

AHRF NEWS

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EDITORIAL

This issue of the AHRF News is a Research Update. Highlights include a summary of the last AHRF seminar day about African Men and HIV (pages 1 –3) and Gillian Elam from the Health Protection Agency has written an excellent article responding to questions raised at the seminar's research methodology session (Pages 4-5). Also in this issue is a short report about migrant Africans in Japan (page 7). Regular readers might notice that this issue does not include the usual section on the latest publications. A full round up of all books, papers and reports published in 2004 can be found in AHRF Update, which is available from the AHRF website or by post (contact details on the back page). All regular sections including the calendar of events and funding opportunities will be back in the next issue.

7th African HIV Research Forum Seminar Day **AFRICAN MEN & HIV**



Delegates at the 7th AHRF Seminar Day

Latest figures from the Health Protection Agency suggest that just under half (49%) of the 6100 African men who have acquired their HIV infection through heterosexual contact remain undiagnosed. This contrasts starkly with the 84% of the 10100 African women who have had their HIV diagnosed, mainly through ante-natal and GUM services. Additionally, evidence based prevention activities specifically targeting African men are limited in number, reflecting the need for research in this area.

In October 2004 the African HIV Research Forum (AHRF) held a seminar day focused on African Men and HIV. Over 100 delegates attended the Methodist International Centre, London to discuss the research and prevention needs of African men living in the UK. ►

African Men and HIV

The day began with co-chair of the Forum, Ade Fakoya, inviting delegates to participate in small group discussion about the main issues. Delegates identified stigma, constructions of masculinity, barriers to testing and the impact of migration on health seeking behavior as areas in need of further research.

The presentations started with Patricia Apenteng and Jane Anderson updating delegates about the latest findings from the African Men Study, a counterpart to last year's qualitative study looking at the lifestyles of African women surviving with HIV in London. This was followed by Priscilla Nkewnti, Deputy Chief Executive of the Black Health Agency, providing a much needed overview of work with African men outside of London. In the last presentation of the morning Reverend Rowland Jide Macauley described the highs and lows of running Club Afreaka, a nightclub for African men who have sex with men funded

by Camden Primary Care Trust. The afternoon research methods session was chaired by Clement Musonda, from the Organisation of Positive African Men (OPAM). After a brief presentation from Gillian Elam, an experienced qualitative researcher from the Health Protection Agency, delegates discussed some of the challenges encountered when conducting qualitative research with black and minority ethnic populations.

The day was brought to a close by Dr Jane Anderson in her new capacity as Co-chair of the AHRF. She replaces Dr Kevin Fenton, who has taken a position with the Centre for Disease Control in Atlanta, USA. Dr Fenton will continue to be part of the AHRF steering committee and plans to return for the eighth seminar day in May 2005.

For more detailed descriptions of the presentations and to download copies of the slides, please visit our website: www.ahrf.org.uk

Men From Africa Living with HIV in London: A qualitative study Jane Anderson & Patricia Apenteng

Dr Jane Anderson, Consultant Physician at Homerton University Hospital, began by updating delegates on the background epidemiology of African men with HIV. According to data from the Health Protection Agency, an estimated 1022 African men were diagnosed with HIV in 2003, representing 28% of all men diagnosed that year. The median age at diagnosis is currently 35-40 for men and 30-35 for women reflecting what has been seen in studies in African countries. The intention of the study is to document the circumstances

of men with HIV from African backgrounds in London and explore their health and social care needs and experiences. Patricia Apenteng, presented the current results based on answers to a questionnaire given to the 37 men (35 heterosexual, 2 men who have sex with men), from 12 African countries, who have completed the study so far.

The men, recruited from four hospitals in East London, had all been diagnosed with HIV for at least 6 months and been in the UK for at least 6 months. The majority of the men were from Uganda, Zimbabwe and Zambia and aged between 30 and 44. Half of the participants had been in the country for over 4 years, although fewer than half had

completed their dealings with the Home Office. Just over half the men (54%) were married or living as married and although 73% of the men had children only a third lived with those children. The men were highly educated with 63% having received A'level qualifications and above. However, 39% of the men had never had a paid job in the UK. The majority of men knew their current CD4 count and viral load.

The research team is now carrying out a framework analysis of the in-depth interviews with the men and trying to identify emerging themes. The results and a report on the study should be available in the latter half of 2005.

Interventions with African men in northwest england

Priscilla Nyah Nkwenti

Dr Nkwenti, Deputy chief Executive at the Black Health Agency, (BHA), began her presentation by setting the context of BHA's prevention work. Although there are large numbers of Africans living in the London region, the policy of dispersal has seen a the growth of African communities in the North of England. There are an estimated 15,481 Africans in the north of England, approximately 10,200 of which live in the Greater Manchester area. The 1991 census data estimated there were around 3000 Africans living in the city of Manchester. The 2001 census data estimated this population at 6655 illustrating the changing population

dynamics in that area. The region houses a number of people living with HIV. Between January and December in 2003 there were 725 newly diagnosed HIV cases in the region and over 80% of these infections were thought to have been acquired in sub-Saharan Africa.

The African Men's Health Initiative was started in 1999 and produces a wide range of health promotion resources for use with African communities from audio tapes, to posters, cards and videos.

African Men's groups have been reluctant to participate in BHA outreach sessions, preferring to leave health issues to the women. BHA managed to breakthrough and reach African men by going to luncheon clubs, mainly

frequented by retired men. In order to reach the younger student population, BHA recruited young African men to drive the Initiative by going to bars, nightclubs and social events such as weddings and christenings, to promote testing campaigns and disseminate prevention resources.

In concluding Dr Nkwenti raised a number of research areas that the Initiative would like to see explored. She highlighted the need to investigate the varying prevention needs of different generations; research around finding effective ways to engage African men in sexual health work and deconstruct sexual norms and sexual roles in order to determine how these values affect HIV prevention work.

Club Afreaka: An Intervention with African men who have sex with men in London.

John Zavuga &
Rowland Jide Macauley

John Zavuga from the African Health Promotion Team at Camden Primary Care Trust (PCT) gave a brief overview of the PCT's work with African Men. In September the team 2000 held the first African Men's seminar. As well as producing a number of health promotion resources the team also run outreach and training programmes targeting men in social clubs, barbershops and other voluntary groups. In 2003 the team began work with African Men who have sex with Men (MSM). They have a number of projects running with MSM, most notably Tumaini, the first conference for gay Africans in the UK (November 2004) and

Club Afreaka a nightclub for African MSM run by Camden PCT.

Rowland Jide Macauley, is a British, gay pastor of Nigerian descent in charge of organising Tumaini and building and promoting Club Afreaka. The club opened it's doors in July 2003, as a result of suggestions from the 3rd African men's seminar. It runs monthly at the Black Cap in Camden, a friendly, welcoming venue that charges Club Afreaka patrons a limited door price (£1 with a flyer). The club aims to address the sexual health promotion needs of African MSM, whilst increasing their visibility within both the African and gay communities. Every month there is a stall within the club, staffed by experienced health promotion specialists distributing condoms and campaign materials.

A short survey carried out on 110 of the club's patrons showed that the majority of respondents had taken condoms (85%) or received health advice (54%) from the staff. The survey also showed that the music policy, (African rather than "urban" music), which is thought to be a key attendance influencing factor, was enjoyed by 95% of respondents. When asked what their expectations were for future events respondents replied that they wanted to see more male acts such as strippers and musicians from Africa.

Club Afreaka has been successful in raising the profile of African MSM and in providing information about the sexual health needs of this group. The future will probably involve a formal evaluation of the club helping others to replicate the

Developing qualitative research with black and minority ethnic populations

By Gillian Elam

What are the challenges to developing qualitative research with black and minority ethnic populations and how to meet them were some of the questions debated at the last African HIV Research Forum (AHRF) seminar day Research Methods session.

Participants in the seminar gave their views on what they thought the challenges were and I offered some answers, drawing on my experiences of using qualitative methods to research general and sexual health-related topics among Africans in the UK. I suggested that well designed and executed qualitative research conducted by trained interviewers can meet many of the challenges identified by participants. But there are also areas where qualitative research needs to be strengthened to ensure that methods are appropriate, relevant and inclusive. However, some of these methods can raise further challenges of their own and often the key to successful qualitative research with black and minority ethnic populations is the development of research strategies in collaboration with study communities.

Many of the challenges for research identified by participants related to those arising when researching communities for whom English is a second language or comprise a range of dialects. The beauty of qualitative research is that the interview provides an ideal opportunity to explore language and the ways in which people construct their accounts of the social world. The words that research participants use to describe a feeling or experience can provide great insight into understanding phenomena. A good interviewer does not impose their own jargon, but is able to negotiate with an interviewee the appropriate words to use in an interview. Nor would they let words or cultural references slip by without exploring what they meant to the respondent and why the respondent has applied them to their behaviour or circumstances. Qualitative interviews and text-based approaches to analysis provide opportunities for exploring perceptions and attitudes through the language used by respondents to tell their stories. But the ability for interviewers to do this well also depends on community collaboration to agree how research questions should be framed and to inform the design of tools used to collect data. Such collaboration is key in any study, including those led

by community researchers, to ensure that population diversity is represented.

For language-based techniques to succeed, it is imperative to work with translators or conduct the interviews in the relevant community languages. Here the challenge can be cajoling funders to resource studies so that the range of languages used in a population can be included, and for researchers to feel confident enough in pursuing this. Often the scope of such studies ends up being focused on a smaller selection of linguistic population groups. This can be adequate, as long as any sample limitations are openly acknowledged, but there is a danger that more vulnerable groups are omitted because of the limited availability of researchers that can speak minority languages. Such groups may be those who are in greater need, for example the more vulnerable members of the population that have recently migrated, or are isolated in care roles at home that limit opportunities to learn new languages, or are dependent on others to mediate their everyday interactions.

One way of ensuring that interviews are conducted in appropriate languages and that vulnerable ethnic groups are included, is the involvement of ethnically matched interviewers. This is a widely used strategy that has been successfully employed in many studies. However, participants identified further challenges, for example a concern that sometimes confidentiality could be compromised if the interviewer is too close to home with the African study population. This can be addressed by: ensuring that interviewers do not work in their own neighbourhoods; including the names of interviewers in recruitment documents so that potential respondents are aware who is conducting the study; collecting data in anonymised forms; storing data in tamper proof holders until it reaches the research centre; or anonymising interview data. The latter can be time-consuming and requires not just the removal of names, but also any references that may lead to deductive disclosure, for example details of employment or voluntary work. An alternative is to explain to respondents what will happen to their interview data and who will see it within the research team, and then storing data with access limited to those named researchers.

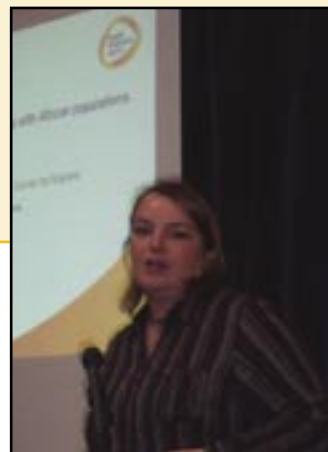
For the interviewer, matched interviewing can be a

challenge too. Matched interviewers often have to draw on a broader skill set than others because in addition to conducting interviews, they may be expected to recruit respondents and translate interviews. During the interview they will have to work hard to adapt their interviewing techniques to remind the respondent to explain any cultural references or practices that respondents may not elaborate on due to assumptions about shared cultural knowledge.

Whilst workshop participants agreed that community researchers were essential, one of the problems faced by researchers engaging with sexual health research among African communities is that the commissioning and funding of such studies tends to be sporadic, providing specialist community researchers with patchy employment opportunities. More does need to be done to invest in the research capacity of African community interviewers and researchers to enable them to develop sustainable research careers and develop their specialist skills in other areas. One approach to this would be to develop a Research Directory so that community researchers could advertise their research and linguistic skills to a broader research and commissioning community.

Moving on from language, other challenges raised included achieving viable samples from such a diverse population as the African UK population. General population studies have used focussed enumeration to improve the representation of black and ethnic minority populations. This involves door-to-door recruitment in electoral wards identified from census data with higher than average black and minority ethnic populations. However, this can be a resource intensive strategy. Often research is with special populations, for example patients, young people or clinic users. Here the challenges include addressing concerns about why Africans are being targeted for research and require dedicated teams of community recruiters who have been sufficiently trained and briefed to feel confident in addressing respondents' concerns. Again, qualitative methods, in the form of purposive sampling, provide a means of rising to this challenge. Those features of diverse populations that are relevant to the research question are identified – another activity best carried out in conjunction with community collaborators - and these are used to guide the selection and recruitment of study participants. A combination of setting sample quotas and ongoing monitoring can ensure that sufficient diversity is achieved to answer the research question.

Participants commented on the difficulties of remaining objective during the analysis of qualitative data and ensuring the reported findings reflected the needs and



Gillian Elam at the 7th AHRF Seminar Day

experiences of the study population. Strategies for analysing qualitative data are well documented and a range of manual techniques and computer packages are available to manage the detail and volume of information generated by qualitative studies. These approaches share some basic tenets to ensure that data handling and interrogation are grounded in the verbatim interview data and that analytical questions are applied systematically throughout the entire dataset. Community review during this process can aid researchers in developing appropriate research questions and challenging any unfounded assumptions.

Finally, seminar participants agreed that it was essential that study communities saw the study outcomes and that promises to disseminate to the community were fulfilled. Putting adequate funding for dissemination in place from the beginning of a study and active participation of community collaborators can help ensure that study findings are accessible.

Throughout the discussion, the central role of community collaborators was clear, but in order for community representatives – who include volunteers and those from poorly resourced enterprises as well as established organisations - to collaborate fully and equally, then investment is also required to provide financial and technical support so that all sectors of the community are represented, not just those with the resources to do so.

A copy of Gillian's presentation is available on the AHRF website. For further information, contact Gillian at the Health Protection Agency, gillian.elam@hpa.org.uk. Some of the ideas discussed here are further developed in *Ethnicity and Health*, 2003; 8(1):15-27. *Researching Sensitive Issues and Ethnicity: Lessons from Sexual Health*, Gillian Elam and Kevin Fenton. Further information about qualitative computer analysis packages can be found at <http://caqdas.soc.surrey.ac.uk/>

Research Update

This section reports research news sent in to AHRF News by members of the Forum or announced at the 7th seminar day.



Key Focus

DIPEX MODULE ON HIV

Jonathan Elford, Damien Ridge, *City University London*; Jane Anderson, *Homerton University Hospital*; Ian Williams, *Royal Free and University College Medical School*; Sue Ziebland, *University of Oxford*

More than 50 million people worldwide seek health information through the Internet. The advantages of getting information through the Internet include its privacy, anonymity and convenience. In the light of its increasing popularity, we are studying what role the Internet could play in relation to HIV infection. In particular, could the Internet provide support to people with HIV, improve their knowledge of services and treatments, help overcome stigma and also play a part in preventing HIV transmission? This research is being conducted in two stages from 2004-2006.

In the first stage we will construct a DIPEX module on HIV. This is an Internet website based on the experiences and narratives of people living with HIV. DIPEX (personal experiences of health and illness) is a charity that produces a unique website with video and audio clips from interviews in which people describe their experiences of health and illness. All participants give fully informed consent before the video and audio clips are put on the website. Between 40-50 people with HIV will be recruited from HIV treatment clinics mostly in London, Brighton, Manchester. People with HIV will come from a wide range of backgrounds and include gay men as well as people from African communities. The interviews will explore each participant's experience of HIV infection including their diagnosis, HIV testing, stigma, disclosure of their status, use of services, HIV treatments as well as sexual behaviour. Video and audio clips in which people talk about these different topics will then be loaded onto the website.

In the second stage, we will explore the possibility of using the narratives and experiences on the DIPEX HIV website for providing support to people with HIV and those at risk of infection. The question we will ask is whether the narratives and experiences available online could lend themselves to web-based interventions. The online interventions will focus on making it easier for people to disclose their HIV status, seek an HIV test, improve their knowledge of HIV treatments and services as well as preventing the transmission of HIV. We will "market-test" the online narratives in focus groups with a diverse range of people who might use the website.

In addition, the DIPEX Internet module could make the narratives and experiences of people living with HIV available to an enormous audience which would lead to a greater public understanding of HIV.

The **Mayisha II Research** team would like to report that the fieldwork for the study was completed at the end of 2004 and is currently being analysed. They would like to thank the fieldworkers and collaborators for their hard work on the study and look forward to presenting results shortly at an AHRF seminar day

Catherine Dodds from Sigma Research announced that they have recently completed a Study on stigma and HIV. The report "*Outsider Status: Stigma and Discrimination experienced by Gay men and African people with HIV*" will be released in December 2004. Please visit www.sigmaresearch.org to download a copy.

Clement Musonda, from the Organisation of HIV Positive African Men (OPAM) reported that a recent investigation into drug and substance misuse and African Men has come to an end. The results of the study should be available for dissemination in December 2004

To include your research news in this section please contact us at African HIV Research Forum, 4th Floor, Mortimer Market Centre, off Capper Street, London WC1E 6AU or email info@ahrf.org.uk

For more information about other research activities please see our website : www.ahrf.org.uk

Africans in Japan

by Ibi Fakoya

In December 2004 I spent a week in Japan as the guest of Masaki Inaba, HIV/AIDS coordinator of the African Japan Forum (AJF). Founded in 1994 this Japan-based NGO has been working to build solidarity between African and Japanese civil society through networking, advocacy and information provision. The main purpose of my visit to Tokyo was to speak at a two day International Symposium "Immigrants and HIV/AIDS in Japan: Strengthening International Networks for care support and advocacy" organised by AJF in conjunction with Share (Services for Asian and African Regions), ayus: Network of Buddhist Volunteers and Criativos – Centre for reference and Support on HIV/STD.

Japan is a relatively homogenous society with just 2% of its population coming from a non-Japanese background. Migrants are disproportionately represented in the Japanese HIV/AIDS epidemic (25% of the 20,000 reported cases). The bulk of migrants living with HIV are undocumented and therefore not entitled to the health insurance systems used to pay for HIV treatment and care.

There are an estimated 30,000 Africans living in Japan, mainly Nigerians (6-8000), Ghanaians (5-7000), Ugandans (3000) and Guineans (2000). Africans from other countries such as Senegal, South Africa Tanzania and Ethiopia are represented in smaller numbers. The majority of Africans in Japan are undocumented male migrant workers employed in the car industry and other factories. Although Africans in Japan live in established communities those who are undocumented are often isolated, choosing to stay away



Workshop at the "Immigrants and HIV/AIDS in Japan" Symposium

from community groups and events for fear of deportation by immigration authorities.

Africans make up around a third of the numbers of migrants living with HIV. As is the case in the UK, a large number of those who test HIV positive do so having been admitted to hospital after presenting with an AIDS defining illness. Because the overall prevalence in Japan is low, HIV prevention activities are few and far between, especially for migrants. Language barriers and cultural differences make it very hard for migrants to access the few voluntary counselling and testing centres.

Once diagnosed migrants also find it very difficult to access healthcare. In addition to language barriers and cultural differences, the cost of treatment for migrants without insurance is prohibitive, more than US\$16,000 compared with US\$200-300 for the insured. HIV is seen as a disease that affects people living in other countries and very little exists in the way of charitable aid for those who cannot find the money for treatment. HIV positive Africans also find it difficult to find secure income and housing, since illness might prevent them from working regularly. The lack of input from Japanese civil society means that social support in the form of community groups, patient groups and charitable social care is unavailable to a lot of people living with HIV.

When immigration authorities eventually catch up with undocumented Africans, the outcome of such an encounter can be catastrophic for those

living with HIV, as Margaret Mawanda from the Mildmay Hospital in Uganda told delegates at the *Immigrants and HIV/AIDS in Japan* international symposium. Generally, Japanese authorities do not prosecute undocumented migrants, but will hold them in detention while they await deportation. Mrs Mawanda told the story of a Ugandan woman living in Japan who, having overstayed her visa, eventually came across the immigration authorities who detained her. While awaiting deportation she fell ill and was diagnosed with tuberculosis and HIV, but was treated for neither infection. She was deported shortly afterwards even though she was gravely ill and arrived in Uganda on the point of death. She collapsed at the airport, but fortunately, was rushed to Mildmay hospital where she had her TB successfully treated and was started on anti-retroviral therapy. Clearly, the cost to both public and individual health far outweighed any potential financial cost of emergency treatment in such a case. Yet this case is not unique; indeed another panellist at the symposium Payap Ranarathorn, a social worker from Thailand, said that he had come across a number of Thai people that had similar experiences with Japanese immigration authorities, as emergency treatment for HIV is not guaranteed for those without insurance.

At the end of the two-day symposium panellists and delegates were invited to review draft recommendations for a new Japanese national policy on HIV/AIDS and immigrants. In addition to asking that the government consider universal access to HIV treatment the symposium recommended that:

Continued overleaf ▶

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culturally appropriate VCT services be established; medical treatment be carried out with interpreters and with informed consent; emergency care is a human right and the health care system must be modified to accommodate this and HIV prevention activities must be improved.

I have yet to hear how the Japanese government has responded to these recommendations but the symposium itself was a great success. In a country like Japan, where both awareness and prevalence of HIV is low, symposia such as this are an excellent way to improve civil society mobilisation. It is imperative that this mobilisation continues and NGOs formulate strategic networks that actively seek to involve members of migrant communities. Three African people, from the Ugandan Association in Japan, were the only non-Japanese delegates at the symposium, illustrating how far Japanese NGOs have to go to get community participation in research and health promotion. Although there

may not be many professional Africans living in Japan there is the potential to capacity build through Embassy and home country patronage. There is a need to involve not only Japanese students interested in African issues, (who were amply represented at the symposium), but also African students studying in Japan.

Japanese NGOs are now building networks with organisations in other developed countries making it harder for the government to continue to underestimate the importance of HIV. I look forward to plenty of collaboration between UK and Japanese organisations and hope that shared knowledge will go a long way to improving the lives of migrants in both countries.

Ibi Fakoya is a Research Assistant at the Migration Ethnicity and Sexual Health (MESH) Programme, University College London. A copy of the slides Ibi presented in Japan, entitled "Africans, Migration and HIV in the UK" is available on the AHRF website.

NAHIP Health Promotion Skills Development Training Course

This National African HIV Prevention Programme (NAHIP) accredited course is divided into three sections comprised of stand-alone modules that will run between April and December 2005. It aims to provide attendees with the technical expertise to deliver successful and effective HIV prevention interventions to African communities.

Section 1: Knowledge and understanding of key components of HIV prevention with African Communities (Starts April)

Section 2: Developing and delivering HIV prevention interventions (Starts September)

Section 3: Evidence based planning, monitoring & evaluation of prevention interventions. (Starts October)

Modules are free. Application forms and further information about the training programme, including the learning outcomes for each module, can be downloaded from www.nahip.org.uk/training. For more information or to request an application form please contact Fletcher Phiri on 020 8741 1879 or email phiri@naz.org.uk.

Visit the African HIV Research Forum Website.

The AHRF website is a community resource, accessible to all those interested in UK African HIV issues. The site is updated weekly and provides information about forthcoming events; research findings, job



vacancies, funding available and much more. If you would like to publicise a conference or tender or announce research findings please feel free to contact us at info@ahrf.org.uk or go to www.ahrf.org.uk/contact_us1.htm and follow the instructions.

Call for papers

The next issue of AHRF News will be a Prevention Update and is due for publication in **May 2005**. We welcome submissions about your research findings and research news from individuals involved in the African HIV sector. Additionally, if you would like to update us about your prevention activities or to submit an article about an event you have hosted, please send your article to the address below. Submissions should be no longer than 1000 words. If you are posting your submission please ensure you include an electronic copy on a PC formatted floppy disk.

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