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# SETTING PRIORITIES FOR HIV/AIDS RESEARCH IN KENYA

## NATIONAL WORKSHOP

***SUMMARY REPORT***

KENYA AIDS NGOS Consortium

Networking and United to Fight AIDS

*COMPILED BY KENYA AIDS NGOS CONSORTIUM WITH FUNDING FROM USAID THROUGH THE POLICY PROJECT*

JULY 1999

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# LIST OF ABBREVIATIONS

| | | |
|---|---|---|
| **AMREF** | ..... | African Medical Research Foundation |
| **CBO** | ..... | Community-Based Organization |
| **DFID** | ..... | Department for International Development |
| **FHI** | ..... | Family Health International |
| **HAPAC** | ..... | HIV/AIDS Prevention and Care |
| **JICA** | ..... | Japan International Co-operation Agency |
| **KANCO** | ..... | Kenya AIDS NGO Consortium |
| **KELIN** | ..... | Kenya Ethical Legal Issues Network |
| **KEMRI** | ..... | Kenya Medical Research Institute |
| **NASCOP** | ..... | National AIDS and STD Control Programme |
| **NGO** | ..... | Non-governmental Organization |
| **STD** | ..... | Sexually Transmitted Diseases |
| **STI** | ..... | Sexually Transmitted Illnesses |
| **UNAIDS** | ..... | Joint United Nations Programme on HIV/AIDS |
| **UNFPA** | ..... | United Nations Fund for Population Activities |
| **USAID** | ..... | United States Agency for International Development |

# SUMMARY

This section summarizes the outcomes of the series of workshops held under the auspices of NASCOP and co-ordinated by KANCO with the support of the USAID Policy Project. The workshops, which developed an agenda for priority areas for research in HIV/AIDS in Kenya, were co-sponsored by three other organisations active in HIV/AIDS research. These are KEMRI, AMREF and the University of Nairobi Population Studies and Research Institute and Department of Sociology.

*The workshops focused on the following thematic areas:*

- Policy, legislation, ethics and human rights;
- Epidemiology, public health and bio-medical research;
- Prevention and Care Programmes; and
- Socio-economic, cultural and behavioural research.

**Policy, legislation, ethics and human rights**

The participants recognized the unprecedented increase in the number of widows and orphans as a result of HIV/AIDS as a key legislative and policy challenge. Caring for this vulnerable group is complicated by several factors, which include statutory and customary laws that are often at variance with one another and bureaucratic procedures dealing with the inheritance rights of widows and orphans. The workshops recommended that laws and regulations governing the rights of orphans and widows be reviewed in order to protect their rights in addition to enforcing strict application of these laws.

*The workshops also recommended action in the following areas:*

The workplace: formulation of guidelines for testing, termination of employment, peer education and confidentiality on the sero status of employees.

Impact on the family structure: Lack of organized and well-documented information on the impact of HIV/AIDS on families and their communities was seen as a major drawback. Impact of mandatory disclosure of HIV status among couples, housing policies and their influence on risk behaviour are areas that require further studies.

Information dissemination and advocacy strategies: The workshop recognized the existence of gaps between information generated from research or programme experiences, and the use of this information in policy making. Action was proposed in developing more effective and creative strategies for disseminating research findings and programme experiences, and for advocating for policy changes.

**Epidemiology, public health and bio-medical issues**

Areas where action is required included modalities for early detection of infected persons and prompt response mechanisms, and the establishment of an effective voluntary counseling and testing service as part of the care process.

**Other areas requiring action:**

*Anti-retroviral therapy*: Working with other International Networks to ascertain the effectiveness and affordability of anti-retroviral therapy in Kenya. The workshop acknowledged KEMRI's work in traditional medicine and clinical studies on the combination therapy of AZT, 3TC and Saquinavir.

*Continuum of care*: Participants underscored the need of equipping lay care-givers with the necessary knowledge to enable them track factors related to disease progression, clinical manifestations and potential complications of HIV/AIDS.

*Maternal and child health*: Prevention of primary infections, prevention of mother to child transmission, care of affected and infected children, and care of mothers and fathers were identified as areas requiring attention.

*Epidemiology*: The issue of whether to continue Elisa tests in the districts or to centralise HIV testing needs to be addressed. Participants also recommended that the role of intravenous drug users and homosexual groups in the epidemiology of HIV/AIDS in Kenya be established.

*Basic sciences* Research in this area in relation to HIV/AIDS is necessitated by differences in both virus strains and populations, and nutritional status and risk groups, among other factors. In Kenya, research should target the status of long-term survivors and non-transmitters of HIV.

*Laboratory and blood safety*: Discussions in this area centred on diagnosis of HIV and opportunistic infections, management and monitoring of patient progress, and surveillance of the epidemic. There is a need to establish a quality control and assurance system in order to determine whether rapid tests should be used for screening and confirming diagnosis.

**Prevention and care**

Discussions in this area centred on behaviour change, general care of HIV/AIDS patients and the role of communication as a whole in the fight against the epidemic. It was observed that the effects of HIV/AIDS had spread across all age groups of the population.

**Main areas of focus were on:**

*Priority high-risk target groups* Findings at the workshop showed that the current trend of increase in the number of people infected and affected by HIV is taking its toll on all sectors of the population. Priority research areas included the need to

establish the most effective means of promoting socially responsible behaviour among the youth, and establishing effective ways of involving opinion leaders in the prevention of HIV transmission.

*Counseling and testing* The adequacy of existing policies, programmes and guidelines in HIV counseling, and the safety of the blood used in transfusion were some of the outstanding issues identified by the participants.

*Care and support systems*: Establishing alternative health care and support systems in order to supplement existing health care resources were identified as necessary. Reform in the health sector was seen as crucial in dealing with the epidemic in the existing socio-economic support systems.

*Information, communication and education*: The major challenges to be overcome were identified as the lack of provision of accurate information on HIV/AIDS, and the use of both appropriate and relevant education methods and communication strategies.

**Socio-economic, cultural, demographic and behavioural issues**

This area had a wide participation from the academia, which comprised mainly academics from various Public and Private Universities. Research findings from a study on the effectiveness of Family Life Education (FLE) among the youth reveal that a combination of FLE and reproductive services contributes to fewer sexual partners, fewer unwanted pregnancies and fewer STDs. Discussions in this area focused on the following:

Population and demographic issues Areas that needed research here were seen to be closely related with the age structure, mortality and morbidity rates, the impact of fertility, age at marriage, first sexual encounter and initiation, and migration patterns.

*Socio-economic issues* The main issues for research here were identified as establishing the relationship between exposure to HIV/AIDS and aspects like poverty, unemployment, and levels of production.

*Social issues* Main research areas identified included establishing the effect of emerging family and other social structures on the youth, and the influence of the media in the control of HIV/AIDS.

*Sexual behaviour and psycho-social issues* The challenge here was seen as designing research that would explain the discrepancy between knowledge and behaviour when it comes to HIV/AIDS. This would involve researching on perceptions and attitudes, the issue of condoms, social stigma and agents that expose people to HIV/AIDS.

*Cultural issues* The way forward was seen as reviewing the relevant economic literature in order to determine whether the necessary information is available and, if so, whether it can be repackaged for HIV/AIDS-related policy-makers. Main areas of concern here included value and belief systems, religion, marriage and cultural rites.

# BACKGROUND

*The Process*

The process that led to the identification of the priority research agenda begun with the initiation of the Policy initiative by KANCO with funding from USAID through FHI and POLICY Project in partnership with NASCOP. The process of policy advocacy and development culminated with the development of the Sessional Paper No.4 of 1997,AIDS in Kenya.

Since 1995, KANCO undertook an initiative on policy development and advocacy where the civil society was involved in identifying priority policy issues, which were incorporated in the Sessional Paper No.4 of 1997,AIDS in Kenya.

Some of the key areas of concern touched on research as a means to providing data for use in advrogramme implementation. The process adopted included an indepth review of the major issues and existing research in the particular theme areas. For some of the issues, it was possible to gather information from research done in other countries. Information on research done both in Kenya and outside were included in a report complied by POLICY Project in collaboration with NASCOP and KEMRI. This report was used as a reference during the four thematic workshops. For some of the issues, it was easy to formulate research questions. However, with others it called for expert discussions and consensus building in deciding the priority research questions or issues.

In all the four thematic workshops the process was a blend of presentation of short papers, discussions in the plenary followed by group discussions on specific issues according to the specific areas within each theme. The group process included individual brainstorming by each participant, followed by discussions of each person's thoughts and then group consensus using the criteria given to them by the facilitators.

Following the group consensus, each of the groups presented their group outcome to the plenary. All participants were asked to vote on the priority issues/questions from the various groups' presentations using a process that gave each participant five votes. The ten questions that emerged as top priority from each of the workshops were then presented to the National forum for consensus.

During the National workshop held in July 19th 1999, the process entailed presentation of the ten priority research questions identified in each of the thematic workshops followed by plenary discussions before arriving at the consensus on the way forward.

Following the publication of the Sessional Paper No. 4 of 1997 on AIDS in Kenya, NASCOP initiated the development of a strategic plan around the priority areas identified in the policy document. Subsequent analysis identified lack of a proper system to co-ordinate or approve research, domination of HIV-related research in the country by outside researchers and research institutions, limited research capacity in the country and lack of an implementation policy on research findings as some of the weaknesses in the areas of HIV-related research in Kenya.

The four workshops covered policy, legislation, ethics and human rights; socio-economic, cultural, demographic and behavioural research; epidemiology, public health and bio-medical research; prevention and care programmes.

**Policy, legislation, ethics and human rights**

anised by the The workshop was held on March 19, 1999 in Nairobi, and was organised by the Keny Consortium-KANCO. Participants were drawn from the legal community, the armed forces, the police, medical institutions, pharmaceutical companies, community organisations and AIDS service organisations. Kenyan industry (both public and private), trade unions and the media also participated, including staff from the Office of the President and the Attorney General's Chambers. However, representatives from invited religious organisations were unable to attend the meeting.

**Socio-economic, cultural, demographic and behavioural research**

The workshop was held in Nairobi on April 29, 1999. It was organised by the University of Nairobi's Population Studies and Research Institute (PSRI) and the Department of Sociology. Majority of the participants were academics and university-based researchers from various public and private universities. Policy-makers from the Ministries of Health, Planning and National Development, Labour, and Transportation also attended the workshop.

Participants were given an overview of major issues and of existing research into the social, economic, cultural and behavioural determinants of HIV and AIDS in Kenya, and of the impact of the epidemic in these areas.

**Epidemiology, public health and bio-medical research**

The workshop was held in Nairobi on May 12 to 13, 1999. It was organised by the Kenya Medical Research Institute (KEMRI). Participants were researchers drawn from different institutions including KEMRI, NASCOP, University of Nairobi, Kenyatta University, the National Health Research and Development Center, Population Council and the Ministry of Health. Also at the workshop was a herbal therapist who made a presentation on his experience in herbal medicine as an alternative therapy for HIV/AIDS.

Participants were given an overview of key issues in the areas of anti-retroviral therapy, continuum of care (clinical, nursing, counselling and social support), maternal and child health, epidemiology, basic sciences and, laboratory and blood safety. This presentation formed the basis for group discussions.

Participants were then divided into three groups, each of which discussed priority issues in one or two of the six sub-topics. Each group then presented to the plenary seven priority areas of research. All participants then prioritized the 21 research questions presented by the groups.

**Prevention and Care Programme**

The African Medical and Research Foundation (AMREF) organized the workshop. It was held on May 18 to 19, 1999 in Nairobi.

The themes identified for discussion were priority high-risk target groups; counseling and testing; care and support systems; and information, education and communication.

The groups presented the range of the research questions and the six top priority areas. All participants then voted for the top ten priority research areas. Research questions in the workshops had to meet formulated criteria of importance and feasibility before being adopted as a national priority.

These criteria, which was used by all four initial workshops, were based on:

- The potential impact of the question on policies and programmes.
- The possibility of implementing the research results.
- The potential use of the research results for advocacy.
- The relevance of the question to the current state of the AIDS epidemic in the country.
- The contribution of the question to the existing research.
- Whether the question can pass through scientific research.
- The political ramifications of the research.
- The availability of resources (including human resources) to undertake the research and disseminate its findings.

# CROSS-CUTTING ISSUES

## BLOOD SAFETY

Safety of donated blood, recruitment of blood donors, and issues surrounding testing of donated blood were concerns articulated by participants in the four workshops. The participants noted Kenya's lack of a policy on blood safety and called for stakeholders to formulate a Kenyan blood screening policy that will help health authorities keep track of what is happening in both public and private hospitals.

***Other emerging issues that can be guided by research:***

***Safety of transfused blood*** in the light of epidemiological research findings that have demonstrated that a significant proportion of blood screened and declared safe being found infected with HIV.

***The procedures for blood screening*** and other control measures like transfusion and diagnosis since the safety of blood supply in Kenya is dependent on how well these processes are conducted.

***The dilemma surrounding blood donors*** who "think" they are safe but are found HIV positive through their donated blood. In the absence of policy guidelines informing individuals of their HIV status, such individuals place other people at risk of infection.

## CARE AND SUPPORT

As HIV/AIDS continues to take its toll on the existing health care facilities, the need to seek alternative health care and support systems was a common theme throughout the four workshops.

**Areas requiring information included:**

- Mechanisms and strategies for providing affordable drugs (including traditional medicines) for the management of HIV/AIDS and other alternative approaches for dealing with the epidemic should be provided to the patients.
- The nature of health care support systems for people living with HIV/AIDS and an evaluation of the effectiveness of such support systems in coping with the epidemic.
- Effective ways of reducing stigma to enhance Home-Based care, including the role of Voluntary Counseling and Testing (VCT) and self-disclosure.
- Evaluation of the quality and outcome of HIV/AIDS counselling.

## COMMUNICATION AND DISSEMINATION OF INFORMATION

*Concerns expressed at the workshops revolved around:*

- Lack of a mechanism to disseminate information on HIV/AIDS that is generated from research or from well documented programme experiences to all those who need such information.
- Education and communication strategies that were ineffective in bringing about behaviour change in HIV/AIDS.
- Behaviour change communication. Strategies for promoting behaviour change among the high-risk groups, the most effective strategies for communicating with the youth, both in and out of school, are areas that the workshops identified as requiring more focus and better approaches.

The workshops expressed the need to undertake studies that will help develop more effective strategies and to formulate policies to guide issues in these areas.

## COORDINATION OF RESEARCH

A clear policy on HIV-related research that will guide both researchers and donors on areas of national priority was an undercurrent in all the workshop discussions. Such a policy will seek to improve the response of HIV/AIDS in Kenya given that resources are limited.

*Other issues that required guidelines or more information:*

- The machinery that the government uses to regulate and co-ordinate (HIV/AIDS) research in the country. The participants called for co-ordination of research effort in HIV/AIDS to avoid duplication of efforts and to create awareness among all stakeholders.
- Modalities for accessing funds for research from the government, multi-lateral and bi-lateral agencies.

# RESEARCH PRIORITIES IN POLICY, LEGAL AND HUMAN RIGHTS

## THE LEGAL ENVIRONMENT

### *Protection for widows and orphans*

HIV/AIDS has drastically increased the number of widows and orphans who often depend on the family of their late husband for sustenance making them vulnerable to exploitation.

However, there exists both statutory and customary laws on the inheritance rights of widows and the rights of orphans, which are often at variance with one another. There is also a body of laws on the adoption of orphans. Provisions relating to the rights of widows and orphans are also found in other statutes such as those on education.

Participants felt that the legal and bureaucratic procedures regulating adoption were cumbersome and welfare services over stretched - even without the added burden of HIV/AIDS. Yet unless the adoption procedures were followed, orphaned children may be discriminated against.

Participants recognised the systematic review of the laws and regulations that govern the rights of orphans and widows as important in protecting their rights. They also called for more stringent enforcement of these laws.

***This may be accomplished by:***

- Tracking and documenting court cases on widows and orphans.
- Assessing the legal needs of orphans and widows in order to identify areas that require action or where gaps exist.

The participants expressed the need to undertake studies to document the following:

- The legal protection (customary and statutory) for orphans and for widows.
- Establishing inputs needed to guarantee property rights for widows and orphans and their access to education, health and other services.

## Individual Rights

Many questions were raised on individual Human rights during discussions. Although all the questions raised require answers, participants recognized the limitation of research in answering such questions since a majority of them were more effectively resolved through policy forums such as ethical boards, the judiciary or a political body.

An example of a question posed by the participants was if the courts could be allowed to order an HIV test in rape cases for a defendant accused of deliberately spreading the virus. This is an important legal issue that requires a clear policy whose formulation does not require a research study. There was a proposal during

infection. Another issue raised related to prisoners who do not have access to condoms yet they are exposed to HIV infection through homosexual practices prevalent in prisons.

**HIV testing, disclosure and confidentiality**

The participants rated issues surrounding HIV testing, disclosure and confidentiality very highly. There was unanimous agreement that policy decisions are needed to guide HIV testing, disclosure of results and other related issues. Concerns raised were many including the **legal implications of firing HIV-infected** employees to the rights of men or women whose spouses are HIV positive.

The legal protection of HIV positive individuals was another issue. While general laws exist to protect the confidentiality of medical information, the workshop was told that in case of HIV positive individuals, this is frequently violated. Policy guidelines are therefore needed to articulate whether such confidentiality may be justified in the interest for example of Public Health, and if so under what circumstances. Little is known about the extent and consequences of illegal or unethical disclosure of HIV status. This includes the extent to which fear of disclosure discourages testing in spite of the prevention opportunities it presents.

Although the participants recognized the limitation made by research, they felt that nevertheless questions surrounding the following issues on confidentiality needed to be answered:

- Circumstances or situations where the right to confidentiality is systematically breached.
- The benefits of confidentiality both to the patient and the public.
- The protective contribution that mandatory disclosure of HIV sero-status may have to primary sexual partners of those infected with the virus.

## THE WORK PLACE

***Research needs in the workplace***

Issues in the workplace were framed by the workshop as policy questions that require further analysis to yield specificto yield specific resea

The following were recognized as priority policy issues that require formulation of policy guidelines.

***Workplace Policies***

**Testing:** The participants noted that countries like Uganda, South Africa and Botswana are among the countries with policy guidelines on testing that Kenya can draw some lessons from.

***Questions posed by the participants covered the following policy issues:***

- Should pre-and post employment testing be permitted and what would be the legal implications of such testing?
- The ethical and (labour) implications of hiring HIV positive employees.
- A [illegible] for securing consent of employees for counselling and testing

- Should confidential testing and counselling be offered to employees as a benefit?
- The advantages and disadvantages of mandatory testing.

**Termination of employment:** The workshop considered the legal, ethical and (labour) implications of firing an employee who tests HIV positive as an important policy issue requiring guidance.

**Peer education:** The participants acknowledged that information exists in this field, including results of a study involving 40 factories in Zimbabwe. Although evidence from Kenya is growing, none of it is from specially designed research studies. Participants called for more effective dissemination of existing evidence followed by action, rather than more research studies. The effectiveness of peer educators in the workplace needs to be well documented.

**Workplace policies:** Documentation of companies that have workplace policies on HIV, the nature of those policies and whom they protect: the employer or the employee is needed.

**Confidentiality:** Whether the employer has a right to know the results of an HIV test and if doctors should disclose results to employers were policy issues posed by the participants. The workshop proposed studies that will help guide policy on the impact of disclosure of HIV status by tracking the relationship between disclosure against termination, access to benefits, training and promotion for employees whose results were revealed to their employer. Participants recognized the ethical challenges of such as study.

*Issues raised but not presented for voting to the larger group:*

- The contribution (or the role) that the creation of the position of an AIDS officer can make at different levels in the workplace.
- Mechanisms through which unions can advocate for the rights of members of their unions who are HIV positive.

## IMPACT ON THE FAMILY STRUCTURE

The workshop recognized lack of organized and well-documented information on the impact of HIV/AIDS on families and their communities as a major impediment in this area. The challenge is to decide where more information is needed to ensure a better legal response; a response that is ethical and protects the rights of infected Kenyans and others affected by HIV and AIDS.

Also of major concern was the capacity of the community to provide appropriate care in the home. This involves investigating the linkages between the hospital and Home-Based care, and whether the community is ready to cope.

*Issues posed by the workshop requiring further studies:*

- The impact of mandatory disclosure of HIV status among couples.
- Effect of spousal separation arising from work and the risk of HIV infection. How does it vary when such separation is voluntary as opposed to enforced separation or that of highly mobile population such as the armed forces were questions posed by the participants.
- The effect of housing policies and their effect on risk behaviour.

The workshop pointed out that information on the effect of spousal separation has been documented in Southern Africa and Kenya could draw some lessons from such studies.

## INFORMATION DISSEMINATION AND ADVOCACY STRATEGIES

The workshop recognized gaps that exists between information generated from research or programme experiences and the application of this information in the policy making arena. Most of the time policy related decisions fail to benefit from information generated from research or programme experiences due to lack of mechanisms for effectively disseminating such information to decision makers in a way that they can use it. In other cases there is lack of information in particular areas or on specific issues creating what the workshop referred to as policy vacuums.

In the third scenario, the problem is different. There is plenty of information generated from research studies or from well-documented programme experiences. An example is sex education for adolescents. Studies show that sex education in schools delays the age at first sex and leads to safer sex when it takes place yet initiating sex education programmes in schools have met many obstacles, which can not be solved through further research. In this instance perhaps a relevant research question would be: how can the current political obstacles to implementing sex education in Kenya be reduced?

*The workshop proposed actions in two areas.*

- Developing more effective strategies for disseminating information generated from research and programme experiences to key stakeholders. This will promote factoring such information in the decision making process.
- Developing creative strategies for advocating for policy changes using arguments supported by information from well-documented studies. The workshop recognized that policy making is influenced by other imperatives besides convincing data.

On policy issues the workshop called for consultation and co-operation with other sectors such as the religious leaders and politicians to build alliances in the fight against HIV/AIDS.

## APPLYING LESSONS FROM OTHER COUNTRIES

While the inventory of studies presented concentrated on Kenya, the workshop recognized the importance of gathering information on relevant studies from other countries from which important lessons can be drawn. The workshop called for the development of a systematic way of gathering information from other countries and drawing lessons from these experiences to improve programmes in Kenya.

## OTHER AREAS OF RESEARCH

*The workshop identified the following issues as deserving attention:*

- Cases on the breach of women's rights are being prosecuted in Kenyan courts and the type of sentences being handed out to those found guilty.
- What happens to people when they are arrested, while in custody or in prison? In the case of arrests for sex work, does this increase vulnerabilities?
- The positive influence of the law harmful on cultural practices such as early marriages, female circumcision and wife inheritance.
- Issues surrounding informed consent. Are research subjects fully aware of the potential consequences of participating in a study?

# RESEARCH PRIORITIES IN SOCIO-ECONOMIC, CULTURAL, DEMOGRAPHIC AND BEHAVIOURAL ISSUES

Participants comprised mainly academics from various Public and Private Universities. The theme on setting priorities on HIV/AIDS research centred in the areas of socio-economic, cultural, demographic and behavioural issues.

The workshop participants were informed that results of a study on the effectiveness of FLE among the youth shows that a combination of FLE and the provision of reproductive services leads to fewer sexual partners, fewer unwanted pregnancies and fewer STDs.

## POPULATION AND DEMOGRAPHIC ISSUES

*Areas of research here include:*

- Age structure
- Mortality and morbidity rates
- The impact of fertility
- Age at marriage, first sexual act and initiation
- Migration patterns

*Priority areas of study were seen as:*

- The use of people living with HIV and AIDS to influence behaviour change.
- The effectiveness of youth programmes in encouraging delay in sexual intercourse until marriage.
- Factors influencing the high rates of HIV/AIDS/STD transmission among the youth.

*Secondary concerns raised and articulated the following issues:*

- That sex is an inevitable part of the evolution process. Therefore, it is not possible to divorce sex from life.
- Widening surveillance to include women groups. Emphasis should be on analysing the impact of programmes on target groups both in the short and long term.
- Harnessing political will from the political spectrum of the country to tackle the HIV/AIDS problem. This, therefore, calls for concerted efforts to fight the disease by all political parties.

- A policy on the transfusion and quality of blood is needed.
- Co-operation between politicians, church leaders and other stakeholders in the fight against HIV/AIDS. One important area of co-operation is in the use of condoms.

## SOCIO-ECONOMIC ISSUES

The workshop reiterated that information about the potential (and inevitable) impact of HIV on various sectors of the economy is crucial to planning. The contribution from both the private and public sectors is invaluable in strengthening prevention programmes within both their workforces and the communities, and ensuring fair treatment for employees with HIV.

*Main issues here include:*

- Poverty
- Unemployment
- Levels of production
- The relationship between poverty and exposure to HIV/AIDS

*Issues for further research were identified as:*

- The impact of HIV/AIDS on different sectors of the Kenyan economy.
- The cost of HIV/AIDS to both formal and informal institutions providing care and support.
- The current geographic distribution and socio-economic status of orphans.
- The role played by NGOs and CBOs on those infected with, and affected by HIV/AIDS.
- The documentation of best practices in prevention and care of HIV/AIDS.
- Measures of safeguarding HIV/AIDS-affected and infected persons from exploitation.
- The role of both formal and informal education in curbing the spread of HIV.
- The contribution of nutrition to the survival of People living with HIV.
- The possibility of petitioning the Insurance Industry to underwrite HIV/AIDS related expenses.

*Other socio-economic issues requiring investigation:*

- Lack of knowledge by people in rural areas about the manifestations of HIV/AIDS. Rural people are more accustomed to STDs and do not see the "logic" of someone dying from AIDS because of engaging in sex a couple of years earlier.
- The "conspiracy" of silence, especially among the rich and educated. Consequently, many people have assumed that HIV/AIDS is a disease of the poor.

- The correlation between income distribution, behaviour change and the spread of HIV. For instance, is there any relation between high or low income levels and the spread of HIV/AIDS?

## SOCIAL ISSUES

***The main areas deliberated by the workshop covered:***

- The structures of the family institution
- Peer groups
- Leisure
- Situations that expose adolescents to risk of HIV/AIDS
- Gender relations
- Rape and violence
- Stigmatisation
- Family life education

***The main social issues for research were identified as:***

- The effect of emerging family structures to the youth.
- The nature of other structures that that put adolescents at risk of HIV infection.
- The effect of peer group pressure on behaviour of both adults and the youth.
- The role of parents in moulding children's behaviour to help curb the spread of AIDS. Research findings in Kenya show that while parents believe they are communicating with their children about reproductive health, most of their communication is negative and one-sided.
- The correlation between rape, violence, STDs and HIV/AIDS.
- The influence of the media in the spread of HIV/AIDS. Intervention projects and research from other countries suggest that the media can play an important role in informing people about HIV, in breaking down stigma and in providing a forum for the open discussion of HIV and its impact.
- The lack of a social policy in Kenya.
- The need to establish the possibility of publicly displaying names of AIDS victims as a testimony of the real threat posed by the disease.

## SEXUAL BEHAVIOUR AND PSYCHO-SOCIO ISSUES

Participants were particularly concerned of the failure of people to change their behaviour even when they were well aware of the nature and dangers of HIV/AIDS.

The discrepancy between knowledge and behaviour can be measured in general population or focused population surveys. However, the challenge is to design research that explains why this discrepancy persists.

*The main areas identified were:*

- Perceptions and attitudes
- The issue of condoms
- Sexual intercourse
- Agents that expose people to risk of HIV/AIDS
- Social stigma
- Exchange of sex for other favours

*The following were the key areas identified for research:*

- The factors that prevent change in people's sexual behaviour.
- The perception, comprehension and internalisation of individuals on the risk of HIV infection and how that affects their risk behaviour.
- The constraints associated with the use of condoms, for example, unavailability, perceptions, poor quality and religious opposition.

**Stigma and discrimination**

The area of stigma and discrimination has proven extremely difficult to research in countries with high-prevalence epidemics. The fear of being stigmatised prevents people from finding out their HIV status, especially where care and support services are limited, and where discrimination exists in sectors such as employment.

The silence that hangs over the epidemic prevents people from seeking out services. and may also stand in the way of prevention. People are also reluctant to adopt safer sexual behaviours for fear of being identified as having AIDS.

*Key issues identified for further research covered:*

- The cause of stigmatisation of HIV/AIDS cases.
- The contribution of stigmatisation to the spread of HIV/AIDS.
- The role of access to voluntary counselling and testing in reducing stigma and increasing HIV care and prevention opportunities.
- The role of health workers in promoting stigma.
- Investigating the role of education in eradicating stigma on HIV/AIDS was underscored.

**Sexual networking**

The elaborate sexual networks that contribute to the rapid rise of HIV/AIDS in the country need to be researched on. For instance, the contribution of changing family structures and value systems needs to be studied.

*Key areas that need to be researched on here include:*

- The emerging sexual networks in the changing family structures.
- The circumstances determining the timing, partner-choice and circumstances of an adolescent woman's first and subsequent sexual encounters.
- The appropriateness and adequacy of skills to address the inequalities inherent in sexual relationships.
- The possibility of legislating against people spreading HIV maliciously to make them liable for charges was another issue raised by the workshop.

## CULTURAL ISSUES

Since research in this category is not HIV-specific, a review of relevant literature should be undertaken to determine whether the needed information already exists and whether it can be repackaged for AIDS policy-makers.

*Main areas here include:*

- Value and belief systems
- Religion
- Marriage
- Communication about sex
- Cultural rites

*Two main issues for research were identified in this category:*

- The norms and values that promoted faithfulness and discouraged sex outside marriage.
- Poverty alleviation and the elimination of poverty and disparities in the socio-economic status of the people.

**In addition:**

- The workshop heard that wife inheritance *per se* is not the real transmitter of HIV/AIDS. The greatest threat is the third party, usually from a different community, who is used to cleanse the wife of the deceased before she is inherited.

## ADDITIONAL ISSUES EMERGING FROM THE WORKSHOP

Most participants were aware of only a small fraction of their colleagues work in their own or related fields. Many participants argued that poor dissemination resulted from a lack of resources dedicated to dissemination.

It was noted that the formulation of a national research agenda and a clear framework to oversee HIV-related research was the first step of ensuring that plans for dissemination are built into research projects from the outset.

It was recommended that research should be focused on ways to motivate the government t1Xe decisively to the HIV epidemic, rather than on generating more knowledge that was less likely to be acted upon.

A related concern was the balance between academic research and operations research, with some participants feeling that in many of the areas enough was already known to move forward to action.

# RESEARCH PRIORITIES IN EPIDEMIOLOGY, PUBLIC HEALTH AND BIO-MEDICAL ISSUES

## CONTINUUM OF CARE

As the HIV/AIDS epidemic grows, overwhelming the capacity of health services to cope, the burden of caring for people with AIDS is being borne by lay care-givers within families and communities. Research has shown that patients prefer home-based care to hospitalization. The former not only provides a familiar environment, but also reduces cost of medical care.

The participants underlined the importance of equipping lay care-givers with knowledge that will enable them track factors related to disease progression, clinical manifestations and potential complications of HIV/AIDS.

*The workshop also identified the need to:*

- Identify a method for early detection of infected persons and prompt response mechanisms.
- Equip the care-givers to carry out the task of nursing people with HIV/AIDS.
- Address the welfare of professional health workers who take care of HIV/AIDS patients.
- Establish an effective voluntary counseling and testing (VCT) service as part of the care process. This includes proper identification and training of counselors to help de-stigmatize the disease.

*Key issues identified by the participants requiring research covered the following areas:*

- The cost of home-based care compared to hospitalization.
- Modalities for developing training programmes of counselors that will help de-stigmatize HIV/AIDS.
- Magnitude and risk of work-related sero-conversions in health care workers.
- Strategies that will make it easy to detect HIV infected persons (blood donors, antenatal mothers, employees etc.) and development of response mechanisms.

## ANTI-RETROVIRAL THERAPY

The workshop recognized the main purpose of using anti-retroviral drugs as that of reducing the viral load and the treatment of opportunistic infections. The participants major concerns centred around the need to make the drugs accessible and affordable, to train doctors on how to use the drugs and to monitor viral load and patient's progress.

The need to work with other International networks to see if anti-retroviral therapy can be made affordable in Kenya was identified as an important issue. The UNAIDS initiative in Uganda on AIDS treatment was cited as an example that Kenya needs to draw lessons from.

The workshop acknowledged the promising work that has been undertaken on traditional medicine by the KEMRI and the clinical study on combination therapy of AZT, 3TC and Saquinavir.

*The workshop considered the following as important areas for research:*

- Alternative therapies especially traditional medicine.
- Development and trials of vaccines against HIV/AIDS.
- Mechanisms for providing affordable therapeutic drugs.

## LABORATORY AND BLOOD SAFETY

Laboratory facilities to screen for HIV infection and make diagnosis have been put in place in Kenya. The standard screening test in Kenya is the ELISA. The Western blot, which was largely used as a confirmatory test became too expensive and today, a combination of Elisas is used in Kenya.

Some Rapid Tests are as sensitive and specific as regular Elisas are. However, blood screened through rapid tests must go through Elisa Test. Discussions in this area centred on diagnosis of HIV status and opportunistic infections, management and monitoring of patient progress and surveillance of the epidemic.

The workshop recognized the need for a system of quality control and assurance to determine whether rapid tests should be used for screening and confirming diagnosis. The participants underlined the importance of ensuring that tests used meets the required level of sensitivity and specificity.

The need to make the current approaches both available and affordable with emphasis on maintenance of a pool of low - risk blood donors was recognized as important by the participants.

*Issues that require research covered the following areas:*

- Operational research to help plan for more effective blood recruitment of blood donors.
- Studies to establish how private laboratories handle HIV test requests and how they present results since some of them lack both pre-test and post-test counseling.
- Efficacy and reliability of different HIV test kits available in the market.

## MATERNAL AND CHILD HEALTH

Data presented at the workshop showed that HIV was the second most prevalent condition in pregnant women after anaemia in Africa. There were 600,000 reported paediatric infections in sub-Saharan Africa in 1998, ninety percent of them attributed to mother-to-child transmission.

The key research areas identified were prevention of primary infections, prevention of mother to child transmission, care of affected and infected children, and care of mothers and fathers.

### *Prevention of primary infections*

Data was lacking on the effectiveness of different Information, Education and Communication packages (e.g. life skills training, family life education, media spots, curriculum based activities, extra - curricular approaches) on risk reduction. The need to determine the role of voluntary counseling and testing in risk reduction among pregnant women, post abortal clients and adolescents was considered important.

### *Prevention of mother to child transmission*

The workshop underlined the need for the co-ordination of research in the area of mother to child transmission and on-going basic science research to determine the mechanisms of mother to child transmission of HIV.

A major priority identified was the need to operationalize what is already known from research on mother to child transmission. This could involve training of health workers and development of appropriate replacement and complementary feeds.

Research needs to be carried out on effective contraception for HIV infected mothers.

### *Care of the child*

There is need to determine the causes of mortality among children who are exposed but not infected with HIV. Neglect and exposure to other diseases may be among the factors for mortality. Research is needed in alternative therapies for HIV infected children.

The psycho-social impact of HIV/AIDS on the affected and infected needs to be described and mechanisms for coping with the problems developed. It is important to develop community strategies for nurturing children affected and infected with HIV and to establish orphan registers with follow-up to determine long-term outcomes.

There is also need to establish locally available and affordable replacements/supplementary foods for babies born of HIV positive mothers since the risk of transmission through breastfeeding is high.

### *Care of mothers and fathers*

There is need to develop strategies for improving the income base of families affected by HIV/AIDS.

## Basic Sciences

Basic science research on HIV/AIDS in Kenya is necessitated by differences in virus strains from those elsewhere, differences in populations, nutritional status and risk groups, among other factors.

Basic science research requires a strong laboratory infrastructure, personnel capacity and interest, and availability of funds. In Kenya, research is needed among long-term survivors and non-transmitters of HIV to establish the reasons.

***Other areas in which research is needed include:***

- The uneven distribution of HIV among various ethnic groups.
- Resistance to anti-retroviral drugs.
- Failure of diagnostic test kits.
- Differences in occurrence of opportunistic infections in relation to viral load levels.
- The types and sub-types of HIV circulating in Kenya.
- The immune and nutritional status and how they affect HIV infection and vertical transmission.
- How genetic characteristics would determine differences in the reaction of different people to HIV.
- Ability of current diagnostic kits to detect all HIV sub-types.
- Socio-cultural determinants of the spread of HIV.

## Epidemiology

According to sentinel surveillance data collected by the National AIDS/STD Control Programme (NASCOP), prevalence rates were reported to have doubled in some areas in Kenya since 1993. Since 1990, HIV monitoring had been conducted in 23 surveillance sites and about 67 screening hospitals. Hospitals were provided with testing and diagnostic kits. NASCOP uses four data collection methods in its HIV surveillance and monitoring activities: monthly AIDS case reports, monthly blood donor reports, HIV/AIDS sentinel surveillance and special studies.

The question on whether to continue Elisa tests in the districts or to centralize HIV testing needs to be addressed. Sentinel surveillance uses only ante-natal clinic data. Is the data representative of Kenya or should other population sub-groups be involved is a question that requires answers.

Participants called for the need to establish the role of intravenous drug users and homosexual gr626Xhomosexual groups in the epip+1XV/AIDS in Kenya.

# PRIORITIES FOR RESEARCH ON HIV/AIDS PREVENTION AND CARE

The core team that deliberated on research issues in HIV/AIDS Prevention and care (HAPAC) identified four theme areas for potential research.

*These are:*

- Priority high risk target groups.
- Counselling and testing.
- Care and support systems.
- Information, communication and education (IEC)

The outcomes of the discussions under these themes are summarized below.

## PRIORITY HIGH-RISK TARGET GROUPS

The workshop identified three categories of risk status for people, families and communities affected by HIV/AIDS.

. *These are:*

- The infected and the affected;
- The ones at risk; and
- The normal population.

Each of the groups above requires a unique approach.

According to findings presented at the workshop, the current trend of the increase in the number of people infected and affected by HIV is taking its toll on all the groups of population with the equilibrium shifting towards the "normal" population.

Consequently, each category representing the various stages of HIV infection must be targeted with care and preventive interventions that is appropriate to the circumstances of each particular group. The workshop identified five main groups of people at risk of HIV/AIDS infection where more information needs to be generated.

*The categories revolve around:*

- Age and sex;
- High-risk behaviour;
- High-risk occupation;
- Health and other professionals who come into contact with HIV/AIDS cases; and
- Geographical location and distribution.

*The workshop identified the following priority research issues:*

- Establishing the most effective means of promoting socially responsible behaviour among the youth in order to reduce HIV transmission.
- Documenting the effective methods of preventing HIV transmission among high-risk groups.
- Modalities of empowering women in all spheres of life to enable them participate effectively in reducing STI/HIV transmission.
- Addressing people engaged in high-risk behaviour like casual sex and drug addiction, in order to reduce HIV infection.
- Devising means of preventing HIV transmission among prisoners and other confined populations.
- Establishing effective ways of involving opinion and other respected leaders in the prevention of HIV transmission in the community.

*Secondary issues for research revolved around:*

- The relationship between age and sex for all age groups – from children to sexually active middle aged men and women going through mid-life crisis.
- The contributory factors for individuals engaged in high-risk behaviour like substance abuse, alcoholism, homosexuality and people with multiple sex partners.
- Health professionals who come into direct contact with patients,
- Professionals who have an influence in the health of people. for example, teachers. clergymen and community leaders, and the mass media.
- Occupations that by their nature expose certain categories of people to high-risk behaviours. People at risk here include long distance truck drivers, commercial sex workers, bar and hotel attendants, and migrant workers.
- Modalities of making condoms available to prisoners, and in public places like hotels and public toilets.

## COUNSELLING AND TESTING

Although counseling and testing for HIV is one of the most talked about interventions with regard to prevention and care of those infected and affected by HIV/AIDS, many questions remain unresolved on the professional approaches of counseling.

Therefore, the workshop expressed the need for policy direction in the following.

**Counselling** The professional qualifications of counselors by training and experience, and the methodologies and impact of counseling.

**Testing** Areas that require policy direction include the methods used for HIV testing; who needs to be tested; qualifications of personnel undertaking the tests; accessibility and affordability of the tests; and use of the results.

*It was also found necessary to establish the following:*

- The quality and outcome of both pre- and post-test counseling services, and the linkages of these counseling services with prevailing health care services in order to check the spread of the disease.
- The adequacy of existing policies, programmes and guidelines in HIV counseling. This also includes the nature of assimilation of people living with, and affected by HIV/AIDS.
- The safety of the blood used in transfusion.
- The rationale behind HIV testing, including who should be targeted for testing.

## CARE AND SUPPORT SYSTEMS

The tremendous increase in the number of HIV/AIDS cases outstrip the capacity of the existing health care resources in public, mission and private health care centres to cope with the epidemic. Alternative health care and support systems are therefore needed.

*The workshop identified the following areas for research:*

- Primary and secondary care for those infected both within and outside health facilities.
- The nature of health care delivery systems, including the reform, decentralization and re-structuring processes.
- Operations of the health services in terms of infrastructure, resources, training, monitoring and evaluation, referral and support systems, and patient care.
- The type and effectiveness of available support systems for those infected with and affected by HIV.
- Establishing the standard of training and the requisite capacity for home-based care providers.
- The kind of relationship present between the risk of acquiring HIV/AIDS and the educational level of individuals.
- The disparities existing between gender, ethnic groups and geographical areas, and the mechanisms used for monitoring and evaluating the care and support given to HIV/AIDS patients.
- Health sector reform that will provide a platform for dealing with HIV/AIDS pandemic within the existing socio-economic support systems for those who are affected76Xaffected by and infIV/AIDS.
- A secondary issue that arose was the need to establish the current position of locally produced HIV/AIDS drugs.

## INFORMATION, EDUCATION AND COMMUNICATION

The workshop recognized lack of provision of accurate information on HIV/AIDS, use of appropriate education methods and relevant communication strategies as major challenges in the prevention and care of HIV/AIDS programmes.

*Issues that need to be addressed include:*

- Establishing the most effective organs of the mass media for different target groups or audiences.
- The nature and effectiveness of inter-personal communication.
- Use of folk media like songs and drama.

*The following were identified as priority study areas:*

- The relationship between access to information, content of message, level and depth of knowledge, attitude and practice, and behaviour change.
- Gender sensitiveness of the current Information, Education and Communication strategies on HIV/AIDS.
- The effectiveness of various behaviour change communication strategies for example those using peer education, mass media and family counselling.
- How to develop partnership with the media in the fight against HIV/AIDS.
- The most effective communication strategies dealing with the youth.
- Ethnic concepts and terminologies used in relation to HIV/AIDS and their role of influencing behaviour change.

*Issues arising included:*

- Establishing the difference between education and information.
- The need to reach the grassroots by publishing HIV/AIDS information and related education materials in vernacular languages.
- Establishing the level of knowledge people have in regard to the manifestations of HIV/AIDS, as opposed to the general awareness of the disease.
- Looking at the cause of mutual lack of trust between local organisations involved in HIV/AIDS research.
- Tncy between "knowledge" and behaviour change.
- Evaluation of the quality and outcome of counselling services.
- Methods of promoting responsible social behaviour among the youth in order to reduce HIV transmission.
- Standards for training and capacity building needed for home-based care providers.
- Identifying the existing support systems (for example, social, religious, educational, medical) for those affected with HIV/AIDS.
- Identifying the level of training of health care workers and standard of care given to HIV/AIDS and STI patients.

helped develop a laboratory testing kit and has trained people in operating the equipment and providing laboratory services.

### USAID

Currently, USAID has no mechanism for directly funding research in Kenya. However, through bi-lateral relationships, cooperating agencies, and contracts already in-place with specific projects (such as POLICY and HORIZONS), USAID is able to channel funds to local NGOs for research activities.

USAID also has capacity for co-funding. The agency has agreements in this regard with the Washington office and allows local USAID offices to draw up detailed plans of action. USAID operations research involves community-level, innovative responses to HIV/AIDS – for example, community mechanisms being used to support orphans, people living with HIV/AIDS, and those living with them; youth programmes; and voluntary counseling and testing.

### Office of the President

This office is responsible for co-ordinating research in Kenya. There is a well established government research policy whereby a technical committee grants research clearance. Some institutions (for example, KEMRI and the universities) are authorised to undertake research. They in turn must report their research findings every year to the Government of Kenya department with whom they are collaborating. Academic research is guaranteed clearance as long as the research is in line with the policies of the research clearing organ.

Thus, those desiring to carry out research must fill out the application forms, assemble and submit a proposal, and pay an application fee. The forms would then be submitted to the appropriate committee that looks at the issues and forwards the package to experts within the area of interest. Approved research programmes are monitored closely by the Office of the President.

### Plenary Discussions: Additional Issues and Comments

The participants were given an opportunity to raise issues and offer comments before drawing a consensus on the research agenda. The following were the major questions and concerns:

- A question arose as to the **role of the Ministry of Health**. The response was that the Ministry of Health is directly responsible for registering any products manufactured or sold in Kenya. It has the capability to ban or to sanction use of certain products. It was noted, however, that the Ministry of Health has been dealing with research issues, especially those involving drugs for HIV/AIDS. An issue at hand was Pearl Omega and Polyatomic therapy. It was said that so far, Pearl Omega and Polyatomic are both banned. It appears to have been a unilateral decision, and there is still confusion regarding how this issue is being handled. It was noted that Kenya differs from other countries in that it has a Ministry of Research, so there needs to be a clear-cut policy on how it works with other organisation/ministries.

- There was heated debate on the whole area of **legal and ethical issues,** especially in relation to HIV/AIDS drugs and the pronouncement of unproven cures. The Ministries of Health and Research were challenged to ensure that the rights of individuals are protected.
- Co-ordination and utilisation of research results were said to be critical. Parties interested in research need to be empowered to collaborate more effectively in conducting research, as well as disseminating the results to stakeholders and policymakers. There is need for co-ordinated planning involving researchers, research agents and beneficiaries. Efforts have to be made to avoid duplication of efforts. There is need to harmonise the various structures and help them function effectively and popularise the systems that are working well.

Several concerns and Research areas were found to be missing from the earlier presentations. The participants sighted some of the areas as follows:

- Information, Education and Communication: Some of the participants felt that there is so far no marked impact through the IEC programmes. There seem to be a break of communication. They said that IEC structures exist in our communities, especially at the grassroots level yet so far they have not been fully exploited in furthering the prevention and control of HIV/AIDS.
- Youth, men and women need to be participants in research and not just recipients of the findings. This gave the impression that these groups have been targeted as research subjects without their full involvement in the design of the research and utilisation of the research finding. Such inclusions would enhance behaviour change, especially in the most vulnerable groups.
- Evaluation research is lacking. We need to identify methodologies employed for behaviour change. There is need to learn what has worked from other projects and replicate.

**The Consensus**

Following the presentations, the Chairman asked the participants to reflect on the priority research areas that had been identified and presented for the specific theme area. It is also important to note that there were key cross cutting issues that needed to be given priority because of their significance in each of the areas. As a result of these workshops, NASCOP has set a National Research Agenda and the priorities in each of the themes identified in these workshops will be adopted.

**Way Forward**

- NASCOP's co-ordination, implementation, and utilisation of HIV/AIDS Awareness research mechanisms and guidance are clearly spelt out in the Sessional Paper No. 4 of 1997: AIDS in Kenya, and in NASCOP's strategic framework for the next 5 years.
- NASCOP and USAID have initiated the development of a national process to document and produce materials on the research already done to be available in the NASCOP Resource Centre.
- NASCOP has a scientific steering committee that needs to be strengthened and in doing so, they will require legal backing, especially from the office of the Attorney general.
- This priority research agenda will be disseminated to other donors and research bodies and will be made available to all interested parties.

- Local and national capacities need to be build to undertake basic research. There is also a need to do evaluation research but the skills among the implementers are limited. Capacity should be built, especially in the districts carrying out IEC, care, and support services.
- To alleviate the poor distributions of research results, NASCOP will operationalise mechanisms for disseminating research findings to stakeholders and other potential users to provide them with information on what to base their interventions.

geographical distribution? What are their property and inheritance rights?

10. How has stigmatisation contributed to the spread of AIDS? Would more access to voluntary counselling and testing reduce stigma and increase HIV care and prevention opportunities?
11. What are the circumstances determining the timing, partner-choice and circumstances (condom use, force, exchange of goods, etc.) of an adolescent woman's first and subsequent sexual encounters?
12. Are we equipping people with appropriate and adequate skills to negotiate safer sex, given the inequalities of power, age, physical strength, and economic security inherent in sexual relationships?
13. What has been the cost of HIV/AIDS to institutions providing care and support, in terms of home care in the community? Who bears these costs – individuals, families, communities or the government?
14. What impact have NGOs and CBOs had on those infected and affected?

## Epidemiology, public health and bio-medical research

1. How do we react to the early detection of HIV in people like blood donors, antenatal mothers, students, employees and insurance policy seekers?
2. What is the impact of current control measures on the spread of HIV/AIDS?
3. How can methods/strategies to provide affordable drugs (including traditional medicines) for HIV/AIDS be developed?
4. What are the social and cultural determinants of the spread of HIV/AIDS?
5. What strategies can be used to reduce/eliminate the social stigma related to HIV/AIDS?
6. Which are the locally available/affordable supplementary/complementary foods for babies born to HIV positive mothers?
7. What factors determine HIV transmission?
8. What strategies can be used to operationalize research findings in the continuum of care of people living with HIV/AIDS?
9. What is the level of availability and adequacy of laboratory quality control/assurance measures for blood screening?
10. What is the impact of primary intervention strategies geared towards the prevention of HIV transmission and promotion of sustainable risk reduction in adolescents and women?
11. What is the feasibility of the various intervention processes formed to prevent mother to child transmission (MTCT) of HIV?
12. Should Elisa tests in the districts continue or should HIV testing be centralised?
13. Is data from Sentinel surveillance representative of Kenya or should other population sub-groups be involved?
14. Are current methods of epidemiological data collection both adequate and appropriate?
15. Care of health care workers: what is the local level of efforts - related sero-conversion and other related diseases?
16. Are current kits for HIV testing satisfactory? Do we need better diagnostic tools for opportunistic infections?
17. What is the nutritional suitability of locally available/affordable foods that can be used as supplementary or complementary foods for babies born to HIV positive mothers?

18. What is the efficacy of voluntary counseling and testing (VCT) compared to other interventions in reducing HIV transmission in women, adolescents and their sexual partners?
19. What are the causes of mortality and morbidity among babies born to HIV positive mothers and how can treatment protocols for the common syndromes be developed?
20. What are the care options for HIV infected women including nutritional support, prophylaxis for common infections, social support and income generating activities?

ctivities?

PPrevention and Care Programmes

1. Why is "knowledge" not linked to behaviour change with regard to access to information, content of message, level and depth of knowledge, attitude and practice?
2. What is the quality and outcome of counselling services and what are their linkages to the current health care management plan?
3. What are the most effective means of promoting responsible and safe social behaviour among the youth in order to reduce HIV transmission?
4. What standards for training and capacity building are needed for home based care providers?
5. What are the existing support systems (social, religious, educational, medical, etc). for those who are affected with HIV/AIDS at home, community, institution and national level?
6. Are health care workers adequately trained and are they providing adequate care for HIV/AIDS and STI patients?
7. How can women be empowered socially, economically and politically in order to participate effectively in reducing of transmission of STI/HIV?
8. What is the effectiveness of various behaviour change communication channels, e.g. peer education, electronic media and family counselling?
9. What are the most effective communication strategies among and for the youth?
10. What is the impact of HIV/AIDS on schooling? What are the gender disparities between the ethnic groups and geographic areas?
11. What are the existing gaps in HIV counselling with regard to counselling needs, policies and programmes, and guidelines and education?
12. Are there appropriate mechanisms for monitoring and evaluating the care and support given to HIV/AIDS patients at all levels of care?
13. How can the risky sexual behaviour of people under the influence of drugs and other substances be addressed in order to reduce HIV infection?
14. What are the dynamics behind stigmatization and denial among the people living with, and those affected by HIV/AIDS?
15. How do we make the media prioritise passing of messages on HIV/AIDS?
16. What role do opinion leaders play in the prevention of HIV transmission in the community?
17. How should the health sector reform be accelerated to address the HIV/AIDS pandemic?
18. How can HIV infection be prevented among prisoners and/or other populations?
19. What is the role of HIV/AIDS counselling in communication and behaviour change?
19. How safe is the blood for transfusion?

## APPENDIX II

## LIST OF PARTICIPANTS AND PARTICIPATING INSTITUTIONS

| | |
|---|---|
| 1. P. I. MUCHIRI | OFFICE OF THE PRESIDENT (OP) |
| 2. Dr KIMANI K. W. | MINISTRY OF HEALTH (MOH) |
| 3. Dr JOHN OGANGE | MOH |
| 4. Dr A. H. AHMED | MOH |
| 5. KIARIE MGUGUA | MOH |
| 6. J. M. MUSYOKA | MOH |
| 7. Prof K. M. BHATI | UNIVERSITY OF NAIROBI |
| 8. AGNES AMAKOVE | NATIONAL AIDS CONTROL PROGRAMME (NASCOP) |
| 9. ABDIKADIR WANDERA | MOH |
| 10. MARY W. KARUTHI | NASCOP |
| 11. JANE GITONGA | NASCOP |
| 12. B. M. KIARIE | NATIONAL PUBLIC HEALTH LABORATORIES (NPHL) |
| 13. AGNES W. KARUGA | MOH/THIKA |
| 14. STEPHEN K. GITONGA | MAUA METHODIST HOSPITAL |
| 15. Dr GEORGE MURITHI | FAMILY PLANNING ASSOCIATION OF KENYA (FPAK) |
| 16. SILVANS OWINO | PUBLIC HEALTH DIVISION/MOH |
| 17. Dr J G. KIBARU | MOH – Thika |
| 18. HERBERT OKUTUYI | MOH – Busia |
| 19. Prof KAIMENYI J. | UNIVERSITY OF NAIROBI (UON) |
| 20. JOSPHAT I. MATEI | MOH – Kitui |
| 21. Dr H. F. O. OLUOCH | MOH – Homabay |
| 22. NICHOLAS DONDI | DEMACOM |
| 23. Dr JADALT C. S. | MOH – Teso |
| 24. Dr RACHEL KMAU | MOH – Nyeri |
| 25. Dr M. S. ABDULLAH | KEMRI |
| 26. ROSEMARY NZISSI | DASCO – NAKURU |
| 27. DAUDI NTURIBI | FAMILY PLANNING PRIVATE SECTOR |
| 28. NJERU MURIUKI | NASCOP |
| 29. MBAE BAINI | NASCOP |
| 30. S. P. NJAU | DIRECTORATE OF PERSONNEL MANAGEMENT |
| 31. SHIRLEY GATHUKA | AMREF |
| 32. Dr OCHIENG' ONDOLO | AMREF |
| 33. Dr NAMARA WARREN | UNAIDS |

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|---|---|
| 34. STEPHEN KIRIGA | DASCO – Isiolo |

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|---|---|
| 35. Prof J. O. NDINYA ACHOLA | UON |
| 36. JUDITH SITTI | DASCO – Teso |
| 37. Dr W. M. KOFI-TSEKIO | KEMRI |
| 38. DISHON GOGI | DASCO – Homa-bay |
| 39. Dr A. ABDULRAHIM | PROVINCIAL MEDICAL OFFICER – NAIROBI |
| 40. G. M. BALTAZA | NASCOP |
| 41. T. TAKONA | USAID |
| 42. CLEMENT WERE | MOH/KAKAMEGA |
| 43. ANDADA FRANCIS | NASCOP |
| 44. DONALD DICKERSON | FUTURES/DFID |
| 45. JOHNSON NYONG | MOH |
| 46. PAULINE NGUNJIRI | JOURNALIST |
| 47. CHARLOTTE LARSEN | UNFPA |
| 48. Dr CATHY TOROITICH-RUTU | FAMILY HEALTH INTERNATIONAL (FHI) |
| 49. Dr P. A. OREGI | KEMRI |
| 50. Dr G. G. MBUGUA | KEMRI |
| 51. Dr K. CHESANG | MOH - Nakuru |
| 52. AMAGOVE M. CHAMBU | MOH -Lugari |
| 53. Dr JANE MUITA | UNICEF, KCO |
| 54. SIMON O. DANDA | MOH -Bungoma |
| 55. RICHARD K. MAWEU | MOH -Nairobi |
| 56. CATHERINE LWENYA | FPLM/JSI |
| 57. Dr SABINE BECKMANN | GERMAN DEVELOPMENT COOPERATION (GTZ) |
| 58. AGNES USAGI | Kabiro Health Care |
| 59. JACKUELINE MAKOKHA | REGIONAL AIDS TRAINING NETWORK |
| 60. ISAAC MALONZA | KENYA MEDICAL ASSOCIATION (KMA) |
| 61. GEORGE NDEGWA | MINISTRY OF TOURISM |
| 62. Dr OLANGO ONUDI | MOH |
| 63. A. R. GACUHI | MRT |
| 64. MICHAEL ANGAGA | NETWORK OF PEOPLE LIVING WITH AIDS IN AFRICA |
| 65. ERIC KAYOTAN | FAMILY PLANNING PRIVATE SERVICE (A) |
| 66. Prof L. SOTTENO | KENYA MEDICAL ASSOCIATION (KMA) |
| 67. GLADYS GATHERU | CULTURE DEPARTMENT |
| 68. Dr M. AWORI | MOH |

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| 69. PAUL KAVUO | MACHAKOS STI PROJECT |

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| 70. Dr JOB BWAGU | UON |
| 71. RACHEAL ODEDE | UNICEF |
| 72. PETER MWAROGO | FAMILY HEALTH INTERNATIONAL (FHI) |
| 73. BRENDA RAKAMA | FHI |
| 74. CHARLES KOMBO | MIB |
| 75. Dr JOSEPH ODHIAMBO | KEMRI |
| 76. Dr DR.S. A. Z. MULINDI | UON |
| 77. DR. T. GAKURURE | MOH |
| 78. DR. G. GAKIRIA | NATIONAL LEPROSY AND TUBERCULOSIS PROGRAMME (NLTP) |
| 79. Dr A. O. ANZALA | UON |
| 80. Dr MAGGWA B. N. | POPULATION COUNCIL |
| 81. CHARLES MWAI | POPULATION COUNCIL |
| 82. GILLY ARTHUR | KEMRI/HAPAC |
| 83. HELENA EVERSOLE | UNICEF, KENYA COUNTRY OFFICE |
| 84. JOSEPHINE S. LESIAN | MOH – KAJIADO |
| 85. MAINA KAHINDO | FHI |
| 86. Dr P. M. TUKEI | KEMRI |
| 87. Prof P. R. KENYA | MOI UNIVERSITY |
| 88. Dr N. R. MBOLOI | KENYATTA NATIONAL HOSPITAL (KNH) |
| 89. Dr O. GAKURU | UON |
| 90. DORCAS MATENGO | NASCOP |
| 91. JOYCE LIKU | NASCOP |
| 92. YOSHIRO KURASHINA | JAPAN INTERNATIONAL COOPERATION AGENCY (JICA) |
| 93. IMISA MASINJILA | KANCO |
| 94. LEAH IRANGI | NASCOP |
| 95. DAVID WABOMBA | NATIONAL AIDS CONTROL PROGRAMME |
| 96. YOSHHIDE FUJIYAYA | KEMRI/JICA |
| 97. NOBUYOSHI KOBAYASHI | KEMRI/JICA |
| 98. ROBERT R. KAMAU | KENYA INSTITUTE OF EDUCATION |
| 99. Dr K. M. WASUNNA | KENYA MEDICAL RESEARCH INSTITUTE |
| 100. J. E. EKIRAPA | OFFICE OF THE PRESIDENT |
| 101. L. N. MUTHAMI | KENYA MEDICAL RESEARCH INSTITUTE |
| 102. JOHN MUSALE | MINISTRY OF PLANNING AND NATIONAL DEVELOPMENT (MOPND) |
| 103. A. M. MURIU | MINISTRY OF PLANNING AND NATIONAL DEVELOPMENT |

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| 104. TERESIA MWIKALI | NATIONAL AIDS CONTROL PROGRAMME |

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| 105. LAWRENCE OKUDO | MINISTRY OF PLANNING AND NATIONAL DEVELOPMENT |
| 106. Brig (Dr) G. K. MULUNGA | DEPARTMENT OF DEFENCE |
| 107. KEZZY MUNIU | MINISTRY OF HOME AFFAIRS |
| 108. CAROLINE NGARE | NATIONAL AIDS CONTROL PROGRAMME |
| 109. MARITIM SONGOK | KENYA MEDICAL RESEARCH INSTITUTE |
| 110. NDENGWAH | MINISTRY OF HEALTH |
| 111. MWOTA SAM | MINISTRY OF HEALTH |
| 112. SAWE J. K. A. | MINISTRY OF HEALTH |
| 113. W. KAIRO | KENYA RED CROSS SOCIETY |
| 114. Dr OMBEGA | UNIVERSITY OF NAIROBI |
| 115. NASIB MAKUWA | CENTRAL ORGANISATIONS OF TRADE UNIONS (K) |
| 116. JUDITH AOKO | STANDARD NEWSPAPERS |
| 117. CATHERINE MUMMA | ATTORNEY GENERAL'S OFFICE |
| 118. MIKE MWANIKI | NATION NEWSPAPERS |
| 119. Dr RASHID J. R. | KENYA MEDICAL RESEARCH INSTITUTE |
| 120. J. WANJAU | PROVINCIAL MEDICAL OFFICER – NAIROBI |
| 121. E. C. WEKESA | OUP/MOPND |
| 122. M. K. KISOU | NASCOP |
| 123. J. W. OTIENO | NASCOP |
| 124. JOSEPH MWONGELA | NATIONAL AIDS CONTROL PROGRAMME |
| 125. MESHACK NDOLO | NATIONAL AIDS CONTROL PROGRAMME |
| 126. NELLIE LUCHEMO | MAENDELEO YA WANAWAKE ORGANISATION |
| 127. OKUTTAH MARK | KTMT |
| 128. ASUNTA WAGURA | KENYA NETWORK OF WOMEN LIVING WITH AIDS |
| 129. Dr P. GATURUKU | MINISTRY OF HEALTH |
| 130. Dr PAUL KIZITO | NATIONAL COUNCIL OF POPULATION AND DEVELOPMENT |
| 131. Dr ELIZABETH BUKUSI | CHRISTIAN HEALTH ASSOCIATION OF KENYA |
| 132. ELIUD SHIVACHI | CENTRAL ORGANISATION OF TRADE UNIONS (COTU) |
| 133. RISPAH ODUWO | NCST/NHRDC |
| 134. JOHN BERMA | PSI |
| 135. DOROTHY HUDSON | PSI |

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| 136. BERLYL ACHIENG | FAMILY RELIEF AND REHABILITATION ORGANIZATION (FRRO) |

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| 137. LILIAN ODONGO | FRRO |
| 138. DR. G. K. MACHARIA | BUTERE/MUMIAS DISTRICT |
| 139. CLAIRE TAYLOR | DFID |
| 140. Dr HOSKAH WAWERU | KNH |
| 141. ALLAN RAGI | KENYA AIDS NGOs CONSORTIUM |
| 142. JIM COCKER | POLICY PROJECT |
| 143. A. SHAWN | POLICY PROJECT |
| 144. ANGELINE TEUEH | POLICY PROJECT |
| 145. Dr PETER GATURUKU | MOH |
| 146. Dr BILHA HAGEMBE | NASCOP (MOH) |
| 147. Hon BASIL CRITICOS | ASSISTANT MINISTER (MOH) |
| 148. GODFREY BALTAZAR | NATIONAL AIDS CONTROL PROGRAMME |
| 149. ROSELYN MULIMI | NATIONAL AIDS CONTROL PROGRAMME |
| 150. MESHACK NDOLO | NATIONAL AIDS CONTROL PROGRAMME |
| 151. Dr IBRAHIM MOHAMED | NATIONAL AIDS CONTROL PROGRAMME |
| 152. MARGARET GATEI | KENYA AIDS NGOs CONSORTIUM |
| 153. ESTHER GATUA | KENYA AIDS NGOs CONSORTIUM |
| 154. ANTHONY KARIUKI | KENYA AIDS NGOs CONSORTIUM |
| 155. LUCY NG'ANG'A | KENYA AIDS NGOs CONSORTIUM |
| 156. JOHN | KENYA AIDS NGOs CONSORTIUM |
| 157. Dr J. A. ODHIAMBO | KEMRI |
| 158. Dr GAKURU | UON |

## APPENDIX III

## WORKSHOP AGENDA

| TIME | ACTIVITY | FACILITATOR | IN CHAIR |
|---|---|---|---|
| 8.00-8.30 | REGISTRATION | NASCOP | |
| 8.30-9.00 | Opening | Guest Speaker | Dr W. Naamara |
| | Welcome and Overview | Dr S. Abdulla | |
| | USAID Support to HIV AIDS | Dona Vogel | |
| | DMS Remarks | Prof J. Meme | |
| | Minister's open remarks | Hon J. Kalweo | |
| 9.00-9.30 | NASCOP's Vision | Dr BON. Hagembe | |
| 9.30-9.55 | Policy, Human Rights, Legislation | Allan Ragi/Esther Gatua | |
| 9.55-10.20 | Socio-Economic, Cultural, Demography and Behaviour Change | Prof ABC Ayayo/Dr Gakuru | |
| 10.20-10.50 | T E A | B R E | A K |
| 10.50-11.15 | Epidemiology, Public Health, Biomedical Research | Dr J. A. Odhiambo | |
| 11.15-11.40 | Prevention and Care | Dr Ondolo | |
| 11.40-12.30 | Discussion | | Sam Kalibala |
| 12.30-2.00 | L U | N | C H |
| 2.00-3.00 | Funding of HIV/AIDS research panel:<br>• GOK/DFID<br>• USAID/WB<br>• UNAIDS<br>• Barclays Bank<br>• Pharmaceutical Association<br>• FKE | | David Nalo |
| 3.00-3.30 | Discussion | | Dr Gaturuku |
| 3.30-4.00 | Tea Break | | |
| 4.00-4.30 | Way-forward | R.Mutemi/<br>G. M. Baltazar | |
| 4.30-5.00 | C L O S I N G | | Director of Research, Ministry of Science and Technology |

## APPENDIX 1V

## GUIDING CRITERIA IN THE PRIORITISATION PROCESS

In essence, the research agenda-setting process sought to answer the following question:

- **What research will lead to a better response to HIV and AIDS in Kenya?**

- **What makes a priority research question?**

Considering that the HIV/AIDS epidemic has been visible for less than 20 years, a remarkable amount is known about the virus, the behaviours that spread it and how its spread can be reduced. Less is known about its effects on families and communities. While the field is far from virgin plenty of information already exists. The task before participants was to decide where more information is needed to ensure a response; a response that is ethical, motivates Kenyans to adopt non –risky behaviour and protects the rights of infected Kenyans and others affected by HIV and AIDS.

It was found necessary to develop criteria to guide the participants in prioritising the priority research questions/issues. The preparatory workshop held in November 1998 identified a number of criteria that should be met by research identified as a national priority.

They fell into two broad categories; *importance and feasibility, as follows:*

**Importance**

- Does the answer to the question potentially have an important impact on policies and programmes?
- Is it likely that the results of the research will be acted upon?
- Might the results be used to advocate for a more effective response?
- Is the question particularly relevant to the current AIDS epidemic in Kenya?
- Does the question fill a gap in existing research?

**Feasibility**

- Is it scientifically possible to answer the question?
- Is it possible operationally and logistically?
- Is the research and its likely outcome politically feasible?

Can the resources (including human resources) to conduct and disseminate the research be found?