

# Forging the Links against AIDS



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# Forging the Links against AIDS

## HIV/AIDS Research, Policy and Practice

Edited by Virginia Bond and Gideon Kwesigabo

Research, policy and implementation are separate activities, requiring specialised skills. To stop people being infected with HIV and dying from HIV there are clearly many overlapping issues involved for researchers, policy-makers and implementers. We need to make sure that community participation is integral to our collective approach without compromising fundamental ethics or the quality of our work.

Agnes Binagwaho, Virginia Bond, Alex Coutinho,  
Helen Jackson, Michael J. Kelly, Gideon Kwesigabo,  
Jessie Mbwambo, Fred Mhalu



# Foreword

To combat HIV/AIDS, strong links must be forged between research, policy and implementation. Research needs to be action-orientated, intervention related and to participate in the formulation of national policy and national programmes. Policy should be formulated on the basis of research findings and best practices. The work of practitioners needs input from research and should be linked to local government coordination and government service provision.

Sida decided to convene a satellite meeting at the 13<sup>th</sup> International Conference on AIDS and STIs in Africa (ICASA) Nairobi 2003, to examine the ‘challenging links’ between research, policy formulation and implementation. We were pleased to be able to gather a panel of five experts representing senior researchers, policy makers and practitioners in Africa<sup>1</sup>. The panel presentations and discussions were stimulating and informative, followed by a lively floor discussion.

This booklet contains the panel presentations and reflects on the main issues in the debates. Two main conclusions were the need to encourage accountability at all levels and the need for greater efforts at coordination. In the

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<sup>1</sup> These five experts were: Professor emeritus Michael Kelly from the University of Zambia, Helen Jackson UNFPA HIV/AIDS regional advisor for the Southern African region, Dr Agnes Binagwaho Director of the Rwandan National AIDS Control Commission (NACC), Professor Fred Mhalu and Dr. Jessie Mbwambo - both from the Muhimbili University College of Health Sciences of the University of Dar es Salaam, and, Dr. Alex Continho Director of the AIDS Support Organisation of Uganda (TASO).

first place, we have a duty towards those infected and affected by HIV/AIDS. Moreover, we have a responsibility to promote prevention strategies and interventions that enable and empower people to protect themselves from being infected with HIV. In the second place, a lot of progress has been made in worst affected countries on coordination of efforts, but much remains to be done. The current scaling-up of national responses, supported by increasing numbers of external actors, necessitates firm commitment by governments to coordination of efforts.

Finally, we would like to thank the panel members, as well as the conference delegates at the satellite, for their contributions. We would also like to thank Virginia Bond and Gideon Kwesigabo for producing this booklet. We trust it will be of use to researchers, policy makers and practitioners in our common efforts for HIV/AIDS prevention, care and treatment, and, impact mitigation.

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Africa Department*

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# Preface

## **Virginia Bond and Gideon Kwesigabo**

This booklet is the result of a satellite meeting convened by Sida's Regional HIV/AIDS Team for Africa – during the thirteenth International Conference on AIDS and Associated Cancers in Africa (ICASA) – that took place 24 September 2003. The theme of the meeting was *Research, Policy and Implementation – The Challenging Links*.

Opening remarks were made by His Excellency Mr Bo Göransson, Swedish Ambassador to Kenya, followed by introductory remarks from the Head of the Sida Regional HIV/AIDS team for Africa, Dr Anita Sandstrom. Six guest speakers gave their panel presentations followed by panel and public discussions. Closing remarks were by Ms Lotta Sylwander, Head of Sida's Regional Department for Africa.

The presentations were written up by panellists for this booklet. The focus flows from the tough realities of gender and economic inequities, within which the HIV/AIDS epidemic is experienced in sub-Saharan Africa, to four case-studies from Rwanda, Tanzania and Uganda detailing experiences of coordinating, and/or forging links between, research, policy and implementation.

Chapter one focuses on ethics and responsibility in inequitable and under-resourced settings, while chapter two concentrates on gendered patterns of HIV infection in sub-Saharan Africa. The emphasis is on the necessity to examine, expose and challenge these wider issues if there is to be successful interaction between research, policy and implementation.

Chapter three relates Rwanda's experience of coordinating research, policy and implementation, pointing out the challenges, difficulties and successes. Chapter four details how research findings have influenced policy, using the experiences of a collaborative Tanzanian and Swedish HIV/AIDS research project, while chapter five presents how research findings on HIV-related stigma were translated into educational materials and communicated to policy makers. Chapter six is based on Uganda's experience of scaling up the delivery of antiretroviral therapy (ART). It pinpoints the different roles of civil society and government and the need for research to rapidly feedback findings into ongoing interventions to improve the delivery of ART.

The last chapter of the booklet is a synthesis by the rapporteurs of the satellite meeting. This is based on the presentations, summaries from both the panel and the public discussion, and their own collective reflections and experiences as researchers involved in applied HIV/AIDS research in sub-Saharan Africa.

# Contents

Chapter 1: Ethical Considerations of HIV/AIDS Research in Africa .....	9
Chapter 2: HIV/AIDS and Gender – Addressing tough realities in research, policy development and implementation .....	19
Chapter 3: The Experience of Rwanda in Coordinating HIV and AIDS Research .....	27
Chapter 4: Translating HIV/AIDS Research Findings into policy – Experiences from a research programme in Tanzania .....	33
Chapter 5: From Research into Action – Experiences from the multi-country research study on understanding HIV-related stigma .....	41
Chapter 6: Challenging Links involved in Research-Policy Implementation – Moving from National Policy to free provision of ARVs in Uganda .....	49
Chapter 7: Reflections on Proceedings .....	57
Abbreviations and Acronyms .....	72
About the Authors .....	73



## CHAPTER 1

# Ethical Considerations of HIV/AIDS Research in Africa

Michael J. Kelly

*Any man's death diminishes me, because I am involved in  
mankind; and therefore never send to know for whom the bell tolls:  
it tolls for thee*

*John Donne*

### **The universal and fundamental ethical challenge of HIV/AIDS**

In a BBC interview prior to World AIDS Day 2003, UN Secretary-General Kofi Annan said the world is losing its war against AIDS as governments fail to confront the threat it poses. The Secretary-General told the BBC that he is saddened by the “*incredible callousness*” of a world that *allows* millions of AIDS patients in developing countries to die from lack of *affordable treatment*” (emphasis added).

The Secretary-General’s disturbing words highlight what should be *the* major ethical issue in a world with HIV/AIDS. The epidemic constitutes a vicious attack on the most fundamental of human rights – the rights to life and health. These rights can be protected by stemming the transmission of the disease, treating it where it has occurred, and acting to mitigate its many potential negative impacts. But currently “there have been steady increases in the number of people living with HIV/AIDS, as well as in the number of AIDS deaths” (UNAIDS, 2003, p 2).

The HIV/AIDS epidemic threatens the transmission of life, childbearing and the continuity of human societies. In the presence of HIV infection sexual intercourse, what should be a life-affirming expression of love, may in fact be

a life-threatening occasion of danger. Childbearing and the promise that attends a new birth are weighed down by the fears and implications of parent-to-child transmission.

HIV/AIDS impacts on what people treasure as most precious and most intimately human, calling forth the fundamental response that this should not be. It is wrong. It is unethical. It should be changed.

### **The science of ethics**

Ethics are based on what it means to be human. The word “ethics” derives from a Greek word meaning custom or conduct (the same word that has entered English as “ethos”, meaning the characteristic spirit and beliefs of a community). What ethics seek to provide is a well-reasoned set of conclusions concerning the kind of voluntary activity that may be judged good or suitable in the context of people’s lives and in their relations to one another. Ethics deal extensively with rights and duties and with maintaining an appropriate balance between these.

From the HIV/AIDS perspective, fundamental ethical principles include:

- Empowering individuals to make life-affirming choices;
- Doing no harm to oneself or others;
- Responding where possible to the basic human needs of others; and
- Minimising risks and the potential risk or harm that an action might occasion for another.

HIV/AIDS highlights and magnifies the ethical implications of such existing situations as gender imbalance, personal and structural poverty, the unequal distribution of the world’s resources, and the infringement of human rights. Additionally, HIV/AIDS raises new issues with ethical dimensions – for example, confidentiality versus public good, stigma and discrimination, access to antiretroviral drugs (ARVs) and vaccine trials.

### **The status of women and rectifying gender imbalances**

The first article of the Universal Declaration of Human Rights states “all human beings are born free and equal in

dignity and rights”. Though different, men and women are essentially equal. This is almost universally accepted in theory, but almost equally universally denied in practice. The reality is that in the majority of countries, and across a whole range of activities and interests, women have an inferior status. They are excluded from many areas of life. Various structures, symbols and practices alienate them and perpetuate their subordination. Discrimination against women is manifest in their unequal access to educational and training opportunities, the disproportionate burden they are called upon to play in family life, the lesser pay they receive for the same work as their male counterparts, constraints on their access to positions of influence when admitted to public life, and in many circumstances, outright violence against their persons.

HIV/AIDS affects women’s lives disproportionately. On physiological and health grounds they are at greater risk of becoming infected with the virus; on social and economic grounds they are more vulnerable to infection; and when HIV/AIDS is present in a household women are likely to carry the larger share of the burden and to be more extensively affected.

Ethically this is not as it should be and until such time as women’s full dignity as human persons and their full equality with men is proclaimed and practised in every walk and stage of life, humanity will remain out of harmony with its best aspirations. It will not be true to itself. Meanwhile, women and girls will remain at the epicentre of the epidemic. The relationship of respect, mutuality and equality between women and men will continue to be violated. In practice, the inherent human dignity of women will be denied. An unethical approach will be maintained and HIV/AIDS will continue to flourish.

### **Poverty and HIV**

Allied to the feminisation of HIV/AIDS is the pauperisation of the epidemic. Although not selective, HIV/AIDS has never been a democratic disease. It would not be true to say that it is a disease of the poor or of poor countries. Nevertheless, the absence of resources restricts poor people’s autonomy and their range of choices. Circumstances over which they

have virtually no control put the poor at higher risk of HIV infection. Such circumstances include:

- A greater likelihood of untreated STIs;
- An absence of information on their own HIV status or that of their sexual partner;
- An increased possibility of high-risk behaviour because of limited ability to access and store condoms correctly (in addition to major constraints on opportunities to use them properly); and
- Economic pressures to resort to the sale of sex to generate household income.

In addition, there are contextual, environmental and social factors, almost entirely outside their control, that make the poor more vulnerable to infection. Long prior to HIV infection, their immune systems may be depressed because of poor health and nutritional status; limited access to health care; inability to meet the cash or opportunity costs involved in accessing health services; an increased exposure to other health hazards such as malaria, TB or gastrointestinal problems. The poor constitute the majority of those who migrate from place to place in search of work and better living conditions. But only too often they only exchange unemployment, overcrowding, poor housing, inadequate sanitation, poor health and educational facilities with similar situations elsewhere. In this way, the poor carry the burden of their HIV vulnerability with them.

Clearly this is not the way things should be for over 40 per cent of humanity. Equally clearly, the continuation of such a situation will not serve to roll back HIV/AIDS. Poverty is perpetuated – and the AIDS/HIV situation is maintained or worsened – by the following:

- The concentration of wealth in the top five to ten per cent of the world population;
- The lacklustre poverty reduction programmes;
- The application of globalisation measures in ways that are to the disadvantage of poorer countries;
- The continued siphoning financial resources off to debt repayments;

- The brain drain that eats away at the human capacity of poor countries;
- The efforts to maximise profits at all costs;
- The corruption and cronyism at all levels;
- The mismanagement, poor governance, and unconcerned leadership that are crippling the potential of many poor countries;
- The concentration of efforts and resources on the retention of political power; and
- Internal and international conflicts and wars.

All of the above are unethical situations; things are not as they should be. All of the above maintain the unethical situation of mass poverty in a world plentifully supplied with means and resources. All of the above contribute unethically to prolonging the wretchedness of HIV/AIDS.

### **Collective responsibility and public good**

Silence, stigma and discrimination related to HIV/AIDS are bound up with a denial process which places responsibility elsewhere, with “them”, with “systems”, with “programmes”. One common and almost universal manifestation of HIV-related stigma is the attempt to dissociate oneself from HIV/AIDS, to see it as somebody else’s problem and not one’s own. Depending on one’s perspective, the disease is envisaged as something affecting commercial sex workers, men who have sex with men, the poor, women, “people in Africa”, migrant workers, intravenous drug users and so forth. There is much less readiness to see that HIV/AIDS as something that affects everyone, a situation for which everyone has responsibility.

In the context of HIV/AIDS, it is necessary to acknowledge that the epidemic is *our* problem and *our* challenge, that we must take responsibility for the collective effort to overcome it. The problem is not “out there”; it is here with us. Neither is the solution “out there”. It is here with us and we are challenged to respond.

Responsibility has been identified as an overarching, integrating structure that provides a framework for dealing with many of the ethical and practical issues arising from the HIV/AIDS epidemic: “Responsibility means enabling the

fullness of life expressed as concern, care for others, and the promotion of the common good” (Bate, 2003). Considering responsibility leads almost automatically to considering obligations and the actions that should be taken, and hence to the ethics of a situation.

HIV/AIDS gives rise to a host of potential conflicts: between the rights of one individual and those of another; between the rights of an individual and protecting the public good. “Arguably the greatest challenge which the law faces with regard to the AIDS epidemic is the reconciliation of the dilemma between the private right of the individual to conduct his or her life with the public right to health” (Orr, 1996, p 94). Dealing with this dilemma involves walking a tightrope between the competing claims of individual and public rights or interests.

In terms of HIV/AIDS, it can be helpful to think in five different dimensions:

1. Responsibility to those who are HIV positive;
2. Responsibility to those who are HIV negative;
3. Responsibility by those who are HIV positive;
4. Responsibility by those who are HIV negative; and
5. Responsibility to those directly caring for people living with HIV/AIDS (regardless of their HIV status).

### **Responsibility to those who are HIV positive**

The responsibility of every member of society, whether HIV negative or HIV positive, and all of society’s institutions:

- To accept, care for, treat and support those infected with the disease;
- To accept, care for and support those who have been affected by the epidemic, such as orphans or vulnerable children;
- To mitigate the harmful impacts of the epidemic on household and national economies;
- To mitigate the harmful impacts of the epidemic on the provision of education, health and other social services; and
- To mitigate the harmful impacts of the epidemic on society’s harmony and well-being.

### **Responsibility to those who are HIV negative**

- Preventing HIV transmission by promoting life-affirming and life-enhancing lifestyles.

### **Responsibility by those who are HIV positive**

This has many dimensions.

Those who are HIV positive have a responsibility to themselves:

- To seek out necessary assistance;
- To lead a lifestyle that will not aggravate their condition; and
- To follow advice about nutrition, rest and the speedy presentation of any medical condition.

Those who are HIV positive have a responsibility to their partner:

- To share information and knowledge about their HIV status. This is a specially pressing responsibility when the partner is HIV negative and one that has implications for practising sex within marriage in ways that will not risk transmission of the virus.

Those who are HIV positive also have responsibilities to the next generation:

- To make responsible decisions on whether or not to initiate a family and have children; and
- To recognise a responsibility to their children to remain healthy and stay alive for as long as possible and take the steps necessary for this.

Finally, those who are HIV positive have responsibilities to others:

- To avoid everything that would put others at risk of becoming HIV infected;
- To adhere to whatever treatment regimen that has been prescribed (so as to avoid, among other things, the development of drug-resistant HIV strains); and

- To be as open about their condition as they find it in their power to be.

### **Responsibility by those who are HIV negative**

This includes the full range of responsibilities to those who are HIV positive. But it goes beyond these to include:

- Developing personal attributes, such as industriousness, integrity, and transparency so that individuals, communities and the wider society may be better equipped to surmount the epidemic and its negative consequences;
- Developing social attributes that will bring individuals together in their struggle with the situation, thereby leading to the groundswell of community responses that are needed for rolling back HIV/AIDS;
- Being concerned and acting to transform unjust social structures and circumstances that perpetuate situations within which the epidemic flourishes.

And finally, there is responsibility for caregivers, enabling them to manage the stresses involved in working with those who have AIDS. This responsibility extends to all who provide HIV-related medical, social or educational services, regardless of their personal HIV status. Individuals, such as home-based care providers, medical personnel, and those providing essential information, education and other social services, need to be protected from burnout and strengthened in their capacity to provide their services effectively, efficiently and positively.

### **The ethics of treatment and prevention**

Ongoing work in developing new ARVs, lowering their prices and making them more accessible all raise urgent, immediate questions with major ethical dimensions. The most fundamental questions relate to the level of responsibility the international community, national governments and local communities all have for realising the human right of access to the “highest attainable standard of health care”. Other questions go on to ask about how to achieve a balance when

walking the moral tightrope between access to adequate health care for every individual, with access to ART for those needing it in circumstances where resources are limited, costs are high, and infrastructure is poorly developed. Further, recognising that prevention must be the mainstay of the response (UNGASS, 2001), ethical as well as practical questions arise about balancing investment in treatment with investment in HIV prevention. Although much synergy exists between treatment and prevention efforts, situations necessitating a choice may arise – hence the need for guiding principles that will facilitate a choice based on human dignity and value.

### **Ethical questions for research, policy and implementation**

In all that has been outlined, safeguarding personal rights is a basic principle. Fundamental questions that should be asked in each case, include:

- Is the research/policy/intervention needed?
- Will it be helpful?
- What risks does it carry for participants?
- To what extent are participants informed about risks?
- What measures are in place to compensate participants for any negative consequences they may experience?  
and
- What are the implications in terms of HIV transmission?

While research ethical committees may articulate these and other questions, individual researchers also have an obligation to bear them in mind. Neglecting such questions risks putting research on the slippery slope that leads to the human person being seen as little more than a statistic or case study. That is not far removed from treating the person as a commodity or disposable object, something that stands in complete opposition to the Universal Declaration on Human Rights and its guiding vision of the integrity of the human family.

## Conclusion

The time of AIDS is a time of deep turmoil in individual lives. Because of the way it enters into the fabric of so much of human life, the epidemic forces us to ask numerous questions: Why should this be? What would have happened if ...? Where have we gone wrong? Would it have been better if we had tried some other way? One particularly difficult question to which no satisfactory answers have yet been found is: Why do people elect to suffer and die, and allow their children to suffer and die, rather than risk public disclosure and possible stigma and discrimination?

These and similar questions are the basic questions of research; the never-ending effort to address unanswered questions, explore those that have not yet been asked, and articulate what lies below the surface of what we observe. Because HIV/AIDS encompasses virtually every facet of human life, there is an almost inevitable ethical dimension to every investigation of the questions raised by the disease and the epidemic. Since these both touch the human person so closely and so deeply, ethical considerations arise, implicitly or explicitly, in every inquiry, policy and intervention. The result is that HIV/AIDS is liberally studded, in a way that may be unique, with ethical issues and problems. Responsible research should remain cognisant of this and conscientiously ensure that it never loses sight of the ethical principles that guide its activities and the ethical implications of its findings.

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## CHAPTER 2

# HIV/AIDS and Gender

Addressing tough realities in research, policy development and implementation

Helen Jackson

For research to translate into sound, evidence-based policy and programming, research questions must be relevant and strategic, addressing the tough realities around HIV/AIDS and not merely the comfortable areas of concern. In particular, HIV prevention cannot be effective unless and until it addresses issues such as the exceedingly high infection risk faced by young women in sub-Saharan Africa, the risks faced by married women and the need for greatly increased condom use. These relate integrally to the profound gender inequity in the region, and to severe poverty and socio-economic inequality, tough realities that are in focus but that are clearly failing to be resolved.

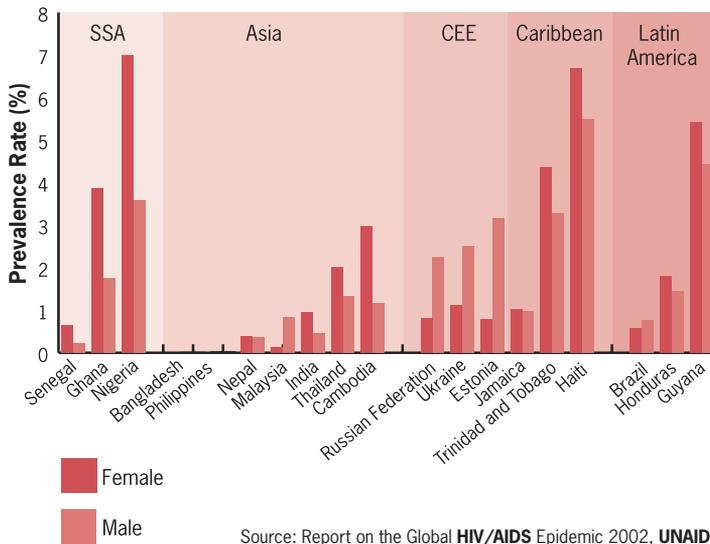
These realities together reflect the serious inadequacies of the direct global, national and local responses to the epidemic *and* to the underlying context that creates serious, endemic risk environments for infection. On present trends, sub-Saharan Africa risks abjectly failing to meet the Millennium Development Goals and UNGASS goals for HIV/AIDS. These trends will continue unless a substantial turnaround in financial and human resources is achieved within a framework that seriously engages with the tough realities the continent faces. This framework, in turn, needs to be founded on a relevant evidence base through focused research that effectively influences policy and programming decisions.

### **Gendered patterns of HIV infection**

The AIDS epidemic is worst in sub-Saharan Africa, and worst of all in southern Africa. In sub-Saharan Africa an estimated

six or seven people are newly infected every minute: 9,600 every day; and 3.5 million every year (UNAIDS, 2002). The continent as a whole is home to two-thirds of all people living with HIV and has experienced by far the most deaths. Africa also has the highest proportion of HIV infection in women of any region. UNAIDS 2003 estimates that 58 per cent of adult HIV infections in sub-Saharan Africa occur in women, a percentage that is increasing every year. Women are infected primarily in their teens and early twenties, and many die in their late twenties or thirties. In the hardest-hit countries in southern Africa, life expectancy for women especially is being dramatically reduced.

### HIV prevalence rates in young people (15–24)



### Report on the Global aids Epidemic, 2002: UNAIDS

Worldwide, except where men having sex with men and/or intravenous drug use drives the epidemic, young women generally have significantly higher risks of infection than their male counterparts (UNAIDS, 2002). In sub-Saharan Africa, their risk is up to five times that of young men. Young women are at greater risk for many reasons:

physiologically they are more readily infected than males, their lower socio-economic and cultural status makes it hard for them to negotiate safer sex, and many are exposed to gender violence and rape. Their control over relationships is particularly weak when their partners are several years older than they are. The common pattern of intergenerational sex is a primary factor behind high HIV rates in young women in Africa, a pattern that appears to be worsening partly because more men seek out virgins or young women in the belief they will be HIV-free.

### **Development implications of early mortality in women**

The impact of escalating early morbidity and mortality of women on children, households and communities is devastating. AIDS in sub-Saharan Africa, especially in the south, has orphaned literally millions of children. Millions of others face declining household security; reduced schooling opportunities and hence loss of livelihood options in the long term; as well as the deep pain of watching their mothers, fathers, aunts and uncles die. Women provide the backbone of small-scale and subsistence farming, they undertake the great bulk of household chores, and are the primary family caretakers. Their loss at a young age and on a wide scale is catastrophic. Their early deaths may, ironically, lead to some positive redefinition of “women’s roles” – but for entirely the wrong reasons; males have to step in where there are no available women of any age, from schoolgirls drawn out of school to grandmothers, to keep the household together.

The early deaths of women also have wide-reaching impacts in the informal sectors such as small-scale farming and vending, and in the formal sectors where women predominate such as nursing and various other service industries. Combined with male deaths, albeit at a higher average age, this increased mortality has fundamental development outcomes throughout the social fabric and the national economy. Even governance and national security begin to be adversely affected as deaths mount. In the worst scenarios to date, in southern Africa, AIDS-related mortality has contributed to widespread food shortages and greatly reduced opportunities for recovery. When faced with drought in the region and, sometimes,

poor economic management, crop production declines. The situation is made worse by lack of buffer stocks and the labour force needed for recovery, particularly for small-scale farmers.

Nobody can argue against the urgent need for more effective HIV prevention and better coping, treatment and mitigation efforts. More research is undeniably required, but much evidence is already there. Yet the full implications of what is happening in much of southern Africa are not being sufficiently understood and acted on in effective policies and programmes, whether at structural levels or at the more immediate level of risk environments for young women or broadly within marriage. It is important to unpack what these risk environments mean in the context of AIDS.

### **Prevention messages and marriage**

The most widespread HIV prevention messages are abstinence, being faithful and using condoms, the so-called ABCs of prevention. Yet these messages have little relevance to many girls and women: they may be coerced into early sex, be raped, or resort to transactional sex as the only means to survive, to pay school fees, or to gain material benefits, status and security. Schoolgirls are at risk from male teachers demanding sexual favours, and from male students. These realities undermine abstinence as an option for many adolescent girls and young women. When a woman marries, on the other hand, she may be completely faithful to her spouse, only to face infection when he is unfaithful to her. Women may want to use condoms, but this is dependent on their partner's willingness to use them consistently. Female condoms are much less available than male ones but, even if women can access them, their consistent use may still depend on the man's consent.

Marriage in Africa (and some other regions) is the institution in which many women have least control over their partners' behaviour. Women often have less control over sexual activity in marriage than in any other relationship – less than sex workers, casual or long-term girlfriends. In marriage, a woman is deemed to have consented to sex whenever, wherever and however her

husband desires. Culturally she cannot say *No* to sex, even if her husband has genital sores from an STI, or she knows that he has HIV. Rape within marriage is not a recognised offence in most countries. Even where it is an offence in law, it is extremely difficult for a woman successfully to charge her husband with rape or to gain the support of her family or community in doing so. Depending on local culture and religion, women may not even have any guarantees or control over whether their husband takes other wives.

Marriage is also the relationship with the least documented condom use of all. A woman does not have the right to demand condom use and she may be assaulted if she does, even in the context of her husband's HIV or other STIs. Typically, men are more willing to use condoms with sex workers or with casual girlfriends, an attitude that often makes sense in terms of reducing their own risk of infection. Men are less likely to use condoms with steady girlfriends or their wives, however, because they trust that these partners will not pass on infection to them – and all too many men do not see it as their responsibility to protect their partner. A number of women also think that in a long-term relationship in which they trust their man, they can stop using condoms because they are not at risk. The desire to have children, of course, also militates against consistent condom use within a long-term partnership.

For many couples fidelity is made more difficult and unlikely because they are frequently apart. This applies to workers in many occupations such as the uniformed forces, parts of the civil service, domestic work, long-distance driving, migrant mine work and a wide range of trade and vending. Mine workers in South Africa, for example, may be apart from their wives for eleven months a year. The majority live in single-sex hostels with few opportunities for recreation beyond alcohol and sex with the readily available sex workers, yet their daily work experience is highly stressful and dangerous. These active men return home once a year to their wives. It would be hard to devise a pattern of migrant labour, lifestyle and marriage more conducive to the spread of STIs including HIV – and

extensive data indeed show the contribution of mining and other migrant labour to the spread of the epidemic.

Family planning programmes, even in southern Africa with the highest HIV prevalence, still widely promote the Pill, injectables or intrauterine devices (IUDs) as the preferred means of contraception. Despite their value as contraceptives, these methods have no benefits in terms of preventing HIV or other STIs and, in some instances, increase infection risks. The logical theoretical position for HIV prevention would be to prioritise dual protection through consistent condom use, with other contraceptive methods as back up for couples with well-established condom use or who test HIV negative and show a strong commitment to staying negative. It is very hard for married women using other means of contraception to introduce condoms at home solely to prevent infection, but potentially easier if they need condoms also for child spacing.

Yet it is proving extremely difficult in practice both to change the attitudes of family planning service providers to prioritise condoms, and to convince policy makers and programmers even to debate this strategy seriously, let alone vigorously to promote it. So married couples remain at risk of infection, while increasing numbers protect themselves only against unwanted pregnancy. Despite the high probability of increased unwanted pregnancy if condoms take priority, can non-barrier methods ethically remain the strategy of first choice regardless of HIV prevalence? Can we afford not to debate this issue widely and to support operational research to inform decisions in this crucial area?

### **What is the way forward?**

The full implications of early female morbidity and mortality on the present scale do not sufficiently inform the policy or programme agenda in all sectors and at all levels. Further, many policies and programmes continue to repeat the same, often ineffective strategies, not fully taking on board the implications of existing research findings and the tough realities highlighted above. This has to change.

At global, regional, national and local levels, risk environments for infection for males and especially females need to be clearly understood and reduced. Far more serious

efforts and resources are required to reduce poverty and socio-economic inequity in all spheres, to reduce population mobility for all reasons and the separation of spouses, and to build social cohesion. Much more effective conflict resolution should be developed to reduce the numbers of refugees and internally displaced persons. And integral to all efforts of poverty alleviation and building social cohesion, the priority on the national and international agenda should be achieving radical social changes in gender inequity at all levels. This requires addressing head on issues of unequal gender power relations at home, at work and in all other spheres; double sexual standards between men and women, and sexuality itself; gender based violence; gender stereotyping; and, centrally, inequitable laws, policies and human rights access of women. Advocacy is needed to make it socially, culturally and politically unacceptable for people to accept the gross injustices against women and girls that today are commonplace.

At a more immediate level, specific risk environments for women (and men) need a greatly strengthened focus. This includes researching and responding in policy and practice to the reasons for high infection in young women and for continued high risk in marriage. It means applying fully the lessons already learned, and not merely paying lip service to them or avoiding their thorny implications. It also means looking at particularly high risk environments geographically (e.g. border towns, mining towns, growth points, prisons); risk environments created by job mobility and by a macho ethos (such as in the uniformed forces); impoverished women (such as widows, unemployed youth, girls seeking to complete school and others, who are in a high risk situation for transactional sex); and violent and unsafe situations for women and girls (whether it is drawing water in a village at night, exposure to male gangs in an urban slum or risks of abduction by rebel forces).

Evidence is needed through socio-cultural and operational research in communities to identify the risks and establish policies and community responses that address the needs realistically and effectively. The relevant stakeholders, particularly beneficiaries, need to be involved

from the start, to have full access to research findings, and to be integrally involved in designing responses that are meaningful to them.

Tight linkages, coordination and cooperation between the research community, widely defined, the policy makers, programmers and the communities themselves are essential. And all must be willing to take on board the issues they would much rather ignore, the tough realities that drive the epidemic. They must embrace the tough discussions, analysis and, above all, actions that these realities demand.

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# The Experience of Rwanda in Coordinating HIV and AIDS Research

Agnes Binagwaho

## **Rwanda's escalating HIV epidemic – girls at greater risk and a large number of orphans**

In the wake of the 1994 genocide and ensuing civil war, the national HIV prevalence for adults aged 15–49 years in Rwanda soared nearly tenfold from 1.3 per cent in 1987 to 10.8 per cent in 1997, with migration and rape being the greatest contributors to the steep rise in prevalence.

Currently Rwanda's prevalence is estimated at between 8.9 per cent and 13.7 per cent, with an upward trend in the rural areas where 90 per cent of the country's population live. It is difficult to establish the actual prevalence due to the lack of systematic epidemiological data on HIV in Rwanda. The latest HIV sentinel surveillance among urban pregnant women was conducted in 2000.

However, it is evident that young girls are most at risk of HIV infection. Their vulnerability is due to a combination of factors, including: having sex at an earlier age than boys; limited access to education; cultural norms; economic dependency; and the large number of female-headed households. In Rwanda 36 per cent of the households are headed by women, many of them poorly educated and outside the market economy.

It is widely recognised that HIV threatens to undermine Rwanda moving from a country in conflict to a country establishing stability and development. Rwanda is moving towards stability and development through strategies aimed at:

- Reducing poverty;
- Establishing democracy;
- Decentralising systems of governance and services; and
- Introducing a participatory justice process (the Gacaca justice system, focusing on confession and contrition aimed at eventual reconciliation).

The impact of the HIV/AIDS epidemic on children has been phenomenal. There are an estimated 65,000 children infected with HIV and 260,000 orphaned as a direct result of HIV, the latter contributing to a huge number of orphans in Rwanda. It is estimated that around 27 per cent of all children in Rwanda have lost one or both parents. Indeed, Rwanda is widely considered to have one of the most serious orphan and vulnerable children (OVC) problems in the region.

Therefore in 2002 the government developed a national OVC policy to address pressing issues regarding the rights of children, access to health services, free primary education, psychosocial support, integration into society, economic support, skills development and the coordination of all OVC programmes and interventions.

### **History of the national response to HIV and AIDS in Rwanda**

In 1987 the Rwandan government embarked on a number of programmes to combat HIV/AIDS including the *Programme National de Lutte contre le Sida* (PNLS), which was the national programme of action for the control of HIV/AIDS. In order to scale up the national response and address the critical issue of multisectoralism, in November 2000 the government established the National AIDS Control Commission (NACC) or *Commission Nationale de Lutte contre le Sida* (CNLS) as it is known in francophone countries.

This Commission was given high status and priority, operating out of the President's office, with the broad mandate to coordinate the national multisectoral response to HIV/AIDS. The membership of NACC/CNLS includes representatives of the public, private and community sectors: from parliament; the cabinet; the army; the police; the Ministry of Education; the Ministry of Local

Administration and Social Affairs; the Ministry of Youth, Sports and Culture; private enterprises; artist and community organisations (e.g. youth groups, women, representatives elected at the grassroots level).

A national strategic framework document for the period 2002–2006 was drawn up with the full participation of key stakeholders and communities. This strategic framework document was adopted by the Cabinet of Ministers in February 2003. The framework defined five key strategies:

1. Reinforcing prevention of transmission;
2. Strengthening HIV/AIDS surveillance;
3. Improving the quality of global care for the infected and affected;
4. Strengthening the measurement of poverty reduction and gender mainstreaming; and
5. Strengthening partnerships and multisectoral responses.

Embedded in the second objective are intermediate objectives – to carry out epidemiological, socio-behavioural and impact studies of HIV/AIDS – in order to strengthen the monitoring and evaluation systems. The NACC/CNLS directorate of monitoring and evaluation is responsible for these activities.

In order to enhance and decentralise the activities of the NACC/CNLS, provincial and district coordination structures were established. At provincial level, twelve *Commission Provinciale de Lutte contre le Sida* (CPLS) were established and 38 *Commission District de Lutte contre le Sida* (CDLS) at district level. However, the district-level structures do not yet cover all Rwanda's 106 administrative districts.

A national multisectoral plan for HIV/AIDS control for 2002–2006, a national monitoring and evaluation plan for 2002–2006 and a national plan for HIV care and treatment have been drawn up in addition to the national strategic framework. The NACC/CNLS is also currently working on a national plan for Behaviour Change Communication.

### **Coordination of research, policy and implementation**

In the health sector, the Treatment and Research on AIDS Centre (TRAC) was established within the Ministry of

Health in 2001. TRAC's responsibilities include:

- A referral laboratory;
- Scaling up voluntary counselling and testing (VCT) and preventing mother-to-child transmission (PMTCT) (currently in three sites but due to be rolled out to all 40 health districts within three years);
- Introducing ART and care; and
- Training health workers.

In order to coordinate the activities of the burgeoning number of partners NACC/CNLS created three umbrella bodies:

1. The Confessions Interfaith Organisations Committee;
2. The National Network of People Living with HIV and AIDS; and
3. The focal point persons in a private and public sector body.

Existing HIV/AIDS forums in the public and private sectors were reinforced and organised, including the NGO forum, a donor forum, a government forum, a National Youth Council and the National Women's Council.

In 2002 the Rwandan government further reinforced its commitment to the fight against AIDS by establishing the portfolio of Minister of State in Charge of HIV and Related Diseases in the Ministry of Health. This Minister of State is a member of all key institutions working directly with HIV – namely the Ministry of Health, NACC/CNLS and the Country Coordinating Mechanism (for the Global Fund). This has helped in guiding the vision of the partners on HIV/AIDS in the country.

### **Challenges and constraints**

Building links between different HIV and AIDS activities is a slow process; yet HIV/AIDS constitutes an emergency and the process needs to be speeded up.

Some of the constraints faced by the Rwandan NACC/CNLS include:

- Resistance to control and coordination, and to submission of regular reports. When the NACC/ CNLS approaches different bodies and asks them to provide reports regarding what they are doing on a regular basis, some of them resent this interference, having been used to a less organised state where they were free to do as they wished.
- Lack of a standard template for reports requested by donor partners. Time is wasted adjusting data to different formats, as required by donor organisations.
- Lack of funds. Although the systems are in place and the plans and policies have been drawn up in partnership with other stakeholders, most activities are desperately underfunded. Sometimes communities depend on the goodwill of their donor partners and are therefore not free to set their own priorities.
- Reluctance of donors to fund institutional capacity building and staff salaries; they may be happy to fund the purchase of a car or a laptop but they are not willing to top up or sponsor civil servants' salaries. Additionally, the HIV work in other sectors is often an added responsibility for underpaid staff without any compensation. And it has been hard to find the money to do the research that needs to be done in Rwanda.
- Lack of personnel. Due to poor salaries locally Rwanda has experienced a brain drain of well-educated people to other parts of the world. It would help if such people could be given attractive packages to stay in their own countries and if people could be trained within Rwanda rather than outside. For the same reasons, there is an additional brain drain from government to donor agencies within Rwanda.

- Lack of capacity and infrastructure. Capacity building in the form of proper communication and information systems, transport and other logistics and administrative systems is urgently needed within government and NGO bodies.

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# Translating HIV/AIDS Research Findings into Policy

Experiences from a research programme  
in Tanzania

Fred Mhalu

Since the first publications on AIDS appeared in 1981 in the USA, the isolation and characterisation of the causative viral agent of the syndrome (Gallo *et al*, 1984) and confirmation of its presence in Tanzania in 1985 (Mhalu *et al*, 1987), research results have played a central role in influencing policy formulation and operationalisation of interventions against this human crisis of the twentieth and twenty-first centuries at global, regional and national levels.

Research findings from Tanzania and other countries were utilised in policy formulation starting off with a National Guidelines Document on HIV/AIDS developed by Tanzania's Ministry of Health in the mid-1980s. In November 2001 this led to the development of a National Multisectoral AIDS Policy approved by the Tanzanian government (National Policy on HIV/AIDS 2001). This policy was accompanied by the passing of an act of parliament establishing the Tanzania Commission for AIDS (TACAIDS) to coordinate and oversee the implementation of a national multisectoral framework.

In order to consider how research has influenced decisions by policy makers or, in other words, how research findings have been used to develop policy in the United Republic of Tanzania, it is instructive to look at the 18-year Tanzania-Sweden (TANSWED) HIV Research Programme.

## **The TANSWED HIV Research Programme**

The TANSWED HIV Research Programme, a bilateral Tanzanian and Swedish research collaboration has

received financial support from Sida's Department of Research Cooperation with Developing Countries (Sarec) since 1986. This research has had the overall aim of obtaining information on the epidemiology, clinical manifestations, virology, serology, immunology and immunopathology of HIV infection in Tanzania as well as on social behavioural factors as risks for HIV infection, and to introduce and evaluate interventions for prevention and control of the crisis.

Over the 18-year period, Sida/Sarec's financial contribution to the programme has exceeded 90 million Swedish Crowns (approximately US\$ 14.5 million).

The programme's aims and objectives have changed over time, reflecting the need to answer pressing research questions and those raised by previous studies. During 2001–2003 the TANSWED HIV Programme included studies into the following:

- Improving the laboratory diagnosis and monitoring of HIV-1 infection;
- Sexually transmitted diseases with emphasis on young people in relation to HIV infection and control in Dar es Salaam;
- Epidemiology towards the control of HIV-1 infection in the Kagera region (North West Tanzania);
- HIV-associated pathology, particularly malignancies;
- Mother-to-child transmission of HIV-1 infection and its prevention and control;
- Follow-up studies of HIV-1-infected individuals with known time of infection in Dar es Salaam (natural history of HIV infection);
- Preparation for HIV-1 vaccine evaluations in Tanzania; and
- Improving clinical case management of HIV/AIDS.

An additional activity has been to strengthen the research capacity of the departments involved in the projects.

The institutions involved in this programme in Tanzania include Muhimbili University College of Health Sciences (MUCHS) and the rest of the former Muhimbili Medical

Centre (currently the Muhimbili National Hospital and the Ocean Road Cancer Institute), the Tanzania National AIDS Control Programme in the Ministry of Health, the City Council of Dar es Salaam, the Kagera Regional Health Authorities, the Health Unit of the Tanzania Police Force, and the Departments of Sociology and Kiswahili at the University of Dar es Salaam. The collaborating institutions in Sweden have been the Swedish Institute for Infectious Disease Control, the Karolinska Institute and Umeå University.

The TANSWED HIV Programme has had two coordinators, one in Tanzania based at MUCHS and the other in Sweden based at the Swedish Institute for Infectious Disease Control and the Karolinska Institute, Stockholm.

There are eight principal investigators in Tanzania and four collaborators in Sweden, as well as more than 30 other investigators and research trainees mainly from Tanzania. So far six Tanzanians have completed PhD training within the programme and up to ten others are expected to do so in the coming four years.

### **Tanzania's National Policy on HIV/AIDS**

Tanzania's national policy on HIV/AIDS was developed following extensive consultations stretching over more than five years among stakeholders in Tanzania and developmental partners.

The national policy on HIV/AIDS replaced more restricted National AIDS Guidelines, developed by the Ministry of Health in the late 1980s, which had neither a nationwide nor a multisectoral mandate. Among the stakeholders involved in formulating the policy were HIV/AIDS researchers who provided the essential scientific bases for the policy statements.

The overall goal of the national policy on HIV/AIDS is to provide for a framework for leadership and for coordination of the national multisectoral response to the HIV/AIDS crisis. Its specific objectives include activities for:

- Preventing transmission of HIV/AIDS;
- HIV diagnostic testing and counselling individuals;

- Caring for people living with HIV/AIDS;
- Sectoral roles and financing activities; and
- Research (including monitoring and evaluation).

Section 3.2 (c) of the national policy elaborates on research:

- Participate in HIV/AIDS research nationally and internationally and establish a system to disseminate scientific information resulting from this research while upholding ethics that govern interventions in HIV/AIDS.
- Government will follow closely and collaborate in HIV vaccine development initiatives.

### **Strategies utilised by researchers in Tanzania to influence HIV/AIDS policy**

Applied HIV/AIDS research is cost-effective only if the findings reach policy makers in a format which can influence policy change towards improved prevention, care and impact-mitigation strategies and activities. To facilitate such a process, the national health research ethical clearance system in Tanzania requires researchers to submit progress reports of their projects at six-monthly intervals to the secretariats of the National Institute for Medical Research and the National AIDS Control Programme. Copies of all publications arising from such research are also required to be deposited with the two secretariats, ensuring that any important new findings are accessible to the policy makers.

Specific strategies for informing and influencing policy makers which have been utilised by the TANSWED HIV Programme include the following:

- Participating in technical expert committee, task forces and other government bodies responsible for policy formulation;
- Organising workshops and research seminars on HIV/AIDS and inviting senior policy makers to the opening and/or closing sessions of such meetings, where presentations are given on key research findings targeted at or leading to policy formulation. Such meetings have included:
  - Workshops on access to HIV/AIDS care and including HAART treatment;

- Voluntary counselling and testing;
- Mother-to-child HIV interventions using ARVs and improved obstetrics care;
- Organising multisectoral AIDS conferences. Two major conferences with important policy implications were the first and second national Multisectoral AIDS Conferences (MAC) held in December 1998 and December 2002 and the National Strategic Planning Workshop on HIV Vaccines held in July 2001.
- Involving mass media during conferences, seminars and workshops for disseminating recent research findings targeted at affected people, including those living with HIV/AIDS, and other individuals and communities who may subsequently advocate policy change;
- Establishing international, regional and national HIV/AIDS Civil Society Organisations (CSOs) with functions including advocating policy change based on research findings, e.g. the Tanzania AIDS Society (TAS) which is a multidisciplinary CSO formed during the first MAC; TAS was the main organizer of the second MAC in Tanzania.

### **Some policy decisions in Tanzania influenced by research findings**

- Same-day voluntary HIV counselling and testing (VCT) using combination of simple/rapid HIV antibody assays (Urassa *et al*, 2002);
- Establishment of youth reproductive health clinics and free VCT facilities for youths in the country (Mwakagile *et al*, 2001);
- Syndromic management of STIs using effective drugs (Mbwana *et al*, 1999);
- Proof of the concept that HIV/AIDS is preventable in Tanzania as demonstrated by declining trends in HIV prevalence and incidence in some parts of the country (Kwesigabo *et al*, 2000);
- Prevention of mother to child HIV transmission (PMTCT) programme and proposed PMTCT plus policy (Petra Study 2002, Kilewo *et al*, 2001);

- Proposed National HIV Vaccine Plan and EU-funded Phase I/II HIV vaccine Trial project (Bakari *et al*, 2000); and
- National access to HIV/AIDS Treatment including access to HAART (Urassa *et al*, 2003, Tanzania HIV/AIDS Care and Treatment Business Plan 2003–2008).

### **Difficulties and challenges encountered in translating research findings into policy**

While significant success has been achieved in translating research findings into policy formulation, the process has been rather slow and not all significant verifiable research findings have resulted in policy change owing to a number of constraints, including:

- A lack of resources (human, financial) coupled with a weak health care delivery system undermine the translation of research into policy and interventions. For example, while research findings since 1987 had shown that use of ARVs could prolong the lives of patients with HIV/AIDS, it was not until 2003 – following the major fall in prices of highly active ARVs accompanied by the availability of generic products – that it was possible for the Tanzanian government to come up with a National Plan on Access to HAART.
- A long process of translating research findings into policy formulation and operationalisation. Unfortunately, there are a variety of reasons why it takes anything from a few years to over a decade before research findings are translated into policy change. This is a particularly critical issue in developing countries. Maybe the problem could be addressed by promoting more policy research where it is possible to identify policy issues requiring research and/or by training researchers how to use research findings to advocate policy change.
- A lack of, or inadequate, opportunities for interaction between researchers and policy makers. Except for the few senior researchers who are involved in national committees, task forces and boards where policies are developed, most researchers have very few

opportunities to influence policy makers except during national conferences, seminars and workshops. More research meetings where policy makers participate should be held instead of research findings just being published in journals.

- A research agenda is not always relevant to the developing countries, since most ongoing HIV/AIDS research in developing countries is funded by development partners and agencies. Efforts should therefore be made to ensure that research carried out in developing countries has the potential for influencing policy change and improving the welfare and development of the country where the studies are done. In Tanzania, the TANSWED HIV Programme has always invited participation of officials from the National AIDS Control Programme in its research proposal development workshops to ensure that studies to be carried out respond to national HIV/AIDS research priorities and needs.

## **Conclusion**

Research has been central to policy formulation in HIV/AIDS prevention and control in Tanzania, and new research projects should be supported. Researchers need to acquire new skills to ensure that verifiable research findings inform and facilitate policy change.

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# From Research into Action

Experiences from the multi-country research  
study on understanding HIV-related stigma

Jessie Mbwambo

## **Addressing HIV related stigma in Africa – a multi-country research study**

In response both to the role of stigma in impeding HIV prevention, care and support, and to the lack of a clear understanding as to the nature of stigma related to HIV and AIDS, the International Centre for Research on Women (ICRW) led research on HIV/AIDS-related stigma and discrimination in three African countries: Tanzania, Ethiopia and Zambia (see Nyblade *et al*, 2003, for the multi-country report). In these three countries, the research partners were the Department of Psychiatry, Muhimbili University College of Health Sciences (MUCHS) in Tanzania; the Miz-Hasab Research Center in Ethiopia; and the Zambia AIDS Related TB Research (ZAMBART) Project and Kara Counselling and Training Trust in Zambia. The research was funded by USAID, with additional support from Sida, the CORE initiative, Glaxo Smith Kline's Positive Action programme and the British government's Department For International Development.

Carried out between April 2001 and September 2003, the objectives of this study were:

- To understand the causes, manifestations and consequences of stigma and resulting discrimination; and
- To provide data to inform programmes and interventions.

The approach of using the research process and the research findings to instigate, inform and direct policy and

interventions oscillated around four strategies – one a strategy from the outset and three which were more organic, responding to gaps, funding and network opportunities. The four strategies were:

1. Formation of Leadership Advisory Groups, with membership from key constituencies at national and community level, to help design, advise and disseminate research and research findings;
2. The development of a resource collection of participatory educational exercises for use in raising awareness about stigma and promoting action to challenge HIV stigma – an anti-stigma toolkit;
3. Securing funding for anti-stigma intervention projects to be carried out by partner NGOs in the research sites in Tanzania and Zambia; and
4. Presenting research findings to parliament in Tanzania and Ethiopia.

### **Inclusion of other key stakeholders to ensure link to policy and action – the Leadership Advisory Councils**

At the outset of the research in all three countries representatives from key constituencies were invited to join a group called a Leadership Advisory Council (LAC). Membership of the group included NGOs and CBOs working with HIV/AIDS, the National AIDS Councils, the Ministry of Health, key health donors and key government ministries. Throughout the life of the project, it was planned that this group would be called upon to help guide design, to contribute to analysis and to plan how they could each integrate stigma reduction in their own organisations. More specifically, the key responsibilities of the LAC members were to:

- Advise and inform the research;
- Identify information and knowledge gaps;
- Develop leadership, advocacy and communication skills related to stigma;
- Formulate recommendations based on the research findings;
- Help to disseminate research project findings; and
- Serve as public spokespersons against stigma and discrimination.

In Zambia, the LAC process started well but was undermined by limited financial and technical support and by staff turnover in the partner NGO. However in Tanzania and Ethiopia the LAC was a successful strategy. In Tanzania, for example, the LAC continued to hold six-monthly one-day meetings throughout the lifetime of the research project. The members of the Tanzanian LAC also went ahead and set up a plan of action for how their organisations would be addressing the issue of stigma reduction activities. During subsequent meetings feedback on the achievements were reiterated.

The Tanzanian LAC then formed a body that will continue to exist and play an advocacy role in stigma reduction beyond the life of the research project. This body called the Advisory Committee for Stigma – consists of experts from recognised institutes and aims to be the lead body in anti-stigma related activities, with the mandate to offer advisory services for the reduction of HIV/AIDS-related stigma, denial and discrimination in Tanzania. The Advisory Committee for Stigma has identified its mission as building community capacity to deal with HIV/AIDS-related stigma, denial and discrimination through information and communication to improve quality of life. The strategies to achieve the mission are:

- To identify and compile pertinent information on HIV/AIDS-related stigma, denial and discrimination for sharing with other stakeholders;
- To orient key service stakeholders and gatekeepers in HIV/AIDS-related stigma, denial and discrimination;
- To advocate tolerance towards persons with specific vulnerabilities and socially disempowered groups (e.g. people living with HIV/AIDS, women, commercial sex workers, intravenous drug users, groups victimised because of sexual practice and orientation, prisoners and so on); and
- To promote mainstreaming stigma-reduction strategies in HIV/AIDS programmes.

### **From research to action: developing the Stigma-Reduction Toolkit**

During training workshops for research assistants working on the development of a resource collection of participatory

educational exercises for use in raising awareness about stigma and promoting action to challenge HIV stigma, it became apparent that there were few educational materials and approaches to address stigma. Therefore they started to design their own, led by an experienced adult educator from Botswana – Ross Kidd (Kidd and Clay, 2003). During this training process, the research assistants explored and debated the causes, forms and consequences of stigma, reflecting on their own stigmatising language and actions.

After training research assistants in all three countries, a package of tools and materials had been developed that could be used beyond the research process. Already, research assistants and trainers had asked for copies of the participatory exercises created for use in their own HIV work.

In Zambia, a two-day community workshop was held in the urban research site at the beginning of fieldwork to introduce the research and to begin to build support for action against stigma. The researchers identified HIV/AIDS community activists (NGO- and government-run local health organisations, church groups, a network of people living with HIV/AIDS and local town councillors) who could incorporate the research results into their activities. Participants at the workshop shared their ideas about stigma and used their experience to investigate the forms, effects, causes and contexts of stigma. They identified potential solutions and started up an informal network to act against stigma. The workshop identified a leadership group which continued to support the research process and whose members later became involved in an anti-stigma intervention.

Following the Zambian community workshop on stigma, and in direct response to the glaring gap in anti-stigma education, the Academy for Educational Development's (AED) CHANGE Project led a collaborative effort in all three African countries to further develop tools and materials to create and deepen the understanding of stigma, provide a process and the capacity to then address it. NGO workshops (involving both civil society and government) were held in late 2002 and early 2003 in all three countries to develop an

“anti-stigma toolkit”. These workshops were opportunities for participants to share their experiences of HIV/AIDS-related stigma, for the researchers to share their preliminary findings and for all participants (including the researchers) to design exercises on different aspects of stigma. A total of 75 participants (from 50 NGOs and three governments) were involved in developing the toolkit.

The design of the resulting toolkit – *Understanding and Challenging HIV Stigma: Toolkit for Action* – is based on key research findings, with the research identifying the key steps and themes and confirming the need for materials that targeted specific areas.

The central themes identified by the research and addressed in the toolkit are:

- Root Causes
  - Naming the problem of “stigma” – identifying what stigma is, how it hurts and our role in challenging stigma;
  - Overcoming incomplete knowledge or fear – tackling misconceptions and fears about HIV transmission and what it means to be HIV-positive; and
  - Sex, morality, shame and blame – tackling the relationship between stigma, sex and morality.
- Working with affected groups
  - Living with and caring for people living with HIV/AIDS in the family – exploring the challenges of caring for people living with HIV/AIDS and providing knowledge and skills to enhance care;
  - People living with HIV and AIDS coping with stigma – strengthen the capacity of PLHA to cope with stigma through sharing experiences and strategies; developing communication and assertiveness skills and building self-esteem; and
  - Understanding stigma faced by children – increasing adults’ understanding of the impact of stigma on children and children’s capacity to cope with stigma.
- Action planning – developing planning tools and approaches at individual and community level.

The toolkit is structured as a participatory, problem-based curriculum to raise awareness and promoting action to challenge HIV related stigma. Trainers can select from the exercises to plan their own courses for different target groups – both AIDS professionals and community groups. Initially printed and put on CD-ROM without the full set of exercises for the thirteenth ICASA, the final version of the toolkit is available from the CHANGE-AED website and there are plans to set up a regional project to roll out, test, revise and adapt the toolkit in sub-Saharan Africa. The toolkit is already being used by the different groups who helped develop it and by others introduced to it through the research, the toolkit development and the dissemination processes.

### **The stigma toolkit in action – community anti-stigma intervention projects**

Towards the end of the research project there was a call for proposals for community interventions to reduce HIV/AIDS-related stigma and discrimination by Community REACH (a centrally-funded USAID programme) in 20 identified countries, including the three research countries. In Tanzania and Zambia researchers decided to give technical support to partner NGOs to submit an application to carry out anti-stigma interventions in the communities where the research was carried out. In the event, both Tanzania and Zambia were awarded grants, and the intervention projects started towards the end of the research project. The researchers in both countries have retained a monitoring and evaluation role in the intervention projects, and plan to use the opportunity to pilot stigma and discrimination indicators.

### **Presentations in Parliament – inclusion of other stakeholders**

In both Ethiopia and Tanzania, the research project managed to hold meetings with Parliamentarians about HIV/AIDS-related stigma and discrimination, using the research findings to advocate for stigma reduction. In Tanzania the first meeting was held during the very early stages of the research project. The first meeting formed the

basis of a second meeting in the form of a workshop with parliamentarians working in smaller groups so as to be able to hold more in-depth discussions on HIV and HIV-related stigma. Discussions also focused on how parliamentarians can help in stigma reduction related activities. Following these meetings the Tanzanian team were involved in sectoral presentations which not only raised the challenges on recognition of what stigma was but also how each sector could address sector-specific stigma reduction activities.

In Zambia three attempts to hold meetings with parliamentarians were frustrated by poor attendance and demands from parliamentarians for per diems or other incentives.

### **Conclusion**

The crucial components that helped make the successful link between research and action in Ethiopia, Tanzania and Zambia were:

- The link between the research funding donors and the implementation funding donors. From the outset, there was a pot of money put aside by USAID to fund, through CHANGE-AED, a limited number of interventions arising out of the research. These interventions were the Leadership Advisory Group and the anti-stigma toolkit;
- The involvement of an adult educator from the region, with considerable experience in theatre for development and advocacy, in the research project. This infused into the research team the necessary training, communication and development skills that were needed to spearhead the development of the toolkit. Researchers have limited implementation and communication skills, so linking with others becomes critical for the successful adoption of research findings in programming and policies;
- The strong links in all three countries between HIV/ AIDS NGOs and the researchers. These links took various forms – for example in Zambia, the research project was housed in and carried out in partnership with a Zambian NGO (Kara Counselling); in Tanzania,

MUCHS was already working closely with a VCT centre run by a NGO in the urban research site; and in Ethiopia, Miz-Harab was already working with a network of people living with HIV and AIDS. These established and active NGO links were crucial to involving a broader group of NGOs in the development of the toolkit. In Tanzania and Zambia the NGO link also led to anti-stigma intervention projects being carried out in the research sites at the end of the research project;

- The strong coordination by ICRW, which drew on ICRW's experience of linking research and action;
- The strong links between researchers and key stakeholders within the government through the Leadership Advisory Council, the sectoral meetings and plans of action; and
- The African ownership of the toolkit, as it was developed within Africa (although it has an audience beyond Africa).

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# Challenging Links involved in Research- Policy-Implementation

Moving from National Policy to free provision of  
ARVs in Uganda

Alex Coutinho

Uganda has been cited as a success story in the fight against HIV/AIDS, mainly because of its remarkable achievement in reducing HIV prevalence from 22 per cent to 6 per cent over a period of ten years to 2002. Nonetheless there are at least 800,000 people living with HIV of whom an estimated 100,000 need of ART today. Uganda is challenged to provide antiretroviral drugs (ARVs) to these 100,000 initially and subsequently to the other 700,000 as they fall ill. Uganda is challenged to replicate its success story in prevention in the area of care and support. Given the poverty of most people living with HIV/AIDS it will be necessary to provide lifelong ART in an environment where this life saving drugs will have to be prioritized and rationed. This chapter gives some insights into the challenges facing the different stakeholders in scaling up ART and the necessary linkages between policy, research and implementation.

## **Uganda's National Policy on ART Provision**

The overall goal of the National Policy is to improve the longevity and quality of life of people living with HIV/AIDS so as to contribute to the economic development of Uganda as well as to the prevention of further transmission of HIV infection. The target is set at having 100,000 people living with HIV/AIDS on ART by the end of 2005 in order partly to contribute to the WHO's global goal of three million people on ART by 2005.

The specific objectives of Uganda's ART policy include:

- Standardising the delivery of ART and related support services for adults and children;
- Building capacity for health workers and physical infrastructure to provide ART services in a safe, effective and integrated manner; and
- Ensuring uninterrupted supply of ARV drugs, laboratory reagents and medical supplies.

Since there are many individuals in Uganda who qualify for ART, criteria were agreed to help prioritise who should get access to this service. The following categories of individuals were classified as priority groups:

- Pregnant mothers identified through prevention of mother-to-child transmission programmes and their HIV-infected family members;
- Children and infants infected through mother-to-child transmission, blood transfusion, sexual abuse and infected needles;
- HIV-infected individuals already enrolled in care and support activities; and
- HIV-infected participants involved in research projects for HIV/AIDS whose access to ARVs is interrupted after completion of the respective studies.

This list was compiled after extensive consultation with several stakeholders – the most important being people living with HIV themselves. The process of consultation was heated and traumatic as people realised that not all people living with HIV/AIDS could receive ART and that many would die while still waiting to qualify. There was even talk of women who were HIV positive purposely getting pregnant in order to meet the required criteria!

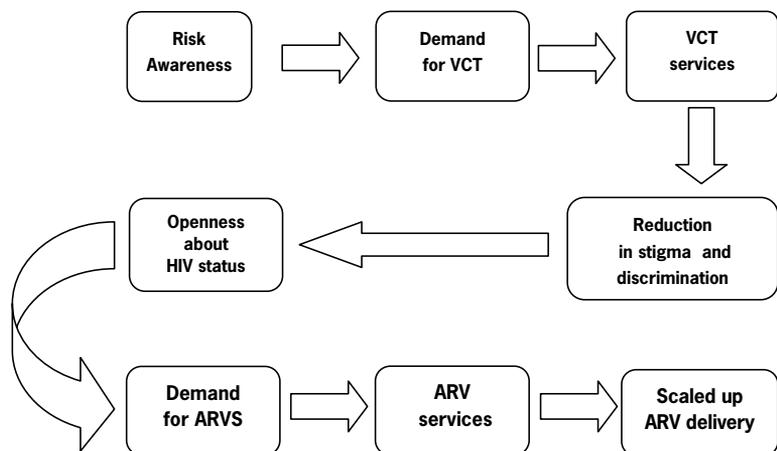
### **Background to ARV delivery in Uganda**

By 2002, there were approximately 10,000 people living with HIV/AIDS who were receiving ART. Out of these, approximately 500 individuals were receiving ARVs as part of a research activity while another 500 received free ARVs. The remaining 9,000 individuals have to pay for their ARVs. Three thousand of them are cared for by private medical

practitioners while the rest are cared for by the NGOs. As of 2003, the Government of Uganda was not yet providing ART to its citizens.

Uganda has had the highest number of individuals on ART in the region and yet the beneficiaries were mainly paying for treatment and were by and large urban based. There had not been any research or experience with rural based ART for poor people until 2003 when TASO in conjunction with CDC commenced a rural based Home Based AIDS Care programme (HBAC). The results of this operational research were intended to inform the Ugandan government and TASO how to scale up ART for the majority of its poor rural population. As it has happened, the new global interest in funding ART will now mean that both TASO and the government of Uganda will scale up ART before the results of this operational research have been fully learnt. Nonetheless important lessons are already being included in the TASO implementation plan even before they are included in Uganda's national policy.

However, what is emerging from the implementation of these and other pilot ART programmes is a critical path that is required for scaling up ART. For proper delivery of ARVs certain components of the cascade of events have to be in place. The following diagram represents such events in the form of a critical pathway.



*Fig 1. Critical path analysis for ARV delivery to communities. Missing links in research-policy-implementation*

### **Missing links in research**

Despite the fact that provision of ARVs is based on evidence that they work, no operational research is in place to iron out the logistical and operational problems to be encountered in all aspects of delivery of ARVs to various communities in Uganda. The number of individuals requiring ART in Uganda is unknown, yet for effective planning, actual figures are needed. And research into ways of reducing stigma and discrimination is essential in improving the delivery of ARVs in Uganda and other African countries.

In most circumstances, research findings take time to be known to those needing such results. This is due partly to the inherent nature of the time needed to develop papers and send them through a review process until they finally appear published in journals. Results need to be fast-tracked into dissemination and, indeed, into ongoing interventions. This is what is happening in the HBAC programme in Uganda although it is too early to translate these early lessons into national policy.

### **Missing links in policies**

A policy environment is required that will allow generic drugs to be imported and distributed, including allowing prescription by doctors and nurses. Perhaps more critical is a policy that will go further to address inequities in provision of ART as well as other inherent inequities in health services and systems. The current policy also does not specifically address the danger that private sector employees and civil servants could access ART meant for indigent people.

### **Missing Links in implementation**

Provision of ARVs to those who need them requires that the drugs are available, the manpower and infrastructure are in place and the client/patient environment is conducive for the uptake of the drugs. Paradoxically, because of the historically high prices there are people in the middle class who do not realize they can afford ART and therefore do not seek VCT or advice about commencing ART. This group could be best reached by mobilising and training the private health providers who treat middle class families.

Without a reduction in stigma, there will be no realistic scale up of treatment and further research into the causes, determinants and remedies for stigma is needed, including how to address it through national policies.

The starting point for gaining access to ARVs is for a person to know their HIV status. This necessitates making sufficient counselling and testing centres available. Demand needs to be created for HIV medication. It is assumed that were ARVs to be made available in health care facilities, individuals may stampede to get the drugs. This is not the case. In Botswana for example, where free ARVs have been made available for those who need them, the uptake has not been as expected. To date only 30 per cent of the predicted number have come forward for the drugs. Several factors may be responsible for this including stigma and lack of community structures for support and mobilisation.

For a programme aimed at providing access to care and support through provision of ARVs to succeed, risk awareness has to be created in the community. People have to realise that they are at risk of being HIV infected and hence may seek counselling and testing services well before they become symptomatic. For this to happen, in turn they have to feel that stigma is minimal and that there is low risk of being ostracised. It should be remembered that, stigma is not only an individual matter, but a matter for the family, the community and – in an African setting – a matter affecting the whole clan as well. Therefore individuals have to feel safe before they declare that they are HIV positive. They have to evaluate the consequences and reactions to and from their children, spouses, other family members and the community in general.

It is virtually impossible to have proper ART unless a person is open about his/her HIV status. Apart from the attending doctor, their status will be known to the nurse, the laboratory technician, the person who follows the client/patient up in his/her residence to ensure regular attendance and uptake of drugs, and maybe someone in the family who might be funding the treatment (and reminding the client to take the drugs on time or according to the required schedule).

In my experience, stigma is bi-faceted; on one side affecting the client and on the other the health care

provider. Health care providers may know the HIV status of their client through routine health care contact but fail to reveal the status to their client due to issues related to stigma. Definitely this will block this individual accessing the required services and at the same time the providers will not be able to supply these services to this client due to lack of transparency throughout the whole interaction.

A link is needed between institutional and community care in order to develop a continuum of care for the recruited clients/patients. This is necessary to minimise short and long-term defaulters including those who may be lost to follow-up. The HBAC program in TASO uses community volunteers as a key component to ensure adherence to ART.

### **Civil society in the provision of ART**

Civil society is much closer to populations (especially rural populations), more flexible and more responsive to the needs of the people, often able to mobilise volunteers to provide additional resources which governments cannot do, often more credible than government or the private sector and with better networks and linkages to provide care. These qualities give civil society certain advantages and, as opposed to government that has an obligation to provide care to entire communities, NGOs and civil organisations can start small and scale up as resources become available and the environment becomes conducive.

In Uganda several factors have been responsible for the success of the civil society role including: the long history of faith-based organisations providing health care for the last 100 years, the enabling political environment fostered by President Yoweri Museveni and his government and the vacuum created by shortage of government services.

NGOs access funds directly with minimal bureaucratic bottlenecks. This has enabled speedy implementation of ARV delivery and access to care and support. However, although NGOs seem to have developed strong programmatic and financial accountability, they may not have the capacity to receive and disperse millions of dollars due to lack of technical strength to do so. Only governments have the vast human resources and geographical coverage to play the latter role.

It should be emphasised that governments ought to take full responsibility for ensuring every citizen has access to care, including free ARVs, in partnership with civil society and the private sector – in partnership but not in competition.

### **Bottlenecks in provision of ART**

Other problems in implementing policies related to provision of ART include:

- Lack of personnel trained in prescribing and monitoring the side effects of respective drugs;
- Lack of appropriate laboratory support both for initiation and monitoring progress and side effects;
- Insufficient VCT services in terms of quantity and quality to cope with the required needs of communities (counsellors in particular are in short supply);
- Lack of community mobilisation and support structures for people accessing VCT;
- Lack of sufficient financial resources to cater for every stage of the critical path to introduce and maintain ARV provision in communities;
- Lack of equity. TASO provides ARVs to a small community but what about other communities? How can they be reached? and
- Lack of skills for managing children with HIV on ARVs, including setting up support structures for such children, both in conventional families and/or orphanages.

### **Conclusion**

As countries are challenged to scale up programmes in areas where there is minimal experience, there is a tendency to move slowly while experience is built and research can inform policy. However, HIV/AIDS represents a global emergency that requires unprecedented action to prevent further death and misery. In such an environment, speed of implementation is important but must be supported by policies that are flexible and built on other communities' experiences. In addition, community involvement in policy

development will give credibility to policies that are forced to be selective and prioritise scarce resources. Research and implementation need to work more than ever hand in hand through operational research and develop rapid feedback mechanisms to continuously inform and improve the quality and scale of service delivery.

# Reflections on Proceedings

Virginia Bond and Gideon Kwesigabo

## **The collective responsibility of collaboration between research, policy and implementation**

At the thirteenth ICASA Sida satellite meeting, Anita Sandstrom, head of Sida's regional HIV/AIDS team in sub-Saharan Africa, stated, "Ultimately we will be judged as to whether our inputs have helped decrease transmission of HIV and improved the lives of those infected and affected". Thirteen years earlier, at a workshop on appropriate AIDS research in Africa, a Kenyan sociologist – Beth Maina-Ahlberg – made a similar point; "The community is disappointed in us as experts. We have knowledge but what do we do with it? Doctors take blood, ask questions, go away. The community is still dying" (cited in Bond, 1998).

The HIV epidemic impels researchers, policy-makers, programmers and implementers to collaborate. The rationale of close collaboration is based on concern, collective responsibility, ethical principles and the need to act in order to stop people being infected with and dying from HIV/AIDS. Chapter one reminds us – we need to work together to tackle the HIV epidemic. The scale and impact of the HIV epidemic in sub-Saharan Africa places high demands on all of us – asking us to maintain quality and reflection whilst making short cuts to conclusions and actions; it asks us to communicate beyond our own profession, play a diversity of roles and learn a "sum of skills" (Johannsen, 1992) whilst recognising the limits of our own involvement and the skills we do and do not have (Grillo, 1985). Moreover, it demands some overriding

coordination and commitment to communicate, and increasingly it asks us to cast our nets wider – to scale up our efforts in an attempt to have a greater impact on mitigating the epidemic. And all this within a wider context riddled with the “tough realities” of poverty and unequal distribution of wealth, gender inequity, a fragmented health system, poor governance, unfavourable or changing political environments, limited human capacity and corruption.

The recent preoccupation with ARVs encapsulates many of these issues. Chapter six exposes the tensions between the need to implement (“act without adequate knowledge and experience”) and simultaneously learn from research within a fragmented health system. Rather than waiting for experiences and research results before implementing, due to the urgency of delivering ARVs, a more symbiotic relationship between research, policy and implementation is proposed. “We are in a global emergency that requires unprecedented action to prevent further death and misery”, hence a policy on ARVs should be in place, ARVs should be delivered (through civil society and government, in urban and rural areas), but there should also be feedback mechanisms and flexibility to ensure that any significant research findings can be built upon and are able to further direct policy and implementation in order to “continuously inform and improve the quality and scale of service delivery”.

Ideally, scientific achievements need to be translated into practical achievements, policy needs to be evidence based (rising out of research and implementation) and policy and implementation need to be monitored and evaluated. It is evident that although occasionally effective collaboration is achieved, with a transfer of findings and lessons flowing in a circular relationship between research, policy and implementation, all too often the collusion is absent. In reality, research often happens without implementation or without feeding into policy; implementation occurs without research (and indeed sometimes without policy), or research might feed into implementation but fail to connect with policy. And all too often, all three occur without enough community participation. As chapter six points out, in the

delivery of ARVs it is essential to involve communities to give credibility to decisions made about how to allocate scarce resources. And a member of the satellite meeting audience reminded us that we need to “engage” with communities and culture – “you need to move from the university, you need to come down to the community”. Binagwaho agreed wholeheartedly in her response, stressing that “in my view, why people don’t change behaviour is because all the messages we give to them come from us not from them! We don’t involve the community in the reflection and whether we have good research or not, we have to involve the community in any behaviour change strategies”.

Although the importance of “strengthening the dialogue” (Sylwander, 2003) between research, policy and implementation is widely understood, it is a challenging process and one that can be easily blocked at all levels by other demands, ownership issues, personality, political environments and change, and, power struggles. And, underlying the three – research, policy and implementation – are the fundamental ethics of: respect for persons; beneficence (responsibility for the participant’s physical, mental and social well-being); non-maleficence (do no harm); and justice (see Rivera *et al*, 2001). We are collectively responsible for adhering to these ethical canons in our HIV activities. We are also responsible for involving the community in our efforts. And, as the panellists reminded us, we are responsible for acting fast.

The presentations and discussions at this satellite meeting tackled some of the difficulties faced in forging the links between research, policy and implementation, and gave some examples of when (and how) these links have been made successfully. The meeting focused more on the mechanisms of adapting research to policy and research to implementation, than on the links between policy and implementation.

### **“Tough Realities” – the wider context**

Almost all the presentations touched on the wider context within which research, policy and implementation occur in sub-Saharan Africa – the “other-things-happening” which govern meaning and the outcome of events (Wallman, 1996). Chapters one and two demonstrate how the HIV

epidemic has deepened the “tough realities” of the wider context – realities of poverty, gender inequity, fragmentation of culture, and, stigma and discrimination. Chapter two goes on to challenge researchers, policy-makers and implementers for being afraid to tackle tough realities head on, pointing out that avoiding tackling these issues does not make them disappear.

Three tough realities were highlighted – poverty (what chapter one calls “the pauperisation of the epidemic” or the lack of autonomy, control and choice of poor people over the HIV epidemic); stigma and resulting discrimination (and the hurt they cause); and how women carry a disproportionate burden of the HIV epidemic. It was the latter gender inequity that dominated the discussion and was emphasised in Bo Göransson’s opening remarks and Lotta Sylwander’s closing remarks at the satellite meeting as well as in chapters one, two and three here. Indeed, Lotta Sylwander referred to gender inequity as “an evil inequity”. Women are “at the epicentre of the epidemic” (see chapter one) and frequently bear the consequences of the HIV epidemic (higher infection rate, higher burden of care) despite, to quote Kelly, that HIV is a “disease of men, originated in men, disseminated by men”. Intergenerational partnerships (between older men and younger women) and the fact that women are infected and die at a younger age than men, perpetuate and amplify a pattern of sexual partnerships that continue to put younger women at greater risk of HIV infection. Male hegemony, including the institutionalisation of gender inequity (with men consistently over-represented in senior positions and positions of money and power), remains a barrier to changing the situation in which women find themselves. As one member of the satellite meeting audience put it – “Gender inequity is institutionalised and nobody says anything about it ... Just to find out that women are not well treated is not enough. Let us go down to people that are causing this problem – the religious leaders, the government leaders and others”.

Chapter two dwells on the way women’s lack of control over reducing the risk of HIV infection within marriage epitomises their added vulnerability to HIV infection. It

demonstrates very strongly that the specific risks faced by married women – for example the problems they face in negotiating condom use and domestic violence – has been overlooked by researchers, policy makers and implementers alike. One of the satellite meeting audience – a church leader – echoed her concern saying, “My question is so simple. What are you doing to educate the African women to say “no!” to unprotected sex? Women do not say “no”, and unless we come out of this, then African women are going to continue dying. I think this is a clear target”. The fundamental need to change gender inequities was a reoccurring theme in the presentations and discussion, raised by men as well as women.

### **The research perspective**

*“Can we in fact, when being honest to ourselves, make a link between what we are doing and keeping people from dying?”*

*Bolton 1995*

### **Research ethics**

Chapter one discusses how the extraordinary nature of the HIV epidemic highlights and magnifies the ethical implications of existing situations and raises new ethical dimensions and issues for research. HIV causes deep turmoil and is “liberally studded in a way that may be unique, with ethical issues and problems”. It draws on the introduction of ARVs to highlight new ethical dilemmas thrown up by the HIV epidemic, as does chapter six. ARVs raise issues about an individual’s access to adequate health care and access to ARVs, and, the balance between investing in prevention and investing in treatment (and the danger of efforts in one area overshadowing efforts in another).

Most sub-Saharan African countries have national ethics committees that judge whether to approve proposed HIV/AIDS research. However, the existence of ethical guidelines and ethics committees does not automatically mean that ethical principles are applied in practice or enforced. Within developing countries membership of ethics committees is often voluntary – a responsibility heaped upon the many other responsibilities of already over-stretched individuals. The existence of many different ethics bodies within one country and/or corruption can further render the system of

ethical approval farcical. Moreover, ethical approval is not often followed by monitoring to ensure that ethical principles are actually put into practice.

### **Research responsibility**

Issues of public good and collective responsibility are laid out in chapter one – what the responsibilities are and owed to whom, by whom. How does research contribute to promoting common good? How accountable is research to its research subjects and communities? In the discussion at the satellite meeting, the question of appropriate research was reflected in the following questions posed to panellists:

- How do we ensure that research topics crafted in universities are relevant to action and policy?
- How do we ensure that governments care whether or not research is irrelevant?
- How do we ensure that research results are taken on board by policy makers and implementers?
- Is there any room for pure research?
- What is to be done about releasing information that might be harmful to communities?

Unfortunately, there was no time during the meeting to give adequate answers to these important questions. Yet the questions alone reflect the cry for research to be relevant and responsible.

### **Research coordination**

Integral to research responsibility, is the coordination of research: the importance of research building upon – and hopefully going one step further than – previous research and the process of researchers consulting each other. If research is not coordinated, there is a chain of consequences including: certain communities (especially urban areas and capital cities) being over-researched; the unnecessary repetition of research; the occurrence of unethical research; and the lack of coordination between research, policy and implementation. Improved documentation, communication and information sharing among bodies coordinating research activities within countries may help to minimise

this. Researchers should have a primary responsibility for providing information as to what they are doing and the results they have obtained, not only to the coordinating bodies but also to fellow researchers and the community at large. It is not unheard of in a research institution for a researcher in one office to be unaware of the research activities of a colleague next door, only to find out at an international conference from other researchers.

### **Research priorities**

It appears that funding bodies, outsiders and experts still often set priorities, without enough African or community ownership. Until more research capacity is built within Africa and African governments spend more on research, it is unlikely that African researchers and communities will take a lead in setting research priorities.

Helen Jackson commented at the satellite meeting, “the great majority of research is telling us things we already know and have already improved, and doesn’t contribute to informing further action”. At the thirteenth ICASA, this sentiment was heard again and again. There appears to have been a collective failure to reach consensus about what is already known and can be acted upon – and what needs to be known now. Further, experts are failing to be innovative and creative (“think out of the box”), bring in diverse disciplines, or to respect ideas and information coming from communities enough (Jackson, personal communication, 2004).

There is another issue of competing priorities which affects researchers based in Africa and which is touched on in chapters four and five. Within Africa the pressure on researchers is to produce findings as quickly as possible to be fed back to the local community and national HIV/AIDS stakeholders (both civil society and governmental). The findings have to be orientated towards interventions and presented in an accessible and friendly form, in a mode that facilitates application. In contrast, the pressure on researcher from institutions and funders outside Africa has been to publish findings in reputable journals, to build research capacity and to make presentations at international meetings. These findings have to be presented differently

with more in-depth analysis, a stronger link between theory and data, and with reference to other literature. For researchers it is hard to strike a balance between making research findings useful and maintaining a name within international academia.

Researchers have to develop a broad range of effective communication skills – this is echoed in chapter four, highlighting the failure of research to reach communities and policy makers.

### **Research quality**

Merely being involved in research labelled as relevant does not automatically mean that the research is good (Strathern, 1985). There is little point in poor quality research directing either policy or implementation. The danger of doing research as quickly as possible is that research findings might translate into policy and implementation before the evidence is good enough, and this can be harmful and cause confusion. The conflicting, indeed harmful, messages about breastfeeding and HIV that filtered through to communities on the ground from the scientific community is an example of the dangers of research moving into policy and programmes too fast, before there is conclusive evidence. Initially the message was that breastfeeding did not carry a high risk of HIV transmission, then the message was that breastfeeding did carry a high risk of HIV transmission and should be avoided (despite the social reality), and then the message was that breastfeeding should be exclusive and not prolonged.

### **Research type**

There is a range of research that can be undertaken and variety of roles that research can play – for example there are large scale, long-term qualitative studies versus small scale, rapid baseline studies; there is socio-cultural research versus clinical research. Social research tends to expose the “mess” of real life and be broader in focus; clinical research tends to have a narrower focus. The types of results they produce have different implications for policy and programming.

## Research gaps

What exactly are the questions that need answering? Why? What is not known? The importance of asking these questions was reiterated during the discussion. Further research on stigma was one research gaps that was identified, as were several others, including:

- What are the reasons lying behind a high HIV prevalence in southern Africa?
  - How can men be involved more comprehensively in HIV interventions?
  - What are the reasons for disclosure of HIV status being so difficult?
  - What are women’s risk environments within marriage?
  - What is the impact of HIV?
  - Why do interventions work with one particular group (or setting) but not in another?
- Community participation in research

The importance of communities being involved in a reiterative process during the research is emphasised in chapters two, five and six. During the satellite meeting Lotta Sylwander questioned how to guarantee community participation in research? Feedback of research findings to the community does not happen often enough in Africa, and communities are beginning to increasingly question the usefulness of research. Chapter five details a multi-country study on HIV-related stigma in sub-Saharan Africa (see Nyblade *et al*, 2003) that during the process of research, and with the research communities, began to develop anti-stigma education materials and a social movement against stigma. This built the foundation for an ongoing anti-stigma intervention project in two of the countries (Tanzania and Zambia). For research findings to be accepted and implemented by communities, communities should be involved at all levels of the research process and any subsequent intervention activity ensure a sense of community ownership of the findings.

## Research capacity

Chapter four indicates that there is limited research capacity and infrastructure in developing countries due to a brain drain of researchers, poor education (at all stages), poor conditions, poor training, poor access to literature, not enough technology transfer within research projects and because of HIV deaths within the research community. In Rwanda, capacity was also undermined by the war and the genocide (and the same would be true of other countries in conflict like Southern Sudan). Chapter four signals the possibilities within long-term research projects and collaborations for research training, giving the TANSWED HIV Research Programme as an example.

Chapter five highlights the limited capacity of researchers to be implementers and to link up with policy-makers, pointing out their limited communication and advocacy skills for producing succinct results that a wide audience can easily access, understand, judge and act upon. Indeed, researchers working with HIV/AIDS in sub-Saharan Africa need to learn new skills to follow through the application of findings, whilst recognising the limits of involvement.

## Research publications and outputs

It is clear that scientific rigour does not translate into action often enough. It is critical to make research results more accessible to a wider audience (including policy makers and programmers). Chapters three, four and five share ideas about how to make research and researchers more accessible, more useful and more used. Recommendations from the satellite meeting include:

- Involving researchers in advisory boards, policy formulation, national plans and strategic frameworks;
- Extending national and community disseminations to all stakeholders – including parliamentarians and other policy makers;
- Inviting programmers and policy makers to workshops and seminars;

- Involving stakeholders in all levels of the research process (including data interpretation) and from the outset, including working in partnership with government and/or civil society;
- Involving the mass media;
- Sharing copies of progress reports and research publications (i.e. depositing research publications in secretariats and resource centres); and
- Producing one-page flyers about research findings.

The UNAIDS *Best Practice* series is an example of an effective way to share research findings and translate them into policy. There are other more creative ways too – including theatre for development, participatory workshops and other participatory approaches.

### **The policy perspective**

Donors and civil servants represented this perspective in the satellite meeting. Bo Göransson, Swedish Ambassador to Kenya, said in his introductory remarks, that he expected research to answer questions about *why* and *how*, giving evidence for the trends of the epidemic and behaviour patterns, or giving evidence about why a particular intervention strategy was effective and should be adopted. As Lotta Sylwander, head of Sida’s Regional Department for Africa, pointed out policy should be based on evidence – “policy should not have a life of its own but should rise out of research and implementation”.

The presentations and participants in the discussion at the satellite meeting reiterated the importance of political commitment in developing and implementing policy. Chapter five touches on successfully engaging Tanzanian members of parliament in the fight against stigma and discrimination. The failure of a similar attempt in Zambia – where the same multi-country research project with its Zambian partner NGO tried unsuccessfully to share preliminary research findings and recommendations with Zambian parliamentarians – is a reminder that political

commitment to HIV/AIDS cannot be assumed but has to be built. Accountability and responsibility within the civil service, and the value of a decentralised and integrated multisectoral approach versus a centralised and vertical approach to HIV and AIDS programming, are other policy issues raised.

Policy is key to scaling up HIV/AIDS activities. Chapter three gives a good example of developing comprehensive HIV/AIDS policies within a strategic planning process in Rwanda through engaging a broad group of stakeholders. This chapter also portrays the ironic situation that Rwanda found itself in late in 2003 – having developed policies and made strategic plans, then lacking the funding and human and economic capacity to implement them. This is also a stark reminder of the role of genocide in slowing development and transmitting HIV infection.

### **The Implementation perspective**

Ideally, implementation should be directed and reinforced by policy, and informed, monitored and evaluated by research. Implementation can also identify research gaps and questions, since people in the field know the problems they face and what questions they need answers to.

Chapter six, dealing with the difficulties faced by a Ugandan NGO trying to provide ARVs, introduces another dimension within the implementation community – namely the role of civil society versus the role of government. Chapter six suggests that civil society has the capacity to respond and implement more locally and rapidly than government, which is often hampered by inertia, bureaucracy and its huge responsibilities. On the other hand, it recognises that government, and not civil society, is responsible for providing services to the nation. This chapter flags the importance of engaging with both civil society and government as researchers and policy makers, whilst recognising their mandates are necessarily different and that government is always going to remain the lynchpin for policy and for interventions that are not restricted to the confines of a particular NGO but can have a wider impact on a wider community. Key to sustainable implementation is flexible partnerships between the different stakeholders with government maintaining a co-ordinating, leading and central role.

Both chapters three and six detail the challenges and constraints faced in the different implementing partnerships. For example, chapter three highlights tensions between donors and government in Rwanda, mentioning donors' unwillingness to fund institutional capacity building in the form of staff salaries.

## **Conclusion**

To a certain extent, research, policy and implementation are separate activities, requiring specialised skills. When these activities are used to understand, address and mitigate the HIV epidemic – to stop people being infected with HIV and dying from HIV – there is an urgent need to work together. There are clearly many overlapping issues involved for researchers, policy-makers and implementers. We are collectively responsible for “fast-tracking” (Continho, 2003) the feedback system between research, policy and implementation, and for “scaling up” efforts, without compromising fundamental ethics or the quality of work. It is necessary to make sure that community participation is integral to the collective approach. And working within societies that are transformed by politics, profit and disease (Redclift, 1985), as seen in chapter two, we *have* to take on these tough realities *despite* the complexities they throw at us. Serious efforts need to be put into the reduction of poverty, socio-economic inequity, gender inequity and stigma and discrimination.

In order to achieve these tricky goals, effective coordination is needed. Logically this coordinating role should lie with governments, yet governments have not always proved to be effective in this role. All three (researchers, policy makers and implementers) are guilty of a lack of coordination, and are too often driven not by need and social reality but by trends, politics and ambition which all serve to undermine coordination and to construct a focus not necessarily based on the needs of communities living with HIV/AIDS.

It would seem essential to enhance the commitment and capacity of government to play out a collaborative role, to strike a balance between the three and to facilitate meaningful and useful encounters between

research, policy and implementation. As Obbo (1995) pointed out, it is easy to pay lip service to such encounters but less easy to follow through the commitment. Are National AIDS Councils (or Commissions) the right bodies to force researchers, policy makers and implementers to knock heads together? The recent WHO initiative to have three million Africans taking ARVs by the year 2005, and the earlier and broader Global Fund initiative, requires not only collaboration and coordination but also integrity.

For researchers, the satellite meeting suggested the links could be forged by:

- Including relevant stakeholders at all levels of the research process;
- Incorporating a strong feedback system at all levels of the research process;
- Learning new skills; and
- Disseminating existing research findings widely and creatively.

For policy makers, the same strategy of involving a broad-based group of stakeholders in developing policy was advocated. For implementers, communicating the questions that need to be answered was paramount. Effective partnership within different types of implementers (for example, civil society and government) is also crucial.

This all requires professionals working with people living with HIV/AIDS to display courage, creativity and speed. They also need to:

- Work where they can be most effective;
- Always remember that lives are at stake;
- Cast a wide theoretical net;
- Have a sum of skills;
- Give more power to communities;
- Think collectively about priorities; and
- Remain ethical.

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# Abbreviations and Acronyms

AED (Zambia)	Academy for Educational Development	OVC	Orphans and Vulnerable Children
AIDS	Acquired immuno deficiency syndrome	PLHA	People Living with HIV/AIDS
ART	Anti-retroviral treatment	PMTCT	Prevention of mother-to-child HIV transmission
ARVs	Anti-retroviral drugs	PNLS (Rwanda)	<i>Programme National de Lutte contre le SIDA</i>
CDLS (Rwanda)	<i>Commission District de Lutte contre le Sida</i>	SAREC	Department of Research Cooperation, Sida
CPLS (Rwanda)	<i>Commission Provinciale de Lutte contre le Sida</i>	Sida	Swedish International Development Co-operation Agency
CSOs	Civil Society Organisations	STIs	Sexually Transmitted Infections
HAART	Highly Active Anti-Retroviral Therapy	TANSWED	Tanzania-Sweden HIV Research Programme
HBAC (Uganda)	Home Based AIDS Care programme	TAS (Tanzania)	Tanzania AIDS Society
ICASA	International Conference on AIDS and Associated Cancers in Africa	TASO (Uganda)	The AIDS Support Organisation of Uganda
ICRW Women	International Centre for Research on Women	TRAC (Rwanda)	Treatment and Research on AIDS Centre
LAC (Ethiopia, Tanzania, Zambia)	Leadership Advisory Council	UNGASS	United Nations General Assembly Special Session
MAC (Tanzania)	Multisectoral AIDS Conferences	USAID	United States Agency for International Development
MUCHS (Tanzania)	Muhimbili University College of Health Sciences	VCT	Voluntary Counselling and Testing
NACC or CNLS (Rwanda)	National AIDS Control Commission or <i>Commission Nationale de Lutte contre le Sida</i>	ZAMBART	Zambia AIDS Related TB Research Project
NGOs	Non-governmental Organisations		

# About the Authors



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A leading paediatrician and HIV/AIDS specialist, Agnes trained in Belgium and France. She moved back to Rwanda in 1996 where she was head of paediatrics firstly in Centre Hospital at the University of Kigali and then in Kanombe Hospital, Kigali. Since 1996, she has been involved in providing technical support to numerous national and international HIV/AIDS committees, including the PMTCT working group, the First Ladies of Africa Conference on HIV/AIDS *and the Child*, and the Global Fund's Country Coordinating Mechanism. Currently she is Director of the National AIDS Control Commission (NACC) or *Commission Nationale de Lutte contre le Sida* (CNLS).



## **Virginia Bond**

Born and brought up in sub-Saharan Africa, Virginia is a social anthropologist based in Zambia working for the London School of Hygiene and Tropical Medicine within the Zambia AIDS-Related TB Research (ZAMBART) Project at the University Teaching Hospital in Lusaka. She has been working with HIV/AIDS since 1987 in rural Uganda, London and rural and urban Zambia. Prior to working for LSHTM, she worked for the Panos Institute and then the University of Hull (UK), University of Zambia and Karolinska Institute (Sweden). Her work on HIV/AIDS includes household coping strategies, peer education on commercial farms, management of TB patients by Home-Based Care organisations, community perceptions of

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### **Alex Coutinho**

A medical doctor who has specialised in public health and HIV management, Alex Coutinho has worked with HIV/AIDS since 1982 when the first AIDS cases began to be apparent in Uganda. From 1989 to 2000, Alex worked in Swaziland building up HIV education, prevention and care programmes for RSSC. Since 2001 he has been the director of The AIDS Support Organisation of Uganda (TASO) which now supports 30,000 HIV positive clients, with a staff of 400. He is also on the board of the AIDS information centre in Uganda. Internationally, he has been a member of the interim board of the Global Fund to fight AIDS, TB and Malaria, a member of the strategic advisory group to World Health Organisation for the WHO HIV/AIDS global strategy and a member of the scientific committee of the Academic Alliance for HIV/AIDS.



### **Helen Jackson**

Raised and educated in the UK (specialising in Human Sciences and Social Work), Helen Jackson has lived in Zimbabwe since 1982. She worked there initially as a teacher and then as a social worker in rehabilitation before becoming a lecturer at the School of Social Work. In the late 1980s her concerns increasingly turned to HIV/AIDS as a result of receiving unscreened blood transfusions when the HIV prevalence in donated blood was already two per cent. The lack of information, research, policy and programmes around HIV/AIDS led her to co-found an AIDS service organisation as well as to undertake extensive research and publication around the epidemic. In 1993 she became a founder and director of a project that developed into the Southern Africa AIDS Information Dissemination Service (SAFAIDS) now a prominent regional NGO. In 2001 she joined the United Nations Population

Fund as HIV/AIDS advisor for the southern Africa region. She is the author of the widely-acclaimed publication *AIDS Africa – Continent in Crisis* (2002), a book being updated and translated in 2004 into French and Portuguese to reach West Africa and the lusophone countries. Helen Jackson is married with two adolescents entering the high-risk age for infection.



### **Michael J Kelly**

Formerly Professor of Education at the University of Zambia, Michael J. Kelly works as a consultant in the field of HIV/AIDS and Education. He is a member of the Mobile Task Team, a virtual organisation of experts from Southern Africa who respond to requests from education ministries to provide technical assistance in the field of HIV/AIDS and education. He is also a member of the reference group that advises the Swedish/Norwegian AIDS Team for Africa. He has participated in numerous HIV/AIDS-related conferences and workshops in Africa, Asia, Europe and the Caribbean, and has authored many books and articles. His most recent book *Education and HIV/AIDS in the Caribbean* was published by the International Institute for Educational Planning, Paris, in October 2003.



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### **Fred Mhalu**

Following training in medicine at the University of East Africa, Makerere University College Medical School Kampala, Uganda; Fred Mhalu pursued training in pathology, microbiology and immunology at the University of Ibadan Nigeria; at the London School of Hygiene and Tropical Medicine; and at the Royal Postgraduate Medical School at London University and the Hammersmith Hospital, London. Since 1977 he has been based at the School of Medicine, Muhimbili University College of Health Sciences, University of Dar es Salaam, where for various periods he served as Head of Department, Dean of the School of Medicine and Director of Postgraduate Studies and Research. From 1986 to date he has been Coordinator of the TANSWED HIV Research Programme involving many other investigators in Tanzania and their Swedish counterparts. He has also served as Coordinator in Tanzania of the Prevention of Mother-to-Child HIV transmission (PMTCT) multicentre study (Petra) between 1996 and 1999. Currently he is coordinator in Tanzania of the Sida/Sarec supported Mother-to-Infant HIV transmission intervention (Mitra) project and principal investigator of the EU supported HIV vaccine immunogenicity project.



### **Jessie Mbwambo**

Jessie Mbwambo received her Medical degree from Muhimbili University College of Health Sciences and a medical residency in Psychiatry in 1993 in the United Kingdom at the University of Manchester, Victoria. She was a Carnegie Fellow in Health and Behavioral Research at Harvard Medical School in the Department of Social Medicine from 1996–1997, where she received advanced training in Transcultural Psychiatry and Ford Foundation Fellow with the International Centre for Research on Women, Washington DC. She has conducted studies on HIV-related violence, stigma, and disclosure, as well as VCT in the context of prevention of mother-to-child transmission projects in antenatal clinics that offer antiretroviral prophylaxis.





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