COSTING THE HIV/AIDS EPIDEMIC

**THINKING ABOUT SCOPE, RESPONSES AND LONG TERM
IMPLICATIONS**

A REPORT PREPARED FOR THE NATIONAL AUDIT OFFICE

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INTRODUCTION

This report was prepared at the request of the National Audit Office. It has seven sections.

Section 1: HIV/AIDS: Basic Information provides a background to the disease and explains why it is of particular concern. It emphasises that the long-term nature of the infection determines the extremely long wave amplitude of the epidemic and its effects**.**

Section 2: An Epidemiological Review of the HIV/AIDS Epidemic describes the distribution of the infection through space and time and argues for the importance of responding in a way which recognises and takes account of these differences.

Section 3: The Origins of the Epidemic briefly reviews the debates about the origins of the disease and the approaches which have been used to discuss and analyse its social and economic impacts.

 Section 4: Key and Emerging Issues looks in some detail at the main issues with which governments, donors and agencies might be expected to have concerned themselves in the past and in the future.

Section 5: Issues and Problems Faced by those affected and infected by HIV/AIDS provides some insight into the personal and community problems which result from the epidemic.

Section 6: A Suggested Methodology for Evaluation offers some suggestions as to how investments in HIV/AIDS work by governments and agencies might be evaluated and warns about the limitations of value for money/cost effectiveness methods in this context.

Section 7: Sources and bibliography: provides a list of electronic sources - mainly about the social and economic aspects of the epidemic in relation to poor countries - and a bibliography for this report.

SECTION 1: HIV/AIDS: BASIC INFORMATION

EARLY APPEARANCE OF THE DISEASE

In 1979 and 1980 clinicians and epidemiologists in the United States observed clusters of some previously extremely rare diseases. These included a type of pneumonia carried by birds (*pneumocystis carinii*) and a cancer called *Kaposi's sarcoma,* until that time usually found in elderly men of Mediterranean or Jewish extraction. The unusual concentration of these conditions was first reported in the Morbidity and Mortality Weekly Report (MMWR) of June 5th 1981, published by the United States' Centers for Disease Control in Atlanta. The MMWR recorded five cases of *pneumocystis carinii*. A month later it reported a clustering of cases of *Kaposi's sarcoma* in New York. Subsequently, the number of cases of both diseases – which were mainly centred around New York and San Francisco - rose rapidly, and scientists realised that they were dealing with something new.

The first cases were among homosexual men. As a result the disease was called Gay-Related Immune Deficiency Syndrome (GRID). American epidemiologists began to see cases among other groups, initially mainly haemophiliacs and recipients of blood transfusions. Subsequently the syndrome was identified among injecting drug users, and infants born to mothers who used drugs. It was apparent that this was not a 'gay' disease. It was renamed 'Acquired Immunodeficiency Syndrome', shortened to the acronym AIDS. The 'A' stands for Acquired. This means that the virus is not spread through casual or inadvertent contact like flu or chicken-pox. In order to be infected, a person has do something (or have something done to them) which exposes them to the virus. 'I' and 'D' stand for Immunodeficiency. The virus attacks a person's immune system and makes it less capable of fighting infections. Thus, the immune system becomes deficient. 'S' is for Syndrome. It is important to note that AIDS is not one disease. It is a syndrome – failure of the immune system presents itself clinically as a number of diseases that come about as the immune system fails.

The illness was seen simultaneously in a number of locations outside the USA. In 1982, reports of a significant wave of deaths in the south of the country began to reach the Ugandan Ministry of Health. In 1983 the ministry sent a team to investigate this new disease in villages along the shores of Lake Victoria in Rakai District. The team concluded that what they were observing, as judged by its clinical presentation, was AIDS. Soon, similar clinical recognition was being reported from other countries in east and central Africa as well as from Haiti in the Caribbean. By late 1983 a team of American and European doctors travelled to Kigali in Rwanda and to Kinshasa in Zaire (now Democratic Republic of Congo) where they identified and described cases of AIDS on the basis of clinical observation.

People with AIDS cases were rapidly identified in all western countries and in Australia, New Zealand as well as some Latin American countries, most notably Brazil and Mexico. From 1981 there was global recognition of the syndrome; clinicians and others now knew what to look for and that it could be given a name.

However, at this time there was still no test for the disease, diagnosis was on the basis of clinical signs and symptoms alone. These included: generalised swollen lymph glands, abrupt weight loss, chronic and continuous diarrhoea, skin lesions associated with *Kaposis sarcoma*, *pneumocystis carinii* pneumonia and several others.   Not only was there no identifying test, the causal agent remained unknown.

THE SEARCH FOR THE CAUSE

Once the new syndrome had been identified, the pace of scientific and epidemiological activity to identify the cause of the disease increased.

In 1983 a team lead by French scientist, Luc Montagnier identified the virus we now know as HIV-1 (the Human Immunodeficiency Virus)[2]. In 1985, a second human immunodeficiency virus, HIV-2 was identified. This is more difficult to transmit and is slower acting and less pathogenic than HIV-1. Initially HIV-2 was found in West Africa with the greatest number of infections outside this area in Angola, Mozambique, France and Portugal. However, this version of the HIV seems to spread less easily and is apparently being displaced by HIV-1 in areas of West Africa.

THE NATURE OF THE HUMAN IMMUNODEFICIENCY VIRUS (HIV)

Viruses are genetic material covered with a coat of protein molecules. They do not have cell walls, are parasitic, and can only replicate by entering host cells. The genetic material of viruses is commonly DNA, or less frequently RNA. Viruses have few genes compared with other organisms. HIV has fewer than 10 genes, smallpox has between 200 and 400 genes. The smallest bacteria have 5,000 to 10,000 genes.   Humans have between 30,000 and 40,000.

HIV belongs in the family of viruses known as retroviruses, scientifically called *Retroviridae*. The first retroviruses were only identified in the 1970s.   All members of this family have the ability to produce latent infections – in everyday language they have a "long incubation period". HIV is in a virus group called the *lentiviruses*.   These develop over a long period, producing diseases, many of which affect the immune system and brain.   The viruses have a unique enzyme, reverse transcriptase which enables them to transcribe their code <u>from</u> RNA <u>to</u> DNA – the reverse of the usual "transcription" process.   Outside the cells they infect, they consist of two strands of RNA. Once they infect a cell they make DNA copies of their own RNA and are able to reproduce. It is this feature as well as the ability of the virus to mutate rapidly which makes development of pharmaceutical responses particularly difficult.

HOW HIV WORKS

For infection to occur, the virus has to enter the body and attach itself to host cells (see Figure 1*)*. HIV attacks a particular set of cells in the human immune system known as CD4 cells. These cells are found in the blood. There are two main types of CD4 cells. The first types are CD4+ T-cells, which organise

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[2] There was a counter claim to precedence in this from the laboratory of Professor Antony Fauci in the USA. In the end it was recognised that the claim was probably based on materials contaminated by samples from the Paris laboratory. The precise settlement of this dispute took place at head of state level.

the body's overall immune response to foreign bodies and infections. These T helper cells are the prime target of HIV. For a person to become infected, virus particles must enter the body and attach themselves to the CD4 cells. HIV also attacks immune system cells called macrophages. These cells engulf foreign invaders and ensure that the body's immune system will recognise them in the future.
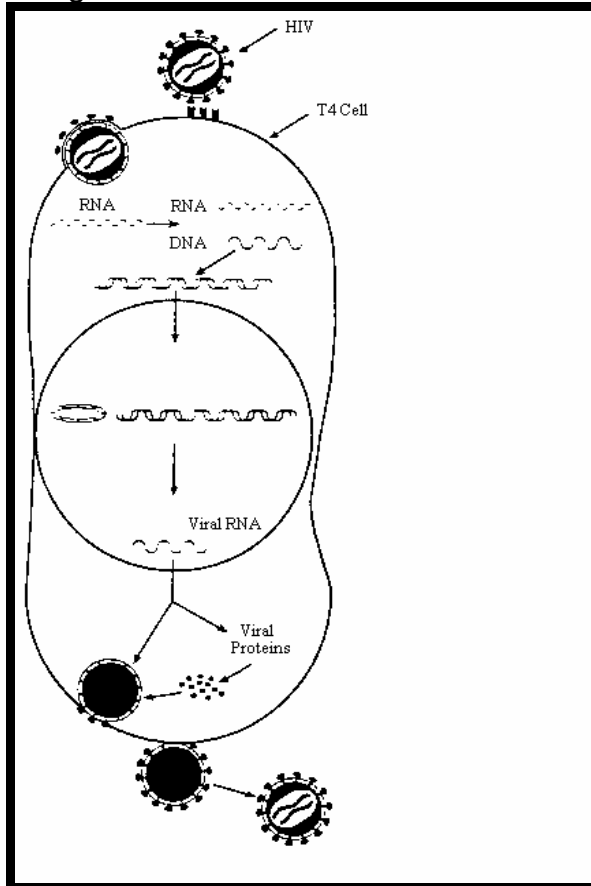

Figure 1: Diagrammatic representation of HIV reproducing itself within a cell of the human immune system
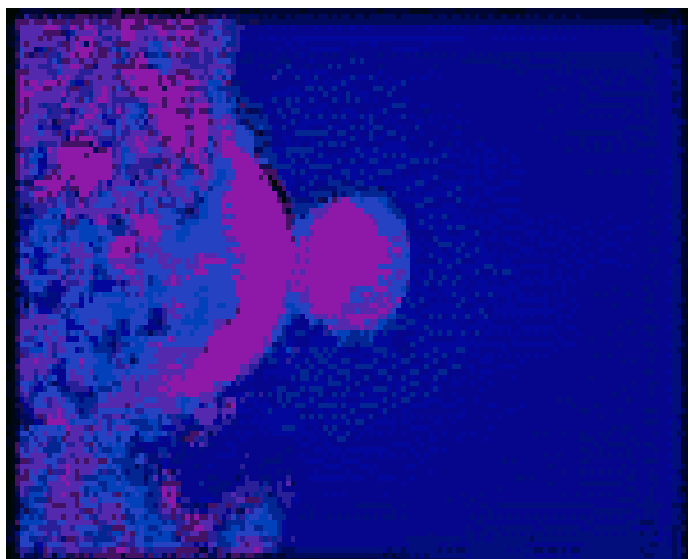
Figure 2: HIV particle attaching to wall of human CD4 cell

Once the virus has penetrated the wall of the CD4 cell (see Figure 2) it is safe from the immune system because it copies the cell's DNA, and therefore cannot be identified and destroyed by the body's defence mechanisms. Virus particles lurk in the cells until their replication is triggered. Once this happens they make new virus particles that bud from the surface of the host cell in vast numbers (see Figure 3), destroying that cell as they do so. These viruses then go on to infect more CD4 cells. During the initial infection process (broadly speaking the first six weeks after infection), viral particles are produced at the rate of many billions per day and although the infected person will only experience a few days of a 'flu like illness, they are very infectious during this time.
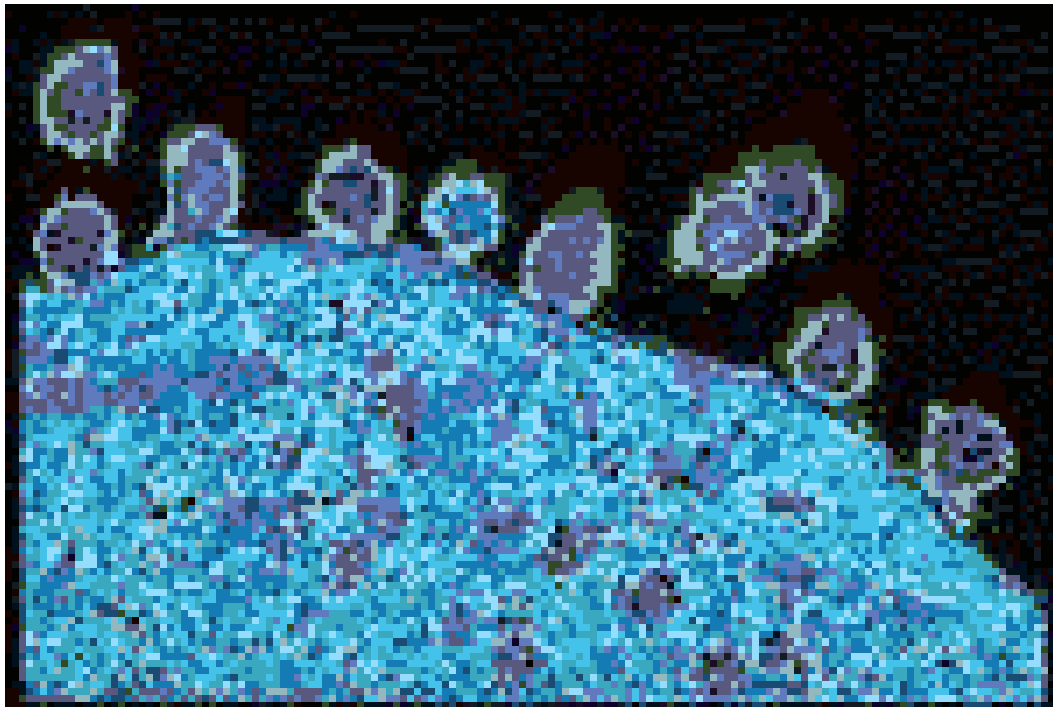
Figure 3: HIV particles budding from an infected CD4 cell

At this time, a person's viral load is high, the immune system is under extreme pressure, and the person's HIV status cannot be detected using standard tests. This is commonly called 'the window period' and lasts several weeks to several months. At this stage a person is highly infectious as their viral load (the number of viral particles they are carrying) is considerable. This fact is of epidemiological importance. The more people there are in the early stage of infection, the greater the chance of effective transmission between people.

The window period is followed by the long incubation stage. During this the viruses and the cells they attack are reproducing rapidly and being destroyed as quickly by each other. Up to five percent of the body's CD4 cells (about 2000 million cells) may be destroyed each day by the billions of virus particles. Eventually, the virus is able to destroy the immune cells more quickly than they can be replaced and slowly the number of CD4 cells falls. In a healthy person there are 1200 CD4 cells per micro-litre of blood. As infection progresses, the number will fall. When the CD4 cell count falls below 200 or 350 depending on differences in medical opinion, opportunistic infections begin to occur and a person is said to have AIDS. Infections will

increase in frequency, severity and duration until the person dies. It is these opportunistic infections that cause the syndrome referred to as AIDS.

AIDS – ILLNESS, DEATH, MUTATION AND ANTI-RETROVIRAL THERAPIES

The period from HIV infection to illness and death is crucial. It was generally believed that, in the rich world, on average people lived for 10 years before they begin to fall ill. Without treatment, the normal period from the onset of AIDS to death was thought to be a further 12 to 24 months. With the development of effective anti-retroviral therapies (ARVs), infected people can

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Box 1: Anti- Retroviral Therapy (ART)

ART suppresses HIV, maintaining the integrity of the immune system and postponing development of opportunistic infections. First introduced in 1986, ART evolved over the next 10 years from mono (single)-drug therapy (AZT or zidovudine) to dual drug regimens (including AZT plus ddI, or AZT and/or ddI with d4T and 3TC) to triple-drug therapy, usually adding a protease inhibitor. Single drug therapy has been shown to have little effect on morbidity and mortality and is no longer used for treatment. Two-drug regimens are only moderately effective in reducing morbidity, add less than one year of disease-free survival and have no real benefit on length of life (Concorde 1994). Effective ART generally requires a minimum of three agents used in combination to show real benefits in disease-free survival times and quality of life. "Highly active" ART (HAART) includes combinations of 3 and as many as 5 drugs, usually from 1-3 different classes of drugs, multiple regimens and combinations, and intensive monitoring of patients for resistance. HAART is an individualized treatment that evolves over time as patients develop resistance or side effects that cannot be tolerated, requiring alternative drug combinations. ART must be taken for life, and requires high physician and patient compliance to be effective. For those who can comply with the therapy, it can greatly enhance the length and quality of life.

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expect to live a reasonable life for a longer time. Indeed, it is hoped that AIDS can be turned into a manageable, chronic disease like diabetes. In this event, people could expect to live longer though they would remain infected.

ARVs act on one of three stages of the viral life cycle: they can interfere in the process whereby the viral particle "docks" onto the cell (Figure 2), where it transcribes its RNA into the cell's DNA or when it "buds" from the cell (Figure 3). Recent evidence suggests that viral resistance to these drugs is growing, approximately 20 per cent of new HIV diagnoses in the United Kingdom are of drug resistant mutations. If, as is feared, this phenomenon is generalised, then the threat from the epidemic is as great in the future as it is in the present and the introduction and use of ARVs in highly epidemic regions of the world may be only a stop gap measure. This is because development and use of anti-retroviral therapies creates new problems.

HIV-1 is not one thing. It is best conceptualised as a range of viral forms around a mean. Thus there are many subtypes of the HIV-1 and these sub-types (or *clades*) can in turn be sub-divided into further sub-types. The viral clades tend to be regionally distributed across the globe.

Because the virus mutates and there are over 120 sites in its structures which can mutate, there are plentiful opportunities for the virus to (a) mutate and (b) recombine different subtypes and clades. This means that with hundreds of millions of virus particles being produced daily within the body of an infected person mutations occur rapidly within and between infected people. This may give rise to a wide range of biological variants even within the same individual. The result is likely to be increased drug resistance, and there is the possibility that if, because ARVs are available, people perceive AIDS as 'just' a chronic manageable condition they may be less inclined to take precautions against infection.

INCUBATION AND PROGRESSION FROM HIV INFECTION TO AIDS

The incubation period in poor countries was thought to be shorter than in rich countries - between six and eight years. This was based on the assumption that people in the poor world had more challenges to their immune systems, poorer nutrition, and less access to health care. It seemed inevitable that they would progress to symptomatic AIDS faster. A recent study found that the time from HIV illness to death is shorter in Uganda for untreated patients than in the rich world, and the spectrum of HIV/AIDS-related disease is different. However the period from infection to illness did not seem to vary. This suggests that tropical diseases and infections such as TB or sexually transmitted infections do not hasten the progression of HIV to AIDS in Uganda.

SIGNIFICANCE OF THE PERIOD FROM INFECTION TO ILLNESS

The issue of how long a person has between infection and illness is crucial for planning for the epidemic's economic and social impact. There is no one easy answer: time from infection to illness and from illness to death appears to be linked to disease environment, availability of health care and other factors. The period from onset of symptoms to death is shorter in poor countries. This has been borne out by a number of studies, which speculate that it is because patients do not receive early and appropriate treatment - an obvious issue in resource constrained environments.

The differences between the poor and rich worlds also apply to the rich and the poor world-wide, and come down to the following: people who are able to eat enough nutritious food, lead stress-free lives, and are not exposed to multiple infections will stay healthy and live longer. This is true generally and does not apply just to those who are HIV infected.

DETECTING HIV AND DESCRIBING AIDS

HIV was hard to locate because it is a retrovirus, hiding itself in the body's immune system. The first tests detected the *antibodies* to the virus rather than the virus itself. Antibodies show that a person has been (and in the case of HIV, is) infected. Even today, most screening and diagnostic tests are based on discovery of antibodies rather than of the virus. These tests have a high degree of *sensitivity* (which means that they do not miss positive results – if the person is infected then they will show this) and *specificity* (which

Table 1: Probability of HIV-1 Infection per Exposure and the importance of STIs as a factor in increased transmission risk

Mode of transmission	Infections per 1000 exposures
Female-to-male, unprotected vaginal sex	0.33-1
Male-to-female, unprotected vaginal sex	1-2
Male-to-male, unprotected anal sex	5-30
Needle stick	3
Mother-to-child transmission	130-480
Exposure to contaminated blood products	900-1000

Source: World Bank, Confronting AIDS, 1997, 59

The presence of sexually transmitted infections (STIs), particularly those involving ulcers or discharges will greatly increase the odds of HIV infection. An STI means that there is more chance of broken skin or membranes allowing the virus to enter the body. Furthermore, the very same cells that the virus is seeking to infect will be concentrated at the site of the STI because these cells are fighting the infection.

means that they do not miss negative results – if the person is not infected the test will not suggest that they are). The most advanced tests have reduced the window period to about three weeks. People are said to be HIV positive when the HIV anti-bodies are detected in their blood.

It is more difficult to define AIDS. In areas where CD4 counts and viral loads can be measured, people are regarded as having AIDS when their CD4 count falls below 200. In most resource - poor settings however the capacity to carry out such sophisticated tests does not exist. In such places AIDS is defined clinically by examining the patient and making an assessment of their condition. A number of opportunistic infections, some of which are common in HIV infected people, take particular advantage of a depleted immune system. TB is one of these. Complicating matters further, ARV therapies make it possible for people to move from a state of AIDS, when they are very sick, to one of being HIV positive and leading a fairly normal life.

MODES OF INFECTION

HIV is not a robust virus and it is hard to transmit. Unlike many diseases it can only be transmitted through body fluids. For a person to be infected, the virus has to enter the body in sufficient quantities. It must pass through an entry point in the skin and/or mucous membranes into the blood stream. The main modes of transmission are:

- unsafe sex;
- transmission from infected mother to child;
- intravenous drug use with contaminated needles;
- use of infected blood or blood products; and
- other modes of transmission involving blood, for example bleeding wounds.

The relative effectiveness of some different modes of transmission is shown in Table 1.

Globally, most of the infections that form the epidemic are the result of

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sexual transmission, in most cases heterosexual transmission.

SUMMARY
This is a serious disease, which has a long incubation period. This means that one infected person can unknowingly infect many others. The rate at which infection multiplies depends on social, cultural and economic factors. There is evidence that inequality and political instability contribute to more rapid transmission. The key points to note are:

- the microscopic characteristics of the organism, its life cycle and mode of transmission mean the resulting epidemic has a very long wave characteristic.
- the organism mutates easily and it is proving hard to develop a vaccine. The available treatments are expensive and require considerable clinical and laboratory support, their misuse could lead to development of viral resistance.

THE GLOBAL DISTRIBUTION OF HIV/AIDS AT THE END OF 2002
In this section, we review the global distribution of infections and begin to describe the implications of this distribution.

Regional HIV/AIDS statistics and features, end of 2002

	Epidemic started	Adults & children living with HIV/AIDS	Adults & children newly infected with HIV	Adult prevalence rate *	% of HIV-positive adults who are women	Main mode(s) of transmission for those living with HIV/AIDS **
Sub-Saharan Africa	late '70s early '80s	*29.4 million*	3.5 million	*8.8%*	58%	Hetero
North Africa & Middle East	late '80s	550 000	83 000	0.3%	55%	Hetero, IDU
South and South-East Asia	late '80s	6.0 million	700 000	0.6%	36%	Hetero, IDU
East Asia & Pacific	late '80s	1.2 million	270 000	0.1%	24%	IDU, Hetero, MSM
Latin America	late '70s early '80s	1.5 million	150 000	0.6%	30%	MSM, IDU, Hetero
Caribbean	late '70s early '80s	440 000	60 000	2.4%	50%	Hetero, MSM
Eastern Europe & Central Asia	early '90s	1.2 million	250 000	0.6%	27%	IDU
Western Europe	late '70s early '80s	570 000	30 000	0.3%	25%	MSM, IDU
North America	late '70s early '80s	980 000	45 000	0.6%	20%	MSM, IDU, Hetero
Australia & New Zealand	late '70s early '80s	15 000	500	0.1%	7%	MSM
TOTAL		42 million	5 million	1.2%	50%	

Source: UNAIDS, 2002

Abbreviations and definitions: this table shows the proportion of adults (15 to 49 years of age) living with HIV/AIDS in 2002, using 2002 population numbers

*** Hetero: heterosexual transmission – IDU: transmission through injecting drug use – MSM: sexual transmission among men*

Table 2: Global Distribution of HIV/AIDS at the end of 2002

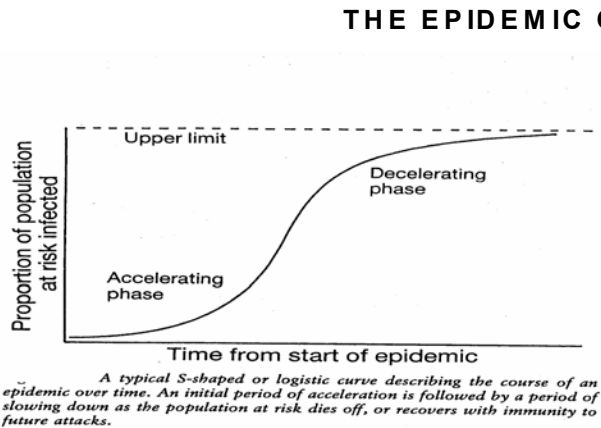SUB-SAHARAN AFRICA AND THE LONG WAVE OF THE EPIDEMIC
Table 2 shows clearly that the worst affected world region is sub-Saharan Africa.

Sub-Saharan Africa is home to 29.4 million people living with HIV/AIDS. Approximately 3.5 million new infections occurred there in 2002, while it is estimated that the epidemic has claimed the lives of an estimated 2.4 million Africans in the past year. Ten million young people (aged 15–24) and almost 3 million children under 15 are living with HIV.

A tiny fraction of the millions of Africans in need of ARV treatment are receiving it. Many millions are not receiving medicines to treat even opportunistic infections.

But this is not the end of the story. While the earliest affected countries such as Uganda are probably now at the peak of their epidemic, others – particularly in parts of West Africa – are still in a relatively early stage. The development of an epidemic must be seen in relation to the standard epidemic curve which describes the development of any infectious

disease epidemic in a living population. This typical S or logistic curve is shown in Figure 4. The critical point to note is that in the case HIV/AIDS, because of the particular features of this *lentivirus* the length of time over which the epidemic develops is certainly around 30 to 40 years and, with after shocks resulting from viral mutation, recombination and re-infections, may be as long as 120 years.

THE EPIDEMIC CURVE

A typical S-shaped or logistic curve describing the course of an epidemic over time. An initial period of acceleration is followed by a period of slowing down as the population at risk dies off, or recovers with immunity to future attacks.

Figure 4: A typical epidemic curve

Thus, even in Africa, a fully-fledged epidemic is only now taking hold in many countries.   The nature of this development and its potential end points can be seen from

Figure 5. It is assumed that the epidemic probably began in Africa in the mid- to late 1970s. Figure 65 shows just how rapidly the epidemic develops in a number of Southern African countries and the peaks of infection that can be reached in a period of twenty years. In fact, the data in that figure have now been exceeded in Swaziland where the most recent seroprevalence report (November 2002) shows adult prevalence a shade under 40 per cent. ***This progression is important to remember in relation to other world regions where, as we shall see, current   infection rates are "only" around 1***
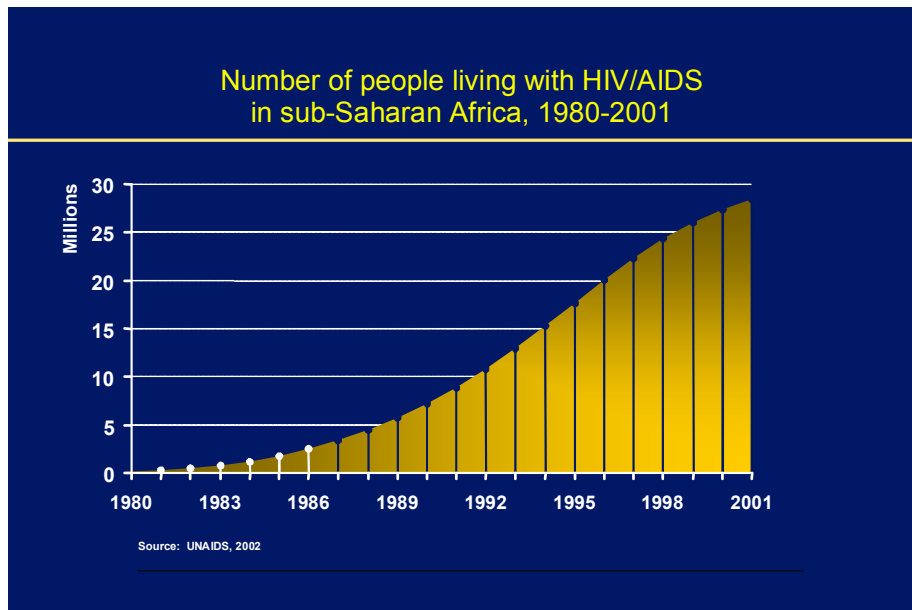
National trends in HIV prevalence
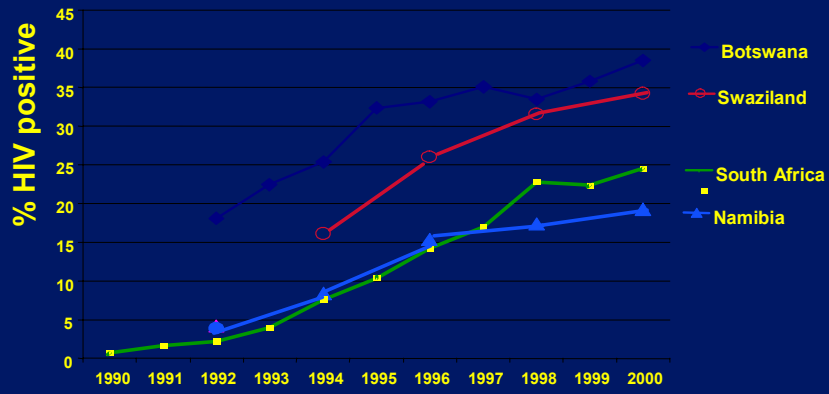
Source: UNAIDS, 2002

per cent of the adult population.

Figure 5: Numbers of people living with HIV/AIDS in sub-Saharan Africa 1980-2001

Number of people living with HIV/AIDS
in sub-Saharan Africa, 1980-2001

Source: UNAIDS, 2002

Figure 6: Southern Africa: national trends in HIV prevalence

THE IMPLICATIONS OF THESE PROGRESSIONS

In the absence of massively expanded prevention, treatment and care efforts, the AIDS death toll on the African continent is expected to continue rising before peaking around the end of this decade. This means that the worst of the epidemic's impact on those societies will be felt in the course of the next decade and beyond. The relation between infection (HIV prevalence), illness and death (AIDS) and the social and economic impact of these events is illustrated in Figure 7. In order to engage with the implications of an epidemic of this magnitude, we must believe and act on the belief that it is not too late to introduce and augment measures that can:

- reduce the impact

- facilitate wider access to HIV medicines

- encourage socioeconomic policy steps that genuinely shield the poor against the worst of the epidemic's effects.
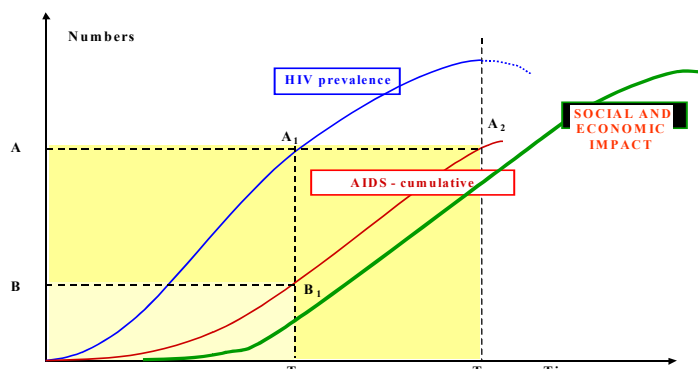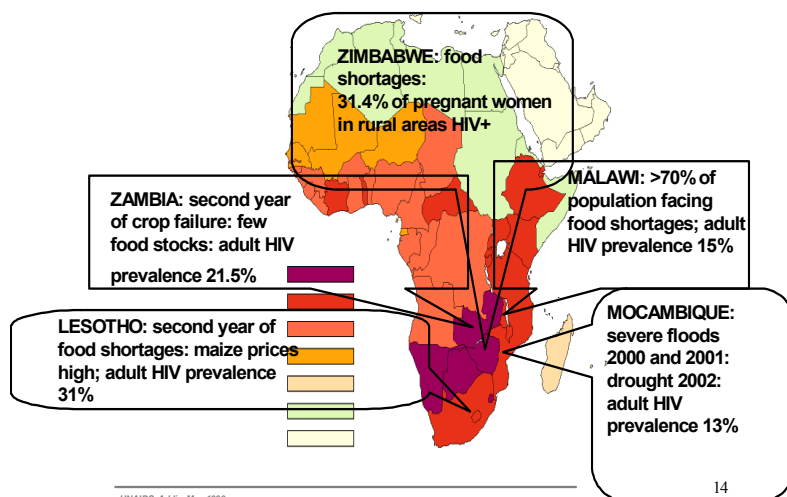
Figure 7: HIV Prevalence, AIDS and Impact - three waves

The worst of the epidemic clearly has not yet passed, even in southern Africa where uncontrolled epidemics are under way. In a number of southern African countries, national adult HIV prevalence has risen higher than was once thought possible, approaching 40 per cent[3] (Figure 6). Although it is difficult to show this, it seems very likely that the current food crises in some southern African countries are linked to the toll of their longstanding HIV/AIDS epidemic, especially on the lives of young, productive adults (see Figure 8).

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[3] Current seroprevalence rates in Botswana, Swaziland and Lesotho have reached 40 per cent.

Figure 8: Southern Africa: Food Crises and HIV prevalence

ARE THERE SIGNS OF HOPE?

UNAIDS argues that despite the awful statistics, there are "new, hopeful signs that the epidemic could eventually be brought under control." It is argued that positive trends seem to be taking hold among younger people in a number of African countries. They cite the following evidence:

- In South Africa, for pregnant women under 20, HIV prevalence rates fell to 15.4% in 2001 (down from 21% in 1998). This, along with the drop in syphilis rates among pregnant women attending antenatal clinics down to 2.8% in 2001, from 11.2% four years earlier) suggests that awareness campaigns and prevention programmes are bearing fruit. A major challenge now is to sustain and build on such tentative success, not least because HIV infection levels continue to rise among older pregnant women.

- A decline in HIV prevalence has also been detected among young inner-city women in Addis Ababa in Ethiopia. Infection levels among women aged 15–24 attending antenatal clinics dropped from 24.2% in 1995 to 15.1% in 2001 (however, similar trends were not evident in outlying areas of the city, nor is there evidence of them occurring elsewhere in the country).

- Uganda continues to present "proof" that the epidemic does yield to human intervention. Recent HIV infections appear to be on the decline in several parts of the country—as shown by the steady drop in HIV prevalence among 15–19-year-old pregnant women. Trends in behavioural indicators are in line with this apparent decline in HIV incidence. Condom use by single women aged 15–24 almost doubled between 1995 and 2000/2001and more women in that age group delayed sexual intercourse or abstained entirely.

Thus, UNAIDS suggests that the evidence from Ethiopia and South Africa shows that prevention work is beginning to pay off for young women, with HIV prevalence rates dropping among pregnant teenagers. This perspective argues that prevention campaigns combined with the people's personal experience of HIV/AIDS related illness and death **do** change behaviour. Unpublished work on data from East Africa suggests that behaviour change occurred in Uganda as a result of broader social and economic processes, most notably the existence of relative social and political stability giving people hope for the future, signs that government was doing something for citizens and dense social networks which facilitated effective transfer and understanding of prevention messages[4].

WHAT WORKS AND WHY?

This is not a straightforward question and it does not have a straightforward answer. It is dealt with from another perspective later in this report.

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[4] By Daniel Low-Beer and Rand Stoneburner

It is obvious that safer sexual practices can protect from HIV and the early successes in the gay male community in the US and Western Europe demonstrated this. However, there are many theories about what is needed to promote sexual behaviour change, and numerous models exist attempting to explain the phenomenon.

Models can be based in theories of psychology, sociology, or other disciplines and UNAIDS (UNAIDS 1999) has published a detailed report reviewing theories and models of behaviour change in regards to sexual behaviour for HIV prevention. There are three broad sets of theories[5]: There are those:

- Focusing on individuals, the most common of these, the *health belief model*, holds that health behaviour is a function of people's socio-demographic characteristics, knowledge, and attitudes.
- Focusing on social factors, such as the theory of *diffusion of innovation theory*, which consider the ways ideas are disseminated through a community.
- Focusing on social and economic structure and environment, which "see human behaviour as a function not only of the individual or his or her immediate social relationships, but as depending on the community, organization and the political and economic environment as well" (UNAIDS, 1999: 11).

From this review, it is possible to conclude that:

- In almost every case, some success was found – which begs the question of which theory is correct, or if they all are, how descriptive and useful can they actually be to inform policy?
- Different people will change behaviour for different reasons. A diverse population will require a diverse number of messages and approaches reaching individuals on the ground. While individually oriented messages may influence some, others may be more influenced by social norms or environmental constraints.
- No one message will cause everyone to change behaviour. The presence of multiple messages from a wide number of orientations (designed for specific communities) will have the greatest chance of exposing any one individual to the one message (or combination of messages) that will produce the desired health promoting changes in behaviour.

- This need for diversity is often ignored when HIV/AIDS prevention activities are designed or recommended at national and international levels.

However, with these reservations as to the theoretical problems of behaviour change, and while there is some evidence which gives cause for optimism, the few positive trends do not yet offset the severity of the epidemic in the countries of sub-Saharan Africa. Now and into the medium term of five to ten years, and in the absence of an effective vaccine[6] of greatly reduced prices for ARVs and also much reduced clinical care and support requirements for their

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[2] The general theoretical approaches are also discussed in Barnett and Whiteside, 2002, Chapter 3.
[6] The results of recent vaccine trials do not give much cause for optimism.

administration, all the countries of the region face massive challenges. These concern not only sustaining and expanding prevention successes, but providing adequate treatment, care and support to the millions of people living with HIV/AIDS or orphaned by the epidemic.

In West and Central Africa, the relatively low adult HIV prevalence rates in countries such as Senegal (under 1%) and Mali (1.7%) are shadowed by more ominous patterns of growth in other countries. It should be recalled that this is a contiguous land mass with continuing, lively and active movements of population across national boundaries.

HIV prevalence is estimated to exceed 5% in eight other countries of west and central Africa, including Cameroon (11.8%), Central African Republic (12.9%), Côte d'Ivoire (9.7%) and Nigeria (5.8%). The sharp rise in HIV prevalence among pregnant women in Cameroon (more than doubling to over 11% among those aged 20–24 between 1998 and 2000), shows how suddenly the epidemic can surge.

TREATMENT PROSPECTS AND PROBLEMS IN AFRICA

Treating and caring for the millions of Africans living with HIV/AIDS poses an inescapable challenge to the continent and the world at large. Relatively prosperous Botswana has become the first African country to adopt a policy to ultimately make antiretrovirals available to all citizens who need them. However, comparatively few people (approximately 2000) are currently benefiting from this commitment. In addition, a handful of companies (such as AngloGold, De Beers, Debswana and Heineken) have announced schemes to provide antiretrovirals to workers and some family members on various cost sharing arrangements. These are important efforts; but they pale into insignificance when measured against the need. To place the question of need in some kind of context, consider the following. In Swaziland, with a population of about one million people, around 390,000 people are HIV+. If we assume that of these one fifth (78,000 people) require ARV treatment now and that the cost of drugs alone per person is about £220, then without clinical supervision and testing, the cost of treatment will be £17,160,000 in the first year. Given rates of transition from HIV+ to illness, then by year five the annual bill will have risen to £85,800,000 per year! And this is a continuing commitment each year every year for the rest of these people's lives. Neither can we assume that further infections will cease. The GDP per capita of Swaziland in 1999 was around £850

LATIN AMERICA AND THE CARIBBEAN

The epidemics in Latin America and the Caribbean are well established. UNAIDS estimates that 1.9 million adults and children are living with HIV in this region—a figure that includes the estimated 210,000 people who acquired the virus in 2002.

Twelve countries (including the Dominican Republic and Haiti, several Central American countries, such as Belize and Honduras, and Guyana and Suriname) have an estimated HIV prevalence of 1% or more among pregnant women. These figures collected from antenatal clinic attendees are usually taken to be a reasonable approximation to the overall adult prevalence. There are marked variations between the countries of the region. Thus, in several Caribbean countries, adult HIV prevalence rates are surpassed only by the rates experienced in sub- Saharan Africa—making this the

second-most affected region in the world. HIV/AIDS is now a leading cause of death in some of these countries. Haiti remains worst affected (with an estimated national adult HIV prevalence of over 6%) along with the Bahamas (where prevalence is 3.5%).

It is important to note that seroprevalence data are sensitive to the quality of the local surveillance system. Thus it is quite possible that localized epidemics in other parts of the region might be escaping detection. Sentinel surveillance data from 1991 to 2001 suggest that HIV prevalence among pregnant women has stabilized or perhaps begun to decline in the Dominican Republic (where estimated adult HIV prevalence was 2.5% in 2001). These findings appear to correlate with evidence of increased condom use among female sex workers and a reduction in the number of sexual partners among men.

The ratio of male to female infections is an indicator of the position that a particular society, sub group or country occupies on the epidemic curve. In the earlier part of an epidemic, the ratio is more men than women; in the geometric and mature stages, the ratio reverses. In this region, over the past decade, the ratio of men with HIV infections to women with HIV infections has narrowed considerably—to about 3-to-1 in Latin America and 2-to-1 in the Caribbean. Paradoxically and because there is apparently a marked tradition of bisexuality in some of these countries, men who have sex with men appear to feature prominently in the increasing feminization of the epidemic. Recent research has shown that a large proportion of men who have sex with men also have sex with women. While HIV/AIDS programmes focusing on men who have sex with men are vital, sexual identities are more fluid than often assumed. This suggests that prevention efforts need to be tailored to apparently widespread—but hidden—bisexual behaviour in this region. This is also true of many parts of Asia. There is evidence that unsafe sex among men who have sex with men may be common in this region.

The spread of HIV through the sharing of injecting drug equipment is of growing concern in several countries, notably Argentina, Brazil, Chile, Paraguay and Uruguay (in South America), the northern parts of Mexico, and Bermuda and Puerto Rico (in the Caribbean). Injecting drug use accounts for an estimated 40% of reported new infections in Argentina and 28% in Uruguay; in both countries, an increasing number of women with HIV are either injecting drug users or sexual partners of male drug users.

As with Argentina, Brazil has adopted a less punitive approach to dealing with the dual challenge of injecting drug use and HIV infection—to good effect. Prevention programmes among injecting drug users have contributed to a substantial decline in HIV prevalence in this population in several large metropolitan areas. In addition, a national survey showed increasing condom use among injecting drug users (from 42% in 1999 to 65% in 2000)—a sign that sustained education and prevention efforts are bearing fruit.

Despite many constraints, the region has made progress in provision of treatment and care, with Brazil continuing to show the way. Though now guaranteed in many countries, access to antiretroviral treatment is still unequal across this region, due largely to drug price discrepancies.
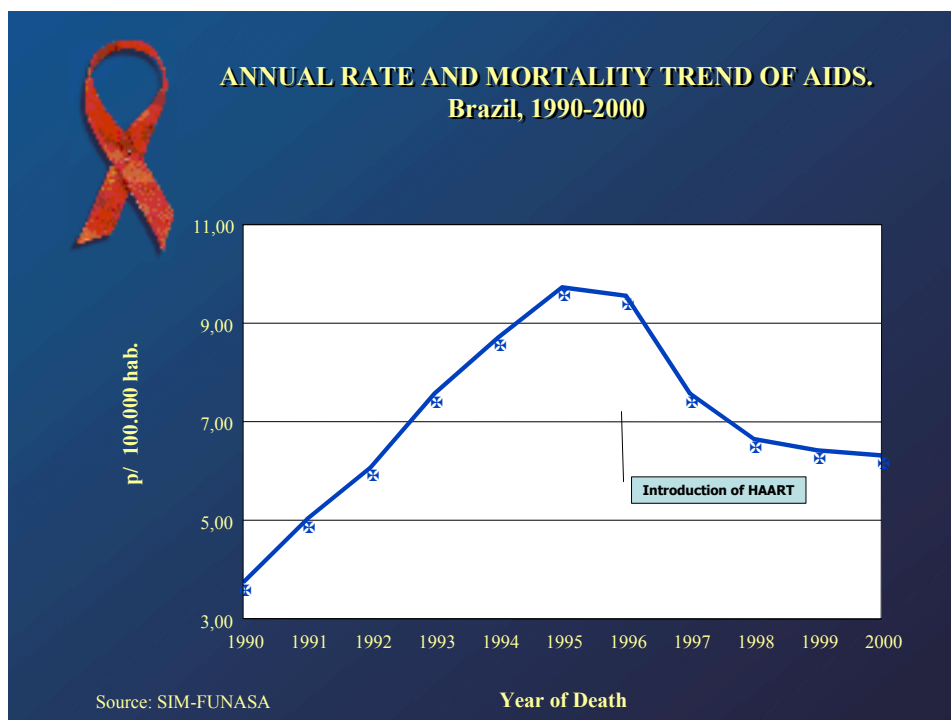
ARV EXPERIENCE IN LATIN AMERICA

Brazil is the first poor country to have implemented a large-scale universal ARV distribution program. About 125,000 patients receive antiretrovirals freely through the official Public Health System. This accounted for more than a third of the estimated total number of people receiving ARV treatment in the entire developing world at the end of 2002.   This programme began in 1991 with distribution of zidovudine (ZDV) capsules. It was given additional impetus by a 1996 presidential decree guaranteeing all those in Brazil who were HIV+ free access to essential medication to combat HIV, including protease inhibitors - distribution of which began at the end of that year.

Criteria for dispensing HIV treatments were established by the Ministry of Health. A network of more than 1000 public care and HIV testing services has been established to provide the necessary infrastructure.   Most important in this initiative has been local production of generic forms of fifteen of the most commonly used ARVs. The indigenous pharmaceutical capacity has been encouraged to undertake local production and this seems to have worked well in a number of ways.   It has intervened in the market and reduced the average price paid by the Ministry of Health for both locally produced and imported drugs, although the fall has not been consistent: the price of locally produced drugs fell on average 82% between 1996 and 2001, while that of imported drugs fell by only 40% in the same period.   In addition to these effects, local production has meant that the Brazilian government has been able to negotiate special deals with some major pharmaceutical manufacturers. Thus, the Ministry of Health has negotiated tiered prices with some major pharma companies. For example, deals were made with Abbott, Merck and Roche, cutting the prices of 4 drugs by more than 50%. Although desirable, these recent decreases must be taken only as an initial step towards much greater cuts. Experience suggests, however, that the effectiveness of this strategy rests upon the credibility of a government using the mechanism of compulsory licensing under the current international regime of intellectual property rights. Thus, domestic production capacity is a crucial element that adds bargaining power to government agencies. The French government has funded larger amounts of research through the Agence Nationale pour Recherches sur le Sida to explore the economics of generic production and of price negotiation as well as the use of the (Trade-Related Aspects of Intellectual Property Rights) agreements. While not the origin of the Brazilian initiative, there is no doubt that this work has strengthened understanding of this whole area and has to be seen as a major, if under-reported, research coup by the French research community with active encouragement from the French government. Why this approach has not been pursued more widely might be a question to be explored further, particularly in the light of the reported cost effectiveness of this strategy.

Thus, a study presented at the XIVth International AIDS Conference in 2002 showed that in Brazil survival rates increased substantially with ARV therapy. In this study, the average survival time before availability of combined therapy was less than 6 months and now is close to 5 years. Occurrence of common HIV-related opportunistic infections declined by 60 to 80%. The number of tuberculosis cases, for instance, has dropped by 75% in the last four years, in the State of Sao Paulo, which has roughly fifty per cent of all AIDS cases reported in Brazil. Moreover, a change was observed in the profile of HIV health care services with a significant increase in the demand for outpatient services, home care and day-hospital services.   The authors of this report

concluded that: "It is unambiguous, therefore, that providing treatment to the millions in need is a basic feature of intervening effectively against the global destabilizing power of the AIDS epidemic. Though costly, it is by any comparison a relatively low amount when compared to the potential loss of unstable nations rigged by underdevelopment and poverty."   The effects of this policy are shown clearly in Figure 9. Issues which might counteract this argument have to do with possible development of viral resistance, inaccessibility of latest generations of ARVs, the difficulties of replicating this experience in countries in Africa (although South Africa has at least the same pharmaceutical capacity as Brazil) and the precise methods for assessing the relative costs and benefits of treating and not treating. We shall return to this issue below when we discuss the question of evaluation methodology.

However, at this stage it is worth noting that there has been a "demonstration effect" across the region. Countries such as Argentina, Costa Rica, Cuba and Uruguay now guarantee free and universal access to these drugs through the public sector, while sharp price reductions have recently been secured in Honduras and Panama. In mid-2002, the Pan Caribbean Partnership against HIV/AIDS signed an agreement with six pharmaceutical companies in a bid to improve access to cheaper antiretroviral drugs. However, actual access to these drugs remains unequal across the region as a whole, partly due to widely varying drug prices.

ANNUAL RATE AND MORTALITY TREND OF AIDS.
Brazil, 1990-2000

Introduction of HAART

Source: SIM-FUNASA

Year of Death

Figure 9: Brazil: Annual Mortality Trends among People with AIDS before and after introduction of ARVs

THE MIDDLE EAST AND NORTH AFRICA
It is hard to know the situation in this region, not solely because of absence of resources to monitor the epidemic but also possibly because of particularly high levels of denial.

Available data point to increasing HIV infection rates, with an estimated 83,000 people having acquired the virus in 2002. This brings to 550,000 the estimated number of people living with HIV/AIDS. The epidemic claimed about 37,000 lives in this region in 2002.

Systematic surveillance remains inadequate, making it very difficult to deduce accurate trends. It is possible that hidden epidemics could be spreading in this region given rates of population movement and mixing. Better surveillance systems (such as those introduced in Iran, Jordan, Lebanon and Syria) will enable more countries to track the development of the epidemic and mount effective responses.

Significant outbreaks of HIV infections among injecting drug users have occurred in about half the countries in the region, notably in North Africa and in the Islamic Republic of Iran.

In Iran, most HIV transmission is observed among the country's estimated 200,000–300,000 injecting drug users, about 1% of whom are believed to be living with HIV. High-risk behaviour is widespread in this largely male population: about half of the users share injecting equipment and as many are believed to have extramarital sexual relations. According to some estimates, a significant percentage (more than 30%) of them is married. Yet condom use is very rare. In addition, about 10% of prisoners are believed to inject drugs and more than 95% of them share needles. HIV prevalence among imprisoned drug injectors was 12% in 2001.

Unless countries promptly introduce harm reduction and other prevention services for injecting drug users, the epidemic could grow dramatically

and spread into the wider population. However, in strictly religious societies with rigorous codes of public behaviour and control of discourses, introduction of such measures is especially problematic.

Overall, recognition of the need for more effective and far-reaching prevention efforts has grown in this region. Some countries are beginning to develop effective responses. Examples include the mobilization of non-governmental organisations around prevention programmes in Lebanon, and harm-reduction work among injecting drug users in the Islamic Republic of Iran.

But appropriate surveillance data on HIV infections and behaviours are in short supply, capacities are still limited, and HIV/AIDS responses are still concentrated almost exclusively in the health sector. A tendency to exaggerate the protective effects of social and cultural conservatism also continues to hamper an adequate response.   In the aftermath of any major regional disruption which could be expected following a war in Iraq, it is very unlikely that improvement in this situation could be expected.

HIV/AIDS is now spreading rapidly in many parts of the CIS, East and South Eastern Europe and the Baltic. Rapid economic and social change and uncertainty, labour migration, civil instability and war often fuel the epidemic in this region. Such conditions provide an ideal *risk environment* for the development of epidemics of infectious disease (See Box 2).

Box 2: Risk Environment

In epidemiology, the concept of "risk" is used in a strictly statistical sense. Thus:

> "the degree of increased risk associated with a specific behaviour or other factor is measured as the relative risk or relative odds of infection comparing those with the factor to those without the factor." (Brookmeyer and Gail, 1994, p 23)

This can be expressed mathematically and produces the concept of a "risk group". A "risk group" is defined as all those individuals belonging to the set with the characteristic that is associated with increased relative risk or relative odds. They are "core" or "super-transmitters". So, if a study shows that commercial sex workers, lorry drivers or people with a high level of education who travel a lot (to note three commonly cited groups) have markedly higher levels of infection than the general population, these may be described *statistically* as "risk groups". The description is merely a statement of the relative probability of finding infected individuals in this group as contrasted with another group.

However, in popular perception the notion of a risk group presents problems.   In the case of human disease, especially fatal sexually transmitted infections, the precise statistical concept of a risk group used in specialised technical discussions within professional journals and conferences, is all too easily translated into another, less precise, vernacular use of the same term. When this happens, "risk" is no longer the observed characteristic which raises the odds of being infected but rather the "risk" which "they" (those who possess an observed characteristic – Haitian, sex worker, African, gay man - but may not be infected) pose to "us" the uninfected. This has occurred with HIV/AIDS. Specialised and precise epidemiological language has been translated into everyday and less precise language, becoming connected to ideas and emotions such as those of blame and stigma.

This is an important point. Sexual intercourse (of whatever variety, oral, anal, vaginal) is not intrinsically a "risky" (in the popular sense) behaviour, beyond the obvious risks of conception in the case of the heterosexual variety. However, when a deadly disease appears **and** the social and economic environment is such as to facilitate rapid and/or frequent partner change, then that environment may be described as a *risk environment* and the act of sexual intercourse becomes a *risk behaviour*. *The riskiness of the behaviour is a characteristic of the environment rather than of the individuals or the particular practices*.

The region is experiencing the fastest-growing epidemic in the world[7].   In 2001, there were an estimated 250,000 new infections, bringing to 1 million the number of people living with HIV/AIDS. Less than 1,000 people are estimated to be receiving anti-retroviral treatment. The Russian Federation remains at the forefront of the epidemic in this region. However, many other

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[7] UNAIDS, Report on the Global HIV/AIDS Epidemic 2002, p. 32

countries are now experiencing rapidly emerging epidemics, as shown in Figure 10.

Except for isolated epidemics in the early 1990s (related to injecting drug use in Poland, and to nosocomial infections among thousands of children in Romania), there were few reports of HIV infection from any country in the region before 1994. This changed dramatically with reports of widespread outbreaks in Ukraine and Belarus in 1995. This was followed with evidence that the epidemic curve was beginning its ascent in other countries of the region: Moldova in 1996, the Russian Federation in 1998, and soon after in Latvia and Kazakhstan.

Numbers of infections continue to increase in the Russian Federation. Newly reported diagnoses have almost doubled annually since 1998. Almost 83,000 new HIV-positive diagnoses were reported in 2001, raising the total number of HIV infections reported since the beginning of the epidemic to more than
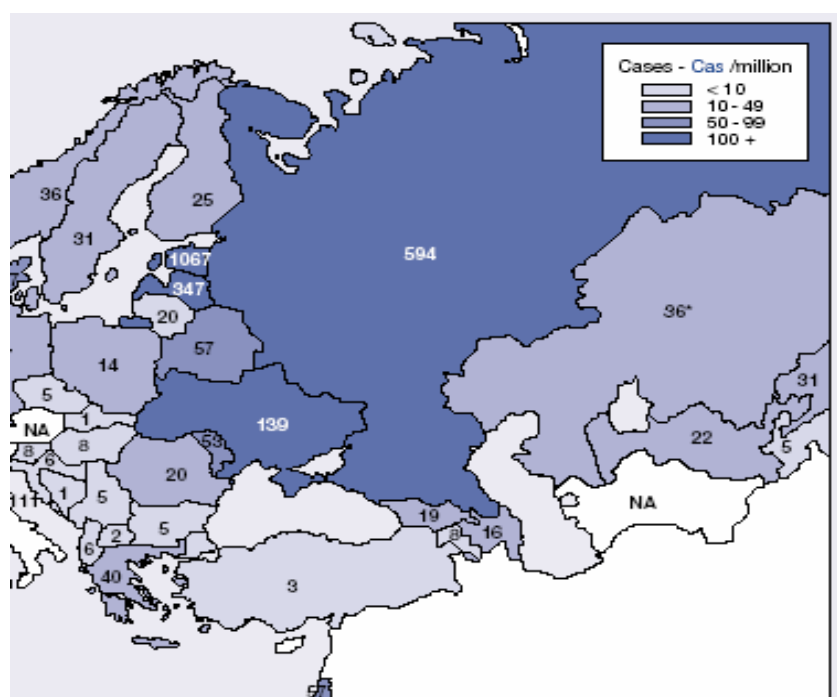
Figure 10: HIV infections newly diagnosed, per million population, WHO European Region, cases reported in 2001[8]

173,000 by 2001, a very marked increase from the 10,993 infections reported at the end of 1998. The actual number of HIV/AIDS infections in the Russian Federation is a matter of estimate and some speculation. Some commentators put it at around four times[9] the reported figures; in October 2000 the Director of the Federal AIDS Centre estimated that the true number of infections was six to ten times higher than the number of notified cases[10].

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[8] Data for the first 6 months of 2001; Source EuroHIV, 2002, o 66, p. 47.

[9] UNAIDS Global Report 2002, p. 32.
[10] Renton, p. 2

Ukraine already has an estimated adult HIV prevalence rate of 1%. It remains the most seriously affected country in the region and, unfortunately, in the whole of Europe. By 2001, something like 250,000 people were living with HIV in a total population of nearly 50 million people. While three-quarters of cumulative HIV infections in Ukraine are related to injecting drug use, the proportion of heterosexually transmitted HIV infections is increasing.

Although for the moment absolute numbers remain small, more people (mostly women) appear to be contracting HIV through sexual transmission and more pregnant women are testing positive for HIV. Assuming that this epidemic follows patterns observed elsewhere – and there is no reason to suspect that it should not – it seems clear that this epidemic is shifting into the general population. However, whether this is happening and whether an epidemic which is generalised could approximate or approach the levels seen in Africa is a hotly contested and highly political issue in this region. This is particularly so in some of the states such as Poland which are about to accede to the European Union.

In the psychological and socio-economic aftermath of the recent conflicts in south Eastern Europe and the Caucasus, young people have become more susceptible to HIV. There is – for the moment - little evidence that the HIV/AIDS epidemic has become well established in these parts of the region. However we know very little about the situation. Surveillance infrastructure is weak and limited surveillance data mean that the shape, distribution and trends of the epidemic remain unclear. A recent extensive rapid assessment study by WHO and UNICEF found high levels of drug injection in some places, along with frequent sharing of injecting equipment. Men who have sex with men and sex workers all reported low levels of condom use. This study also found strong overlap between these groups at higher risk. For example, in Serbia, 20% of sex workers and 18% of men who have sex with men were found to inject drugs.

In the Commonwealth of Independent States, the great majority of reported HIV infections are among young people. In the Russian Federation there are now 10 territories where prevalence is greater than 200 per 100,000 total population and we can infer that *the prevalence among males and females in the 15-30 year age group in these areas is in excess of 0.5% and 1% respectively.* These infections among young adults are chiefly among those who inject drugs. It is estimated that up to 1% of the population of those countries is injecting drugs, placing these people and their sexual partners at high risk of infection. It is important to note that injecting drug use at these levels and in these age groups means that in some senses this epidemic is already "in" the general population because many of these young people live at home with their families.

There is evidence that young people in several countries are becoming sexually active at an earlier age and that premarital sex is increasing. A steady rise in premarital sex is observable among Romanian adolescent girls aged 15–19. The percentage of reported premarital sexual relations in 1993 (9%) had more than doubled to 22% in 1999, while a 2000 report in Ukraine

found that about 51% of women aged 15–24 had had a premarital sexual relationship[11].

In 2001, in some Central Asian republics, awareness of HIV/AIDS was still poor among highly susceptible groups such as adolescent girls in the age cohort 15–19 years old. Among this group in Tajikistan, a mere 10% had ever heard of HIV/AIDS. In the same year, in Azerbaijan and Uzbekistan, fewer than 60% of young women were aware of the disease. The proportion of young girls harbouring at least one major misconception about HIV/AIDS ranged from 94% to 98% in these countries. In Ukraine, only 9% of adolescent girls were aware of HIV prevention methods.

Although improving in some countries, levels of condom use remain very low. In 2000 reports from Ukraine indicated that only 28% of young women had used a condom when they first had sex. Meanwhile, as we have seen above, very high rates of sexually transmitted infections continue to be found in Eastern Europe and Central Asia. This compounds the odds of HIV being transmitted through unprotected sex. In 2000 the number of newly reported cases of syphilis in the Russian Federation stood at 157 per 100,000 persons, compared to 4.2 per 100,000 persons in 1987. Similar general trends are visible in the other countries of the CIS, in the Baltic States and in Romania.

HIV risk is also high among men who have sex with men, among whom multiple partners and unprotected sex are widespread. While laws penalising homosexual activities with imprisonment have been struck off the statute books in most countries of the former Soviet Union, this group remains highly stigmatized. Recently, gay groups have started HIV prevention activities for men who have sex with men in Belarus, Ukraine and several Central Asian republics. Overall, though, coverage remains minimal.

THE HIV/AIDS EPIDEMIC IN THE BALTIC, EAST AND SOUTH EAST EUROPE AND THE BALKANS: A SUMMARY[12]

We see that this region is experiencing the fastest-growing epidemic ever in the history of the global epidemic with the number of new HIV infections rising steeply (Figure 11).

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[11] UNAIDS Global Report 2002, p. 34.
[12] This summary is derived from a document prepared by Dr Henning Mikkelsen of UNAIDS to whom thanks are due.
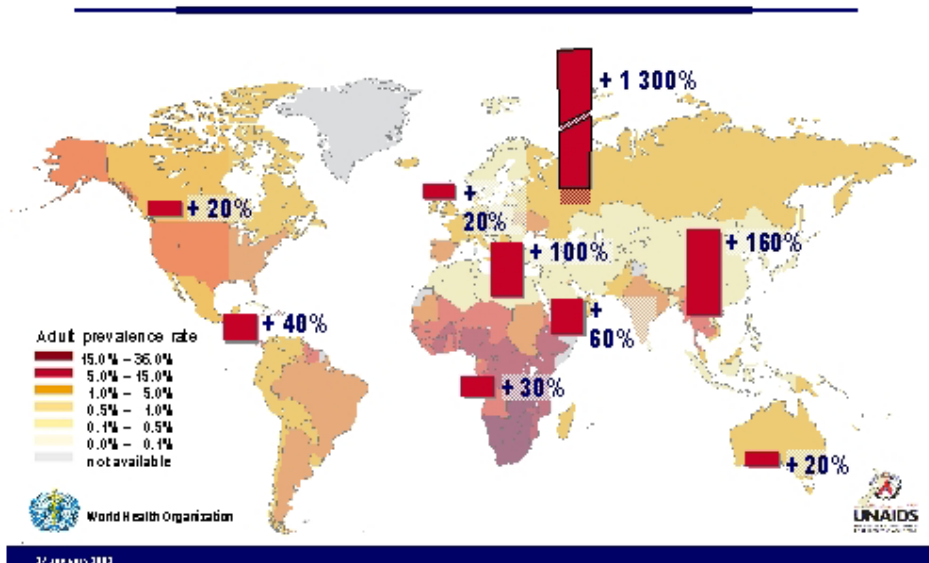
Figure 11: HIV: current prevalence and recent changes, 1996–2001

In the Russian Federation, the very steep rise in HIV infections seen in recent years is continuing. Reported diagnoses have almost doubled annually since 1998. The total number of HIV infections reported since the epidemic began was 177,354 by the end of 2001. A very conservative estimate would put the number of people now living with HIV in the Russian Federation at least 4 times higher than the reported figures, quickly approaching an HIV prevalence rate of 1 percent in the adult population.

The HIV crisis is escalating in other countries of the region too. In Estonia new reported HIV infections jumped from 12 in 1999 to 1,474 by the end of 2001, and in Latvia the incidence jumped from 25 cases in 1997 to 807 cases in 2001. The epidemic is tightening its grip in Kazakhstan, where after the first outbreak of HIV in 1997, 1,175 HIV infections were reported in 2001. Rapid spread is also reported in Kyrgyzstan, Tajikistan, Uzbekistan, Azerbaijan and Georgia. With an adult HIV prevalence rate of 1%, Ukraine remains the most seriously affected country in the region. The steep gradient of the epidemic curve is shown in Figure 12.
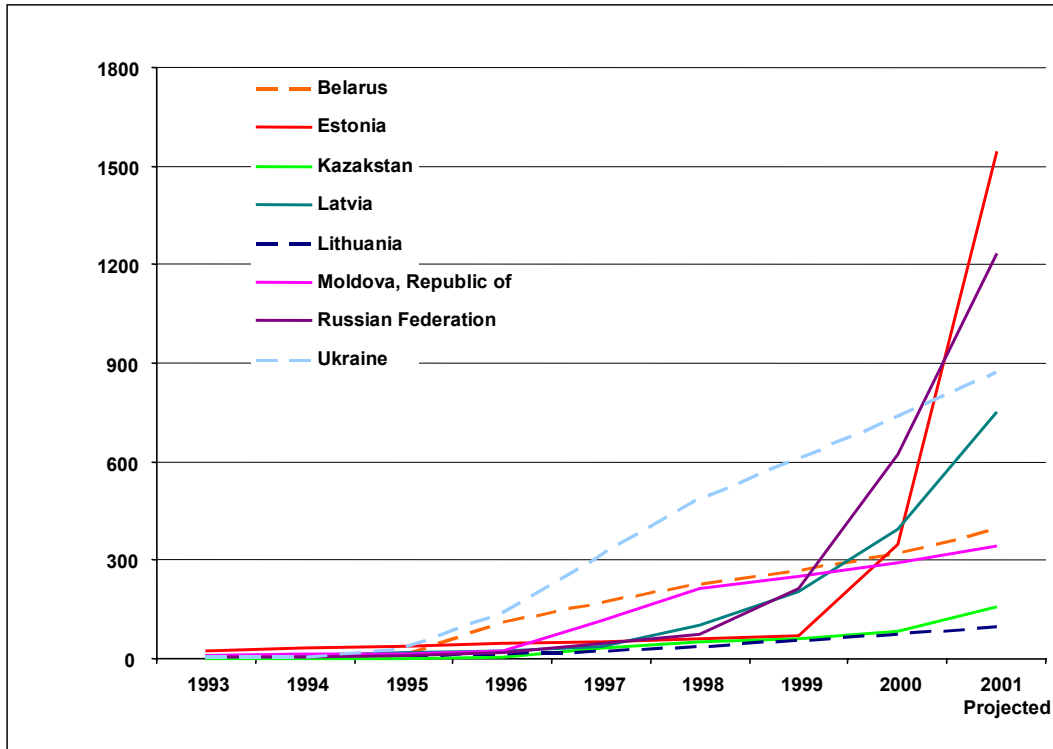
Figure 12: Cumulative reported HIV cases per million population, selected Eastern European countries, 1993-2001

IS THIS A REGIONAL EPIDEMIC?

The answer to this question is not straightforward. The current situation is fairly clear:

- One country out of 23 (Russia) accounts for close to 70% of all infections in the region.
- Two countries (Russia and Ukraine) make up some 95% of all infections in the region
- Adult infection rates are around 1% in three countries: Russia, Ukraine, Estonia
- Infection rates between 0.2% and 0.4% are found in three countries: Belarus, Moldova, Latvia
- Prevalence at or lower than 0.1% is found in 17 out the 23 countries in the region
- Poland has a considerable number of infections, but a low adult infection rate because of the size of its population
- Russia + Ukraine shift the region-wide average adult infection rate to 8 times the average of the other countries.

Is this then a Russian, a Ukrainian or an Estonian problem? Experience elsewhere shows that such responses are unconstructive and are part of general denial. The epidemic today is worse in Russia, Ukraine and Estonia than elsewhere. But we must remember that what we know about the epidemic depends on the reporting system in place in each country. Reporting systems across the region are very variable. Given the rates of increase of these epidemics, the level of social disruption and the proximity to the European Union it seems clear that this region should be a high priority for assistance from the European Union.

Almost 1 million people in Asia and the Pacific acquired HIV in 2002, bringing to an estimated 7.2 million the number of people now living with the virus - a 10% increase since 2001. A further 490,000 people are estimated to have died of AIDS in the past year. About 2.1 million young people (aged 15–24) are living with HIV.

With the exception of Cambodia, Myanmar and Thailand, national HIV prevalence levels remain comparatively low in most countries of Asia and the Pacific. That, though, offers no cause for comfort. In vast, populous countries such as China, India and Indonesia, low national prevalence rates blur the picture of the epidemic. It is clear that both China and India are experiencing serious localised epidemics that are affecting many millions of people. Indeed, India will soon have the largest number of people HIV+ of any country in the world. Estimates over the past five years have swung wildly from a high of around 10 million people HIV+ through 3 million to the current estimate of around 4 million.

India's national adult HIV prevalence rate of less than 1% does not provide a clear indication of the serious situation facing the country. An estimated 3.97 million people were living with HIV at the end of 2001—the second highest figure in the world, after South Africa. HIV prevalence among women attending antenatal clinics was higher than 1% in Andhra Pradesh, Karnataka, Maharashtra, Manipur, Nagaland and Tamil Nadu.

The epidemic in China shows no signs of abating. Official estimates put the number of people living with HIV in China at 1 million in mid-2002. Unless effective responses rapidly take hold, a total of 10 million Chinese will have acquired HIV by the end of this decade. Officially, the number of reported new HIV infections rose about 17% in the first six months of 2002. But HIV incidence rates can soar abruptly in a country marked by widening socioeconomic disparities and extensive migration (an estimated 100 million Chinese are temporarily or permanently away from their registered addresses), with the virus spreading along multiple channels.

All "national" epidemics are made up of numerous "local" and "sub-group" epidemics. It seems that there are several HIV epidemics in different population groups in various parts of this vast country. Serious localised HIV epidemics are occurring among injecting drug users in nine provinces, as well as in Beijing Municipality.

The most recent reported outbreaks of HIV among injecting drug users have been in Hunan and Guizhou provinces (where sentinel surveillance among users has revealed HIV prevalence rates of 8% and 14%, respectively). There are also signs of heterosexually transmitted HIV epidemics spreading in at least three provinces (Yunnan, Guangxi and Guangdong) where HIV prevalence in 2000 was as high as 11% among sentinel sex worker populations. The onward sexual transmission of HIV by people who became infected when they sold their blood to collecting centres that ignored basic blood-donation safety procedures poses a massive challenge, as does the need to provide them with treatment and care. Signalling the gravity of the situation, one 2001 survey in rural eastern China found alarmingly high HIV prevalence—12.5%—among people   who had donated plasma. Most of the

country's estimated 3 million paid blood donors live in poor rural communities.

Those now living with HIV/AIDS in provinces such as Henan (as well as Anhui and Shanxi, where similar tragedies might have occurred) face limited access to health-care services while having to endure severe stigma and discrimination.

Recent social and economic upheavals in Indonesia appear to be fuelling a sharp rise in injecting drug use, and, with it, the risk of rapidly increasing HIV spread. Virtually unknown in Indonesia just a decade ago, drug injection is now a growing phenomenon in urban areas. Official estimates suggest that between 124,000 and 196,000 Indonesians are now injecting drugs. And data from the largest drug treatment centre in Jakarta reveal that HIV prevalence is rising very steeply in this population.

IS THIS AN INJECTING DRUG USE EPIDEMIC?

Throughout the region, injecting drug use offers the epidemic huge scope for growth. Upwards of 50% of injecting drug users already have acquired the virus in parts of Malaysia, Myanmar, Nepal, Thailand and in Manipur in India, while HIV infections among Indonesia's growing population of injecting drug users is soaring. Very high rates of needle sharing have been documented among users in Bangladesh and Vietnam, along with evidence that a considerable proportion of street-based sex workers in Vietnam also inject drugs (a phenomenon detected in other countries, too). If the epidemic is to be stemmed, it is vital that injecting drug users gain access to harm reduction and other prevention services.

Male-to-male sex occurs in all countries of the region and features significantly in the epidemic. Countries that have measured HIV prevalence among men who have sex with men have found it to be high—14% in Cambodia in 2000 and roughly the same level among male Thai sex workers. Homophobia or dominant cultural norms mean that many men who have sex with men hide that aspect of their sexuality. Many might marry or have sexual relationships with women.

Among the Pacific Island countries and territories, Papua New Guinea has reported the highest HIV infection rates. New surveillance data reveal an HIV prevalence of 1% among women attending antenatal clinics in the capital Port Moresby, indicating that a broadened epidemic is under way in the city. Among people seeking treatment for other sexually transmitted infections in the capital, HIV prevalence was 7% in 2001 (double the level in 2000). Very low levels of condom use and wide sexual networking (amid low awareness and knowledge of HIV/AIDS) mean the country could be facing a severe epidemic. Heightening that prospect are findings that 85% of surveyed sex workers in Port Moresby and in Lae did not use condoms consistently in 2001, and that rates of other sexually transmitted infections ranged as high as 36%. There is a dire need for rapid expansion of prevention efforts.

In Thailand, recent modelling suggests that the main modes of transmission have been changing. Whereas most HIV transmission in the 1990s occurred through commercial sex, half of the new HIV infections now appear to be occurring among the wives and sexual partners of men who were infected several years ago. There are also   indications that unsafe sexual

behaviour is on the increase among young Thais.

This underlines the need to expand and revitalise strategies that can prevent this highly adaptable epidemic from spreading further in Thailand. In addition, adequate treatment and care should remain a priority.

Cambodia is the Asian country with the highest adult HIV prevalence. It has reported stabilizing levels of infection, along with still-decreasing levels of high-risk behaviour. HIV prevalence among pregnant women in major urban areas declined slightly from 3.2% in 1996 to 2.8% in 2002, according to the latest available data. Prevalence among sex workers declined from 42% in 1998 to 29% in 2002, according to the latest surveillance data, with the decline most pronounced among sex workers under 20. Given the high turnover of sex workers in Cambodia (almost three-quarters engage in sex work for less than two years), this steady decline suggests that prevention efforts focused on sex workers are yielding positive results among the succession of new entrants into sex work. Consistent condom use by sex workers appears to be the most important behavioural change achieved; it rose from 37% in 1997 to 90% in 2001.

Once again, as in many other regions, many of the factors facilitating HIV transmission (including periodic economic upheaval and high rates of population mobility) are rife throughout this region. Thus no country is immune to a rapidly spreading and wide-scale epidemic. UNAIDS believes publicly that most countries still have a window of opportunity for mounting and sustaining HIV/AIDS initiatives that could avert such an outcome.

SUMMARY AND IMPLICATIONS OF THIS EPIDEMIOLOGICAL LANDSCAPE FOR INTERVENTIONS BY INTERNATIONAL AGENCIES

On its website, the UK Department for International Development states that:

> *"The bulk of DFID's assistance is concentrated on the poorest countries in Asia and Sub-Saharan Africa. In addition, DFID contributes to eliminating poverty and supporting sustainable development in middle-income countries, as well as helping countries in Central and Eastern Europe ('transition countries') to try to ensure that the largest number of people benefit from the process of change."*

This environment and the strategic decision reflected in the above quote has implications for all agencies, work to produce appropriate outputs in relation to limited funds, human resources and political support. Agencies have to make the following decisions:

1. **How does HIV/AIDS weigh in the balance as an issue against other issues of concern in any particular geographical area?**

2. **A key question arising from this landscape is whether International Agencies should have seen this coming?**

3. **Do agencies have in place adequate epidemic modelling information to be able to predict the likely development of regional and national epidemics in areas where they are likely to face substantial demands?**

4. **How does the scale of the epidemic affect the need for agencies to co-operate with each other when agencies working in the same regions whether multilateral, bilateral or NGOs?**

5. **In which geographical areas and sectors does HIV/AIDS present the greatest threat to achievement of agencies' policy goals?**

SECTION 3: THE ORIGINS OF THE EPIDEMIC AND THE EVIDENCE FOR ITS SOCIAL AND ECONOMIC IMPACT

THE ORIGINS OF HIV

The question of when and how HIV entered human populations has been a source of great debate. We know that at some point the virus entered the blood of humans and then spread through sexual contact from person to person. In West Africa the less virulent HIV-2 spread from macaque monkeys. HIV-1 spread from chimpanzees into humans in central Africa. Four lines of evidence have been used to substantiate the zoonotic origin of AIDS:

- Similarities in organisation of the viral genome;
- Phylogenic[13] relatedness of a particular HIV strain to that of (Simian Immunodeficiency Virus)(SIV) in the natural host;
- Geographical coincidence between the SIV and particular HIV strains;
- Plausible routes of transmission.

How did HIV cross the species barrier? We know that it is not an easily transmittable disease. It is carried in body fluids, with the highest concentration in blood, semen and vaginal secretions. For transmission to occur it had to enter the human body and reach the infectable cells. It thus had to breach the skin or mucosal barriers. There are a number of hypotheses as to how this might have happened.

- **Bush meat**. It is not hard to imagine a hunter killing, or someone butchering, an infected monkey and in the process contaminating a cut on their hand with the monkey's blood.
- **Contaminated vaccine**. It has been suggested by Hooper (1999) that experimental polio vaccination campaigns in central Africa in the 1950s using vaccine cultivated on chimpanzee kidneys, may have provided the opportunity for the virus to cross the species barrier.
- **Contaminated needles**. The arguments above may explain how the virus cross into humankind but do not explain the rapid spread. It has been suggested that vaccine campaigns and poorly equipped clinics in rural Africa may have contributed to this through the use of unsterilised needles on one patient after another.
- **Ritual behaviour**. Finally it has been suggested that use of monkey blood in certain ritual might have caused transmission. This hypothesis reflects a high degree of ethnographic ignorance and no little prejudice as no one has described these rituals or given any examples as to where they take place.

The second and third hypotheses place the beginnings of the epidemic in the 20th century. Hooper suggests that the polio campaigns of the late 1950s in

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[13] Phylogeny is the classification of organisms in terms of their distance from each other as measured by particular characteristics. In the case of HIV this classification is done in relation to the presence or absence of different proteins on the coat of the virus. Different systems of classification will suggest differences in relatedness both contemporary and evolutionary.

Congo and Rwanda were the spark that ignited the fire. The cut hunter view has been used to suggest that the epidemic originated in infection across the species barrier in the 1930s.   Interestingly, in this case the transfer of the virus from an animal into a human may have happened on a number of previous occasions. However, because on those occasions each infected person did not in turn infect more than one other person, the potential epidemic petered out. There could have been a pool (or pools) of infection among isolated peoples in some parts of Africa for many years. What was different about the hypothesised crossing of the species barriers in the 1930s (and the subsequent pattern of the epidemic) was the environment into which the virus was introduced. The upheavals of the colonial and post-colonial periods and development of modern transport infrastructure allowed HIV to spread quickly out into the global community.

THE SOCIAL AND ECONOMIC IMPLICATIONS OF THE EPIDEMIC
Until recently there has been surprisingly little work on this area.   Here we briefly review the types of study and main conclusions. More detailed discussion of these studies can be found in Barnett, Whiteside and Desmond (2000) and Barnett (2001).

Demographic Impact Studies: There have been three approaches main approaches to demographic impact projections. These are those developed by:

- The United Nations,
- the US Census Bureau
- The World Bank.

The models all share similar logics but differ in their assumptions. These differences revolve around:

- the estimates of base year prevalence
- the projection of future levels of adult HIV prevalence
- the length of the incubation period
- the perinatal transmission.

Almost all of the differences in findings between the models could be put down to different assumptions concerning the above factors plus the estimate of current adult HIV prevalence and the projection of prevalence into the future.

There is now broad agreement among demographers that African population growth rates are unlikely to fall below two per cent per year during the next 20 years, although in a few countries the population growth rate will decline more dramatically.   There will also be marked changes in the population structures of many countries. These will have adverse social and economic effects.

Economic Modelling Of The Impact On Health Provision And On Health Related Services

Here the aim has been to:
      (i)   elucidate the global and national burden of disease
      (ii)   analyse the impact of the epidemic on health related services
      (iii)   make some estimate of the indirect costs - an important technical issue which shares something of the same problems as those faced in endeavouring to make a value for money estimate of HIV/AIDS programmes.

Economic Modelling of the effects of HIV/AIDS on entire economies:
Using various standard economic modelling techniques, the approach here has been to make estimates of the effects of the epidemic on whole economies. The agreed overall effect is that economic performance will be made negative by around 1-4 per cent per year for a decade or so.   These studies are summarised and discussed in Barnett and Whiteside, 2002, chapter 11. However, a recent unpublished paper by Ventelou et al (2003) makes a strong case for the inclusion of an hedonic element and therefore for much higher costs associated with the epidemic than other modellers have concluded.   The only exceptions to this approach have been the social and economic impact studies of Ukraine, which have been referred to above (Barnett and Whiteside, 1997).

Sectoral Impact

Studies have been made of the impact of the epidemic on the agricultural and rural sectors, on commercial agricultural enterprises and on a number of businesses as well as on the educational and health sectors. A variety of techniques have been used ranging from familiar accountancy based methods to more complex multi-disciplinary approaches. Regardless of methodologies and within the analytical limits set for each approach, the epidemic is shown to have moderate to serious effects across the economy.

Orphan studies

This is the most frequently studied population sub-group and the numbers and impacts are very large. The studies are reviewed at length in Barnett and Whiteside, 2002, chapter 8. The importance of these types of studies in the context of this scoping study is that they raise in an especially poignant form the difficulties of making cost effectiveness, cost benefit and value for money assessments in relation to investments which must be assessed over many decades.

SECTION 4: KEY CONCEPTS AND EMERGING RESPONSES TO THE PROBLEM OF HIV/AIDS IN DEVELOPING COUNTRIES

<u>Concepts</u>

<u>Concept 1.Timing and targeting</u>
Responses and their targets depend on the stage of the epidemic. Early response should focus on prevention. If this fails and prevalence rises, impact must be considered. There are waves of spread and waves of impact.

Table 3 shows six stages as an epidemic evolves. Although some countries have reached Stages 4 or 5, there is little evidence that any country has moved beyond that. At the sub-national level, some regions and communities that reached Stage 5 within the last decade may be approaching Stage 6. Anecdotal evidence exists at the sub-national, community, and enterprise level of Stage 5 and 6 impacts.

Table 3: The Evolution of the HIV/AIDS Epidemic and its Consequences.

Stage	Epidemiology and prevention	Impact and response
Stage 1: No-one with AIDS identified; some HIV infections	HIV prevalence >0.5 percent in high risk groups, targeted prevention	Planning only required
Stage 2: A few cases of AIDS seen by medical services; more people are infected with HIV	HIV prevalence < 5 percent in high risk groups, targeted prevention	Impact on medical demand and use of facilities: need to plan for this
Stage 3: Medical services see many with AIDS. Some policy-makers aware of HIV infection and AIDS. The incidence of reported TB cases increases.	Prevalence > 5 percent in high risk populations. Targeted prevention but general information	Impact still mainly medical but need to begin Human Resource planning and targeted mitigation especially for most vulnerable groups, institutions and sectors
Stage 4: AIDS cases threaten to overwhelm health services. Widespread general population awareness of HIV/AIDS	Prevalence > 5 percent in antenatal clinic(ANC) women. Information available to all, continuing targeting of high risk groups.	Impact now broader – need to start looking at education sector and all government activities. Private sector plans for impact.

Stage 5: Unusual levels of severe illness and death in the 15–50 age group produce coping problems, large number of orphans, loss of key household and community members. TB is a major killer.	Prevalence > 20 percent in ANC clinic attendees and has been so for 5 years. Full battery of prevention according to resources.	Impact at all levels. Responses need to be equally diverse. They may include targeted relief or targeted Anti-Retroviral Therapy.
Stage 6: Loss of human resources in specialized roles in production and economic and social reproduction decreases the ability of households, communities, enterprises and districts to govern, manage, and/or provision themselves effectively. Responses range from creative and innovative ways of coping to failure of social and economic entities.	Prevalence >15 percent in 15- 49 age group and has been so for 5 years. Most cost effective prevention now needs to be focused on key groups and interventions. Efforts to reach those below age 15 and for over 15s emphasis on Voluntary Counselling and Testing	This impact requires massive intervention at all levels. The emphasis should be on children in crisis including orphans. Local programmes need to be scaled up and made sustainable perhaps with donor money.

Concept 2. Information, observation or instruction

For prevention to be successful, individuals must be able to make decisions to protect themselves, *and have the conditions and incentives that enable them to stick to those decisions*. Effective impact mitigation requires understanding the effects that the epidemic will have and reacting to them, preferably in advance. There are three ways in which prevention and mitigation responses can be triggered:

- by information;
- through observation;
- via an instruction.

Information-based decisions are grounded on messages and the theory of reasoned action and planned behaviour (See Section 2) rather than experience or observation. People learn what is happening or may happen, they process this information and make decisions to change (or not change) their behaviour.

An observation-based decision is one where behaviour change is based on what people see or of which they have personal experience.

Instruction-based decisions are where people are told to do things and do them.

The relative roles of information, observation and instruction are important for HIV/AIDS prevention programmes, for design and for understanding why they have succeeded or failed. It is important to note that the 'instruction' option does not work unless the authorities have legitimacy and sanction.

As already noted in Section 1, information requires:

- the appropriate medium
- the ability of the target audience to access it
- the conceptual framework to understand it and translate it into action
- legitimacy and a framework for information to be processed

To educate people about potential impacts of the epidemic may itself be an integral part of prevention. This raises important questions about the evaluation of money spent on research concerning long-term impacts and the time period over which we consider the return to an investment. Money spent on research and on educating political leaders may seem to have low returns in the short term and even in the long term because opinion change may bring about policy movements which avoid the worst effects of the epidemic. This is discussed further in the next paragraph.

Concept 3. Advocacy and ownership
This consists of three processes:

- Identification of the disease. People need to understand that there is an organism that causes illness.
- Ownership. People have to recognise that the illness has implications for them and their societies.
- Empowerment. People have to believe that there is something that can be done and they can be part of it.

Advocacy is necessary to ensure that people are aware of the problem and are prepared to act on it. There is however no point in people being aware if they do not feel it is their problem and that they can do something about it. This has important implications for prevention programmes. Voluntary counselling and testing (VCT) has been an important part of prevention but it is likely to be more effective if there are opportunities to offer people hope as an incentive. Thus, availability of ARVs may become an important component of effective use of VCT as part of a prevention strategy.

Concept 4. Process versus product
In HIV/AIDS prevention or impact mitigation while there may be a distinction between process and product, in some cases the process is the product. This perspective engages directly with the question of the value of research findings and their use, which is discussed further at the end of this section.

Process can be setting up a National AIDS Control Plan or a perspective study of the potential impact of the disease on supply and demand in the education sector. The *product* is the resulting study or plan which, in an ideal world, leads to implementation. Over the years it has become apparent that process is sometimes more important than product because it leads to "ownership" and engagement on the part of decision makers and politicians. The Ugandan Multi-Sectoral Response experience is a good example of this.

Concept 5. Scaling up and Sustainability
There are examples of remarkable AIDS interventions run by committed and concerned people. These include prevention, care and dealing with impact through theatre groups, orphan care and income generating projects. However these have not stopped the epidemic nor alleviated much of the misery associated with it. The reason is they are small-scale and localised. There is a potential conflict between donor need to spend large amounts of money and local needs for specific and detailed responses. The donors seek to scale up; the beneficiaries probably need differentiated responses. Thus we see that:

- Prevention has to be done at a differentiated level - after all it is individual behaviours that must be changed in a community context. A multitude of small-scale programmes across a country is needed. These will make a difference.
- In contrast, care and impact responses need to be scaled up because the numbers are large. While it is important to provide education for orphans in one area or home based care through a particular church, these responses must be expanded.

Thus, the challenge is to achieve large-scale responses and remain sensitive to geographical and cultural variation – all within severely resource-constrained situations.

This epidemic raises important questions about sustainability. People understand sustainability to mean that when the core funding, be it government or donor, runs out, the local community or administration will be able to continue the project using their own resources. This may be a laudable target for many projects. It makes sense that communities should be asked to cover the recurrent cost of providing clean water and should manage this themselves. Micro-credit projects take pride in being self-sustaining. However AIDS changes things and this is especially true for projects designed to assist people impacted by the disease.

Sustainability may not be achievable. "Sustainability", like "coping" is often another way of asking people to do more with less. Sustainability is not a blanket criterion that can be used to judge the viability of projects in AIDS affected areas. There are two main reasons for this:

- First the epidemic means resources are being lost in communities and nations at the same time as demand rises.
- Second the time frame for support is important. The most extreme example is where young children are orphaned. They will need care and support at least until they are 16 years old and possibly longer. Donors need to look at long term assistance – something most cannot do because they have neither the time frame nor budgets to make this sort of commitment.

These are important considerations are important in considering the cost- effectiveness and value for money evaluation of donors' work.

Concept 6: The idea of coping

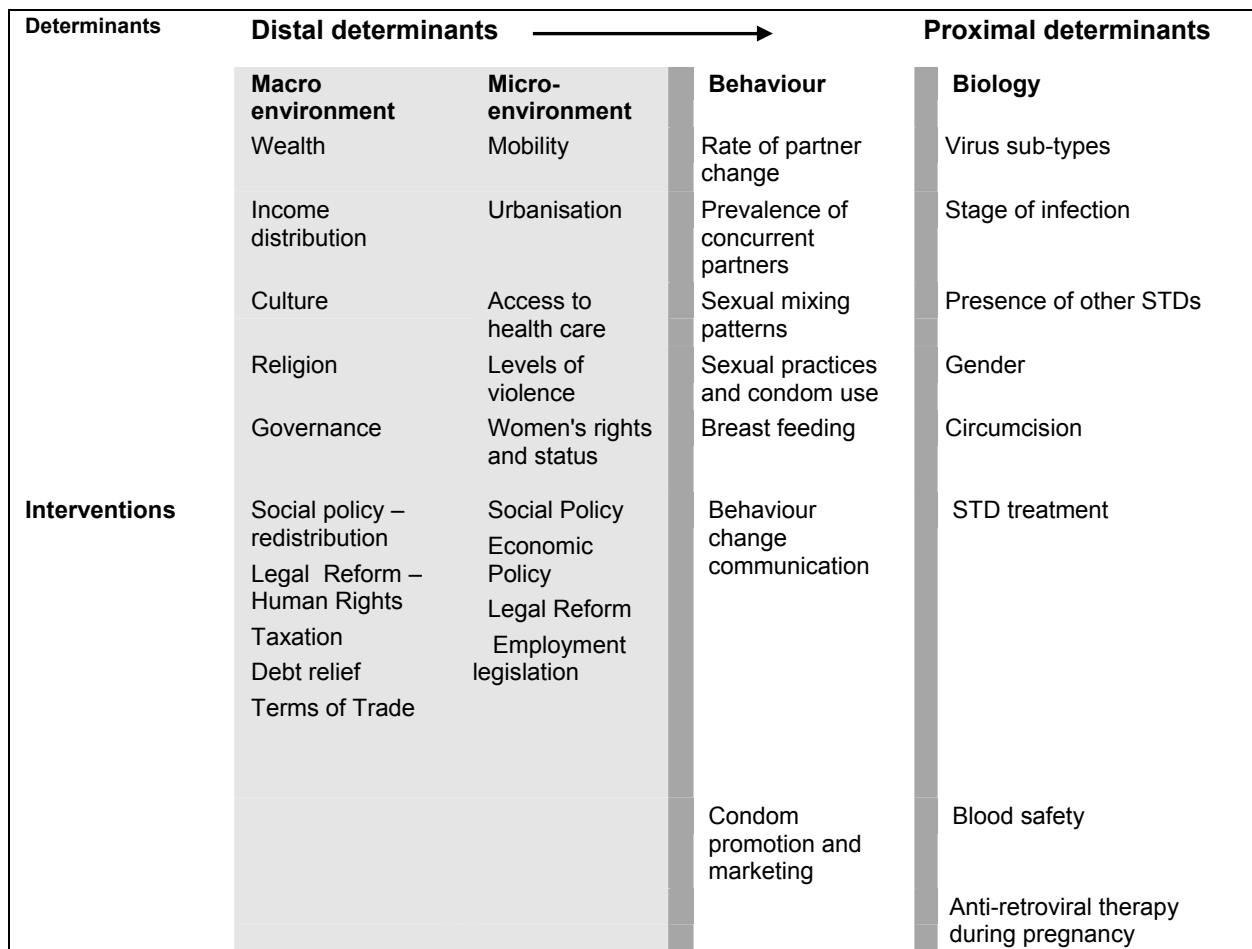Like sustainability, the idea and language of "coping" has to be questioned in relation to HIV/AIDS and its impacts. People "cope", the alternative - not coping - means households dissolving or people dying. Here we engage directly with the key issue of the time period for which it is reasonable to evaluate returns to donors' investments. Individuals and communities may "cope" over the short to medium term but we have noted in Section 1 that this is a very long wave event. Thus, in evaluating the value for money or cost effectiveness of a programme or project we have to make some difficult and conceptually complex decisions as to the time period with which we are concerned.

WHAT WORKS?

This is <u>the</u> key question and surprisingly little is known. Here we look at a number of issues:

1.1. Prevention.

Preventing new infections remains a primary goal. Identifying prevention as a goal is easy. It is more difficult to decide what to do.   It is useful to think about this issue in relation to proximal and distal determinants of the epidemic. These are described in Figure 13.

Determinants	Distal determinants ──────────▶			Proximal determinants
	Macro environment	**Micro-environment**	**Behaviour**	**Biology**
	Wealth	Mobility	Rate of partner change	Virus sub-types
	Income distribution	Urbanisation	Prevalence of concurrent partners	Stage of infection
	Culture	Access to health care	Sexual mixing patterns	Presence of other STDs
	Religion	Levels of violence	Sexual practices and condom use	Gender
	Governance	Women's rights and status	Breast feeding	Circumcision
Interventions	Social policy – redistribution Legal Reform – Human Rights Taxation Debt relief Terms of Trade	Social Policy Economic Policy Legal Reform Employment legislation	Behaviour change communication	STD treatment
			Condom promotion and marketing	Blood safety
				Anti-retroviral therapy during pregnancy

Source: Barnett, Whiteside, Decosas, 2000.

Figure 13: Proximal and Distal Determinants and Intervention Sets

PROXIMAL DETERMINANTS, BIOLOGICAL AND BEHAVIOURAL INTERVENTIONS

Most interventions have been biomedical and behavioural and these areas have been key components of donors' engagement with the epidemic. These biomedical interventions are obvious and are reviewed in what follows.

1. Blood Safety

Provision of safe blood and blood products are universal goals. Testing all donated blood and anti-selection – discouraging people in high-risk groups from donating - should largely accomplish this. Where this is done, including in the poor world, blood becomes much safer. In many poor countries, this response has been in train since the mid-1990s but it is still not complete and/or sustainable in many countries and there can be no doubt that support for this should form an important part of any HIV/AIDS programme.

In terms of infections avoided, this is a very important and cost effective intervention although limited to those few areas where blood transfusions are likely to be offered by medical services. However, it is an important intervention because blood transfusion is sometimes offered as a   treatment for infant and child malaria.

2. **Provision of clean injecting equipment**

A recent article by Gisselquist and collaborators (published in November 2002 in the Journal of Sexual Infections) argues that much of the African epidemic can be explained by reference to reuse of injecting equipment. This is not a very convincing article as it uses old data from the 1980s and early 1990s and does not explain the particular age distribution that characterises the infection in a population. However, in some countries, there is no doubt that injection equipment used in some medical facilities could be a serious risk factor and that this is an area where intervention might be very cost effective. A very recent publication notes:

> "The frequency of therapeutic injection use is high in Egypt and may contribute to blood-borne pathogen transmission. The Ministry of Health and Population (MOHP) is developing interventions targeted towards promotion of injection safety and reduction of injection overuse on community basis as part of a comprehensive strategy to prevent blood-borne pathogen transmission in Egypt." (Tropical Medicine & International Health, Volume 8 Issue 3 Page 234 - March 2003).

This suggests that in some countries (and HIV rates in Egypt remain unclear although there is a serious epidemic of Hepatitis C that has the same infection channels) attention to provision of injection equipment could be an important component of prevention strategies.

3. Treatment of Sexually Transmitted Infection (STIs)

STIs enhance HIV transmission by increasing both susceptibility of HIV-negative individuals and the infectiousness of HIV-positive individuals. Treatment of STIs should assist control of HIV spread. However the first two trials of this strategy gave apparently contradictory results. In the early 1990s randomised-controlled trials of STI treatment for the prevention of HIV-1 infection were conducted.

- The Mwanza trial, conducted between November 1991 and December 1994, in Tanzania involved **case management** of STIs.
- The Ugandan trial in Rakai (South Western Uganda) involved **mass treatment** of STIs.

The Mwanza study suggested that reduction in HIV incidence by 38% in a rural population over a two year period could be achieved by improving syndromic[14] STI treatment services. In

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[14] The syndromic approach to STI treatment is based on diagnosing STIs using a set of easily observed symptoms such as genital discharge. These are treated with a broad spectrum of drugs aimed at treating all the infections that could potentially account for these symptoms.

this study only symptomatic STIs were treated and therefore it was expected that the results would underestimate the proportion of HIV infections attributable to STI infections.

The Rakai trial involved parallel cohorts of HIV negative individuals enrolled in control and intervention groups respectively with each group exhibiting similar STI prevalence rates. At the 20 month follow-up the intervention group displayed significantly lower incidence of syphilis and trichomoniasis but the incidence of HIV infection was 1.5 per 100 persons-years in both groups. The study concluded that STI intervention had no effect on incidence of HIV infection.

It is probably safe to conclude that interventions designed to treat symptomatic STIs promptly and effectively can achieve a substantial reduction in HIV incidence in general but that treating STIs to reduce the incidence of HIV is likely to be most effective at earlier stages of the epidemic. **This suggests that treatment of STIs in the early stages of an epidemic can be an important and effective intervention and is probably cost effective in terms of infections avoided.**

4. Mother to Child Transmission (MTCT)

Prevention of mother to child transmission has been widely researched. In the last few years a great deal of this work has been done under the auspices of the French National AIDS Research Agency (ANRS).

It seems clear that this is a cost-effective approach because relatively simple and inexpensive interventions can greatly reduce the chance of transmission. In the absence of intervention, between 15 and 45 percent of children born to infected mothers will themselves be infected. These children can be infected before birth (in vitro), during delivery or through breastfeeding after birth. Infection at delivery is most common. Antiretroviral drugs decrease the mother's viral load and inhibit viral replication in the infant, thus decreasing the risk of MTCT.

The cost of these regimens is relatively low and results in avoidance of substantial numbers of infections. Total cost of such interventions runs to around $60 per mother/child including the cost of counselling and testing the mother as well as six months' formula feed for the infant.

However, the cost effectiveness/value for money return on such an intervention raises serious questions as the intervention saves the child but it is orphaned in its early years as the intervention does nothing for the mother's health.

5. **Condoms**

This has been one of the most widely recommended and perhaps used interventions. However, the inexorable spread of the epidemic in Africa could be said to demonstrate the failure of this intervention. There are many reasons why the condom has been so heavily favoured. These include: (a) the initial appearance and identification of the epidemic in a gay male community (b) the existing capacity for condom distribution among the population control movement and NGOs at the time of the appearance of the HIV/AIDS epidemic (c) failure to recognise the limitations of this quick fix solution early enough. The result is that the male condom remains one of the most widely recommended interventions.

The female condom has proved more problematic: whilst in theory giving more control to the women there must be serious doubts as to the generalisability of such a complex technology requiring a degree of male cooperation and knowledge and involving relatively high cost and adaptation of many cultural and personal sensitivities.

All aspects of support for condom based programmes and projects should certainly be examined in terms of measures of (a) known adoptions (b) numbers distributed (c) sustainability (how far can people afford to purchase them; which people in terms of gender and income group) (d) estimates of numbers of infections avoided.

It seems likely that male condoms have been an important element in keeping the infection under relative control at early stages in the epidemic in some countries. Condom campaigns in core groups of potentially infectious individuals such as commercial sex workers and lorry drivers have probably had some impact – the Thai 100 per cent condom campaign in brothels has apparently been effective.

6. **Microbicides**
There has been relatively little research on microbicides and there are some difficult and complex problems associated with the use of candidate substances. In particular there may be problems associated with long term use and resultant fear of liability among the pharmaceutical companies.

A microbicide is a substance (gel or foam) that a woman can insert into her vagina prior to intercourse, to kill viruses and bacteria. Microbicide could provide women with more control over their own protection in sexual encounters. Development of microbicides has been incomprehensibly slow, almost certainly because these preparations would have their main markets among poor women in poor countries – a market sector not renowned for it spending power!

This is potentially a very good value for money intervention, which would have enormous impact in empowering women, and poor women in particular.

7. Vaccines

Recent trial results have been disappointing. But of course this is the best hope for controlling the epidemic. Such a vaccine seems a long way off and even if one were developed it would need a high level of efficacy. The danger is that a vaccine might give people a false sense of security and actually increases the spread of HIV.

Vaccine development is resource intensive and most research is in the rich world. Such vaccines may not be appropriate or affordable for the poor world. The challenge is to find an acceptable, effective, affordable and deliverable solution. It has been necessary to persuade major pharmaceutical companies to pursue vaccine development with the enthusiasm they have devoted to anti-retroviral development. Unfortunately, there is potentially profit in treatment, which is repeated for life than in a vaccine, which could be a one-time shot.

International partnerships form an important component of vaccine development, as do private sector collaborations. Assessment of the value for money or cost effectiveness of these contributions is difficult and it cannot be made until either a vaccine is found or research ceases. Alternatively each component piece of research must be evaluated on its own terms – in other words, was the output what the researchers said it would be? **Once again, we are engaged with the fundamental methodological question of the time period. But we also have to engage here with another question – the evaluation of an investment in a joint activity where contributions to that activity or set of activities from various donors cannot be easily if at all disaggregated in relation to achievements.**

8. Behaviour

The second set of interventions is behavioural. Much has been written about these and there are numerous Knowledge Attitude Practice and Behaviour (KAPB) studies. It is increasingly recognised that knowledge is not enough. Most people are aware of AIDS and HIV. The problem is they do not see **themselves** as at risk. The need is to move beyond individual awareness to appreciation of the importance of risk environments. For example, both condom use and microbicides (if these were available) require behavioural changes. The problems with behavioural changes are:

- they assume that people can act rationally (when they either cannot, will not or their rationality is specific to their circumstances) and
- attempts to change behaviours may involve interference in intimate and culturally important areas of people's lives
- the possibility of stigmatising particular social groups and their practices/traditions.

<u>Voluntary counselling and testing</u> has been discussed previously. This is increasingly seen as an important component of prevention. The idea is to provide people with access to rapid testing in an environment where they will receive pre- and post-test counselling. If they are negative then they have an incentive to stay that way. If infected, the message is positive living. Such an intervention only works in a supportive environment – or one where levels of stigma are not high – and ideally where people can access some form of care. Its evaluation should take account of the expectedly marked difference in take up in communities with and without available and affordable ARVs.

<u>Intravenous Drug Users:</u> In areas where the epidemic is primarily among intravenous drug users, harm reduction interventions are needed. These involve needle-exchange programmes, teaching addicts to clean their injecting equipment and trying to reduce the levels of drug abuse. Once again, context is important. In countries where drug possession is a capital crime, harm reduction policies raise issues around criminality. In some countries in Eastern Europe and the CIS, particularly the Russian Federation, possession of injecting equipment is an arrestable offence which means that support for harm reduction strategies may come into conflict with local legislation.

In parts of the CIS, IV drug use in prisons is widespread and combines with men who have sex with men relations to make prisons into "condensers" of the epidemic. Interventions in relation to in-prison harm reduction strategies may be potentially cost effective at the early stages of the epidemics currently being seen in these regions.

However, experience in the UK and in the Netherlands shows that harm reduction strategies can be and have been very effective in preventing spread within the IV drug using community and from them to the wider society.

9. Upstream Interventions

This has been very contentious.

The problem has been that because HIV/AIDS is an infectious disease, it has been medicalised from the beginning. Policy makers and activists have not tended to look beyond biomedical and behavioural interventions. They have not seen the importance of factors that determine susceptibility to infection, that frame the behaviours that put people at risk.   For this reason, until recently policy makers and agencies have been inclined to categorise HIV/AIDS under "health".

Responses must take account of determinants of the epidemic and address them. They must put in place 'upstream' interventions. The goal is to empower people to make decisions that reduce risks of infection, or to stick to existing behaviours that have the same effect.

Although specific susceptibilities will vary from country to country, priorities might include broader policy engagements with the following issues:

- Migrant labour systems e.g. (migrant miners in South Africa and commercial sex workers in Thailand and India) which fuel the epidemic in many parts of the world. Workers might be targeted with prevention messages – which is an individual approach – or alternatives to migration might be explored – which is a social and economic policy approach.

- Enhancing the status of women. Actions range from training women and providing capital to assist them to become entrepreneurs, to tougher laws on rape, sexual harassment and protection of inheritance rights.

- Children, and particularly orphans, are vulnerable to sexual molestation. This subject must be discussed openly, and children placed in caring and protective environments.

- Home ownership and electrification are potentially beneficial. Home-owners in some African settings are less likely to be infected because they have a long term perspective and avoid risky behaviour. Electrification raises people's standard of living and gives them access to a range of recreational activities in addition to sex.

- Displaced persons: these people can be given individual messages – probably inappropriate at times of extreme stress – or displaced persons camps can be designed with HIV/AIDS in mind.

10. Responding to Impact

There is no prescription for dealing with impact. There has been no national or regional plan that addresses this in a holistic manner. Experience shows that there exists a sparse range of responses. These are listed in Table 4.

Table 4 : Responses

	Examples of Targets	Responses	Examples
Group specific	Orphans in an area, People living with AIDS	Care for orphans Home based care	NGOs: e.g., Francis Xavier Bagnoud Foundation, World Vision International agencies e.g., UNICEF Various national NGOs Many national NGOs
Ministry Specific	Revenue and expenditure Education	Plan for changes Changed demand and supply	Ministry of Finance Ministry of Education
Industry Specific	Labour supply Employee benefits	Plan for labour shortages Reduce benefits	Various companies
National	Human resources Welfare benefits	Plan for changing populations and welfare transfers	There are none as yet

IS IT POSSIBLE TO SAY WHAT WORKS?

It is not possible to answer this question in general terms. In the preceding, we have explored and assessed the key issues and indicated how they *may* have worked. However, in terms of what *seems* to work, there is little in the armoury. We know that some or all of the following are important components:

11.1 National leadership and political commitment at all levels
Where the epidemic has been controlled at the national level there has been consistent and high level leadership. Examples of relative success include experience in Uganda, Thailand and Senegal. In contrast, failure of leadership has been woefully apparent in South Africa

11.2 Targeted Interventions make Public Health *and* Economic Sense.

Most countries facing AIDS epidemics are poor both financially and in administrative and human resources. Furthermore AIDS is not the only problem they face. It has been observed by Ainsworth and Teokul (2000, p 55-60) that "government AIDS control strategy documents typically embrace everything that might be done to fight AIDS". The result is that many activities and pilot projects are launched by government, donors, and NGOs, but very few are implemented on a scale that would register an effect on the overall epidemics and the activities selected are not necessarily those that would yield the greatest impact.

Assessment of interventions will have to take account of how decisions were made, on what criteria, when and with what goals in mind. The key questions will always be:

- **On the knowledge available when the policy was introduced, did this seem a sensible way to spend money**
- **Could a good outcome have been expected**
- **When were potential outcomes measured**
- **When were decisions taken to discontinue this investment or to continue it**
- **When funds were put into multilateral channels, how were outcomes monitored and if it was recognised that such monitoring was difficult or impossible, were the expected outcomes clear.**

11.3 Multisectoral Approach

Following the Ugandan experience, a common feature of countries with large epidemics has been to claim the existence of a multisectoral approach. Where this has "worked" it seems to develop commitment across a society, from political leaders at all levels through to religious leaders, NGOs, the private sector and, where appropriate, traditional leaders. In particular, the Ministries of Health have had to relinquish ownership of the disease.

"Multisectoral responses" mean looking beyond prevention to the whole epidemic. This includes treatment, policies and programmes to mitigate the impact of AIDS, and policies that will change the societal factors that influence long run susceptibility and vulnerability to HIV/AIDS.

12. Good STD Services are Important.

In Senegal and Thailand public STD services have been in place for many years. The Thai STD network was not sufficient to prevent the epidemic – an important point - but its existence was critical to monitoring the success of the 100 percent condom use campaign. In Senegal the STD service provided health checks and clearances for commercial sex

workers and played a crucial role in information and condom distribution programmes.

The lesson seems to be that while STD service cannot prevent the spread of HIV they are an important part of the portfolio of responses. Furthermore the longer they have been around the more likely they are to be accepted and respected.

13. Changes in Sexual Practices

It has been observed above that this is one the most contentious and sensitive areas. It asks whether there are common sexual practices that have helped prevent the spread of HIV? Key issues are:

- Male circumcision as a preventive measure – there is now little doubt that male circumcision reduces transmission rates
- Levirate marriage – a man's inheritance of his dead brother's wives as a high risk practice
- Particular sexual practices which cause genital abrasions and thus open infection portals.

The difficulty with these interventions is that they can take on complex political and ethical complexions and are all too easily mis-used by enthusiastic missionaries of one kind or another or all to easily dismissed as attempts to change "our traditions" by those who would oppose them.

14. The role of treatment

This has to be the most important and key current issue.

With regard to ARVs, it might argued that in many circumstances (for example where 40 per cent of the young adult population is HIV+ as in Swaziland) **this is the most cost-effective and value for money intervention over the long term – and because of the nature of the epidemic, it is over this long term that the value for money must be assessed. Plus, of course, it is also probably the investment with the largest hedonic returns.**

With regard to opportunistic infections (OIs), people who are infected with HIV require treatment. Prior to treatment is 'positive living' where people are encouraged to eat healthy balanced diets, avoid stress, give up harmful substances such as drugs and alcohol and lead more balanced lives. When their immune systems begin to fail they contract opportunistic infections such as TB, diarrhoea, and thrush. Most of these can be treated or in some cases prevented by judicious use of drugs, which cost only a few dollars per patient per year. However, OI treatments are limited in their effectiveness and, without ARV, people die.

These are discussed briefly as follows:

1. **Interface between agencies:** This is problematic as existing agency strategies are not coordinated. The large numbers of agencies, divergent national interests and emphases together with differences of scale and institutional mission all make it difficult to arrive at clear international strategies. While UNAIDS and the Global Fund for AIDS, TB and Malaria all have coordinating influences and possibilities, it must be acknowledged that response to the challenge of HIV/AIDS takes place in an environment that can only be characterised as having an infinitely variable geometry. The greatest challenge is to work towards greater consensus and less variability. This is particularly difficult in relation to an epidemic of *sexually* transmitted infection where cultural, ethical and religious perspectives on sexual behaviour and morality may all come into collision with pragmatic responses and obscure the building of long term strategies and alliances.

2. **Knowledge production and use:** There are many sources of information about the full range of issues associated with HIV/AIDS. These range from the detail of virology, through clinical practice to social and economic policy. One of the greatest challenges is effective deployment of and access to this knowledge. Most international and national agencies just do not have sufficient capacity and organisational "redundancy" to permit effective use of information. The result is that at the level of national and international policy development, practice is either based on dated experience and information – or even on inaccurate information. Furthermore, with regard to some areas of concern, for example how to respond to the social and economic impact of the epidemic, little is known for certain. The result is that the pressure to do something can lead to inappropriate disinterment of approaches that are not relevant to the social and economic circumstances of heavily AIDS-impacted societies. An example of this is the suggestion that "labour saving technologies" might be used to compensate for labour loss in rural agricultural communities. Here the problem becomes clear: we just do not know that such technologies – where they exist and are likely to be adopted – are appropriate to the circumstances of rural communities where demographic structures and social capital endowments have been adversely affected by the epidemic (Barnett and Grellier, 2003).

3. **Regional differentiation and response**

The epidemic is globally differentiated and responses must be calibrated and adapted to the needs and requirements of these regions.   However, while it is vital to recognise the specificities of and differences between regions, it is important not to omit the possible learning opportunities between regions.

An important lesson to be learned from the initial (and to some extent continuing) approach adopted by the WHO and UNAIDS is that one size does not fit all. Thus, in each of the sub-heads below, specific approaches will be required:

- Prevention: some of these issues have been discussed above but certain important questions need to be examined afresh to inform policy and strategy. These include:
  - Does prevention work?
  - What is the evidence?
  - Under what conditions and where can it be said to have worked?
  - What theories are available to inform future practise?
  - Are these theories appropriate to all world regions?
  - How much does prevention work need to take account of marked local and regional variation?
  - How can this best be achieved?
  - Assessment of experience and relevance of male condoms.
  - The potential for development and use of virucides,
  - Expansion of harm reduction strategies.

- Treatment and care: this has to be the most important and pressing issue with which governments and agencies must engage. Its implications for donor countries go beyond overseas development assistance and may impinge on domestic policies and relations with industry.   Here agencies and governments could become vulnerable to charges that they have not made a clear or foresightful enough set of decisions. This observation is relevant in the following areas:
  - Treatment of OIs – where price reductions and effective distribution can result in direct relief of human suffering

and some contribution to prolongation of people's lives.

- ARVs – this is a key issue, and in some senses the role of agencies in relation to this issue may be the one on which they are judged over the next five to ten years.
- Health infrastructure: this marches hand in hand with ARVs and treatment of Ois.
- Syndromic management – the future role of this in prevention/treatment and its expansion and scaling up in programmes should be examined.
- There is no doubt that the issue of internationally unequal access to health care (and ARV access is only one example) is an issue which will affect the work of governments, agencies and donors for decades to come. Current international migration is often in search of medical treatment and there are doubtless some who travel specifically in search of ARV treatment.

- <u>Engagement with impact and impact mitigation</u>**:** Examination of the potential impact in some regions can form part of an effective prevention effort; in others it will provide important insights into whether or not HIV/AIDS is a potential threat to social and economic development. Very few whole country studies have been completed[15] and some more might be attempted. In the meantime, while quite a lot is known about some of the following issues in parts of Africa (marked by an asterisk), very little at all is known about them in all other world regions.
    - Agriculture and rural livelihoods*
    - Industrial and commercial*
    - Macro-economic*
    - Education
    - Governance.

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[15] See: Barnett, T., and Whiteside, A., The Social and Economic Impact of HIV/AIDS in Ukraine, 1997 plus Balakeriva et al, 2001. These appear to be the only attempts at whole country studies, which have been completed

<u>SECTION 5: ISSUES AND PROBLEMS FACED BY THOSE AFFECTED AND INFECTED BY HIV/AIDS</u>

These fall into the following categories:

- Infected
  - Experience of illness
  - Search for treatment
  - Death

- Affected
  - Impoverishment
  - Household
  - Community

These will not be discussed in that order, as they are closely interlinked.

THE EXPERIENCE OF ILLNESS

HIV disease is an extremely unpleasant form of illness. It is characterised by a range of opportunistic infections, which slowly destroy the body and the person experiences these over a long period in the certain knowledge that the end point is death. HIV/AIDS disease is not unique in this respect but it is perhaps unique inasmuch as it is both acutely stigmatising and extremely common in many societies. Hence the sufferer knows that not only are they going to die unpleasantly but also that they will suffer stigma and lack of sympathy. The next paragraph describes the processes of suffering involved in dying from AIDS. They are taken from a confidential report on a particular individual from an African country:

> "During this period of many months, X would have to be cared for at home by her relatives and within the resources available to them. In the case of a poor household this will place an intolerable burden on them as X becomes unable to leave her bed and requires round the clock nursing. Care for her will generate many additional trips to the well (which is 1.5 kilometres from the house) each day, purchases of soap and occasional purchase of aspirin to alleviate her discomfort. This person will experience acute mental and physical suffering. Her suffering would be made up as follows:
>
> - Mental suffering: the knowledge on diagnosis that she had to look forward to a long period of discomfort, extreme pain, indignity and mental and emotional confusion;
> - Mental suffering: that she would know that she would become a burden to her family;
> - Mental suffering: that she would know that her children would be orphaned and undoubtedly lack care in a society where there are already many tens of thousands of AIDS orphans;
> - Mental suffering as she began to experience the first OIs.
> - Physical suffering: with the onset of OIs, she might experience any of the following: extreme and florid fungal infections of the mouth, genitals, nose, anus, throat and upper respiratory system with attendant irritation, choking,   inability to breathe, inability

to swallow, internal itching, discharges and unpleasant odours. She might experience a form of cancer called Kaposi's sarcoma and a form of shingles, which is extremely painful. This latter is most likely as she already suffers from herpes zoster. Generalised acute itching.

➢ Physical suffering from AIDS defining illness: she would very likely contract TB, experience bouts of acute pneumonia, suffer blindness and mental confusion – these latter most likely as she is already infected with cytomegalovirus (CMV). She would have swollen and painful lymph glands, acute, continuous and uncontrollable diarrhoea, wasting, dehydration, extreme pain. Terrible weakness as she lost body weight and acute nerve pains.

➢ All of the preceding with the expectation that all the treatment she might realistically expect to receive would be simple analgesics. In her final days she would struggle with the disorientation of dementia, blindness, urinary and faecal incontinence."

THE SEARCH FOR TREATMENT:

There is no doubt that many individuals and households have been impoverished by the fruitless search for treatment. In circumstances where there are few medical facilities outside of urban areas, where those in urban areas are of a poor standard and where free treatment is rare and of poor quality with patients having to purchase their own medications, food and even rubber gloves for examinations, the costs borne by individuals and their families soon mount up. In countries where state spending on all health care provision is probably less than £3 per head per year, where GNP per capita is in the region of £300 per year and where many people live on the edge of poverty, the search for treatment is the last straw. It may create not only poverty but also destitution. The creation of more destitute people is of especial significance an epidemic, which impoverishes and makes destitute, is storing up later demands that will probably require disaster relief similar to that being seen today in Southern Africa and Ethiopia.

So, the question might be posed, is it better value for money to spend money on helping people to receive treatment now and over the longer term than to have to respond with relief assistance to greater numbers of people at increasing intervals over the next decades? This is a question, which goes beyond national governments expenditures and raises the broader issue of synergistic versus conflicting action by government departments.

THERE ARE NO LONGER ANY UNAFFECTED

In early work it was conventional to make a distinction between households which were infected, affected and unaffected. The affected being those who while not sick were affected by increased care responsibilities whether in paying for care, losing a worker or caring for orphans. Today we know that in many parts of Africa the effects of the epidemic are so bad that it is not possible to speak of unaffected households or communities. The effect has been to weaken the ability of households and communities to cope and to care for themselves. This is a process of long-term material impoverishment and the creation of new and enduring destitute groups in societies, which previously were only poor.

The significance of this is that in many parts of Africa and perhaps in other world regions, the HIV/AIDS epidemic will alter the terrain in which international development agencies operate.

The implications of this are as follows:

HIV/AIDS IS NO LONGER A "MERE" DEVELOPMENT PROBLEM.
It is a new phenomenon which questions whether development is possible and if it is how it is to be done.

In most of Eastern, Central and Southern Africa, we are seeing one part of this long wave event, a full-fledged, long-wave emergency. This is only the first such emergency: others will be nested within the larger curve of the long wave event. Such an emergency cannot be resolved by short-term injections of food aid and agricultural inputs (seeds, tools, etc.). This new category of emergency has specific characteristics with critical implications for food security and, therefore, for the work of agencies. We do not know the full extent of its potential duration.

The specific characteristics of such a new variant emergency include:

i. The magnitude of the epidemic -- in terms of
   - Adult HIV/AIDS prevalence rates
   - AIDS related illness and death
   - Cumulative, systemic impact will span 2-40 years in many affected countries.

ii. **The crisis develops over a very long period**. This means that there is a choice:
   - Fail to act because it is happening slowly (which is what has occurred so far), or
   - Respond now so as to change the future
   - Respond pro-actively in areas not yet visibly affected

iii. **Recovery potential is diminished** by the HIV/AIDS epidemic:
   - community structure is weakened, safety nets break down
   - because in mature epidemics women are affected by HIV/AIDS more than men, the gender balance is altered. Thus, assumptions about the availability of women's labour and skills for household and farm work will not hold.
   - dependency ratios are made worse
   - many adults who are alive are sick, thus the technical dependency ratio based on counting living individuals appears better than the "real" dependency ratio derived from counting active adults available to work.
   - working adults have to care for those who are sick and the days are punctuated by funeral obligations

iv. **Long term demographic changes alter the technical response possibilities**: changed gender and age balances in a population will challenge existing technologies which are based on assumptions about the age/gender balance of "typical" communities

v. **The contours of destitution are redefined** and now include the very young and the very old, and among these women in particular. The numbers of destitute people in rural areas are also increasing – people whose destitution reflects inability to access resources or decreased ability to use available resources as a result of weakened social, economic and in some cases, environmental, infrastructure

vi. HIV infection tends to cluster in families, households and communities. This means that some communities will be affected by AIDS related destitution more than others.

vii. Generalised seroprevalence measures are not fine-grained. They obscure the ways that communities and households within them are selectively affected by HIV/AIDS and subsequently impoverished.

viii. In most situations of advanced food insecurity – which may be described as famines –men have died in greater numbers than have women. This has implications for recovery and coping responses. In a mature HIV epidemic, more women than men are infected. This is likely to result in a different distribution of capabilities, technical competencies and culturally mediated expectations of caring and management roles.

The implications of these changes for agencies' HIV/AIDS work may be illustrated in relation to the rural sector as follows:

- **The starting point for intervention**–by governments and agencies--**is different** from what it has ever been before. The demographic base of communities has changed, household labour and skill profiles have been impoverished and community safety nets have been weakened.

- **Assumptions about social networks and community safety nets have to be reviewed**. Pre-existing structures and institutions may be impaired or will have ceased to function.

- **A particular skill loss is women's knowledge of how to survive in adverse conditions**-–the importance of this is currently apparent from interviews in Zimbabwe where unattractive roots have nutritional value but are known and gathered only by women.

- Expectations for the future: all previous recoveries have been underpinned by expectations of a better future. This may not be the case in the context of an HIV/AIDS epidemic where the **foreseeable recovery time may exceed most human life expectancies.** Many rural populations may have had their morale sapped and lack the subjective capacity to recover. In such circumstances, personal, household and community

strategic planning becomes difficult to commence or sustain.

- In a society impacted by a mature epidemic and other crises, such as drought or flood, the process of strategic withdrawal from full production to gathering wild foods may accelerate from a year or two to mere months or even weeks. This situation demands that ability to respond is similarly rapid and in place before the process commences.

Once again the question of value for money assessment is raised in a very acute form and in particular the issue of time period between expenditure and effect is posed.

Hence we turn in the next section to a consideration of the methodological issues in undertaking an assessment of HIV/AIDS work and in particular to a consideration of the question of cost, effectiveness and returns on investment in relation to this very large magnitude long wave event.

SECTION 6: A SUGGESTED METHODOLOGY FOR EVALUATION

KEY CONCEPTUAL ISSUES

The guiding principle of the work of the National Audit Office is to make an assessment of value for money. This apparently simple approach is in fact problematic in many contexts and perhaps more so in relation to making judements about returns to investment in relation to HIV/AIDS interventions.

WHAT DO WE MEAN BY "VALUE FOR MONEY"?

Value for money is problematic. It assumes that there was a clear and specific goal in mind at the time when the expenditure or investment was commenced. We are all familiar with the simple view of this from childhood, confronted with a selection of sweets on a shelf and a limited amount of money, which one to purchase? The decision is the result of subjective and objective factors.

Value for money may be taken to approximate to cost effectiveness analysis. Cost-effectiveness attempts to assess what is the lowest cost method of achieving a given target benefit. The benefit can be specific in terms of its scale, e.g. an absolute number of women's lives saved or number of households lifted out of poverty; or, it can be scale independent, e.g. cost per life saved or per household lifted out of poverty. Scale independence might suggest the possibility of widespread replication and a more strategic decision-maker; e.g. this is the most cost-effective method to reduce household poverty in Pakistan, rather than in a particular village.

Cost-effectiveness has problems in terms of choosing the target. The target needs to be relatively easily observable, but also sufficiently abstract and "developmental" to have multiple methods of hitting it. The target of "ten young person in this village going into more productive employment" is more useful for cost-effectiveness analysis than the target that "ten young people go into vocational education". The former suggests there may be multiple routes to achieve this development goal. The latter narrows down the target and are more about the efficiency of delivering vocational education than effectiveness in achieving a developmental goal.

THE PROBLEM OF VALUE FOR MONEY IN RELATION TO HIV/AIDS

Here we proceed to consider some of the methodological problems associated with making a value for money assessment of its work in relation to HIV/AIDS. It is assumed that value for money/cost effectiveness analysis will not be the only technique used in this evaluation as it will be quite clear from the following discussion that while such techniques have a place, <u>they are very limited in what they can tell us about performances in relation to HIV/AIDS.</u>

A simple view of cost effectiveness/value for money analysis assumes that there is a set of discrete targets to decide between and that these are in some sense measurable, however many organisations' strategic aims do not meet these criteria. In fact they are nested vertically and interlocking horizontally.

Vertical nesting refers to the ways that each project or programme of work should in principle be logically derivable from overarching policy frameworks and derivable working principles.

On first sight, this presents a kind of decision algorithm through which any project or programme planner should have worked when developing an idea for implementation. One might assume that each project or set of projects forming a programme would then have been examined at a higher level to ensure consistency with the requirements of the policy algorithm and that agency senior manager would feel able to justify each and every detail and explain that the designed "outputs" reflected the best use (value for money/cost effectiveness) of each unit of input. The output being the best buy. Of course no real organisation works in this way, although such a model may be an administrative and management ideal.

A cost effectiveness/value for money analysis would have to begin with the following questions:

(a) when was HIV/AIDS first identified as relevant to an agency's work?
(b) what changes in policy strategy framework have occurred in the organisation since the earliest identification of HIV/AIDS as an issue?
(c) when was the policy/strategy structure just described established?
(d) what institutional changes were put in place at each stage of the development of policy/strategy?
(e) how cost effective were these administrative/management and policy responsibility responses?
(f) who took the decisions or did not take the decisions?
(g) against the background information in answer to the above, how far was value for money a consideration and how can that be demonstrated?

Thus, in relation to the concept of vertical nesting we might want to make the key value for money questions:

(a) how rapidly could an agency have been expected to develop a response to HIV/AIDS? What evidence existed at each stage of the development of policy and how much value was generated for each stage of the response process? Value here could be defined in relation to:

- numbers of new projects specifically created to deal with some aspect of HIV/AIDS
- numbers of new staff and levels of staff taken on or allocated to deal specifically with HIV/AIDS
- numbers of documents published directly by the organisation or financed by more than x per cent by that organisation and dealing with HIV/AIDS
- numbers of people estimated to have been beneficiaries of projects generated

(b) Was this a value for money use of resources in relation to the defined problem at that time?

The difficulty here is that problem definition will have been unclear for many reasons, including that at first nobody understood just how serious this issue might become. This is where the value for money/cost effectiveness framework breaks down. The question then becomes one of how to assess cost-effectiveness in conditions of such unclarity with regard to targets. The answer might be to approach the issue in relation to the concepts of *response time* and *knowledge processing*.

Response time: refers to the time that it took for the need for a response to be recognised and the type of response that was instituted at that stage. These could be measured in months from the first appearance of the epidemic in the medical literature (1981) and the type of response could be measured in terms of a scale from weak (addition of a watching brief to an existing workload) to strong (commitment of one person of x level of seniority to work on this full time). These responses could then be considered in terms of their outputs – but here we will come up against the time problem, which is discussed below.

Knowledge Processing:
 This sees knowledge as a product, which is to be produced and used. This is an important concept and should contribute to the value for money/cost-effectiveness evaluation. The organising question is: "How rapidly did the organisation get a return on its investment in knowledge production?" To answer this we pose some subsidiary questions:

(a) what structures exist for gathering and distributing knowledge to appropriate parts of the organisation?
(b) How has this system changed in response to the epidemic and is there any evidence that knowledge is being

gathered and deployed effectively and rapidly?

(c) Can organisations point to efficiency changes as a result of the introduction of any revisions to the ways that knowledge is generated, gathered and deployed? This might be measured by reference to changes in the response time to an innovation or insight from new knowledge.

(d) In particular, what gains in response time have occurred as a result of innovations in organisational knowledge systems?

(e) How much has been spent by an organisation on programmes of knowledge generation, distribution and use, how many and what types of product and how many and what types of specific use of this information so produced have occurred within an agency?

These are only sketches of how the value for money evaluation might be done in this area by combining the concepts of response time and knowledge process in order to arrive at some measure of input output relationship.

(c) What changes were identified as required to meet the challenge of HIV/AIDS at the various stages of its entry into organisational policy? How were funds allocated to reach this goal? How much and what was the identifiable output from the changes?

Horizontal Interlock

This term refers to the other side of the equation: the difficulty of arriving at a view of the degree to which investments have enabled cross hierarchy synergies to be generated. We have seen that HIV/AIDS is a multi-sectoral issue *par excellence*. To make a value for money evaluation here requires an assessment of the degree to which specific horizontal activities were introduced or strengthened in response to HIV/AIDS and at what times.

THE PROBLEM OF WORKING IN AN INDETERMINATE CONTEXT

This problem will be apparent from what has already been said. HIV/AIDS has been a moving target – worse than that it has been a multisectoral, regionally differentiated moving target. This has meant that organisations have had to decide between this target and others in terms of their attention. The key question then becomes one of leadership and the assessment of value for money in leadership. This may be a difficult issue to confront because it risks personalisation. However, it can and should be approached by addressing the question of who was responsible for responding to HIV/AIDS at what stages of the epidemic's development,   what outputs in terms of policies,

strategies and interventions were developed during their incumbency. Particular questions to address include: what strategic decisions did they take and what were the payoffs (or not)?

This has already been alluded to in several aspects of the preceding discussion. These points will not be repeated. But two important considerations must be taken on board:

> (a) This is a very long wave event – the evaluation process must take this into account
> (b) The effects of an HIV/AIDS epidemic may be in the hedonic[16] as well as the material, easily measurable realms and thus the return to investment must be considered in relation to hedonic, less easily measured criteria.

The most important issue is the datum point for measurement of any output in relation to input. To take an example from the author's own work, the research on community coping mechanisms in 1988-90 (Barnett and Blaikie, 1990). At year one from the report, the attention it received would have indicated low return to the investment of almost £170,000. In year three, it still received little attention despite publication of a book drawn from it. However, the UN FAO and UNDP commissioned a replicative study of four African countries as a result of this work; until 2000 little attention was ever paid to the findings of this research apart from among a very small group of specialists. Since 2000 the findings are widely considered to have been foresightful and the 1990 report and the 1992 book can be seen to have generated a large amount of subsequent work, policy awareness and very shortly a flood of interventions. The question is: "at what stage would it have been appropriate to make a judgement as to cost-effectiveness/value for money?

The same question inevitably arises in relation to research on syndromic management of STIs. It is even more pronounced if we consider areas such as orphan care, provision and development of ARVs for prevention of mother to child transmission(MTCT) or treatment of people who are sick, or the development of labour saving technologies to assist rural populations affected by the epidemic.

The practical response to this particular methodological challenge is:

> (a) to recognise the possibility of multiple datum points and that value for money analysis will only be a provisional judgement
> (b) the importance of hedonic factors in the return to investment so as not to underestimate the returns.

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[16] For an introduction to these issues, see Frey and Stutzer, 2002.

While value for money/cost effectiveness analysis can be used as <u>part</u> of an evaluation process, in this instance it is important to note its limitations.

The approach is simpler than Cost Benefit Analysis (CBA). But it is not unproblematic conceptually or empirically. The greater simplicity of cost effective analysis (CEA)/ value for money (VFM) comes at a cost. For instance, it tends to de-integrate decision-making into intra-sectoral choices, choices between projects and programmes and to assume unrelated targets. It also plays downs community contributions and effects – the frequently mentioned *hedonic* aspect of the problem. In addition it cannot deal with the issue of time.

SECTION 7: WEB SOURCES AND BIBLIOGRAPHY

KEY WEB SOURCES SOCIAL AND ECONOMIC ASPECTS OF HIV/AIDS ISSUES

International AIDS Economics Network

IAEN INFORMATION RESOURCES SURVEY
April 2004

The International AIDS Economics Network (IAEN / http://www.iaen.org) recently polled its members in 130 countries about the best information resources available to AIDS professionals worldwide. The polling returned 258 completed surveys from 64 countries listing over 2700 information resources. Approximately half of the returned surveys were from developed countries, half from developing countries.

The following tables list those resources cited most often by IAEN members and other respondents. (Note that the IAEN itself scores highly, a figure that is inflated compared to other resources because the IAEN network was used for the survey). Additional data and analysis from this survey will be available at the IAEN website <http://www.iaen.org>.

1) CUMULATIVE RESULTS

This table lists those information resources cited most frequently across all the questions of the survey – over 2700 resources cited in total:

Order	Resource	URL	Votes
1	UNAIDS	http://www.unaids.org	339
2	IAEN	http://www.iaen.org	305
3	World Bank	http://www.worldbank.org	204
4	WHO	http://www.who.int	126
5	Kaiser Family Foundation	http://www.kff.org	100
6	USAID	http://www.usaid.gov	57
7	Centers for Disease Control / US	http://www.cdc.gov	56
8	Global Fund	http://www.theglobalfund.org	43
9	Synergy AIDS	http://www.synergyaids.org/	38
10	AIDS India eForum	http://groups.yahoo.com/group/AIDS-INDIA/	35
11	AF-AIDS (Southern Africa AIDS Listserve)	http://archives.healthdev.net/af-aids/	34
12	UN	http://www.un.org	31
13	Aegis	http://www.aegis.org	29
14	Development Gateway	http://www.developmentgateway.org	29
15	Google	http://www.google.com	29
16	IRIN	http://www.irinnews.org	28
17	Eldis	http://www.eldis.org	27
18	Aidspan	http://www.aidspan.org	26
19	Global Health Council	http://www.globalhealth.org/	25
20	aidsmap	http://www.aidsmap.com	24
21	UNDP	http://www.undp.org	24
22	SEA-AIDS (Southeast Asia AIDS Listserve)	http://archives.healthdev.net/sea-aids/	22
23	HIV Insite	http://hivinsite.ucsf.edu/	20
24	The Body	http://www.thebody.com	19
25	Medscape	http://www.medscape.com/	17
26	Family Health International	http://www.fhi.org	16
27	The Communications Initiative	http://www.comminit.com/	15
28	National AIDS Control Organisation / India	http://www.naco.nic.in/	15

29	National Institutes of Health / US	http://www.nih.gov	14
30	BBC	http://www.bbc.co.uk/	13
31	Gender and AIDS	http://www.genderandaids.org/	13
32	Saathi	http://www.saathi.org	12
33	3x5	http://www.who.int/3by5/en/	11
34	Afronet Online	http://www.afronet.com	11
35	Gates Foundation	http://www.gatesfoundation.org	11
36	International AIDS Society	http://www.ias.se	11
37	World Economic Forum	http://www.weforum.org	11
38	AIDS Alliance	http://www.aidsalliance.org/	10
39	Yahoo	http://www.yahoo.com	10
40	Johns Hopkins University	http://www.jhuccp.org/	9
41	The Lancet	http://www.thelancet.com	9
42	UNICEF	http://www.unicef.org	8
43	CNN	http://www.cnn.com	7
44	Foundation Center	http://www.fdncenter.org	7
45	New York Times	http://www.nytimes.com	7
46	aidsmeds.com	http://www.aidsmeds.com	6
47	CABA Forum	http://synergyaids.org/Caba/cabaindex.asp	6
48	PAHO	http://www.paho.org	6
49	PubMed Central	http://www.pubmedcentral.nih.gov	6
50	UNRISD	http://www.unrisd.org	6

http://www.lse.ac.uk/collections/DESTIN/whosWho/barnettt.htm

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