit of communal engagement and the ownership by Zimbabweans of the research process and the intervention.

The research/intervention is currently being conducted in Luton and targets Zimbabweans. It aims to assess, among the target group, level of HIV awareness and awareness of HIV services in Luton.

In Luton it has been difficult to engage Africans in HIV research. The approach employed here therefore challenges the traditional research model where evidence is captured without taking the opportunity to deliver interventions to ‘hard-to-reach’ groups. The research employs a number of qualitative methods, eg one-to-one in-depth interviews and observation, and a questionnaire. The research tools are developed in a participatory process that includes the target group. Local Zimbabweans are trained to distribute and administer the questionnaire, to conduct interviews and to deliver interventions.
in a wide range of everyday settings, including homes, workplaces, streets, pubs and clubs. Peers working collaboratively with the health authority feed the information directly into the service development process.

Funding: Bedfordshire Health Promotion Agency

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Disclosure – Telling Children about HIV in African Families
September 1997 to October 2000; further analysis ongoing

This research explores the disclosure of HIV to children in African families in London. The research aims to identify who in the family is being told about HIV, whether children are being told, and the reasons for telling or not telling children. The answers to these questions will give an insight into the state of childhood in HIV affected African families. Quantitative methods are used in this research together with a qualitative approach that places emphasis on reflectivity. Children and young people affected by HIV are also engaged in the study, articulating their views about disclosure.

The study has recruited 53 adults and 135 children and young people. Early findings suggest that children were affected by their lack of information about HIV, and that sex and sexual health issues are not the subjects of everyday discussions between African parents and their children. Although African children and young people wish for information on matters that affect their lives, they do not associate this wish with ‘rights’ as the language of ‘rights’ is often associated with a lack of respect for their elders. The word ‘rights’ does not sit easily within African children’s ways of knowing about family relations. Some parents, though appearing to be acting in an individualistic manner in withholding HIV related information from their children, were actually negotiating disclosure within a complex fabric of family culture that includes respect and a wish not to cause harm to their children. Talking to children about sex and HIV is a new family contract that parents have to make sense of.

Although the PhD research is now complete, the data set is undergoing continuing analysis. Further findings will be published in peer-review journals in due course.

Funding: University of North London

HIV Treatment Information among African People with HIV
January 2002 to December 2002

This project is a collaboration involving the African HIV Policy Network (AHPN), the National AIDS Trust (NAT), National AIDS Manual (NAM) and Sigma Research.

African people in the UK today account for 24% of all HIV cases and 35% of new diagnoses. They are often not diagnosed with HIV until they present with AIDS-defining illnesses. Many are immigrants and face challenges in accessing HIV treatment and care. There is a need to know what HIV interventions will be the most appropriate for African people to enable them to develop better dialogues with health care professionals.

Much of the research with HIV positive people has not included sufficient numbers of African respondents. This may be because survey tools have not been culturally and linguistically appropriate. This study is community-based and uses an action research methodology. This sort of method has already been piloted and demonstrated as an effective means of researching African communities with respect to HIV and sexual health.

This study aims to recruit approximately 300 HIV positive people from African communities across England. Stratified recruitment methods will be employed to ensure representation of the African countries most affected by HIV in the sample. About 25 community-based interviewers, drawn from a range of African fora and AIDS service organisations, will undertake recruitment and structured interviewing. Each forum and organisation will be invited to designate at least one person to participate in the research as an interviewer.

Since interviewees will be recruited directly by respondents from within their personal and service networks, they may be undertaken in any shared language. The research schedule is being designed as an HIV intervention. All interviewers will be trained to be able to answer basic queries, distribute written materials and make direct referrals into services where appropriate.

Funding: Camden and Islington, East Surrey and Croydon health authorities; London HIV Commissioners (NHS); GlaxoSmithKline, Bristol-Myers Squibb, Gilead and Boehringer Ingleheim

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The Department of Health, in conjunction with the London HIV Commissioner’s Consortium, in 2001 funded the National AIDS Trust (NAT) and the African HIV Policy Network (AHPN) to lead the development of national HIV policy for African communities. This has resulted in two draft frameworks:

- National Prevention Framework
- Health and Social Care Framework

These evidence-based frameworks are informed by literature reviews and a number of studies. They encourage a coordinated approach to working with African communities, and provide guidance on planning, good practice and strategic developments.

Both documents, and their supporting literature, now exist in pre-publication formats – see list in this panel. The National Prevention Framework has been submitted to the Department of Health for final approval and publishing. The Health and Social Care Framework is in its final stages of consultation, before submission to the Department of Health. It is expected that the Department of Health will publish this work in spring 2002.


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Focus Consultancy Ltd. Social mapping and needs assessment for African communities in West Sussex. West Sussex Health Authority, July 2001. Available from Julie Weston, Focus Consultancy, Focus Consultancy Ltd, 38 Grosvenor Gardens, London SW1W OEB. £5.00 plus p&p. Tel: 020 7730 3010; email: julieweston@focus-consultancy.co.uk

IN PRINT

The Mayisha study (previously featured in CHER issue 6) was conducted between April 1998 and March 2000 and assessed the knowledge, attitudes and sexual behaviours associated with the transmission of HIV and other sexually transmitted infections within high risk sub-groups of London’s African communities – particularly those from Uganda, Kenya, Zimbabwe, Zaire/Congo and Zambia. Based in the district of Camden and Islington Health Authority, the research involved several of the African community-based organisations (CBOs) working in the district as centres of recruitment, and of skills and service development. The study objectives were: a) to determine the feasibility of establishing collaborative partnerships for sexual health promotion between researchers, sexual health providers and African CBOs; b) to conduct a social mapping exercise by describing the social and demographic distribution of the so-called ‘vulnerable’ African communities and the sexual health promotion activities aimed at these communities; and c) to undertake a needs assessment quantifying knowledge, attitudes and behaviour associated with HIV and STIs in an attempt to model risk behaviour. Results were disseminated through written reports, journal papers, seminars and community group presentations and feedback. A report of the Mayisha study is available from Avert, 4 Brighton Road, Horsham, West Sussex, RH13 5BA. Tel: 01403 210202; fax: 01403 211001.

MISCELLANY
Between February and November 1997, The ExES Study: Exploring Ethnicity and Sexual Health (previously featured in CHER issue 1) aimed to provide a greater understanding of the cultural differences which influence the sexual attitudes and lifestyles of three selected ethnic minority communities resident in London and particularly affected by HIV or poor sexual health. The research explored sexual attitudes, lifestyles and practices, and the factors which influence them, and so provides an understanding of the behavioural and cultural norms related to sex and sexual behaviour within these groups. Seventy in-depth interviews were undertaken within the South Asian (Indian and Bangladeshi), Jamaican and Black African (Nigerian and Ugandan) communities. The final full report encompasses the main areas covered in the study: learning about sex; first sexual experiences and intercourse; current sexual lifestyles; sexual attitudes; sexual health services. The research summary (April 1999) condenses the essential findings and policy recommendations – copies can be obtained from Sue Johnson at the National Centre for Social Research, 35 Northampton Square, London EC1V 0AX. Tel: 020 7549 8520; email: s.johnson@natcen.ac.uk

On 25-26 March 2002, Terrence Higgins Trust Lighthouse and Camden & Islington CHS NHS Trust jointly organised the 2nd National African HIV Prevention Conference. The conference attracted participants from all over the UK, Europe and Africa, and brought together key stakeholders in HIV prevention work with African communities. This two-day event provided an opportunity for health professionals, community workers and people with HIV to share their experiences and knowledge in HIV prevention, exchange information and formulate recommendations for the provision and purchasing of prevention services. On the first day delegates to the conference covered developments in epidemiology, national policies on HIV health promotion and sexual health, the new NHS structures, and developments in research. The second day featured keynote speeches on developments in HIV prevention initiatives around the UK followed by a range of parallel presentations of work being conducted in the community, in clinical settings and in the research field. A website has been set up and seminar reports will be posted on the site at www.napc.org.uk

The African HIV Policy Network (see feature article and In Print section in this issue) progresses a significant level of its work through seven sub-committees. Co-option to sub-committees enables wider professional participation and the involvement of key individuals in setting the agenda to address the African epidemic in Britain. The Research and Strategy Sub-Group aims to: develop a strategic framework within which African work takes place; ensure the AHPN informs and responds to international, national and regional strategies affecting African communities; and promote evidence-based practice through research. The sub-committee’s research objectives include: to advocate increasing resources to an expanded evidence base through supporting research; to commission research (funds permitting); to identify research priorities. Membership includes Winnie Ssanyu Sseruma, Susie McLean, Max Sesay, Tom Ojwang, Lillian Ndawula, Josephine Namusisi, Martha Chinouya and Dorothy Mukasa (chair). Several members also sit on the African HIV Research Forum Steering Group (see feature article). For more information please contact the AHPN on Tel: 020 7814 6722.

THE NATIONAL HIV PREVENTION INFORMATION SERVICE

NHPIS is a free specialist information service on HIV health promotion serving professionals in England. It was established in 1990 and is managed by the HDA on behalf of the Department of Health.

Abstracts cited in Current HIV Education Research are held on NHPIS' Research and Practice/Interests Database (RAPID) and most are now available to view on the NHPIS website. Contributing to RAPID is easy – call or email Simon Ellis at NHPIS, or send relevant documentation, free of charge, to: NHPIS, Health Development Agency, FREEPOST LON8557, London SW1P 2BR.

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