



Improving information about HIV and sexually transmitted infections among the UK African population for UK health professionals

Feedback from the SESA Conference

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Forward

It is a pleasure to introduce the first report of our Special Emphasis Surveillance Activity (SESA) conference on African communities in Britain. This represents a further strengthening of our initiatives to improve access to, and utilisation of, information on the sexual health of these communities. In this our first conference report, we bring together information on the HIV and STI epidemics in Britain, the behaviours that underpin their transmission, and outline ways in which the Health Protection Agency may further improve the dissemination of information to our stakeholders.

Since hosting this conference, the HPA and our UK Collaborative Group for HIV and STI Surveillance partners have published our 2004 annual report "Focus on Prevention", available at www.hpa.org.uk/. This contains more up-to-date epidemiological data as well as information on the outcomes of several national prevention programmes. Taken together, we hope that both reports will continue to improve the utility of the available surveillance and research information on HIV and STIs among Africans in Britain today.



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Improving information about HIV and sexually transmitted infections among the UK African population

Feedback from the SESA Conference

Summary

Introduction

Special emphasis surveillance activities (SESA) were established by the HIV and Sexually Transmitted Infections Department at the Communicable Disease Surveillance Centre (CDSC) during 2003 with the aim of providing a more integrated, prevention-orientated approach to surveillance among populations in the UK that are disproportionately affected by HIV and STIs. During February 2004, over 100 representatives from agencies and community groups working with African populations in HIV prevention, treatment, surveillance and research activities gathered for the first of the conferences to emerge from the Centre's special emphasis surveillance activities.

Conference Aims

The SESA conference was hosted by the Communicable Disease Surveillance Centre with the aim of improving access to information about HIV and STIs among those working with populations in the UK that are disproportionately affected by HIV and STIs. The objectives of the conference were to:

- raise awareness of the range of activities at CDSC that generate data on the epidemiology of HIV and STIs among Africans in the UK;
- obtain feedback from professionals working with African populations on their information needs and views on the data produced by CDSC;
- provide insight into the latest trends in HIV and STIs among the UK African population; and
- explore ideas for enhancing data outputs.

Feedback from participants

The conference programme was structured to provide participants with opportunities to share their experiences of accessing and interpreting information about HIV and STIs. CDSC scientists presented the latest data for the UK (summarised in Section 3) and facilitated small discussion groups with participants to explore reactions to current trends and to identify ways of improving the coverage and dissemination of data reported by CDSC (discussed in Section 4). Participants then provided feedback from their discussion groups to the rest of the conference. A copy of the conference programme is included (see appendices).

Respondents to the evaluation questionnaire agreed that the conference provided insight into the

latest trends in HIV and STIs and that the presentations were informative. Despite excellent feedback, many participants commented that the presentations tended to be too technical or contained jargon. However, the vast majority left the conference feeling that the event had raised awareness of activities at CDSC and that they had learnt something new. In terms of discussion, there was sufficient time for this. The discussion groups were regarded as being useful, particularly the focus group moderation and the opportunity to share views and review issues with others from similar professional backgrounds interested in the same data. Respondents had been able to express their information needs and views of CDSC data and agreed that the conference had provided opportunities to explore ideas for enhancing data and to share views.

Key issues emerging from the conference

African men who have sex with men were identified by workshop participants as a group that was regarded as poorly represented in UK HIV and STI surveillance data. Cultural perceptions of same-sex activity and masculinity together with worries about discrimination or exclusion were thought to prevent some African men from feeling confident about disclosing their sexuality or same-sex experiences when they test for HIV, are first diagnosed or first seen for treatment. Consequently, any same sex activity that may have arisen is not identified during the routine reporting activities that occur in clinics and are used to inform national surveillance data. Conference participants were concerned that prevention initiatives and the development of appropriate treatment pathways would not reflect the needs of African men who have sex with men if this group remained under-represented.

Participants also discussed problems in obtaining comprehensive ethnicity data and felt that improvements could be made to the collection of ethnicity data during clinical reporting. There was a perception that ethnicity data could contain discrepancies due to variance in both the assignment of a patient's ethnicity by health professionals and in self-assigned ethnicity.

Surveillance data, particularly SOPHID data, was put to a wide range of uses by conference participants in their different areas of planning,

training prevention and treatment related work. Participants stressed the importance of accurate data in fulfilling these needs. More information about Africans living outside London was requested as well as more locally specific information, greater coverage of other regions outside London and guidance on the relevance of national trends to local situations. Commissioners required evidence to further understanding of the care needs of Africans. Requests were made for training in how to use surveillance data, surveillance systems and the role of the HPA, for example what the HPA can and cannot do in terms of data provision and better management of expectations of the HPA's services and outputs. Participants were sometimes unclear about how to analyse and interpret data, the uses that could be made of it and which datasets were appropriate their different information needs.

Participants queried a perceived focus on skin colour in the categorisation of HIV diagnoses, inferred by the use of the term 'black African' in data outputs. Some regarded the use of the term 'black Africans' in data categories as stigmatising and expressed the view that such terminology could sometimes be offensive. There was also a view that such categorisation led to the needs of other significant African populations in the UK being overlooked, for example Asian / Indian-Africans, East Africans, North Africans and Somalis. There was a view that country of infection would be a more appropriate form of categorisation, but also a concern that estimates of the probable country of infection were driven by in-country prevalence at the expense of other explanatory factors. There was also a perception among some that the HPA could be over sensitive regarding adverse reactions to publicising routes of transmission or country of acquisition and as a consequence not provide sufficient information regarding where Africans living with HIV in the UK acquired the virus or which communities were at risk and in need of targeted services.

The addition of a social science dimension to data outputs to aid interpretation and understanding of the data was widely supported by conference participants. Contextual information, for example socio-economic data and links to other data sets such as Home Office data was regarded as essential in the application of surveillance outputs to the formation of appropriate prevention and treatment initiatives. Better understanding of demographic factors aside from ethnicity was requested, for example common features of the experiences of young African and Caribbean people.

A number of problems in accessing surveillance data were identified, the most significant of which was difficulty in finding HIV and STI data on the existing HPA website. Other problems included:

- Difficulties encountered downloading graphs from website;
- Fearfulness and lack of clarity about how local data can be used when it is issued with the proviso that it is confidential and should not be repeated; and
- Where to access quarterly figures on a regional basis.

Recommendations

Surveillance activities

- Investigate concerns that black African men who have sex with men (MSM) may not disclose same sex activity when seen for care and are under-represented in surveillance data. Consult with clinicians regarding ways of improving disclosure and reporting.
- Enhance surveillance activities with social research to provide interpretation and contextual explanations and further understanding of care needs.
- Investigate reasons why more women than men are included in reports of newly diagnosed infections.
- Review reporting of ethnicity data and whether improvements are required.

Delivery of surveillance data

- *Data categories*
 - Review the categorisation of data by ethnicity, nationality and route and country of infection and provide rationale for use of term 'black African'.
 - Consider use of census age categories.
- *Website*
 - Improve the site so that it is more user friendly, for example better signposting and shorter pathways to HIV and STI data;
 - Core tables relevant to the black African population are highlighted and located together to improve access
- *Access*
 - Presentations and written outputs to use simple, non-jargonistic language that can be understood by data users that do not have training in statistics or epidemiology.
 - More data that is relevant to the regions outside London, guidance on where to access regional data on a regular basis and how to use local data that is issued on a confidential basis.
 - Inclusion of explanations for statistical terminology and technical language.

Support for users of surveillance data users

- Repeat the SESA conference on a regular basis.
- Publish regular thematic briefings.
- Issue guidance on how to use surveillance data and which data is suitable for different uses, for

example clinical work, target community groups' activities or to plan and commission services.

- Tables and charts to include narration on their layout and content, guidance on interpretation and limitations; implications for prevention; and social science perspectives.
- Provide guidance on access to regional data and how to apply national and regional trends to local situations.
- Publicise guidance on the role of the HPA, alternative sources of information and appropriate contact points within CDSC.

Overall, the conference was regarded as a useful forum for improving access to the data and requests were made for events such as this to be repeated and similar events exploring the impact of HIV and AIDS on black Caribbeans and focussing on STI data.

1 Introduction

During February 2004, over 100 representatives from agencies and community groups working with African populations in HIV prevention, treatment, surveillance and research activities gathered for the first of the HPA, Centre for Infections, Communicable Disease Surveillance Centre's (CDSC) conferences to emerge from the Centre's special emphasis surveillance activities (SESA).

SESA groups were established by the HIV and Sexually Transmitted infections Department at CDSC during 2003 with the aim of providing a more integrated, prevention-orientated approach to surveillance among populations in the UK that are disproportionately affected by HIV and STIs. SESA groups seek to achieve this by working with users of surveillance data to foster focussed and integrated approaches to the utilisation and dissemination of HIV / STI surveillance data and to ensure that those involved in sexual health promotion, disease prevention and policy development are aware of the work of CDSC and kept abreast of changes in sexual health outcomes and disease epidemiology. Specific objectives of the SESAs are to:

- Critically examine and, where appropriate, develop current HIV / STI surveillance data in order to improve information available on target groups, including reviewing existing HIV / STI surveillance data, making recommendations for improvement and identifying key indicators for monitoring;
- Ensure timely dissemination of relevant surveillance data to key stakeholders working with target groups, including publication of annual SESA reports;
- Take a lead in developing and refining the media response to questions related to the interest group;
- Develop academic and research activities in collaboration with external colleagues;
- Facilitate liaison with key stakeholders within and outside the HPA regarding the appropriate use and dissemination of surveillance data, including identification of key stakeholders and meeting their representatives to discuss and review current surveillance data; and
- Develop and up-date fact sheets for public dissemination and produce integrated surveillance reports and publications on for specific target groups.

The UK African population formed the focus of this first in CDSC's series of SESA conferences. The prevalence of heterosexually acquired HIV infections in the UK, including those amongst pregnant women and the numbers of new HIV diagnoses, continues to reflect the focus of the pandemic in sub-Saharan African countries with close social, economic, migration and travel links to the UKⁱ. The 2003 annual report issued by the HIV and Sexually Transmitted Diseases Department, 'Renewing the focus'ⁱⁱⁱ, reports that, of heterosexually infected patients seen for care in 2002, 68% were black-African, a 330% increase since 1997. Undiagnosed HIV infection and late diagnosis of long-standing HIV infection remain features of the treatment histories of black African heterosexual men and women, particularly men and those living outside of London. However, the transmission of HIV from mother to child in the UK has been greatly reduced since the introduction of universal offer and recommendation of HIV testing in pregnancy.

2 Conference aims

The conference was hosted by the Communicable Disease Surveillance Centre with the aim of improving access to information about HIV and STIs among those working with populations in the UK that are disproportionately affected by HIV and STIs. This first conference focused on African populations. The conference brought together HIV prevention and care professionals working with African populations from a range of perspectives, including: genito-urinary

medicine (GUM) and sexual health, health promotion, research, commissioning, policy making, clinical, community groups and epidemiology.

The objectives of the conference were to:

- Raise awareness of the range of activities at CDSC that generate data on the epidemiology of HIV and STIs among Africans in the UK;
- Obtain feedback from professionals working with African populations on their information needs and views on the data produced by CDSC;
- Provide insight into the latest trends in HIV and STIs among the UK African population; and
- Explore ideas for enhancing data outputs.

The conference programme was structured to provide participants with opportunities to share their experiences of accessing and interpreting information about HIV and STIs. CDSC scientists presented the latest data for the UK (summarised in Section 3) and facilitated small discussion groups with participants to explore reactions to current trends and to identify ways of improving the coverage and dissemination of data reported by CDSC (summarised in Section 4). Participants then provided feedback from their discussion groups to the rest of the conference. A copy of the conference programme is attached.

3 Conference proceedings

3.1 Diagnosed HIV

Diagnosed prevalence of HIV

The conference opened with a description of the Annual Survey of Prevalent HIV Infections (SOPHID). This survey collects residential and epidemiological data on all diagnosed individuals seen for HIV-related care within a calendar year. The 2002 data shows a 20% increase in the numbers being seen for care since 2001. Black Africans comprise over a third of all people reported as being seen for care during 2002 and account for much of the recent increase in numbers. Of the 9,712 black-Africans seen for care in 2002, they were mainly heterosexually infected (88%), the majority of whom were women (67%) and age 25 to 39 years (63%). Six per cent of black African men seen for care were infected through sex between men. The majority of black Africans are treated in their Strategic Health Authority (SHAs) of residence. Since 1997 there has been an increase in the numbers being seen for care in the SHAs that border London. Participants were interested in explanations for the 25% drop out rate among those seen for treatment and whether these patients re-appeared elsewhere. Other topics of interest included whether some aspects of the data could be explained by route of infection rather than ethnicity; the impact of dispersal of asylum seekers to regions outside London on where patients are being seen for care and the difficulties in tracking the impact of this policy; and mapping SOPHID data by social deprivation indices.

New diagnoses of HIV

New diagnoses include both long-standing infections and recently acquired infections. A new diagnosis is reported via up to four sources: HIV laboratory forms; the Clinician's HIV Report (CHR); AIDS reports from clinics and death records from National Statistics. Data collected includes date of birth, sex, route of infection, date and place of diagnosis and ethnicity. UK data results from the combined efforts of CDSC, Scottish Centre for Infection and Environmental Health; and the Institute of Child Health. Country specific data are based on country of infection, country of birth and usual country of residence. New diagnoses data are used to indicate changing patterns in HIV diagnoses. AIDS cases and deaths help identify treatment failure and late diagnoses. The data can be accessed via the quarterly surveillance tables which are updated and published on the HPA website every three months. Key tables for understanding the impact of the epidemic on black Africans the UK include tables in series 5, 6, 7 and 12. A slideset, updated twice a year, is also available. Local data is distributed to SHAs via their Consultants in Communicable Disease Control (CCDC). Participants discussed the

disparity between the numbers of men and women recorded as newly diagnosed, with far more women being reported than men. During discussion, different explanations, were offered, for example the reluctance among men to test for HIV; the greater access and uptake to health services among women; and the burden of the HIV pandemic in sub-Saharan Africa on women, but participants felt that more work was required in order to establish explanations for this phenomena that could inform prevention initiatives.

Late diagnosis of HIV

Systems for monitoring late diagnosis of HIV infected adults and its relevance to treatment and prevention were described. AIDS diagnosis or a CD4 count under 200 cells/mm³ are markers of late diagnosis. These data indicate that despite declines in the overall number of late diagnoses over time, CD4 data indicate that newly diagnosed black African individuals are more likely to be diagnosed late than white individuals diagnosed in London. AIDS data suggest that heterosexuals are more likely to have AIDS at the time of their diagnosis than men who have sex with men, and that black Africans, particularly men, are more likely to be diagnosed late.

AIDS and Tuberculosis

The latest knowledge regarding co-infection with HIV and TB was discussed during this session. TB is a major cause of morbidity and mortality among people living with HIV, but unlike HIV, TB, a notifiable disease, is curable. Reporting for both diseases is currently via clinician and laboratory reports. Since 2000, the percentage of AIDS diagnoses reporting TB has been rising. Matching of a TB dataset, created from merged TB laboratory reports and TB enhanced surveillance from clinician reports, with a HIV data set comprising laboratory and clinician reports permits a limited investigation into TB-HIV co-infection. Analysis of matched data reveals that 2.7% of TB patients in the 1998-2000 dataset were co-infected with HIV, however, this is likely to be a considerable underestimate. HIV status is not always reported for TB patients and TB may not be reported for HIV patients, especially those previously diagnosed with another AIDS defining illness. Results from London hospitals suggest co-infection reports as high as 17 to 25%. Of those TB patients in the 1998-2000 dataset who were co-infected with HIV the majority are black African and live in London. Nearly two-thirds are male and three-quarters were born abroad. The rising numbers of co-infected individuals and limitations of the dataset suggest that the matching exercise needs to be improved, and further research into TB-HIV co-infection is required.

Epidemiology of HIV among Africans in Scotland

As in the rest of the UK, the rising number of reports of heterosexually acquired HIV in Scotland over the past ten years or so reflects the focus of the HIV pandemic in sub-Saharan African countries with close links with the UK. The majority of HIV diagnoses among Africans living in Scotland are among women aged under thirty-five years and around a third report exposure in Zimbabwe. Diagnosis of HIV tends to be in the Greater Glasgow or Lothian regions, but there are also significant reports in Grampian and the rest of Scotland. Diagnoses occur in hospital outpatients, GUM clinics and counselling clinics and, as in the rest of the UK, late diagnosis is a feature of the treatment histories of Africans in Scotland.

3.2 Undiagnosed HIV and STIs

Monitoring overall and undiagnosed prevalence of HIV

The Unlinked Anonymous Prevalence Monitoring Programme (UAPMP) monitors both diagnosed and undiagnosed HIV infection levels among groups perceived as being at increased risk of infection and those at lower or general risk. The monitoring programme tests residual, routinely taken blood samples for HIV from: syphilis samples from a survey of 15 GUM clinic attendees; surveys in pregnant women based on antenatal booking bloods, dried blood spots / Guthrie bloods and pre-op blood typing samples in selected regions of London and the rest of England; and tests voluntary oral fluid samples from intravenous drug users (IDUs) in contact with services. These samples are irreversibly unlinked from patient identification prior to HIV testing and limited demographic and exposure data are retained. The survey of GUM clinic attendees indicates that the prevalence of previously undiagnosed HIV infections among gay and bisexual men has decreased dramatically since 1999, however, the prevalence among

heterosexuals, particularly sub-Saharan African born, has continued to increase. The surveys in pregnant women report a small, but persistent increase in overall prevalence of HIV infection in pregnant women, particularly among those resident in inner and outer London and additional analysis of the enhanced dried blood spot survey that links samples to birth registration records while maintaining the unlinked and anonymous status of this survey, indicates that this increase is predominately among women born in sub-Saharan Africa.

Diagnoses of HIV among pregnant women

For HIV infected pregnant women, avoidance of breastfeeding, use of antiretroviral therapy antenatally, during delivery and for the infant and elective caesarean section delivery can reduce the likelihood of transmission of HIV from mother to baby from a 1 in 4 chance to around 1%. However, these interventions can only be offered to pregnant women who are aware of their HIV infection. National HIV testing targets state that an HIV test should be offered and recommended to all pregnant women along with other screening tests as an integral part of antenatal care and that this offer should be recorded. Data combined from the UAPMP survey of pregnant women and the National Study of HIV in Pregnancy and Childhood carried out by the Institute of Child Health are used to provide an estimate of the proportion of maternal infections diagnosed. Results to 2002 indicate that since universal implementation of the national testing programme among pregnant women, the proportion of HIV-infected pregnant women diagnosed before delivery has continued to increase and the proportion of exposed children becoming infected with HIV has been decreasing.

The epidemiology of N. gonorrhoeae in black Africans in England and Wales

The Gonococcal Resistance to Antimicrobials Surveillance Programme (GRASP) comprises isolate collection among 26 participating GUM clinics and laboratories. Clinical, demographic and behavioural data is collected retrospectively from the participating clinics. Results from the programme indicate that gonococcal infection is concentrated in urban areas and among three population sub-groups: young women aged 20 years or less; gay and bisexual men; and black ethnic groups. The majority of infections diagnosed among black ethnic GRASP GUM clinic attendees are among black Caribbean men and women. A smaller proportion of infections occur among black Africans (5% of the total GRASP collection) and these are mainly in heterosexual men (71%) and to a lesser extent, women and gay and bisexual men. Three in four black Africans identified in GRASP live in London. Gonococcal infections diagnosed in black African women tend to be among those aged 16 to 24 years, whereas among both heterosexual and gay and bisexual men, they are highest among those aged 25 to 34 years. Co-infection with chlamydia for women and heterosexual men is common whereas co-infection with syphilis is a feature of diagnosis among men who have sex with men. There is no significant difference in the prevalence of antimicrobial resistance in black Africans compared to other ethnic groups.

4 Feedback from discussion groups

4.1 Perceptions of groups under-represented in surveillance data

African men who have sex with men (MSM) were identified by workshop participants as a group that was regarded as poorly represented in UK HIV and STI surveillance data. Conference participants were concerned that prevention initiatives and the development of appropriate treatment pathways would not reflect the needs of African men who have sex with men if this group remained under-represented.

The reasons for the under-representation of African men who have sex with men were perceived to include:

- African men in the UK tend not to take up voluntary HIV testing; and
- Among those that do test and are diagnosed with HIV, cultural values and stigmatisation of same sex behaviour in the African community leads to:

- under-reporting of same-sex transmission; or
- information relevant to the transmission route only surfaces at later stages of patient's interactions with health professionals, some time after completion of HIV and AIDS surveillance-related reports.

Participants, including clinicians involved in completing the CHR, shared the view that for African men who have sex with men, disclosure of information regarding sexual behaviour and transmission route is a process. Cultural perceptions of same-sex activity and masculinity together with worries about discrimination or exclusion prevent some African men from feeling confident about disclosing their sexuality or same-sex experiences when they test for HIV, are first diagnosed or first seen for treatment. Consequently, any same sex activity that may have arisen is not identified during the routine reporting activities that occur in clinics and are used to inform national surveillance data.

Conference participants had a number of suggestions to improve the representation of African men who have sex with men in surveillance reports:

- Although there is an open comment field on the CHR for new diagnosis, participants wanted the reporting of individual patient information to include more opportunities to 'unpack' and explain perceptions of transmission routes rather than relying on tick boxes;
- Clinician's HIV reports do sometimes include expressions of uncertainty regarding the patient's probable route of transmission in the CHR, however participants were not all aware that this was an option when making reports, and that such reports were followed up by Research Nurse Epidemiologists in the Department;
- Develop ways of encouraging patients to talk more openly about their sexual behaviour and risk episodes;
- Target African men for knowledge of status / HIV testing interventions;
- Follow-up African men for whom the route of transmission is possibly related to same-sex activity to establish whether this is the main factor; and
- Finally, participants expressed interest in country of infection data for MSM. This data is included for MSM, but missing data is not followed up as is done for heterosexuals.

Participants also discussed problems in obtaining comprehensive ethnicity data and felt that improvements could be made to the collection of ethnicity data during clinical reporting. There was a perception that ethnicity data could contain discrepancies due to variance in both the assignment of a patient's ethnicity by health professionals and in self-assigned ethnicity. Participants suggested that it would be useful to identify ways of improving data collected at GUM level to reflect ethnicity and to improve ethnicity reports.

4.2 Uses made of surveillance data by conference attendees

Surveillance data, particularly SOPHID data, was put to a number of uses by conference participants in their different areas of work, including:

- Training and awareness raising of HIV and STIs in the community, among employees, with organisations and community groups, and among risk populations, for example young people;
- As a management tool to plan HIV prevention interventions with the African population;
- Confirm experiences in the field and provide evidence of need;
- Provide evidence in support of service development and funding;
- Inform efforts to increase access and reduce prejudice;
- Head count of numbers requiring specific prevention and treatment-related services; and
- Develop health promotion activities.

Participants stressed the importance of accurate data in fulfilling these needs. Some concerns were raised regarding the relevance of surveillance data to the range of information needs present among sexual health care and prevention professionals, for example:

- More information about Africans living outside London was requested as well as more locally specific information and greater coverage of other regions outside London;
- Guidance on the relationship between national and local data was sought, for example the extent of variance between national and local trends and the relevance of national trends to local situations. Participants questioned how far national data could be applied to local situations and wanted guidance on understanding regional variations; and
- Commissioners required evidence to further understanding of the care needs of Africans.

Participants also raised specific questions regarding the data, for example reasons why women present later diagnosis. Participants also wanted to see more data regarding: period of infection; incidence; country of origin data and contextual information. In particular, participants wanted data outputs to include social science and behavioural perspectives to aid understanding of the epidemiology of HIV in the UK and its impact on the African population. A request was also made for guidance on surveillance systems and the role of the HPA, for example what the HPA can and cannot do in terms of data provision and better management of expectations of the HPA's services and outputs.

A request was made for training in how to use surveillance data. Participants were sometimes unclear about how to analyse and interpret data and the uses that could be made of it. Guidance on which surveillance data sets are appropriate for the different uses professionals are likely to make of the data was highlighted as a major information gap by conference participants. Participants expressed difficulty in understanding which data would be useful to them and felt that an overview of possible uses of surveillance data would be useful. Indeed, many regarded the SESA conference as a much needed training event.

4.3 Analytic categories used in data outputs

Participants queried a perceived focus on skin colour in the categorisation of HIV diagnoses, inferred by the use of the term 'black African' in data outputs. Some regarded the use of the term 'black Africans' in data categories as stigmatising and expressed the view that such terminology could sometimes be offensive. There was also a view that such categorisation led to the needs of other significant African populations in the UK being overlooked, for example Asian / Indian-Africans, East Africans, North Africans and Somalis. Participants noted that different descriptors regarding people of African origins in the UK were in use, including 'Africans', 'black Africans' and 'African communities'.

There was a view that country of infection would be a more appropriate form of categorisation, but also a concern that estimates of the probable country of infection were driven by in-country prevalence at the expense of other explanatory factors. Participants wanted to know why some data outputs were categorised by nationality and to see the development of a rationale for ethnicity variables. Others wanted access to more data about African communities from different countries and analysis of sub-populations. There was also a perception among some that the HPA could be over sensitive regarding adverse reactions to publicising routes of transmission or country of acquisition and as a consequence not provide sufficient information regarding where Africans living with HIV in the UK acquired the virus or which communities were at risk and in need of targeted services.

A suggestion was also made for the age categories used in the census to be applied to SOPHID data, this improving comparability with other datasets.

4.6 Improvements to the data commentary

The addition of a social science dimension to data outputs to aid interpretation and understanding of the data was widely supported by conference participants. Contextual information, for example socio-economic data and links to other data sets such as Home Office data was regarded as essential in the application of surveillance outputs to the formation of appropriate prevention and treatment initiatives. Participants wanted to see a stronger relationship with psycho-social science perspectives and for HIV and STI epidemiology to be presented in relation to the 'bigger picture' regarding social aspects of disease and inequality. Better understanding of demographic factors aside from ethnicity was requested, for example common features of the experiences of young African and Caribbean people.

Other changes to data outputs that would improve understanding and appropriate use included:

- Narration of key points and full descriptions of the layout and content of tables and graphs;
- Use of simple language and clear explanations and descriptions that can be understood by non-scientists;
- Explanations of statistical terminology and technical language;
- Making the links between key findings and implications for prevention more visible;
- Guidance on to how to use the data and the target audience / user groups for different data sets; and
- Direction on any limitations of the data.

4.7 Accessing data

A number of problems in accessing surveillance data were identified, the most significant of which was difficulty in finding HIV and STI data on the existing HPA website. Other problems included:

- Difficulties encountered downloading graphs from website;
- Fearfulness and lack of clarity about how local data can be used when it is issued with the proviso that it is confidential and should not be repeated; and
- Where to access quarterly figures on a regional basis.

Regarding wider dissemination of the data, participants were very concerned that data could be used to further stigmatisation and discrimination of minority groups, but others felt that the HPA could be over sensitive about data. . Participants felt that more work was required to improve control of data ways in which data was reported in the popular press and to foster better relations with the media.

A number of suggestions were made to improve access to data:

- Thematic 'snap shots' of data relating to particular issues;
- Publicity regarding who to contact within the HPA for data and queries;
- An overview of what data is available;
- A more user friendly website;
- Regular briefings;
- Bigger print on the graphs on the website;
- More data presentation meetings; and
- More timely data outputs.

The conference was regarded as a useful forum for improving access to the data and requests were made for events such as this to be repeated and similar events exploring the impact of HIV and AIDS on black Caribbeans and focussing on STI data.

4.8 Perspectives on the conference proceedings

About half of those attending completed conference evaluation forms. These respondents identified themselves mainly as professionals working in HIV prevention and health promotion (51%), those engaged in clinical care (26%), or policy (10%). The remaining others described themselves as academics, surveillance scientists and representatives of community based organisations.

Respondents to the evaluation questionnaire agreed that the conference provided insight into the latest trends in HIV and STIs (92%) and that the presentations were informative (97%). They commented that the event was “*very useful*” and “*interesting*” and that the programme was “*comprehensive*”. Of particular interest was the presentation on TB and HIV co-infection. Participants welcomed the attempt to link HIV prevalence with other diseases, and would like to also see similar analysis in relation to STIs. Participants also picked out the sessions on the dried blood spot and unlinked anonymous surveillance programmes, maps of Africa and information about SOPHID, which was widely used by participants, as being very relevant. Participants also welcomed the data on pregnant women and the links to current policy and practice regarding antenatal care. Despite excellent feedback, many participants commented that the presentations tended to be too technical or jargonistic; that there were too many presentations with excessive volumes of data being presented quickly within them; and that better explanations of the data were required. However, the vast majority left the conference feeling that the event had raised awareness of activities at CDSC (95%) and that they had learnt something new (95%).

In terms of discussion, there was sufficient time for this (89%) and the discussion groups were regarded useful (92%), particularly the focussed group moderation and the opportunity to share views and review issues with others from similar professional backgrounds interested in the same data. Respondents had been able to express their information needs and views of CDSC data (95%), although there was a suggestion that advance notice of this as a discussion topic would have assisted participants in preparing for the conference and better presenting their organisation’s needs. There was a request for one of the group sessions to be mixed across disciplines to permit greater discussion between different professions, for example among clinicians and community groups and a suggestion that participants would benefit from choosing to attend groups focussing on individual topics, for example using data in clinical work, for community groups or to plan and commission services.

Respondents agreed that the conference had provided opportunities to explore ideas for enhancing data (82%) and to share views (95%), that the event was ‘*a step in the right direction*’ and ‘*a good start*’ towards improving communication and improving access to data to inform HIV prevention. The event was very popular. Participants appreciated the opportunity to find out more about the Health Protection Agency and how to use the data and requests were made for future events of a similar nature

5 Recommendations

Recommendations from the conference participants included:

Surveillance activities

- Investigate concerns that black African MSM may not disclose same sex activity when seen for care and are under-represented in surveillance data. Consult with clinicians regarding ways of improving disclosure and reporting.
- Enhance surveillance activities with social research to provide interpretation and contextual explanations and further understanding of care needs.
- Investigate reasons why more women than men are included in reports of newly diagnosed infections.

- Review reporting of ethnicity data and whether improvements are required.

Delivery of surveillance data

- *Data categories*
 - Review the categorisation of data by ethnicity, nationality and route and country of infection and provide rationale for use of term 'black African'.
 - Consider use of census age categories.
- *Website*
 - Improve the site so that it is more user friendly, for example better signposting and shorter pathways to HIV and STI data;
 - Core tables relevant to the black African population are highlighted and located together to improve access
- *Access*
 - Presentations and written outputs to avoid jargon and use simple language that can be understood by data users that do not have training in statistics or epidemiology.
 - More data that is relevant to the regions outside London, guidance on where to access regional data on a regular basis and how to use local data that is issued on a confidential basis.
 - Inclusion of explanations for statistical terminology and technical language.

Support for users of surveillance data users

- Repeat the SESA conference on a regular basis.
- Publish regular thematic briefings.
- Issue guidance on how to use surveillance data and which data is suitable for different uses, for example clinical work, target community groups' activities or to plan and commission services.
- Tables and charts to include narration on their layout and content, guidance on interpretation and limitations; implications for prevention; and social science perspectives.
- Provide guidance on access to regional data and how to apply national and regional trends to local situations.
- Publicise guidance on the role of the HPA, alternative sources of information and appropriate contact points within CDSC.



Communicable Disease Surveillance Centre
Department of HIV and Sexually Transmitted Infections

Improving information about HIV & STIs among the UK African population

20 February 2004 - CDSC, 61 Colindale Avenue, London NW9 5EQ

PROGRAMME

9.00 – 9.30	Registration Coffee	All participants	CDSC Reception Seminar Rooms A and B
9.30 – 9.45	Welcome	Kevin Fenton	Wilson Lecture Theatre
Session 1	Diagnosed HIV	Chair Max Sesay	
9.45 – 10.05	Diagnosed prevalence of HIV	Bela Patel	Wilson Lecture Theatre
10.05 – 10.25	New diagnoses of HIV	Katy Sinka	Wilson Lecture Theatre
10.25 – 10.45	Coffee	All participants	Seminar Rooms A and B
10.45 – 11.05	Late diagnosis of HIV	Tim Chadborn	Wilson Lecture Theatre
11.05 – 11.25	AIDS and TB	Josh Forde	Wilson Lecture Theatre
11.25 – 11.45	Epidemiology of HIV & STIs among Africans in Scotland	Mary Livingston	Wilson Lecture Theatre
11.45 – 12.45	Discussion groups	All participants	Seminar Rooms A and B Wilson Lecture Theatre CDSC Library
12.45 – 1.30	Lunch	All participants	Seminar Rooms A and B
1.30 – 2.15	Feedback from discussion groups	Chair Brian Rice	Wilson Lecture Theatre
Session 2	Undiagnosed HIV and STIs	Chair Walter Gillgower	
2.15 – 2.30	Monitoring overall and undiagnosed prevalence of HIV	Louise Logan	Wilson Lecture Theatre
2.30 – 2.45	Diagnoses of HIV among pregnant women	Sue Cliffe	Wilson Lecture Theatre
2.45 – 3.00	Gonorrhoea	Elizabeth Rudd	Wilson Lecture Theatre
3.00 – 4.00	Discussion groups	All participants	Seminar Rooms A and B Wilson Lecture Theatre CDSC Library
4.00 – 4.30	Feedback from Groups	Chair Katy Sinka	Wilson Lecture Theatre
4.30 – 5.00	Overview and conclusions	Kevin Fenton	Wilson Lecture Theatre

APPENDICES – Participants list

Name	Job title / role	Organisation
Ms Fatima Adam	Project Worker	Barnardos – African Community Service
Dr Olufunke Adedeji	Consultant in Public Health	Northamptonshire Heartlands PCT
Miss Anna Aguna	Senior Health Promotion Specialist	Health First
Mr Mesfin Ali	Horn of Africa HIV Prevention Co-ordinator	Ethiopian Community Centre in the UK
Ms Keira Allen	Information Assistant	HPA North West
Ms Rose Ambrose	Staff Nurse	Trafalgar Clinic, Queen Elizabeth Hospital
Dr Jane Anderson	Honorary Senior Lecturer	Centre for Infectious Diseases, Barts and the London
Ms Anne Barwell	Senior Health Promotion Specialist	Bristol South and West PCT
Ms Teresa Battison	Project Manager	Medical Foundation for AIDS and Sexual Health
Mr Edwin Bernard	Editor (AIDS Treatment Update)	NAM
Mr Andrew Bibby	Consortium Manager	Croydon PCT
Miss Louise Bradley	Communications Officer	Hayward Medical Communications
Ms Ros Brown	HIV Clinical Nurse Specialist	Waltham Forest PCT
Dr Rita Browne	HIV Medicine	St Stephens Centre
Mr Thomas Bubi	Co-ordinator	African Support and Project Centre
Dr Cecilia Bukutu	Research Fellow	City University
Dr Kathy Cann	CCDC	Buckinghamshire & Milton Keynes HPU
Dr Robin Carlisle	Specialist Registrar	Doncaster Central PCT
Mr Chris Carmona	Public Health Specialist	Islington PCT
Dr Zvururami Chikobvu	Health Promotion Specialist	Heart of Birmingham Teaching PCT
Ms Diana Chituka	Health Promotion Advisor	City & Hackney PCT
Mr Glen Codere	BBV / STI Information Manager	Scottish Centre For Infectious & Environmental Health
Miss Ros Constable	Clinical Nurse Specialist/ Team Leader	City & Hackney Teaching PCT
Ms Sandra Delamere	Advanced Nurse Practitioner	Guide Clinic St James Hospital
Professor Jonathan Elford	Professor in Evidence Based Health Care	City University
Miss Claire Emeleus	Health Promotion Specialist	Crawley PCT
Ms Kate Ezeoke-Griffiths	Snr Health Improvement Co-ordinator	Redbridge PCT
Ibi Fakoya	Research Assistant	MESH, UCL
Mrs Ninette Fitzgerald	Clinical Nurse Specialist	North Surrey PCT
Ms Joan Flynn	Nurse Manager	Guide Clinic St James Hospital
Ms Mitzy Gafos	Primary Care Lead	Department of Health
Mr Walter Gillgower	Head of African Promotion Services	Terrence Higgins Trust
Ms Wendy Hachmöller	Health Improvement Advisor	Directorate of Public Health, Newham
Professor Graham Hart	Associate Director	MRC Social & Public Health Sciences Unit
Dr Rebecca Ingram	Research Associate	Imperial College
Ms Sukainah Jauhar	HIV Development Officer/Public Health Specialist	Lambeth PCT
Mrs Jacinta Jenkins	Senior Sister	St Georges Healthcare NHS Trust
Ms Linda Johnson-Laird	Team Member	Department of Health

Name	Job title / role	Organisation
Mrs Josephine Joseph-Hunter	Sexual Health Trainer	Brook Birmingham
Mrs Annabel Kanabus	Director	Avert
Mr John Kennedy Nyabwa	Secretary	African Health & Education Services
Dr D Kuku	Specialist Registrar	Royal Berkshire Hospital
Mr Luke Kwamya	HIV Contract Manager	Brent PCT
Ms Eunice Kyalo	Health Promotion Advisor	Hammersmith & Fulham
Dr Linda Lazarus	Senior Scientist	Department of Health
Dr Mary Livingston	Epidemiologist	Scottish Centre For Infectious & Environmental Health
Ms Maria Loizou	Health Promotion Specialist	Health First
Dr Lul Lojok Deng	Health Team Leader	African Community Council for Regions
Miss Juliet Lubega	Senior Health Promotion Specialist, African Communities	Camden PCT
Dr Suzanna Mathew	Specialist Registrar Public Health	CDSC
Dr Charles Mazhude	Consultant Physician	University Hospital Lewisham
Dr Jeanette Meadway	Consultant Physician and Honorary Senior Clinical Lecturer	Mildway Hospital
Mr James Miller	Senior Manager	Livingwell Hammersmith & Fulham PCT
Ms Thoko Mlungwana		Homerton Hospital
Dr Rahmat Mohammad	Project Director	Woman Being Concern
Dr Kailash Mohanty	Consultant Physician	Diana Princess of Wales Hospital
Ms Dorothy Mukasa	Policy & Planning Officer	L B Tower Hamlets
Ms M Mulenga	Projects Co-ordinator	African Culture Promotions
Mr Simon Mwendapole	Services Development Manager	Uganda Aids Action Fund
Miss Edna Nafula-Mukasa	Assisted Information Officer	Terrence Higgins Trust
Miss Syson Namaganda	Black Health Agency	Services Strategy Manager
Dr Usharani Natarajan	Specialist Registrar	Royal Sussex County Hospital
Mr Melusi Ndebele	Health Promotion Specialist	Luton Teaching PCT
Ms Chinelo Nwajiobi	Health Improvement Manager	Enfield PCT
Mr Tim O'Keeffe	HIV Counsellor	Whipps Cross University Hospital NHS Trust
Mr Gerry O'Kello	Planning & Commissioning Officer	Lambeth Social Services
Mr Norbert Obonyo		African Refugee Community Health & Research Organisation
Dr Femi Oduneye	Director of Public Health	Blackwater Valley and Hart PCT
Mr Tom Ojwang	Joint Commissioning Manager, HIV Services	Hammersmith and Fulham PCT
Ms Kay Orton	Sexual Health Team Leader	Department of Health
Ms Stella Oryang	Health Promotion Adviser	Hammersmith & Fulham PCT
Ms Lucy Osman	Monitoring Officer	Positively Women
Mrs Gertrude Othieno	Director	African Culture Promotions
Miss Sarah Pasternak	Senior Programme Leader HIV/AIDS	Health Promotion/North Stroke PCT
Mr Neil Pepper	HIV Project Worker	Health Promotion
Mr Elias Phiri	Health Promotion Officer	THT
Ms Sarah Pulle	HIV Prevention & liaison Officer	Newham Social Services
Ms Hannah Rapport	Health Development Manager	L B Lambeth Health Team
Mr Nadarajah Rathakrishnan	IT Support Officer	BHR Trust
Luci Richards	Health Adviser	West London Centre for Sexual health

Name	Job title / role	Organisation
Mr Sam Robbin-Coker	Project Director	West African Networking Initiative
Mr Manjit Rooprah	Co-ordinator	HIV Service User Involvement Project
Dr Samantha Rowland	Research Associate	Imperial College
Ms Kirsty Roy	Epidemiologist	Scottish Centre For Infectious & Environmental Health
Ms Catherine Sandy	Health Promotion Specialist	Health Promotion Service
Mr Justin Schofield	SLA Officer	SWL HIV & GUM Commissioning Consortium
Mr Fred Semugera	HIV Prevention Specialist	Croydon PCT
Dr Max Sesay	Chief Executive	African HIV Policy Network
Ms Winnie Ssanyu-Sseruma	Chair	African HIV Policy Network
Mrs Mary Stafford	Senior Nurse Family Planning and Sexual Health	Southend PCT
Ms Pauline Stephenson	Teenage Pregnancy Co-ordinator	L B Brent Youth and Voluntary Sector Support
Miss Heidi Stevens	Marketing Executive	GSK
Ms Anne Streater	Assistant General Manager	Cambridge Diverse
Ms Cathriona Sullivan	Clinical Nurse Specialist	Caldecot Centre, Kings College Hospital
Dr Ann Sullivan	Consultant Physician	Chelsea and Westminster
Ms Adrienne Testa	Research Officer	Trust for the Study of Adolescence
Mr Cheikh Traore	Health Inequalities Programme Lead	Greater London Authority
Dr Chris Wood	HIV Consultant	North Middlesex Hospital
Mr Adam Wilkinson	Regional Manager – Lighthouse West London	Terrence Higgins Trust
Mr Imran Yunus	Policy Officer	East Sussex

References

ⁱ Cortina-Borja M, Cliffe S, Tookey P, Williams D, Cubitt WD, Peckham C. HIV prevalence in pregnant women in an ethnically diverse population in the UK: 1998-2002. *AIDS* 2004;**18**:535-540.

ⁱⁱ Sinka K, Mortimer J, Evans B, Morgan D. Impact of the HIV epidemic in sub-Saharan Africa on the pattern of HIV in the UK *AIDS* 2003;**17**(11):1683-90.

ⁱⁱⁱ Health Protection Agency, SCIEH, ISD, National Public Health Service for Wales, CDSC Northern Ireland and the UASSG. *Renewing the focus: HIV and other Sexually Transmitted Infections in the United Kingdom in 2002*. London: Health Protection Agency, November 2003.