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1 – Introduction

A call to arms

The grey-haired old man had to be helped up the steps onto the stage, and he walked slowly over to his chair, beaming at the warm reception and applause that he was receiving. He sat for a moment and listened as the conference chairman introduced him, describing him as "*an icon of our times*"; and then he stood to address the 12,000 delegates attending the closing ceremony of the XIIIth International AIDS Conference.

Held in July 2000 in Durban, South Africa – then the country with more HIV-positive people than any other in the world – this conference had been beset by controversy before it even started. The meeting's slogan was '*Break the Silence*', and 'silence' was indeed in short supply. Disputes were raging in South Africa over the cause of AIDS, with different groups pointing to HIV, to poverty-induced malnutrition, or even to the antiretroviral drugs used to treat the condition (Swarns, 2000; Sunday Independent, 2000). The protagonists on all sides held deeply entrenched views, with the mainstream scientific community holding firmly to the position that HIV causes AIDS (Durban Declaration, 2000), and South African President Thabo Mbeki allying himself with the so-called 'AIDS dissidents' who believed in the various alternatives (Mbeki, 2000). It was a classic case of the complex interplay between politics and science, and it had been the focus of much anger and angst during the conference.

But now, Nelson Mandela saw the opportunity to put the discussion back – as he saw it – on track. His speech to the conference was carefully crafted, and it touched on several important themes. Mention was made of the controversy in South Africa, but in what some saw as a reprimand to his successor, the former President argued that this acrimonious debate should now be consigned to history. The urgency of the situation demanded that attention be turned fully to reversing the inadequate response that had prevailed across most of the African continent since the very first AIDS cases were identified around the border between Uganda and Tanzania way back in the early 1980s.

"*The ordinary people of this continent*," he pointed out with an unmatched authority, "*and of the world – and particularly the poor who on our continent will again carry a disproportionate burden of this scourge – would, if anyone cared to ask their opinions, wish that the dispute about the primacy of politics or science be put on the backburner and that we proceed to address the needs and concerns of those suffering and dying… In the face of the grave threat posed by HIV/AIDS, we have to rise above our differences and combine our efforts to save our people.*

"*History will judge us harshly if we fail to do so now, and right now. Let us not equivocate: a tragedy of unprecedented proportions is unfolding in Africa. AIDS today in Africa is claiming more lives than the sum total of all wars, famines and floods and the ravages of such deadly diseases as malaria. It is devastating families and communities; overwhelming and depleting health care services and robbing schools of both students and teachers*."

After this stark beginning, Mandela then moved to discuss the considerable experience and knowledge that had accumulated since AIDS first emerged, which, he argued, collectively could provide powerful tools for action. "*Something must be done as a matter of the greatest urgency. And with nearly two decades of dealing with the epidemic, we now do have some experience of what works. The experience in a number of countries has taught that HIV infection can be prevented through investing in information and life skills development for young people. Promoting abstinence, safe sex and the use of condoms and ensuring the early treatment of sexually transmitted diseases are some of the steps needed and about which there can be no dispute. The experiences of Uganda, Senegal and Thailand have shown that serious investments in and mobilisation around these actions make a real difference.*"

Mandela's speech concluded with the recognition that Africa cannot fight this alone, that AIDS in Africa can only be challenged and ultimately overcome through the co-operation of people from many different levels of the global community. "*The challenge*," he told us, "*is to move from rhetoric to action, and action at an unprecedented intensity and scale. We need, and there is increasing evidence of, African resolve to fight this war. Others will not save us if we do not primarily commit ourselves. Let us, however, not underestimate the resources required to conduct this battle. Partnership with the international community is vital. A constant theme in all our messages has been that in this inter-dependent and globalised world, we have indeed again become the keepers of our brother*

and sister. That cannot be more graphically the case than in the common fight against HIV/AIDS" (Mandela, 2000).

I was seated far from the stage in the huge conference hall, and though I could see the small figure of Mandela in his trademark, colourful shirt up at the front, I watched him speak via one of the large, strategically placed TV screens. His speech was frequently interrupted by applause, and after he finished, Jerry Coovadia, the South African paediatrician who had chaired the conference, told Mr Mandela: "*You cannot imagine how your speech is music to our ears. It has answered so many spoken and unspoken questions*." And when the conference was formally declared closed a few minutes later, there was a buzz of optimism and excitement as people filed from the hall and out into Durban's dazzling winter sunshine. "*At last*!" I overheard an African delegate exclaiming to her friend. "*The silence has really been broken*!"

The primacy of politics or science?

Many people have questioned the good actually accomplished by these huge biannual International AIDS Conferences, which have been accurately described as the "*trade fairs of the international AIDS industry*" (Altman, 1998: 239). Thousands of advocates, NGO workers, scientists and journalists gather in a major world city for a few fevered days of meetings and presentations. Business cards are swapped, declarations are made to loud applause, and at the end, the exhausted delegates troop home to where nothing has changed.

But in at least one important respect, Durban was different. For all their flaws, the International AIDS Conferences are "*arguably the most visible arena in which international discourses around HIV/AIDS are established and legitimised*" (Altman, 1998: 241). And since Durban was the first International AIDS Conference to be held in a developing country – and the only one ever to be held in Africa, the world centre of HIV, with 70% of all those infected worldwide – it had served as a powerful global platform for raising awareness about the sheer scale of the African epidemic as well as the totally inadequate response to it. With 24.5 million HIV-infected people, and 4 million new infections in 1999 alone, Africa's AIDS epidemic was profoundly affecting the social, economic and demographic underpinnings of the continent's attempts to develop (UNAIDS, 2000). And by the year 2000, it really was, as Mandela had powerfully argued to his international audience, time for action.

Based on the new discourse promulgated at Durban, significant action did indeed follow on from the conference. A new paradigm had been established, and although Durban was not the only event contributing to what amounted to a shift in global AIDS policies, it certainly represented a watershed in the history of the African AIDS epidemic. The conference provided a huge political boost in particular to scaling up the provision of antiretroviral therapy (ART) for African people living with AIDS. Subsequently, the establishment in January 2002 of the Global Fund to Fight AIDS, Tuberculosis and Malaria, as well as enormous increases in funding from the US government and the Bill and Melinda Gates Foundation provided much of the financial basis for implementing the scale-up of these services throughout Africa.

A key observation about this process is that these changes were brought about not so much by an avalanche of scientific innovation at Durban – there had been no revolutionary discoveries announced for either the prevention or treatment of AIDS – but rather through a simple recognition by many top level actors that it had become politically unacceptable to continue with the general abandonment of Africa to HIV. A tipping point had been reached at which, politically speaking, there was now more to lose by inaction than there was to gain. In his speech, Mandela had referred to the "*dispute about the primacy of politics or science*" in relation to the unresolved debate in South Africa regarding the relationship between HIV and AIDS. But this idea of the primacy of politics or science can also be applied to the transformations that followed the Durban conference in terms of developing political will and establishing global financing mechanisms to tackle AIDS. There can be little doubt that it was politics and not science that had primacy in bringing about this all-important transition.

If politics was driving the changes, what, therefore, was the role of science in addressing Africa's AIDS epidemic? I had attended the Durban conference as a delegate from Uganda, where I was working as a behavioural scientist with the British-funded Medical Research Council (MRC) Programme on AIDS. My own contribution to the meeting had been a presentation of data from a community-based HIV prevention intervention trial on which I had been working in the south-western rural district of Masaka for the previous four years (Kinsman et al., 2000). My colleagues and I did not know at that stage whether, or the extent to which the intervention may have had any effect, and my presentation had focused on basic

issues of training and support for community AIDS educators, programmatic sustainability, and condom distribution strategies. My general thrust was simply – just as Mandela had also pointed out – that these things *can* be done if there is sufficient will, money and organisation to do them.

Uganda had featured prominently throughout the conference, with many speakers praising the country's efforts. Uganda has the longest history of AIDS of any African nation, and its national AIDS Control Programme mounted a campaign very early on in the epidemic, since when HIV prevalence has fallen dramatically. While prevalence among pregnant women attending two hospitals in Kampala was estimated at 29% in 1992, for example, it had fallen to 10% and 12% respectively by 1999; and similar prevalence patterns were reported from most other parts of the country (ACP, 2000:4). Furthermore, one of my MRC colleagues had presented in Durban the very first data from the entire African continent showing a significant decline in HIV incidence[1] in a general population. Like my own data, his had also been recorded in Masaka district (Mbulaiteye et al., 2002). For an AIDS scientist, this was data at its most exciting: evidence clearly indicating that things were improving. Conference delegates were watching and listening, a sign that information and ideas were being 'exported' from Uganda to the rest of Africa. By the closing sessions, there was some pride to be had in wearing a conference name badge on which one's country was identified as 'UGANDA'.

Politics may have had primacy at Durban, therefore, but the science was certainly playing its role too. When I returned to Masaka, however, my faith in the value of science for AIDS control – or at least for HIV prevention – was shaken. Analysis of the dataset from the HIV prevention intervention that I had been working on was finally completed a few months later, and it became apparent that our work had been in vain: the intervention had had absolutely no measurable impact on HIV incidence. The Masaka Intervention Trial had been a large – and I believed well conducted – project, with a volunteer, community-based work force of 550 people

[1] HIV incidence refers to *new* cases of infection, and is usually presented as the percentage of the uninfected population which is infected in a given year. HIV prevalence, by contrast, represents the proportion of the whole population that is infected at any given time, and which therefore includes people who were infected some time ago. Although HIV incidence is technically much harder to measure than HIV prevalence – hence the long lapse in Uganda between demonstrating falls in prevalence and demonstrating falls in incidence – it is the key indicator for determining current trends in infection rates.

implementing the intervention. We had recorded over 80,000 HIV prevention educational activities, 390,000 individual attendances at these activities, the treatment of 12,000 cases of sexually transmitted diseases, and the sale of 1.5 million condoms. Over 13,000 study participants had been interviewed, bled for serological assessment, and then followed up for an average of three and a half years for the evaluation (Kinsman et al., 2002; Kamali et al., 2003). If this degree of effort and intensity had failed to have a demonstrable impact on HIV, it was hard to imagine what could.

Two points emerged in my mind from this. First, Mandela had presented the conventional wisdom in Durban – which had accrued, in part, out of the Ugandan experience – when he said that "*The experience in a number of countries has taught that HIV infection can be prevented through investing in information and life skills development for young people. Promoting abstinence, safe sex and the use of condoms and ensuring the early treatment of sexually transmitted diseases are some of the steps needed and about which there can be no dispute*." In other words, he was saying, simply put, 'we know what works'. But the evidence we had produced in Masaka now suggested that the situation was far more complicated than this. The solid ground "*about which there can be no dispute*" was no longer quite as solid as it had seemed.

The second point was perhaps even more galling. As will be detailed in Chapter 6 of this book, very limited attention was paid to the findings from the Masaka study, or to their broad implications for HIV prevention in the country – either in Uganda or further afield. This was in spite of its being a rare and rigorous evaluation of widely adopted HIV prevention strategies. Of course, evidence of intervention success is much more exciting than evidence of failure, but it is equally important to understand the causes of failure, and then to address those causes. In this case, however, our findings were more or less completely ignored, and it was my wish to understand how and why this was that formed the starting point for this book.

The initial plan when I started work on the book in March 2003 was to examine the evolution of AIDS control in Uganda specifically from the perspective of research. By using an anthropological approach to investigate the means by which particular research projects had, or had not contributed to policy changes, I hoped to be able to make some sense of what happened to the Masaka study. I soon realised, however, that this would provide only a partial picture. More would be gained if I used a

similar anthropological strategy also to examine the evolution of particular policies, to see what, in addition to research, had influenced them. Thus, I would be looking at the broad issue of AIDS control in Uganda from opposite directions: from the perspective of research (the Masaka Intervention Trial), and from the perspective of policy (through which I would focus on behavioural HIV prevention, and the scale-up of ART provision). I also planned to include an additional investigation into the process through which the need for an AIDS control policy in Uganda was recognised in the first place.

Two important points should be noted here. First, the policies to be discussed in the book are strategic, concerned with the broad approaches to HIV prevention or the provision of antiretroviral therapy. The book is not concerned with the more technical policies to do with such issues as drug regimens or treatment algorithms. Second, it was clear from the start that both policy and research are the products of influences and processes working at many different levels. Thus, as explained in further detail below, a multi-level approach would be necessary in order to build the fullest possible picture.

The overall objective of this book, therefore, is *to identify and explain the key influences and processes that have guided AIDS control in Uganda, from the start of the epidemic up until 2005* [2,3]. The specific research questions can be divided into two categories, one looking at the issue from the perspective of policy, the other from the perspective of research. Each empirical chapter addresses one or more of each of these specific questions, with the overall objective of the book running as a theme throughout.

Policy-related questions:

1. How has AIDS control policy evolved in Uganda? Which events, at which levels, have been especially influential in this evolution, and which actors have most influenced policy formation?

2. How has international level policy impacted upon the development of Ugandan national policy – and vice versa?

[2] I use the term 'AIDS control' to include both the prevention of HIV infection and the treatment of people who have AIDS.

[3] I finished my main field work session in late 2004, but followed up certain issues during working visits to Uganda between 2005 and 2007.

Research-related questions:

3. To what extent has research played a role in policy development at national and international levels? Which evidence has been used, and how?

4. What has been the rationale for conducting particular research projects on AIDS control in Uganda? What has been the reaction – from fellow scientists, policy makers, practitioners and the target populations – to the results? What has been the impact of the findings subsequently on research, policy and practice?

Methodological issues

The experience of living and working in Masaka between 1996 and 2001 planted the seeds for the questions tackled in this book, and provided much of the initial raw material and understanding of the subject. Once I had started work on the project, I finalised the research questions and then began formal data collection with respect to the policies and the study concerned.

My overall methodological strategy was to follow what could be described as the 'life stories' of three particular AIDS control policies and of one particular research project as they evolved, taking into account the respective inputs of actors from many different geographical areas and from different periods. The use of life stories in anthropology usually applies to individuals, with a narrator giving an account of his or her life, and addressing the question: "*what events have made me what I am*," or, otherwise put, "*what you must know about me to know me*" (Linde 1993:20). The approach here adapts the principle by taking a policy or a research project to be an individual, if very complex entity which can only be really 'known' through the eyes of the various actors who have shaped it, and through their understanding of how it has become what it is over the course of time. Thus it is historicised: presented and interpreted as a product of particular historical developments.

Part of the methodological inspiration for my approach has come from the Overseas Development Institute (ODI), Britain's leading independent think tank on

international development and humanitarian issues. For a number of years now, researchers from the ODI have recognised that under-utilisation of evidence frequently hampers development policy and practice. As part of the process of bridging this gap, the ODI recommends that research into the research-policy relationship looks both from the perspective of policy (to assess the role of research in clear policy shifts), and from the perspective of research (to assess the policy impact of specific research projects) (ODI, 2004a:6). This book follows that approach; and as such, it could be described as a historical, multi-level reconstruction of AIDS control in Uganda. Below, I examine some of the methodological issues that I encountered during the process of data collection, analysis and writing.

The study includes analysis of three different types of data. These are: (i) published and unpublished documents from the particular period under consideration in any given chapter, including material from libraries and archives in Kampala and Masaka as well as the internet; (ii) my own journal notes written in Masaka between 1996 and 2001; and (iii) material collected during interviews conducted explicitly for this study, between 2003 and 2005, which I have been able to verify and substantiate during subsequent working trips to Uganda up until 2007. Most of my research has therefore been based on what other people have written or told me, and I have sought to reconstruct events through this. Consequently, the empirical chapters that follow should not be seen as '*an objective representation aimed at complete empirical coverage*' (Beuving, 2006:56); or, as the founder of modern history, Leopold von Ranke, famously put it, "*how it really was*" (Ranke, 1824). Rather they are presented as the closest fit to actual events that I have been able to produce.

Returning to the three types of data that I have used: The advantage of the first two of these – documents and journal notes – is that they were produced 'at the time', which means that the contents do not suffer from the treacherous historiographical practice of 'presentism'. In other words, they have not been re-analysed with the benefit of hindsight, with present day ideas or perspectives anachronistically introduced into them[4]. I have files full of faded, yellowing papers collected during

[4] A classical example of presentism is given by Fischer (1970), who writes about the so-called 'Whig history'. He describes how certain eighteenth- and nineteenth-century British historians wrote history in a way that used the past to validate their own political beliefs. This interpretation was presentist in the sense that it did not depict the past in what could be described as 'objective' historical context, but instead events were viewed through the lens of contemporary Whig (or, as the party evolved, Liberal) beliefs.

the late 1980s and throughout the 1990s, representing a veritable gold mine of historical information about AIDS in Africa. Yet it has struck me how easy it is to skim-read this material, since so much of what was written then seems to be so obvious now. Could people seriously have questioned whether HIV is transmissible from women to men? Is it not obvious that belief in the potential efficacy of condoms would increase the chance of people using them? But that is a 'presentist' mental approach which does not give this material the credit it deserves. After all, at the time these were cutting edge research issues. The knowledge that AIDS professionals collectively currently possess has grown so fast that what was considered a few years ago to be radical and new is now taken completely for granted. If viewed carefully, these older documents can therefore open a window directly onto a former world, providing a bird's eye view of an earlier era in the particular life story being discussed.

Having said that, careful viewing and analysis is essential, as it cannot be assumed that the sources of these documents were necessarily neutral as they wrote (I include myself as the journal writer in this statement). The information included cannot therefore be taken as simple, straightforward fact. As Furay and Salevouris (1988:223) argue, a critical approach is required when reviewing any such historical material, since one is "*not study[ing] the events of the past directly, but the… interpretations of those events*". Arnold (2000:78) takes the point further, suggesting that "*sources are not innocent; their voices talk to certain ends, intend certain consequences. They are not mirrors of past reality, but events in themselves*."

In a similar vein, the third type of data used in this book – interview material – must also be viewed critically. Bourdieu (1977:18-19) outlined his epistemological critique of the information derived during social scientific interviews in three points; these could apply whether the research relates to either a present-day or a recent historical issue. First, he suggests that much of an interview may remain at a level at which the basic assumptions which constitute the sine qua non of what is being discussed remain unstated. The very essence of the issue at hand is therefore avoided, potentially leading to a shallow or simply incorrect interpretation. Second, since the discussion is usually initiated by the researcher, it will flow as an 'outsider-oriented discourse', which means that the respondent may presume the researcher to be relatively unfamiliar with the topic, and especially so if the questioning appears to be uninformed. Hence the discussion may remain at a general level, eschewing

potentially important details. Third, informants may wish to impress the interviewer with their mastery of the issue in question, which can lead to a tendency to dwell on the extremes of the range of possibilities on the topic – the "*most esteemed or reprehended*". This can lead to a skewed or biased dataset.

Strong as these points are, they are not necessarily fatal to research that uses interview material. Jenkins (1992) points out that most sociologists and anthropologists tend to be wide-ranging in their techniques for data collection, adopting what he describes as a "*cheerful promiscuity of method*" (Jenkins, 1992:55). Such triangulation reduces the reliance on potentially misleading interview material, and through the extensive additional use of documentary data, as well as information garnered from different levels, I have taken such a cheerfully promiscuous approach during the research for this book. Thus one type of data either supports what emerges from another, or frames it in another light. But even if social scientists do decide to rely primarily on interview material for their work, Jenkins argues that Bourdieu "*overstates the case massively*", and he questions "*the degree to which the testimony of research subjects is, by definition, unreliable*" (Jenkins, 1992:56). In other words, care must be taken with such material, but it can still be used as an effective source.

Nonetheless, the material presented over the following chapters concerns very complex phenomena – the life histories of policies for AIDS control and of a large AIDS research project – which means that conflicting views and interpretations of events will inevitably arise among those who have been involved. No single account could satisfy everyone. Furthermore, while I have sought to reduce bias in analysis and interpretation to an absolute minimum, what I write in this book is inevitably shaped to some extent by my own prejudices and preconceptions. As such I make no universal claims about what is presented over the following pages. Rather, it is my interpretation of events based on data that I believe to be valid and reliable, and no more.

In his speech, Nelson Mandela made reference to "*this inter-dependent and globalised world*", a recognition of the many different geographical and professional arenas that play a role in a phenomenon as complex as AIDS control in Africa. Given this, I decided right at the start of this project that the only way to study my topic effectively was to take a multi-level perspective as a conceptual and methodological

framework (van der Geest et al., 1990). As such, the data collection process required interviews with, and observations of people from a wide range of backgrounds, living and working in many different settings. The intention has been to give voice to the actors at each of three levels – international, national and local – through which it is hoped to develop an understanding of their various *emic* perspectives[5] of the particular issue under discussion. For example, although the financing and much of the ostensible power originates in the 'higher', international levels, an important point that will become clear over the course of the book is that the relationship between levels is often based on a surprising degree of interdependence. The international actors need the national and local level actors to sustain their legitimacy just as much as the local level actors need funding from 'above'. A more detailed theoretical consideration of the multi-level perspective is given in Chapter 2, which highlights the importance of these relationships and linkages. The three levels are merely introduced here.

The term 'International' refers here primarily to people working at the centres of research and policy-making that give much of the direction to AIDS control activities for developing countries. These centres include such places as the World Health Organisation and UNAIDS, as well as the London School of Hygiene and Tropical Medicine; and the individuals employed by them could be described as part of the global elite of AIDS professionals. I chose to include people for interview at this level who are not based in Uganda but who nonetheless have insights and knowledge into particular aspects of the Ugandan AIDS epidemic. They comprised primarily social scientists, epidemiologists, physicians and policy makers, and I met them either by appointment at their respective offices or opportunistically at scientific conferences. This field work took place between July 2003 and June 2004.

For the national and local level research, I spent an intensive period in Uganda between August and December 2004, supplementing the basic foundation I had built around my research topic developed during the five years I lived in Masaka between 1996 and 2001. At national level (which refers essentially to Kampala, where decisions are taken for Uganda as a whole), I spoke with people in the Ministry of Health; a large number of NGOs; research institutions such as Makerere University,

[5] An 'emic' perspective describes behaviours and understandings in terms meaningful (consciously or unconsciously) to the actor. By contrast, an 'etic' account is a description of a behaviour in terms meaningful to the observer.

private consultancy firms, the Centres for Disease Control, and the Institute of Public Health at Mulago hospital; and journalists.

The local level is defined here as the three contiguous districts of Masaka, Ssembabule and Rakai[6], and it includes the district capitals as well as the more remote rural areas (see map on page vii). At this level, I interviewed health care providers; NGO workers; local political leaders; numerous 'ordinary' people with no direct professional relationship to the issue at hand; and field workers employed by medical research organisations. My travel around the local area was greatly facilitated by my driver Ssalongo Mugerwa, who – due to the limitations in my understanding of the vernacular, Luganda – also acted as an invaluable linguistic and cultural interpreter.

I have subsequently made several further working visits to Uganda, all of which focused in one way or another on social aspects of antiretroviral therapy. In addition to conducting the work, the trips provided me with the opportunity to substantiate and check various issues with some of the same people whom I had previously interviewed during my own field work. Thus between 2004 and 2007, a continuum of visits to Uganda has allowed me to follow the development of policies and events first hand.

Altogether I formally interviewed 114 people for this study, some of them more than once. All could be described as 'knowledge-rich' within at least one of the particular areas I was investigating. Of my respondents, 30 worked at the international level, 31 at national level, and 53 were Masaka-based. It is important to note, however, that some people straddle different levels and I have categorised each individual here into just one. I also made extensive notes from innumerable informal meetings and conversations held at each of the three levels. Depending on the setting, respondents were selected on a convenience basis – either I already knew them or was given an introduction – with subsequent snowball sampling where appropriate. One of the reasons for there being more interviews in Masaka than at national or international

[6] The former Masaka district has, over the years, been subdivided into these three districts, so they can be seen collectively as the greater Masaka region. This covers an area of 9,400 square kilometres, and had a population in 2002 of slightly over 1.4 million people. Over 80% of these people live in rural areas (Uganda Bureau of Statistics, 2002 – 'Projected Midyear population by region and district based on census 2002').

levels, for example, was the relative ease of snowballing within that smaller community.

My overall objective during interviews – which ranged in length from 20 minutes to an entire evening – was to collect a maximum variation of perspectives on the evolution and mechanics of AIDS control in Uganda (Hardon et al., 1994:266). Interviews were mostly conducted face-to-face, but some had to be done over the telephone for logistical reasons; and I always had a set of specific questions written out for each respondent. I did, however, allow myself to use and adapt these questions quite freely according to the turn a particular interview was taking, making these, in the truest sense, semi-structured interviews. Most of my respondents, from all three levels, were apparently candid and uninhibited; and although I did encounter some challenging respondents, there was not a single case of outright refusal to take part.

Depending on the type of respondent and the context, I would either request that the interview be recorded (some international level respondents explicitly did not want to be recorded), or I would take notes and write these up within hours, maintaining as far as possible the respondent's precise turn of phrase. Minor editing has been necessary in places in order to make the text more readable – for example, removing unnecessary repetition, as well as '*ums*' and '*ers*' – although I have sought at all times to remain faithful to what I understood to be the original meaning.

The issue of protecting respondents' anonymity – or not – has proven to be somewhat complex in the writing of this book. From a multi-level perspective, it is striking how the desire for anonymity increases with the respondent's level. I faced several interview situations with senior government or UN officials who said they would have to receive special authorisation or were otherwise very reluctant to go 'on the record' with me. At the lower, more local levels, however, the need for anonymity becomes less relevant. Indeed, van der Geest (2003) describes how several of the old people he interviewed for a study on old age in rural Ghana were actively disappointed when their names did not appear in the book that he wrote about them. It is possible, therefore, that some of my own respondents might also regret that their names are not given next to the words that they spoke. However, given the sensitive political nature of some of the interviews, as well as the positions of some of my respondents, it seemed fair to stick to a standard and simple rule of

thumb that applies across the board: If I have been unable to verify with someone that what I have written accurately represents what they told me, I have not named them. Further, I have not named anyone whose permission I did not have to do so[7]. This rule does not apply to people named and quoted in other documentation, or who are quoted as speaking in a public forum, since whatever they said is therefore already in the public domain. Furthermore, I have given relevant professional details of a number of respondents, though not enough to make identification possible.

A final note is due here concerning my writing style for this book. Given that a number of different disciplines and areas of expertise are involved – from the recent history of Uganda to the epidemiology of AIDS to the politics of international health and research – it is likely that some readers may be familiar with certain of these areas but not with others. In order to make the material accessible to as wide an audience as possible, I have therefore held in mind during the writing process a person whom I would identify as an 'Intelligent Ignoramus'. My model reader knows little of a given subject, but is bright enough nonetheless to pick up the thread quickly to the point where she can offer valuable insights and critiques into the work. I saw my own task during the writing as providing as clear a presentation of the material and its analysis as possible, both by avoiding "*unintelligible 'thick description' and esoteric jargon*" (van der Geest and Hardon, 2006) and by providing footnotes to explain any technical terms that may not be widely understood. Through this I have sought to make the reader's task as straightforward as possible.

The anthropologist as both actor and observer: conflicting roles?

My own relationship with Uganda had broadly positive methodological implications for field work in the country. In other words, the fact that I had once been an AIDS research 'actor' in the country facilitated my becoming an AIDS control 'observer'. I still had a reasonable social and professional network from my 'acting' days when I returned for field work in 2004, and I was also fortunate to have a couple of well placed contacts in Kampala who provided me with the details of

[7] I have made one exception to this rule, a respondent whom I tried to contact many times over a period of several months in an attempt to secure permission to quote him: by email, phone, and letter (both mailed and hand-delivered to his front door). Since I am sure he must have received my message at some stage, I decided to take his non-response as a tacit agreement to be quoted.

potential interviewees, as well as permission to use their names as references. This helped enormously to facilitate meetings, since people in central Ministry, research and NGO positions are constantly beset by academics, NGO officials and journalists from abroad who want to come and interview them about various aspects of the Ugandan AIDS 'success story'. Many are consequently wary of yet another intrusion into their working space, and the introductions I received as well as my former work with a reputable research organisation greatly assisted in the opening of doors.

With respect to the writing itself, however, my own presence in the text is perhaps somewhat more complicated. On the one hand, it seems unreasonable to maintain that the presence of an anthropologist in his own writing is inherently problematic. I do not hold to the view that one's presence necessarily "*[gets] in the way of what we should be reporting about [by] introducing noise*," even if it can, "*at worst, [engage us] in the self-indulgent practice called 'vanity ethnography'*" (Law, 2000:7). Rather, I would argue that qualitative data cannot be disconnected from the person who has collected it, since their background, character and status inevitably shape the process by which it is gathered, internalised and then interpreted (Clifford and Marcus, 1986). Just as epidemiological research papers usually provide precise details of the particular statistical packages employed for analysis, failure by the anthropologist to present any equivalent details of himself could reasonably result in the charge of claiming "*the god-trick of seeing everything from nowhere*" (Haraway, 1991:189). Any such pretense of omniscience would be highly misleading.

That said, my presence in parts of the book – specifically Chapter 6, which focuses on a research project in Masaka to which I devoted five years of my life – is somewhat precarious, since I am not simply an observer and interpreter of events. Rather, I appear in this chapter both in my former role as actor *and* in my subsequent role as observer and interpreter of the events that I once acted in. While I am not the first AIDS social scientist to work in such a way (see, for example, Farmer (2001) and Campbell (2003)), this nonetheless presents a potential methodological pitfall, since my own participation in the events in question well could impede my interpretation of what happened – and especially so since I was so personally disappointed with the outcome of our work. In an attempt to reduce the risk of seriously biased interpretation, I have had to make a conscious effort to stand back while writing, just as the French mathematician and religious philosopher Pascal said he did: "*I cannot judge of my work while doing it. I must do as the artist, stand at a distance; but not too far*"

(quoted in Bourdieu, 1999:8). Bourdieu's thoughts on the '*objectification of the act of objectification*' (Bourdieu, 1992) – i.e. seeking first to analytically observe the processes relevant to the research topic, and then also seeking to scrutinize the analytical stance itself – have been useful in this regard. As with Pascal, I have been assisted by the passage of time, which has provided some of the distance necessary to enable me to judge the work I was involved with, or at least to interpret the processes that accompanied it rather more dispassionately than I could have done at the time.

One of my explicit intentions in undertaking this book was to try to transform the frustration that arose first out of the failure of the Masaka study to demonstrate any effect, and then out of the widespread apathy which met this lack of effect. Part of the means by which I attempted to turn these feelings into something more positive was to seek to develop an understanding of what was driving the decision makers to move in the ways that they did. In other words, by becoming an 'observer' I hoped to resolve some of the complex issues that had arisen while I had been an 'actor'. Only by doing this could I move on professionally. As well as investigating the issues at hand, therefore, this book in a certain respect also describes my own journey.

Outline of the book

The book includes seven chapters, with the first two offering background and theoretical context. The present chapter has given the introduction to the research topic, the research questions, discussion of methodological issues, and brief reflections on the anthropologist as both actor and observer. Chapter 2 provides details of the three major theoretical concepts and themes that will appear throughout the course of the book. These include (i) the multi-level perspective; (ii) the construction, nature and use of evidence; and (iii) the links between research, policy and practice. Collectively this will help place the empirical chapters of the book into a wider context.

As explained above, I examine the research-policy relationship both from the perspective of policy (to assess the role of research in clear policy shifts), and from the perspective of research (to assess the policy impact of a specific research project). As such, Chapters 3, 4 and 5 of this book take up the perspective of policy, by

presenting the evolution of three particular AIDS control policies in Uganda. Chapter 3 discusses the early epidemic in the Masaka area, up until 1986, when it was recognised that a national policy response to the burgeoning epidemic was actually necessary. Chapter 4 is concerned with the evolution of behavioural HIV prevention policy between 1986 and 2004; and Chapter 5 presents a history of treatment policy for people with AIDS in Uganda from the late 1980s up until 2005, with a particular focus on antiretroviral therapy. The way evidence was used to support policy shifts is a primary focus here, though political and other influences are also examined.

Chapter 6, by contrast, looks at matters from the opposite perspective – i.e. that of research – by examining the life story of an HIV prevention study conducted in Masaka with which I was personally involved. The study is placed into its broad scientific and political context, its results are explained, and reaction to the findings from people in various different settings is then examined.

Chapter 7 concludes the book, with an analysis of the various threads presented in the empirical chapters. Taking the multi-level perspective as a basis for discussion, I focus first on the complex relationship that has been observed between AIDS research and AIDS policy making in Uganda. I then conclude with an analysis of the major factors that have guided AIDS control policy and practice in the country over the course of the epidemic.