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# **Back to Basics**

Putting the Epidemiology Back into Planning and Monitoring HIV Prevention Programmes.

Case Studies in Indonesia

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PhD Thesis 2006

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## **Abstract**

### **Background**

In under 30 years, some 65 million people have become infected with HIV worldwide. New infections continue to rise despite unprecedented global spending on HIV prevention. Evidence about the distribution of HIV and risk behaviour appears to be underutilised in prioritising and managing effective HIV prevention efforts.

### **Objective**

To strengthen the HIV-related surveillance system in Indonesia, and to develop an analytical framework which can be used to relate the epidemiology of HIV clearly to HIV prevention and care efforts. To use this framework with public health officials to improve planning and management of HIV prevention in Indonesia.

#### Results

Efforts to strengthen and institutionalise HIV surveillance systems in Indonesia were successful. New methods for populations size estimation and management of surveillance data have been adopted as best practice by international institutions. An analytical framework was developed focusing on three sequential factors: the likelihood of an HIV-infected person having sex or taking drugs with an uninfected person, the likelihood that body fluids are exchanged in a discordant contact, and the likelihood that an exposed, discordant contact will result in a new infection. The focus on discordancy draws attention to the need for appropriately targeted programmes, and the framework obliges programme planners to clarify the mechanisms through which their efforts will lead to reduced transmission of HIV. The framework was successfully used with local health officials to identify prevention priorities and to suggest improvement to existing programmes. However limited human resources and distorted incentives currently constrain the institutionalisation of this type of analysis.

### Conclusion

Strong national surveillance systems are achievable in resource-constrained settings. A simple analytic framework can focus attention on HIV prevention priorities and lead to improved prevention efforts. International policies should demand evidence-based planning and HIV programme management, and support long-term efforts to increase capacity for appropriate analysis.

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# **Declaration by Candidate**

I have read and understood the School's definition of plagiarism and cheating given in the Research Degrees Handbook. I declare that this thesis is my own work, and that I have acknowledged all results and quotations from the published or unpublished work of other people.

Signed:	 	 	
Data:			

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# Chapter 1: Evidence-based decision-making in HIV prevention

## 1. Introduction

Public health research generates information to guide a society's choices in safeguarding the health and well-being of the population. Surveillance and systematic reporting of disease and consequent policy action have been common for centuries and have been fundamental to the success of some of the great public health triumphs of our times, such as the eradication of small pox. (Halperin, Baker et al. 1992). However it is only fairly recently that the ideas of "evidence based decision making" and "results based decision making" have gained currency in the political dialogue surrounding health and development.

This work begins with a review of the history of evidence-based decision making in the field of HIV/AIDS – arguably the defining pandemic of the late 20<sup>th</sup> century. The very scale of the pandemic of HIV – an infection preventable through just a few, technologically simple methods — stands as testimony to our poor use of evidence to date. The reasons for this failure are examined in Chapter 1. It is argued that they include a poor evidence base, an inappropriate analytical framework, and limited incentives for improved decision-making. The failure to keep the basic principles of infectious disease epidemiology at the heart of analysis, in particular, has led to poor decisions about prevention and care programmes.

The remainder of the work seeks to overcome these failures, in the context of Indonesia, a low-income country where HIV remains concentrated largely among those who inject drugs and buy and sell sex. At the outset of the research, in 2001, the country's surveillance system was patchy, and data generated by the system were not used to set prevention and care priorities or to manage programmes. Chapter 2 describes work undertaken to build a coherent government-managed surveillance system providing all the information needed to inform the planning and management of HIV prevention initiatives. This included development of new methods for

population size estimation and data management, as well as new approaches to donor collaboration. The successes and limitations of these efforts are discussed.

In Chapter 3, I propose a simple framework for analysis of the epidemic situation which focuses on the factors upon which the spread of HIV depends – the likelihood that an infected person will take drugs or have sex with an uninfected person, the likelihood that body fluids will be exchanged if infected and uninfected people do have contact, and the likelihood that HIV will be transmitted if body fluids are exchanged between an infected and an uninfected individual. The framework rearranges the elements of the reproductive rate of infection identified by Robert May and Roy Anderson in 1987 into a sequence that takes into account population size and background HIV prevalence levels, and is of immediate relevance to HIV prevention efforts. It is suggested that this framework is appropriate for use with public health officials in settings where analytic capacity (and sometimes understanding of the basic epidemiology of HIV) is limited, since it focuses attention very clearly on the areas where transmission is most likely, and draws attention to the potential impact of different prevention efforts.

Chapter 4 gives an example of this analytic approach in action, using data generated by the Indonesian surveillance system for the capital city, Jakarta. The analysis uses a matrix constructed in a simple Excel spreadsheet to look at which behaviours are the source of the largest number of unprotected, discordant acts of sex or injection with an elevated risk of HIV transmission. Simple examples are given of the use of this analytic approach to assess the actual or potential impact of different HIV prevention programmes. This chapter provides examples of how the framework might be used together with routine surveillance data to answer the question: What should we be doing in HIV prevention?

Most HIV surveillance guidelines mention that surveillance data can be used not just to set prevention and care priorities, but to monitor and evaluate programme efforts. However there are very few examples of data being used in this way. In Indonesia, we developed a simple sequence of core questions that can be asked of surveillance and programme monitoring data in order to improve the understanding and management of HIV prevention programmes. Described in Chapter 5, this question sequence links programme effort to the analytic framework outlined in Chapter 3, to

help determine the extent to which prevention and care efforts are altering the course of the epidemic.

The penultimate chapter, Chapter 6, describes experiences using the framework in three rather different epidemic and institutional settings, two in Indonesia and one in China. Examples of the resulting analysis are given, and the effects that the analysis had (or didn't) on programmes is described. The chapter concludes with a summary of lessons learned while using the framework with public health workers, and discusses the appropriateness of the approach across different epidemiological and institutional settings.

Finally, Chapter 7 revisits the issues that were identified in Chapter 1 as standing in the way of the use of data as a basis for programme planning and management. It assesses the extent to which the advances in the collection, management and analysis of surveillance and programme data achieved in Indonesia since 2001 have overcome weaknesses in the evidence base. It reviews the utility of an analytic framework, described in Chapters 3-5, that links epidemiology closely with programme delivery and performance, and assesses the relevance and generalisability of that framework in different situations. The chapter also weighs up the success of efforts to create structures and incentives that support data-based decision making in HIV prevention and care. The implications of the Indonesian work for both policy and research are discussed.

# 2. Evidence-based decision making in health

Health research aims to provide information that will help people to live longer, happier lives, either by affecting the decisions they make about their behaviour, making new technologies available, or influencing policies that affect health and well-being. Research results do not, however, always lead to such changes.

In a paper for a 1998 symposium on translating epidemiological evidence into public health policy, Alfred Sommer declared "The central premise of this symposium, that data can drive public policy, is both laudatory and even vaguely plausible. The historical record, however, is not encouraging." The very fact that the symposium

("From Epidemiology to Policy: a Symposium on the Translation of Epidemiologic Evidence into Public Health Policy.") was deemed necessary suggests that basing treatment, prevention, investment and other health-related decisions on evidence has not been the norm. (Matanoski 2001; Brownson, Royer et al. 2006). But it is an indication, too, of a growing interest in basing decision-making in medicine and health policy on strong evidence.

In the field of international health policy, an important impetus for refocusing health programmes on evidence was the World Bank's 1993 World Development Report, "Investing in Health". Although its methods and assumptions continued to be hotly debated several years after its publication (Anand and Hanson 1997; Musgrove 2000), the premise – that countries could greatly improve health outcomes by refocusing their attention on the local causes of disease and disability, as well as on primary prevention and care rather than tertiary curative facilities – has gained currency. The call for a strengthening of basic health systems and more comprehensive use of the local evidence base within those systems influenced development assistance thinking in several countries, including the United Kingdom and Canada. (Dean 1994; de Savingy, Kasale et al. 2004)

# a Evidence in practice: the Tanzanian experiment

In response to the 1993 World Development Report, Canada provided funding to test the premise that small overall increases in health funding could achieve significant results in improved health outcomes if decisions about policies and programmes are made locally, guided by local data. The project, eventually known as the Tanzania Essential Health Interventions Project (TEHIP) was implemented in two Tanzanian districts where a comprehensive Demographic Surveillance System was available to provide data for estimates of the local burden of mortality.

The TEHIP project began from the premise that health policies are never based entirely on data. "Formative research into the health systems planning process confirmed that planning was not being conducted as a response to the burden of disease, but instead was driven by a wide range of factors including donor agencies' agendas, bureaucratic inertia, and simple guesswork." (de Savingy, Kasale et al.

2004) Taking this into account, the project aimed in part to change the incentives within the system to reward evidence-based planning. An important step was to get multiple donors to commit to a sector-wide funding approach, so that local governments would have the means to act on locally-specific plans, without being hijacked by donor-specific programme priorities. The project was also able to provide a small amount of top-up funding for service provision in areas that were found to be epidemiologically important in the local context, to encourage investment in those areas. Budgetary flexibility that provides funds to act on analysis/research findings as necessary can be a very important mechanism in translating the results of surveillance or public health research directly into action. (de Savingy, Kasale et al. 2004)

The failure of epidemiologists to take into account the costs of various alternative courses of action has also been cited as a reason why good research does not translate into action. (Matanoski 2001) The 1993 World Development Report puts cost effectiveness of various interventions at the core of its analysis. The TEHIP project provided simple tools to track budget allocations in health, although it had a harder time tracking the actual costs of specific packages of interventions or assessing coverage, in part because information on the denominator was hard to come by. The bigger question of the allocation and effectiveness of spending on health versus in infrastructure development, education, national defence or other priorities was not addressed.

Another important obstacle to data-based decisions is that policy-makers don't have the time to sift through data for the one or two key, actionable findings, and analysts rarely do it for them.(Matanoski 2001) There are several reasons for this. In industrialised countries, some people trained in the skills to provide this sort of policy advice feel that doing so compromises their integrity as scientists. (Rothman and Poole 1985; Poole and Rothman 1998; Savitz, Poole et al. 1999; Editor-in-Chief 2001; Weed 2001) In developing countries, analysis skills are most likely to reside in academic institutions – academic researchers may have limited interaction with policy makers and therefore not understand their needs, or they may have limited professional incentives to present data in an easily digestible format to a policy audience. (Brownson, Royer et al. 2006) People who work within the public health

system may also have analytical skills, but may be better rewarded financially or professionally for spending time on other tasks. (Pervilhac, Stover et al. 2005)

The TEHIP project designed simple tools for the analysis of distribution of disease and of budget allocation, and trained and paid staff to use them. These tools automatically generated a small number of simple graphics focusing on the things that policy makers care about and react to.

The outcome of the Tanzanian project (which overlapped with part of a WHO-backed multi-country evaluation of Integrated Management of Childhood Infections - IMCI) was considered positive. Before the analysis of the local burden of disease and local health budget allocations, just over a tenth of spending was allocated to malaria in Morogoro district, although it accounted for nearly a third of the disease burden. Four years later, after the analysis and mapping tools had been institutionalised, the fraction rose to over a quarter. Similarly, funding for sexually transmitted infections (STIs) increased around five-fold to just under 10 percent, after it was shown that they accounted for close to 15 percent of the disease burden. (de Savingy, Kasale et al. 2004) The project believes that this shift has contributed to a major improvement in health outcomes, most notably a 40 percent reduction in under-5 mortality, the result in part of a strengthening of IMCI services.

The intention is to expand the TEHIP experience, including the tools and the management structures, to other districts in Tanzania's decentralised administrative system, and possible to other countries. (de Savingy, Kasale et al. 2004) The success of this venture will be determined in part by one of the central challenges in databased decision making: the availability of quality data. The TEHIP district analyses were possible because the districts had demographic surveillance systems. There are a growing number of such systems worldwide, but they remain few. The InDepth network, which acts as a forum for exchange of experience and technical knowledge for demographic surveillance sites in the developing world, lists just 37 sites in 18 countries in the developing world (including the TEHIP sites). Most countries (and all but a handful of districts in developing countries) will not have DSS-type data to inform their decision-making. This begs the question: how much locally specific data is necessary to inform decisions, and what is the most cost-effective way of

collecting such data? The discussion of surveillance systems later in this chapter will return to this issue.

The question of data availability does not diminish the central lesson of the seven year TEHIP experience – that money spent on adequate services that address the sources of ill-health in a community will result in less sickness and death, compared with money spent on conditions which are not of great importance in the local disease picture. This confirmed in practice the World Bank's assertion that a minimum package of primary interventions guided by local data would produce better health outcomes for roughly the same investment as was already being made.

# b The multi-country evaluation of IMCI services

International organisations, or those working in the international health and development arena, are under pressure to come up with policies, guidelines, handbooks and toolkits which are applicable in a wide variety of situations. Very often, these are the product of an idea that has been developed and worked well in one country, and which then gets written up in a generic form and distributed around the world. While the guidelines inevitably recommend adaptation to local conditions as appropriate, this adaptation is rarely adequate, and often altogether absent. (Lush, Walt et al. 2003; Bryce and Victora 2005)

The guideline development process is often very consultative, and international organisations are staffed by people whose breadth of experience is considerable. This means that guidelines that are issued may well subsume experience from and address the needs of many countries. But it may also contribute to a tendency to be prescriptive and to promote operating procedures rather than analytical approaches. As Haines et al. said: "Many stakeholders involved in implementing public health interventions do not appear to perceive investment in rigorous evaluation to be a priority: they believe they know what should be done, and their main priority is to put their beliefs into practice." (Haines, Kuruvilla et al. 2004)

An admirable effort to conduct a rigorous evaluation of the use of global guidelines in local practice was initiated by the WHO's Department of Child and Adolescent Health, which conducted a multi-country evaluation of the implementation of the

WHO's guidelines for IMCI. (WHO 1997) As the evaluation's author Jennifer Bryce notes, IMCI guidelines were developed as a generic international standard for countries with high under 5 mortality, particularly related to malaria, diarrhoeal disease and acute respiratory infections. Institutional enthusiasm resulted in their being promoted for use far more widely. The WHO issued guidelines on adapting the original guidelines, and trained a core of consultants to help countries with this process. The results were slow, clumsy and far from satisfactory, especially in the countries whose childhood disease profiles diverged substantially from those for which they were originally intended. (Bryce, Victora et al. 2005)

Like TEHIP, the multi-country evaluation of IMCI found that structural issues such as staff turnover, staff motivation, budgetary and financial constraints, and mechanisms for translating policy into field operations were critical to determining the success of implementation, even though they were not specifically addressed in the guidelines.

The other major finding also mirrored that of TEHIP, although it was not intended as a primary focus of the evaluation: the success of the IMCI approach depended on its successful adaptation to local epidemiological conditions. So much so, in fact, that the authors of the evaluation conclude that it would be better to start from the local epidemiology and administrative framework and work up to a child survival strategy than to start from global guidelines. "It is time for a paradigm shift in child survival:...from single approaches requiring massive adaptation at country level to bottom-up approaches that begin with local epidemiology and apply tools developed for specific epidemiological profiles". (Bryce, Victora et al. 2005)

## c What constitutes "evidence"?

Both the TEHIP and the IMCI evaluation were based largely on data collected in routine health information systems, albeit systems greatly strengthened by the existence of the evaluation itself. Certainly, every text book or set of guidelines on public health surveillance starts with a definition that claims a central role in improving decision-making for surveillance data. (For example the textbook "Public"

Health Surveillance", begins with the quote from the United States Centers for Disease Control and Prevention (CDC) that defines public health surveillance as:

"the ongoing, systematic collection, analysis and interpretation of health data essential to planning, implementation and evaluation of public health practice, closely integrated with the timely dissemination of these data to those who need to know. The final link of the surveillance chain is the application of these data to prevention and control. A surveillance system includes a functional capacity for data collection, analysis and dissemination linked to public health programmes." (Halperin, Baker et al. 1992)

And yet there is very little discussion of the role of routine surveillance systems in the literature surrounding evidence based policy and, particularly, medicine. Rather, the debate is dominated by discussions of the relative merits of evidence generated by different study designs, and the importance, or lack thereof, of randomised controlled trials. (Rosenberg and Donald 1995; Bero, Grilli et al. 1998; Sheldon, Guyatt et al. 1998; Sheldon, Sowden et al. 1998; Cooper 2003)

In an editorial in the British Medical Journal, Muir Gray maintains that there are strong similarities between evidence based clinical practice and evidence based policy making. (Muir Gray 2004) However the types of evidence required for decision-making in these contexts may differ. Randomised controlled trials are obviously important for establishing efficacy. But for many public health issues, especially in the developing world, the efficacy of a solution is not in question. The feasibility of implementing it within a given health infrastructure, at a certain cost and in the face of opposition from particular entrenched interests may well be in question. But as the multi-country IMCI evaluation found, these are specific to particular localities – even if the underlying epidemiologies of a problem were the same, randomised controlled trials that seek to address population-level issues may generate results that cannot be replicated elsewhere in any case, because the infrastructure, resources or obstacles encountered are entirely different to those that were overcome in the study's intervention wing.

We are reminded that not all study designs are appropriate to all situations by the seminal paper by Smith and Pell (BMJ): "Parachute use to prevent death and major

trauma related to gravitational challenge: systematic review of randomised controlled trials" and, more soberly, by Geoffrey Rose, who points out that determinants of a disease which are very common in a population will not be captured by study designs that compare individuals within a population. (Rose 1985; Smith and Pell 2003) Nonetheless, these study designs are the best we have in our arsenal. And yet evidence produced by even these study designs is often considered "soft" by policy makers. (Matanoski 2001) The challenge of basing policy advice on imperfect but much more widespread routine surveillance systems is greater still. (Brownson, Royer et al. 2006)

# 3. Evidence and decision-making in the response to AIDS

HIV is probably one of the best documented epidemics in history. In the two and a half decades since AIDS was identified, the syndrome and the virus that leads to it have been tracked and studied across the globe. A huge body of epidemiological research reliably identified all routes of transmission within just a few years. By 1987, when a clear understanding of perinatal transmission completed the picture of HIV transmission modes, some 5,500 papers focusing on HIV had been published in the major medical journals listed in the PubMed system. By early 2006, the total stood at over 147,000 papers. This body of evidence has shown convincingly that the virus is spread through a limited number of behaviours, all of which are technically easy to modify so that the risk of HIV transmission is greatly reduced or eliminated.

In addition, AIDS and HIV surveillance systems were set up relatively quickly in many countries where the virus was known to be spreading. By 1995, 57 developing countries had HIV sero-surveillance systems that were considered by WHO to be "fully implemented" and another 83 had at least some functioning surveillance system. (Garcia-Calleja, Zaniewski et al. 2004) Behavioural surveillance was slow to follow, but many countries now also have fully implemented behavioural surveillance. (Pervilhac, Garcia-Calleja et al. 2004) The components of surveillance systems are discussed more fully below.

As early as 1990 (when more than 40 countries had sentinel surveillance systems for HIV), WHO reviewed the use of the data these systems generated. The review said that data were being used for:

- enhancing the commitment of policy makers, funders and staff
- targeting activities for population groups and areas
- programme monitoring and evaluation
- the development and testing of interventions
- resource allocation and long-range planning
- the educational value for individuals

(World Health Organization 1990).

However it was able to give concrete examples of data use in only the first two and the penultimate of these areas. A decade later, guidelines for second generation surveillance came up with a remarkably similar list: situation analysis, strengthening commitment, resource mobilisation, targeting interventions, planning and evaluation of interventions, and programme assessment and evaluation. (UNAIDS and World Health Organization 2000) It was another three years before examples of data use in each of these areas were published. (UNAIDS, World Health Organization et al. 2003) A recent review of data use for decision-making found that data generated by HIV surveillance systems and HIV-related research have been used quite effectively to raise political awareness, commitment and money. But in all the other areas listed above, data use was judged to be woefully inadequate. (Pervilhac, Stover et al. 2005) In under three decades, around 65 million people have become infected with HIV, and 25 million of them have died. An estimated 4.9 million people became newly infected in 2005. (UNAIDS 2005) These facts surely stand as testimony that existing data and evidence have not been well used in preventing the spread of HIV. This despite the fact that simple and cheap technologies (condoms, sterile injecting equipment, and effective screening for contaminated blood products) which could prevent infection have been available since very close to the start of the epidemic.

<sup>&</sup>lt;sup>1</sup> I wrote the publication in question for WHO; the majority of examples of data use were drawn from work in Indonesia described later in this thesis.

Most of the reasons for the failure to base decisions on sound evidence can be grouped in to the following areas:

- Limitations in the evidence base
- Distorted incentives for data-based decision making
- Inappropriate analytic frameworks

The remainder of this chapter will discuss the challenges in these areas.

# 4. The evidence base: HIV surveillance systems

The scientific evidence base for appropriate public health responses to HIV can be divided broadly into two categories – epidemiological research studies and routine surveillance data. The first has provided us with our understanding of transmission routes, the natural history of infection and intervention efficacy. Research designs have also been used to test programme effectiveness. Apparently conflicting results have sometimes led to confusion (for example in the interpretation of the results of STI treatment trials in East Africa). (Grosskurth, Gray et al. 2000) As Gail Kennedy and colleagues noted, "keeping abreast of the overwhelming and ever-increasing volume of research is an almost impossible task". (Kennedy, Peersman et al. 2002) Increasingly, efforts are being made to synthesise the lessons of all of this research. For example the Cochrane Collaboration has published 29 reviews of HIV-related research and has another 38 in the pipeline (www.chochrane.org), while the United States CDC's HIV/AIDS Prevention Research Synthesis has created a database of behavioural research, and the Policy Project has developed a database of intervention programme outcomes. (Kennedy, Peersman et al. 2002; Bollinger, Cooper-Arnold et al. 2004) These efforts have introduced a measure of "quality control", and made it easier to access the most recent thinking in a rapidly changing field. Overall, this body of research has provided us with a fairly good understanding of the major prevention options, answering the question: "In my epidemic situation, what should I be doing?"

It is the second of these two categories—routine surveillance systems — which provide answers to the equally important question: "Well, what *is* my epidemic situation?" What was found to be true in TEHIP and the multi-country evaluation of

IMCI must also be true for HIV prevention: there is no point thinking about solutions until we have correctly diagnosed the problem. This is the starting point for any effective response to HIV. Reliable and sufficiently complete surveillance data must therefore be at the foundation of any body of evidence that will be used in effective decision-making.

What follows is a brief review of the development of HIV and related surveillance systems, their growing strengths and continuing limitations, with a focus on developing countries.

## a The early years: case reporting and HIV serosurveillance

In the early years of the AIDS epidemic, surveillance systems concentrated on reporting AIDS cases. By the late 1980s, AIDS was a notifiable disease in most countries. The limitations of AIDS case reporting were, however, manifest from the start. Diagnostic criteria were unclear and frequently revised, capacity for diagnosis was limited in many settings and ham-strung by the stigma associated with AIDS in others. Even in situations where AIDS case reporting was relatively complete, the long period between HIV infection and the development of AIDS reduced case reports to a proxy for incident HIV infections a decade earlier. (Chin 1990; Colebunders and Heyward 1990; Buehler, De Cock et al. 1993; World Health Organization 1994; Centers for Disease Control and Prevention 1999)

In 1988, the World Health Organisation proposed systematic cross-sectional HIV testing among specified populations as a way of tracking the epidemic. (Slutkin, Chin et al. 1988) The 1998 proposal stressed the need for comparable samples and methods over time, so that trends in HIV infection could reliably be tracked. Unlinked, anonymous surveillance was proposed. However the paper was vague about the selection criteria for populations to be included in sentinel HIV surveillance. Clients at antenatal clinics (ANC) and clinics for the treatment of sexually transmitted diseases (STD) were specifically recommended as "target populations", and prostitutes, truck drivers and military recruits were also mentioned. No mention was made of risk behaviour.

The WHO's Global Programme on AIDS (GPA) developed draft guidelines for unlinked, anonymous HIV sentinel surveillance in 1989, (World Health Organization 1989) and supported many countries in developing surveillance systems for HIV and AIDS. More attention was paid to generating data than to setting up sustainable systems within routine health information structures; when GPA came to an end in 1995, to be replaced by UNAIDS, there was a hiatus in active support for HIV surveillance. The number of countries with sentinel surveillance systems judged to be adequate to their data needs dropped significantly between 1995 and 2001 (Garcia-Calleja, Zaniewski et al. 2004). It has been rising again in recent years, in part because of a rise in available resources and an increased demand on the part of institutions providing those resources for quantifiable measures of programme impact.

## b Bringing in behaviours

Questions about the adequacy of existing sentinel surveillance systems began to arise in the mid-1990s, when the proportion of women testing positive for HIV at urban antenatal clinics in Uganda began to fall. The steepest declines were registered among the youngest age groups. Similar reductions in prevalence were indicated by more rigorous cohort studies in the same country (Kamali, Carpenter et al. 2000). This raised several questions. Firstly, was the fall real, or was it an artefact of changes in sampling or surveillance methodology? Secondly, if the fall was real, was it the result of fewer people becoming newly infected with HIV, or of more infected people dropping out of the pool tested because of infertility, death or some other reason? Finally, the question of greatest interest to policy-makers -- if there was a real decline in new infections, could it be attributed to HIV prevention efforts? (UNAIDS 1999) A meeting called to review the evidence in Nairobi in February 1997 looked carefully at a number of behavioural studies in Uganda (principally nationally-representative cross-sectional surveys of sexual behaviour conducted in 1989 and 1995), as well as data from cohort studies, and compared changes in reported behaviour in different age groups with changes in HIV prevalence. The meeting concluded that a reduction in risk behaviour was likely to have contributed to a real reduction in HIV prevalence among young Ugandans (Asiimwe-Okiror,

Opio et al. 1997; UNAIDS 1998). It also led to preliminary recommendations for wholesale changes to national HIV surveillance systems, described below. (UNAIDS 1998) It was at that meeting that we first used the term "Second Generation Surveillance" to describe the systems that were emerging as the new model.

The only other developing country to have registered falls in HIV infection by the mid-1990s was Thailand. Thailand began to establish a comprehensive HIV sentinel surveillance system in sub-populations with high risk behaviour as early as 1989. National surveys of sexual behaviour were carried out in 1990 and 1993, and behavioural surveillance was also established among populations with high risk behaviour, including sex workers and mobile male groups. (Mills, Benjarattanaporn et al. 1997) Data from detailed tracking of HIV and STI infection and risk behaviour among male military recruits were also available. These data indicated that sharp falls in HIV infection among some groups – including female sex workers and military recruits – were preceded by reductions in unprotected commercial sex, STI prevalence and STI cases. (Nelson, Celentano et al. 1996; UNAIDS 1998)

## c Second generation HIV surveillance

The reviews of the Ugandan and Thai experiences focused attention on the central importance of behavioural surveillance in understanding and interpreting trends in HIV prevalence. A review of early experiences in behavioural surveillance led to recommendations for more appropriate and more systematic use of behavioural surveillance at the national level. (Pisani, Brown et al. 1998)

In 2000, the UNAIDS/WHO working group on surveillance published new guidelines for national HIV surveillance systems "Guidelines for Second Generation HIV Surveillance" -- (UNAIDS and World Health Organization 2000). The guidelines differ from earlier WHO guidance on surveillance in two major ways. Firstly, they recommend that behavioural and STI surveillance be institutionalised as integral parts of national surveillance systems for HIV. Secondly they move away from the "one-size-fits-all" approach adopted by the Global Programme on AIDS, stressing the importance of designing a surveillance system that is appropriate to the different types of epidemics found in different parts of the world. In addition, there is

a call for a greater focus on prevalence rates among young people in high prevalence epidemics driven principally by non-commercial heterosexual sex, since infections among younger people are more likely to mirror incident infections, and trends in prevalence are less likely to be affected by changes in mortality and fertility. The guidelines also make recommendations about the more effective triangulation of data from different sources. The guidelines on second generation HIV surveillance are far from perfect, but overall they have prompted several countries to focus more closely on the populations most likely to be driving the HIV epidemic, and have greatly increased the attention paid to the collection of appropriate and high quality behavioural data. (Pisani, Lazzari et al. 2003)

The box reproduces a summary definition of the characteristics of Second Generation surveillance systems which I contributed to the UNAIDS publication: National AIDS Programmes: A guide to Monitoring and Evaluation.

#### Panel 4: Second Generation Surveillance Systems: What's new?

### Second generation systems look at behaviour as well as HIV infection

Traditional surveillance systems tracked HIV infection or other biological markers of risk such as STIs. Since HIV infection among adults must be preceded by one of a limited number of behaviours, such as unprotected sex with an infected partner or injection with contaminated needles, we know that if these behaviours change, there will be a change in the spread of HIV. Second generation surveillance systems monitor risk behaviours, using them to warn of or explain changes in levels of infection. Thus, second generation surveillance uses data from behavioural surveillance to interpret data gathered from sero-surveillance efforts.

#### Second generation systems are tailored to the type of epidemic

As the diversity of HIV epidemics becomes more apparent, it also becomes evident that there is no "one-size-fits-all" surveillance system. Efficient surveillance of a predominantly heterosexual epidemic in a country where one adult in six is infected will differ radically from surveillance in a country where HIV infection is growing rapidly in drug injectors but has yet to spread to the general population. In general, surveillance systems can be divided into three broad types directly related to the type of epidemic: • In *generalised* epidemics where HIV is over one percent in the general population, surveillance systems concentrate on monitoring HIV infection and risk behaviour in the general population.

- In *concentrated* epidemics where HIV is over five percent in any sub-population at higher risk of infection (such as drug injectors, sex workers, men who have sex with men), surveillance systems monitor infection in those groups and pay particular attention to behavioural links between members of those groups and the general population. They might ask, for example, whether male sex workers have wives or girlfriends, or whether drug users finance their habit through sex work. In these situations, surveillance systems also monitor the general population for high-risk sexual behaviour that might lead to rapid spread of the virus if it were introduced.
- In *low-level* epidemics where relatively little HIV is measured in any group, surveillance systems focus largely on high-risk behaviours, looking for changes in behaviour which may lead to a burst of infection. Such changes have recently been recorded in several Eastern European countries, for example, where a surge in injecting drug use was followed by very rapid growth in HIV infection.

# Second generation systems use data in ways that maximise their power to explain the epidemic

A classic antenatal clinic (ANC) surveillance system may show that HIV prevalence among women 15-49 years attending ANCs rose rapidly from 0 to 12 percent over eight years, and then levelled off. In the rising phase the upward trend meant more new infections (increasing HIV incidence), probably at all ages. But once the curve flattens out, the explanatory power of that single figure is lost. Prevalence may be unchanged for any number of reasons: because as many women are dying as are becoming newly infected, for example, or because many infected women are no longer becoming pregnant and so have dropped out of the pool of women tested at sentinel sites.

Some of these problems of interpretation can be reduced by concentrating analysis to women in the youngest age groups, who are less subject to biases of mortality or reduced fertility and whose infection is more likely to reflect recent trends in the epidemic. Analysing the ANC data together with data from other sources, such as general population surveys or behavioural surveys, also increases the explanatory power of sero-surveillance systems. The need to focus on young women in antenatal clinics was acknowledged several years ago when WHO/GPA designated two of its prevention indicators to HIV and sero-syphilis prevalence among women 15-24 years.

#### Second generation systems make the best possible use of resources

By concentrating surveillance in areas where it provides the most information and tailoring systems to a country's capacity, second generation surveillance ensures that money and expertise are used as efficiently as possible. For example, sentinel sites are carefully chosen to provide reliable information from a minimum number of sites, while sampling for behavioural data collection takes sentinel sites into account so that strong inferences can be made in comparing behavioural and serological data sets.

Strengthened surveillance systems also make an effort to ensure that all data gathered are actually used, something which, perhaps surprisingly, has not been the case in the past. Syphilis data from ANC clinics have rarely been analysed for surveillance purposes, for example. Despite the association between HIV and TB, TB surveillance data are rarely included in HIV surveillance reports. For more information see <a href="https://www.unaids.org">www.unaids.org</a>

## d Choosing the right surveillance system

The "Guidelines for Second Generation HIV Surveillance" suffer from the same tension as most guidelines issued by global organisations – the desire to be general enough to be of use to all countries, while simultaneously being specific enough to be of use to any single country. However the guidelines did try to address this issue specifically, by giving different recommendations for different types of epidemics. This was in part the result of a growing recognition that epidemics would not necessarily follow an inevitable path, along which the virus travelled from "core" groups with high risk behaviours into the general population. It was increasingly considered possible that in many developing countries, HIV would remain concentrated in the same populations most likely to be infected in the industrialised world – drug injectors, homo/bisexuals, sex workers and their clients. Since most of these are men, infection concentrated in these groups will not be captured in surveillance systems that focus on testing pregnant women.

To help guide governments in the design of their surveillance systems, the Second Generation guidelines used epidemic categories first introduced by the World Bank (The World Bank 1997), which classify epidemics as "low level", "concentrated" or "generalised". Low-level epidemics are those where no significant epidemic spread has been detected in any sub-population. Concentrated epidemics are those in which most HIV infections occur among people engaging in behaviours that carry an identifiably high risk of exposure to HIV – commercial sex, anal sex between men, and drug injection. There may be onward transmission from those with higher risk to their regular sex partners, but patterns of sexual networking in the population at large are not sufficient to sustain a heterosexual HIV epidemic if the high risk groups are taken out of the equation with effective prevention programmes. Every country that has any epidemic at all in Asia, Europe, North America, North Africa and the Middle

East has a concentrated epidemic. So do most countries in Latin America and Australasia (the exceptions may include Guyana and Papua New Guinea). Many West African and Caribbean nations also fit the "concentrated" pattern.

Generalised epidemics are those where patterns of sexual networking in the adult population, combined with factors affecting the transmissibility of HIV, are enough to sustain an HIV epidemic for more than a generation even if all identifiable "high risk" sub-populations, including sex workers and their clients, were taken out of the equation. Most East and Southern African nations fit this "generalised" pattern.

An important weakness of the Second Generation guidelines is that they use numerical proxies to help people figure out which epidemic type they have. An epidemic is classified as "generalised" if HIV prevalence exceeds one percent among pregnant women in urban areas (reduced from five percent in the original World Bank classification). This has caused confusion in several areas (including Cambodia, Thailand, Myanmar, parts of India and Indonesian Papua) where antenatal clinic (ANC) prevalence has passed the one percent threshold. In some of these countries there has indeed been a shift towards a higher proportion of infections occurring within regular partnerships. Where HIV prevention programmes have successfully cut risk in situations such as commercial sex, for example in Cambodia, new infections transmitted in "low risk" partnerships now outnumber those contracted during commercial sex. (The Cambodia Working Group on HIV/AIDS Projection 2002) Almost all of these new infections, however, are being acquired from people who were infected when they were either buying or selling sex. There is little evidence that the virus is circulating beyond people who are currently or formerly members of identifiable high risk groups and their primary sex partners. In other words, despite having passed an arbitrary threshold, there is nothing "generalised" about Cambodia's HIV epidemic. This has important implications both for surveillance and for prevention. (Monitoring the AIDS Pandemic 2004)

# e Surveillance and information needs in concentrated epidemics

Much of the thinking about HIV surveillance and information needs in the developing world has been informed by experience in sub-Saharan Africa. This is understandable. Nearly two thirds of people currently living with HIV are African, and the continent has several of the world's longer-established sentinel surveillance systems. But a strong case can be made that the HIV epidemic in Africa is substantially different from that found anywhere else in the world. It is by no means clear that the lessons of the generalised HIV epidemics of sub-Saharan Africa are applicable elsewhere. Indeed, the assumption that systems appropriate to Africa will be equally appropriate elsewhere has sometimes led to recommendations for surveillance and data collection that fail to meet the needs of concentrated epidemics. The standardised indicators for HIV prevention proposed by GPA, and their associated data collection methods, are largely inappropriate for countries outside of sub-Saharan Africa. (Mertens, Carael et al. 1994) Many indicators appropriate only to Africa have now been enshrined in binding international declarations such as that issued by the United Nations General Assembly Special Session on AIDS, (United Nations 2001). This commits governments to measure the indicators even when they are not relevant to the local epidemic, creating the danger of disruption to surveillance systems that should be focused on providing the actionable information that is needed to track the local epidemic.

Where HIV is concentrated among sub-populations with particular risk behaviours, both the information needed to plan and monitor a response and the methods needed to collect that information differ from those appropriate in generalised epidemics. (Schwartlander, Ghys et al. 2001; Mills, Saidel et al. 2004)

Firstly, surveillance systems in concentrated epidemics need to **track HIV infection** in the sub-populations most at risk of exposure in a country. These sub-populations typically include some or all of the following: female, male and transgendered sex workers and their clients, injecting drug users (IDU) and men who have sex with other men. They are often referred to as "hard to reach" or "hidden" populations. (Schwartlander, Ghys et al. 2001) This can be a misnomer. Sex workers depend on making themselves available to clients and are therefore usually easy to

find. (Ghys, Jenkins et al. 2001) Where homosexuality is stigmatised, men may hide the fact that they have sex with other men. But those that we are most interested in for the purposes of HIV prevention (and therefore surveillance) are those who change partners regularly – they can often be found in the places that they themselves go to find new partners. (McFarland and Caceres 2001)

IDU are among the hardest to reach, but sentinel populations representing IDU do exist. Just as pregnant women at public ANC clinics are sampled as a proxy for sexually active women in generalised epidemics, so drug users in treatment programmes or in detention can be sampled as a proxy for those at risk for HIV because of drug injection in concentrated epidemics. Choice of sentinel population will undoubtedly affect surveillance results, as discussed below, but reaching these "hard to reach" populations for surveillance is definitely feasible. Indeed a recent review of behavioural surveillance systems found that 14 out of 33 countries with concentrated epidemics (and 7 out of 11 in Asia) had what was termed a "fully implemented" sero surveillance system and 17 countries (9 of them in Asia) a "fully implemented" behavioural surveillance system. (Garcia-Calleja, Zaniewski et al. 2004; Pervilhac, Garcia-Calleja et al. 2004)

Secondly, behavioural surveillance is of paramount importance in concentrated epidemics. (Brown 2003) Where HIV is currently concentrated in just a few subsectors of the population, the future course of the epidemic will depend first on their sexual links with other populations. Particularly early on in the epidemic (and even before HIV is established in the highest risk populations) behavioural data will indicate where the risk of exposure lies. Bangladesh and the Philippines both provide examples of the use of behavioural data as an "early warning" of the potential for HIV to spread both within and between sub-populations -- critical to planning effective prevention in concentrated epidemics. (Bangladesh National AIDS/STD Program 2001; Philippines Department of Health 2002)

Behavioural surveillance is important, too, in tracking the reach of prevention programmes targeted at high risk groups. In a generalised epidemic, where all sexually active people may be at risk of exposure, the reach of an STI screening programme can be ascertained from programme monitoring data alone. But in a concentrated epidemic, this is not the case. We need to know not just that services

were provided, but that they were provided to those most in need of the services, because they are most at risk of exposure to HIV. Behavioural surveillance allows us to asks members of high risk populations whether they received certain services.

In generalised epidemics, unprotected sex within the general population will determine the course of the epidemic, so sexual behaviour can and should be measured in general population surveys. However in concentrated epidemics, many of the behaviours that are likely to lead to exposure to HIV are either too rare to be measured in general population surveys, or they are too illegal or too much frowned upon. (Mills, Saidel et al. 1998; Fenton, Johnson et al. 2001; Ghys, Jenkins et al. 2001; Mills, Saidel et al. 2004; Zaba, Slaymaker et al. 2004). An exception is the consumption of commercial sex by men. It has been argued that in societies where this is common enough to contribute significantly to the spread of HIV, it is not particularly stigmatised and can be measured in general population surveys. (Brown 2003)

Thirdly, surveillance systems in concentrated epidemics must provide **estimates of the size of risk populations**. In a generalised epidemic, this is not necessary, since the denominator for HIV estimates is the adult population. In concentrated epidemics, the surveillance system measures HIV prevalence in populations at high risk. But unless we know how many people there are in each of those groups, we don't know the denominator for those prevalence figures, and we therefore can't estimate the number of people living with HIV. Population size data are critical in concentrated epidemics for estimating the burden of disease, planning provision of prevention and care services, and tracking the coverage of interventions.

## 5. Current issues in HIV surveillance

Second Generation Surveillance systems envisage a high level of integration between the different parts of a surveillance system, in the design of the system, in the collection of data, and most importantly at the analysis stage. However in practice many of the components remain quite distinct; they are discussed separately below. This thesis presents a model which was designed primarily for use in the concentrated epidemics that cover most of the globe. The discussion of the current status of various components of national surveillance systems will therefore focus largely on the issues that are of central importance to these epidemics. They include: HIV and AIDS case reporting, HIV sentinel surveillance, risk behaviour surveillance, STI surveillance and estimation of the size of populations at high risk for HIV. Programme monitoring systems are also discussed. Other components of surveillance which are particularly important in generalised epidemics and in epidemics with widespread access to antiretroviral therapy such as the monitoring of drug resistance are not discussed in detail here.

## a HIV and AIDS case reporting

Reporting of HIV and AIDS cases remains extremely weak in most countries. In the industrialised world, this is in large part because of public health laws which either forbid or fail to require case reports. This is a hangover from the early history of AIDS, an incurable syndrome concentrated in sub-populations that were socially marginalised but sometimes, especially in the case of homosexuals, vocal and highly organised. An AIDS diagnosis and even a positive HIV test could lead to substantial discrimination, and since little was available in the way of care, the upside of knowing one's status was limited. In a raging debate that pitched those who supported classic infectious disease control methods such as named reporting and contact tracing against those who sought above all to protect the privacy and rights of individuals infected with HIV, AIDS came to be seen as different from other infectious diseases. (Bayer 1991; Bayer 1991; Stryker and Bayer 1993; Bayer 1997)

Recently, the debate has been rejoined. "AIDS exceptionalism" – the term coined by Bayer in 1991 to describe the neglect of public health principles in the approach to HIV – is increasingly seen as a barrier to control of HIV, both in the industrialised world and in developing countries – particularly those with generalised epidemics. (Frieden, Das-Douglas et al. 2005; De Cock, Bunnell et al. 2006) Increasingly, there are calls to normalise testing, to strengthen case reporting and case management, and

to strengthen systems to track AIDS incidence and mortality as a means of monitoring coverage of expanding treatment programmes.

With the exception of Brazil (the first developing country to provide widespread access to care for the HIV-infected), few countries with concentrated epidemics have to date focused on improving HIV or AIDS case reporting. The problems that plagued HIV and AIDS reporting in the early years of the epidemic persist. The advent of antiretroviral therapy has further confused an already complex and sometimes conflicting set of recommendations about case definitions. Diagnostic facilities remain limited, much HIV testing takes place during unlinked, anonymous surveillance, or in private laboratories, sometimes unlicensed. Health reporting infrastructures are poor. The result is that AIDS and, especially, HIV cases remain vastly underreported. While AIDS case reports may give some information about the distribution of new infections a decade earlier, in many countries HIV reports reflect the distribution of testing as much as the distribution of infection. Analysis of these data alone can lead to important misunderstanding about the evolving epidemic.

Despite this, and the fact that many countries are making significant efforts to improve their estimates of the true numbers of people living with HIV, case reports remain among the most frequently cited statistics in government publications as well as in the press.

### b HIV sentinel surveillance

An attempt systematically to evaluate the quality of HIV sentinel surveillance systems in place until 1999 (Walker, Garcia-Calleja et al. 2001) and improvements until 2002 (Garcia-Calleja, Zaniewski et al. 2004) show that the recommendations of the Second Generation surveillance guidelines are still far from fully implemented.

Three issues currently dominate the agenda in discussions about HIV sentinel surveillance: representativeness of the sentinel populations, the potential of new technologies, and the ethics of unlinked anonymous surveillance.

## How representative are sentinel surveillance systems?

In generalised epidemics where sentinel surveillance focuses on pregnant women at public ANC clinics, the questions of representativeness are:

- To what extent do pregnant women in public ANC clinics included in the surveillance system represent all pregnant women?
- To what extent do pregnant women represent all currently or formerly sexually active women?
- To what extent do sexually active women represent currently or formerly sexually active men?

These questions have been exhaustively addressed in the literature, especially in recent years since population-based sero-surveillance has been conducted as part of nationally-representative Demographic and Health Surveys (DHS) in several sub-Saharan African countries. (Calleja, Marum et al. 2005) These surveys, and other population based surveys, have allowed for an investigation of the systematic biases associated with clinic-based sentinel surveillance, and for the appropriate adjustments of national estimates of infection. Briefly, the comparisons revealed that HIV prevalence in women attending sentinel ANC tends to be higher than in other pregnant women (because of an over-representation of relatively high prevalence urban sites in sentinel systems), that pregnant women have lower HIV infection rates than non-pregnant women (because HIV reduces fertility, so HIV positive women are less likely to get pregnant and show up at ANC), and that HIV prevalence is higher in women than in men (for demographic and behavioural as well as physiological reasons). (Boisson, Nicoll et al. 1996; Zaba and Gregson 1998; Glynn, Buve et al. 1999; Zaba, Carpenter et al. 2000; Hunter, Isingo et al. 2003; Zaba, Terceira et al. 2003; Way 2004)

In concentrated epidemics, variation in sentinel populations is much greater and the questions of representativeness are different. The original idea of sentinel surveillance was that facilities providing services to members of a population and taking biological specimens for other purposes could act as a source of specimens for disease surveillance. In the case of HIV, blood samples taken for other purposes such as syphilis screening would be stripped of identifiers and tested anonymously to allow for tracking of HIV prevalence in the population as a whole. As long as something is known about the relationship between the people attending the facilities

and other members of the population of interest who don't attend the facilities, biases can be assessed. The problem in concentrated epidemics is that many of the populations at risk for HIV are very poorly served by routine health interventions; there is not necessarily an obvious institutionally based source of samples.

There are exceptions. STI clinics takes samples when they provide routine STI screening and treatment to sex workers in many countries, often as part of a "health card" system. STI clinics providing curative services for men are also sometimes used as a source of specimens to track HIV infection in "high risk men", thought to be a proxy for the clients of sex workers. However the representational issues in these two sentinel populations, and therefore the interpretation of surveillance results, differ markedly. In the first case, the intention is to provide universal screening for all sex workers. The question then is simply: to what extent do sex workers who come for screening compare with sex workers who don't come for screening (for example illegal immigrants, freelance sex workers in a brothel-dominated system, etc.)? In the case of men who come for curative services, the question is different. To what extent do men at STI clinics represent all men who buy sex from sex workers? Men presenting with an STI have by definition had recent unprotected sex with a non-monogamous partner. HIV prevalence among these men may well reflect prevalence among men at risk for HIV because they have unprotected commercial sex. But they will not represent those clients who use condoms (who will avoid infection with STIs as well as HIV). If condom use in commercial sex is rising, then men in STI clinics will become steadily less representative of all clients of sex workers. Trends in HIV prevalence in this group will be very difficult to interpret.

Other common sentinel facilities are drug treatment centres, which take samples to test for Hepatitis and other blood borne pathogens in incoming patients. Some occupational cohorts of men found in behavioural surveillance to be likely to buy sex (e.g. policemen, soldiers, miners) have routine in-service health screenings.

These situations are not, however, the norm. Without a source of routine specimens from health facilities or other institutions, surveillance systems have devised alternatives. One is to access institutional settings and take specimens solely for the purpose of HIV surveillance. Prisoners or people in detention centres for drug-related offences or for selling sex are a common source of samples for HIV surveillance.

Since these specimens would not otherwise be taken, some countries require participants in surveillance to give informed consent in these situations. In theory, this introduces the possibility of refusal bias. In practice, in most institutions where these procedures are used, the likelihood of refusal is minimal. Countries vary in their adherence to protocols meant to ensure anonymity in testing in institutional settings.

The second, increasingly common, approach is to do surveillance in the community, following sampling protocols originally developed for behavioural surveillance. Time-location sampling is the norm, although other methods such as "hot-spot" based samples and respondent driven sampling are becoming common, too. (Weir and Boerma 2002; Magnani R 2005)

In population-based surveillance the right to refusal is much more frequently exercised, possibly introducing refusal bias into prevalence measures. Another important source of bias is deviation from sampling protocols. Surveillance staff are usually poorly paid civil servants. Population-based sampling protocols often require them to work anti-social hours in socially uncomfortable and even dangerous locations. Requirements for rigorous documentation of field implementation of surveillance are few, and documentation tools fewer still. Surveillance staff frequently take short cuts. These may affect the representativeness of a sample designed to be a probability sample, which in turn affects the ability to interpret trends in HIV prevalence over time. (Morineau, Pisani et al. 2006)

Time-location sampling methods have been criticised because they only provide access to the visible members of the population. As mentioned earlier, this has created debate about who *should* be included in surveillance systems – a question that comes up particularly frequently in the case of men who have sex with men (MSM). Because of the history of the HIV pandemic, there is a perception that anal sex carries a high risk for HIV infection. Some developing countries newly encouraged to include MSM in their surveillance systems have turned to respondent driven sampling methods which they believe will help provide access to "hidden" MSM – for example those who do not openly express their sexuality. In truth, while anal sex does carry a higher risk for HIV transmission than vaginal sex, sex between men is very similar to heterosexual sex. The risk is not having sex, but having sex

with a person likely to be infected with HIV. For this reason, in concentrated epidemics, surveillance systems focus on sex workers and their clients rather than on married couples – they are looking to capture trends in infection among those most likely to be exposed. The same logic should hold for male-male sex. We are interested in capturing those most likely to be exposed because they have multiple partners. In developing countries most of the MSM at highest risk of exposure to HIV can still be found in locations where they go to meet sex partners. These locations can be mapped and sampled for surveillance using time location methods. The result will be a prevalence rate which does not represent all men who have sex with men, but which may represent those men who have sex with men who are most likely to be at risk for HIV.

## Technological advances in HIV surveillance

HIV sentinel surveillance systems have always measured HIV prevalence. This will continue to be important for many reasons, including estimates of the burden of disease, and the need for planning prevention and care services.

However, because HIV is a chronic disease which correlates poorly with recent behaviour, prevalence measures tell us little about trends in new infections. Rather, HIV prevalence reflects cumulative infections minus cumulative deaths. Changes in mortality over time (due to the natural history of infection in a maturing epidemic or introduced by changes in treatment and care which increase the length of life for those infected) will complicate the interpretation of prevalence measures. If HIV prevalence rises, are we measuring the failure of our prevention programmes, the success of our treatment programmes, or simply changes in the dynamics of the epidemic over time? It is extremely difficult to say.

What we really want in order to monitor the impact of prevention programmes is some way of tracking incidence rather than prevalence. Until recently, measuring incidence required expensive and logistically complex cohort studies fraught with ethical difficulties, and was not considered feasible in routine health information systems. Because of this, the Second Generation Surveillance guidelines recommended restricting analysis of trend data in prevalence to data from 15-24

year-olds. With a median survival time of around 9 years from infection to death in a pre-treatment, developing country setting, it was believed that this restriction would minimise the effect of mortality (and reduced fertility in long-term HIV-infected women) on our ability to interpret incidence. (Morgan, Mahe et al. 2002)

This solution, while simple, is at best partial. It is particularly inadequate in concentrated epidemics, where because of heterogeneity in the characteristics of drug injectors, MSM and those engaging in commercial sex (especially on the client side) the age distribution of infection is more varied that it tends to be in generalised epidemics.

From the mid 1990s, it became possible to test for viral RNA using polymerase chain reaction (PCR) testing for reverse transcriptase, so very recent infections could be detected. A growing understanding of the potentially important contribution of risk behaviour during early infection in propagating the HIV epidemic has led some people in industrialised countries to argue for routine PCR testing of blood samples taken from high risk populations, as a precursor to active case management of highly infectious incident infections. (Pilcher, Eron et al. 2004) However these tests -- and similar tests for p24 antigen -- remain sophisticated and expensive, and are unlikely to be feasible in routine surveillance in developing countries.

For routine surveillance purposes, the goal is not currently to identify recently infected individuals, but rather to track trends in new infections. To this end, two other methods have been proposed. The first, the de-tuned assay method, tests specimens using a sensitive and a less sensitive enzyme immunoassay (EIA) test for HIV-1 antibodies. This method is based on the fact that when people are first infected with HIV, they have no antibodies to the virus. Antibody production begins shortly after infection, but the concentration of antibodies takes time to develop. The current generation of EIA tests will give negative results for around a month after HIV infection occurs – the time of the first positive test depends partly on the sensitivity of the assay. If a specimen tests positive on a very sensitive assay but negative on a less sensitive assay, it can be assumed to be a recent infection, an infection in a person who is early in the process of seroconversion. If the less sensitive assay gives a positive result, then it reflects a high concentration of antibodies associated with a full sero-conversion. In other words, it can be assumed

to be a less recent infection. Early tests of this method were reported by Janssen and colleagues in 1998. (Janssen, Satten et al. 1998) The assays they used gave "discordant" results reflecting newer infection covering a period of an average of just over four months.

The early work on detuned assays was all undertaken on specimens infected with HIV-1 subtype B, the subtype most common in North America and Western Europe. A review of experience with the method presented at a conference on surveillance in Ethiopia in 2004 concluded that it was "not ready for prime time" use in developing world settings with different subtypes, in part because of continuing uncertainties about the appropriate sensitivities of the assays. (Bernard Branson, during the presentation: Serologic Testing Algorithm for Recent HIV Seroconversion (STARHS) for estimating incidence- Addis Ababa, January 26, 2004)

A second method to measure incidence from single samples is known as the BED capture enzyme immunoassay (BED CEIA). (Parekh, Kennedy et al. 2002) The BED method was initially tested on samples collected in routine surveillance among sex workers in Cambodia. Results, which showed a fall in new infections among younger but not among older sex works, have contributed to the debate about the success of HIV prevention programmes in that country. (Vonthanak and Parekh 2004; McDougal, Pilcher et al. 2005) It appeared early on that BED worked for all subtypes of HIV. However further testing has called that into question. A recent statement from the UNAIDS Reference Group on Estimates, Modelling and Projections suggests that assay characteristics vary by sub-type, and that current BED methods over-estimate incidence. The group recommends against the use of BED methods in estimating incidence or in trend monitoring until further research has been done. (UNAIDS Reference Group on Estimates 2006) Certainly, these technologies are not currently able accurately to identify newly-infected individuals, and they cannot, therefore be used as a prevention tool to try and identify those who might be highly infectious (see Chapter 3).

BED and de-tuned assays both have limitations, largely related to calibration of the assays and validation of assumptions about antibody development during seroconversion. Work on these methods continues, and a feasible way of tracking

new infections at reasonable cost at the population level is expected soon. (McDougal, Pilcher et al. 2005)

The potential for integrating these new technologies – as well as tests for CD4 counts and plasma viral loads which will grow increasingly important as access to treatment expands – depends to a large extent on laboratory infrastructure and quality assurance procedures. It is worth mentioning here that while much attention has been paid in international guidelines to the quality of surveillance data in terms of sampling and representativeness, far less attention is paid to laboratory quality, and less still to such mundane issues as specimen handling for routine surveillance. Poor laboratory procedures can be an important source of error in surveillance systems; investment in strengthening laboratory capacity and quality assurance will be needed as sero-surveillance systems expand. (Martin, Hearn et al. 2005)

#### The ethics of sentinel surveillance

Unlinked anonymous surveillance for HIV was promoted to reduce participation bias in routine surveillance at a time when the infection was very highly stigmatised, and when little could be done about it. Surveillance guidelines that propose unlinked anonymous surveillance usually remark that the functions of public health surveillance and diagnostic testing are different, and include the refrain that voluntary counselling and testing for HIV should be easily accessible to those at risk for HIV, in parallel with surveillance systems. In many countries, including a large proportion of those with concentrated epidemics, this is palpably not the case.

In these situations, both the ethics and the wisdom of anonymous surveillance are increasingly being questioned. (Zaba, Slaymaker et al. 2005; De Cock, Bunnell et al. 2006) The ethics are questioned because surveillance systems put us in contact with people at high risk of being exposed to HIV, and we are ascertaining the HIV status of members of this population, but then denying them the opportunity to learn their status and seek care and prevention services as appropriate. The wisdom is questioned because (in concentrated epidemics) these are people who may have extremely limited contact with the health system. It is argued that surveillance

provides an important access point to people who may need to be referred to appropriate prevention and care services. (Yip 2004)

It has been suggested that where HIV testing is routinely incorporated into health care provision, such as antenatal care, hospital admission etc, or where uptake of voluntary testing services is sufficiently widespread, these systems might generate sufficient data to render sentinel surveillance unnecessary. (Hladik, Masupu et al. 2005) This is unlikely to be the case in concentrated epidemics, where infections are concentrated among people least likely to have contact with routine health services.

So if decision-makers and programme planners are to have access to data on trends in HIV infection, sentinel surveillance may still be necessary. One proposed solution is to develop a hybrid system where sentinel surveillance is not anonymous, but where results are provided, with referral to counselling and treatment as necessary. This has been tried during integrated biological and behavioural surveillance in several settings, and on a vast scale in China. In most cases, the work has been extraordinarily resource intensive, and the quality of counselling has often been poor. However with better staff training and more efficient referral systems, these constraints may be overcome (Wu Zunyou, China National Center for STI/AIDS Control, personal communication). In China, the exercise (which in its first, "mass screening" incarnation was closer to case finding than to surveillance) has greatly increased the number of people accessing free treatment and care services. Most of those so far identified in these screenings are former plasma donors. The success of case finding policies among drug injectors and other marginalised groups is still unknown.

One major concern about integrating surveillance with access to test results is the interpretation of trends in surveillance data. (Zaba, Slaymaker et al. 2005) Refusal bias is always a concern in forms of surveillance that are not anonymous. If people have access to their results, this bias may increase, since people who have tested positive in the past may be less likely to agree to participate in new rounds of surveillance. Over time, then, the measure will shift from being a measure of prevalence to being closer to a measure of incidence. Eventually, it may re-establish as a proxy for incidence. The potential impact of such a shift on our ability to interpret trends in surveillance data in the short and medium term is uncertain.

## c Behavioural surveillance

Systematic behavioural surveillance evolved largely as a way of meeting information needs for HIV programme planning and – to a greater extent – evaluation, without drowning in a tsunami of baseline surveys, KABP surveys, and pre-and-post intervention evaluations. These were the norm in the early years of the HIV epidemic, a time when it was considered more important to "act" by implementing prevention programmes in developing countries than to give careful thought to how to measure the effects of that action. Prevention efforts were planned and evaluated in ways that were far from systematic. Surveys were often poorly designed, with small sample sizes, unclear sampling methods and inconsistent measurement, and were carried out by staff with little training. Results were rarely analysed fully; even where data were of sufficient quality, the capacity to perform meaningful analysis in the prevention organisations that carried out the surveys was extremely limited. There was a huge amount of duplication as multiple small programmes each carried out their own surveys. (Pisani, Brown et al. 1998) The US-funded AIDSCAP HIV prevention programme alone carried out over 400 surveys in the 45 countries in which it worked. (MacNeil and Hogle 1998)

Behavioural surveillance aimed to use systematic methods to sample populations at high risk for exposure to HIV in a representative and replicable way, and to collect sufficient high quality data to meet the HIV programme planning and evaluation needs of multiple users. (Mills, Saidel et al. 1998)

Behavioural surveillance shares many of the same challenges as HIV surveillance, most notably those related to the representativeness of the sentinel populations. This is especially true in concentrated HIV epidemics, where there is a growing tendency to use similar sampling methodologies for biological and behavioural surveillance. The challenges of accessing these populations and obtaining reliable data have contributed to work that led John Cleland and other veterans of efforts to monitor sexual behaviour to the view that "more striking and imaginative advances in research design have been made in the study of special groups than in the study of general populations". (Cleland, Boerma et al. 2004) The challenges of access and representativeness have been rehearsed in the preceding section, and will not be

repeated here. However the issue of linking biological and behavioural surveillance is a matter of considerable debate these days; it will be discussed on page 49 below.

Other than the question of access to populations, the issues most frequently raised in relation to behavioural surveillance are data validity, institutional sustainability, and cost.

## **Data validity**

Behavioural data, and particularly data about behaviours such as sex and drug injection which generally take place in private and are inherently difficult to witness, are considered "soft" by many policymakers and even epidemiologists. (Vlahov, Des Jarlais et al. 2001). The assumption is that people will not tell the truth about their sex lives.

Three decades of nationally representative surveys of reproductive behaviour in developing countries, starting with the World Fertility Surveys and continuing with the Demographic and Health Surveys, have shown that people are perfectly prepared to talk about sexual partnerships and contraceptive use. (Cleland, Boerma et al. 2004) Since the AIDS module was introduced into the DHS in 2002, both men and women have been asked about HIV related knowledge and attitudes. People of both sexes regularly report premarital and extramarital partnerships, although analysis of changes in cohort responses over time indicates that people become more honest about "socially dubious" behaviours as those behaviours recede in time, or as social mores change, so that it seems more acceptable to report them. (Copas, Wellings et al. 2002; Zaba, Pisani et al. 2004) Population based surveys in countries with generalised epidemics using questionnaires similar to those in the DHS and also collecting biological markers have found evidence that young women are particularly likely to underreport risky behaviour (for example, when girls who say they have never had sex test positive for pregnancy or STIs). (Cowan, Langhaug et al. 2002; Nnko, Boerma et al. 2004; Plummer, Ross et al. 2004)

The internal consistency of answers to different questions is sometimes proposed as a measure of data validity. As Potterat and Brody point out, when the questions are all posed to the same person, this may be a measure of reliability (how likely a person is

to give a certain answer) rather than validity (how likely a certain answer is to be true). (Potterat and Brody 2000) However this objection cannot easily be raised when there is consistency on the same points between different individuals, for example in intra-partnership reports of frequency of sexual activity. Most reviews comparing reported sexual behaviour data for consistency between sources conclude that there is little reason to believe that people are dramatically untruthful when asked about their sexual activity. (Padian, Shiboski et al. 1997; Gray, Li et al. 2003) Discrepancies between rates of sexual activity reported by men and women in countries with concentrated HIV epidemics may be accounted for at least in part by under-reporting of commercial sex among men, as well as under-sampling of women with the highest partner numbers. (Wadsworth, Johnson et al. 1996; Brewer, Potterat et al. 2000)

It has been noted also that the major purpose of behavioural surveillance is to track trends in risk behaviours over time. Biases such as underreporting of premarital sex by young women that are consistent over time are less of a concern than biases which may change over time, for example an increased likelihood to over report condom use as HIV prevention programmes become more widespread and condom use is considered more "correct". (Family Health International 2000; Zaba, Slaymaker et al. 2005)

Even those who accept the overall validity of population-based surveys of sexual behaviour in African countries have raised questions about the possibility of collecting good quality data from the more "marginalised" groups usually included in surveillance in concentrated epidemics. (Zaba, Slaymaker et al. 2005). It is often said that because the behaviours of drug injectors, sex workers, clients and men who have sex with men are frowned upon by society, people will not report them, or not report them accurately. (Mills, Saidel et al. 1998; Ghys, Jenkins et al. 2001; Mills, Saidel et al. 2004; Zaba, Slaymaker et al. 2004). It is true that illegal and stigmatised behaviours are likely to be underreported in general population surveys. (Fenton, Johnson et al. 2001; Family Health International 2002) But it does NOT follow that people who have agreed to participate in surveillance because they are a member of a high risk group necessarily have any difficulty in talking about their behaviour, or any particular incentive to misreport it. A sex worker, being interviewed because she is a sex worker, has no obvious reason to tell an interviewer that she had 3 clients or

11 clients in the previous week, when in fact she had 7. The time reference period of the question, and the associated difficulties in accurately recalling behaviours, especially those that are very frequent, may be greater sources of measurement error in behavioural surveillance in high risk populations than deliberate misstatement. (Catania, Gibson et al. 1990; Fenton, Johnson et al. 2001). Choice of interviewer may also contribute to bias, particularly when interviewers are peer educators or come from organisations that have been promoting behaviour change. (UNAIDS, Family Health International et al. 2002)

Certainly, there is evidence that people under-report risk behaviours, especially in contexts where surveillance or research are closely associated with HIV prevention activities. In a longitudinal study of drug injectors in Bangkok, for example, Hudgens and colleagues recorded 100 seroconversions among injectors in periods when they reported no needle sharing. (Hudgens, Longini et al. 2002) But overall, surveys of self-reported data among drug injectors, those buying and selling sex and of men who have sex with men appear to be less problematic than many of their critics assume. High levels of internal consistency, and plausible relationships between behavioural and biological outcomes as well as between programme effort and behaviour change provide grounds for optimism, at least in Asian surveillance datasets. Where these relationships have been examined, they indicate that second generation surveillance systems in concentrated epidemics are producing data that are of reasonable quality, and are potentially extremely valuable in planning and monitoring HIV prevention and care efforts. (Family Health International, USAID et al. 2001; Monitoring the AIDS Pandemic 2004)

It is important to review the internal consistency of behavioural surveillance data, and triangulate it with data from other sources where possible to ascertain that it is valid enough to be useable. But even if data are valid enough to be useable, it does not follow that they are necessarily useful for understanding risks or planning or evaluating prevention and care programmes. Behavioural surveillance systems need to produce not just good data, but the right good data.

Behavioural surveillance in developing countries was essentially pioneered in response to demands from the United States Agency for International Development (USAID) for better evaluation of programme outcomes. (Mills, Saidel et al. 1998)

This meant that the initial focus of behavioural surveillance systems was skewed towards meeting the information needs of donors, who were at the time in the process of agreeing to simple, standardised indicators for HIV prevention programmes that could theoretically be used worldwide, rather than on providing the information countries needed to guide their response to HIV. (Mertens, Carael et al. 1994; De Lay and Manda 2004)

## Integrating biological and behavioural surveillance

One of the reasons there has been much hand-wringing about the validity of self-reported data on sexual behaviour is that cross-sectional surveys that have been able to link behavioural and biological data at the individual level find rather poor correlations between current reported risk and current HIV infection. (Cleland, Boerma et al. 2004) A well-publicised example was a comparative survey of risk behaviours and health outcomes in four Africa cities. This found that circumcision and herpes simplex type 2 (HSV-2) infection were more strongly associated with HIV infection than any measures of sexual behaviour. (Buve, Lagarde et al. 2001)

This may be in part because there is still uncertainty about the measures that best reflect risk for exposure to HIV, particularly in generalised epidemics. Most surveys measure exposure over a relatively short period, where as HIV is a chronic infection which may be the cause of risk behaviour many years previously. (Mills, Saidel et al. 2004) Most analysis looks at measures of central tendency such as means and medians when comparing levels of risk between groups, where as the transmission of STIs including HIV is affected more by a small proportion with the highest risk. In addition, surveillance is very poor at disentangling network effects and partner selection, although these are critical in explaining who becomes infected and who does not. (McGarrigle, Fenton et al. 2002; Aral 2004)

In explanatory terms, there is not a great deal to gain from linking behavioural surveillance with HIV surveillance at the individual level, at least in the short term. Analysis of linked data over the longer term may be more revealing, but routine surveillance systems do not follow individuals over time. Linking biological and behavioural data adds to the complexity of implementation in the field, and may

increase refusal for behavioural as well as HIV surveillance. Specimens are linked to significant amounts of demographic and behavioural data, upping the ethical ante to provide access to test results, even in anonymous surveillance. On the positive side, a linked survey means that the difficult processes of mapping, developing sample frames and accessing the population only have to take place once for each round of surveillance. This saves time and money, and reduces "surveillance fatigue", especially in risk populations of limited size with low turnover.

The information advantages in linking data are limited, while the practical challenges are considerable. For this reason, Second Generation Guidelines as well as behavioural surveillance guidelines recommend against linking biological and behavioural surveillance at the individual level, recommending instead that two separate samples be drawn from the same, or similar, sample frames (unless a facility based sentinel site was available for HIV surveillance). (Family Health International and UNAIDS 1998; Family Health International 2000; UNAIDS and World Health Organization 2000) And yet a growing number of international organisations are promoting what is being called IBBS (integrated biological and behavioural surveillance).

There is no doubt that is feasible to do linked biological and behavioural surveys in populations at high risk for HIV. (MacLachlan, Baganizi et al. 2002) But it is not clear that it is possible to do this repeatedly and at sufficient quality within the administrative and financial context of a national surveillance system.

#### Structural issues in behavioural surveillance

Most governments support disease surveillance systems of some kind. HIV sentinel surveillance was often strongly supported by WHO and other technical agencies in its early years, but it is widely accepted that HIV surveillance is the responsibility of government. (Garcia-Calleja, Zaniewski et al. 2004) The same is not true of behavioural surveillance.

In developing countries, behavioural surveillance among sub-populations at high risk for HIV was first actively promoted by USAID. USAID-funded technical agencies such as Family Health International (FHI) worked with a variety of local

implementing agencies, including universities and private research firms, to develop behavioural surveillance. It was rare that government agencies were actively involved in the implementation of behavioural surveillance, and virtually unheard of for government to fund this activity. Despite the fact that surveillance is by definition a long-term activity, little thought was given to developing institutional structures that would ensure the long-term sustainability and national reach of behavioural surveillance systems. For these reasons, behavioural surveillance was not perceived as part of a national system of data collection. (Brown 2003)

In recent years, other funding and technical agencies (including WHO, UNAIDS, the European Union, the Asian Development Bank, Britain's Department for International Development or DfID, US CDC, UNICEF, the World Bank) have become more interested in behavioural surveillance. In some countries, such as Cambodia, a number of these agencies began to work closely together early on to support the development of a truly national behavioural surveillance system, which is an integral part of the a national second generation surveillance system. More frequently, however, what appears on paper as support for behavioural surveillance in fact boils down to funding individual surveys in programme areas of interest, with no emphasis on developing a coherent national system. These individual surveys often use methods, questionnaires, and implementing agencies that are divorced from the national surveillance system. Many examples have recently surfaced in countries that have received Global Fund grants, since Global Fund proposals typically require baseline surveys in areas where Fund-supported programmes are planned.

The "raise it, spend it, prove it" ethos pioneered by the Global Fund and embraced by many other partners has undoubtedly increased the importance of data collection systems, in the eyes of both donors and recipient countries. (Wilson 2004) But it does not follow that this attention is being focused on creating and strengthening coherent, sustainable national surveillance systems. Both the "spend it" and the "prove it" dictats apply to the many different agencies involved in funding and supporting HIV programmes. Data collection is a good way to "spend it", especially when it can always be justified by the need to "prove it". The current fashion for integrated behavioural and biological surveillance appears to mirror the early years of behavioural surveillance. Multiple surveys funded and supported by different

international technical agencies are generating data that are rarely part of a coherent national system. These surveys may produce data that are useful for programme planning and evaluation, just as the early behavioural surveys did. But they are not contributing to the development of a national surveillance system, and may even threaten to displace routine surveillance activity. (Pisani, Zhong et al. 2004) Experience to date dictates that data generated outside a national system are rarely used effectively in guiding national policy. (Brown 2003; Pervilhac, Stover et al. 2005)

Behavioural surveillance is often considered expensive, but there is little systematic information on the cost of implementation. As with all routine data collection systems, initial investment in developing tools, training materials and institutional systems may be considerable, but costs of implementation should decrease over time as sample frames are developed and as the system becomes institutionalised. Simple logic dictates that a single national system that collects, processes and analyses data systematically for all users will be more cost effective than a duplication of every part of the system, from interviewer training to developing data entry forms, which has been the norm where surveys have been run in parallel on behalf of different sponsors. Efforts at coordination between donors are sometimes undermined by competition to access resources among host country institutions.

## d STI surveillance

Second generation surveillance systems are designed to include the systematic, repeated surveillance of STIs in populations at high risk for HIV, most particularly among female sex workers. (World Health Organization 1999) Curable STIs are potentially important markers for high risk for HIV infection for a number of reasons. Firstly, they share a route of transmission with HIV (unprotected sex with a non-monogamous partner). Secondly, the presence of an STI other than HIV increases the likelihood that HIV will be transmitted in unprotected sex between discordant partners. (Fleming and Wasserheit 1999; Galvin and Cohen 2004)

Some STIs, especially in women, are asymptomatic or go untreated. However most curable STIs are usually symptomatic and somewhat unpleasant, and treatment is

often sought. This means that curable STIs are a better indication of recent unprotected sex with non-monogamous partners than HIV or other viral STIs such as Herpes Simplex Virus Type 2 (HSV-2), which may be the result of risk behaviour and infection many years previously. (UNAIDS and World Health Organization 1999; UNAIDS and World Health Organization 2000) The relationship between current behaviour and current infection is complex. (Aral 2004) However curable STIs can play an important role as a "hard" biological indicator of changing risk behaviour, especially in evaluating the outcome of interventions.

Guidelines for the surveillance of STIs as part of a second generation surveillance system for HIV were published even before the second generation surveillance guidelines themselves. And yet STI surveillance is unquestionably the most neglected of the elements that are described by WHO/UNAIDS as making up a second generation surveillance system. Indeed, a recent review of HIV-related surveillance described the perfect system as follows: "Ideally, an HIV/AIDS surveillance system should monitor the levels and trends in the prevalence and distribution of HIV-related risk behaviors, the number of incident cases of HIV occurring in a year, the prevalence of HIV, the number of new AIDS cases occurring in a year, the level of HIV drug resistance, the prevalence of AIDS, and the number of deaths in a year attributable to HIV." (Diaz, De Cock et al. 2005). While drug resistance has been added to the list of essential elements to track in a surveillance system for HIV (an important addition as treatment expands), in this 2005 review STI surveillance has been dropped entirely from the list of elements of an ideal surveillance system.

There are very few examples where routine national STI surveillance has contributed to the understanding of HIV epidemic spread or programme performance. The best known is probably the example of Thailand, which has an extensive, nation-wide system of publicly funded STI treatment clinics, a programme of systematic screening for HIV among sex workers, and a very strong public health infrastructure. These factors together contribute to a case-reporting system that yields valuable data. Sharp declines in STI case reports almost exactly paralleled a sharp increase in self-reported condom use in commercial sex in Thailand in the 1990s. This evidence was considered important in validating the self-reported behavioural data and in

attributing reductions in HIV prevalence to effective prevention programmes. (Brown, Sittitrai et al. 1994; UNAIDS 1998)

Few, if any, other developing countries have been as successful with their STI surveillance systems as Thailand. There are many reasons for this. Systems based on case reports require a good public health infrastructure that facilitates reporting and analysis of data. And cases have to be recognised to be reported, which means that they have to present at health facilities. In many countries, self-treatment or no treatment are the norm, so people infected with STIs don't come to health facilities. (Monitoring the AIDS Pandemic 2004)

As with HIV surveillance, an alternative to case reporting is active sentinel surveillance – the testing of specimens collected cross-sectionally from members of a particular population. Many HIV sentinel surveillance systems are based around the collection of blood for syphilis testing. Some systems do routinely test samples for syphilis and report the results through the public health channels. Serological tests for syphilis are cheap and reliable, but syphilis test results are notoriously hard to interpret. (Miller, Skov et al. 1999; Goh 2005)

Sentinel surveillance for other STIs is even more complex. Specimens and tests vary for different STIs; diagnostic sensitivities change over time, challenging the interpretation of trends; tests are often expensive. (Mabey and Peeling 2002) The promotion of syndromic approaches to STI management has reduced the push to increase the laboratory diagnostic capacity that would be necessary for useful sentinel surveillance of STIs. (Lush, Walt et al. 2003) Including treatable conditions in regular sentinel surveillance systems also increases the need to provide treatment for those infected; this increases the logistical complexity and cost of surveillance activities. Finally, in some countries there is an institutional divide between those units of government responsible for STI programmes and those responsible for HIV programmes, which may have reduced the incentives for HIV surveillance units to use their typically much more generous budgets to strengthen STI surveillance.

Together, these factors have weighed heavily against any systematic efforts to establish functioning STI surveillance systems within the framework of second generation surveillance systems for HIV.

## e Population size estimation

In countries with concentrated HIV epidemics, information about the size of the populations at high risk of exposure to HIV is crucial. This was not envisaged at the time UNAIDS/WHO developed the Second Generation Surveillance guidelines, but it constitutes a serious gap in the evidence base enabling policy makers to response adequately to HIV.

Sporadic efforts had been made to estimate the size of particular risk populations at the local and in some cases at the national level, in a number of countries. Formal guidance is available on methods for estimating the number of drug injectors, but this is largely appropriate for countries with good services and health information systems. (Hay, McKeganey et al. 1999; Wiessing, Hartnoll et al. 2000) In addition, a number of studies have been conducted to evaluate methods such as capture-recapture, nomination and multiplier methods. (Larson, Stevens et al. 1994; Mastro, Kitayaporn et al. 1994; Neugebauer and Wittes 1994; Cox and Shipley 1997; Archibald, Jayaraman et al. 2001). However there was no overall guidance available for national surveillance authorities needing systematic, low-cost methods for estimating the numbers in all populations at high risk for exposure to HIV.

Backed by FHI and UNAIDS, I initiated efforts to develop this guidance in 2002. Available methods and data sources were reviewed, recommendations were made about the most appropriate methods for estimation at different levels, including the national level, and guidelines were developed. (Family Health International 2002) In general, multiplier methods are recommended as being most appropriate for national level estimates. A source of "benchmark" data is first sought for the population at high risk. These data must be commonly available within a country's routine data reporting systems, and members of the population to be estimated must be included in the data. Examples might include drug users in treatment or detention, sex workers on a registry or attending STI screening. More detailed surveys or studies in a small area are used to characterise the relationship between the members of the population captured in the benchmark data, and the wider population of interest. For example prison data might give the number of people in jail for drug offences in every district over the preceding year, while recent behavioural surveillance among IDU recruited

in the community might give the proportion of IDU who were in jail in the previous year for three cities. From these data, it is possible to arrive at an estimate of the relationship between the number of prisoners on drug offences and the number of IDU in the community. The ratio can then be applied to other areas where only the jail data are available.

There are obviously many limitations to simple multiplier methods (reviewed in detail in Family Health International 2002). However they constitute an improvement when compared with earlier years where estimates, if they were made at all, were based on best guesses. As experience with estimation grows, countries are becoming more aware of which data are needed to arrive at more reliable estimates of the numbers at risk of exposure to HIV. Surveillance systems are being enriched to collect these data.

In the past three years, routine estimates of the size of sub-populations at risk for HIV using methods developed in Indonesia have become a core part of surveillance activities in a number of countries with concentrated epidemics including China, Nepal and the Russian Federation.

## f Programme monitoring data

Virtually all of the international guidance on surveillance states that surveillance data can be used to monitor and evaluate the success of prevention programmes. (Family Health International and AIDSCAP; Chin 1990; Family Health International 2000; UNAIDS and World Health Organization 2000; WHO 2000; Pisani, Lazzari et al. 2003; Rugg, Carael et al. 2004; Diaz, De Cock et al. 2005). Zaba and colleagues are exceptional in pointing out that this can only happen in conjunction with sound programmatic data, but stop short of suggesting that the collection of programme monitoring data should be a routine part of surveillance work. (Zaba, Slaymaker et al. 2005)

Guidance for collection of programme monitoring data are limited, and guidance on analysis and use of these data more limited still. The fact that international proclamations such as the "Three Ones" (which includes one national Monitoring and Evaluation system, see page 81) are honoured largely in the breach is in part

because few countries have developed a sound system for the collection and compilation of programme monitoring data. (Wilson 2004) A UNAIDS-sponsored effort to develop a standardised database for programme monitoring indictors set ambitious targets. Seventy countries have reported to UNAIDS that they are using the standardised data base, known as the Country Response Indicator System or CRIS, to manage the indicators that are requested from countries by the UN system and other donors. (Paul Delay, UNAIDS, personal communication 11/04/06) It is not clear to what extent these data are being used within countries to manage the national response.

The collection of programme monitoring data at the national level is fraught with difficulty. The reality of HIV prevention and care programming in developing countries is that it is both funded and implemented by a plethora of different organisations, with different institutional cultures, different reporting requirements and different capacities. They have been implemented piecemeal over time, often by small NGOs whose skills lie in providing services to marginalised populations rather than record-keeping. Where programme monitoring data are regularly reported, their quality varies; increasingly "target driven" funding may increase the incentive to misreport information. There may be significant double reporting on the part of organisations who receive funding from more than one source, and this may influence the reliability of nationally aggregated data. (Wilson 2004)

Programme monitoring data are often difficult to aggregate across programmes because they are collected in slightly different ways – for example one organisation may report all outreach contacts with sex workers, while another may only report new contacts. Even if programme data are collected in the same way, there is no reason to believe that they will be passed on to the national level, or made available to other programmes. Competition between NGOs, government units and donor agencies is a reality. Programme monitoring data is the equivalent of sales and marketing data in the private sector – not something that is willingly shared with "the competition".

Cost data – another critical ingredient for sensible decision-making – is even less in evidence. (Walker 2003) The disincentives to sharing cost data mirror obstacles to sharing programme data. In addition, accounting practices that report along

categorical lines (salaries, other recurrent costs, commodities etc.) make it virtually impossible to disentangle the costs of different elements of a prevention and care programme, to calculate the "unit cost" of effective implementation.

## Limitations in the evidence base guiding HIV programme decisions: key points

- Early surveillance systems were largely inappropriate for epidemics in which HIV remains concentrated among people, mostly men, with specific high risk behaviours.
- By the mid-2000s, there was a closer focus on monitoring both HIV and risk behaviour in appropriate sub-populations.
- Difficulties in identifying appropriate sentinel populations for HIV surveillance in concentrated epidemics persist in some areas
- Progress towards more coherent national systems may be undermined by increasing demands from donors
- Insufficient attention has been paid to STI surveillance, population size estimation and the collection of reliable programme monitoring data

## 6. The incentives for evidence-based decisions

The effort that has been put into improving methods for the systematic and repeated collection of data about HIV and the behaviours that spread it is beginning to pay off. There are still weakness in the systems in most countries, but surveillance systems are not designed to give us scientifically perfect data. The data simply have to be "good enough" to guide programme and policy decisions (Mertens, Carael et al. 1994; Brown 2003; Mills, Saidel et al. 2004; Zaba, Slaymaker et al. 2005) To that extent, surveillance systems are increasingly doing their job; they are beginning to provide much of the information that is needed adequately to plan and monitor the response to HIV. (Pisani, Lazzari et al. 2003)

The effort to increase the production of reliable data has not been matched by a similar effort to ensure that data are used. (Pervilhac, Stover et al. 2005). And without such an effort, there is little reason to believe that decision-making will become more appropriate, from a public health point of view.

As Alfred Sommer noted: "The process (of health policy formation) is subject to a complex array of considerations and influences, only some of which, sometimes

none of which, have anything to do with data or with the public's health....Translating science to policy ... involv(es) societal priorities, resource allocation, opportunity costs, changing cultural mores, special interests, politics, prejudice, and pure greed." (Sommer 2001)

This is at least in part because of a distortion of incentives around the production and consumption of reliable data.

## a Supply side incentives to produce good data and analysis

The section on the evidence base above hinted at some of the disincentives for countries, organisations and individuals to focus on constructing solid and sustainable systems to collect the maximum amount of relevant data at minimum cost, to report it up through the system, and to analyse it for maximum impact.

Surveillance and data collection activities involve money. Donors get to spend it, and since the "burn rate" is a major indicator of performance in many organisations, there is little incentive to join together with "competing" organisations to make sure that it is spent efficiently. This is especially true when efficient spending involves the building of complex long-term systems: -- while significant amounts can be spent in this way, it often takes some time to get systems in place to allow for disbursement to begin. In addition, spending on necessities such as measurement and monitoring systems provides fewer photo-opportunities for major donors than spending on treatment. From the national side, duplication in data collection is sometimes seen an as opportunity to share development money between different institutions. This leads to inefficiencies in data collection, but also in data use. Data are a valuable commodity, and timely, open access to data is a sensitive issue in most countries. Where surveillance data are collected by different bodies in different geographic areas or at different times, or where different parts of the surveillance system (HIV, behavioural and STI) are managed by different institutions, access to data will always be difficult. This is especially the case where international technical agencies or donors have paid for parts of the data collection. Even though these agencies now routinely make a point of working with the national government as "partners" in surveillance, the data are often perceived of as "belonging" to CDC, or FHI, or some

other outside partner. The complementary analysis of data from all the different components of a surveillance system stands at the core of the second generation surveillance concept. In practice, however, data from different parts of the system are rarely easily available to the same analysts.

Data analysis is a time consuming business, requiring a fair amount of intelligence and skill. In many countries, only a handful of people are trained in these skills each year, and many will end up working in other fields. This is in part because data analysis is what is known in some countries as a "dry" task, with few opportunities for income supplementation. In many countries, public health staff cannot survive by salary alone; the extra income gained from attending workshops and trainings, from supervisory travel, from negotiating contracts with suppliers of computers, test kits or other commodities and other similar activities are essential to maintain a decent standard of living. Motivated staff cannot afford to sit analysing data. (Elmendorf, Jensen et al. 2004; Pervilhac, Stover et al. 2005) In addition, analysts are usually in a unit entirely divorced from programme implementation. They may therefore have little idea which questions are of greatest interest or relevance to policy makers or programme implementers.

For epidemiologists and other analysts based in academic institutions, including those in industrialised countries, the rewards of working extensively with routine public health data are slim, since the quality of these data are often questioned and they rarely result in high profile publications. (Brownson, Royer et al. 2006) A further disincentive to good analysis (from the point of view of the analyst), is that it often takes place in the context of evaluations, where the pressure to show evidence of good performance is strong. It is hard to overstate the aversion to performance analysis on the part of many field level implementing agencies, or the pressure to show good results on the part of donor-funded programmes. (De Lay and Manda 2004)

This last obstacle might be overcome if there were clear demand for objective analysis on the part of people higher up the decision-making "food chain". But this is not always the case, as the following section shows.

# Demand side incentives to produce good data and analysis

## **National pressures**

Most reviews of surveillance policy begin from the implicit (and sometimes explicit) assumption that the primary consumers of surveillance data are national governments wanting to plan appropriate responses to the HIV epidemic. (Schwartlander, Ghys et al. 2001; Pisani, Lazzari et al. 2003; Diaz, De Cock et al. 2005; Pervilhac, Stover et al. 2005)

As Sommer noted, governments have many concerns beyond public health -political and economic interests are generally paramount among these. As De Lay
and Manda (2004) have observed, when governments perceived an acknowledged
HIV epidemic as something that might reduce national stature, trade or tourism, they
tended to deny the epidemic. There was little high-level support for systems that
would track the spread of the infection – if there are no data demonstrating that there
is a problem, then it is easy not to acknowledge a problem. (Pisani 1998; Sommer
2001)

In concentrated epidemics, particularly, HIV has always been easier to deny. Failure to support data collection in the groups most likely to be affected has been a subtle way of facilitating the denial, as well as putting the brakes on efforts to develop proven prevention mechanisms. (Sommer 2001) For at least a decade, inappropriate surveillance systems and inappropriate programme focus went hand in hand. Vlahov and colleagues (2001) note that a ban on federal funding of needle exchange programmes to reduce transmission of HIV and other blood-borne viruses in the United States was imposed until it could be shown that such programmes were safe and effective. The same legislation blocked funding for any research that might show such an outcome. This was essentially because a "zero tolerance" approach to drug use had become an important part of a political platform aimed at consolidating support among conservative voters. The political gains from espousing this approach were judged to be far greater than any gains that might come from providing services to reduce the risk of HIV infection for a small minority of people who were highly unlikely to raise their political voices. Data showing that such programmes were

effective and money-saving would put the government in the inconvenient position of having actively to deny affordable services known to save lives. Again, no data, no problem. (Vlahov, Des Jarlais et al. 2001)

In the last decade, the annual funding available for the response to AIDS in low- and middle-income countries has increased 28-fold, from US\$ 300 million to US\$ 8.3 billion. (UNAIDS 2005) De Lay and Manda note that the recent flood of HIV-related funding has reduced the incentive to deny the HIV problem in a country, and in fact seems to have prompted some governments to exaggerate the problem because they see it as a way of getting funds. There is certainly greater willingness now for governments in countries with concentrated epidemics to make public statements warning of an impending upsurge in HIV. The publication of new, lower HIV estimates by China in early 2006 was held up for over two months in part because of concern that lower figures would lead to a lowering of commitment and funding. (Meeting between UNAIDS/WHO and China CDC, 12/11/05, Beijing)

Greater willingness to acknowledge an epidemic does not, however, necessarily translate into greater willingness to acknowledge or effectively address the particular behaviours that spread HIV in concentrated epidemics. Particularly in democracies, governments tend to look after the perceived interests of the majority. As Muir Gray observed in 2004, evidence based policy making has to consider not only the evidence and needs of the population but also the values of that population. "In the end values will always be more influential than evidence" (Muir Gray 2004) The behaviours that spread HIV in concentrated epidemics are by definition minority behaviours; if they were not, the epidemic would not remain concentrated. So the political impetus rarely favours action that benefits these groups if that action also carries any risk of offending the sensibilities of a political majority.<sup>2</sup>

This is true regardless of the strength of the evidence that shows the effectiveness of these actions, or the eventual cost-effectiveness for society as a whole. The resistance to the widespread provision of needle exchange programmes in numerous countries

<sup>&</sup>lt;sup>2</sup> While it is considered very politically incorrect to say so, it is perhaps no coincidence that many of the programmes that are most frequently lauded for preventing HIV have been initiated by governments that were, at the time, virtually unchallenged in their power – Yoweri Museveni in Uganda and Hen Sen in Cambodia effectively ran one party states, and Thailand's 100 percent condom programme was initiated after a military coup.

including the United States, Thailand, Indonesia, and Myanmar is well known, even though data that show convincingly that needle exchange programmes reduce transmission of HIV, abscesses and other harms associated with injecting are equally well known. (Asian Harm Reduction Network (AHRN) 1999; Stimson 2000; Vlahov, Des Jarlais et al. 2001) The failure to make condoms available in 99 percent of US prisons is cited by De Lay and Manda as a situation "illustrating the triumph of politics and ideology over science". (De Lay and Manda p 26)

The recognition that governments are rarely prompted to act in the interests of drug injectors and people who do not conform to socially acceptable sexual norms has led to an increasing focus on the dangers that these populations pose to "the general population". (Brown 2003; UNAIDS, World Health Organization et al. 2003; Mills, Saidel et al. 2004) The suggestion is that prevention efforts are needed not for the benefit of groups at high risk, but for the benefit of the general population who may eventually be threatened by their behaviour. This has led to distortions in selection of surveillance populations as well as programme focus. (Brown 2003; UNAIDS, World Health Organization et al. 2003; Mills, Saidel et al. 2004; Diaz, De Cock et al. 2005)

Further distortions are introduced by pressure groups calling for treatment, and reinforced by international initiatives such as the WHO's "3 by 5" campaign. While increasing access to care is important in all countries, any tendency for care initiatives to displace prevention efforts will be most damaging in early concentrated epidemics, where the potential for effective prevention remains great. (Global HIV Prevention Working Group 2004) However governments in many countries with concentrated epidemics have embraced the care initiatives with far greater enthusiasm than they show for prevention programmes.

All of these distortions are evident in a recent analysis of AIDS accounts in Latin American countries, which shows that prevention activities are greatly under-funded compared with care, while programmes for men who have sex with men, drug injectors and sex workers are greatly under-funded compared with less focused interventions aimed at young people or the "general population". (UNAIDS 2004)

#### International pressures

The preceding discussion of the incentives and disincentives national governments face in weighing up HIV-related data presumes that it is national governments that call the shots on HIV policy and programming. But to what extent is this really the case?

An OECD review recently found that 3.7 billion of the 6 billion dollars spent on HIV in developing countries in 2004 was provided by international organisations or other external sources. External AIDS funding for 2002-2004 compared with 2000-2002 increased by 700 percent in Zambia, 1100 percent in Lesotho and 394 percent in Tanzania. In some countries this massive flow of external funding for HIV/AIDS has swamped the entire budget available for all other health needs. (Lewis 2005)

HIV/AIDS is the leading cause of illness, death and lost productivity in a number of the countries in question, and it is proper that resources should be made available to deal with the problem. But it does beg the question: who is in charge of how these external funds are spent? Some sources of external funding, such as the Global Fund, make a point of allowing nations to make decisions about spending priorities, through discussions in the Country Coordinating Mechanism – bodies which generally include representatives from government, local and international nongovernment organisations, and major external technical and funding agencies. (Brugha, Donoghue et al. 2004) There is growing support in some institutions for "sector-wide approaches", where all donors contribute to a basket of funding which can be distributed according to the priorities set by the recipient government. (Lewis 2005) However some major donors have been reluctant to embrace these principles. Australia's AusAid continues to channel most of its support for HIV programmes in other countries through Australian for-profit sub-contractors. (Wade 2002) The US taxpayer funded President's Emergency Fund for AIDS Relief (PEPFAR) is extremely prescriptive about how funds are spent, and organisations implementing US-funded prevention programmes face sanctions if they follow national policies that contradict those set by Washington. (Office of the United States Global AIDS Coordinator 2004) An unclassified cable to USAID offices worldwide issued in late 2002 reminded staff that "All operating units should ensure that USAID-funded programmes and publications reflect appropriately the policies of the Bush

administration. Careful review of all programmes and publications should ensure that USAID is not perceived as using U.S. taxpayer funds to support activities that contradict our laws or policies." (Cable from the USAID Administrator, State 267675, 2002)

Under these circumstances – where money is spent according to domestic political priorities in other countries regardless of local realities -- it is perhaps understandable that national governments do not see the need to invest a lot of time or energy in collecting or analysing data that will elucidate the needs of the local HIV epidemic.

## Does "spend it" outweigh "prove it"?

The pressure to "increase the burn rate" has undermined incentives to invest in long-term systems that will improve the overall capacity for data collection and use. But it has also undermined the incentive to use surveillance and monitoring data to guide an effective response. (Mertens, Carael et al. 1994) Until very recently, the pressure to be seen to be doing something in response to HIV has far outweighed the pressure to be seen to be doing something effective. As Bennet and colleagues recently stated somewhat baldly: "The many global stakeholders who are committed to stopping the HIV/AIDS pandemic in its tracks and alleviating its dire social consequences have been cavalier in their disregard for the importance of evidence that assesses control efforts." They point to the paucity of evidence for effective prevention packages, as well as inappropriate evaluation models. (Bennett, Boerma et al. 2006)

In 1993, the then head of the Global Programme on AIDS, Mike Merson, said that spending of US\$ 1.5 to 2.9 billion a year would halve the number of expected new HIV infections in the developing world, effectively braking the epidemic. (Horton 1993). In 2001, Schwartlander and colleagues estimated that 9.2 billion would be needed in 2005 to achieve an effective response, providing prevention services for the 22 million people in developing countries who most needed them.

(Schwartlander, Stover et al. 2001) Financial resources available from public and philanthropic sources to respond to HIV in the developing world have now reached close to those levels. However there has been very little analysis of why these increased resources have failed to deliver the reversal in the epidemic that the

advocates predicted could be achieved if only the cash were available. (Lewis 2005) In fact, governments and their partners in HIV prevention and care have been getting progressively more resources, without ever having to show that the resources they already have have been used effectively. One of the underlying propositions of the World Bank's 1993 World Development Report "Investing in Health" was that a redistribution of resources away from inefficient tertiary services towards prevention and basic care for the diseases that cause most misery locally would have a major impact on well-being, even in the absence of extra resources. There has been little discussion of a similar analysis and redistribution in HIV-related resources, and less still of the displacement effect that AIDS funding might have on other important health and development initiatives. (Bennett, Boerma et al. 2006)

It could be argued that, without more rigorous analysis of whether the existing funding is making a difference, we are inviting the world's taxpayers to throw good money after bad. If there is no requirement to ensure that donor money is being spent where it will be most effective, decision-makers are open to the alternative of spending money where it will be most popular with voters. In the case of HIV epidemics concentrated among drug injectors, the consumers and suppliers of commercial sex and men who have sex with men, effectiveness and popularity are rarely synonymous.

In the last year or two, it has frequently been said that more money for HIV prevention and care is leading to more scrutiny over how that money is spent. (Rugg, Carael et al. 2004; Wilson 2004) Performance based disbursement and the introduction of a multiplicity of international indicators such as those tracking the Millennium Development Goals and UNGASS are held up as examples of an increasing desire to see accountability in HIV programming. Some have criticised an over-emphasis on performance based disbursement based on pre-agreed "landmark" indicators, because it reduces the incentive to use programme monitoring data to make necessary mid-course corrections, and may encourage misreporting. (De Lay and Manda 2004) Others argue that such performance-based disbursement creates important incentives for governments to create functional monitoring and evaluation systems. (Wilson 2004). But there is a difference between developing monitoring systems that show *that* money has been spent, and systems that indicate whether the

money spent is making any difference to the course of the HIV epidemic or the lives of those affected. It is to these systems, and the analytic frameworks that underpin them, that we now turn our attention.

## Distortions in the incentives for generating good data and using it well: Key points

- "No data = no problem": in the past, a lack of appropriate data collection systems has allowed governments to ignore or deny HIV epidemics
- Currently, incentives may work in the opposite direction and dissuade countries from honest appraisals that point to where their epidemics are focused
- Data are often fragmented and data from different sources are rarely available to the same people. This may be exacerbated by donor-driven data collection
- Analysis of routine surveillance data is not personally or professionally rewarding. This has contributed to severe human resource constraints
- There is little point investing in quality data collection and analysis if programme choices are dictated by domestic or international politics
- Competition to spend money means even bad programmes get funded, so there is little need to invest in understanding which programmes work

## 7. The analytic framework

Many different analytical frameworks have been proposed for understanding the HIV epidemic; each reflects an underlying ideological approach to the epidemic. There is some overlap in the approaches, and much confusion as to the utility of the various frameworks. Essentially, they break into two broad categories: explanatory frameworks and monitoring frameworks. Explanatory frameworks seek to guide our understanding of the epidemic, either by elucidating the engines of incidence or by describing the factors that have contributed to or affected a current pattern of prevalence. Monitoring frameworks seek to explain the relationship between interventions, behaviour and HIV, and to define indicators that can be used to measure the influence of prevention programmes. Often, however, the distinction between these types of frameworks is not clear. Frameworks that were developed primarily as a way of explaining the current state of the epidemic have been pressed

in to service to help guide efforts to monitor and evaluate responses, while those designed to elucidate the spread of the virus, or sources of incidence, have become subsumed in frameworks that aim to explain prevalence. In this section, I shall attempt to disentangle these different factors, dealing first with explanatory frameworks and then with evaluation frameworks.

## a Explanatory frameworks

In his seminal 1985 paper "Sick individuals and sick populations", Geoffrey Rose reflects on the differences between individual level risk factors and population level risk factors. (Rose 1985) He stresses the importance of social determinants of illness, while pointing out that most of the tools in the epidemiologist's kit tend to favour individual level analyses. The more widespread a risk exposure is within a population, the more difficult it will be to ascertain its influence on disease status in any study which compares behaviours (or other exposures) within that population. His discussion centred on non-infectious diseases, but it holds true for infectious diseases, with the distinction that in the case of infectious diseases the presence of the infectious agent is itself an important determinant of the effect of different risk behaviours on eventual disease outcome. (Schwartz and Diez-Roux 2001) The distinction between individual risk behaviours and social determinants of disease has been fundamental in the history of the HIV epidemic, and heavily influences the analytic frameworks developed to explore the development of the epidemic.

#### Infectious disease frameworks

Very early approaches to predicting the course of the epidemic were strictly epidemiological, and were expressed most succinctly by May and Anderson in their much-quoted paper of 1987, "Transmission dynamics of HIV infection". (May and Anderson 1987) They reiterated a fundamental principle of infectious disease epidemiology: for an infection to survive in a population, each infected individual must on average pass the infection on to more than one other individual. In other words, the basic reproductive rate of infection – the average number of people who will become infected through contact with each infected person – must be greater

than one. The basic reproductive rate of infection (and later in an epidemic the effective reproductive rate) can be broken down into three component parts: the rate of NEW partner acquisition, the likelihood of infection per contact, and the duration of infectiousness. The reproductive rate will be the product of these three factors; if any one of them is reduced to zero, transmission will stop entirely.

Close to two decades of research since that time has shown that in the case of HIV infection, none of these three factors are constant. Duration of infectiousness (i.e. survival time from HIV infection to death) appears to vary by age at infection, host factors at the time of transmission, and access to treatment for opportunistic infections and HIV infection. Likelihood of infection per contact depends on type of contact (e.g. vaginal sex, anal sex with or without lubricant, injection) on host factors (especially viral load but also co-infection with other pathogens) and on factors affecting the susceptibility of the uninfected partner. All of these are discussed at greater length with references in Chapter 3. The rate of acquisition of new sex partners is extremely heterogeneous throughout a population. For sexually transmitted infections, a small fraction of the population will be responsible for a large proportion of new infections. (Garnett 2002a; Aral 2004) In addition, the way individuals are linked in sexual networks and the difference between serial and concurrent partnerships may be more important in determining the spread of STIs, including HIV, than the simple rate of partner acquisition described by May and Anderson. (Potterat, Muth et al. 2000)

This heterogeneity of risk behaviour is fundamental to understanding HIV, particularly in countries with concentrated epidemics. An epidemic will persist in any sub-population in which the reproductive rate of infection is greater than one, but it will not spread widely into any part of the population where those conditions do not hold. (Garnett 2002a)

The different components of the reproductive rate of infection have been known for many years, and yet they have been overlooked in many frameworks that seek to investigate the relationship between sexual behaviour and HIV (and other STI) infection. (Aral 2004) This may be in part because a focus on these elements centres the analysis firmly on the individual, and does not take account of the population-level variables which Rose identified as potential determinants of disease. In addition,

because of the variations across populations and over time in the components of the reproductive rate of infection, this framework may be more suited to investigating the potential for the future spread of HIV than it is for explaining a current epidemic or the difference between different epidemic states.

## Frameworks focusing on social factors

When AIDS (and eventually HIV) were first identified, they were quickly associated with homosexual and drug injecting behaviour, and with promiscuity. This led to a culture of blame; the infection was clearly the result of individual behaviour, and individuals were responsible for their own behaviours. There was a vocal response to suggestions of retribution, most prominently in a battle for protection of privacy and a resistance to traditional infectious disease control methods. (Bayer 1991; De Cock, Mbori-Ngacha et al. 2002; De Cock, Marum et al. 2003) In fact, once HIV became better understood and prevention services were made easily available for those most in need, many people did act to protect themselves and industrialised countries saw dramatic drops in unprotected sex with high risk partners and in needle sharing.

As the extent of HIV spread in Africa began to become clear, it was hoped that the response would be similar. Once people knew about the risks of HIV and had access to condoms, they would reduce their risk of infection. This optimism proved to be unfounded, leading to frustration among those promoting prevention. (Mertens, Carael et al. 1994; Hogan and Salomon 2005) If people did not change their behaviour when they knew of the risks and had access to condoms, then there must be other factors preventing them from acting on their knowledge. Thus began the shift to a greater emphasis on "vulnerability". Societal factors such as poverty, discrimination against women, political oppression and the lingering effects of colonialism were posited as the driving forces for HIV. (Mane 1997; Dowsett, Aggleton et al. 1998; Rivers and Aggleton 2001; Aggleton and Parker 2002) HIV was no longer a health issue, whose prevention centred on individuals avoiding exposure to the virus. It was a development issue, and the solution was buried deep in the social fabric. In the words of Daniel Tarantola, then advisor on HIV to the Director General of the WHO: "To uproot the pandemic would involve attention to civil, political, economic, social and cultural determinants of vulnerability to

HIV/AIDS, best understood under universal human rights principles". (Tarantola 2000)

The focus on vulnerability distorted efforts to concentrate analytic attention on factors which could be changed by effective programmes. (The World Bank 1997) It also resulted directly in a lost opportunity to provide services for those who were most likely to need them. "Despite the large differences in rates of HIV infection between and within societies, prevention messages emphasised universal risk and the need for all to take equal precautions." (De Cock, Mbori-Ngacha et al. 2002) While some efforts, such as efforts to reduce stigma associated with HIV infection, do need to be universal, most prevention efforts will be more effective if they meet the specific needs of those most at risk. (Des Jarlais, Padian et al. 1994)

It is true that risks (and protective behaviours) cluster within and between societies. We cannot ignore the political, economic and cultural factors which influence these behaviours and may cause this clustering.(Aral, Padian et al. 2005) But in considering these factors, it is important to focus the analysis on the pathways through which they might influence risk, and that means elucidating the relationship between population level variables, and the components of the reproductive rate of infection. (Mertens, Carael et al. 1994)

#### **Proximate determinants frameworks**

Of course, as Rose pointed out, population level factors do influence health outcomes. But they must do so through individuals. All individuals are influenced by the context in which they live. (Durkheim 1964). But these contexts – social, economic, cultural, environmental -- must be expressed through a biological mechanism in an individual if they are to result in disease or otherwise impact on health. (Schwartz and Diez-Roux 2001)

This has long been recognised in the field of demography, which studies the socioeconomic and sociocultural influences of fertility, mortality and migration. As early as 1956, Davis and Blake published a framework for the study of the sociology of fertility which identified intermediate variables with both a social and a biological dimension through which any "contextual" influence on fertility must work. They

were grouped into three clusters: factors affecting exposure to intercourse, factors affecting exposure to conception and factors affecting gestation and successful delivery. Any of these may be changed by changes in the socioeconomic or cultural landscape, but because of their biological dimension, a change in any of these determinants must automatically lead to a change in fertility. (Davis and Blake 1956) John Bongaarts, who further developed the framework in 1984, termed the intermediate determinants of fertility "proximate determinants". Bongaarts developed a formula which quantified the impact of changes in each of the proximate determinants on a notional "natural fertility", thus allowing for the prediction of the impact of changes in contraceptive prevalence, breastfeeding practices and sexual behaviour on fertility. (Bongaarts and Potter 1983; Bongaarts 1984)

Attempts were later made to adapt the proximate determinants approach to explain differences in child survival. (Mosely and Chen, Van Norren 86). In 1986, Becker and Black quantified the framework and included a dimension of programme coverage. This analytic framework was adapted as the basis for the multi-country evaluation of infant and child mortality described on page 19 but it has not been widely used in comparative studies of child mortality, in part because it does not capture differences in the background epidemiology of the infections to which a child may be subject in different contexts. (Bryce, Victora et al. 2005)

A proximate determinants approach has been proposed by Boerma and Weir to try to marry the "vulnerability" and the "infectious disease" approaches to the analysis of HIV epidemics. (Boerma and Weir 2005) As with Davis and Blake's framework, the proximate determinants framework for the analysis of HIV identifies three biological factors leading to infection: the rate of contact between susceptible and infected partners, the efficiency of transmission during exposure between susceptible and infected partners, and the duration of infectivity. In other words, the three components of the reproductive rate of infection. The "proximate determinants" are factors which are largely behavioural, or which can be influenced by treatment seeking and other behaviours. They are listed in Figure 1, which is reproduced from Boerma and Weir 2005.

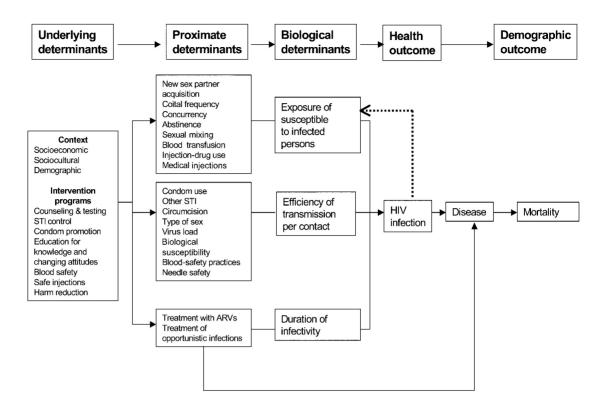


Figure 1 Proximate-determinants conceptual framework for factors affecting the risk of sexual transmission of HIV. (Boerma and Weir, 2005)

This framework makes it clear that any changes in the socio-economic causes of vulnerability must affect behaviour or service use before they can hope to have an impact on HIV infection, Even then, there will be no change in infection unless the change in behaviour or service use has an impact on one or more of the biological determinants of infection. It is only through this limited set of pathways that any structural changes in society can affect the spread of HIV. As Boerma and Weir point out, "For the determinants of incidence (or prevalence) of HIV and other STIs, statistical analyses that indiscriminately include underlying and proximate determinants in the same model and that do not take advantage of the multilevel structure outlined in the framework will produce estimates likely to be difficult to interpret." (Boerma and Weir 2005)

This is an important step forward from approaches which infer a direct link between socio-economic characteristics and HIV status. And it does include a feed-back loop between the outcome, HIV infection, and one of the biological determinants of infection – the likelihood that a susceptible person will be exposed to an infected

person. However, this framework does not sufficiently recognise the importance of the level and distribution of HIV infection as a fundamental determinant of the spread of HIV. In the case of an infectious disease, no amount of "risk" will result in infection if there is no infectious agent present. In the case of a sexually transmitted infection, no practice – not multiple partnerships, or anal sex, or dry sex, or any other of the proximate determinants of infection – will result in a new HIV infection if neither of the partners is infected. (Pisani and Winnithana 2001; Pisani, Garnett et al. 2003; Aral 2004)

Boerma and Weir propose their framework principally for the study of the distribution and determinants of disease, although they suggest it may also be used for intervention research. There is no specific mapping of programme effects to changes in the proximate determinants, and no clear indication of how the epidemiological context is to be taken into account in analysis guided by this framework. The authors suggest that it is difficult to quantify the effect of changes in any one of the proximate or biological determinants of HIV infection because the effect of changes in one parameter of the reproductive rate of infection depends on the other two. "For instance, if condom use increased as a consequence of a successful intervention, the effect of such an increase would depend on the extent to which condoms were used during sexual contact between infected and susceptible partners." (Boerma and Weir 2005) This could be overcome in part by a more linear analysis such as that proposed in Chapter 3. But for any given epidemiological context, simple quantification of the type that Bongaarts was able to develop for fertility would still be thwarted by the variability in the components of the reproductive rate of HIV infection, particularly the variability in the efficiency of transmission per contact.

The proximate determinants approach weds the concepts of social determinants of infection which operate at a population level with the behavioural and biological determinants which operate at the individual level. But it does not help us to assess at what level intervention will be most effective. As Douglas Weed notes, Geoffrey Rose distinguished between investigating the causes of disease (which can be both societal and individual) and investigating the best path for prevention. (Weed 2001) We may well need to search for population level solutions to achieve changes in

behaviour or exposure at the individual level, particularly if the risks are common. Indeed the more common the risks, the harder it is to intervene at the level of the individual, and the more effective it is to move backwards up the causal chain to deal with the factors that determine the exposure of a significant proportion of those at risk. (Schwartz and Diez-Roux 2001) But we will only be able to do that effectively if we have a clear understanding of the pathways through which societal changes might affect exposure to infection at the individual level. Understanding how HIV prevention efforts can change risks at either the social or the individual level is another significant challenge, to which we now turn.

# b Monitoring and evaluation frameworks

Frameworks that seek to explain the relationship between context, behaviour and health outcomes have much in common with frameworks that seek to investigate the effect of interventions on those outcomes, but they are not identical.

	"Process	s" Outcome"		
inputs	Outputs	Effects	Impact	
Labour/effort:	Services	Reported behaviours	Health	
Staff	Visits	Awareness		
	Diagnosis	Knowledge	STD/HIV levels	
Knowledge/skills:	Tests	Attitudes		
Administrative	Treatments	Motivation	Social status	
Medical	Pamphlets	Maintenance		
Training Communication	Radio/TV prog.		Economic status	
	Condoms	About/of:		
Materials:	Gloves	Risk		
Facilities	Drugs	Prevention		
Equipment Supplies	Outreach	Condom use		
		Medical care		
Funds:		Counselling		
Allotments				

Figure 2: Proposed framework for monitoring HIV programmes (Source: Mertens et al 1994)

#### The GPA prevention indicators framework

One of the earliest frameworks for evaluating national AIDS programmes was proposed by Thierry Mertens and colleagues in 1994, and is reproduced in Figure 2.

In this framework, programme "outputs" and "effects" are classified as measures of programme process, while "effects" and "impacts" both qualify as outcome measures. While the discussion of the framework recognises the importance of contextual factors in determining the success of prevention programmes, social and economic status are included in this framework at the impact rather than at an earlier level, suggesting that successful HIV programmes can change these in positive ways. The framework does not include any measures of epidemiological context until the outcome level. Most importantly, it does not distinguish in the category of programme effects between those elements that have a direct relationship with the reproductive rate of infection (such as condom use and treatment seeking behaviours) and those that do not (such as increases in awareness of risk and knowledge about prevention)

The proposed framework was accompanied by a list of standardised prevention indicators, which were eventually published by WHO's Global Programme on AIDS to provide guidance to national prevention programmes. (World Health Organization 1994) A review of the experiences of a number of countries with programme monitoring in general and with the WHO prevention indicators in particular found that they were not particularly useful in countries with concentrated epidemics. Even in countries with generalised epidemics, the indicators had not led to any visible improvements in HIV prevention programming, in part because of difficulties in showing how programme implementation related to changes in the indicators. In addition, new and emerging areas of HIV prevention and care programmes were not covered by the indicators or the framework underlying it. (MEASURE Evaluation 2001) This led to an international effort to develop a monitoring and evaluation framework, and accompanying indicators, which better reflected the needs of national programmes.

#### The UNAIDS monitoring and evaluation framework

The results of this effort, published as the UNAIDS document "National AIDS Programmes: A Guide to Monitoring and Evaluation" (UNAIDS 2000) was based around a framework that was much more clearly rooted in the proximate determinants approach. Figure 3 reproduces that framework. It shows a clearer distinction than previously between programme effects which have a direct impact on the components of the reproductive rate of infection (here classified as outcomes)and those that do not. So knowledge, which may indeed be affected by HIV prevention programmes, is nonetheless here classified as an output of the programme, rather than an outcome.

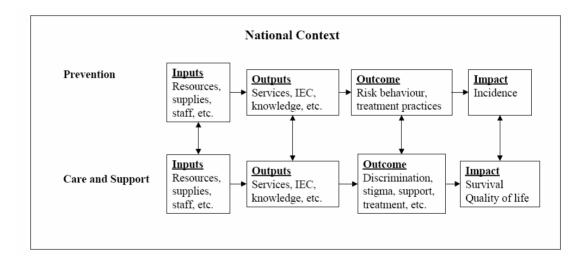


Figure 3: A framework for the selection of indicators for monitoring national HIV programmes (Source: UNAIDS 2000)

The UNAIDS M&E guide makes suggestions, further elaborated in subsequent guidance and training materials on M&E, about the appropriate level of data collection, a discussion which is placed firmly within the context of second generation surveillance systems for HIV. It suggests that input data must be collected at the level of an individual prevention or care effort, as part of their regular record keeping. Much of the output level data also come from projects monitoring service provision, although some will come from facility and population based surveys. The majority of outcome data will come from behavioural surveillance (although facility surveys also play a part), while impact data are provided by HIV and STI surveillance.

The guide stresses the importance of the left hand side of the framework – the information about programme implementation. In monitoring HIV programmes, the first step must be to show that a programme has been implemented. Only if it has been implemented is it worth looking for changes in behaviour, and only if there have been changes in behaviour is it worth trying to relate any changes in HIV incidence or prevalence back through those changes to programme effort. In fact, programme implementation data are so hard to come by that most early attempts to evaluate the impact of prevention efforts looked directly for behaviour change, rarely considering whether there was any evidence that observed changes were actually linked to programme efforts. (UNAIDS 1999)

The epidemiological context, including background levels of risk behaviour and infection and the relative size of populations at risk for HIV are not addressed specifically in this framework, but are subsumed in the all-encompassing concept of "national context", which also covers socio-economic determinants of behaviour and risk of exposure to HIV.

#### **Epidemiological context in the M&E framework**

In the view of Grassly and colleagues, this failure to be more specific about the local epidemiological context will fatally undermine the ability to understand the impact (or to predict the potential impact) of HIV prevention and care programmes. (Grassly, Garnett et al. 2001) To the classic "Input – output – outcome – impact" framework, they add three levels of influence. The first, which determines the outputs that will be achieved for any level of inputs, is the influence of existing health service capacity. The second, which determines the outcomes in terms of changes in behaviour and effective treatment for STIs and opportunistic infections, is the influence of social, economic and legislative context. Finally, and most importantly, comes the influence of epidemiological context. This, in Grassly and colleagues' view, "determines whether the outcome of an intervention translates into a reduction in HIV incidence...It is the ultimate determinant of the success of HIV prevention interventions". (Grassly, Garnett et al. 2001). This framework is designed to interpret the impact of interventions that are already underway, rather than to plan them. In other words, the epidemiological context is considered towards the end of the

analytic process, to determine whether a particular intervention with a particular outcome is likely to have an impact, given the epidemiological context.

This approach, which answers the question "is what we are doing making any difference?" is of more than academic interest. But by considering the epidemic context so late in the process of programme evaluation, it reduces the ability to ask the more important question: "are we doing the right thing in the first place?" Since HIV epidemics and the behaviours that spread them are dynamic, the most appropriate focus of prevention and care efforts will change over time, so this question must be asked repeatedly over time. Pisani and colleagues argue that every country and even regions within countries need to put an analysis of the epidemiological context at the start of any attempt to plan and then monitor effective responses to HIV. (Pisani, Garnett et al. 2003) We propose a simple framework that considers the size of populations at risk, current levels of HIV and STI prevalence within those populations, and current levels of risk behaviour, in order to indicate where most new infections are coming from. Rather than trying to explain the current situation, the framework takes the current situation as a starting point, allowing countries to assess whether their current prevention programmes are focused appropriately. It does not, however, propose a way of analysing whether prevention programmes are likely to be effective with measured levels of effectiveness or coverage.

The importance of doing the right thing in the first place is acknowledged in a monitoring and evaluation framework proposed by Rugg and colleagues The first step in the framework is problem identification, which seeks to "identify the nature, magnitude and course of the overall epidemic". (Rugg, Carael et al. 2004). The authors mention situation analysis, gap analysis and response analysis as activities in problem identification, but no specific analytic steps are proposed.

None of the frameworks discussed given any serious consideration to cost or cost-effectiveness of different approaches; this remains a major gap in the evaluation of the response to HIV. (Walker 2003)

### c Monitoring and evaluation of what, for whom?

The distorted incentives for better M&E were discussed earlier, but it is worth revisiting the issue now that the dominant frameworks have been discussed.

#### Accounting for success, or lack of it

The development of the UNAIDS M&E guide for national programmes was prompted in large part by a realisation that national HIV programmes were struggling to meet the different reporting needs of multiple donors. A single agreed set of indicators would allow for one, rationalised data collection system to track the success or failure of the "national response" as a whole – in other words the outcome and impact of the sum of various HIV prevention and care efforts in a country, regardless of who they are funded or implemented by.

In the framework proposed by the UNAIDS guidelines, the national AIDS authority establishes a monitoring and evaluation working group led by its own M&E unit. All major implementing and funding partners participate in this working group. All these government, non-government and private sector implementers are expected to contribute their programme monitoring data for collation and analysis at the national level. This allows the M&E unit to collate data on how many peer outreach workers have been trained to approach drug injectors, how many are actually working in the field and what their rate of contact with injectors is, how many needles and condoms have been distributed in the preceding month etc. The M&E unit will also receive data from the bodies implementing serological and behavioural surveillance. Analysing the programme data and the surveillance data together, they will look for evidence that programmes have contributed to behaviour change, and to a reduction in exposure to HIV (and ultimately to a reduction in HIV prevalence) nationwide. A similar evaluation model is proposed by the World Bank: the M&E unit in the national AIDS authority coordinates the analysis and use of data collected by various implementing agencies and national information systems. (World Bank and **UNAIDS 2002)** 

The principles of collaborative M&E, under which all donors would support a single, national system that measures the product of the national response rather than trying

to attribute particular changes to their own programmes was enshrined as one of the "Three Ones". The Three Ones was a joint declaration by a number of important donors in the field of HIV, including the Global Fund for AIDS, TB and malaria, the WHO's "3 by 5" programme on access to treatment, and the broad US government initiative known as PEPFAR. It commits signatories to work collaboratively in each country, supporting a single national AIDS authority, and a single national strategic plan developed by that authority. Under the third "key principle" of the "Three Ones" all international donors pledge to support "One agreed M&E framework for overall national monitoring and evaluation" (UNAIDS 2004).

An important aspect of the UNAIDS approach is that it is also designed to meet the M&E needs of the implementers and funders of individual interventions, through the "plausible contribution" model of evaluation. Intervention programmes need to demonstrate that they are being implemented as planned (in other words, they need to measure the process level indicators that record training, contacts with client populations, services provided etc.). Changes at the proximate determinant or outcome level – changes in sexual behaviour, treatment seeking behaviour, needle sharing etc. – are measured by national systems through routine behavioural surveillance, while eventual changes at the impact level – changes in HIV prevalence - are measured through HIV sentinel surveillance. In other words, individual intervention programmes do not have to show that they are responsible for specific changes. They merely need to demonstrate that they have implemented their programme as planned; if they can show this, then they are in a position to claim that they have made a plausible contribution to changes measured in national data. This works better at the early stages of a country's response to HIV, when there are relatively fewer programmes on the ground, than when a large number of interventions of varying quality are reaching the same populations.

This model was developed in large part to avoid duplication of effort in areas of prevention programming which are well-established and which do not require experimental or quasi-experimental designs. It has worked well in situations where national surveillance systems record positive trends in safe behaviour (e.g. Cambodia, Tamil Nadu). However it has proven problematic where little change is seen or risk behaviours and infection are rising (e.g. Indonesia, Bangladesh). In this case, the

contribution of specific interventions in changing behaviour among their client populations may be "drowned out" by continued high risk behaviour among people not reached by the programme, so that even programmes that are "successful" in meeting the needs of their clients may appear to be failing.

This is where the tension between intervention-level monitoring and national level monitoring becomes most critical. From the national perspective, it is indeed possible to argue that programmes that do not result in a change in behaviour measurable at the level of regular surveillance systems are a failure, since they are not achieving the kind of coverage or level of behaviour change necessary to make a dent in HIV transmission at a national (or in some cases site) level. Yet very few individual intervention programmes seek to have an impact at the national level – most are content to be effective at the local level and within the populations they serve.

To measure their performance with data that were designed to reflect changes at the level of an entire risk population is considered harsh by many programme implementers. The alternative, however, is to revert to a system where each small project attempts to measure behaviour change in the population it serves – a system that has in the past generated poor quality data, led to misunderstandings about the success of prevention efforts, and wasted human and financial resources (Mills, Bennett et al. 1996). The pressure for attributability in monitoring comes largely from the very large funders who need to demonstrate the success of the programmes supported by taxpayers and other shareholders. A review of the first three rounds of the Global Fund by Brugha and colleagues found that most people at a country level felt that the Global Fund promoted duplication, particularly in the area of proposal preparation, monitoring, evaluation and reporting. (Brugha, Donoghue et al. 2004) De Lay and Manda, who work in the monitoring and evaluation unit at UNAIDS, noted in 2004 "Most donors still require data directly linking their financial investments in programmes to improved or saved lives". (De Lay and Manda 2004) Ironically, it is these same funders who are the principle proponents, in international fora, of a unified approach to surveillance, monitoring and evaluation.

The very institutions which have espoused this unified M&E framework recognised explicitly in April 2004 that it was not working successfully. In the words of UNAIDS "No functional "best practice" model for monitoring and evaluation (M&E)

for country-wide responses has yet to be accepted. The absence of an operational common M&E framework in most countries has hampered efforts to increase capacity for quality assurance, national oversight and adequate use of M&E for policy adaptation." (UNAIDS 2004, page 4).

This statement, made in the initial report on the new "Three Ones" policy, was followed by a renewed commitment to make the "plausible contribution" model of M&E at the national level work. Two years later the verdict on the willingness of the major funders to stand by this commitment is not encouraging, in the opinion of Bennet and colleagues. "The biggest stumbling block to a coordinated assessment is the incentives that the global HIV/AIDS initiatives— Global Fund, PEPFAR, and MAP—face at present. Without changes in incentives the HIV/AIDS initiatives will continue to pursue restricted, initiative-specific assessments." (Bennett, Boerma et al. 2006)

#### Monitoring for programme improvement

Essentially, international pressure has turned monitoring into an accountability tool rather than a management tool. The frameworks reviewed above focus on counting inputs, outputs and outcomes; none of them suggest ways of identifying areas of programme failure, much less exploring possible solutions. (Quinn Patton 2004; Wilson 2004)

There has been a great deal of talk about building capacity for programme monitoring and evaluation at the national level, but this "capacity building" has so far taken the form largely of workshops, and has focused largely on constructing and reporting standardised indicators, rather than on building institutional capacity to analyse data to guide performance at the point of service delivery or decision-making. (Meda 2004) Very little guidance is available on how programme monitoring and surveillance data can be analysed within the context of routine programme management.

#### Inappropriate analytic frameworks: Key points

- Frameworks for analysing the HIV epidemic can be categorised broadly as those which try to explain the epidemic, and those which focus on evaluating a response
- Early explanatory frameworks focused on the biological risk of exposure and infection, in particular the components of the reproductive rate of infection
- Frustration with failure of prevention efforts that focused on individuals led to the
  development of frameworks focusing on the socio-economic determinants of
  vulnerability to infection. Causal pathways between determinants and health
  outcomes were not clear
- Proximate determinant frameworks clarified the pathways through which social context may determine biological outcomes, but the epidemiological context was not clearly specified in the framework
- Monitoring and evaluation frameworks have evolved to reflect the proximate determinants approach, but the importance of evaluating the response in the light of the epidemiological context has been overlooked until recently
- The dominant M&E frameworks are better suited for assessing the impact of existing programmes than for determining whether they are appropriate to the current state of the epidemic
- The M&E agenda is dominated by international accountability needs; local programme management needs are poorly served

# 8. The analytic tools

It is important to have a clear analytic framework to guide decision-making in public health. However it is also important that the framework is easy to use in the decision-making process. In practice, many analytic frameworks are translated into practical decision-making tools through the use of mathematical models. Mathematical models can explore and help explain transmission dynamics, can predict the future course of an epidemic, and can allow the potential impact of different intervention approaches to be explored without having to go to the time and expense of setting up field trials.

In the opinion of some mathematical modellers, models have been under-used in making policy decisions. Geoff Garnett suggests that this is because of a mismatch between modellers and their audience. "Often mathematical modellers are

responsible, either by describing complex and irrelevant detail, or, alternatively, simply presenting a "black box" without ever explaining the assumptions that are critical to the results derived."(Garnett 2002) In the past, there has been something of a gulf between modellers and the programme implementers and field epidemiologists who should be providing input data on which the models are based. (Pisani 1998; Aral and Roegner 2000) Communication between modellers and policy makers is poor. John Stover, a U.S. based modeller whose work has probably been among that most widely used in policy settings, observes: "Modellers do not necessarily see it as their role to ensure that policy makers understand and use their results. Policy makers often think that modelling is not understandable, answers the wrong questions, or suggests unrealistic solutions." (Stover 2000)

Modellers tend to be interested in using models to explore general principles. (Garnett 2002) But decision-makers, especially at the national or regional level, are interested in their own specific situation – models based on generic or "typical" scenaria are much less likely to sway them than models using local data. (Rachmat 2003; Saidel, Des Jarlais et al. 2003)

Even where local data are used to quantify assumptions that are explicit, their appropriateness depends upon the quality of the data systems that generate inputs. Models are often constrained by the data available; this increases their simplicity but may reduce their ability to produce results that accurately reflect reality. (International AIDS Economics Network) As long as the limitations are clearly understood, this is not necessarily a shortcoming.

Many extremely sophisticated models have been used both in explaining the epidemic and in looking at the effects of different interventions. A handful of important examples from this vast literature include: (Kaplan and Lee 1990; Padian, Shiboski et al. 1990; Leynaert, Downs et al. 1998; Blower 2001; Blower, Aschenbach et al. 2001; Gray, Wawer et al. 2002; Gray, Li et al. 2003). The models most commonly promoted for widespread use in understanding HIV and HIV programming and in guiding decision-making fall into two broad categories – those aiming to understand the current magnitude of the epidemic and its future course, and those exploring the potential impact of different interventions.

# a Estimation and Projection Models

Most models that seek to estimate the number of people living with HIV and project the future course of the epidemic are curve-fitting models, which use mathematical equations to fit prevalence curves to observed data points. Once the curve has been fitted, information about demographic structure of the population and the natural history of HIV infection is used to estimate numbers of people living with HIV, numbers newly infected, mortality etc. Commonly used projection models include:

- EpiModel, used by GPA to make estimates of current prevalence for most developing countries in 1994, and again by UNAIDS in 1997 and 1999. (Chin and Lwanga 1991; Chin 1995)(Schwartlander, Stanecki et al. 1999) The model requires very few data inputs, giving the modeller significant control over the outcome. It can not be used for declining epidemics.
- The AIDS Impact Model, developed by the Futures Group International to predict HIV-related morbidity and mortality, and considered influential in drawing the attention of policy-makers to the magnitude of the HIV epidemic in several African and some Latin American nations. (Stover 1997)
- The UNAIDS Estimation and Projection Package (EPP) which replaced EpiModel as the model of choice for countries with mature epidemics and good time series data. (UNAIDS Reference Group on Estimates 2002; Walker, Stanecki et al. 2003)
- The UNAIDS Workbook method, extensively developed in Indonesia as a byproduct of this work, and recommended by UNAIDS for use in countries with
  low level or concentrated epidemics and limited time series data. (UNAIDS
  Reference Group on Estimates 2003; UNAIDS Reference Group on Estimates
  2004)(Walker, Stover et al. 2004)

#### b Intervention models

Intervention models aim to help decision-makers predict the effects of different programme choices in reducing the spread of HIV. They range from extremely simple models which look at the effect of interventions in a single population to very

complex representations of ongoing transmission in a large number of interacting groups. Most intervention models focus on heterosexual transmission, including within the general population, and are largely appropriate for use in the generalised epidemics of sub-Saharan Africa. Some of the common models include:

**Avert**, one of the simpler intervention models, Avert calculates the sexual infections that would be prevented given various changes in condom use and STI treatment. It can only be used for one type of partner interaction at a time (e.g. sex workers and clients, or clients of sex workers and their wives). (Weinstein, Graham et al. 1989) (Rehle, Saidel et al. 1998)

HIV Tools models are similar in concept to Avert but more detailed, including multiple iterations and variations in infectiousness by length of infection. Separate models are available for looking at the impact of interventions targeted at sex workers (though not at clients), at IDU, at school based educational programmes and at blood safety. There is also a component which can be used with all the models which addresses costs and cost-effectiveness. (Watts, Vickerman et al. 1999).

STDSim lies at the other end of the complexity spectrum. It is a stochastic microsimulation model which was designed largely for use in a research context. It is particularly well suited to modelling the effects of STD programming in generalised epidemics and requires very detailed data inputs. (Korenromp, Van Villet et al. 1998; Korenromp, Van Vliet et al. 2000; Nagelkerke, Jha et al. 2002)

The **Asian Epidemic Model** was developed to project the growth of concentrated epidemics in countries where commercial sex, drug injection and male-male sex are major drivers of HIV. It is a curve fitting model, but unlike the others described above, it includes a large number of behavioural parameters. It includes interactions between different populations (e.g. male IDUs buying sex from female sex workers) and can be used to predict the impact of different levels of behaviour change, but does not currently include a programme coverage parameter. (Brown and Peerapatanapokin 2004)

**Goals** was developed in the early 2000s by the Policy Project to help governments decided how to allocate resources across programme components. It contains default values for the amount of behaviour change produced by various interventions at

given levels of programme coverage, and has an internal HIV transmission model. Goals estimates the infections and costs averted if a given amount of money were allocated to different intervention strategies in a country. Its default structure is skewed towards generalised epidemics.

# c The perfect model: a Quixotic quest?

In general, estimation tools have been more widely used than intervention tools. In a review of the use of both types of models, not a single example of the routine use of intervention simulation models to guide prevention programmes at the country level could be found. (Stover 2000) This may be in large part because there is less variation in the transmission of HIV than there is in the potential responses to that transmission. Models that aim to calculate infections averted have to deal not just with the uncertainties about transmission, infectivity and epidemic progression, but also with all the unknowns surrounding the relationship between prevention services, behaviour change and effective outcomes. Those that deal also with costs bring in a whole new wave of uncertainties.

It is probably not possible to develop a single "public domain" model that meets the needs of all programme planners and managers. Chapter 3 will propose instead a question-driven analytic framework which tries to focus attention not on an absolute quantification of infections averted, but on an understanding of the likely sources of exposure to HIV, and the potentially effective points for reduction in exposure.

#### Mathematical models for understanding HIV: key points

- Many extremely sophisticated models have been developed to understand the dynamics of HIV transmission, risk behaviour and the effect of interventions.
- A limited number of models have been promoted for widespread use in developing country settings.
- Estimation models are available for various levels of data availability; these have gained quite wide currency among public health officials.
- Intervention models continue to be used largely by, or with strong support from, academic and international technical institutions.
- Few models are adapted to the needs of concentrated epidemics

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### 9. Conclusion

This chapter has discussed recent attempts to improve the contribution of evidence, largely from routine health information systems, to decision-making in public health in general, and in HIV prevention and care in particular. The shortcomings of current approaches can be grouped into three major areas: limitations in the evidence base, and particularly in routine surveillance systems, incentive structures which undermine the benefits of investing in good data collection and use, and analytic frameworks which have not facilitated clear thinking about which prevention and care efforts might prove most effective, nor encouraged the active management of programmes to improve their effectiveness. In addition, projection and intervention models have in general been too complex for routine use to inform programme planning at the local level.

It is my hypothesis that by strengthening the evidence base and developing a clear analytic framework centred on the epidemiology of HIV infection, we could greatly improve decision-making in HIV programming. Further, I believe we can do this by using the knowledge and brainpower of people already working in the field of public health, with no need for specialised analytical tools.

The remainder of this work describes the steps taken to test this hypothesis in a single country, Indonesia. The steps are as follows:

- Strengthen the national surveillance system, in order to ensure that national authorities have access to adequate data on: HIV prevalence and risk behaviour among drug injectors, MSM, and female and transvestite sex workers and their clients, STI prevalence among sex workers, population size estimates for all relevant sub-populations, and programme monitoring data for all areas of programming. Develop data management systems that ensure data are user-friendly. (This step is described in Chapter 2)
- Develop an analytic framework which takes into account the current epidemic state, concentrates on the limited number of epidemiological factors which

determine the spread of HIV, and focuses attention on the impact of specific interventions on these epidemiological factors. Express the framework in a simple form which can be used in areas where human capacity is limited. (This step is described in Chapters 3, and a quantified example of the use of the framework to set prevention priorities and investigate programming options is given in Chapter 4)

- Develop a blueprint for programme analysis that looks for evidence that programme inputs and outputs are associated with changes in the epidemiological factors determining the spread of HIV. The analysis should function as a tool for active programme management, encouraging the identification of programme weakness and suggesting areas for improvement. Express the blueprint simply enough for use in areas where human capacity is limited. (This step is described in Chapter 5)
- Use the improved data, the analytic framework and the programme analysis model with policy-makers and programme managers at the local level, to determine programme priorities and to evaluate and manage existing programme efforts. If successful, integrate the analytical process into the national surveillance system structures. (These steps are described, with examples, in Chapter 6)

The final chapter evaluates the success of these efforts, and discusses implications for policy and for research.

# Chapter 2: The evidence base: strengthening Indonesia's surveillance system for HIV

### 1. Introduction

The success of any analytic approach depends in large part on the relevance, completeness and validity of the data which are to be analysed. The major sources for the information that informs decisions about public health are routine surveillance and health information systems, usually managed by public health authorities.

This chapter begins with a brief overview of the history of HIV-related surveillance in Indonesia prior to 2001, when this work began. At that time, Indonesian authorities decided to adopt Second Generation Surveillance as national surveillance policy. I was requested to assist the Ministry of Health's Directorate for Communicable Disease Control in strengthening the surveillance system, beginning in May 2001.<sup>3</sup> This chapter describes the needs that were identified and the steps that were taken to strengthen the system. The work included the following elements:

- Comprehensive assessment of current surveillance efforts
- Publication of existing data on HIV and STI prevalence and risk behaviour
- Revision of national HIV surveillance protocols; training of staff in new protocols
- Expansion of the behavioural surveillance system; institutionalisation of behavioural surveillance into government systems
- Development of software and data management procedures for behavioural and biological surveillance data; integration of procedures into national systems
- Development of methods for population size estimation; training and integration of methods into national system

<sup>&</sup>lt;sup>3</sup> This work was funded by USAID and implemented by Family Health International's Aksi Stop AIDS (ASA) programme

- Development of STI surveillance protocols; partnership with government in implementing STI surveillance<sup>4</sup>
- Development of a single, national programme monitoring database with data contributed by all major donors and programme implementers
- Securing central government funding for core surveillance efforts; ensuring multidonor support for a single national surveillance system

Efforts to build capacity for data analysis and to institutionalise analysis for priority setting and programme management were also included as part of this work; they are described in Chapter 6.

# 2. Surveillance in Indonesia prior to 2001

# a HIV and AIDS case reporting

The first AIDS case in Indonesia was identified in a foreign homosexual man in Bali in 1986. The public health system responded relatively rapidly, making AIDS case reporting mandatory almost immediately. HIV case reporting was later requested, but never mandated

As in all countries, AIDS cases are likely to have been greatly underreported. The case definition required a Western Blot confirmation until 2005; until at least the late 1990s, only one national reference laboratory was equipped to provide such confirmation. In addition, by the turn of the century HIV/AIDS was still not covered in the normal curriculum of Indonesian medical schools, so physician recognition may have been limited. This is likely to have been compounded by limited access to medical facilities for the marginalised populations most affected by HIV (particularly transvestite sex workers and injecting drug users) as well as deliberate misdiagnosis resulting from the stigma associated with AIDS – factors commonly associated with underreporting of AIDS in other countries also.

<sup>&</sup>lt;sup>4</sup> This work was led by Dr Endang Sedyaningsih and others; I was not directly involved in STI surveillance.

HIV case reporting is encouraged but not mandatory. The Ministry of Health's case reporting database has been of little value in illuminating trends in the epidemic since individuals identified diagnostically, anonymous cases found in cross-sectional surveillance, and blood donations testing positive for HIV have been entered indiscriminately as individual records. This system promotes duplication and tells us more about who gets tested than about where infection is concentrated. An indication of the magnitude of this problem was provided by a preliminary inspection of the HIV case report data base in mid 2004 suggested that some 1,900 of 2,700 HIV cases reported up to that time were actually samples found to be positive in sentinel surveillance. (Endang Sedyaningsih, Brad Otto, e-mail communications).

Although they do little to illuminate the current state of the epidemic or even to illustrate trends, case reports are frequently quoted by politicians and in the press. The limitations of case reporting are never discussed; this inappropriate use of poor data has led to considerable confusion among policy-makers and the public about the "true" extent of HIV infection.

#### b HIV sentinel surveillance

Indonesia was one of the first countries to begin systematic serosurveillance among high risk groups, starting with sex workers in Jakarta and East Java as early as 1988. The following year, Bali and Yogyakarta were added to the system, and in 1990 Riau and North Sumatra provided data for the first time. In 1991, surveillance was also conducted in West Java, Central Java and West Nusa Tenggara. By 1994, 15 sentinel sites operated around the country. All sentinel sites focused on female sex workers, largely because it was assumed that Indonesia's HIV epidemic would follow the course of Thailand's, where HIV prevalence among female sex workers had risen to 33 percent by the mid-1990s.

National guidelines and standard operating procedures were introduced in 1998 that strongly endorsed explicit and standardized sampling, unlinked anonymous testing and routine reporting. The guidelines were extremely rigid in some regards. For example, surveillance in any site that could not meet a sample size of 250 individuals was classified as an "ad hoc" serosurvey rather than sentinel surveillance, and results

were not always included in trend analyses. "Ad hoc" surveys were also common among groups other than sex workers; they were only rarely repeated over time. (Ministry of Health records) Little training accompanied the release of the new national guidelines; it seems likely that understanding about appropriate populations for surveillance and sample selection remained limited. As an example, the Excel spreadsheet held at the central level reporting surveillance results for the province of Bali shows that since the 1998 guidelines were issued, "surveillance" has been conducted among motorcycle taxi drivers, pregnant women, housewives, fishermen, farmers and hotel staff as well as high risk groups. Some of these "surveillance" groups had sample sizes of a single person.

There appears to have been a distrust of the quality of data generated by the national sentinel surveillance system in the late 1980s and early 1990s. National and international advisers working in Indonesia at the time report that consistently low prevalence was interpreted by some as sign of a cover-up. (Elmendorf, Jensen et al. 2004) In consequence, the number of samples included in surveillance became very large. The sentinel surveillance system—focusing as was appropriate on groups at high risk and achieving relatively good geographic coverage with sample sizes large enough to provide robust results—compares well with surveillance in most countries (including many industrialised countries) at a similar point in time. Indeed it could be argued that it was far more comprehensive than was needed at a time when all data were pointing to extremely low rates of infection even among those at highest risk. Table 1 summarises the findings of the HIV serological surveillance system in the years before any behavioural data collection was added.

While the quality of laboratory testing was called into question by some projects aiming to provide laboratory support (World Bank 1996), studies conducted by foreign research institutions using foreign laboratories or the U.S. Navy-run laboratory in Jakarta (NAMRU) found results no different from those registered by the national surveillance system. (Joesoef, Linnan et al. 1997)

Some surveillance guidelines warn that blood donation data may be of limited use as an indication of trends in HIV because people with a history of risk are deferred (leading to possible underestimates of infection), while donations that test positive are discarded without confirmation (leading to possible overestimates). It is worth

noting that in the mid-1990s the Indonesian Red Cross, which conducts the screening of donated blood, had no deferral criteria for high risk individuals, and that all positive blood samples were confirmed using Western Blot tests.

Table 1: HIV prevalence data from national surveillance, 1990 – 1994/5

Year	Population	Number tested	Number positive	HIV Prevalence (%)
1990	Female sex workers	4,420	0	0
1991/92	Female sex workers	20,293	0	0
1992/93	Female sex workers	38,444	0	0
993/94	Female sex workers	52,870	3	0.006
1994/5	Female sex workers	39,790	12	0.03
1993/94	Pregnant women	572	0	0
1994/5	Pregnant women	4,750	0	0
1992/93	Blood donors	533,865	8	0.002
1993/94	Blood donors	705,345	5	0.001
1994/5	Blood donors	748,813	17	0.002

The first rises in HIV prevalence were recorded among waria (transgender sex workers). With sample sizes of between 230 and 250, prevalence of 0.2 percent was recorded in 1994, rising to 6 percent in 1997, when surveillance in this group was dropped, apparently because external donor funding for this activity dried up. (Lubis, Master et al. 1994; Lubis, Master et al. 1997)

Injecting drug users were added to the surveillance system in 1996, when RSKO – Rumah Sakit Ketergantungan Obat, the nation's only public drug treatment hospital situated in Jakarta -- became a sentinel surveillance site. Sample sizes in the first years were small (<65), because injectors in treatment were few. No HIV was found in surveillance among IDUs until 1999, when a prevalence of 16 percent was recorded in a sample of 247 injectors. Within three years, prevalence was 47 percent (MoH, national surveillance data).

#### c STI surveillance

While a passive surveillance system for STIs has theoretically been in place in Indonesia for many years, it has been largely dysfunctional. Only a small fraction of those with STIs go to the public facilities that are supposed to report cases to the surveillance system. Those facilities do not have the means to perform the aetiological diagnosis required by the reporting forms.

In order to get blood samples for unlinked, anonymous HIV surveillance, Indonesia tests for syphilis in high risk populations during the period designated for HIV sentinel surveillance. Treatment is provided as necessary to those who seek their syphilis test results, and many HIV sentinel surveillance sites report syphilis seropositivity as well as HIV seropositivity in their surveillance reports. Syphilis test results are notoriously difficult to interpret in relation to risk behaviour. The Indonesian surveillance system has always used a test for treponemal seropositivity, giving the proportion of a given population that is TPHA positive. This marker of life-time exposure to treponemal infection may differ widely from markers of active syphilis and has not proven a useful as a marker of recent unprotected sex with multiple partners.

Some donor-funded programmes conducted occasional cross-sectional STI surveys in various high and low risk populations between 1995 and 2001, but no attempt was made to integrate these activities into routine public health monitoring systems.

#### d Behavioural surveillance

Indonesia was one of the first countries to begin annual surveys of HIV-related knowledge and risk behaviours in systematically sampled sub-populations, including those at high risk for HIV surveillance. The efforts were implemented by the University of Indonesia's Centre for Health Research (CHR) in three cities – the capital Jakarta, the second largest city and busy international shipping port of Surabaya, and the large fishing port of Manado/Bitung. Funded by USAID, the surveys were supported technically by the HIV/AIDS Prevention Project, implemented by Family Health International. (Utomo, Dharmaputra et al. 1998) In

1998 and 2000, an AusAid funded programme contracted CHR to replicate the surveys in three further sites: Bali, Kupang and Makassar.

The surveys followed standardised methods, constructing sample frames from a thorough mapping of populations, and using standardised pre-coded questionnaires administered by trained interviewers. (Family Health International 2000)

The primary weakness of the early behavioural surveillance efforts in Indonesia is that they were not integrated into national surveillance efforts in any way. Involvement of government agencies was minimal. (Silfanus 2001) Sites and populations were chosen to match donor-funded programme priorities rather than to tie in to national sentinel sites for HIV, and behavioural data were never related to HIV or STI data.

## e Population size estimation

Indonesia's first recorded attempt to estimate (rather than project) the number of people at risk for HIV occurred in March 2001, when epidemiologist James Chin and other colleagues spent a day reviewing existing data and making an estimate of those infected. The number of infected sex workers was derived directly from case reports, and the number of infected male clients from FSW estimates, so no population size estimates are available for these groups. No estimates for either population size or infection are included for transgenders or men who have sex with men. An estimate was given for drug injectors as follows: "Estimates (for IDU) ranged from a conservative 100,000 or less, up to 1.2million! For this estimation workshop an estimated number of 250,000 was selected." (Chin 2001) No methodology or basis in data is given.

# 3 Use of early surveillance data

For all its limitations, the system described above was by 2001 providing data that compared favourably with most other countries of Indonesia's level of epidemic development. However there is very little evidence that these data were analysed

systematically or used to set programme priorities or to manage programme implementation. Some examples, summarised by Elmendorf and colleagues, include:

 Finding: Extremely sharp rises in HIV among injection drug users, for whom no prevention programmes existed

Response: None

• **Finding**: Rising HIV prevalence among transvestite sex workers **Response**: None. Group dropped from regular surveillance

• **Findings**: High STI prevalence among sex workers; low STI prevalence among women in reproductive health and MCH services

**Response**: Continued training of reproductive health and MCH workers in syndromic management of STIs.

• **Finding**: No change in condom use in commercial sex in areas with condom promotion programmes for sex workers

**Response**: No change in programming

(Elmendorf, Jensen et al. 2004)

Indonesia did not publish any national report on HIV prior to 2001. The results of behavioural surveillance were summarised in English language reports given to the donor agencies. These reports gave tables of indicators but did not include any bivariate analyses or make programme-specific recommendations. Reports of STI sero-surveys did include programme recommendations. Some of these led to changes in programme emphasis within donor agencies but they did not influence national policy.

# 4. Steps undertaken in strengthening Indonesia's surveillance system

# a Taking stock of the surveillance system

In April 2001, Indonesia's Ministry of Health's Directorate for Communicable
Disease Control held a national workshop on HIV surveillance. The group
recommended that the surveillance system be strengthened in line with the principles

of Second Generation Surveillance, and established a national working group on surveillance to guide this work. Chaired by the Director for Communicable Disease Control, the working group meets on an ad-hoc basis, at least once a quarter and more frequently if necessary. The working group – which includes representatives of the National AIDS Control Commission, a number of government agencies, donor agencies and technical advisors – acts as a steering committee for the development of surveillance activities and the dissemination of results.

One of the first recommendations of the national Surveillance Working Group was a comprehensive review of the existing HIV sentinel surveillance system. This review, supported by Family Health International's Aksi Stop AIDS programme (ASA) in 2002 and conducted jointly with MoH staff, confirmed the limitations in surveillance procedures described above, and identified others. (Miller and Nugrahini 2002) While the review concentrated on HIV sentinel surveillance, many of the problems identified are common to behavioural and STI surveillance and other areas. The major shortcomings identified by the review and the surveillance working group include:

- No secure funding for public health surveillance
- Outdated HIV sentinel surveillance protocols that fail to meet the needs of the developing epidemic
- Inadequate training for staff implementing sentinel surveillance
- Marginalisation and fragmentation of behavioural surveillance; limited access to data
- Marginalisation and fragmentation of STI surveillance; limited access to data
- No programme monitoring data
- No useable population size estimates
- Failure to analyse, publish or use existing data

The remainder of this chapter describes these problems in greater detail, and focuses on efforts made to strengthen these weaknesses.

# b Secure funding for public health surveillance

#### The problem

Throughout the 30-year rule of former President Suharto, Indonesia's government and budgetary structures were extremely highly centralised. Since 2001, however, the country has undergone an extremely rapid and somewhat chaotic decentralisation of public finance and service provision. Funding mechanisms for public goods are currently unclear. (World Bank 2003) Public health surveillance remains the responsibility of the central government on paper, but in the 2001/2002 budget the central government was only allocated money for procurement of reagents. Operating costs were to be covered by district budgets. This meant that local legislatures must vote through funds for anonymous surveillance of a highly stigmatised, fatal disease that remains confined largely to sub-populations that local politicians would prefer to ignore.

Where local funding has been made available, it has increasingly been with strings attached. Pressure for named case finding is strong and local policy makers feel that they, rather than national MoH officials, should have control over choice of sentinel sites and populations. This threatens the availability of trend data, which is central to useful surveillance. (Miller 2001; Pisani 2003)

#### Steps taken

The problems were described in detail by a Surveillance Working Group briefing paper (Pisani 2003), which was circulated to the Ministry of Health's planning department, the State Planning Board, the Ministry of Finance and other organisations that influence financial allocations such as the World Bank. Shortly thereafter, P2M developed proposals for a "core" HIV surveillance system, which designates a limited number of sites for both sentinel HIV and behavioural surveillance which would be funded out of the central government budget, as a

<sup>&</sup>lt;sup>5</sup> Throughout this document, the word "district" refers to the Indonesian administrative unit known as the "kabupaten". The kabupaten is the largest unit of government after the province, and under the 2001 decentralisation law is the unit responsible for the planning and delivery of most services, including health and education services. Strictly speaking, kabupaten should be translated as "regency"; I use the term district because it is more familiar to most readers.

national public good. provides secure national funding for. These sites are chosen in consultation with provincial P2M offices to ensure adequate geographic coverage and distribution of risk groups (in particular ensuring that IDU and MSM are adequately represented). The sites are obliged to use national sampling protocols and standard operating procedures. The centre covers all costs, including operational expenses, and provides extra training and supervision directly to the implementing agency (i.e. the district health bureau).

After intensive lobbying efforts, funding for the core HIV surveillance system was secured for 42 sites beginning in 2005. Central funding was also provided for behavioural surveillance in three sites. The number of centrally funded sites is expected to increase further in 2006. The existence of this "core" system, structured partly around existing sentinel sites with good trend data, does not preclude districts maintaining other sites. It simply ensures that a minimum of national sites will continue to provide quality data to the national level, regardless of any effects of decentralisation

Table 2: Populations included in the Indonesian surveillance system to 2005, and in the national core sentinel system, with number of sites

Population	Behavioural surveillance	HIV "sentinel site"	STI surveillance	Core system sites*	
Female sex workers	18	20	10	20	
High risk men**	17		0	7	
Waria	4	2	0	2	
Male sex workers	4	1	0	1	
Gay men	4	0	0	1	
IDU	5	1	Not needed	5	
Pregnant women	Not needed	0	0	2	
Prisoners+	Not needed	2		4	
Youth	3	Not needed	Not needed	Not needed	

<sup>\*</sup>These are sites designated as core, centrally-funded HIV sero-surveillance sites under the planned "core sentinel surveillance system"

<sup>\*\*</sup> High risk men are men in occupations whose circumstance and culture support frequent buying of sex. They include sailors, truck drivers, moto-taxi drivers and port workers

<sup>+</sup> In some sites, only prisoners convicted of drug-related offences are included

# Outdated protocols and operating procedures

#### The problem

The 2002 review conducted by the Ministry in conjunction with the ASA programme found that population selection, sampling procedures, data reporting and confidentiality were all poorly understood or incorrectly implemented. This was in part because of inconsistencies and a lack of clarity in the 1998 guidelines and standard operating procedures for HIV surveillance.

The review found that many of the major sub-populations with risk behaviours are included in the national HIV surveillance system at least in theory. However inclusion criteria were unclear, and sampling protocols poorly described. This is particularly important in the Indonesian context, because much HIV sentinel surveillance activity is population-based rather than institutional. In other words, rather than using blood samples left over from sex workers who are attending a routine STI screening, Indonesian health officials visit brothels and massage parlours and approach sex workers working there for inclusion in surveillance. This represents an extra and often unwelcome workload for health staff. Sampling frames and protocols potentially have more of an influence on results in population-based surveillance than in institution-based surveillance, because the range of people who can possibly be approached for inclusion is wider. Target-driven sampling has in the past led to the inclusion of people who did not necessarily represent those intended for inclusion in surveillance – for example hotel staff were substituted for sex workers, while fishermen visiting from other countries were included to make up samples for high risk men.

Some at-risk populations have been under-represented. Injection drug users, a major contributor to HIV spread in Indonesia, were represented by a single sentinel site. Some groups were not represented at all. Transgender sex workers, the only group to have registered substantial levels of infection in the mid-1990s, were dropped from surveillance in 1997, and no information was available at all for men who have sex with men (other than transgenders). This led to the "no data = no problem" syndrome – in national estimates of HIV infection made in 2001, no mention was made of any

infections contracted through male-male sex. (Chin 2001; Republic of Indonesia 2002)

#### Steps taken

National guidelines for HIV sentinel surveillance and standard operating procedures were comprehensively revised with technical assistance from FHI, AusAid and WHO, and published in 2004. (Indonesia Ministry of Health 2004)

The core surveillance system has allowed for the central designation and support of sites which broadened coverage of the harder to reach surveillance populations – IDU and MSM. The latter was in part a consequence of the active involvement of government surveillance staff in my 2002 sero-survey of transvestite sex workers, male sex workers and gay men, which demonstrated the feasibility of routine surveillance in these populations. (Pisani, Girault et al. 2004)

National protocols now envisage HIV surveillance in the following populations:-

Direct female sex workers (women who work in brothels or on the street, and who derive their principle income from selling sex). A sample frame of direct sex work locations is drawn up by the national bureau of statistics (BPS). BPS start with listings of entertainment establishments from the Ministry of Social Affairs (which maintains a list of brothels, although these are not legally recognised), the Ministry of Tourism (which licences bars and discotheques) and the Ministry of Health (which licences massage parlours). They also interview key informants, and a team of enumerators spends up to five days conducting a physical mapping to complete the sample frame. A two-stage cluster sample is drawn from this using random selection at the first level, and take-all at the second level.

**Indirect female sex workers** (women who work as masseuses, karaoke bar hostesses etc. but who may derive additional income from the sale of sex). Sampling as above.

**Male STI patients** at first visit to STI clinic during the surveillance period. Sampled at clinic, consecutively until sample size is reached.

**Transgender sex workers** (biological males who live as women and who sell sex to men). Sampled at the workplace/ on the street, using the same method as for female sex workers.

**Injecting drug users** at first visit to rehabilitation/ drug treatment clinic during the surveillance period. Sampled at clinic, consecutively until sample size is reached.

**Pregnant women seeking antenatal care**, at first visit to maternal and child health clinic during the surveillance period. Sampled at clinic consecutively until sample size is reached. This population is currently only indicated in three provinces where HIV prevalence is highest.

Prisoners in detention houses or jails during the surveillance period, without regard to the cause for incarceration, or known drug using history.<sup>6</sup> This population was originally included simply because it was easily accessible and thought to represent "orang nakal" ("naughty people") who might be at high risk for HIV. As HIV prevalence rose in prisons they came to be seen as proxy for IDU sites. Since 2004, a few prisons have been set up exclusively for drug offences. These are being prioritised as sentinel surveillance sites. A sample frame is drawn up of prison blocks, and a two-stage cluster sample is drawn from this using random selection at the first level, and take-all at the second level

**TB patients** at first outpatient visit during surveillance period.<sup>7</sup>

High risk men, representative of clients of sex workers, remain a poorly defined surveillance population. The 2004 protocols suggest using STI clinic patients as a proxy for high-risk males. This is problematic operationally, because high rates of self-medication, poor service provision in the public sector and a preference for private treatment combine to limit the number of men accessing public STI clinics.

 $<sup>^{6}</sup>$  Indonesia's detention system is complex but can be broken down into three major areas -1) jails, where people are sent once sentenced, often for long periods 2) detention centres, where people can be held for considerable periods while their case is being heard. 3) police holding cells, where people can be held for renewable periods totalling up to around four months without charge. The latter are not included in sentinel surveillance populations.

<sup>&</sup>lt;sup>7</sup>TB patients have not been previously included as a sentinel surveillance population. By mid 2005, there was still no regular sentinel site established in this group, although one Jakarta treatment clinic conducts opt-out testing and makes data available to P2M.

Several districts continue to include samples of men drawn from occupations known to support norms of commercial sex, such as long-distance transport and sea-faring.

While provincial and district health officials are strongly encouraged to select sentinel populations according to the guidance given in national protocols, the central government can not ensure that they do, except in the case of the centrally-funded "core" sites.

# d Inadequate training and supervision for surveillance staff

#### The problem

Under the current decentralisation law, national ministries may provide guidelines, training and support to provincial departments. Very few provincial governments provide training to district level staff, and there is no clear mechanism to finance such support. It is district level staff, however, who actually implement surveillance. Turnover among district level staff is high, and specialised skills are extremely limited; it is they who most need training. This is true of HIV and STI surveillance activities. Behavioural surveillance is conducted by the Bureau of Statistics, which has maintain a centralised training structure.

#### Steps taken

The core surveillance system secured as of 2005 provides a central budget for training and supervision of surveillance staff at the district level, with or without the cooperation of provincial level staff. FHI and AusAid also helped develop new training curricula and supported training for surveillance staff. The simultaneous introduction of the core surveillance system and the SSHIV data management system described below provided an opportunity to provide that training to district level officials – the ones who actually implement surveillance but who have rarely had direct access to training in the past. Separate training was also provided in confidentiality procedures and ethical issues, and in data analysis and use.

Despite these efforts, training remains grossly inadequate. One major limitation is that there are very, very few staff with the skills to provide the necessary training at

the lower levels, and all of them are currently engaged in administering two Global Fund grants. Turnover of district health staff – high at the outset of these efforts – is growing rapidly as new districts are formed and competent staff are promoted to new management positions. Efforts to interest schools of public health in strengthened surveillance curricula have not succeeded so far. This is again in part because so few people are available to provide adequate support.

# e Marginalisation and fragmentation of behavioural surveillance

#### The problem

In the early years, behavioural surveillance carried out by the University of Indonesia on behalf of USAID and AusAid funded programmes provided quite useful data that were published in many separate reports in English, stretched the capacity of the implementers, and were roundly ignored by the government. As other institutions (such as UNFPA and UNICEF) became interested in HIV programming in Indonesia, they commissioned more, similar behavioural surveys, duplicating the work of questionnaire development, training and data management and creating more, slightly incompatible and largely inaccessible data sets which were rarely analysed fully, and never analysed in conjunction with data generated by other parts of the surveillance system.

#### Steps taken

Integrating behavioural surveillance into routine government data collection systems is a challenge. Behavioural surveillance requiring face-to-face interviews is fairly resource-intensive. In comparison with serological surveillance, which tends to record a maximum of six variables (location, target group, age, sex, HIV test result, syphilis test result), behavioural surveillance generates large amounts of data. The raw data-set for behavioural surveillance among sex workers in Indonesia, for example, includes 141 variables, while over 11,000 individuals a year are now included in the behavioural surveillance system. In addition, because questionnaires

include complex skip patterns, careful recoding work must take place before the data can readily be used.

The Ministry of Health at the district level often assigns just one person to all of public health surveillance, while its Jakarta-based research wing has no representation in the provinces. When P2M decided in 2001 to expand its HIV surveillance system in accordance with WHO/UNAIDS Second Generation Surveillance guidelines, it was clear that the Ministry of Health did not have the capacity to undertake behavioural surveillance on the scale necessary. It was equally clear that this work could not be undertaken by a single university.

In late 2001, it was suggested to the surveillance working group in a discussion paper that oversight of behavioural surveillance be assumed by P2M, while the responsibility for implementation be handed to the Central Bureau of Statistics (BPS). (Pisani 2001) This was endorsed by the surveillance working group. BPS agreed to

Table 3: Behavioural surveillance sites and populations, Indonesia, 1996-2004/5

Site	Female sex workers	High risk men (truckers, seafarers, taxi)	Military	IDU	Transgender sex workers	MSM	Male sex workers	School children/ youth	Factory workers/ civil servants
Jakarta	1996-2000, 2002/3, 2004/5	1996-2000, 2002/3, 2004/5		1999, 2002/3, 2004/5	1999, 2002/3, 2004/5	2002/3, 2004/5	2002/3, 2004/5	1997, 1999, 2002/3, 2004/5	
Surabaya	1996-2000, 2002/3, 2004/5	1996-2000, 2002/3, 2004/5		2002/3, 2004/5	2002/3, 2004/5	2002/3, 2004/5		1997, 1999, 2004/5	1996, 1998
Manado/ Bitung	1996-2000, 2002/3, 2004/5	1996-2000, 2002/3, 2004/5						1996, 1998	
Medan	2002/3, 2004/5	2002/3, 2004/5		2004/5					
TanjungPinang	2002/3, 2004/5	2002/3, 2004/5	2002/3		2002/3, 2004/5	2002/3, 2004/5			
Palembang	2002/3, 2004/5	2002/3, 2004/5							
Bandung	2002/3, 2004/5	2002/3, 2004/5		2002/3, 2004/5					
Semarang/Kendal	2002/3, 2004/5	2002/3, 2004/5							
Karawang/Bekasi	2002/3, 2004/5	2002/3, 2004/5							
Ambon	2002/3, 2004/5		2002/3,						
Jayapura	2002/3, 2004/5		2002/3,						2004/5
Sorong	2002/3, 2004/5	2002/3, 2004/5							
Merauke	2002/3, 2004/5	2002/3, 2004/5						2002/3	
Kupang	1998, 2002, 2002/3	1998, 2002, 2002/3							

Denpasar	1998, 2002, 2002/3	1998, 2002, 2002/3		1998, 2002		
Makassar	1998, 2002, 2002/3	1998, 2002, 2002/3	1998, 2002, 2002/3			
Pontianak	2004/5	2004/5				

carry out behavioural surveillance among sex workers and high risk men in 13 provinces (10 funded by USAID and 3 funded by AusAid). Working with technical assistance from UICHR and ASA/FHI, BPS revised existing questionnaires, updated sampling and field protocols, developed interviewer and supervisor training materials, and developed a data entry and management system. (Indonesia 2004)

The new materials were field tested in three sites (Jakarta, Medan and Riau). Close supervision was provided by senior BPS staff, including the Director of Methodology and the Director of Social Welfare Statistics. Following the field testing, procedures, manuals, questionnaires and budgets were revised as necessary before continuing implementation in other sites. BPS were cautious in their approach to this new work, which differs significantly from the more common household and consumer price index surveys. They did not wish to take on the more "difficult" populations of male or transgender sex workers, men who have sex with men, or injection drug users, until they had developed well-tested methods and a corps of staff trained in surveillance of sexual and drug-related behaviours. For this reason, UICHR continued to implement BSS among these other groups in 2002/3, with BPS taking over in the 2004/5 round of surveillance.

Table 3 shows the sites and populations in which behavioural surveillance has been conducted, from 1996 to 2005, by year of survey.

A thorough review of the behavioural surveillance system was conducted after the 2002/2003 round. Some weaknesses were identified in the system, and steps were taken to rectify them

### Documentation of sampling methods

It was found that mapping procedures, sample frames, sample selection and refusal rates had been very poorly documented in the 2002/3 round of behavioural surveillance. This made it difficult correctly to calculate sampling weights and so impossible to conduct weighted analyses. As a result, BPS developed new software known as the Cluster Information Sheet, or CIS. This requires the field coordinator to enter data from the mapping procedure, including the population size at each sub-site (often an institution such as a brothel or disco, or a physical location such as a park

or street corner). Once all the data have been entered, CIS automatically clusters the data appropriately and generates a sample based on a random selection of clusters, and a fixed number of respondents per cluster. During the fieldwork, supervisors are required to keep records of the size of at risk populations, and refusal rates. These are entered into CIS for documentation and later calculation of sample weights.

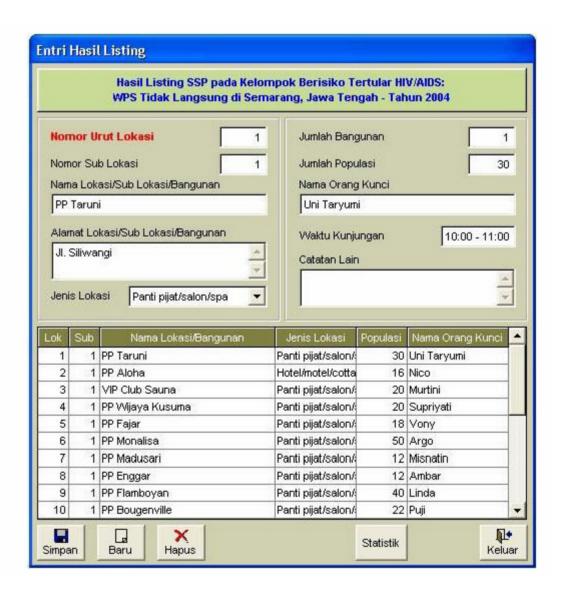


Figure 4: Example of the Cluster Information Sheet software mapping results page for Semarang, Central Java, 2004

The Cluster Information Sheet has greatly increased the efficiency of the sampling process, and improved documentation of sampling procedures. It is now being used by P2M in sample selection for HIV and syphilis sentinel surveillance.

### New sampling methods for IDUs

In Indonesia, male, female and transvestite sex workers and the highest risk MSM are all relatively easily accessible in places where they go to meet partners. This is not true of drug injectors. In the first IDU survey in Jakarta in 1999, simple snowball sampling was used. In 2002/3, we tried two methods. In Surabaya, injecting "hot spots" were mapped as primary clusters, and all IDU regularly found at the selected clusters were approached through a cluster key informant. In Jakarta and Bandung, we attempted the then newly-developed method known as "respondent driven sampling" (RDS) – a systematic extension of the snowball method which limits the referrals per respondent and is said to give a probability sample. (Heckathorn 2002; Heckathorn, Semaan et al. 2002; Magnani R 2005) The method was poorly explained to the field supervisors, and very poorly documented. Respondents were given a pocket calculator in thanks for their time if they completed an interview, but cash incentives were not used and no payment at all was made for referral of further respondents.

In 2004/5 BPS introduced a more traditional form of RDS, complete with incentives for those successfully referring as well as respondents. Software was developed to track coupon distribution and payment, and the process was carefully documented. The success of this approach, which has proved problematic in other resource-poor settings, is currently being evaluated by BPS. (Morineau, Pisani et al. 2006)

### Secure funding for behavioural surveillance

Until 2004/5, all behavioural surveillance in Indonesia was funded by foreign donors. The creation of a single national system has rationalised funding and allowed for cost-sharing between donors – by mid-2005 USAID, AusAid and WHO were all funding behavioural surveillance sites through the national system, and it appears likely that UNICEF, DfID and the Global Fund will follow suit. BPS has put together a "package" budget for surveillance at the local level, in the hope that some local administrations will choose to fund this activity themselves. The package, covering 250 direct sex workers, 250 indirect sex workers, and 400 high risk men, costs 140,000,000 Rupiah (around US\$ 15,000). Because it does not include costs associated with methods and software development, training of central level staff etc,

this is considerably less than the amount charged to foreign donors who have funded systems development. At least one district administration, that of Timika district in Papua, has requested this service at their own expense. Central government funding for behavioural surveillance was secured for three sites in the 2005 budget under the "core surveillance" proposal. This will become effectively available in 2006. This is an important precedent, but the national share of funding for behavioural surveillance must continue to increase if the system is to survive in the long term.

### f Marginalisation and fragmentation of STI surveillance

### The problem

No other STIs are currently included in the routine national sentinel surveillance system in Indonesia. However, data from university research programmes are available in some areas, while donor-funded programmes have conducted several cross-sectional studies of STIs. In the largest of these, the USAID-funded HAPP/ASA programme, the same sampling methods have been used in four rounds of repeat cross-sectional surveys of STIs among sex workers. The first two rounds were conducted without government involvement. The AusAid funded research was conducted in partnership with government, but not as a routine public health surveillance activity. Both sets of surveys had important policy implications, but the data were not widely used.

Trend data are difficult to interpret because testing methods have changed between surveys. In the earlier studies, tests for gonorrhoea used culture and Gram stain, while chlamydia was detected using direct fluorescent antibody tests. Later on, Genprobe testing was used for both infections. In 2005, polymerase chain reaction (PCR) testing was introduced. These progressively more sensitive tests would certainly affect the outcome of the surveys, and influence interpretation of results.

### Steps taken

In the most recent rounds of USAID-funded STI surveillance (2003 and 2005), active partnerships were established with P2M at the national and district levels, national

protocols were established, and intensive training was provided to P2M staff, who did the bulk of the field work on the survey. The capacity has thus been created to conduct routine sentinel surveillance for STIs in high risk populations in Indonesia within the national system. Global Fund money will be used by P2M to extend the survey to other locations, using this new capacity. However no funding mechanism has been identified to secure this activity beyond the life of donor-funded projects; without such funding, it is unlikely to be integrated into routine government activities.

Table 4 shows the years of cross-sectional STI surveys in various population. Because they are not part of a national surveillance system, these studies do not necessarily follow the same methods or use the same sampling techniques, although there has been an effort to maintain consistency across those surveys (shown in bold) which were implemented through the HAPP/ASA programme.

Table 4: Cross-sectional surveys of STIs in various study populations, Indonesia

	Sex workers	Women (MCH)	STI clinic (m & f)
Jakarta	1996, 1998, 2003, 2005		
Surabaya	1992/3, <b>1996, 1998</b> , 2001/2, <b>2005</b>	1992/93	
Manado/ Bitung	1996, 1998, 2003, 2005		
Medan	2003, 2005		
Tanjung Pinang 2003, 2005			
Palembang	2003, 2005		
Bandung	2005		
Semarang	2003, 2005		
Banyuwangi	2003, 2005		
Jayapura	2003, 2005		
Kupang	1999		
Denpasar	1997-1999, 2004	1999	1999
Makassar		1999	1999

The variability of results introduced by different testing methods has been hard to adjust for. For an example, see Table 20 on page 235.

### g Lack of population size estimates

### The problem

In concentrated HIV epidemics, the magnitude of the HIV problem depends not just on the proportion of any given at-risk sub-population that is infected with HIV but also, crucially, on the absolute number of people in that sub-population. At the start of 2001, Indonesia had no reliable estimates of the size of sub-populations at risk, and no methods for developing such estimates.

### Steps taken

During a regional meeting called by FHI and UNAIDS in Bali in 2002, Indonesia and neighbouring countries reviewed the methods and data sources available for making national level estimates of HIV infection, chose methods most appropriate to their data, and made plans to conduct national estimates of populations at risk for HIV. (Family Health International 2002) Indonesia went on shortly thereafter to develop systematic estimates of the size of sub-populations at risk for HIV and detailed estimates of HIV infection at the provincial level. The methods and results have been published by the Indonesian Ministry of Health. (Indonesia Directorate General of Communicable Disease Control and Environmental Health 2003; UNAIDS/WHO Working Group on Global HIV/AIDS/STI Surveillance 2004).

In brief, these steps were followed:

Decisions were made about which populations to include in the estimates. It was
decided that the sub-populations whose own behaviour put them at highest risk
(transgender, male and female sex workers, clients of sex workers, injection drug
users, men who have sex with men) should be included. The opposite-sex
spouses of these populations should also be included in the estimates. Prisoners
were included in part because high rates of infection are recorded in prisoners in

HIV sentinel surveillance, while street children were included for purely political reasons.

- A meeting was held to bring together all the agencies, institutions, NGOs and
  other groups that might have access to data about these populations. The purpose
  of the estimates was explained, and data were requested, broken down by
  province if possible.
- Available data were reviewed, and the most appropriate estimation method was selected for each population. Every method involved some kind of multiplier – appropriate data were selected as benchmarks and to calculate multipliers.
- A spreadsheet was prepared, using data for each population for each province, with a national summary sheet. Benchmark data were listed on the population sheets, the appropriate multipliers were applied, and results entered into the provincial sheets.

The results, summarised in Table 5, gave high and low estimates for the numbers of people exposed to HIV through their own risk behaviour or that of their primary sex partner, and allowed for the calculation of the number of people living with HIV using the Workbook method. (Walker, Stover et al. 2004)

The Indonesian estimates were the first time any country had produced systematic, transparent, data-based estimates of the number of people in all high risk populations at the provincial level. The process and the methods used in Indonesia are the subject of a UNAIDS Best Practice collection case study, and have been recommended by the UNAIDS Reference Group on Estimates and Projections as the gold standard for countries with concentrated epidemics and limited time series data. (UNAIDS 2003; UNAIDS Reference Group on Estimates 2003)

### Improvements in the population size estimation process

The 2003 estimates were remarkable for having been achieved in a short period of time, at low cost, and for giving data at a provincial level for the first time. It was recognised, however, that data available in Jakarta often did not reflect accurately the wide disparities across Indonesia. Applying multipliers derived from a handful of

data points to all provinces was problematic – similarly a single high and a single low value for HIV prevalence applied to a given risk population across a whole province was likely to give misleading results.

The surveillance working group reviewed the process, and made several recommendations for its improvement. Firstly, key pieces of data that would have improved the estimates but were not readily available in 2003 were identified, and systems were set up for collecting them. In some cases, this involved small changes to behavioural surveillance questionnaires, while in others it required the addition of questions to on-going survey series such as the Indonesian Demographic and Health Survey (IDHS) and the Survey of Village Potential (Podes, a triennial census of service provision and economic capacity at the village level). Secondly, it was decided that the following round of estimates should be made at the provincial level, using district level data where available. It was believed that this would improve the accuracy of the estimates at the provincial level, and, by expanding the involvement of local officials, increase the likelihood that data would be used in planning an appropriate response at the provincial and district levels.

**Total Population 15-49** 

**Estimated** 

**Adult HIV prevalence** 

0.119

Table 5: National estimates of number of people exposed to HIV through different behaviours, estimated HIV prevalence and average number of people living with HIV, Indonesia, end 2002

Populations at risk of exposure to HIV	Populat	ion Sizes	Estimates of	HIV Prevalence	Estimated people living with HIV
	Low Estimate	High Estimate	HIV Low (%)	HIV High (%)	Average
IDU	123,849	195,597	19.18	34.35	42,749
Non-IDU Partners of IDU	94,125	148,654	6.39	11.45	10,830
Sex workers	193,234	272,844	1.98	5.20	8,369
Clients of sex workers	7,004,573	9,384,081	0.20	0.61	32,845
Reg. Partners of clients	5,025,521	7,160,256	0.03	0.11	4,452
Gay	574,904	1,724,713	0.40	1.34	10,021
Male sex workers	2,100	2,900	2.74	5.29	100
Female partners of male sex workers	992	1,372	1.00	1.99	18
Waria	7,831	14,712	9.34	14.33	1,334
Clients of waria sex workers	173,050	339,927	1.88	2.87	6,085
Regular partners of waria	2,128	3,972	4.37	6.59	167
Prisoners	73,794	73,794	8.61	15.38	8,851
Street children	70,872	70,872	0	0.17	59
TOTAL	13,027,988	18,901,288			125,880

115,214,749

Beginning in late 2003, provincial estimates were made in a number of pilot provinces, with technical guidance from Jakarta. The process, involving district health officials, provincial officials from other agencies (such as the police, the department of social affairs, the department of justice) and NGOs, mirrored the process that had taken place at the national level in 2003. No clear guidance was available to direct choice of data, parameters for assumptions or other important decisions in the estimation process, and there were wide variations between pilot provinces, making it difficult to aggregate data into a national estimate without substantial revision at the national level.

A further review led to the development of national protocols for population size estimation, and for the estimation of the number of people living with HIV. (Republic of Indonesia 2005) These protocols provided for the systematic assistance of the statistics bureau, BPS, in the estimation process. A standardised spreadsheet for estimation was developed, and BPS was responsible for adapting the spreadsheet to meet the needs of each province, and for filling in all centrally held data (such as census data) before the provincial estimation process began. BPS is also responsible for documenting data sources and assumptions. The process remains led by P2M at the national and provincial levels. Aggregation of provincial estimates into a national total is the responsibility of P2M.

### h Lack of programme monitoring data

### The problem

Virtually all of the international guidance on surveillance states that surveillance data can be used to monitor and evaluate the success of prevention programmes. (Family Health International and AIDSCAP; Chin 1990; AIDSCAP 1997; Family Health International 2000; UNAIDS and World Health Organization 2000; WHO 2000; Pisani, Lazzari et al. 2003). None of the guidelines, however, consider programme monitoring data to be a routine part of surveillance work. Guidance for collection of programme monitoring data are limited, and guidance on analysis and use of these data more limited still. As Chapter 1 noted, international commitments such as the "Three Ones" (which includes one national Monitoring and Evaluation system) are

rarely adhered to in practice. This is in part because few countries have developed systems under which all programme implementers (and the different donors who generally heavily influence monitoring and reporting formats) agree to contribute comparable programme monitoring data to a single national data base. Indonesia was no exception.

### Steps taken

In late 2002, Indonesia's largest donor-funded programme, the USAID funded ASA programme, began to redesign its Monitoring and Evaluation framework. The new structure, discussed at length with USAID, stressed the collection of data useful for understanding and managing programmes in Indonesia on an ongoing basis, rather than simply reporting indicators required by global indicators databases.

Information and indicators most appropriate to the local situation were discussed and agreed with other partners also. These included P2M, which runs the Ministry of Health's HIV prevention and care programmes as well as administering funds allocated in Global Fund rounds 1 and 4, the National AIDS Commission, which is tasked with coordinating the HIV-related activities of all government sectors, AusAid, which has a large bilateral programme, and UNAIDS, which coordinates the M&E activities of United Nations agencies.

By late 2004, it appeared that a single national M&E database was a real possibility. All agencies agreed to collect comparable information in similar formats. The statistics bureau BPS was contracted to design a data base which would allow for online data entry from multiple sources. The data are automatically aggregated and can be viewed at different levels – for example the number of clean needles given to IDU by all programmes combined in the city of Medan in the first quarter of 2006, or the number of patients currently supported on antiretroviral therapy by Global Fund Round 4 implementers. Each partner agency has access to confidential data (such as funding by implementing agency) about their own programme, but access to these is restricted for other partners – only agreed aggregate data are included in the shared access part of the data base.

Development of the data base has been slow, in part because large volumes of historical data must be entered, and much of this is in formats that differ slightly from the structure that was eventually agreed between partners. However a Beta version became operational in early 2006. The web-based software allows individual implementing agencies to input their data online. The data base includes indicators from the national behavioural surveillance system as well as from programme monitoring, which can be accessed without a password. There is also a public access section giving the standard UNGASS indicators for Indonesia. Programme activities can be viewed by target population, geographical area, sponsoring sector or institution, or implementing agency. The Beta database can be viewed online at: www.fhi.or.id/~pif

As far as we are aware, this is the first national M&E database which serves the needs of multiple national institutions, donors, programme managers and implementing agencies, and has broad public access. It is hoped that ease of access to programme data will encourage analysis of programme coverage and contribute to a realistic assessment of programme needs and potential effectiveness, ultimately leading to a better distribution of resources.

### i Failure to analyse, use or publish existing data

### The problem

By the time of the 2001 review, Indonesia had had a functioning HIV surveillance system for over a decade, and five years' worth of behavioural surveillance data. However there were very few examples of the active use of these data to plan or manage appropriate HIV prevention programmes, and no national report on HIV had ever been published.

The failure to use data was in part because of poor data reporting and management systems. Reporting of sentinel surveillance data appears to have been acceptable until the late 1990s, but data management and storage at the central level were extremely poor. Most data have been stored in hard copy files that are poorly organised. Major trends were missed because data from the same site were filed in

different places. Only a fraction of the data reported to the centre were transferred on to Excel spreadsheets; there was no system for double entry or error checking, no central data base, an no protection against viruses which ate through much of the available data in 2002.

Since decentralisation, local administrations have been under no obligation to report data to the centre, and many do not. The central government has been extremely sensitive to the rights of the provinces and districts, and put very little pressure on the districts or provinces to report data. This meant that for the first few years after decentralisation laws were passed, data were often not available for analysis by the national HIV prevention unit even where quality surveillance was carried out in accordance with national protocols.

Behavioural data were better managed, but the sheer volume of data (which existed for numerous populations in different geographic locations across different years) and the diversity in the questionnaires meant that datasets were clumsy and hard to handle. In 2002/3, each data set was initially recoded separately – this led to confusion and potential inconsistency between data sets where changes to recode files were necessary. Since data files were not combined, aggregate analysis became extremely clumsy, and it was not possible to run statistical comparisons between populations.

### Steps taken

The first step was to publish a summary of the data that already existed. Indonesia's first national report on HIV "HIV and Other Sexually Transmitted Infections in Indonesia: Challenges and Opportunities for Action" was prepared by the surveillance working group and published in English and Indonesian in time for the International Conference on AIDS in Asia-Pacific, held in Melbourne in October 2001. (Republic of Indonesia 2001)

### Managing HIV surveillance data

The next step was to improve data reporting and to facilitate simple analysis at the site level. To this end, we developed software (known as SSHIV), designed to

facilitate the use of surveillance data locally as well as to improve reporting to the provincial and central level. SSHIV software is driven by menus that are derived from national protocols, and includes checks such as error messages if entered sample sizes are below the minimum required by protocols. It generates tables and graphics that show trends over time in HIV and syphilis prevalence, together with confidence intervals and tests for statistical significance of trends. Results can be submitted electronically to the central level at the touch of a button. Figure 4 shows a summary page that gives results in tabular and graphic form of HIV, syphilis and behavioural surveillance over time in a single sentinel site. Providing training in the use of SSHIV has proven to be a useful "back door" to strengthening training for district officials in basic surveillance protocols and data use, as well providing an opportunity for quality control. The process of inputting data into the SSHIV system has revealed many anomalies in the surveillance system and highlighted areas for further training and quality control.

SSHIV has not yet been rolled out to all districts, and although all provinces have been introduced to the software, not all are using it. Where data quality allowed, efforts have been made at the central level to enter into the system data from previous years (since 1995) that are currently held in hard copy or on Excel spreadsheets.

Persistent difficulties in collecting data at the central level mean that it is not possible to state accurately how much HIV surveillance is going on in Indonesia – the SSHIV data base to early 2005 gives data for 216 separate sites since 1995, and 71 sites since 2003. Of these, 58 are classified as sentinel sites, the remainder are deemed "ad-hoc" (P2M surveillance records). Despite the new system, by early 2005 just four provinces had submitted any data for 2004 to P2M in Jakarta. By mid-year, no active effort had been made to follow up on missing data.<sup>8</sup>

<sup>&</sup>lt;sup>8</sup> The staff member designated to manage the sentinel surveillance data base has, in addition to her full-time job in P2M, been given the supplementary duties of managing the counselling, care and treatment components of Indonesia's 77 million dollar Global Fund programme.

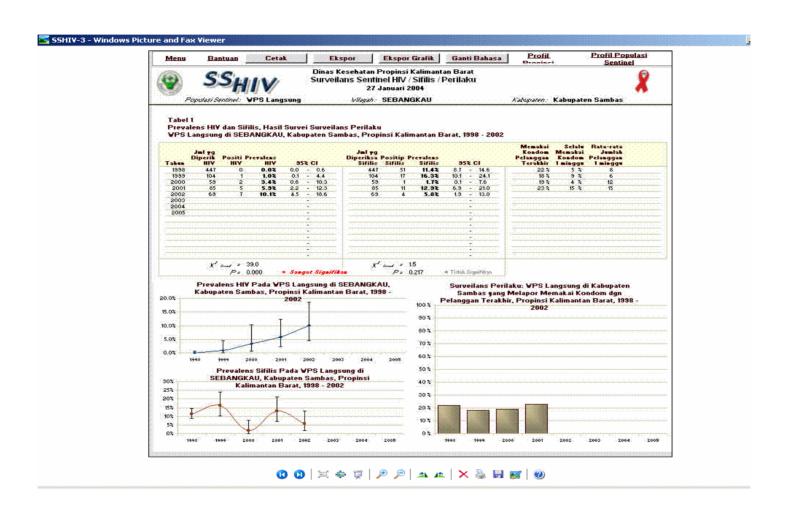


Figure 5: Example of SSHIV data results sheet

### Managing behavioural data

The challenge for behavioural surveillance was to develop data sets that would facilitate manipulation of data across populations, time and space. BPS is accustomed to managing large volumes of data. From the start of the agency's involvement in behavioural surveillance, data entry forms with consistency checks were designed using FoxPro software, and data were double entered and cleaned. Once difficulties with multiple recodes were recognised, they were resolved by recoding all data sets to a single standard codebook, bilingually labelled in Indonesian and English, and combining them. The result will be a single, comprehensive data set combining data for all populations, all sites and all years. 9

An important part of this work has been to identify the recodes that are most appropriate and most useful for the analysis of HIV prevention needs and programme effects. The input of prevention and care programme implementers was sought, and variables were specified in ways that responded to programme analysis needs rather than donor reporting needs. Removing the complex and arduous task of recoding data sets with frequent skip patterns, and giving end users data sets which they can use without any preparatory work, has proven to be a very important part of increasing the use of behavioural surveillance data in Indonesia. The lessons learned during this process have become the basis for new guidelines on data management which I recently prepared at the request of the WHO/UNAIDS Surveillance working group, and which are published in the WHO/UNAIDS/CDC/FHI surveillance series. (Family Health International 2006)

# 5. Continuing gaps in surveillance and monitoring systems in Indonesia

As a result of the efforts made since 2001, Indonesia now has one of the more comprehensive HIV-related surveillance and monitoring systems in any country.

<sup>&</sup>lt;sup>9</sup> As of the end of 2005, All data sets for sex workers and high risk men from 2002/3 and 2004/5 had been combined, creating a database of 20,452 respondents. The other high risk populations have been combined across sites for the years BPS has been conducting behavioural surveillance in these groups: 1,795 IDU in a single data set, and 1,250 transgender and male sex workers and MSM in another. The work of combining these three data sets and integrating them with data from previous years continues as this paper is being submitted.

Many gaps remain to be filled; most have been alluded in the relevant sections of this chapter. The single largest gap, however, is the capacity to use the large amount of increasingly high quality data to its full potential.

Ideally, a single unit specialised in epidemiological analysis would have access to the case reports, HIV surveillance data, STI survey data, behavioural surveillance data, population size data and programme data at the national level. This unit would be in a position to bring the data together and analyse it for both programme planning and management purposes, using a simple analytical framework such as that suggested in Chapter 3. Although financial resources have been available to support such a unit since the idea was first raised and approved by the surveillance working group in 2003, it has not yet been possible to create one. The problems are largely institutional. Although the National AIDS Control Commission (KPA) has expressed an interest in taking on this role, the natural home for such a unit is more likely to be P2M's sub directorate for STI and HIV control, which is responsible for HIV surveillance and which is much more closely associated than the KPA with all the other data sources. P2M has stated in working group meetings that it supports the development of such a unit, and has assigned staff to be trained in analysis. These staff already have full time jobs (for which they are paid a salary of between 100 and 200 dollars a month). In addition, the more qualified get supplementary salaries for their role in managing two rounds of Global Fund money, totalling some US\$ 77 million. None has been able to attend a week of training in data analysis.

Attendance at workshops, trainings, field supervision and other activities away from the office generate per diems and other salary supplements. This creates disincentives for government staff to dedicate time to office-bound work such as data analysis; the most able are much in demand at the many donor-funded workshops and trainings and are particularly unlikely to analyse data. (Elmendorf, Jensen et al. 2004) In any case, health ministry staff rarely have the skills to perform such analysis. Only a small fraction of staff have any training in epidemiology or statistics, and the human resources policy – based on seniority and connections rather than skills or aptitude -- does not guarantee that those who have training will be in a position to use it. An alternative would be to second staff who are not regular government employees to a unit within P2M and to pay them at professional rates which would compensate for their not being eligible for perks related to public service; this

strategy has met with resistance because of perceived inequities in salary and possible conflicts in lines of reporting. A further option would be to second staff from another government agency such as BPS; their capacity for data analysis is already excellent, those who have worked on the behavioural surveillance programme have a very good grasp of HIV programme needs and some have attended basic training in epidemiological analysis. Secondments are not, however, popular within the Indonesian government because opportunities for promotion depend on visibility within one's own institution.

In short, while it would not be hard to develop the technical capacity to perform sound epidemiological analysis of all the available data sources, it has proven institutionally difficult at the central level. It is possible that this is related to limited demand for this type of analysis within the government. The model of monitoring and evaluation promoted by international organisations suggests that the national government at the central level (usually under the leadership of a multisectoral AIDS council) should be leading the formulation of strategies and programmes. It is therefore the national government who should be "using" data from surveillance systems to refine HIV prevention and care activities in the country. In the case of Indonesia, in as much as Indonesian authorities have any real voice at all in decisionmaking about HIV programmes, the power has been devolved to the district level, complicating this model. But in practice, decisions are often made elsewhere. Bilateral and multilateral donor-funded programmes finance the bulk of HIV prevention and care efforts in Indonesia. Although central government expenditure on HIV in Indonesia has risen in recent years (and P2M is the principal recipient for Global Fund AIDS money), it still accounted for only around a quarter of total spending in 2003. Some of that was in "in kind" contributions such as space for meetings, which helps to meet donor co-funding requirements. (Elmendorf, Jensen et al. 2004) Practically, then, donor-funded prevention and care programmes retained extensive decision-making power in planning HIV-related interventions throughout the 1990s and beyond, simply because they hold the purse strings and write their own workplans. Bluntly, they continue to drive the HIV agenda. In consequence, they ought to be among the primary users of surveillance data from programme planning, and are also in a position to use the data to help monitor and evaluate the success of particular programmatic interventions.

Interestingly, the greatest government contribution to HIV programmes has come at the local level, in a handful of districts where commitment is high. It is likely that this trend will become more pronounced as government decentralisation takes hold (and if the advocacy and capacity-building efforts of bilateral programmes produce results). Analysis of local data by local health staff and their partners may provide a way out of the current data use impasse. Early experiences (described in Chapter 6) have been positive. The volume of data is more manageable at the local level, and local intervention workers and health staff are more readily able to identify the reasons behind surprising findings in the data, and to suggest appropriate solutions. On the other hand, human capacity is often very limited at the local level.

It is important that locally-based analysis is driven by the facts rather than by local politics or assumptions. The analysis must be possible to achieve with local data and local capacities (including computing power, software and brains, which are not evenly distributed across the different levels of government or throughout the archipelago). User-friendly data and tools are needed, as is a simple, logical framework to guide analysis. If these can be made available and taught to local health officials in the space of a few days, they may contribute significantly to improving the use of the increasingly large volumes of quality surveillance and programme monitoring data generated by the HIV surveillance and monitoring system in Indonesia. The remainder of this work proposes such a framework, and tests its merits using Indonesian data.

### HIV surveillance systems in Indonesia: Key points

- Indonesia's HIV and behavioural sentinel surveillance and monitoring systems have been enormously strengthened and improved since 2001.
- The country now has all the recommended elements of a second generation surveillance system for concentrated HIV epidemics, and has added routine population size estimation and standardised programme monitoring to the national system – both innovations that have since been recognised as best practice at the global level.
- HIV and behavioural surveillance cover all high risk groups and are conducted routinely, within the national governmental structures. Training and funding structures have been secured. All major donors support a single surveillance system routinely implemented by government institutions.
- Data management programmes have been developed; Indonesian methods for management of behavioural data have also become the basis for global guidelines
- STI surveillance and HIV and AIDS case reporting remain weak; funding for STI surveillance is not secured.
- Data from different sources are still not routinely analysed together. Capacity to
  use the data to its fullest extent remains weak. This is in part because of
  institutional constraints. Training in the use of a simple analytical framework at
  the appropriate level may overcome some of these constraints.

# Chapter 3. Back to basics: A simplified framework for HIV programme planning and analysis

Chapter 1 reviewed some of the literature about the generation and use of data for public health policy making, particularly in the field of HIV. It posited that there are three major reasons why data are not better used. The first is that data generated by routine health information systems do not necessarily meet the needs of those wishing to use the data to plan and manage effective responses to HIV. The second is that the incentive systems which currently dominate HIV-related decision making in developing countries do not encourage the production or use of high quality data analysis. The third is that the dominant analytical frameworks do not focus attention clearly enough on the relationship between the epidemiological context and the effect of programmes.

Chapter 2 described efforts to fill the data gaps in Indonesia. While some work remains to be done, Indonesia's national surveillance system was by 2004 producing most of the data needed to plan and monitor effective HIV programmes. My attention now turns to developing an analytic framework that better meets the needs of policy makers and programme implementers in countries with concentrated epidemics and limited capacity in public health analysis. The framework should allow analysts and policy makers to slot information generated by the local surveillance system in to an easily understandable sequence following the epidemiology of HIV infection, to answer the question:

### What should we be doing to prevent HIV, in this epidemic at this time?

The other questions commonly raised in monitoring and evaluation:

### Are our current programmes working? How could we do better?

are irrelevant until it has been established that we are doing the right thing in the first place. Programme management and evaluation questions will be addressed in Chapter 5. This chapter proposes a framework which can be used to analyse the current state of the epidemic and to set priorities for prevention. Chapter 4 will give a step-by-step example of the use of the framework to set programme priorities and to

investigate the potential effect of different prevention programme choices, using data from the Indonesian capital Jakarta.

# 1. Back to Basics: a framework for setting programme priorities.

Many of the frameworks described in Chapter 1 had their roots in the search to understand general principles underlying the spread of HIV. They seek to explain the current situation. But the reality for public officials is that they care less about how we arrived in a certain situation than about how we move forward. And they care less about general principles than about the specific situation which they face locally in their daily jobs. For this reason the framework proposed here takes the current epidemic situation as a starting point. I will call it the "Back to Basics" framework; it has its roots in a concept published under that name by Pisani and colleagues in 2003. (Pisani, Garnett et al. 2003)

The "Basics" are similar, but not identical, to the components of the reproductive rate of infection. They are restated as questions which we should be able to answer, at least partially, with surveillance and programme data. Most importantly, they are arranged sequentially, so that the effect of prevention programmes on the different parameters can more easily be disentangled. They start from an assessment of the current distribution of infection, so that the analysis takes the current epidemic state as its point of departure.

The questions are as follows:

- Who is infected with HIV, and who is uninfected?
- How likely is it that an HIV positive person will take drugs or have sex with an HIV negative person?
- IF an HIV positive person has sex or takes drugs with an HIV negative person, how likely is it that there will be an exchange of body fluids between them?
- IF an HIV positive person and an HIV negative person exchange body fluids, how likely is it that a new infection will result?
- IF a new infection results, how long will the newly-infected person survive?

This last question feeds back into the first question: who is infected and who is not, since longer survival increases HIV prevalence.

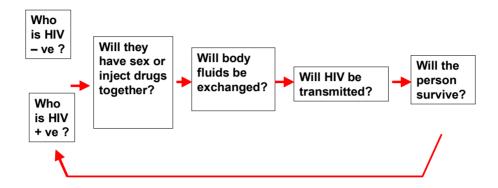


Figure 6: The Back to Basics Framework: key questions for programme planning

By arranging our analysis in this sequence, which is necessarily the sequence of events in any new infection, we are able to eliminate some of the confusion identified by Boerma and Weir and discussed in Chapter 1. (Boerma and Weir 2005) They state that the effect of the change in one component of the reproductive rate of infection on the ultimate outcome – HIV incidence – will depend on the value of the other parameters. But in fact, in planning and evaluating programmes, we only need to think about one thing at a time, as illustrated in Figure 6. The simple sequence of events shown in Figure 6 conceals far more complex interactions and feedback loops. But it provides a starting point for understanding the potential effects of various prevention and care interventions, and for prioritising those interventions. The framework also overcomes the limitations described by Grassly and colleagues, since it takes the current epidemic state as its starting point. (Grassly, Garnett et al. 2001)

### "Basic" One: Infected person has contact with uninfected person

The first "Basic" determinant of the spread of HIV is discordancy, which is determined by the current distribution of HIV infections, and the sexual networking between infected and uninfected individuals and groups.

The importance of discordant contact is probably the factor most frequently overlooked in the planning of effective HIV prevention programmes. If all mixing is between people who are already infected, we need not worry about new infections. On the other hand, a group of people who are all uninfected can have as much sex as they like without running any risk of infection with a sexually transmitted disease. No amount of increase in condom use will dent the HIV epidemic if all the increase is in populations who are uninfected and having sex with other people who are uninfected. This fundamental point has largely been overlooked in planning HIV prevention programmes in concentrated epidemics. Many countries continue to promote interventions for "youth" and "the general population", without any careful analysis of whether infected and uninfected people within these populations are having sex or taking drugs together.

To understand discordancy, we need to know who is currently infected with HIV, and which uninfected people they are most likely to be taking drugs or having sex with. There are two approaches to understanding the distribution of HIV infection, discussed in greater detail below. The first is to try to identify which individuals are infected, through widespread use of routine and repeated HIV testing. The second is to identify which sub-populations are likely to encompass high proportions of HIV-infected individuals, through sentinel surveillance. These two approaches are by no means mutually exclusive. However countries that rely heavily on sentinel surveillance to understand where HIV infections are clustered (a group that currently includes most developing countries with concentrated epidemics) will find that prevalence rates alone are not enough to describe the distribution of HIV infection; we need to know the size of the different sub-populations at risk for HIV so that estimates of the absolute and relative numbers of people who are HIV-infected in each sub-population can be made.

It is one thing to establish where infection is concentrated. It is another to establish whether infected individuals, or more commonly sub-populations among whom

infection is concentrated, are likely to be linked in sexual or drug-taking networks with people who are uninfected.

Analysis undertaken to answer this question must distinguish between two different types of mixing: mixing within a sub-population, and mixing between sub-populations. Mixing within a sub-population, such as between drug injectors, can carry the virus between geographical areas with high HIV prevalence and areas with low prevalence. Eventually, however, mixing within a high risk sub-population will result in a "saturation" level of infection – new infections in that population will then be determined largely by turnover in the population. Sexual mixing between sub-populations with higher and lower levels of prevalence provides a conduit through which the virus can enter a new sub-population. Examples of the quantification of this sort of mixing are given on page 140. Failure to consider and examine the links between infected and uninfected individuals and population groups represents one of the great lost opportunities in prioritising HIV prevention efforts.

It is important to note that the probability of a discordant contact depends not just on the HIV prevalence in the two interacting populations, but in the number of partnerships that each person has with a member of the other population. If HIV prevalence among sex workers is 20 percent and prevalence among clients is 4 percent, then the likelihood that an uninfected sex worker will have sex with an infected client is 3.2 percent (the probability that she is uninfected: 80 percent, times the probability that he is infected, 4 percent, if we assume that mixing between clients and sex workers is random). The probability that an uninfected client will have sex with an infected sex worker is much higher (19.2 percent), because prevalence among sex workers is higher. But that is the probability of discordance per partnership. If a client buys sex from 10 different sex workers in a year, while a sex worker has 250 different clients, there will be far more partnerships in which the client is infected and the sex worker is uninfected than the other way around.

### Basic Two: Infected person and uninfected person exchange body fluids

The second "Basic" determinant of HIV transmission is the transfer of body fluids between infected and uninfected people. A great deal of programme effort is dedicated to interrupting the chain of transmission at this point. But we only need

consider the behaviours that determine whether body fluids will be transferred once it has been established that they are likely to involve people of different HIV infection status.

In epidemics in which HIV is concentrated among sub-populations with behaviours that carry a high risk of transmission, the situations in which body fluids are exchanged between infected and uninfected people are dominated by: needle sharing between drug injectors, unprotected sex between injectors and non-injectors, unprotected commercial sex and unprotected anal sex between men. These behaviours are relatively easy to quantify: examples are given on page 143. The exchange of body fluids can only happen at the partnership level (by definition, the exchange is happening between two individuals), so the proportion of discordant sex or injecting acts that result in an exchange of body fluids can be calculated at that level. But we do need to consider the absolute number of exchanges in each discordant partnership, because once body fluids are being exchanged between infected and uninfected people, there is a risk of HIV transmission in every single exchange, not just in each partnership.

Condom use tends to be highest with the partners that are perceived as "high risk", such as commercial partners, and lower with "low risk" partners such as spouses. Frequency of sex per partnership is the opposite, higher with low risk partners and lower with high risk partners. So within a given discordant partnership, the risk that body fluids will be exchanged is often greater in "low risk" partnerships than in "high risk" partnerships.

### Basic Three: The exchange of body fluids results in a new HIV infection

The third "Basic" determinant of HIV transmission is the likelihood that a new infection will occur if body fluids are indeed exchanged between infected and uninfected people. This area is the most complex to predict or to measure, but some of the factors most likely to influence the establishment of a new infection are well known. They include: the type of interaction between the infected and the uninfected person (e.g. injecting, anal or vaginal sex etc.), the viral load for the HIV-infected person, and the presence of other sexually transmitted infections, in particular symptomatic ulcerative infections. These are discussed in detail following page 146,

but in general, the factors facilitating HIV transmission are found more commonly in discordant contacts between "high risk" partners than between "low risk" partners.

Of the factors influencing the likelihood that HIV will be transmitted, only concomitant STI infection has so far been the focus of major HIV prevention programmes. The expansion of antiretroviral treatment will increasingly affect viral load. However there may be opportunities to influence other factors. Certainly, any analytic framework should distinguish between exposures that carry a higher and a lower risk of a new HIV infection taking place if body fluids are exchanged between an infected and an uninfected person.

If a prevention programme is to claim that it is contributing to reducing new HIV infections, it must be able to show that it is changing at least one of these factors:

- the likelihood that an HIV positive person will have sex or inject drugs with a negative person
- the likelihood that body fluids will be exchanged if there is contact between discordant people
- the likelihood that infection will occur if body fluids are exchanged between discordant couples

It is as simple as that. Or is it? Later in this chapter, each of the "basics" is discussed in greater detail. I focus particularly on the evidence for different prevention interventions for each step of the framework. First, however, the use of the framework at a policy level is discussed.

### 2. Using the Back to Basics Framework

### a Setting programme priorities

In concentrated epidemics, many different types of risks may be taking place simultaneously. The first challenge for programme planners is to try to identify which sub-populations and behaviours are potentially contributing most new infections at the current time. Only when these have been clearly identified should attention turn to the most appropriate combination of prevention initiatives for those populations.

The Back to Basics framework can be used to quantify the relative contribution of different sub-populations and behaviours to the current epidemic, following the simple steps described in detail in the next chapter. The example uses a matrix to describe interactions both within and between different risk populations (for example male drug injectors buying sex from sex workers, men having sex with one another, clients of sex workers having sex with their wives). The number of people in each group is calculated, together with the number of partners they have in the interacting group. Then we calculate the likelihood that any given person will have a discordant contact, and the number of those discordant partnerships. For each discordant partnership, the absolute number of contacts is calculated. Using information about needle sharing and condom use, the number of discordant contacts in which body fluids will be exchanged can be estimated for each type of interaction. Finally, the proportion of discordant, exposed contacts that meet the criteria for high transmission probability, medium transmission probability and low transmission probability are calculated.

The final product is an estimate, for each of the "risk groups", of the absolute number of acts of injection or sex in which body fluids are exchanged and HIV transmission is more (or less) likely. We can see at a glance where most new infections are likely to take place, and where prevention programmes are most needed in the short term.

### b Estimating programme impact

The Back to Basics framework can be used fairly easily to investigate the potential impact of different prevention programmes, or the actual impact of a programme at a measured level of effect, with a given level of coverage. Figure 7 is a graphic representation of the programme effects discussed earlier in this chapter. It shows at what level of the framework each prevention and care programme is most likely to operate.

The effect of any prevention programme on the epidemic depends on two things: the magnitude of the change it brings about in any one of the three "Basics" in the population that it is targeting, and the importance of that population in the local epidemic.

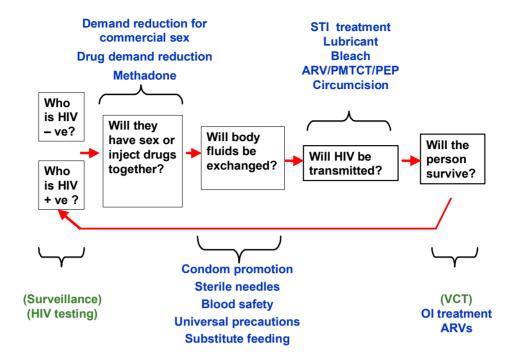


Figure 7: The Back to Basics framework: Bringing in the programmes

If we have an idea of the coverage of a prevention programme and the magnitude of the changes in the "Basics" it has contributed to, we can simply plug those values into the same analysis as we used to investigate where most risk is taking place, and compare the results. Equally, we can plug in hypothetical levels of coverage and/or results, to help estimate the potential effect of different programme approaches, and to inform decisions about the best mix of interventions.

Simple examples of this type of analysis are given after the initial priority setting analysis in Chapter 4.

The direct link between HIV prevention programmes and impact on the epidemic illustrated in Figure 7 is an innovation that carries the analytical framework into an area of direct practical relevance for programme analysts and policy makers. They are reminded at a glance how their programme efforts relate to changes in the epidemic, and are invited to consider how effective those efforts will be, given the current epidemic state.

### 3. Where do "enabling" interventions fit in?

This framework focuses very closely on the factors that have a direct influence on whether HIV will spread in a population, and to what extent. It explicitly considers the interventions that have a direct impact on these factors. It does not, however, explicitly consider the socio-cultural context which will influence whether or not those interventions can or will be implemented, or are successful. This is not to suggest that these factors are not important. In fact, they are critical. Rather, the Back to Basics framework aims to oblige public health officials to consider explicitly the consequences of the decisions they make in the light of what is culturally appropriate, economically possible or politically advantageous.

The framework challenges decision-makers to face the major sources of new infections in their epidemic, and the implications of different policy choices. If an analysis of the epidemic situation shows that most of the high-risk exposures between infected and uninfected people are taking place during drug injection in jail, then policy-makers should be prepared to justify themselves if they continue to ignore this problem and continue to press for the expansion of MTCT programmes. The reason that they cannot or will not address the problem may well have social, cultural and political roots. The Back to Basics approach presumes it is easier to find the root of a problem by working backwards from the problem itself, than by starting from a wide array of cultural and economic influences that may be very general in scope. In choosing to invest in "enabling interventions", decision-makers ought to be able to specify exactly which change in the "Basics" they are expecting to enable. In monitoring the success of these interventions, we should expect to be able eventually to measure a change in those basics. For example, there may be an assumption that poor education and limited employment opportunities for women force women into sex work. Environmental interventions may include increased investment in education for women. The success of such an intervention would eventually be reflected in a reduction in the estimated number of sex workers, and may also be measured through a rise in the average age of sex workers and the average time in sex work (since there will be fewer new entrants to the trade). Such changes would reflect a change in the first Basic: the likelihood that an uninfected person (new entrant to sex work) has sex with an infected person (client).

The remainder of this Chapter goes through the questions in the Back to Basics framework one by one, with a detailed discussion of data sources that can be drawn on to inform each step of the analysis. The different programme options shown in Figure 7, each acting at a specific step of the framework, are also discussed in some detail, and the scientific literature supporting their relevance in the framework is reviewed.

# 4. Question 1: Who is currently infected with HIV, and who is uninfected?

This is the first, most fundamental question in understanding the current state of an epidemic, and planning prevention and care needs.

### a Data sources

The two major approaches to answering this question are a matter of some debate. The more established approach in concentrated epidemics (at least in developing countries) is to use sentinel surveillance to identify which sub-populations (behavioural and geographical) have the largest concentration of HIV infections. Lately, some countries have espoused an approach promoted in the United States and in African settings that comes closer to case finding. Proponents of the second approach argue that identifying the specific individuals who are currently infected with HIV and providing them with intensive prevention and care services will be the most effective way of interrupting the chain of transmission. (Janssen, Holtgrave et al. 2001; De Cock, Marum et al. 2003; Yip 2004)

Sentinel surveillance alone can be very misleading as a source of information about the distribution of infection, since it gives only a prevalence rate. To be meaningful in terms of priority setting for prevention and care, sentinel surveillance data must be applied to a denominator to get an idea of the absolute numbers infected in different behavioural and geographical sub-populations. Population size estimates are essential to understanding the true distribution of infection. The Indonesian surveillance system now produces estimates of the size of risk populations at the district level, in spreadsheets which also automatically calculate the estimated number of people

living with HIV in each sub-population – these can be used directly when analysing the distribution of HIV infection.

It is important, too, to register who is NOT infected, since targeting programmes at uninfected populations which do not interact with HIV-infected populations is a waste of resources. There is a belief, inherent in the concept of vulnerability and made explicit through World AIDS Campaigns and other advocacy offensives, that certain groups are necessarily more likely to be infected with HIV, or immediately threatened with infection, than others. Recently, these have included refugees, migrants and youth. Data for these groups can sometimes be provided by services that screen the blood supply, or (in the case of countries that export workers) by preemployment screening for overseas workers.

Improved access to treatment will have a direct impact on HIV prevalence by extending the life of those infected. If people on treatment continue to engage in the behaviours which would cause them to be included in surveillance samples, this should be reflected in rising prevalence in sentinel surveillance. However treatment data may be used to validate surveillance data and to guide necessary adjustments to estimates of numbers and distributions of those living with HIV.

## b Programmes aiming to increase knowledge of who is HIV infected and who is not infected

Understanding who is infected and who is not will not have an immediate impact on HIV transmission, unless at least one of the basic determinants of transmission is altered as a consequence.

Recently, there has been an increased focus on expanding access to HIV testing for people likely to be at risk, and on designing HIV prevention programmes that provide services specific to the needs of those who know they are infected. Access to HIV testing is also a prerequisite for the expansion of antiretroviral therapy, which in turn has implications within the Back to Basics framework both in terms of increasing HIV prevalence (and therefore potentially increasing the likelihood of discordant contacts) and in terms of reducing infectivity among those infected with HIV.

In many countries with HIV epidemics concentrated among specific sub-populations, including Indonesia, these efforts are not yet widespread. In these situations, however, anonymous sentinel surveillance can provide information about the distribution of infection at the population level. This information is sufficient for the targeting of the majority of prevention interventions that do not require knowledge of an individual's sero-status to succeed, such as promotion of condoms, lubricant, and sterile needles and the provision of STI screening and treatment.

# 5. Question 2: Will HIV infected people have sex or take drugs with uninfected people?

The importance of discordant contact has frequently been overlooked in HIV prevention planning. Contact between groups with different "background" levels of prevalence carries the virus into new sub-populations, while contact between individuals within a sub-population determines the eventual reach of the epidemic within that population.

An example is provided by a study conducted among men who have sex with men in Cambodia in 2000, a time when HIV prevalence among female sex workers was already some 30 percent. (Girault, Saidel et al. 2004) Over four fifths of the respondents in the study were male sex workers – many of them had sex with men for cash and with women for pleasure. The study found that men who had had recent unprotected sex with female sex workers were three times as likely to be infected with HIV as men who had not, even after controlling for other risk factors. The sequence of events can not be determined from the cross-sectional study, but the data strongly suggest that HIV was probably introduced to the MSM community in Cambodia by male sex workers who were themselves infected during sex with the already highly-infected pool of female sex workers. Nonetheless, since the study reported high levels of risk within the MSM population, the authors conclude that prevalence in that population was likely to rise over time. Prevalence in the MSM population was half that of female sex workers, at the time of the study – around 15 percent. But even then, 37 percent of infections were already in men who reported never having had sex with a woman.

It has been noted that the major concern of policy-makers is the potential for spread of HIV in "the general population", by which people generally mean those members of the general population who do not inject drugs, have sex with people of their own gender, or sell sex – the status of clients of sex workers as members of "the general population" is more fluid. (Brown 2003; Mills, Saidel et al. 2004) The ultimate size of the epidemic in "the general population" will always depend on the absolute number of people in that population who are sex partners of those at high risk of exposure, together with patterns of sexual networking within the general population.

The question of whether infected people will have contact with uninfected people must be answered by looking at the extent of sexual mixing within high risk groups, but much more importantly by looking at whether members of a lower prevalence group interact with members of a potentially higher prevalence group, either through drug taking or sex.

### a Data sources

Data on drug taking and sexual behaviour are collected in behavioural surveillance. Because of the importance of inter-population mixing in determining the course of the epidemic in countries with concentrated HIV epidemics, it is important that behavioural surveillance questionnaires include questions that will allow mixing between sub-populations to be quantified. In other words, surveillance among IDU must ask about buying and selling of sex and sex between men, while surveillance among "high risk men" must ask about commercial, non-commercial and male partners as well as about drug injection.

In an effort to strip questionnaires to a minimum, early behavioural surveillance often omitted these questions, but they are now becoming standard. Behavioural surveillance in Indonesia routinely collects information on drug injection from all sub-populations, on male-male sex from all male populations, and on commercial sex from all populations except schoolgirls. The information on frequency of these behaviours – needed to estimate the absolute number of contacts between members of sub-populations with higher and lower levels of prevalence -- is more limited.

Note that regular surveillance data do not tell us anything about partner selection. In most cases, especially in commercial encounters, we assume that partners are

selected randomly, and can thus calculate the likelihood of discordancy from the prevalence levels in each group. Intra-group mixing may be more likely to be assortative – people may choose partners more like themselves. For example uninfected IDU may choose to inject in closed networks with other uninfected injectors. This will not be captured in the current framework. This limitation is especially important in generalised epidemics, where most HIV transmission takes place within the "general population" and it is harder to use surveillance data to calculate the likelihood of a discordant contact.

## b Programmes aiming to reduce contact between HIV positive and HIV negative people

There are two major ways in which prevention programmes can try to reduce the likelihood that HIV infected people take drugs or have sex with HIV uninfected people. The first works with lower prevalence populations to avoid contact with higher prevalence populations, the second does the reverse.

An example of the first approach is provided by programmes that discourage men in the general population (low prevalence) from visiting sex workers (higher prevalence). Such programmes have apparently succeeded in Thailand, Cambodia and Tamil Nadu (Celentano, Nelson et al. 1998; AIDS Prevention and Control Project 2003; Gorbach, Heng et al. 2003; Monitoring the AIDS Pandemic 2004). Life skills programmes that enable people to stay away from drugs would also qualify if they reduced the proportion of young people (low prevalence) potentially exposed to HIV by mixing with drug injectors (higher prevalence). Programmes to reduce transition from use of non-injected to injected drugs have also been suggested, although their effectiveness remains unproven. (Vlahov, Fuller et al. 2004) Note that in most concentrated epidemics, programmes promoting abstinence among young people would not qualify, because by and large they are preventing contact between general population men (low prevalence) and general population women (low prevalence). The likelihood of them reducing discordant contacts is thus extremely low.

On the other side of the coin is a focus on people who are already infected. (Janssen, Holtgrave et al. 2001) Intensive counselling programmes for HIV positive people

(100 percent prevalence) that act directly to discourage multiple and casual partnerships (some of whom are not yet infected therefore lower prevalence) have been successful in some cases, for example among gay men in the United States. (Padian, Shiboski et al. 1997) Methadone maintenance programmes targeted specifically at those who are HIV positive aim to take HIV positive injectors out of the pool of people who might put others at risk through needle sharing. (National Institutes of Health 1997) HIV testing services are obviously a prerequisite for all programmes targeted specifically at those who are HIV-infected.

These programmes are summarised in Table 6. The primary target population for programme implementation is shown in bold.

Table 6: Prevention programmes that aim to reduce contact between higher and lower prevalence populations.

Higher prevalence population	Lower prevalence population	Programmes			
Sex workers	Clients	Discourage men from buying sex			
IDU	Young people	Discourage initiation of injection			
IDU (+ve)	IDU (all)	Methadone maintenance to reduce injection			
IDU (+ve)	Potential partners of IDU (all)	Promotion of sexual abstinence/ partner reduction			
MSM (+ve)	Potential partners of MSM (all)	Promotion of sexual abstinence/ partner reduction			
HIV +ve	HIV-ve at high risk of exposure	Vaccines to reduce the number of people susceptible			

The last row in the table deserves comment. The questions so far have centred on who is HIV infected and who is uninfected. In practical terms, since HIV is an incurable disease to which there is apparently no effective natural immunity, this is correct. However the more correct terms would be infectious and susceptible. A vaccine would reduce the number of susceptible people, again altering the likelihood that an infectious person would inject drugs or have sex with a susceptible person. If vaccines come into use, it is at this level of the framework that their effects would be considered

# 6. Question 3: If infected and uninfected people take drugs or have sex together, will they exchange body fluids?

If the prevention efforts described above fail, and HIV-infected people do take drugs or have sex with uninfected people, then there is only the risk of a new HIV infection if body fluids (and more particularly blood, seminal and cervico-vaginal fluids) are exchanged. This can take place through the sharing of needles during drug injection, and in vaginal, anal or oral sex if condoms are not correctly used.

The framework focuses on drug injecting and sex because they are the main routes by which body fluids are exchanged between infected and uninfected individuals. However there are other ways in which body fluids get exchanged, and they, too, are the target of prevention programmes. Blood transfusions and needlestick injuries are preventable routes by which body fluids can be transferred. Infants are exposed to a mother's body fluids at birth and during breastfeeding.

## a Data sources

Data on the potential for the exchange of body fluids between HIV positive and HIV negative individuals come largely from behavioural surveillance. Surveillance data should give rates of condom use with different partner types, as well as information about needle sharing among drug users. Questions are usually asked two ways, to give a cross-sectional measure and a measure of consistency. The cross-sectional measure is derived from asking if a condom was used at the last sex act with a given partner type (or if a sterile needle was used at last injection). The measure of consistency most commonly asks whether condoms/sterile needles were never, rarely, often or always used. The cross-sectional measure appears to give the most robust estimate of absolute levels of condom use between given partner types. (Family Health International 2000)

It has been noted that risk and protective behaviour tend to cluster, and may be related to the infection status of the partner: "people are more likely to have safe sex with risky partners and risky sex with safe partners". (Aral 2004) In industrialised countries, and particularly in surveys among men who have sex with men, HIV status

of the respondent and of the respondent's sex partners is sometimes asked. This is not asked in Indonesia or (to my knowledge) in other developing countries with concentrated HIV epidemics. Because questions are asked about different types of partners (commercial partners, casual partners, regular partners etc.), it is possible to make inferences about the likelihood of body fluids being exchanged between higher and lower prevalence populations in general. In intra-population risk such as malemale sex or drug injection, it is not, however possible to measure whether exposed contacts are concentrated within partnerships known to be either concordant or discordant.

In this context, integrated behavioural and biological surveillance (IBBS) can provide useful indications of the future spread of HIV, because it allows us to measure the extent to which members of the interacting population may be exposed to the body fluids of infected members of the sentinel population.

For example, 78 percent of the transgender sex workers (known as waria – a contraction of the Indonesia words "wantia", woman, and "pria", man) who tested positive for HIV in linked surveillance in Jakarta in 2002 reported unprotected anal sex with clients in the preceding week, compared with 51 percent of waria who were not infected with HIV (p 0.006) (Pisani, Girault et al. 2004). In other words, infected waria are more likely than uninfected waria to expose their clients to body fluids. If we assume that infected clients do not selectively gravitate towards infected waria, then we must conclude that in discordant contacts between waria and their clients, the risk of exposure is greater than suggested by the mean level of condom use reported by the population as a whole.

## b Programmes aiming to reduce the exchange of body fluids between infected and uninfected individuals

The most common of all programmes to reduce the exchange of body fluids in discordant encounters are those **promoting condom use**. In concentrated epidemics, these are targeted largely at increasing condom use in commercial sex and in anal sex between men. There have been notable successes in these areas in a number of countries. Data from regular surveillance systems show that over the past decade, reported condom use in commercial sex has risen dramatically in Cambodia,

Thailand, parts of India, Vietnam and China. Because clients of sex workers are distributed throughout society, many countries have focused efforts to promote condoms on female sex workers. Very few have used STI services as an entry point to promote condoms actively among men likely to be at high risk of exposure. The countries that have had greatest success in promoting condoms in commercial sex, however, are those that have focused their efforts on the male clients, either directly through social marketing or indirectly by working with the power structures within the sex industry. (Monitoring the AIDS Pandemic 2004; Kerrigan, Moreno et al. 2006)

There have been more limited efforts to promote condom use among men who have sex with men in Asian countries, but condom use rose significantly in most industrialised countries throughout the 1980s and early 1990s, and there is evidence of rising use among MSM in Latin America also. (Winkelstein, Wiley et al. 1988; Coates, Faigle et al. 1995; Elford, Leaity et al. 2001; McFarland and Caceres 2001; Johnson, Hedges et al. 2003) Promotion of condom use among drug injectors has been more limited and generally less successful. (Strathdee and Sherman 2003) The exception has been programmes that work consistently over time with IDU who have tested HIV positive. Vanichseni and colleagues found that counselling of HIV negative IDU had no effect on their sexual behaviour. However among those IDU who were told that they had tested HIV positive and counselled about sexual risk reduction, unprotected sex with a regular partner fell from 34 percent in the period before seroconversion to 24 percent after learning their serostatus. (Vanichseni, Des Jarlais et al. 2004) Similar findings have been reported in other settings. (Friedman, Jose et al. 1993)

These results are encouraging to those who believe that prevention programmes are most effectively targeted at those who are already infected, since only they can pass on the virus. Other studies have also shown that HIV positive people reduce their risk behaviour after learning of a positive HIV diagnosis, in particular with regular partners, and the most common form of risk reduction is an increase in condom use. (Padian, Shiboski et al. 1997; Colfax, Buchbinder et al. 2002; Bunnell, Ekwaru et al. 2006) However all these studies report significant ongoing unprotected contacts between people who know they are HIV infected and those who are HIV uninfected or whose infection status is unknown. A review of studies of behaviour among

people known to be HIV infected, mostly from industrialised countries in the era before highly active antiretroviral therapy (HAART) was available, found that roughly a third of those at high risk of exposure continue to have contacts that carry a risk of transmission of body fluids with people of discordant or unknown serostatus. (Pinkerton, Abramson et al. 2000) More recent studies in the United States find around half the rates of exposed sex and drug injection between known seropositives and seronegatives quoted by Pinkerton; they find that these encounters are significantly more likely to be with casual than with regular partners. (Weinhardt, Carey et al. 1999; Morin, Steward et al. 2005)

Sharing needles is one of the more efficient ways of exchanging body fluids. Programmes to **reduce needle sharing** among drug injectors take several forms. The most common are syringe/needle exchange programmes, where injectors are given sterile injecting equipment, and used equipment is collected to prevent reuse. There is ample evidence that these programmes effectively reduce needle sharing in a wide variety of settings. (Gibson, Flynn et al. 2001; Vlahov, Des Jarlais et al. 2001) Marketing of sterile needles at subsidised prices from convenient locations ("social marketing") has increased access and reduced sharing in some locations such as Southern China. (China National Center for AIDS/STD Control and Prevention 2004) Some programmes do not deal directly with access to needles, but try to reduce sharing by changing social norms among injectors so that sharing becomes socially unacceptable. This approach may have worked early in the epidemic, when the dangers associated with needle sharing were becoming increasingly apparent. (Wiebel, Jimenez et al. 1996) Intensive, repeated counselling within the context of a cohort study has also been reported to reduce needle sharing even in the absence of needle distribution. (Choopanya, Des Jarlais et al. 2003; Vanichseni, Des Jarlais et al. 2004). In a situation where over 90 percent of IDU have been tested for HIV, there is evidence that HIV infected IDU are less likely than those not infected to pass on needles to other users. (Des Jarlais, Perlis et al. 2004)

Focusing the promotion of condoms and sterile needles on those known to be HIV infected requires those who are infected to know, and to care, that they may put others at risk. This is more likely to be the case in industrialised countries where voluntary testing services are widely available and actively promoted among groups at risk. And yet even in these situations, testing is far from universal among those

most at risk. In several European countries, the proportion of people discovering their infection status within six months of an AIDS diagnosis has increased rapidly in recent years. (Castilla, Sobrino et al. 2002; Longo, Pezzotti et al. 2005) In developing countries, testing facilities are generally more limited, and active promotion of such facilities for those most at risk is rare, so a far higher proportion of people who are infected are likely to be unaware of their status. In addition, evidence from Vietnam, China, India and Indonesia suggests that people who know their status are just as likely to report on-going risk behaviour as those who have never been tested for HIV; even having received post-test counselling makes little or no difference to behaviour. (Monitoring the AIDS Pandemic 2004) This may in part be because of poor quality counselling services, or a failure to link testing and counselling to other prevention services. Until quality testing facilities can be made more widely available and acceptable, there will be limits to the potential of efforts aimed specifically at persuading those who know they are infected to use condoms and clean needles so as to reduce the exchange of body fluids in contacts with uninfected partners. Rather, efforts will need to focus on the entire sub-populations in which discordant contacts are most likely to take place. These programmes have been more successful in changing behaviour within populations (raising condom use in anal sex between men, increase the use of sterile needles among IDU) than between populations (for example increasing condom use between drug injectors and their sex partners, where programmes have only made a difference for those who know they are infected). This may be in part because prevention programmes aimed at specific subpopulations have generally put less effort into reducing the "secondary" risk factors for a given population. It may also be because altruism does not motivate behaviour in the abstract, but may be more likely to do so after a positive HIV diagnosis.

While condom use is the most common way of preventing the exchange of body fluids among those who have sex, some prevention programmes have also attempted to **promote non-penetrative sex**. Very little information is available about the success of such programmes.

Besides sex and drug injection, there are other situations in which body fluids can be exchanged between infected and uninfected individuals, either directly (for example from mother to infant during breastfeeding) or indirectly (for example in blood transfusion). Those that are the focus of interventions are shown in Table 7; they are

not discussed in detail here principally because there is no evidence that they currently contribute significantly to HIV transmission in Indonesia, or in many other relatively young, concentrated HIV epidemics.

Table 7 Prevention programmes that aim to reduce exchange of body fluids in contact between higher and lower prevalence populations

Higher prevalence population	Lower prevalence population	Programmes
Sex workers	Clients	Condom promotion
MSM		Condom promotion
IDU		Sterile needle promotion
IDU	Non-injecting sex partners of IDU	Condom promotion
Blood donors (+ve)	Recipients of blood donations	Deferral and blood screening
Pregnant women (+ve)	New-born babies	Delivery by Caesarean section
Mothers (+ve)	Infants	Breastmilk substitutes
Patients (+ve)	Health care workers	Universal precautions to prevent needle stick injury and other exposures

# 7. Question 4: If body fluids are exchanged between an HIV-infected person and an uninfected person, will a new infection occur?

Not every exchange of body fluids between an infected and an uninfected person will result in the uninfected person becoming infected with HIV. Many studies and reviews have sought to determine the "average" likelihood of transmission per contact that is one of the key components of the reproductive rate of infection. (Wiley, Herschkorn et al. 1989; Downs and De Vincenzi 1996; Royce, Sena et al. 1997; Leynaert, Downs et al. 1998; Shiboski and Padian 1998; Quinn, Wawer et al. 2000; Gray, Wawer et al. 2001; Galvin and Cohen 2004) Recorded (and sometimes modelled) transmission rates per act are typically very low, as Table 8 shows, although there is considerable variability within a given route of exposure — estimates of transmission rates in oral sex range from the zero to the very high figure

of 1 in 16. One reason that most observed rates are low is that many of the data come from studies of discordant couples. The design of discordant couple studies which provided much of the early data on infectivity per act may have contributed to underestimates of infectivity as well as early misunderstanding of heterogeneity in infectivity of HIV. Unless discordant couple studies are nested within longitudinal cohort studies and only look at infection among the partners of newly-infected individuals, they will be biased towards infectivity among people with established HIV infection. The effect of increased infectivity in primary infection will be missed in such studies. Equally, if there is heterogeneity in infectivity among individuals, discordant couples studies will be biased towards those with less infectious strains (since those with more infectious strains will be more likely to have infected their partners, and therefore less likely to have been recruited as a discordant couple).

**Table 8: Per act transmission probability by route of exposure** (Reproduced from Galvin and Cohen, 2004)

Infection route	Risk of infection				
Sexual transmission					
Female-to-male transmission	1 in 700–1 in 3,000				
Male-to-female transmission	1 in 200–1 in 2,000				
Male-to-male transmission	1 in 10–1 in 1,600				
Fellatio	0–1 in 16				
Parenteral transmission					
Transfusion of infected blood	95 in 100				
Needle sharing	1 in 150				
Needle stick	1 in 200				
Needle stick/AZT PEP	1 in 10,000				
Transmission from mother to infant					
Without AZT treatment	1 in 4				
With AZT treatment	<1 in 10				

These rather low per-act risks have been used recently to support analyses of the HIV epidemic that suggest that the role of parenteral transmission of HIV has been greatly underestimated in Africa. (Gisselquist, Rothenberg et al. 2002) Over time, however, it has become increasingly apparent that the infectiousness of HIV is not constant. There are a large number of factors that affect both the infectiousness of the infected person and the susceptibility of the uninfected person. Some remain poorly

understood, and the interactions between them can be complex. Some can easily be addressed by prevention programmes; others can not. They include:

- Viral load
- Stage of infection
- Clade of HIV
- Type of sex act
- Presence of other STIs
- Concentration of receptor cells

The body of literature describing these factors is vast; the following (far from exhaustive) review focuses largely on those areas which have an implication for planning or understanding the effects of prevention and care programmes in concentrated epidemics.

## a HIV viral load: the effect of acute primary infection

In the early 1990s, it became apparent that the likelihood that HIV would be passed from an infected to an uninfected partner during sex or when sharing needles was time dependent, with the probability apparently declining strongly soon after infection and the rising again as the asymptomatic phase of infection drew to an end. In 1994, Jacquez and colleague reviewed reports of per-contact infectivity of HIV in anal sex between men. They concluded that the per-act probability of infection was 0.1 - 0.3 during a highly infectious period shortly after first infection, that it dropped to between  $10^{-4}$  and  $10^{-3}$  in the period of asymptomatic infection, and that it rose again to  $10^{-3}$  and  $10^{-2}$  during late stage infection. (Jacquez, Koopman et al. 1994) Simulations using these parameters led the authors to conclude that variations in infectivity over time, and in particular very high infectivity at the time of first infection, was an important contributing factor to the very rapid growth and subsequent stabilisation of HIV prevalence among men with high partner turnover early in the homosexual epidemic in the United States.

In a study of discordant couples, Downs and De Vincenzi found that HIV was transmitted to 10 percent of female partners of HIV-infected men after fewer than 10

unprotected sex acts. After over 2000 unprotected sex acts, HIV prevalence in female partners was 23 percent. The authors concluded it was thus highly improbable that infectivity was constant over time. (Downs and De Vincenzi 1996) By fitting a model of variable infectivity, Leynaert and colleagues found that "persons who are in the process of seroconverting may be much more infectious than asymptomatic infected persons, whatever the type of contact." (Leynaert, Downs et al. 1998)

More recent work has deconstructed the reasons for the time-dependence of infectivity. In 2000, Quinn and colleagues published findings from a study following a cohort of 415 sero-discordant couples identified during a large community based study in rural Uganda. The work provided convincing evidence that the likelihood of HIV transmission was strongly associated with plasma viral load. They found no instances of sero-conversion among uninfected people whose infected partners had a viral load of under 1500 copies of HIV-1 RNA per millilitre. However after controlling for other factors, they found that each log increment in the viral load carried a rate ratio of 2.45 for seroconversion. For the sex partners of people whose viral load was over 50,000 copies, the incidence rate was 23 seroconversions per 100 person years of exposure. (Quinn, Wawer et al. 2000) The authors found that "The viral load is the chief predictor of the risk of heterosexual transmission of HIV-1" (p 921). This finding has been mirrored in a number of other studies in similar but also in different settings. (Pedraza, del Romero et al. 1999; Hisada, O'Brien et al. 2000; Tovanabutra, Robison et al. 2002; Buchacz, Hu et al. 2004; Castilla, Del Romero et al. 2005)

Many recent studies have pointed to the association between recent infection and high viral load. Again, these studies come from a variety of settings, and were conducted among people with a variety of transmission risks. (Celum, Buchbinder et al. 2001; Chakraborty, Sen et al. 2001; Gray, Li et al. 2004; Routy, Machouf et al. 2004)

Many of the studies looking at the relationship between seroconversion and viral load are cohort studies that see people at risk at intervals of several months. These studies commonly assume seroconversion to have taken place at the mid-point between the last visit with a sero-negative result and the first visit with a seropositive result. This limits their ability to describe viral dynamics in very early infection. Since most rely on antibody testing to identify new infections, these studies can

provide no information at all on people who are infected but have not yet seroconverted.

A few studies, however, have been able to be more precise. Fiebig and colleagues tested frozen, stored plasma taken at on average four day intervals from plasma donors who eventually sero-converted for HIV. They distinguished five distinct phases in the short period between first infection and full sero-conversion. The study found that peak viral loads occurred between five and 20 days after infection, before full sero-conversion took place. (Fiebig, Wright et al. 2003) Pilcher and colleagues, using a probabilistic model based on empirical data on plasma and seminal viral load, calculate that viral load peaks some 20 days after infection, and takes a further 34 days to fall back to a "set point". (Pilcher, Tien et al. 2004) The authors calculate that this period of high viral load during primary infection may account for an 8 – 10 fold increase in the probability of heterosexual transmission, compared with transmission risks after the set point is reached. Elsewhere, an increase of up to 20-fold is suggested as a possible effect of primary infection in the first month or so after HIV transmission. In most people, viral loads then recede to reach a set point at between four and six months (Pilcher, Eron et al. 2004)

There is considerable heterogeneity between studies in estimates of the time between peak viral load and stabilisation at a low set point. In an earlier study, Shakler and colleagues show that median viral load was highest in the month after infection, at 235,000 copies/mL. By the end of the second month this had plummeted to 46,000 copies/mL, continuing to decrease until approximately six months after infection. (Schacker, Hughes et al. 1998) Similarly, Kauffman and colleagues found that viral loads peaked within the first 30 days of infection, before dropping to a set point at around six months. (Kaufmann, Cunningham et al. 1999) Among IDU in Bangkok, however, Buchacz and colleagues found that for 63 percent of participants, HIV-RNA levels peaked after their first positive visit (which because of the study design was estimated to be 4.1 months after seroconversion), and viral loads remained relatively elevated at 6 months. (Buchacz, Hu et al. 2004)

Most studies measure plasma viral load rather than seminal viral load. Where these have been compared they appear to rise and fall in parallel. (Pilcher, Tien et al. 2004) Seminal viral load shows greater variability than plasma viral load, and may be associated with higher infectivity of HIV in sub-Saharan Africa. (Dyer, Gilliam et al.

1997; Vernazza, Dyer et al. 1997; Chakraborty, Sen et al. 2001; Pilcher, Tien et al. 2004; Gupta and Klasse 2006)

Modelling the effect of acute primary infection on the spread of HIV, Xiridou and colleagues show that the proportion of HIV incidence attributable to infection passed on during primary infection in the index partner depends on partner turnover, as well as on the age of the epidemic. The younger the epidemic, the higher the proportion of new infections can be attributed to primary infection, a time when HIV is usually undetected. The higher the turnover of partners in the population, the greater the relative contribution of acute primary infection to new HIV infections. (Xiridou, Geskus et al. 2004) This means that undetectable and undetected infections may play a particularly significant role in epidemics where commercial sex is an important factor, contributing to the high per-act transmission risks observed in emerging epidemics in countries such as Thailand and India. Indian researchers have reported that nearly half of a cohort of HIV-infected men who report no risk for HIV other than commercial sex became infected after fewer than 10 visits to sex workers. (Ramalingam, Kannangai et al. 2000) In Thailand, a mathematical model constructed using seroprevalence and retrospective self-reports of contacts with sex workers estimated female to male transmission of between 0.03 and 0.06 on average, considerably higher than estimates made in discordant couple studies in longerestablished epidemics. (Mastro, Satten et al. 1994; Ramalingam, Kannangai et al. 2000)

One recent exploration using molecular analysis was able to demonstrate very clearly the effect of high infectivity in primary infection in a single case. A male actor in porn movies had unprotected sex with 13 uninfected women in the 26 day period between testing HIV negative and testing HIV positive on a PCR test. Three of the women became infected with viral strains that matched those of the index case, giving an attack rate of 23 percent. (Brooks, Robbins et al. 2006)

The importance of primary infection is great in situations where mixing in sexual and drug-injecting partnerships changes over time. In most societies, patterns of sex and drug taking are far from constant. In their sexual lives, people have periods of high mixing, often in youth and after the break-up of a partnership, interspersed with periods of greater stability. People are more likely both to contract and to transmit HIV when they are in what Koopman and colleagues call "high contact mode".

(Koopman, Jacquez et al. 1997) In a paper investigating risk behaviours at or around the time of sero-conversion among gay men, IDU and heterosexual women in the United States, Celum and colleagues report that multiple potential exposures were the norm in all groups. Fewer than one in 10 in any group reported only one seropositive partner in the nine months before they tested positive for HIV. (Celum, Buchbinder et al. 2001) More than half of gay men reported insertive anal sex without a condom around the time they were sero-converting with a partner who was not known to be HIV infected. The initial median plasma viral load among these men was 4.6 log/mL, suggesting a high level of infectiousness and a high likelihood that HIV would be passed on to any uninfected partners. (Colfax, Buchbinder et al. 2002)

For drug injectors, periods of "high contact" typically occur at the start of an injecting career, and during periods of restricted access to drugs and injecting equipment, such as during incarceration. Hu and colleagues trace a period of very high HIV incidence among outpatients in drug treatment in Bangkok to a crackdown which led to high rates of imprisonment. (Hu, Subbarao et al. 2002)

The concentration of risk increases the importance of primary infections in spreading HIV. This has important implications for HIV prevention programmes in concentrated epidemics.

Even in established, generalised epidemics, primary infection may play an important role in determining the likelihood that a new infection will occur if an infected person has unprotected sex with an uninfected person. Waver and colleagues observe that 48 percent of all HIV transmission recorded in the Rakai serodiscordance study took place within five months of the infection of the index partner. They calculate that transmission probabilities per act of unprotected sex within the first five months are eight times higher than they are during established infection. They rise again to half their peak levels during late stage infection, the two years before death. (Wawer, Serwadda et al. 2003)

The viral load in pregnant women has been shown to be significantly associated with the likelihood that an HIV-infected mother will transmit the virus to her infant. (Brocklehurst 2002)

## Other factors affecting viral load

It appears that innoculum at infection my affect viral load (and therefore infectivity), with a higher initial innoculum leading to higher viral loads. This may explain the finding that chronically infected IDU have significantly higher plasma viral loads than MSM or heterosexuals, even after HAART. (Routy, Machouf et al. 2004)

Viral load may develop differently according to HIV-1 subtype. Hu and colleagues found significantly higher viral loads in IDU newly-infected with sub-type E (or more properly CFR01\_AE) compared with subtype B. The difference was significant at first test and persisted for six months thereafter, though by 12 months the difference was no longer statistically significant. (Hu, Vanichseni et al. 2001) Subtype C may be associated with higher seminal viral load when compared with other subtypes. (Pilcher, Tien et al. 2004)

Super-infection with a second type of virus in people who are already infected with HIV and dual infection (with two types of virus contracted at or around the same time) appear to lead to higher viral loads, regardless of mode of transmission or subtypes. (Gottlieb, Nickle et al. 2004; Grobler, Gray et al. 2004; Smith, Wong et al. 2004; Yerly, Jost et al. 2004) Among IDU in Bangkok, Hu and colleagues found incidence of a second subtype to be 2.2 per 100 person years of exposure in IDU who were already infected. (Hu, Subbarao et al. 2005)

## b Type of sex or injecting act

The likelihood that a new infection will occur in sex between an infected and an uninfected person varies according to the type of sex act. Different injecting practices also affect the likelihood that a new infection will result if equipment is shared.

The principal mechanism through which the type of sex act affects the likelihood that HIV transmission will take place is disturbance of the mucosal barriers which act as natural protection. This means that anal sex carries a higher risk than vaginal sex. Logically, unlubricated sex, both anal and vaginal, is more dangerous than sex using natural or artificial lubrication unless the lubricant itself proves damaging to mucosal barriers (as appeared may have been the case with the spermicidal lubricant Nonoxynol – 9). (Hillier, Moench et al. 2005; Wilkinson, Ramjee et al. 2006) No data are available to estimate the effect that lubricant use might have in reducing the

transmission of HIV in anal sex, however. This is probably in large part because lubricant use in anal sex is the norm in the industrialised countries where most studies on transmission risks have been carried out. For example Carballo-Dieguez and colleagues report that over 90 percent of Latino MSM in New York use lubricant in anal sex – rates of lubricant use were similar with and without condoms. (Carballo-Dieguez, Stein et al. 2000)

Sexual practices which increase trauma to mucosal barriers will increase the likelihood of HIV transmission; Brooks and colleagues identified double penile-anal insertion and other trauma-inducing practices as contributing to the 23 percent attack rate identified from an infected male in the porn industry. (Brooks, Robbins et al. 2006) The use of drying agents in the vagina have also been implicated in high rates of HIV transmission. (Sandala, Lurie et al. 1995; Halperin 1999)

## c Sexually transmitted infections

The relationship between infection with other STIs and the likelihood that HIV will be transmitted in unprotected sex between an infected and an uninfected partner is complex, and has been investigated in a huge number of studies in many settings, ably summarised in a number of comprehensive reviews on the subject. (Fleming and Wasserheit 1999; Galvin and Cohen 2004) Infection with an STI in the HIV-infected partner appears to increase the likelihood that HIV will be transmitted to an uninfected partner, while STI infection in someone not currently infected with HIV will increase susceptibility in people who are exposed to the virus through unprotected sex with an HIV-infected partner. These effects are the result of a number of biological mechanisms as follows:

## Increased infectivity among people infected with both HIV and STIs

Genital ulcer disease (GUD) increases shedding of HIV in genital tract fluids in both men and women. (Ghys, Fransen et al. 1997; Schacker, Zeh et al. 1998; Pilcher, Eron et al. 2004) Non-ulcerative STIs increase shedding in men. (Moss, Overbaugh et al. 1995) Evidence for increased cervico-vaginal shedding of HIV among women infected with non-ulcerative STIs is less clear, though some studies have shown increased shedding. (Ghys, Fransen et al. 1997; Mostad, Overbaugh et al. 1997)

HIV viral load in blood plasma increases in men with GUD and during acute episodes of infection with other STIs, notably Herpes Simplex Virus Type 2 (HSV-2), a common cause of GUD. (Schacker, Zeh et al. 1998; Gray, Li et al. 2004) HIV viral load in seminal fluid increases in men with ulcerative and non-ulcerative STIs. (Cohen, Hoffman et al. 1997; Dyer, Eron et al. 1998; Dyer, Hoffman et al. 1999)

#### Increased susceptibility to HIV among people infected with STIs

Immune response to STIs attracts HIV-susceptible cells to the ulcer surface in people with GUD, and to the endocervix in women with non-ulcerative STIs.

Evidence for the causal link between symptomatic STIs and higher infectivity of HIV is supported by studies showing that effective treatment of STIs lowers both viral shedding and viral load. (Cohen, Hoffman et al. 1997)

The interaction between HIV and STIs is bidirectional: immunosuppression associated with HIV infection results in more frequent and more severe episodes of GUD and may increase susceptibility to other STIs. (Laga, Manoka et al. 1993; Corey, Wald et al. 2004)

The magnitude of the effect of infection with ulcerative and non-ulcerative STIs on the likelihood of HIV being transmitted in unprotected sex between an infected and an uninfected partner is unclear. Ulcerative STIs have a more pronounced effect than non-ulcerative STIs, with many studies giving odds ratios or rate ratios of infection with HIV for those with a recent history of ulcerative STIs of between 3 and 5 compared with those with no STIs. Odds ratios associated with non-ulcerative STIs are more commonly in the range of 1.5 - 2.5. The increase in per-act infectivity of HIV during the period of symptomatic STI infection will be greater than the odds ratio, which reflects cumulative risk over a period that may include no infection and asymptomatic infection as well as symptomatic infection.

There is evidence that co-transmission of HIV and other STIs may be common. For example Pilcher and colleagues found that 2.5 percent of men presenting with an STI in Malawi were newly-infected with HIV. (Pilcher, Price et al. 2004) STIs are a marker of recent risk; it is possible that they are also a marker of recent HIV infection. Some of the association between STIs and HIV transmission may therefore be linked to the association between primary infection and high infectivity. Regardless, since many of the biological mechanisms mentioned above are

associated primarily with symptomatic STIs, rapid diagnosis and correct treatment of symptomatic STIs may play an important part in reducing infectivity in those who are most likely to be infectious.

## d Other factors affecting the likelihood of HIV transmission

The presence of a foreskin has been shown to be significantly associated with the likelihood of acquiring HIV during unprotected sex with an infected partner, probably because of the density of Langerhans' cells, which act as efficient receptors, in the foreskin. The influence of uncircumcised status on infectiousness is less well established. (Siegfried, Muller et al. 2003)

## e Programmes aiming to reduce the likelihood that a new HIV infection will occur if an HIV-infected person exchanges body fluids with an uninfected person

Until recently, the most common interventions aiming to reduce the likelihood that HIV infection would result from an exchange of infected body fluids were those relating to the **treatment of STIs**.

There has been much debate recently about the effectiveness of community level interventions to reduce STIs on HIV transmission rates in generalised epidemics, following the results of three community randomised trials using different approaches and in different epidemiological conditions. (Grosskurth, Mosha et al. 1995; Wawer, Sewankambo et al. 1999; Pickering, Whitworth et al. 2005) However less attention has recently been given to the potential effects of STI-related interventions in concentrated HIV epidemics. (Neilsen 2005)

Mathematical modelling suggests that reductions in STIs will have a greater effect early in an epidemic, and when HIV is concentrated among definable groups at high risk. (Galvin and Cohen 2004) Where unprotected sex between discordant people is concentrated in small sub-sections of the population such as sex workers and their clients, reductions in infectivity will be more important than reductions in susceptibility (because a single infected person with high risk behaviour could potentially infect every other person they have exposed contact with, whereas it is unlikely that every person a susceptible person encounters will be infected with HIV).

(Garnett 2001) This suggests STI-related interventions targeted at those infected with HIV are potentially more important than those targeting people with STIs but not HIV.

Reduction in the prevalence of symptomatic STIs requires that symptomatic STIs in the index patient be effectively treated. Effective treatment may be hard to achieve. Treatment may be expensive and logistically difficult to administer, as in the case of suppressive therapy for episodes of the incurable viral infection HSV-2 with acyclovir, or the effectiveness of standard treatments may be reduced as resistant strains of STIs spread. In addition, programmes to reduce symptomatic infection may also require effective treatment of asymptomatic infections in the sub-population with whom those most at risk regularly interact, since without such programmes the risk of reinfection in the index patient or group may be high. (Grassly, Garnett et al. 2001)

There are several ways of targeting STI treatment in concentrated epidemics. Several countries operate a registration system for sex workers or for entertainment establishments, requiring regular screening of female employees for STIs, with treatment where appropriate. Screening varies from visual inspection using specula to the use of simple lab tests at the point of screening, and some programmes opt for periodic mass treatment, which may be cost-effective where population turnover is very high. A few operate services for pimps, male entertainment establishment employees and regular partners of sex workers, in the belief that these men act as a reservoir that allows for the rapid re-infection of female sex workers. Regular STI screening and treatment for male and transgender sex workers is rare.

Outreach services encouraging men likely to be at high risk (because they buy sex) to attend clinics for STI screening and treatment have been associated with a rise in treatment seeking and a drop in self-treatment in some situations, but the effect of these programmes on STI prevalence has not been directly measured. Partner referral services are thought to be weak.

The contribution of the use of **safe lubricant** in anal sex to reduction in the likelihood of HIV transmission has not been measured. Common sense suggests that the effect may be significant, particularly when water-based lubricant is replacing no lubrication at all, or the use of perfumed skin creams which are the norm in some

parts of the world. (Monitoring the AIDS Pandemic 2004) Some programmes for MSM focus in part on trying to promote the use of lubricant to reduce trauma and inflammation that may increase susceptibility to HIV.

Programmes promoting the use of **bleach to clean needles** between users when drug injectors share needles are also poorly evaluated, but they provide another example of prevention efforts that seek to reduce the likelihood of a new infection occurring if needles are passed from an HIV infected to an uninfected user.

Perhaps the most significant recent development in prevention efforts at the level of reducing infectivity is the spread of **antiretroviral therapy** (ARVs). Correct use of ARVs reduces viral load in people infected with HIV, and since the infectiousness of a person is strongly correlated with their viral load, it follows that ARVs will also reduce the likelihood that an infected person will pass on HIV if they exchange body fluids with an uninfected person.

There is some evidence that ARVs may have less effect on seminal and cervicovaginal viral load than they do on blood plasma viral load. (Coombs, Reichelderfer et al. 2003; Galvin and Cohen 2004; Gupta and Klasse 2006) Those differences notwithstanding, it seems clear that people who are adherent to effective ARV therapy are less likely to transmit HIV to their uninfected partners even if unprotected contact continues. Castilla and colleagues found that 8.6 percent of steady partners of index seropositive people not treated with antiretrovirals were infected with HIV, while there were no infections in the partners of people on HAART. (Castilla, Del Romero et al. 2005) Tracking the progress of the HIV epidemic in San Francisco, Porco and colleagues estimate that per partnership transmission of HIV among gay men fell from 0.120 per act of unprotected anal sex prior to widespread use of HAART, to 0.048 after the widespread use of HAART- a decline of 60 percent. The authors note that transmission rates rose again after 1999, the end of the period covered by the analysis. (Porco, Martin et al. 2004) Routy and colleagues found that there was a significant fall in the mean viral loads of people chronically infected with HIV from 4.3 log copies/mL in 1996 to 2.9 log copies/mL in 2000, a period during which the proportion of study participants on HAART rose from 37 percent to 69 percent. The proportion with undetectable viral loads rose from 14 percent to 55 percent over the same period. (Routy, Machouf et al. 2004)

Bunnell and colleagues report that viral load among people on treatment in a cohort in Uganda fell dramatically during the first six months in treatment. Whereas at baseline just one out of 126 participants has a viral load of less than 1700 copies/mL (the threshold under which Quinn and colleagues observed no HIV transmission), after 6 months of treatment 94/96 patients were below the threshold. Only one of 49 known seronegative spouses of patients on ARVs seroconverted in a year; he reported inconsistent condom use with his wife and unprotected sex with an HIV positive casual partner. (Bunnell, Ekwaru et al. 2006)

At the individual level, then, an HIV infected person on antiretroviral therapy will be less likely to pass the virus on in unprotected sex or during drug injection than an infected person who is not on antiretrovirals. However, there are other important factors to consider at the population level when considering the overall effect of ARVs as an element of HIV prevention programmes. They work at each level of the "Back to Basics" framework.

- The availability of ARV therapy increases the incentive to be tested among those who may have been exposed to HIV, increasing the proportion of people who know they are infected, and the proportion of infected people who have had some contact with potential prevention and care services.
- ARV treatment increases survival, which increases prevalence. This may lead to increases in the likelihood that an infected person will have sex with an uninfected person.
- ARV treatment decreases the gravity of HIV as an infection. This may lead to increases in the likelihood that body fluids are exchanged in discordant contacts, as uninfected people become less concerned about prevention.
- In developing countries, ARVs are provided largely to people with advanced HIV disease. The reduction in infectivity provided by ARVs will not affect those with acute primary infection. It appears that most HIV is passed on during this early phase of high vireamia.

Modelling the potential effects of widespread antiretroviral therapy on the continuing spread of HIV, Gray and colleagues conclude that ARV treatment alone would not be enough to reduce the reproductive rate of infection to below 1 in a generalised epidemic, even without any "behavioural disinhibition" -- the factors described by

the second and third bullet points above. The model links transmission probabilities to viral load, and takes viral load distribution from the Rakai discordant couples study. (Gray, Li et al. 2003). This may have had the effect of understating the effect of untreated high vireamia in early infection, thus overstating the prevention potential of ARVs in this setting. The magnitude of "behavioural disinhibition" (referred to by some authors as "risk compensation") associated with growing access to antiretroviral treatment has been much studied and discussed (Cassell, Halperin et al. 2006) but remains poorly quantified. There is as yet little evidence of rising risk in the limited developing world settings where ARVs are available. (Moatti, Prudhomme et al. 2003; Bunnell, Ekwaru et al. 2006) In concentrated epidemics in industrialised countries, the picture is more worrying, with rising risk behaviour recorded in some populations associated with expectations of reduced infectivity in those who are on ARVs. (Strathdee, Martindale et al. 2000; Dukers, Goudsmit et al. 2001; Crepaz and Marks 2002; Tun, Celentano et al. 2003; Gremy and Beltzer 2004; Stolte, Dukers et al. 2004)

The high fraction of infections apparently related to a period of high vireamia in early infection has caused some to advocate for **aggressive prevention efforts targeted at those who are newly infected.** These include early screening of people at risk, ARV therapy to bring down viral load during this period, tracing of recent sex or injecting contacts and possible post-exposure prophylaxis. (Koopman, Jacquez et al. 1997; Dukers, Spaargaren et al. 2002; Pilcher, Eron et al. 2004) Some of these interventions rely on sophisticated diagnostic techniques and all require an extremely strong public health infrastructure. The practicality of these interventions in developing countries is likely to be limited. In addition, their effectiveness is not well known. For example concern has been expressed that interruption of early ARV therapy can cause viral rebounds that are similar in magnitude to those seen during primary infection. (Tubiana, Ghosn et al. 2002)

Our inability reliably to identify newly infected individuals leaves us with little choice but to target, equally aggressively, the sub-populations and situations where the largest concentration of newly-infected individuals are likely to be found. In other words, it is necessary to use the surveillance and behavioural data we have to identify sub-populations in which a high proportion of infections are likely to be incident. An obvious candidate in southeast Asian settings is prisoner populations.

There is no shortage of evidence that HIV outbreaks occur in prisons in the region. Since incarceration times are short, the likelihood that people will be released and will interact with drug injectors and sex partners outside the prison setting while still in a highly infectious state is fairly high. Rapidly changing societies that are providing opportunities for mixing between gay men in newly emerging gay bars and clubs – such as those now mushrooming around urban China -- may be another example. Focusing interventions in these areas, and seizing every opportunity to provide effective prevention services for people with signs of recent risk (such as STIs, current abscesses, current or recent incarceration) may be the most effective way to reach a high proportion of those who are newly infected with HIV, and very infectious.

One area in which antiretroviral treatment has been well established as an effective way of preventing HIV transmission is by **administering ARVS in late pregnancy and around childbirth** as a way of interrupting the chain of transmission between mother and infant. (Brocklehurst and Volmink 2002) Post-exposure prophylaxis with ARVs had also been shown to reduce HIV infections when body fluids have been very recently exchanged, for example as the result of a needle-stick. (Gutierrez, Lopes et al. 2005; Puro, De Carli et al. 2005)

**Male circumcision** has long been associated in observational studies with reduced risk for acquisition of HIV, and the biological plausibility of the association is high. (Siegfried, Muller et al. 2006) In a newly published randomised controlled trial, male circumcision was associated with a 60 percent reduction in the risk of acquiring HIV infection. (Auvert, Taljaard et al. 2005) The potential for targeted circumcision programmes in concentrated epidemics is unclear.

Table 9 summarises the main interventions that work to prevent HIV transmission if programmes to prevent the exchange of body fluids between infected and uninfected people fail.

Table 9: Prevention programmes that aim to reduce the likelihood that a new infection will occur if body fluids are exchanged between discordant partners

Programme	Effect		
STI treatment (+ve partner)	Reduced infectivity		
STI treatment (-ve partner)	Reduced susceptibility		
Promotion of needle bleaching for IDU	Reduced infectivity (?)		
Promotion of lubricant in anal sex	Reduced susceptibility (?)		
Antiretroviral treatment during pregnancy/at birth	Reduced infectivity		
Antiretroviral treatment (+ve partner)	Reduced infectivity		
Antiretroviral treatment post-exposure (-ve person)	Reduced susceptibility		
Male circumcision (-ve men)	Reduced susceptibility		

## 8. Question 5: Will the newly-infected person survive?

If all prevention efforts fail and a new infection occurs, its impact on the epidemic will be determined by the length of time the newly infected person survives. In populations where treatment is not available, survival time appears to be related to early immunological response. Higher innoculum of the virus at infection may also increase the speed at which HIV-related disease progresses. (Mindel and Tenant-Flowers 2001)

Prophylaxis for common opportunistic infections, treatment for infections as they arise, and antiretroviral therapy all have the potential to increase the healthy lifespan of HIV-infected people considerably. Clearly, for a constant rate of incidence, longer duration of infection will increase HIV prevalence in a population. The contribution that longer survival will have on incidence will depend on whether the surviving, infected person has sex or takes drugs with uninfected people, whether body fluids are exchanged in those encounters, and whether a new infection results if body fluids are exchanged. In other words, we go back to the start of the "Back to Basics" framework, and begin the questioning process again.

## 9. Areas of uncertainty: keeping it simple

The Indonesian surveillance and monitoring system described in Chapter 2 now provides much of the information needed to answer the questions:

- Who is infected with HIV and who is not?
- How likely is it that an infected person will have sex or take drugs with an uninfected person?
- How likely is it that body fluids will be exchanged in sex or injections between an HIV-infected and an uninfected person?

Some of the information needed to answer the final question in the transmission analysis framework (if an unprotected, discordant exposure does take place, how likely is it that HIV will be transmitted?) is available in the surveillance system. But this is the area of greatest uncertainty. It is necessary to put a value on the probability of HIV transmission per act of exposed, discordant contact if we want to predict a total number of new infections, (and later, the absolute numbers of infections that might be averted through different combinations of prevention programmes). "Infections averted" is the preferred output of most models that estimate the effect of different prevention programmes. The majority of these models try to minimise complexity by ascribing a constant per-act infectivity for each type of exposure (male to female vaginal, female to male vaginal, anal and injecting), varying it only for co-infection with STIs. This approach ignores the extremely important role of primary infection in spreading HIV, and also makes it difficult to disentangle the effects of various prevention approaches.

Even if it were technically possible to do in a transparent model simple enough for use at the field level, it is not necessary to calculate exact number of infections averted for the purposes of setting prevention priorities. Instead of trying for an exact quantification of the transmission probabilities in any act of exposure, we can instead categorise different exposures as having a high, medium or lower risk of transmission. Prevention programmes can then focus on trying to reduce the exposures that are most likely to result in a new infection, either by eliminating the exposure (intervening successfully to eliminate the exchange of body fluids in setting where infectiousness is high) or by reducing infectivity in those exchanges.

Exposures that carry a lower risk of transmission would merit less attention even if they are numerically greater.

Just as assigning specific transmission risks affects the outcome of "infections averted" models, so the categorisation of different transmission probabilities into high, medium and low will influence which prevention efforts are estimated to have most impact. Following the review above, a categorisation is proposed below. This categorisation focuses on the sexual and drug-taking exposures that are the dominant modes of transmission in concentrated epidemics.

#### High risk of transmission if body fluids are exchanged

- Any exposure where the HIV-infected person is newly infected (<= 6 months)
- Injection with an unbleached shared needle

#### Medium risk of transmission if body fluids are exchanged

- Injection with a bleached shared needle
- Any anal sex where one partner has an STI
- Anal sex without lubricant
- Vaginal sex where one partner has an STI

### Lower risk of transmission if body fluids are exchanged

- Anal sex with lubricant and no STIs
- Vaginal sex with no STIs
- Any exposure where the HIV-infected person is adhering to ARV therapy

Evidence for this categorisation is relatively strong except in the case of anal sex with and without lubricant. While it is highly likely that use of water-based lubricant in anal sex protects the integrity of mucosal barriers to HIV, the effect may not be enough to move such an exposure into the "lower risk" category. In addition, there is limited information about the effectiveness of bleach in reducing HIV transmission if a needle is passed from an infected to an uninfected partner.

This categorisation helps us to prioritise the various intervention options – in other words, to answer the first of the questions with which we begun this chapter: in this epidemic situation, what should we be doing? Chapter 4 will give an example using

Jakarta data. The use of data in assuring not just that we are doing the right thing but that we are doing it well will be addressed in Chapter 5.

#### The Back to Basics Framework: Key Points

- To be useful to policy makers, analytic frameworks should start from the current situation and identify current HIV prevention priorities
- To prevent new HIV infections, a prevention programme has to change at least one of three things: the likelihood that an HIV infected person will have sex or take drugs with an uninfected person, the likelihood that body fluids will be exchanged if they do have contact, and the likelihood that HIV will be transmitted if body fluids are exchanged.
- These risks can be quantified for different populations using data from good quality second generation surveillance systems.
- Simple analysis following this framework can give an at-a-glance idea of where most new exposures are taking place in a given epidemic, and of the possible contribution of different prevention interventions
- The innovations in this framework include: Taking the current epidemic state as
  point of departure for analysis, sequential arrangement of the factors determining
  the spread of HIV (including an initial focus on discordancy), immediate and
  clear programme relevance, and ease of communication.

## Chapter 4: The Back to Basics framework in operation

The previous chapter laid out a framework which uses basic questions about the epidemiology of HIV to develop an understanding of the risk of exposure to HIV in the local epidemic. Chapter 3 described issues that must be taken into consideration in operationalising the framework, and discussed many of the potential interventions which can be used to change parameters in the framework and alter the likelihood of HIV transmission.

This chapter puts the Back to Basics framework into operation in understanding the HIV epidemic in Jakarta, the capital of Indonesia. Jakarta has an official population of close to 9 million – larger than several Southeast Asian nations including Cambodia, Laos and Singapore. The surveillance system in Jakarta is among the most complete in Indonesia. This chapter walks through each of the questions suggested by the Back to Basics framework, to arrive at an understanding of which behaviours, within and between which sub-populations, are most likely to be the source of new HIV infections in Jakarta in the mid-2000s. After the current situation is described, and prevention priorities are identified, the same approach is used to look at the impact of an actual prevention programme among transvestite sex workers, which is generally considered to be a success story in the context of HIV prevention in Jakarta. The framework is also used to predict the potential effect of different prevention approaches for drug injectors.

The example uses an Excel workbook to show the calculations at each stage of the analysis. A copy of the workbook is provided to the examiners, and the figures in this chapter give the relevant cell numbers, for ease of reference. Unless otherwise stated, these refer to cells in the spreadsheet named "Baseline".

## 1. Question 1: Who is infected with HIV, and who is not infected?

The question "Who is infected with HIV"? is answered relatively simply.

Surveillance data tell us what proportion of each behavioural risk group is infected

with HIV. By applying those data to estimates of the size of each of the risk groups, we know how many HIV positive people there are in each group. In the case of Indonesia, these calculations are performed on a routine basis as part of the biennial estimates of HIV infection, and are available in spreadsheet form for every district and province. An example of such a spreadsheet is shown in Figure 8.

Propinsi DKI Jakarta	Besar populasi			Prevalens HIV			Estimasi ODHA	
Populasi berisiko tinggi				Prevalens			pop rendah prev	pop tinggi prev
terekspose ke HIV	Estimasi rendah	Estimasi tinggi	Estimasi rata2	rendah	Prevalens tinggi	Prevalens rata2	tinggi	rendah
Pengguna Narkoba suntik	19,790	24,540	22,165	44.81	58.62	51.71	10,996	11,600
Pasangan IDU yang bukan pemakai	5,650	7,020	6,335	14.91	19.55	17.23	1,047	1,104
Wanita penjaja seks langsung	15,320	17,770	16,545	9.48	12.76	11.12	1,684	1,955
Wanita penjaja seks tidak langsung	20,260	20,260	20,260	2.80	8.99	5.90	1,822	567
Wanita penjaja seks (semua)	35,550	38,030	36,790	6.63	9.86	8.25	3,506	2,522
Pelanggan WPS langsung	271,660	315,390	293,525	1.89	2.55	2.22	5,976	6,939
Pelanggan WPS tidak langsung Pelanggan wanita penjaja seks	175,480	175,480	175,480	0.56	1.80	1.18	3,159	983
(semua)	447,140	490,880	469,010	1.61	2.04	1.83	9,135	
Pasangan Pelanggan WPS langsung Pasangan Pelanggan WPS tidak	157,560	182,930	170,245	0.16	0.85	0.51	294	1,341
langsung	122,130	122,130	122,130	0.60	0.73	0.67	733	896
Pasangan Pelanggan WPS (semua) Homoseks risti (termasuk penjaja seks	279,700	305,060	292,380	0.34	0.80	0.57	1,027	2,237
pria)	1,650	7,050	4,350	2.10	19.22	10.66	148	317
Waria penjaja seks	1,130	1,130	1,130	21.92	33.38	27.65	377	248
Pelanggan waria penjaja seks	23,710	23,710	23,710	4.40	6.70	5.55	1,589	1,043
Narapidana pria	6,870	6,870	6,870	23.92	33.59	28.75	2,308	1,643
Jumlah Risiko Tinggi	795,820	687,040	741,430				25,202	23,909
Pria	480,500	343,880	412,190				18,852	17,233
Wanita	315,320	343,160	329,240				6,350	6,676
Populasi Risiko Rendah	4.710.470	4,819,250		Pre	evalens HIV		_	-
Pria dewasa risiko rendah	2.217.210	2.353.830		0.00	0.00		_	_
Wanita dewasa risiko rendah	2,493,260	2,465,420		0.00	0.00		_	_
	ES	TIMASI RATA-RATA	l.			RANGE RENDAH		
	Pria	Wanita	Total		Pria	Wanita	Total	
Jumlah populasi	4,372,350	4,353,300	8,725,650		4,372,350	4,353,300	8,725,650	
Jumlah populasi 15-49	2,697,710	2,808,580	5,506,290		2,697,710	2,808,580	5,506,290	
Estimasi jumlah ODHA 15-49	18,042	6,513	24,555		17,233	6,350	23,583	
Estimasi prevalens HIV	0.67	0.23	0.45		0.64	0.23	0.43	

Figure 8: Estimates spreadsheet showing population sizes and numbers HIV positive for Jakarta, 2004 (Source: P2M National estimation process)

From this, we can get an idea of which behavioural groups include the largest numbers of people with HIV. However, it does not answer the question: in which situations are HIV positive people most likely to meet HIV negative people?

# 2. Question 2: How likely is it that an HIV-infected person will inject drugs or have sex with an HIV-uninfected person?

The interaction within and between groups is complex, but it stands at the core of the spread of HIV, and must be considered before any locally appropriate models can be constructed. Essentially, there are three factors which must be considered:

#### **Interaction WITHIN a group**

In some sub-populations, the majority of risk takes place between different

individuals in the same sub-population. This is notably the case for IDU, MSM and prisoners.

### **Interaction BETWEEN groups**

Some sub-populations interact only with other groups; the members of the groups are mutually exclusive. This is the case for female sex workers and their clients, waria (transgender sex workers) and their clients, and members of high risk groups and their regular sex partners who do not themselves engage in high risk.

### Individuals belonging to more than one group

In concentrated epidemics, it is not unusual to find "constellations of risk" where the same individuals engage in more than one risk behaviour. For example female IDU may sell sex, male IDU may be clients of sex workers, waria may inject drugs etc. These "overlapping" risks can be a very effective way of moving HIV from one subpopulation to another in an emerging epidemic. If substantial enough, they may deserve special attention in prevention programming. Overlap may also affect the structure of even simple models constructed to look at the effectiveness of different prevention programmes.

These different interactions and overlaps vary greatly between cultures. For example the World Health Organisation issued a report on the HIV epidemic in Asia which drew on the experience of behaviours of drug injectors in Western countries, among whom sexual activity is limited. The report dismissed the danger that sexually active IDU would spread HIV to non-injectors. (World Health Organization 2001) Behavioural data from a number of countries in Asia, including Vietnam, China and Indonesia, found that IDU were in fact highly sexually active, and likely to both buy and sell sex. <sup>10</sup> (Pisani and Winnithana 2001)

A starting point for understanding any local epidemic is to understand the magnitude of the interactions within and between sub-populations, and the degree of overlap. The choice of sub-populations will be specific to the national or local context. As discussed in Chapter 2, HIV was first detected in any significant way in Indonesia among transgender sex workers in Jakarta – a group that may not exist in other settings. In addition, Indonesia has chosen to include prisoners as a separate risk group, because there is evidence that people in prison engage in behaviours, drug

<sup>&</sup>lt;sup>10</sup> The WHO report was subsequently withdrawn from the website.

injection and possibly anal sex, that they did not engage in before incarceration, and that put them at risk for HIV during the period of incarceration, and their partners at risk after their release. The methods used to make estimates for IDU and MSM mean the people engaging in these behaviours in prison are not included in population size estimates. Because Indonesia has quite an effective blood transfusion service with very high rates of screening, there have been no HIV infections reported as a result of blood transfusions for many years. There is no evidence of infections transmitted in health care settings or through practices such as tattooing, and these are not included in the current estimates. Except in the ethnically and culturally distinct province of Papua (described in Chapter 6), the majority of people currently infected with HIV in Indonesia are men. Most HIV infections in women are among female sex workers, whose use of contraception is high. The number of infants at risk for HIV is therefore relatively small. The framework, as constructed for Jakarta, is therefore restricted to looking at the risk of new infections among adults.

Understanding interactions between populations can begin with a matrix detailing the interactions both within and between the various sub-populations at potential risk for exposure to HIV. An example is given in Figure 9. Each of the populations at potential risk for exposure to HIV appears down the side and across the top of the matrix. The population down the side of the matrix is the "index" population, the denominator population for the percentage in the row. So for example in Row 2, Female IDU are the denominator population. If we look across to column 3, Female sex workers, we see that 35 percent of female IDU report selling sex. However if we look at the inverse combination, (row or denominator population is female sex workers, column or numerator population is female IDU) we find a different figure: just 1 percent of female sex workers report injecting drugs.

These data are provided by the behavioural sentinel surveillance system.

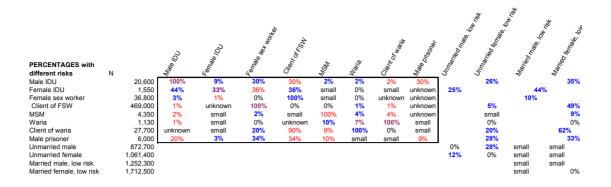


Figure 9: Matrix showing percentage interaction/overlap between and within groups (Spreadsheet: A2:N15)

(Data: P2M/BPS, Jakarta BSS 2004/2005)

The matrix is colour coded in order to distinguish between mixing within a group (purple), mixing between groups (blue) and overlapping memberships, where a certain percentage of individuals in the denominator group also belong to the numerator group (red).

The matrix includes all the percentages which are reported in routine BSS in Indonesia. In a few cases, no data are available at all (for example, we have no information at all on sexual interaction between prisoners). In most cases, data are available from at least one of the interacting groups. For example, clients of sex workers report their marital status, even though no BSS is conducted among married women. In other cases, data on interaction are reported by more than one sub-population – for example, sex workers report client numbers, while clients report number of sex workers visited. Note that the matrix includes interaction between male prisoners and sex partners, including wives, casual partners and female sex workers. These interactions do not occur in prison; the data on the extent of these interactions is taken from reports recorded in BSS among IDU who report being in prison at some point during the last year. For prisoners, estimates are based on half of the annual prison population in jail (interacting only with one another) and half recently released (interacting only with other populations).

Figure 10 applies the percentages in the matrix in Figure 9 to the average estimated population size in Figure 8. The coloured pairs represent populations which give two different data sources for a single interaction or overlap (some colours are repeated

because of limitations in the software's palate; the matched pairs split down the diagonal).

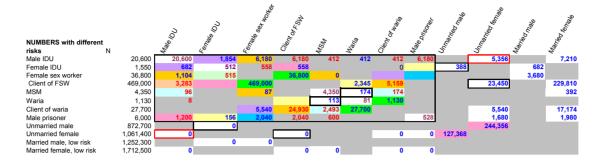


Figure 10: Matrix showing estimated numbers in each interaction/overlap group (Spreadsheet A16:N28)

In the case of overlapping membership of populations (red numbers), these proportions, applied to their respective denominator populations, ought to represent the same number of individuals. This allows us to perform checks for internal consistency. In some cases, the different data sources give very similar results. In the example picked out earlier, the very different proportions of "overlap" reported by female IDU and female sex workers, when applied to the respective estimated population sizes, give almost identical estimated numbers of injecting female sex workers in Jakarta. However other estimates are far more disparate. Take the overlap between MSM and clients of waria for example. No BSS is available directly for clients of waria. However clients of waria can be identified in BSS conducted among occupational cohorts of men in industries with high consumption of commercial sex (mostly sea-farers and truck drivers). Fewer than 1 percent of these men said they bought sex from waria in the last year. Of those who did, 9 percent said they also had anal sex with another man; this is the percentage given in the matrix in Figure 9. Applied to the estimated number of clients of waria, it gives an estimate of close to 2,500 clients of waria who are also MSM. In BSS among MSM recruited in cruising areas, around 4 percent reported buying sex from a waria in the past year; this is reflected in Figure 9. Applied to the estimated number of high risk MSM in Jakarta, it gives an estimate of just 174 MSM who are also clients of waria.

Why the discrepancy? In this case, it is almost certainly because of the sample populations. Indonesia's national estimates of populations at high risk for HIV infection include only those MSM thought to be at high risk for exposure to HIV

because they have multiple partners. Most of these are part of a gay sub-culture, or actively seek male partners on the internet or through commercial establishments. The men who reported in BSS among high risk men that they had bought sex from a waria and had anal sex with another man are unlikely to fall into this category. Most of them also reported sex with female sex workers and other women; it is likely that their sexual relations with other men were sporadic and opportunistic. In general, Indonesian men regard sex with waria as a variation on sex with women, rather than with men. Waria themselves dislike and avoid "gay" clients. (Pisani, Girault et al. 2004) With this background information, the lower estimate seems more reasonable than the higher. In this case, the estimates were harmonised at the 25th percentile of the combined estimates. Similar adjustments can be made to reconcile other discrepancies, using information about biases in sampling, gaps in data etc.

The overlap groups will affect programme choices and may also inform the construction of a simplified model to investigate programme effects. But it is interaction within and between groups that is key to answering the question: How likely is it that an HIV infected person will have sex or inject drugs with an uninfected person? The rest of this analysis will focus on these interaction groups.

As we have seen, the numbers of individuals in two groups that interact with one another may be quite different. But in sex between the groups, the number of different partnerships must be the same. For example, there may be 10 sex workers and 50 clients. The actual number of partnerships must lie between 50:

```
each client has sex with only one sex worker: 50 \times 1 = 50
each sex worker on average has sex with five clients: 10 \times 5 = 50
```

and 500:

```
each client has sex with every one of the 10 sex workers: 50 \times 10 = 500 each sex worker on average has sex with 50 clients: 10 \times 50 = 500
```

Although many HIV prevention efforts focus on a single sub-population, the unit of interest in planning and evaluating HIV prevention programmes (and therefore in the Back to Basics framework) is not the individual person, but each individual act of sex or injection between an infected and an uninfected individual. In other words, the interest is in the partnership, not the individual. The number of different partnerships is calculated simply by multiplying the number of people in each index interaction

category with the average number of partners in the interaction category with whom they interact (as shown in the sex-worker/client example above).

This requires information on partner numbers, provided by behavioural surveillance. Again, this is sometimes provided from the populations on both sides of the interaction, and sometimes just one. In a few cases no information is available at all.

The data required are the different number of individuals contacted, but many behavioural surveillance data sets give overall number of contacts (rather than number of different individuals contacted). For example, waria report 4.6 anal sex clients per week on average. However from qualitative studies we know that a portion of clients are regular. If we assume that 25 percent of clients in any given week are regular clients, and that each regular client visits monthly (except for during Ramadan), then we can calculate that each waria has on average 4.6\*.25\*48/11 regular clients, i.e. 5 regular clients. The remainder of clients are one-off, i.e. 4.6\*0.75\*48, i.e. 165.6, for a total of 170.6 different clients annually. Assumptions are documented on the spreadsheet, which shows data from the Jakarta behavioural surveillance system. It gives the matrix shown in Figure 11.

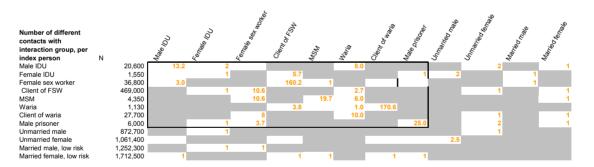


Figure 11: Matrix showing average numbers of partners in the interaction group for each index person with a given risk behaviour (Spreadsheet A30:N42) (Source: Jakarta BSS 2004/5)

There are relatively few gaps in this matrix, just as there are few gaps in the number of people in interaction categories shown in the matrix in Figure 10. If the number of people in each interaction group shown in Figure 10 is multiplied by the average number of different partners they report in a year (shown in Figure 11), we get the estimated numbers of partnerships shown in Figure 12.

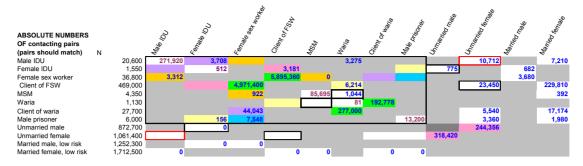


Figure 12: Matrix showing number of different pairs in each category of interacting risk. (Spreadsheet A44:N56)

In this matrix, the colour-matched pairs should be the same. We can use this information both to fill in blanks in the earlier matrices, and to make adjustments to our earlier input data to correct for possible biases in the source data as necessary. For example, from behavioural surveillance among high risk men (shown in Figure 9) we can estimate the number of clients of female sex workers who buy sex from waria (2,345). We also know that that each client of a female sex worker who buys sex from waria buys sex from waria 2.7 times a year, on average. This means there are an estimated 6,214 different partnerships between clients of sex workers and waria in a year. BSS among waria does not distinguish between clients who are also clients of female sex workers and those who are not. We have no reason to believe that men who buy sex from women selectively favour particular waria. All waria may be equally likely to have some clients who are also clients of female sex workers. We can calculate how many of their clients are also clients of female sex workers by multiplying their total client numbers by the proportion of all client visits that are visits from men who buy sex from women. In this case:

Number of clients a year who are also clients of female sex workers =
annual clients per waria \*

((clients of FSW buying from waria\* waria per FSW client)/(client of waria

((clients of FSW buying from waria\* waria per FSW client)/(client of waria\*waria per client)

using the Jakarta data:

Now we have estimated number of partnerships between waria and clients of FSW, and an average number of FSW client partners per waria, so it is easy to calculate the

estimated number of "index" waria who have contact with clients of female sex workers:

(total partnerships between waria and clients of FSW) / (client of FSW per waria) 6,214/3.8 = 1,635

This number can be filled in in the partnership matrix at the intersection between the index waria population and the interacting clients of sex workers population. (cell F92)

This is among the more complex examples – most other gaps in the matrices can be filled more simply, as shown on the accompanying spreadsheet (any assumptions and adjustments are recorded using the comments function). The pairing of total partnerships can also be used to make appropriate adjustments for estimates from BSS data where one of the two sources is more representative than another.

The resulting estimates for the total number of people in each index sub-population by category of interacting risk is shown in Figure 13.

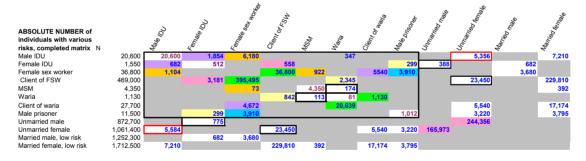


Figure 13: Completed matrix giving the total number of people in each index subpopulation, by category of interaction (Spreadsheet A86:N98)

We can see that numerically, some of the highest numbers of interactions are between people considered at "low risk", in part because these populations are so large. However the Back to Basics framework is not concerned with interaction between individuals of all sorts, it is concerned with interaction between people who are likely to be HIV infected and people who are likely to be HIV-uninfected. This means calculating the number of sex or drug injecting acts in which partners are discordant.

If the unit of interest is the partnership, why bother with back-calculations to fill parts of the matrices which apply to only one side of the partnership? This is

necessary because when we come to calculating transmission risks, we need to know which sub-population the infected partner belongs to, for each discordant contact. In other words, we need to calculate discordant exposures separately for each side of the partnership before adding them up to estimate the "per partnership" or "per behaviour" risks.

The first step to calculating discordant sex or injecting acts per index infected individual is to estimate the number of infected index individuals in each category in the matrix. This simply requires multiplying the estimated numbers of people in each group given in Figure 13 by the prevalence in the index group, taken from HIV surveillance data and summarised in the estimates spreadsheet shown in Figure 8.

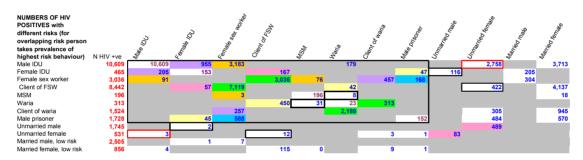


Figure 14: Matrix showing estimated number of HIV-infected people, by different interaction categories (Spreadsheet A100:N102)

Discordant contacts for infected individuals are calculated by:

Infected people in index group \*
proportion of interaction category that is uninfected

This entails multiplying the numbers shown in Figure 14 by (1 – the index group prevalence rates), taken from Figure 8. The result must be multiplied by the total number of different partnerships a person in the index group has with the interacting group, to get the absolute numbers of discordant partnerships in which the index person is infected.

The result is shown in Figure 15. Comparing Figure 15 with Figure 12 and Figure 13, we can see that the importance of the "low risk" interaction categories such as unmarried men having sex with unmarried women has greatly diminished. Since HIV prevalence in both of these groups is low, even a very large number of sexual partnerships translates into a rather limited number of discordant partnerships.

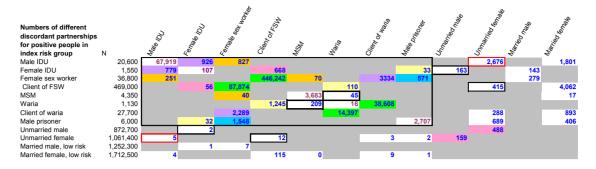


Figure 15: Matrix showing estimated number of discordant partnerships for HIV-infected people in the index population, by different interaction categories (Spreadsheet A128:N140)

Note also that the direction of discordancy is not what we might initially expect from looking at prevalence figures, and depends on whether we are considering individuals with ANY discordant contact, or the total number of discordant partnerships. We see that although HIV prevalence is higher in female sex workers than in clients, there are close to 7,000 infected clients who have sex with uninfected sex workers (cell E118), compared with fewer than 2,800 infected sex workers who have sex with uninfected clients (cell F117). This is important; the number of uninfected individuals who have sex or take drugs with ANY infected partner gives us an absolute maximum number of new infections in that population – one uninfected sex worker with six infected clients can still only lead to a maximum of one more infected sex worker, at least in the short term. However as noted in Chapter 3, the number of different discordant partnerships is a product of the absolute size of the interacting populations and the number of partnerships per person in each of the populations as well as the their respective prevalence rates. One sex worker has on average 160 different clients in a year and one client visits on average 13 different sex workers in a year (see Figure 11). So the absolute number of partnerships between an infected sex worker and an uninfected client is around 447,000 (cell F131), far more than the partnerships in which a client is infected and a sex worker is uninfected (88,000, cell E132).

This analysis of discordancy goes a long way to answering question 2 in the Back to Basics framework. However in the framework, we need to consider not just the number of discordant partnerships, but the number of discordant acts of injection or sex, since each unprotected act of sex or injection between a positive and a negative person will carry a risk of HIV transmission. This requires information about the number of times people in each of those discordant partnerships have sex or inject

drugs together. This is not always easy to come by – BSS questionnaires ask about numbers of partners but rarely ask about frequency of sex with each partner, so most of these data are based on assumptions. Some of the assumptions simplify measured realities. For example frequency in commercial sex tends to be binomial in distribution, with a small number of regular clients having repeated exposure, and the great majority of non-regular clients having one-off or very irregular exposure. Averaging the frequency would tend to overstate exposure for the majority while continuing to greatly underestimate it for the minority of regular clients. In this case the frequency that applies to the large majority is used in the spreadsheet. Figure 16 shows data measured in BSS or based on qualitative research or other assumptions documented on the spreadsheet; frequency of sexual contact tends to be higher in "low risk" partnerships – between spouses and girlfriends/boyfriends – than in higher risk partnerships.

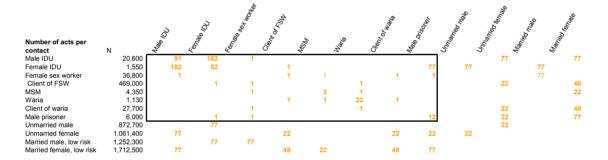


Figure 16: Matrix showing estimated annual frequency of sex or injection for index partners in each partnership with the interaction group (Spreadsheet A143:N155)

Multiplying the number of discordant partnerships by the number of acts of sex or injection per partnership changes the outcome in terms of risk once again, as Figure 17 shows. Because drug injection is a very frequent activity, the absolute numbers of discordant injections is very large. While sex between people at risk and their spouses represented rather a small proportion of discordant partnerships, its importance rises again in looking at discordant sex acts, because of the greater frequency of sex within marriage compared with frequency per commercial partnership.

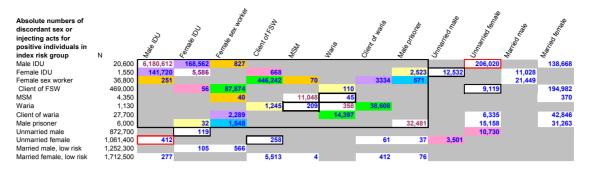


Figure 17: Matrix showing estimated numbers of discordant sex or injecting acts for HIV-infected people in the index population, by interaction category (Spreadsheet A157:N169)

To recap, the numbers shown in Figure 17 represent the estimated number of discordant sex or injecting acts in which the person in the index population is positive and the interaction population is negative. If we return our attention to the unit of interest for HIV prevention -- the risk behaviour -- we can add up the discordant injecting or sex acts on both sides of the "interaction equation" to get estimates for each interacting risk. For example, the number of sex acts between an HIV-infected female sex worker and an uninfected client (446,242) is added to the number of sex acts between an HIV-infected client and an uninfected sex worker (87,874) to get a total estimate of over 530,000 discordant sex acts between men and women in commercial sex. The absolute number of discordant acts by risk partnership are shown in Figure 18.

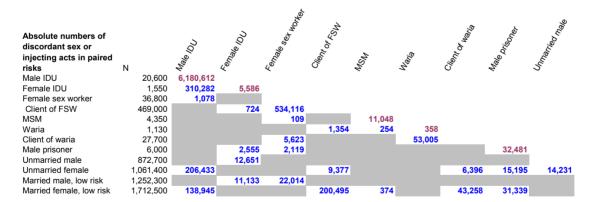


Figure 18: Absolute numbers of estimated discordant sex or injecting acts for each risk interaction group (Spreadsheet A171:K183)

To simplify further, we can group some of these risks into blocks of relevance to prevention programmes, as shown in Table 10. Note that these categories are not mutually exclusive; for example a non-injecting female sex workers having sex with

an injector will be counted in both sex between injectors and non-injectors and in commercial sex between men and women.

Table 10: Estimated number of discordant acts, by risk behaviour group

	Number of	
Risk behaviour	discordant acts	Rank
Injecting, not prisoners	6,496,480	1
Sex between injectors and non-injectors	373,518	3
Injecting, prisoners	32,481	8
Sex between prisoners and non-prisoners	51,207	6
Commercial sex between men and women	543,046	2
Waria and their sex partners	54,972	5
Sex between men who buy sex and non-commercial partners	259,525	4
MSM	11,048	9
All other	36,620	7
TOTAL*	7,853,144	

With this, we have answered more fully the second question in the Back to Basics framework: How likely is it that an HIV positive person will take drugs or have sex with an HIV negative person? The likelihood has been calculated by categories of risk behaviour, using the following information:

- Number of people in each at-risk population (from national estimates)
- % HIV infected in each at-risk population (from HIV surveillance)
- % of people interacting with other at-risk populations (from behavioural surveillance)
- Number of individuals contacted by each person in an interacting population (from behavioural surveillance)
- Number of acts of sex or drug-taking per partnership (from behavioural surveillance)

While some adjustments and simplifying assumptions were made, most of the necessary information was provided by the surveillance system described in Chapter 2.

The results show that in Jakarta, drug injection continues to account for by far the largest number of discordant acts, with commercial sex in second place. The sexual behaviour of drug injectors is of immense concern, accounting for the third largest

number of discordant acts, although sex between clients of female and waria sex workers and their non-commercial partners is not far behind.

# 3. Question 3: IF an HIV positive person has sex or takes drugs with an HIV negative person, how likely is it that there will be an exchange of body fluids between them?

As outlined in Chapter 3, the major factors affecting the exchange of body fluids in contacts between HIV positive and HIV negative people in concentrated epidemics are the use of condoms in sex and the extent of needle-sharing during drug injection. Behavioural surveillance data cover these issues fairly comprehensively: the simplest approach is to apply the average levels of condom use or needle sharing for each risk behaviour to each discordant act within that behavioural group. For example, the total number of discordant acts in commercial sex would be multiplied by the proportion of sex workers/clients not using condoms at last sex to get the absolute number of unprotected commercial sex acts.

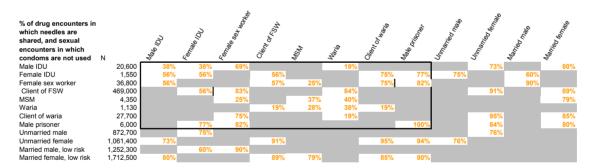


Figure 19: Matrix showing levels of needle sharing and unprotected sex reported by index partners for different interaction categories. (Spreadsheet A185:N197 (Source: Jakarta BSS 2004/5 unless specified in comments)

Figure 19 shows the matrix for reported needle sharing and unprotected sex. The condom use figures are calculated from the response to the question: "The last time you had sex with (partner type), did you use a condom?" This measure is thought to give the most robust estimates of the overall fraction of sex acts which are protected by condoms, as discussed in Chapter 1. But because the question refers to different acts of sex, the reported levels of condom use may vary depending on who is asked, even across the same partnership type. These estimates must be reconciled to get an

estimate of exposed risk for each risk behaviour. If the numbers are close an average may be taken. However in some cases adjustments may be made to compensate for weaknesses in the data. For example, in Jakarta all the "client" reports on condom use come from sailors. An analysis of reported price data show that they tend to buy sex from down-market "direct" sex workers. More expensive "indirect" sex workers, who dominate the industry in Jakarta, have higher rates of condom use. In calculating the absolute numbers of unprotected commercial sex acts, it therefore makes more sense to use a condom usage rate closer to that reported by all sex workers than to that reported by the sub-set of clients included in the male BSS.

Note that countries which link behavioural and biological surveillance at the individual level would enter here the levels of needle sharing and unprotected sex reported by those people who tested positive for HIV, since the denominator at this point is already discordant partnerships.

Figure 20 multiplies the number of discordant acts shown in Figure 18 by the percentage of acts in which needles are shared or condoms are not used (shown in Figure 19, adjusted for consistency as necessary)

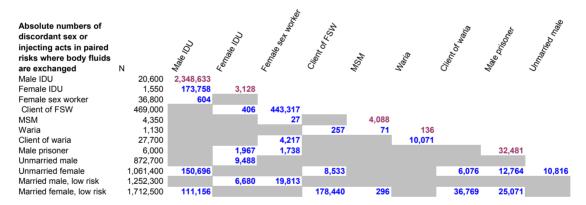


Figure 20: Matrix showing the estimated absolute number of acts of unprotected sex or needle sharing between HIV-discordant people (Spreadsheet A199:N211)

Judging from the continued high levels of needle sharing and unprotected sex, HIV prevention efforts in Jakarta have not been hugely successful to date. Unprotected contacts are the norm in all risk categories except between waria and their clients and among MSM, and over a third of injectors share needles. This being the case, it is not surprising to see that the distribution of unprotected exposure between discordant people shown in Table 11 does not differ greatly from that given in Table 10.

Table 11: Estimated number of discordant acts in which body fluids are exchanged, by risk behaviour group

Risk behaviour	Discordant acts with exchange of body fluids	Rank
Injecting, not prisoners	2,525,519	1
Sex between injectors and non-injectors	280,996	3
Injecting, prisoners	32,481	6
Sex between prisoners and non-prisoners	41,539	5
Commercial sex between men and women	449,902	2
Waria and their sex partners	10,536	8
Sex between men who buy sex and non-commercial partners	229,818	4
MSM	4,088	9
All other	30,924	7
TOTAL*	3,601,494	

The only difference of any note is that waria and their sex partners have slipped down the table of risk because condom use between waria and their clients has recently reached quite high levels in Jakarta.

With this, we have answered the third question in the Back to Basics framework: IF an HIV positive person has sex or takes drugs with an HIV negative person, how likely is it that there will be an exchange of body fluids between them? We have gone further to calculate the absolute numbers of injection and sex acts that result in an exchange of body fluids between and HIV infected and HIV uninfected person, by risk behaviour, using the following information:

- absolute number of discordant contacts for each risk behaviour category (calculated as described for question 2)
- % of sexual contacts in each partnership type in which condoms are not used (from behavioural surveillance data)
- % of injections in which needles are shared (from behavioural surveillance data)

Almost all of the requisite information on condom use and needle sharing was provided by behavioural surveillance. Few assumptions were necessary.

## 4. Question 4: IF an HIV positive person and an HIV negative person exchange body fluids, how likely is it that a new infection will result?

The likelihood that an exposed, discordant sex or injecting contact will lead to a new HIV infection depends on a variety of complex, sometimes interdependent and occasionally poorly understood factors. As discussed in Chapter 3, three of the most important are: type of exposure (parenteral, anal sex, vaginal sex etc), viral load (related to time since infection and treatment status) and presence of other STIs.

Chapter 3 proposes a categorisation of different combinations of these factors into high, medium and low transmission risk categories, reproduced here for ease of reference

### High risk of transmission if body fluids are exchanged

- Any exposure where the HIV-infected person is newly infected (<= 6 months)
- Injection with an unbleached shared needle

### Medium risk of transmission if body fluids are exchanged

- Injection with a bleached shared needle
- Any anal sex where one partner has an STI
- Anal sex without lubricant
- Vaginal sex where one partner has an STI

#### Lower risk of transmission if body fluids are exchanged

- Anal sex with lubricant and no STIs
- Vaginal sex with no STIs
- Any exposure where the HIV-infected person is adhering to ARV therapy

A step-by-step approach similar to that in Question 2 can be taken to classify the exposed discordant contacts estimated in the matrix in Figure 20 into these three categories. However it should be noted that there are many more data gaps in this process than in the preceding steps. No methods for measuring incident infections are used in Indonesia's surveillance system, so there are almost no measured data on the

proportion of infections that have taken place in the last 6 months, and STI data are missing for many populations.

In an emerging epidemic such as Indonesia's, where most people have been engaging in risk for a relatively limited time, we can estimate the proportion of infections which are "incident" (i.e. have taken place in the last 6 months) as follows:

#### prevalence /(2 x median years of exposure)

Alternative data are available to estimate incidence among prisoners. The national surveillance protocol stipulates that prisoner samples should be drawn randomly from all prisoners. In a prison in West Java, in the suburbs of Jakarta, this was done from 1999 to 2001: HIV prevalence rose from 1 percent to 7 percent to 21 percent. In 2002, the prison departed from protocol and sampled only newly arriving inmates. HIV prevalence was 5 percent among these incomers. A year later, the prison returned to the national protocol and sampled a random cross-section, including newcomers and those who had been incarcerated for longer: HIV prevalence was back at 21 percent. This provides very strong evidence that the rise in HIV prevalence was not simply because more prisoners were infected at entry, but because transmission is taking place in prison, where the average length of incarceration is 11 months and a significant proportion are held for six months or less.

Table 12: Estimated percentage of HIV infections which occurred in the last 6 months, and STI prevalence estimates (Derived from Jakarta surveillance data, 2004, RTI survey 2004, MSM survey 2003)

	Proportion infected in 6 months	STI prevalence
Male IDU	12%	4%
Female IDU	13%	18%
Female sex worker	17%	51%
Client of FSW	7%	14%
MSM	7%	6%
Waria	5%	45%
Client of waria	5%	28%
Male prisoner	60%	4%
Unmarried male,low risk	17%	1%
Unmarried female, low risk	25%	1%
Married male, low risk	5%	1%
Married female, low risk	5%	1%

The exact incidence estimates depend on turnover of inmates in the course of a year, but it may be assumed that a minimum of 60 percent of new infections in inmates have occurred in the last six months.

The calculations of proportion incident are shown on the workbook sheet "Data"—
the results are shown in Table 12. The proportion of infected people who are newly
infected or who are on antiretrovirals affects our classification of transmission risks,
but these proportions will vary depending on which partner is infected. (The other
influences – STIs, bleach and lubricant operate at the partnership level). So at this
stage, it is necessary to retreat from partnership level analysis and revert to making
estimates separately for each category in which the index partner is positive and the
interaction partner is negative. From earlier steps, we have matrices for the absolute
number of discordant sex or injecting acts where a member of the index group is
infected (Figure 17), as well as for the fraction of sex acts unprotected and injecting
acts with shared needles. The sum of these unprotected interactions by partnership
type was shown in Figure 20. The full matrix with exposures disaggregated by index
group is shown in Figure 21.

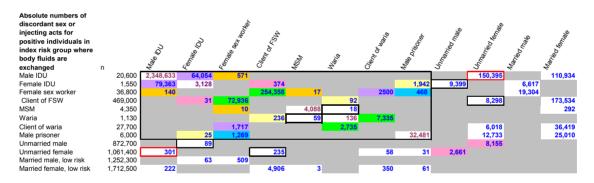


Figure 21: Matrix showing the estimated absolute number of acts of unprotected sex or needle sharing between HIV-discordant people in which the index partner is HIV infected (Spreadsheet A213:N225)

For all sexual risks, the number of discordant, exposed sex acts that fall into the highest risk category is simply the number in which there is a likelihood that the infected partner is recently infected and therefore likely to be highly infectious. However because the "highly infectious" period is considered to last six months while sex and injecting acts are based on contacts over a year, roughly half of a newly-infected person's contacts will fall into the high risk category. So for each category in which the index person is positive, the number of high risk exposed acts is simply:

(number of acts of discordant unprotected sex in which index is infected \* % of index group infected in the last 6 months)/2

For injecting risk, high transmission probabilities include: any injection where at least one of the injectors has an incident infection, PLUS any injection in which neither injector has an incident infection but where no bleach is used.

(number of discordant injections with shared needle \*% of IDU infected in the last 6 months)/2 +

(total number of discordant injections with shared needle - (number discordant injections with shared needle \*%of IDU infected in the last 6 months)/2)\*% not using bleach

The number of high risk contacts in each of the partner groups within an interaction can then be summed up to give the number of high risk contacts per partnership type. The results are shown in Figure 22.

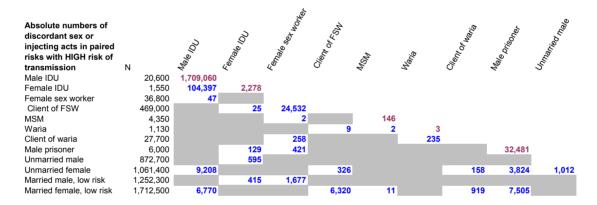


Figure 22: Matrix showing the estimated absolute number of acts of unprotected sex on needle sharing between HIV-discordant people that carry a HIGH risk of transmission (Spreadsheet A241:K253)

Because of the very high incidence of HIV in prison populations, injecting between prisoners moves up the ranking sharply, as Table 13 shows. Sex between clients of sex workers and waria and their wives and other non-commercial partner falls out of the top five – most of these exposures do not carry a high risk of HIV transmission.

Table 13: Estimated number of discordant acts in which body fluids are exchanged which carry a HIGH risk of transmission, by risk behaviour group

	Exposed,	
Risk behaviour	discordant acts	Rank
Injecting, not prisoners	1,815,734	1
Sex between injectors and non-injectors	17,188	4
Injecting, prisoners	32,481	2
Sex between prisoners and non-prisoners	11,878	5
Commercial sex between men and women	25,261	3
Waria and their sex partners	249	8
Sex between men who buy sex and non-commercial partners	7,723	6
MSM	146	9
All other	2,700	7
TOTAL*	1.912.763	

For simplicity's sake, it is easiest next to calculate the number of acts that have a low probability of transmission. This does not include any injection risk, even if antiretrovirals are used. Discordant, unprotected sex acts are classified as having a low risk of transmission if the infected partner is on antiretrovirals. Theoretically, this might override the high risk associated with incident infections. Some researchers in industrialised countries believe that active detection of newly-infected individuals and early antiretroviral therapy could reduce HIV transmission significantly. However in practice in the Indonesian epidemic (and in most other countries) it is exceptionally unlikely that newly-infected individuals would be on antiretroviral therapy. Firstly, most HIV is not discovered until it is symptomatic, much later in the course of infection. Secondly, national guidelines for ARV therapy are based on CD4 counts rather than viral load; therapy would rarely be indicated in early infection. For practical purposes we can assume that the proportion of people on antiretroviral therapy and the proportion suffering from incident infection are mutually exclusive categories. They are treated as such in this analysis.

In addition, to classify as low risk, both partners in the sex act must be free from other STIs. STI prevalence data are rather poor in Indonesia, because STI surveillance is weak, as described in Chapter 2. Recent, reliable data are available for female sex workers from the RTI study in 10 cities – Jakarta was included in the second round. Syphilis data are available for waria and MSM from 2003, and there are some STI clinic data on rectal gonorrhoea. Small studies of STIs among women attending health services are available for cities other than Jakarta. Apart from that, most estimates are derived from self-reported symptoms. Estimates are given in

Table 12, above. In calculating low transmission risk contacts, STI rates for sex workers and clients apply to any interaction between a female sex worker (including female injectors who sell sex) and a paying male partner. Similarly, waria and waria client rates apply to waria and any man that pays them for sex.

Data on use of antiretroviral therapy are also poor. Programmes sponsored by the Global Fund and WHO and implemented through the ministry of health and a few NGOs have not input data into the national monitoring database. Specialists in the field report that a "rough number" on treatment by Dec 2005 would include 1657 adult males, 264 adult females and 19 children. (Hendra Widjaya, personal communication, 28 March 2006) No data are available about the risk behaviours of those on therapy. Waria are considered males in the national health care system; no prisoners have access to antiretroviral treatment. The reported number on treatment represents 6.8 percent of HIV-infected males and waria estimated to be living in Jakarta, with the exception of prisoners. The females on treatment represent 5.4 percent of estimated infected individuals. These proportions have been applied to all groups in the calculations below.

The calculation for low risk transmission in sex between men and women for a given index group is:

((total number of acts of discordant unprotected sex in which index is infected which do not have high probability of transmission)\*% of index group on ARVs) + ((remaining non high risk discordant acts where index is infected)\*(100 - % STI) prevalence in index group)\*(100 - % STI) prevalence in interaction group))

In anal sex, there is the added dimension of lubricant use:

((total number of acts of discordant unprotected sex in which index is infected which do not have high probability of transmission)\*% of index group on ARVs) + (((remaining non high risk discordant acts where index is infected)\*(100 - % STI) prevalence in index group)\*(100 - % STI) prevalence in interaction group))\*% using lubricant in anal sex)

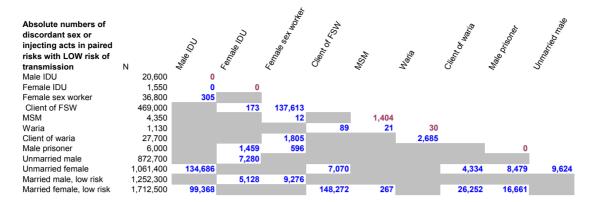


Figure 23: Matrix showing the estimated absolute number of acts of unprotected sex on needle sharing between HIV-discordant people that carry a LOW risk of transmission (Spreadsheet A283:K295)

The remaining discordant, exposed acts will fall into the medium risk category.

If we combine the acts with high and medium risk of transmission, we find that the results are rather consistent with earlier findings, as shown in Table 14: most new infections in Jakarta in the short term are likely to come from injecting. The number of higher risk injections between discordant partners using shared needles is 12 times greater than the number of acts of unprotected commercial sex carrying a higher risk of transmission. There is another large gap before the next risk category; discordant unprotected commercial sex acts with a higher risk of transmission are four times more common than discordant, unprotected sex acts between men who buy sex and their non-commercial partners. In fourth place, sex between injectors and injecting in prison run neck and neck.

Table 14: Estimated number of discordant acts in which body fluids are exchanged that carry a high or medium risk of HIV transmission, by risk behaviour group

	Exposed,	
Risk behaviour	discordant acts	Rank
Injecting, not prisoners	2,495,177	1
Sex between injectors and non-injectors	32,704	4
Injecting, prisoners	32,481	5
Sex between prisoners and non-prisoners	14,345	6
Commercial sex between men and women	193,656	2
Waria and their sex partners	7,787	8
Sex between men who buy sex and non-commercial partners	43,889	3
MSM	2,684	9
All other	11,757	7
TOTAL*	2.832.424	

This has contributed to answering the question: IF an HIV positive person and an HIV negative person exchange body fluids, how likely is it that a new infection will result?

The categorisation of levels of risk has limitations, as discussed in Chapter 3. But it allows us to form a clearer picture of the likely source of new infections than if we look at risk behaviour or HIV prevalence alone. If we equate any extramarital sex with "risky behaviour", we would have estimated that around 410,000 young, unmarried people in Jakarta were at risk for HIV because they have sex with one another, compared with 22,200 drug injectors. However only 650 of those young people are likely to have any discordant contact over a year, compared with 5,600 injectors. Most importantly, young, unmarried people will between them only engage in around 1,200 sex acts that carry a high or medium risk of transmission over the course of a year. Injectors, on the other hand, will share 2.5 million injections that carry a high or medium risk of HIV transmission over the same period.

The numbers in Table 14 represent the total number of acts that carry a high or medium risk of HIV infection. They suggest that 88 percent of riskier acts occur during drug injection. Does that mean that 88 percent of new infections will be among drug users? Not necessarily, because no matter how many acts of needle sharing and unprotected sex IDUs engage in, there cannot be more new infections among IDU than there are HIV-negative IDU who have any contact with an HIV-positive person.

From the analysis presented above, we can estimate the absolute maximum number of people that could become infected in any given group: it is the number of HIV-uninfected people who have sex or inject drugs with any HIV-infected partner. Earlier in the process, the matrix was used to calculate the number of different partnerships in which an index person is infected with HIV, and an "interaction group" person is uninfected. The results were shown in Figure 15 on page 182. There are an estimated 88,000 partnerships in which a client of a sex worker is infected and a sex worker is uninfected. If each of the infected clients has sex with a different sex worker, then there would be a maximum of 88,000 HIV-uninfected sex workers potentially exposed to HIV because they were having sex with an infected client. But we know that infected clients can not all be having sex with different uninfected sex workers, because the estimated number of sex workers in Jakarta is only 36,800 (and only 33,800 of them are uninfected). So in this case, the absolute maximum number of discordant partnerships between an uninfected sex worker and an infected clients is the same as the number of uninfected sex workers: 33,800.

Even though there are only 3,000 infected sex workers, because sex workers have a very large number of clients there are some 446,000 partnerships in which a sex worker is infected and a client is uninfected. If each of the infected sex workers has sex with a different uninfected client, then there are 446,000 clients who could potentially become infected. Since there are an estimated 461,000 clients overall, we know that there are at least 15,000 clients who have no chance of having sex with an infected sex worker and are at no risk for infection in Jakarta.

Of course each uninfected client may also be exposed to infection by other sex partners as well as by sex workers. The matrix shown in Figure 15 shows the estimated number of discordant partnerships for all interaction groups. The rows represent those partnerships where the index group is infected and the interaction group is uninfected. To calculate the maximum potential partnerships where a member of the index group is uninfected, it is necessary to look at the values in the columns. The fourth column, for example, represents all the partnerships where the interaction group is clients of sex workers. In other words, this represents all the partnerships a client of a sex worker might have where the client is uninfected and the partner is infected. If we sum the values for this column, we get the absolute maximum number of partnerships of any type in which an uninfected client of a sex worker has sex with a person who has HIV. This probably over-represents the true number of clients at risk for HIV, since it is possible that the same client may have partnerships with more than one infected person. But it sets an upper limit on the potential number of new infections in this group.

Table 15: HIV infected and uninfected individuals by sub-population, with the maximum number of uninfected people who have sex or inject with any HIV-infected partner (Spreadsheet A367:E367)

	Number of people in index group	Number of people in the index groupwho are HIV infected	Number of people in the index group who are HIV uninfected	Maximum number of uninfected people in the index group with any HIV- infected partner
Male IDU	20,600	10,609	9,991	9,991
Female IDU	1,550	465	1,085	1,085
Female sex worker	36,800	3,036	33,764	33,764
Client of FSW	469,000	8,442	460,558	448,281
MSM	4,350	196	4,154	3,962
Waria	1,130	313	817	817
Client of waria	27,700	1,524	26,177	26,177
Male prisoner	6,000	1,728	4,272	3,314
Unmarried male	872,700	1,745	870,955	322
Unmarried female	1,061,400	531	1,060,869	4,555
Married male, low risk	1,252,300	2,505	1,249,795	422
Married female, low risk	1,712,500	856	1,711,644	7,178

Table 15 shows the number of HIV-uninfected people in every group, and the maximum number of partnerships involving an uninfected person in that group and an infected person.

For the "high risk" groups, the number of potential discordant partnerships often exceeds the total number of uninfected people in the group, so maximum number of people who could potentially inject or have sex with an infected person is the same as the uninfected population size. But in the "low risk" groups, the differences are vast – for example of 1.7 million married women who are HIV negative and do not sell sex or inject drugs, just 7,000 have any possibility of having sex with an HIV-infected partner. This gives an idea of the maximum number of total new infections in each group. But it does not reflect the second two "Basics" -- the likelihood that discordant contacts will be unprotected, and the likelihood that they will carry a high, medium or low risk of HIV transmission

The earlier analysis classified unprotected, discordant acts into different categories: each act carried a high, medium or low risk of HIV transmission. Ideally, we would like to calculate how many HIV-negative *individuals* have the possibility of any unprotected sex with a positive partner that carries a high or medium risk of infection, since this gives the best idea of the potential new infections in absolute numbers. This is difficult within the confines of such a simple analysis, because one negative individual may be exposed to different partners with different levels of risk. In addition, the calculations of the number of exposed acts with different transmission probabilities took into account the fraction protected and the number of acts. Some of the modifiers, such as use of bleach or lubricant, work at the partnership level and may vary over time within the same partnership.

We can, however, get a crude approximation of the distribution of risk in terms of number of individuals exposed by assuming that each act within an individual partnership has the same degree of risk. In that case, we can divide the total number of risky acts within a given category by the acts per discordant partnership, to get an estimate of the number of discordant partnerships at a particular level of risk. An individual may have partnerships at several levels of risk. But if we assign each individual to the highest risk they could possibly have, we get an idea of the

maximum number of negative individuals potentially exposed to a positive partner with that level of risk.

We have established, for example, that some 7,000 uninfected, married females may be at risk for HIV because their husbands are infected. Earlier in the analysis, we established that HIV-infected male IDU have a total of 9,200 exposed sex acts with their wives that carry a high risk of HIV transmission (Spreadsheet cell N228). We have assumed that each married IDU has sex with his wife on average 77 times in a year (Spreadsheet cell N144). So those 9,200 high transmission risk acts represent some 120 marriages in which an infected IDU is putting his wife at the highest risk for HIV infection (probably in this case because his is an incident infection). Similar calculations for all the other categories of men and their wives can be made, and we can sum the column values to get the maximum number of HIV-uninfected wives who may have an exposed, discordant contact with a high risk of HIV transmission with their husband. (Spreadsheet A339:N351)

As before, the maximum number of people at high risk for HIV transmission cannot exceed the maximum number of HIV negative people with any discordant contact in a given group. We can make the same calculations to get a rough estimate of the maximum number of people in any interaction category that have any discordant contact with people that subjects them to a medium probability of becoming infected with HIV. (Spreadsheet A353:N365) If we assign people to the highest risk category of any in which they are likely to have any exposure, then the number at medium risk of transmission cannot exceed the number with any discordant contact who do NOT have high risk contact. And the maximum number that only has discordant contacts that carry a low risk of HIV transmission will be the number that has neither any high risk exposure nor any medium risk exposure.

The results of these calculations are shown in Table 16.

Table 16: Potential exposure to HIV in Jakarta, Indonesia, showing the maximum number of uninfected people who could be exposed in each risk group, by highest level of risk exposure

	Number of people in index group	Number in index group who are HIV infected	Number of people HIV negative in index group	Max number of index negatives with positive partners	Max number with any high transmission probability	Max number with any medium but no high transmission probablity	Max number with ONLY low transmission probability
Male IDU	20,600	10,609	9,991	9,991	9,991	0	0
Female IDU	1,550	465	1,085	1,085	309	132	644
Female sex worker	36,800	3,036	33,764	33,764	3,064	30,700	0
Client of FSW	469,000	8,442	460,558	448,281	21,960	127,596	298,725
MSM	4,350	196	4,154	3,962	52	896	3,014
Waria	1,130	313	817	817	72	745	0
Client of waria	27,700	1,524	26,177	26,177	383	6,479	19,314
Male prisoner	6,000	1,728	4,272	3,314	2,749	239	325
Unmarried male	872,700	1,745	870,955	322	23	23	277
Unmarried female	1,061,400	531	1,060,869	4,555	344	237	3,974
Married male, low risk	1,252,300	2,505	1,249,795	422	27	126	269
Married female, low risk	1,712,500	856	1,711,644	7,178	334	758	6,086

Figure 24 shows the absolute number of people with any discordant contact, grouped by risk behaviour. The colour of the bars show the maximum number of negative people within that programme group who are exposed to any high probability of HIV transmission, those who are exposed to at least some medium transmission probability acts (but no high probability acts), and those who are exposed only to acts with a low probability of HIV transmission. Commercial sex dominates the picture, although more than half of the people potentially exposed to HIV through commercial sex have no exposures that carry a medium or high risk of infection.

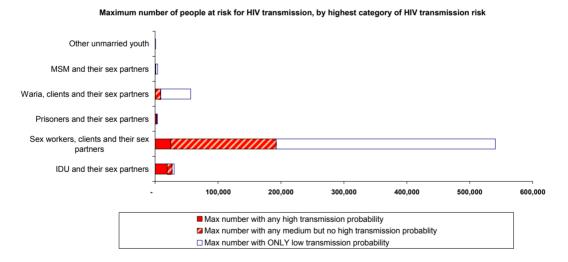


Figure 24: The maximum number of people with any discordant sex or injecting partner, distributed according to the estimated highest possibility of HIV transmission

If we ignore the low risk acts (increasing the scale and allowing us to look in greater detail at the exposures most likely to transmit HIV, as in Figure 25) we see that there are virtually no high risk acts among unmarried youth or the spouses of high risk people.

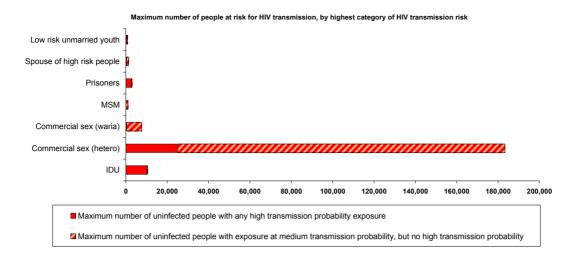


Figure 25: The maximum number of people potentially exposed to acts of sex or injection that carry a high or medium probability of HIV transmission

Most of the likely new infections in Jakarta given current patterns of infection and behaviour will occur in commercial sex between men and women, although injection both in and out of prison will account for a substantial portion too. For policy-makers, the message is simple: focus on the red.

### 5. Question 5: IF a new infection results, how long will the newly-infected person survive?

This question does not inform decisions about prevention directly, except inasmuch as it creates a feedback loop into prevalence. It is especially important to include this question in any model that seeks to look in the slightly longer term at the effects of prevention and care efforts that focus heavily on the provision of life-prolonging therapy. Increasing access to therapy is a central goal of most national programmes, and as discussed in Chapter 3, it may affect transmission dynamics in many ways. However we do not need to answer this question when using the Back to Basics framework in a cross-sectional analysis of the current situation intended to examine immediate prevention priorities.

### 6. Limitations in this use of the Back to Basics framework

Any approach that seeks to reduce the extraordinary diversity of human behaviour and the complexities of HIV infection to a series of simple steps accompanied by simple mathematical equations will have many shortcomings.

The efforts described in Chapter 2 sought to overcome the shortcomings in the information needed to undertake this sort of basic analysis of risk for new HIV infections in Indonesia, but some important gaps remain. STI surveillance is all but non-existent in any group other than sex workers, and many STI data among men and MSM come from self-reported symptoms. Estimates of the proportion of current infections that are newly acquired are crude, at best. Data on the behaviour of prisoners is limited – these estimates almost certainly understate the risk of HIV transmission between prisoners because they consider only injection risk, not the risk of anal sex, for which virtually no data are available.

A major limitation of the simple approach outlined above is the time frame. These matrices make estimates of discordant contacts over a one year period. However HIV transmission will take place during the course of that year, and prevalence, estimates of discordant contacts and assumptions about the proportion newly infected will change as a consequence. As Watts and colleagues have shown, the use of large time steps can introduce serious inaccuracies into calculations. (Watts, Vickerman et al. 1999) A more accurate picture of exposure dynamics would require an iterative process in smaller time steps. More complex models such as HIV Tools provide this. However they do not provide a comparative overview of exposure in all interacting groups.

A perhaps even more important limitation is that this approach gives a snapshot of priorities at a single point in time. It tells you where the greatest risk of new infection is NOW, but does not look forward to the longer-term consequences of continued transmission. In a young and dynamic epidemic such as Jakarta's the engine provided by drug injection may soon run dry, as most susceptible individuals become infected. Secondary sexual transmission from injectors will then logically assume a relatively greater role. The inability to make long-range forecasts restricts the use of

this approach to an immediate planning tool; this may be especially useful to people planning for a single funding cycle.

It is worth noting that this approach takes the current situation as the starting point. The current situation is the product of all the prevention and care successes and failures to date. If a programme has been quite successful in reducing the likelihood of unprotected sex between infected and uninfected partners, then the importance of that type of partnership as a potential source of new infection will, in the sequential steps of the Back to Basics approach, become diminished relative to others where prevention has been less effective. An example is the effect that high levels of condom use between waria and clients had in reducing the rank of commercial sex with waria as a source of unprotected discordant contacts in Jakarta. There is a danger that this may lead to a substitution of effort (abandoning the waria programmes and shifting all the emphasis to commercial sex between men and women, for example), rather than an increase in effort to sustain success in the waria programme and improve outcomes in other programmes. It is important to be able to distinguish between a behavioural interaction that is genuinely low priority from the point of view of HIV prevention because it involves very few discordant contacts, and one that is currently low because it is being contained by successful prevention activities that need maintaining. It may be necessary to use this framework to construct "counterfactual" scenaria that show what the situation would be in the absence of a successful intervention. In a sense, the waria analysis given below is an example of this kind of analysis.

The approach outlined here takes advantage of the different sources of data that exist to do a limited amount of consistency checking and adjustment of data from routine sources. For the most part, however, it uses population average rates for parameters such as use of condoms, lubricants and clean needles, as well as partner numbers. In this framework, the likelihood that body fluids will be transmitted is calculated only for discordant contacts. People who have behaviours which carry a high risk of transmission if body fluids are transmitted (such as injection or anal sex) who have repeated contact with the same individual, and who consistently do not use sterile needles or condoms, are more likely to pass HIV on than people who sometimes use protection. In other words, partnerships where protection is rarely used are less likely to be discordant than partnerships where protection is sometimes used. Equally,

partnerships in which protection is always used are also less likely to be discordant. Use of population averages to represent behaviours in discordant partnerships may misrepresent the truth in either direction, depending on majority behaviours. On the other side of this coin is the advantage that, if evidence emerges of differential use of protection by HIV status, this can easily be incorporated into calculations because only partnerships where one partner is positive are included in the final analysis of transmission risks.

The main disadvantage of using population averages is that they do not adequately reflect the potential for prevention success. An increase in condom use from 20 percent to 40 percent, applied as an average, will still mean that 60 percent of all acts in the relevant interaction category are assumed to be unprotected. These are randomly distributed across the whole population, so that on average, each individual experiences a reduction in the number of discordant contacts which result in the exchange of body fluids. Everyone's risk is reduced, but no-one's risk is eliminated. Together with the model's failure to deal with assortative partner selection, this explains why, with very high risk populations such as drug injectors, the model will show near-saturation of the susceptible population. In reality, however, adoption of protective behaviour is not evenly distributed. Some people will not increase their condom use at all, while others may shift to consistent use. Those who use condoms all the time are no longer at any risk for HIV, and should be shifted out of the denominator of the susceptible population. This is difficult to achieve in a simple model. However if data suggesting risk elimination are available, it would be possible to add a step to the analysis that reduces the denominator in each category of the matrix to reflect the proportion of the population adopting entirely safe behaviours. A similar approach has been used to look at the effect of programmes at different levels of coverage, because there is evidence in some areas that behaviour change is confined to those who are reached by programmes, while behaviours among those not receiving prevention services remains unchanged.

### 7. Using the framework approach to compare programme effects

This framework can be adapted fairly readily to look at the potential impacts of different programme approaches, as well as to estimate actual programme effects.

The process so far has estimated the number of expected exposed, discordant contacts at various levels of transmission risk, given the current levels of HIV and STI prevalence, patterns of mixing between populations and behavioural risk (partnership numbers, use of sterile needles, bleach, condoms and lubricants) and therapy.

We can alter any one or any combination of these parameters in accordance with changes seen in prevention programmes in the Back to Basics framework, applying the changes to the whole population or just to a fraction of the population reached by the programme, depending on data sources. By comparing the resulting estimates with the original estimates, we can estimate how many acts of exposed sex between discordant partners carrying a high (or a high and a medium) risk of HIV transmission have been averted by the programme. The approach can be used retrospectively (looking at changes that have actually occurred) or hypothetically (for example to compare the potential impacts of different programme approaches).

An example is given on the accompanying matrix spreadsheet, looking retrospectively at the effect of the prevention programme for waria that was developed following a 2002 survey in Jakarta which showed shockingly high rates of HIV and syphilis infection among waria, together with high partner turnover and very limited lubricant use. Condom use was higher among waria than female sex workers, but still left much to be desired.

The "baseline" scenario presented throughout this chapter uses data from the 2004/2005 surveillance round, so reflects changes in behaviour that have taken place since the implementation of the new prevention programme. To look at the effect of the programme, we can re-run the framework using the 2002 behavioural and STI estimates, and see whether a continuation of that scenario (i.e. the absence of the changes that have been observed at the population level following the introduction of the programme) would have led to significantly more transmission risk. It is not

believed that the size of the waria programme has changed significantly between the 2002 survey and the 2005 surveillance round. However the number of anal sex clients per week was higher in the second round (mean of 4.6 compared with 2.6 in the earlier round). This implies that the number of clients must have risen between the two rounds, possibly related to the strengthening of the Indonesian economy during that period.

The major changes, however, were behavioural. In discussions which followed the release of the study results to waria, community leaders opted for a "No condoms, no sex" campaign. "Safe Sex Packs" were aggressively promoted through the very structured waria hierarchy, and by 2004/2005 surveillance round, 84 percent of waria were familiar with the safe sex packs and could describe their contents without prompting. The campaign appears to have contributed to an increase in reported use of condoms with last anal sex client from 43 percent to 81 percent – among the highest registered for any group in Indonesia. The proportion of waria not using condoms with any of the men buying anal sex from them fell from 45 percent to just 4 percent, while use with all clients doubled from 27 to 56 percent. The safe sex packs, which included information on HIV and STI transmission in anal sex as well as small sachets of water-based lubricant, appeared greatly to increase lubricant use, also. The proportion of waria using water-based lubricant with their most recent anal client rose from 13 to 43 percent.

In addition, the study and subsequent prevention programmes gave waria an opportunity to get their HIV and syphilis test results, with counselling. Two clinics were set up to provide free STI screening and treatment on a regular basis, and outreach workers provide regular referrals. The proportion of waria who reported having been tested for HIV voluntarily, getting counselling and getting their results was 28 percent by the second surveillance round, compared with 2 percent reporting ever accessing VCT for HIV in the first round. Those who reported recent VCT in this high prevalence population in the second round of surveillance did not differ significantly in condom or lubricant use from those not knowing their HIV status. Self-reported STI symptoms did not change significantly between rounds, but clinic data show reductions in syphilis and rectal gonorrhoea for those with repeat visits.

With the "baseline" values – the values that include the behavioural changes as a result of the programme, it is predicted that there will be some 7,700 unprotected sex

acts that carry a high or medium risk of HIV transmission in Jakarta during sex between waria and their partners (mostly clients).

Entering the 2002 behavioural values as well as the population sizes into the framework, we find that the expect number of encounters would be closer to 8,900. For a programme that is considered highly successful in changing behaviour in one of the highest HIV prevalence populations, this seems like a very small gain – just 12 percent of riskier exposures between waria and their partners have been prevented, 0.4 percent of the sexual exposures, and just 0.04 of all expected riskier exposures in the Jakarta epidemic. The differences in the estimated number of high and medium risk contacts made by the programme compared with what would have been estimated if behaviour had remained the same as in 2002 is shown in Table 17.

Table 17: Estimated number exposed discordant contacts with medium or high risk of HIV transmission, before waria intervention and with intervention

	Exposedcontacts		Exposed contacts	% change
Risk behaviours	before programme R	ank	with programme	on baseline
Injecting, not prisoners	2,495,177	1	2,495,177	0%
Sex between injectors and non-injectors	32,704	4	32,704	0%
Injecting, prisoners	32,481	5	32,481	0%
Sex between prisoners and non-prisoners	14,345	6	14,345	0%
Commercial sex between men and women	193,656	2	193,656	0%
Waria and their sex partners	8,868	8	7,787	-12.2%
Sex between clients and non-commercial partners	43,889	3	43,889	0%
MSM	2,684	9	2,684	0%
All other	11,757	7	11,757	0%
TOTAL*	2,833,505		2,832,424	-0.04%
Sexual only	305,847		304,766	-0.4%

The reasons for the relatively small change are several. Firstly, while waria are indeed a highly-infected population, their absolute numbers are small; client numbers, while not insubstantial, pale by comparison with the clients of female sex workers. Secondly, condom use was already higher between waria and clients than in other partnerships. Thirdly, this framework focuses only on the short term – the changes in risk behaviour are not yet considered to have fed back into changes in HIV prevalence (such changes should, eventually, be tracked in the surveillance data but they have not yet been seen in the waria population). This means that there is not yet any reduction in the number of discordant partnerships between waria and clients, let alone any "knock on" effect in terms of reduced discordancy between clients and their other partners. Additionally, it appears that client population numbers grew between 2002 and 2004. This means that even though behaviours may have been safer, a larger absolute number of clients were potentially exposed to HIV. Had client

numbers been the same in 2002 as in 2004, the spreadsheet would have predicted 11,000 exposed discordant contacts in partnerships between waria and sex partners that carried a medium and high risk of HIV transmission. So without the change in client numbers, the measured changes in behaviour would have prevented 30 percent of exposures in this group – although still only 0.8 percent of sexual risk. Finally, the overwhelming importance of drug injection in the Jakarta epidemic dwarfs other risks, even when programme coverage in this high risk population is 100 percent.

There is little evidence that the prevention efforts among drug injectors in place by mid-2005 made much difference to HIV transmission in Jakarta or elsewhere in Indonesia. This is probably because what was on offer – peer outreach providing bleach and water but not needles, and referring to counselling and HIV testing but not free methadone maintenance or detoxification services – did not meet the needs of most injectors. The prison system – an easy entry point for reaching injectors and potentially HIV-infected people, was not used as an access point for either prevention services or care. We can use the framework described above to estimate what the effect of particular programme efforts might be. For example, what if methadone maintenance services were promoted widely among HIV-positive injectors, to try and reduce HIV prevalence among the pool of people who continued to share needles (in other words, to try to reduce the likelihood that an infected person would take drugs with an uninfected person)? This would cut discordant contacts in drug injection immediately, directly in line with the proportion of HIV positive injectors or prisoners who stop injecting because they are on methadone. So getting 25 percent of infected male injectors, 15 percent of harder-to-reach female injectors and 50 percent of infected prisoners on to methadone maintenance would reduce the total number of discordant contacts with a high or medium probability of HIV transmission by around 21 percent. However it would probably have no effect on sexual transmission. While methadone maintenance for HIV positive injectors should reduce discordance between injecting partners (by taking infected people out of the pool of injectors), there is little reason to believe that it would stop those same infected people from having sex. 11 If methadone programmes were also used successfully as a platform for active promotion of condoms and/or antiretroviral

<sup>11</sup> Unpublished data from Southwest China suggest that some women who sell sex to support a drug habit give up selling sex when they join methadone maintenance programmes. However numbers are small so far. No similar evidence is available for Indonesia.

treatment for HIV-infected injectors, then the number of exposed, discordant sexual contacts could fall by up to 3 percent, avoiding four hundred times as many discordant sex acts with a high risk of transmission in a single year than the waria programme. Table 18 shows the difference in expected high and medium transmission risk contacts if methadone maintenance with the coverage described above succeeded in reducing injection, if 90 percent of IDU clients of methadone maintenance programmes used condoms, 20 percent of prisoners used condoms after release from prison, and 30 percent of prisoners not in primary infection had access to ARVs after release

Table 18: Estimated number exposed discordant contacts with medium or high risk of HIV transmission, with current IDU interventions (baseline) and with methadone maintenance and condom promotion

Post bales to an	<b>-</b>	B!	Exposed contacts with strengthened	% change
Risk behaviours	Exposedcontacts now	Rank	programme	on baseline
Injecting, not prisoners	1,879,632		1 <b>2,495,177</b>	-25%
Sex between injectors and non-injectors	26,048		4 32,704	-20%
Injecting, prisoners	16,240		5 <b>32,481</b>	-50%
Sex between prisoners and non-prisoners	13,609		6 <b>14,345</b>	-5%
Commercial sex between men and women	193,424	:	2 <b>193,656</b>	0%
Waria and their sex partners	7,787		8 <b>7,787</b>	0%
Sex between clients and non-commercial partners	43,889	;	3 <b>43,889</b>	0%
MSM	2,684	!	9 <b>2,684</b>	0%
All other	11,757		7 11,757	0%
TOTAL*	2,193,312		2,832,424	-23%
Sexual only	297,439		304,766	-2.4%

This illustrates the use of the framework to examine the potential of different prevention options in reducing the likelihood of new HIV infections in the short-term.

### 8. A note on the "framework" workbook

This chapter has sought to give an example of an analytic approach, rather than to describe a model or piece of software. Indeed the "Back to Basics" analytic approach described here has not currently been formalised into an automated spreadsheet that can be used "off the shelf" to compare different programme approaches. The examples provided were developed on an Excel spreadsheet that was intended to show every step of the calculation process, in order to clarify the thinking behind the analytic approach described here. The result is somewhat clumsy, and the many different steps involved may cause readers to question the repeated use of the word "simple" throughout this text.

The steps followed are, however, simply calculations based on the three "Basics" which drive the spread of HIV. They can be followed for any combination of at-risk populations for whom data are available, and can be used to look at the effect of any programme which alters at least one of the "Basics".

In its current incarnation, the spreadsheet certainly falls down on concision and elegance. If the approach were to be widely used in the context of a specific epidemic, it would be worth building on a "front end" that allowed users more easily to enter programme scenaria and compare outputs, graphically as well as numerically. It would also be relatively easy to hide elements of the calculation, while still allowing local users to follow each step of the analysis, and to see clearly at which level different programmes operate. This would avoid the "black box" effect of many models, where HIV prevention workers cannot easily see where interventions are making a difference, or failing to.

It is worth noting that it is perfectly possible to use the framework described here to guide analysis of the local epidemic and programme effects without using a spreadsheet at all: examples of such analysis in the field will be given in Chapter 6.

#### **Back to Basics in Operation: Key points**

- Quantifying the Back to Basics framework obliges analysts to focus on the relative size of different risk populations and their interactions
- The focus on discordancy pinpoints areas where active prevention interventions are most likely to be necessary and highlights areas where prevention is less useful, but does not reflect assortative partner selection within risk populations
- The categorisation of exposure into high, medium and low risk for HIV transmission draws further attention to areas where programmes could be most effective
- The framework can be used to evaluate the impact of existing programmes, and to compare prevention scenaria in the short term

### Chapter 5: A simple approach to monitoring and improving prevention programmes

Chapter 3 proposed a framework that focuses on understanding the contribution that different sub-populations and behaviours are making to the spread of HIV. It can be used to set priorities for prevention and care programmes, as well as to investigate the contribution of different prevention approaches to controlling the epidemic, as demonstrated in Chapter 4.

Chapters 3 and 4 focused on answering the question: **What should we be doing?** However almost all of the international guidance on use of surveillance data suggests that these data can be used not just to identify programme priorities, but to monitor and evaluate programme efforts – in other words to answer the question **How well are our programmes doing?** 

The "Back to Basics" framework discussed in Chapter 3 suggests that HIV programmes can only be considered a success if they achieve at least one of the following goals:

- reduce sexual or drug-taking contacts between HIV infected and HIV uninfected people
- eliminate the exchange of body fluids in sex or drugs between those people
- reduce the likelihood that a new infection will occur if body fluids are exchanged between those people

Measuring change in the indicators that track the "Basics" is not, however, enough to evaluate the success or failure of a programme. We need to establish not just that these things have changed, but that they are likely to have changed as a consequence of programme effort.

This is not possible unless programme data are routinely collected and collated as part of the national HIV information effort. As described in Chapter 2, this work included the establishment of a coherent national programme data reporting system and database covering the HIV programmes of all government units and donor-funded programmes – to our knowledge the first in any developing country.

Although several "M&E frameworks" were described in Chapter 1, none gives any guidance on how to relate programme process data to outcomes or impacts. This Chapter describes efforts to develop a question-led approach that links programme data to surveillance data within the framework of a Back to Basics analysis. The aim is to guide analysts and programme managers through the questions they should be asking of their data if they are to manage their HIV intervention programmes effectively.

### 1. Defining the programme logic

Even the simplest type of quantative programme monitoring requires decisions about what should be measured. As the decade-long struggle to define universal standardised indicators shows, this is not easy. As we saw in Chapter 1, the list of standardised indicators sometimes determines what is measured, without thought to what the programme is seeking to achieve. This puts the cart before the horse. Indicators and monitoring questions need to follow the logic of the programmes, rather than programme design being dictated by the need to report certain internationally standardised indicators.

The first step in programme monitoring and evaluation must always be to define the logic that underlies the programme design. As Bryce and colleagues found while planning the IMCI multi-country evaluation, this is not always easy. A review of programme proposals, grant agreements and M&E plans covering a six year period in Indonesia and East Timor suggests that programme logic is very poorly specified at the start of most programmes. Generally, the overall goal and the target/beneficiary populations are given, but there are few details about which specific services will be delivered, how they will be delivered, or how the delivery of those services will lead to achieving the overall goal.

Reproduced in the box below, for example, is the totality of the plans for condom promotion in Indonesia's Global Fund Round 1 proposal. The proposal talks of scaling up programmes, but does not give any evidence that the programmes in their current limited form have had any impact, nor does it explain how the services provided (often unspecified) will help to reduce HIV transmission.

II. 1. Scaled up Condom Promotion &100% Condom Use will cover districts in the 4 provinces of highest prevalence.

Limited scale efforts have been carried out in six donor-supported provinces. This needs to be scaled up in at least 4 provinces of highest prevalence.

Availability of quality health education materials, women's empowerment strategies and the provision of providing user friendly services for high risk groups and condom availability will be the strategies for the programme.

The Ministry of Health (Director General of CDC and EH) has issued a circular in 1996, to all Chiefs of Provincial Health Office in Indonesia to promote 100% condom use among high- risk groups. However, consistent condom use is still below 10%. 100% condom use project in entertainment establishment is being initiated in as a pilot project in Merauke municipality, Merauke district, which has the highest prevalence of HIV, with technical support from UNAIDS/WHO.

Following the same international best experiences Indonesia will scale up the 100% condom use in entertainment establishments in selective\ districts within the 4 priority provinces. This will massively increase prevention as well as increase empowerment of women especially the sex workers in protection themselves from infection with the virus.

At the same time, mobilized increase responsibility from all persons with high-risk behaviour in prevention further transmission of sexually transmitted infections. It will be implemented in collaboration among Sectoral ministries, NGOs, local government, community, peers, and stakeholders.

The beneficiaries will be Programmers; Target Populations such as CSWs & clients, partners of clients, families and communities

This proposal, which was a central component in a successful application for US\$ 11 million, is by no means atypical of the level of detail found in project proposals and programme plans. It is clearly implied that the aim of this programme is to increase condom use in commercial sex, but without knowing what the programme is hoping

to provide, how, to whom and with what expected result, it is virtually impossible to develop a meaningful M&E plan.

In HIV prevention, the programme's aim must always be to change at least one of the three "Basics" that determine the spread of the virus. But the programme should also be able to specify how it expects to achieve such a change. Questions that must be asked when constructing a monitoring plan include:

- What is the aim of the programme: which of the "Basics" will it change?
- What services will the programme provide?
- Who will provide the services?
- Who will "receive" the services? How will the providers reach them?
- How will use of the service change the "Basics" of HIV transmission?

In order to give an example of the use of a simple programme monitoring approach based on the questions above, I have chosen to look at programmes to reduce the risk of HIV transmission in commercial sex implemented by the Aksi Stop AIDS programme (ASA), for which programme logic was more clearly defined. This analysis was first conducted at the request of programme managers in the port city of Manado/Bitung, in north Sulawesi (hence the focus on this area in the analysis). It was they who described the programme logic.

Programme managers define the programme logic as follows:

Commercial sex between men and women accounts for a significant proportion of the discordant contacts between HIV infected and uninfected people in Indonesia. Preventing new infections in clients will also prevent new infections in their non-commercial partners.

The goal is to reduce the risk of HIV transmission in commercial sex by:

- increasing condom use in commercial sex (reducing the likelihood that body fluids will be exchanged in any discordant contact)
- providing regular screening and treatment for STIs to all female sex workers (reducing STI prevalence, thus reducing the likelihood that HIV will be transmitted in discordant contacts where body fluids are exchanged)

 providing STI treatment for symptomatic men who may be clients of sex workers (reducing the duration of STI infection, thus reducing the likelihood that HIV will be transmitted in discordant contacts where body fluids are exchanged)

The analysis will focus on the STI programming element, whose logic was specified as follows:

#### Reducing STI prevalence among sex workers

Outreach workers will contact sex workers at their place of work, giving information about STIs, including asymptomatic STIs, and the benefits of screening and treatment. They will give all sex workers referral cards for an ASA-sponsored STI clinic.

All sex workers will present at the clinic at least monthly for screening and treatment by trained staff as necessary. Curable STIs will be correctly treated according to national guidelines, and cured. <sup>12</sup> Sex workers will be given prevention counselling to avoid reinfection. Condom use will rise, STI prevalence will fall.

### Improving STI treatment among clients

Outreach workers will contact men who are likely to be clients of sex workers, both in areas where sex is sold and in areas where men in occupations that support norms of commercial sex congregate. In group contacts, outreach workers will give information about the link between HIV and STIs and the importance of correct treatment.

In individual contacts, outreach workers will ask men about recent experiences of unprotected commercial sex, or current symptoms that may indicate a sexually transmitted infection. Men who report recent high risk behaviour or current symptoms will be given referral cards for an ASA-supported STI clinic.

Men referred will present at the clinic for screening and treatment by trained staff as necessary. Curable STIs will be correctly treated, and cured. Infected men will be

<sup>&</sup>lt;sup>12</sup> Seroprevalence of antibodies to the incurable viral STI HSV-2 is extremely high among sex workers in Indonesia – the most recent round of the RTI study found 94 percent prevalence in 2,500 sex workers sampled in 10 cities. However genital ulceration is rare in both men and women. Just 11 of the 2,347 sex workers who tested positive for HSV-2 presented with signs of genital ulceration. Of 2,670 men attending STI clinics for whom patient records are available, just 6 (0.2 percent) had ulcers. Suppressive therapy for incurable STIs is not offered.

told of the dangers of reinfection, and will be given condoms and referral cards for their regular sex partners. Sex partners will also present at the clinic and be treated as necessary.

Efforts to increase treatment seeking among men will be supported by a mass media campaign in media that target the socio-economic group in which clients of direct sex workers are concentrated. The media campaign will discourage self-treatment for STIs. This will reinforce treatment seeking at clinics – self treatment will fall, treatment at medical facilities will rise. A higher proportion of STIs will be appropriately treated and cured. Duration of STIs will fall among infected clients of sex workers and other men.

### 2. Developing a monitoring framework

Stating the programme logic in this way allows for measurement at every stage for which appropriate data are available. This makes for a clear monitoring plan, and easy identification of unexpected problems with the programme delivery (and sometimes with the programme logic). Many of these can rapidly be rectified to improve programme performance. Other difficulties identified during monitoring analysis may lead to a rethink of programme strategies.

Most of the questions listed here can be answered with routine programme monitoring data, with behavioural surveillance data, or with routine data from other parts of the second generation surveillance system.

The monitoring plan for a given programme component should always be based around the stated programme logic. However there is a sequence of questioning which will be more or less invariable.

- Does the programme exist?
- Is it reaching its intended target market, and are the intended beneficiaries using the services?
- Is the programme producing the intended changes in behaviour or risk of HIV transmission?
- If not, why not?

- What can we do to improve programme performance?
- Is it good value for money?

In the pages that follow, an example of this question sequence is applied to the STI component of the commercial sex programme described above. The analysis focuses particularly on services provided by the YBHK clinics in the port city of Manado/Bitung in North Sulawesi, but also uses data from other sites and nationally aggregated data, in order to compare the Bitung site with other areas. This gives some indication of the common threads between different areas, and can help identify strengths and weaknesses that are specific to a given area (usually indicative of management or implementation issues), and those that are common to all areas (often indicative of programme logic issues).

The data used in this analysis are:

- ASA Programme Monitoring data
  - Data on programme inputs and outputs, reported by implementing NGOs in Manado and Bitung in standardised formats on a monthly basis to ASA's central M&E unit in Jakarta before being forwarded to the national database.
- Behavioural surveillance data

Data on risk behaviour, STI history, treatment seeking and programme contact, Collected by the national surveillance system, for two rounds (2002/3 and 2004/5). The BSS data used here come from direct and indirect sex workers in Manado, Bitung and other cities. The male data are from occupational groups in which the consumption of commercial sex is common – sailors in Bitung port, sailors, drivers and port workers in other sites.

Reproductive Tract Infection study

Data on STIs, RTIs and behaviour among sex workers in Bitung and other cities for two rounds (2003 and 2005). These were collected by a team from ASA and P2M, as a prototype for the national STI sentinel surveillance.

## a Question 1: Does the programme exist?

In the mid-1990s, changes in HIV prevalence in Uganda and the failure of the relatively well-monitored Senegalese epidemic to take off like the epidemics of East

Africa led to a flurry of analysis that sought to establish whether the prevalence trends were the result of prevention efforts or not. (Meda, Ndoye et al. 1999; UNAIDS and Wellcome Trust 1999) Most of the analysis focused on demonstrating that observed trends in prevalence were consistent with observed changes in behaviour. Efforts to link those behavioural changes with the existence of specific prevention efforts were much more limited. We have tended to work backwards through the monitoring and evaluation framework – if HIV is rising, our programme is failing. If risk behaviour is falling, our programme is succeeding. The "inputs" and "outputs" side of the framework have until recently rarely been carefully measured.

The first step of any programme monitoring analysis is to show that the planned services are being delivered. Have the staff been trained? Do the staff who were trained work in the programme, or have they been transferred elsewhere? Have the drugs been imported, or are there unforeseen procurement difficulties? Did the media campaign aimed at high risk men ever run, or was it cancelled after a public protest?

Routine programme monitoring data ought to record basic outputs; these are usually reported by the local implementing unit to a more central level in a standardised format on a regular basis for aggregation and analysis.

Table 19: Routine programme monitoring data from NGOs providing STI-related outreach and services in Manado/Bitung, Jan 2003 - May 2004 (Source: ASA programme monitoring data)

,	1 0	O		
			Sex	NO
			2003	0.

	Sex workers		High risk men	
	2003	01/05 2004	2003	01/05 2004
Average outreach workers working per month*	2003: 41		J-M 2004: 59	
Target population contacts, total	5217	4118	15,990	15,220
Average contacts per outreach worker per month*	2003: 517		J-M 2004: 327	
Average monthly referrals to STI services	163	98	187	696
Average monthly referrals presenting for screening	151	78	173	106
Average number of STIs treated monthly	139	135	150	62
Average number of partner referral counselling sessions	n/a	n/a	0	0

n/a: not applicable

<sup>\*</sup>summary data do not distinguish between outreach workers reaching the different populations so these figures are for sex workers and men combined

If it cannot be shown that the programme exists and that it is actively providing the planned services, then attention should turn immediately to identifying and overcoming the obstacles to service delivery. There is no point proceeding any further to look for outcomes of a programme that does not exist.

Table 19 shows routine monitoring data aggregated from 4 NGOs providing STI related outreach and clinical services in the Manado/Bitung area. If reported data are correct, outreach workers have been trained, and are active in the field. People are being referred for STI services, and are showing up. STIs are being treated. Partner referral is not taking place, despite the fact that it is part of the stated strategy for male clients of STI clinics.

During a programme review in July 2004, implementing NGOs were questioned about the lack of partner referral services. They said their clients were largely transient men who had acquired an STI from a sex worker and whose regular partners were in a different city. They felt partner referral was a waste of time and resources. Programme managers at the central level eventually agreed that partner referral could be dropped from treatment protocols in the local situation.

## b Question 2: Is the programme reaching its target market?

The fact that a programme is generating outputs does not necessarily mean that the outputs are reaching those for whom they were intended. The intended beneficiaries should have been clearly stated when the programme logic was defined, and they should have been defined with reference to the epidemiological factors summarised in the Back to Basics framework. In concentrated epidemics most HIV prevention efforts should be aiming to reach the people most likely to be engaging in exposures with a high risk of HIV transmission.

In the Manado example, the programme logic states that men who are at high risk for STIs, either because they report recent unprotected commercial sex or because they report an STI symptom, should be given a referral card for the STI clinic, which is run by a separate NGO. Outreach workers report monthly how many people they have referred for STI services. The clinic, in turn, reports the number of men who present for services with referral cards, and the number who, after screening, are

given treatment. It also reports the number who are given counselling about partner referral.

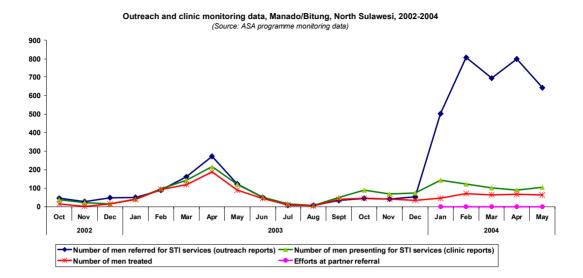


Figure 26: Programme monitoring data showing outreach workers' referrals of men to STI clinics, and clinic records for men attending, treated and counselled

Monitoring data reported to the Jakarta office of ASA by the implementing NGOs is shown in Figure 26. The data suggest that pressure to increase referrals after December 2003 led outreach workers to abandon the referral criteria required by the programme logic. Numbers coming for screening rose, but the proportion needing treatment dropped sharply. In other words, the growth in numbers presenting at the clinic represented an increase in the "worried well" seeking subsidised health checks. This increased costs to the programme, while the absolute number of STIs treated fell.

These programme monitoring data can be cross-checked, somewhat crudely, by looking at behavioural surveillance data. Participants in BSS are asked if they have had contact with an HIV prevention outreach worker in the last three months, and if so, whether they have been referred for STI services. The most recent round of BSS in Manado was in early June 2004, directly after the period covered by the monitoring data shown in Figure 26. Overall, 40 percent of men who did not report recent unprotected commercial sex or STI symptoms reported any contact with an outreach worker, compared with 49 percent of men who did report exposed, high risk sex or an STI. So outreach coverage is quite high, at close to half of the most at risk population.

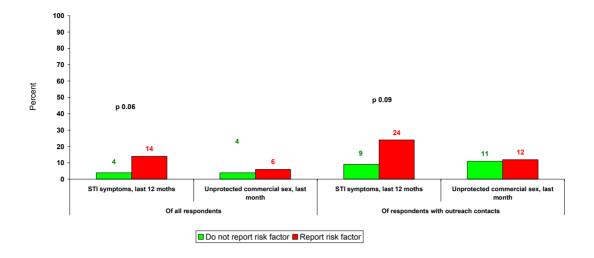


Figure 27: % of men reporting referral for STI treatment in the last three months, by self-reported risk criteria. In the left side of the graph the denominator is all respondents, on the right side it is only respondents reporting outreach contacts

(Source: BSS Bitung, June 2004)

If criteria were respected, we would expect that men who report being referred for STI services would be more likely to report an STI symptom in the last year, and more likely to report unprotected commercial sex than men who do not report being referred. Figure 27 shows that the expectation holds true for men who report STI symptoms.

Data were collected just after the peak in referrals reported by outreach workers. Figure 27 shows that 11 percent of men reporting contact with outreach workers but not reporting any risk criteria for STI referral were referred to the clinic. Much more worrying are the high proportions that did report risk but were not referred for treatment – including fully 82 percent of men who were contacted by outreach workers and reported unprotected commercial sex in the last month. Since around half of sex workers in the Manado/Bitung area were infected with at least one curable STI at the time of the survey, these men were clearly at risk of exposure and should at least have been given the opportunity for a check-up. Among those who were contacted by outreach workers and report STI symptoms in the last year, over three quarters were not referred for STI treatment. Some may have experienced symptoms many months before, but this high proportion alerts us to the possibility that opportunities for referral are being missed.

It is important to bear in mind that routine behavioural surveillance data are "dirty". Surveillance is not designed specifically for programme evaluation. These data are

collected infrequently (after years of collecting data every year and seeing almost no change between rounds, Indonesia has switched to a biennial schedule for its large behavioural surveillance programme) and they are particularly poorly placed to measure the effect of geographically fixed programmes in mobile populations. In the example above we know that all the interventions in Manado/Bitung are funded by the ASA programme, but there is no way of knowing, when a respondent reports contact with outreach workers, whether the contact took place in Manado or elsewhere. In addition, self-reported STI symptoms in the last year are far from ideal as an indicator of the need for referral.

With sex workers the comparison is a little easier; in programme monitoring data, we would expect the number of women contacted to be roughly the same as the number referred on a monthly basis. Yet programme data show this is not the case. From the start of the programme in late 2002 until May 2003, outreach workers reported contacting an average of 470 women a month, but only reported referring an average of 70 a month to the STI clinic.

This can be cross-checked with information from two surveys among sex workers themselves: the BSS data, and data from the periodic RTI study, in which behavioural data are linked to STI outcomes.

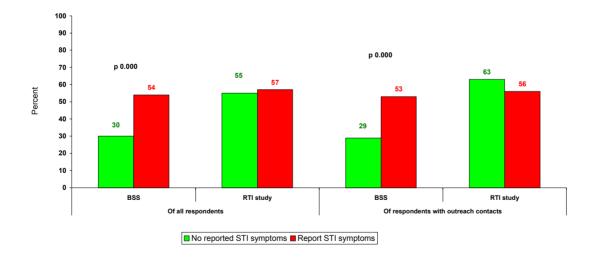


Figure 28: % of sex workers reporting referral for STI treatment in the last three months, by survey. In the left side of the graph the denominator is all respondents, on the right side it is only respondents reporting outreach contacts

(Source: BSS Manado/Bitung, June 2004, RTI study Bitung April 2005)

In the 2004 BSS in Manado and Bitung, 63 percent of sex workers reported contact with an outreach worker, compared with 71 percent in the RTI study, which was conducted 10 months later in the port area of Bitung – an area dominated by downmarket direct sex workers.

As Figure 28 shows, in behavioural surveillance in June 2004, those sex workers who reported symptoms of STIs in the preceding 2 months were significantly more likely to have been referred for STI screening and treatment than those who reported no STI symptoms. However, even among those who were contacted by outreach workers and report symptoms of STIs, just 53 percent reported any referral. The programme logic dictated that *all* sex workers should be systematically referred for screening and treatment. So clearly, the programme is not being implemented fully as planned. An analysis of referral by location shows that women in brothels and on the streets are far more likely to report being referred for screening than those working in massage parlours, karaoke bars and other more "up market" locations.

The programme monitoring and BSS data were reviewed by the ASA M&E team in July 2004, and brought to the attention of national and local programme managers. It became apparent that neither the outreach NGO nor the clinic had fully understood the differences in strategy in referral for men and for women. When it was clarified, the clinic objected, fearing being swamped if all sex workers attended regularly. Changes were made to the payment structure to ensure that a greater workload would be adequately compensated. By the time of the RTI survey in April 2005, 77 percent of sex workers who had been contacted by outreach workers reported having been referred for STI treatment, compared with just 34 percent of the sex workers sampled in Bitung in the 2004 BSS.

### c Question 2b: Is the target population using the service?

Even if the referral strategy is correctly implemented, it does not guarantee that the service is actually used. If people feel they have no use for the service, if it is inconvenient or perceived to be of low quality, it may well not be used by the target population. Monitoring data can highlight differences in the number referred and the number using the service. As Figure 26 showed, for men there was a close correlation between referral and service use as long as selection criteria were being

used in accordance with programme plans. When people were apparently being referred more randomly, a substantial gap opened up between reported referrals and service use.

While only a minority of sex workers were referred to the clinic, programme monitoring data show that over 90 percent of those referred did present for screening and treatment. This is confirmed by BSS data: 90 percent of sex workers who said they were referred for STI screening went to a clinic at least once in the three months preceding surveillance, compared with just 33 percent of those who said they did not receive a referral

If it cannot be shown that the service is reaching its target population and that members of that population are using the service, attention should turn to identifying the reasons why services are not being used as anticipated. There is no point in proceeding to look for evidence of impact from a service which is not being used. In the case of STI services in Manado/Bitung, some weaknesses in targeting have been identified. On the whole, however, services do appear to be up and running, to be reaching at least some of the target market, and to be actively used by those targeted. That being the case, the analysis can proceed to the next question:

### d Question 3: Is the service making any difference?

This is the central question for programme evaluators. If (and **only** if) it has been shown that a service is provided, that a service is reaching its target market, and that the target population is using the service, we should proceed to look for evidence that the service is producing the changes that we expect. Ultimately, we need to see a change in at least one of the three factors that constitute a "Basic" of HIV transmission. But it is also possible to look for interim changes that indicate whether or not the programme logic is working.

Programme exposure and outcome can be compared to look for evidence of programme effect at several levels. We can look for differences

- At the population level, by programme exposure
- At the individual level, by programme exposure
- At the individual level, over time

#### • At the population level, over time

Data are rarely available to allow for all four types of analysis, but the more different perspectives one can take the stronger the case for (or against) a programme effect.

#### Differences at the population level, by programme exposure

If prevention programmes have adequate geographical coverage in a given area, then it is expected that behaviour in the target population in that area will be safer than in a similar population in an area with no programme (or where earlier monitoring has shown programmes are not delivering services to the target population). This type of analysis requires that the behavioural surveillance system is not centred exclusively on areas where programmes are active. Historically, such data are somewhat limited because behavioural surveillance has often been equated exclusively with programme monitoring and donors have selectively funded surveys and surveillance in sites where they pay for interventions.

The programme we are looking at in this analysis aims to reduce STI prevalence, in part by ensuring that all sex workers are regularly screened at a medical facility, using outreach as an entry point. To look for evidence that the STI strategy in Manado/Bitung is effective in this regard, we can compare STI service use in Manado with other areas with different levels of programme coverage.

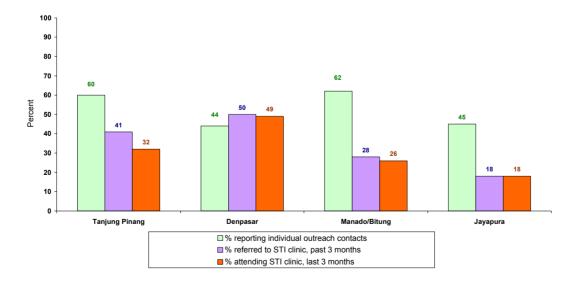


Figure 29: % of sex workers reporting contact with outreach workers, referral to STI services and attendance at STI services in preceding 3 months, by city (Source: Indonesia national BSS data, 2004/2005)

Figure 29 shows data from four sites in the national surveillance system. The data suggest that there is a very close correlation at the population level between referral to STI services and use of those services for sex workers in all sites. There is a significant difference, though, in the relationship between outreach contact and referral. In Denpasar (Bali), the area that has achieved the highest level of screening for sex workers, STI referral slightly exceeds reported outreach contact. In some other areas, including Manado/Bitung, fewer than half of those contacted by outreach workers get referred for services. Denpasar is the only one of the four areas shown here that is not covered by an intervention funded by the ASA programme. Local NGOs in Denpasar have a somewhat different programme approach – rather than focus outreach on individual sex workers, they work more actively with the owners of entertainment establishments to encourage screening in institutional groups. (Dewa Wirawan, Yayasan Kerti Praja, personal communication)

Data from high risk men are harder to interpret. Men are not asked directly if they went to a clinic for an STI check-up. Men who report any symptom of an STI in the past 12 months are, however, asked what they did about it. Figure 30 shows data for two ASA sites with relatively high outreach coverage, and two non-ASA sites with far lower coverage. Fewer than half the men who said they had experienced STI symptoms in the preceding 12 months reported having sought medical treatment for their STI symptoms in any of the sites. "Correct" treatment seeking is highest in Manado/Bitung, the area with the highest outreach coverage. However there was no obvious relationship at the population level between outreach services or even referral and the likelihood that a man would seek medical treatment in other areas. The area with the second highest outreach coverage had the lowest levels of use of medical services for STIs.

<sup>&</sup>lt;sup>13</sup>Data for all sites were examined; presenting them all graphically would be visually confusing. The three additional sites were selected to include one that was a non-ASA site, and two that had two rounds of data for both behavioural surveillance and the RTI study.

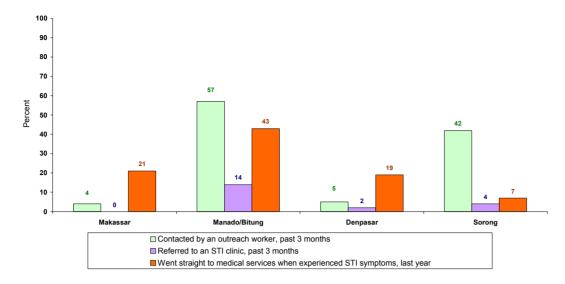


Figure 30: % of those men who reported STI symptoms in the last 12 months who: report contact with outreach workers, report being referred to STI services by an outreach worker, and say they sought medical treatment for STI symptoms with no prior self-treatment, by city

(Source: Indonesia national BSS data, 2004/2005)

The simple comparison of areas with high and low programme coverage, then, suggests that outreach can be used as a successful entry point for increased routine screening for sex workers, although the Manado programme does not perform particularly well in this regard. Among men, the effectiveness of outreach in improving STI treatment seeking remains to be demonstrated.

#### Differences at the individual level, by programme exposure

For most types of interventions, individuals who report exposure to a prevention programme would be expected to differ with respect to outcome measures from those who report no exposure. This type of analysis requires that measures of programme exposure are included in behavioural surveillance, and that these measures are sensitive enough to differentiate between different types of prevention services.

To continue with the example above, we can compare screening between women reached by outreach workers and those not reached in the various sites. The results, shown in Figure 31, are clear – women are significantly more likely to attend STI screening services if they have had contact with an outreach worker than if they have not has such contact, in all sites. This provides additional evidence for the effectiveness of outreach in opening the door to routine screening. It is interesting to note, however, than close to a quarter of sex workers in Bali went for a routine

screen even without the outreach contact – suggesting that less labour intensive approaches may also be possible.

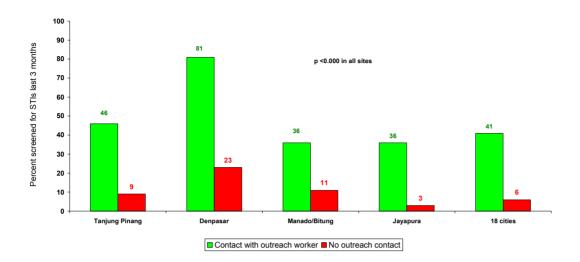


Figure 31: % of sex workers who report attending an STI clinic for screening in the last 3 months, by city and reported contact with outreach workers

(Source: Indonesia national BSS data, 2004/2005)

Figure 30 above has already suggested that there is unlikely to be a close correlation between outreach and use of medical services for males with symptoms of STIs.

Another aim of the male STI programme was to reduce self-treatment.

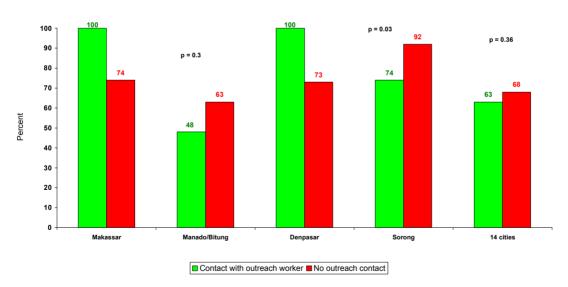


Figure 32: % of men reporting STI symptoms in the preceding 12 months who self-treated the symptoms, by city and reported contact with outreach workers in the preceding 3 months

(Source: Indonesia national BSS data, 2004/2005)

To see whether outreach achieves this goal, we can compare self-treatment among men with STIs who report contact with outreach workers in Manado, and in other sites, with those who do not report such contact.

The data, shown in Figure 32, go in the right direction in both sites with relatively high coverage of outreach among high risk men, but not elsewhere. This suggests that the difference may be due more to the content of outreach in Manado than to any effect of a mass media campaign, which ought to be seen nationwide. <sup>14</sup> In the Manado/Bitung area, men who report outreach contacts were a third less likely to self-medicate than men who had no contact with outreach workers. However since the denominator is restricted to men reporting STI symptoms in the last year, numbers are relatively small and the difference was not statistically significant. In Sorong, men with STIs who were contacted by outreach workers were significantly less likely to self-treat than those who were not contacted, but levels of self-treatment still exceeded those of men outside the programme in Manado/Bitung. In South Sulawesi where outreach coverage is very low, just one individual reported an STI symptom and outreach coverage (so the 100 percent bar represents a single individual), while in Bali just three men fell into this category. Aggregating data from the 14 national sites with BSS among mobile male groups, we see no significant difference in self-treatment between those who report contact with outreach workers and those who don't. In both groups, around two thirds of those who reported STI symptoms reached for off-the-shelf drugs before they did anything else.

So far, the analysis of STI programme effects have followed the programme logic as far as the effect of programmes on treatment seeking behaviour. The logic seems to work relatively well for sex workers, and to be less convincing for their clients. However if the prevention efforts are to have an impact on HIV transmission, improvements in treatment seeking behaviour are not enough. It has been established that exposed sex acts between HIV infected and uninfected people in commercial sex accounts for a significant proportion of HIV transmission risk in Indonesia. To reduce this transmission risk, STI programmes have to reduce prevalence and duration of STIs among sex workers and their partners.

<sup>&</sup>lt;sup>14</sup> In fact, the mass media campaign was pulled after a very short run prior to the first round of BSS because of opposition from religious groups. It was reinstated in a different form shortly after the second round of BSS.

The programme logic dictates that sex workers who present for routine STI screening and get treated if necessary should have lower STI prevalence than women who do not use these services. The next step, then, is to look at whether sex workers who use screening services have lower STIs than sex workers who do not use screening services. STI prevalence data for sex workers are available for three of the cities shown above (and seven other cities), and these data are linked to behavioural data. The data in Figure 33 show that in two of the three sites, the association is as expected: women who report routine screening do have significantly lower STIs. But it is not true of Manado/Bitung, or any of the seven other sites for which data are available.

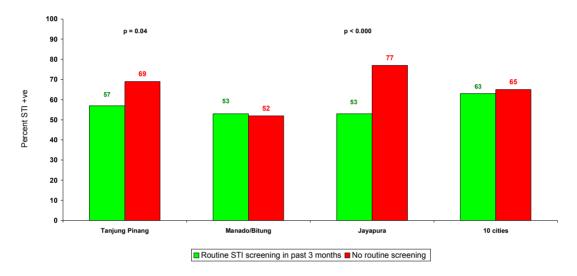


Figure 33: % of sex workers testing positive for one or more of chlamydia, gonorrhoea, syphilis or trichomonas, by city and use of routine screening services in the previous three months

(Source: Indonesian national RTI study, 2004/5)

So far, then, it appears that the approach of the ASA programme for STI treatment in women works at the individual level in a minority of areas, but in many locations the assumption that outreach leads to referral, which then leads to routine screening, which in turn leads to reduced prevalence, stumbles at the first hurdle (outreach workers are not referring sex workers to screening) and falls at the last hurdle (screening is not leading to reduced prevalence).

#### Differences at the individual level, over time

The measures so far have all be cross-sectional measures. Evaluations that track individuals, seeking to compare behaviour or other outcomes before and after

exposure to an intervention, are generally not possible in routine surveillance settings. However some forms of programme monitoring data – particularly those related to clinical services such as STI screening and treatment and management of HIV infection – may provide information that allows for the tracking of risk behaviour and STI infection in individuals over time. More simply, behaviours of those with a certain number of programme visits can be compared with those of less frequent participants to look for changes related to repeated exposure – a sort of "dose-response" relationship.

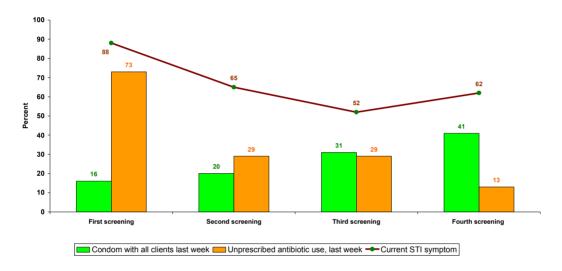


Figure 34: Condom use, self-medication, and clinical symptoms of STIs among sex workers by number of clinic visits, YBHK clinics, Manado and Bitung (Source: ASA clinic monitoring data, July – October 2004)

Figure 34 shows data from the clinic monitoring data base for the YBHK clinics in Manado/Bitung from the time of the creation of ASA's national clinic database in July 2004 until October of the same year. At their first screening visit, sex workers are more likely to have taken non-prescription antibiotics in the previous week than at later visits, and are less likely to report using a condom with all clients over the preceding week. At each successive visit, sex workers become less likely to report self treatment or unprotected sex. The proportion of sex workers who have a clinical symptom of a reproductive tract infection falls. These data suggest that women are becoming progressively less likely to be exposed to high risk of contracting or passing on an HIV infection the longer they are in active contact with the STI screening programme.

If the programme logic held, we would expect that cross-sectional data from the RTI study (the second round of which took place in April 2005 in Bitung) might confirm this relationship – women who report more frequent routine screening in the last three months should have lower STI prevalence than women with less frequent screening. But as Figure 35 shows, they do not. STI prevalence is not related to frequency of screening visits, either in aggregated national data or in Bitung.

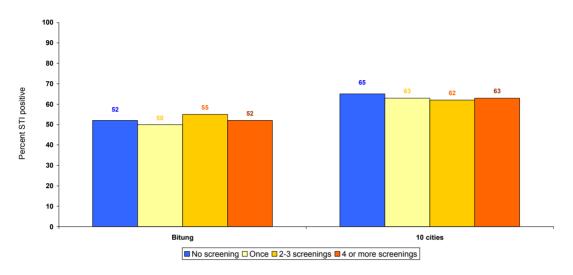


Figure 35: % of sex workers testing positive for one or more of chlamydia, gonorrhoea, syphilis or trichomonas, by frequency of routine screening services in the previous three months, Bitung and aggregate data for 10 cities

(Source: Indonesian national RTI study, 2004/5)

The overall test of whether the approach is working is: is it making a difference at the population level, over time? Given the apparently weak relationship between clinic attendance and STI prevalence, it seems unlikely that this will be the case, but it is worth looking at for the sake of thoroughness.

#### Differences at the population level, over time

In an area of programme activity, outcome behaviours should change over time, at least during the earlier years (the hope is that with ongoing service provision, safe behaviour will eventually plateau at high levels which constitute a new population norm). The case for programme effect is strengthened if these same changes over time are not observed in areas with no prevention efforts. This type of analysis requires that the outcome measures have been asked consistently over time.

For men, the only available data at the level of an outcome that could have a direct effect on the likelihood of HIV transmission in an unprotected, discordant sex contact is self-reported STI symptoms in the last 12 months. However, changes in self-reported STIs are not helpful to understanding the success of programmes to increase correct treatment-seeking for men who have already contracted STIs, which is the focus of the male STI programme. The best available measure of programme effectiveness in this regard may be changes in the proportion of men who sought medical treatment as a first reaction to symptoms (rather than after self-medication failed to clear up the infection).

Figure 36 shows changes in "correct" treatment seeking for men reporting STI symptoms over time. In Manado, with a relatively active outreach programme for mobile men rolled out between the two surveillance rounds, first-stop treatment at a medical facility more than doubled to the highest level among the 12 cities with comparable data. In Sorong, which also had high outreach coverage, the programme had no apparent effect, while in Bali, with very low outreach coverage, the proportion of men seeking medical treatment for STIs without first self-treating fell by half.

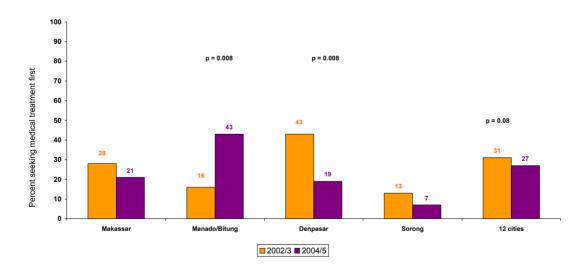


Figure 36: % of men reporting STI symptoms in the last year who went straight for medical treatment, without first self-medicating, by city and surveillance round (Source: Indonesia national BSS data, 2002/3 and 2004/2005)

For women, the aim of the regular screening and appropriate treatment programme is actually to bring down STI prevalence at the population level. The data shown in Figure 33 have already suggested that if there are any changes at the population level,

they are unlikely to be related to the STI screening programme. However it is still possible that we might see reduced prevalence, because success in other parts of the prevention programme, such as condom promotion, would also have the effect of reducing STI prevalence.

Table 20 shows STI prevalence levels among sex workers in seven cities for which data are available for two rounds of surveillance. Gonorrhoea has dropped markedly in several sites and appears to have fallen at the aggregate level, although it is difficult to draw firm conclusions because the tests used for gonorrhoea and chlamydia are not comparable between rounds and the comparison is based on an estimate. Differences in trichomonas and syphilis (for which the same tests were used in both rounds) are not statistically significant.

It is critically important to stress that the analyses presented above are merely indicative. Surveillance systems are designed principally with the aim of tracking trends in infection and behaviour over time at the population level. They are not designed first and foremost to measure the effects of particular prevention programmes. The problem of attributability was addressed in Chapter 1. As services multiply, it becomes more and more difficult to discern the effects of individual programmes, or even of different components of the prevention effort. Increasingly, at the outcome level, we must fall back on the "plausible contribution" approach described in Chapter 1. This is especially true of programmes that try to work at a structural level, changing norms that affect exposure across a whole population, regardless of individual exposure to programme services.

Even for services provided at the individual level, programme exposure measures available from behavioural surveillance are necessarily blunt. However, as the example has shown, if programme monitoring data show that the programme has been implemented and is reaching its target as planned, it is possible to use routine surveillance data to get a good idea of whether or not it is achieving the desired effect.

Table 20: STI prevalence among sex workers in three Indonesian cities, and aggregate data for seven cities with two rounds of surveillance

(Source: Indonesian national RTI study, 2004/5)

Site	Gonorrhoea		Chlamydia		Trichomonas		Syphilis	
	Round 1*	Round 2	Round 1*	Round 2	Round 1	Round 2	Round	Round 2
							1	
Tanjung Pinang	41.1	27.2	52.5	43.2	11.2	12.4	11.2	8
Bitung	29.3	18.0	37.8	34.8	17.6	21.6	9.2	6
Jayapura	28.2	30.0	33.9	44.4	7.2	23.6	6.8	6
7 cities	34.9	28.7	39.5	43.1	9.5	16.2	10.8	9.1

<sup>\*</sup>Estimation. In Round 1, Genprobe LCR testing was used, in Round 2, more sensitive PCR tests were used. In Round 2, a subset of 613 samples were tested using both LCR and PCR testing, giving estimates of the relative sensitivity of LCR tests (78% for gonorrhoea and 63% for chlamydia). These prevalence rates are the estimated PCR equivalent of the LCR results reported in Round 1.

# e Question 4: If we are not seeing the anticipated changes, why not?

Routine programme and surveillance data cannot answer all the questions needed by programme managers in order to diagnose and fix problems. However, they can given an indication of where the problems might lie. Conflicting results in the analyses above can be particularly illuminating. Different types of inconsistencies suggest different avenues for further questioning. Some of the most common inconsistencies are discussed in this section.

#### There are changes at the individual level but not at the population level

If individuals who report exposure to the programme have safer behaviour than those who are not exposed, but there is no difference at the population level over time or between programme and non-programme areas, look at coverage. Programmes with limited coverage may well be effective for the few individuals who access them, but will have no impact on behaviours measured across the risk population as a whole. Such programmes can be dressed up to look quite successful for donors who are interested only in the outcome of the activities they fund. However when the effect is considered in the context of the "Back to Basics" framework that also takes into account the absolute size of the populations at risk, it will disappoint.

Take, for example, the initially impressive looking programme effects shown in Figure 34 above. It seems clear that the more frequently a sex worker comes to the clinics in our programme, the better the outcome. What Figure 34 does not show is the relative frequency with which individuals come for repeat visits. In the YBHK clinic in Bitung over a four month period in late 2004, 79 percent of sex workers had a single visit, 17 percent two visits and just 3 percent three or more. This may reflect poor record keeping, in part, but it may also be an indication of low service quality, or very high turnover in the population. Certainly, a higher proportion of sex workers themselves report repeat visits for screening within a similar time frame, as Figure 37 shows (although we cannot know whether or not they were screened at ASA supported clinics).

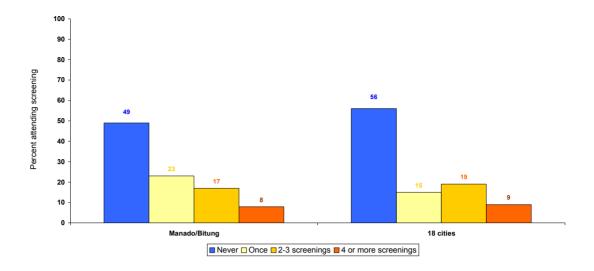


Figure 37: % of sex workers reporting STI screening in the preceding 3 months, showing the frequency of screening visits in that time period.

(Source: Indonesia national BSS data, 2004/2005)

Nationally, however, fewer than a third of sex workers report attending an STI clinic for screening more than once in a three month period. Without higher coverage, it is a lot to expect regular screening to result in changes in STI rates at the population level.

#### The effect of programme exposure diminishes over time

It is not uncommon to see large differences in behaviour between those reached and those not reached in the early stages of prevention efforts, and then see the difference diminish over time. If the difference is diminishing because rates of safe behaviour in those reached are diminishing, it may be an effect of programme expansion. It is possible that as more people are reached, less time and attention or fewer services are provided to each person reached, and the behaviour of those reached will not change as much. If the difference is diminishing because rates of safe behaviour in those not reached by programmes is increasing, it may be an effect of "positive contamination": prevention programmes are having the trickle-down effect of changing social norms even in areas where they are not specifically active. Again it is important to consider these changes within a framework such as the "Back to Basics" framework, which takes population size into consideration. Relatively smaller changes in the risk of exposure across a larger number of those likely to have discordant contacts may have

more effect than large changes confined to a small denominator, or found in populations where contact between HIV infected and uninfected people is limited.

It is not currently possible to look at the STI programme data in this context because information on programme exposure was collected only in the 2004/5 round of BSS.

# The programme doesn't appear to make a difference even at an individual level

If the programme is being delivered as planned but individuals reached by the programme report the same behaviours (or have the same biological outcomes) as those not reached, there may be a problem with the programme logic. In this case, it is important to look for evidence of why the expected associations are not appearing.

In the example above, the programme logic works to a point, at least for sex workers. Those who are referred for screening are likely to show up. But Figure 33 and Figure 35 indicate that sex workers who are getting screened, including those with regular screening visits, are no less likely to test positive for an STI than those who are not screened at all. This is probably in part because of errors in referral practices – as we have seen, women reporting symptoms were more likely to be referred for services, and those referred by an outreach worker were much more likely to attend than those not referred.

Possible reasons for the poor association between service use and lower STI prevalence include STIs being incorrectly diagnosed, or incorrectly treated. It is possible to look at this in the ASA clinics, where routine monitoring data include quality control monitoring. Every month, a proportion of lab tests are repeated by an independent QC panel, and a subset of records are reviewed for correct diagnosis and prescription.

Figure 38 shows data for the YBHK clinic which provides services to sex workers in Bitung. A very high proportion of the clients screened are given medication, but the QC data shows that diagnostic accuracy was high after the first few months of the programme. The proportion given "correct" treatment according to national STI treatment guidelines dipped in early 2004, but stayed above 80 percent for the most part. Clinic records do not report any stock-outs of essential drugs, even in the period in early 2004 where correct treatment falls.

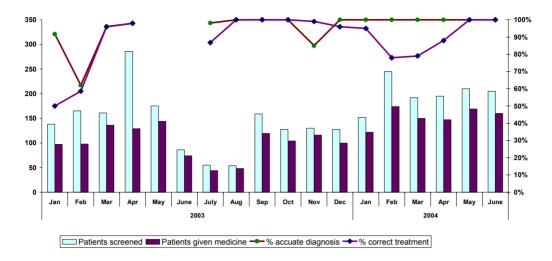


Figure 38: Number of clients screened and treated (left scale), % of QC samples judged to have accurate diagnosis, and % of records reviewed with correct treatment (Source: YBHK clinic, Bitung, monthly monitoring data, Jan2003 – June 2004)

Apparently, then, sex workers screened at the YBHK clinic are for the most part correctly diagnosed and correctly treated, according to national guidelines. Another potential reason for continuing high rates of STIs is repeated unprotected sex with a client population that has high rates of STIs. Additionally, it is possible that treatment deemed "correct" according to national guidelines is in fact ineffective in curing STIs.

It is clear from the analysis so far that the sex workers being referred to the clinic and coming to the clinic in Bitung are not a cross-section of all sex workers, but those most likely to be at risk for an STI. Patient records at the clinic, which include a few behavioural questions, confirm that consistent condom use with clients among sex workers visiting the clinic is the exception – just 18 percent of sex workers screened report using a condom with all clients in the preceding week, while 58 percent say they did not use condoms with any client. This differs from reports among sex workers in the 2004 BSS in the same area – in BSS 32 percent report using a condom with all clients in the last week, while just 16 percent report never using them. These high levels of ongoing exposure among sex workers using the clinic could explain the lack of relationship between reported use of screening services and current STI infection seen in the RTI study data. In addition, while STI prevalence is significantly lower among sex workers who report using a condom with all clients in

the last week, it still stands at a remarkable 55 percent infected with at least one of: gonorrhoea, chlamydia, trichomonas or syphilis. Some of this may be because of untreated STIs contracted earlier and some may be because condom use is overreported. However it is also worth noting that 42 percent of these women report boyfriends or regular sex partners, for whom condom information is not available. In BSS, however, sex workers report condom use with boyfriends at half the levels of condom use with clients. This raises the possibility that boyfriends are a source of reinfection for sex workers, and that referral for regular partners should be included in the clinic's service delivery strategy for female sex workers.

The Indonesian surveillance system does not include routine surveillance for antibiotic resistance in STIs. However ongoing high levels of STI infection led programme epidemiologists to consider that antibiotic resistance may also be a factor, and a limited amount of monitoring of antibiotic resistance was initiated in association with the ASA STI programme, as well as in Bali. In Bali, the largest clinic network providing screening services for sex workers worked with a US laboratory to monitor resistance. They found that all 147 isolates of N. gonorrhoeae were highly resistant to tetracycline and 40.1 percent were resistant to ciprofloxacin. Some 18 percent were susceptible to penicillin. (Donegan, Wirawan et al. 2006) Specimens collected in ASA-supported clinics in East and Central Java and tested in Indonesian and Australian laboratories had similar findings. All 279 isolates of *N*. gonorrhoeae were found to be resistant to tetracycline. In the Indonesian lab, 41 percent of all isolates were judged to be resistant to ciprofloxacin using Kirby Jones criteria while in a subset of 92 isolates tested in Australia, 53 percent met criteria for resistance. Some 68 percent of the same subset were found to be resistant to penicillin. All isolates were susceptible to azithromycin.

Indonesia's national STI treatment guidelines recommend ciprofloxacin as the drug of choice for the treatment of uncomplicated gonoccocal infection. Doxycycline (a tetracycline) is commonly prescribed for chlamydial infections, and continues to be wrongly prescribed for gonoccocal infections also. The YBHK clinic in Bitung reported a total of 1,287 clients treated with antibiotics from the start of the service until June 2004; drug supply records show 1138 doses of Ciprofloxacin (500mg) and 16,455 doses of Doxycycline (100 mg) were given out to clinic clients.

Besides being widely prescribed in clinics in accordance with current national guidelines, the data show that tetracyclines are widely used without prescriptions. Two thirds of the sex workers in the antibiotic resistance study reported self-medicating in the week before coming to the clinic, and 57 percent of them had used a tetracycline. Men reporting self-medicating for STI symptoms in the second round of BSS were asked what medication they used: 40 percent said they used tetracycline (in Indonesia sold under the brand name "SuperTetra"), 14 percent mentioned amoxylin, and 24 percent other antibiotics.

It seems very highly probable, then, that one of the reasons there is no clear association between use of screening and treatment services and STI outcomes is that the services, while prescribing drugs that are in accordance with national guidelines, are also prescribing drugs that are largely ineffective in curing infection.

At this point, we turn to the most important question in programme monitoring:

# f Question 5: What are we going to do to improve the programme?

The most important part of programme monitoring is to use the data to improve performance on an ongoing basis. As indicated above, this question should actually be asked after each of the previous questions. If the programme is not being delivered, obstacles to delivery must be sought and fixed. Until that has been done, no further analysis is needed. The same is true if services are not reaching or being used by the target population.

If it is established that the services are being delivered but the hoped-for changes are not seen, then analysis of the type described above can help to begin to diagnose why that might be. Is it that the programme is working but is too small in scale to have an impact, or might it be that the assumptions underlying the programme logic are flawed or incorrect?

It is clear that routine information systems providing quantative data cannot provide answers to all the "why?" questions that must be answered if programmes are to be improved. It is traditional to call for qualitative research at this point. (Family Health International and UNAIDS 1998; Power 1998) As traditionally conceived, qualitative research can be slow and cumbersome, and can be difficult for

programme managers to organise. Some areas, such as Tamil Nadu in India, have built rapid qualitative surveys in response to unexpected quantative results into their routine surveillance systems, but this is rare. It may also be unnecessary. Very often, questions such as "why don't sex workers come to this clinic more regularly?" can be answered in a single evening by chatting to a handful of sex workers.

Even routine data sources can suggest important changes that would result in better programme outcomes, however. In the above example, obvious changes would be:

- Clarify referral strategy for female sex workers with existing implementing agencies operating outreach services. Ensure that outreach workers refer *all* sex workers to screening services on at least a monthly basis.
- Look more closely at using referral systems that are less resource intensive than one-on-one outreach, for example working with institutional bosses (brothel owners etc.) to create incentives for regular screening of sex workers.
- Work with the Ministry of Health to revise national guidelines for STI treatment, taking into account resistance data. Make financial and logistic provision for change of treatment protocols in programme clinics.
- Rethink outreach-based STI referral strategy for high risk men
- Rethink partner referral efforts for both sex workers and mobile men

## q Question 6: How much has it cost?

Cost monitoring may be the most neglected area of programme monitoring. In my experience, it is virtually impossible to get reliable cost data, except in the context of a handful of special studies. This is in part because of accounting practices which do not break down costs across different programme components or which are less than frank about the "true" costs of maintaining programmes which are serviced by vast national and international bureaucracies.

Increasingly, programmes providing specific services such as STI screening and treatment are being shifted from a block grant system to a "fee per service" system. This increases the amount of financial data available. It aims to increase the incentive to provide quality services. In some sites, this shift in financing has prompted implementing agencies to set up mobile and satellite services that have greatly

increased service coverage. It may also increase the incentive to misreport service provision, or diminish the incentive to keep services provision focused closely on the target population, where (if the target is correctly selected in accordance with the framework outlined in Chapter 3) it has the potential to have the greatest impact on the transmission of HIV.

# 3. Tools to increase data use for programme management

As Wilson points out, the "monitoring" frameworks that are the subject of most discussion and promotion internationally are actually reporting frameworks. (Wilson 2004) They focus on accounting to donors for money disbursed, and they do so largely by reporting standardised indicators that have extremely limited value in programme management.

A programme manager looking at UNGASS indicators will know whether knowledge, access to services or risk behaviour has gone up or down. The analysis will rarely allow for comparisons across geographical areas, and it will not be related to service provision.

To be useful for programme management, data must be analysed in ways that follow the programme logic. There is far too much variation in prevention programmes to allow for this to be reduced to standardised indicators. It is, however, possible to create user-friendly data sets which can be picked up and used to follow the analytic sequence described above by anyone who can run a cross-tabulation. (Family Health International 2006)

Standardised data sets, developed during the course of this work in Indonesia, are an important output of quality Second Generation Surveillance systems. Although they remain a rarity, they are now available for East Timor and Pakistan and are being developed for China, India and Cambodia, following the Indonesian model. Essentially, all of the exposure and outcome variables which might be useful in examining programme effects are coded using the same variable name and denominator for all populations in all years, regardless of changes in questionnaire sequence numbers, skip patterns etc. A programme manager wanting to know

whether contact with outreach workers affects uptake of VCT services in different target populations can simply type

#### bysort target: tab outreach anyvct, row chi2

into Stata to get the response, with statistical tests for the significance of any association. In the case of the Indonesian data, this replaces the need to open up around 40 different data sets and code the skips appropriately in each one (assuming the analysis were restricted to a single year).

If the aim is to improve use of data at the level of programme managers and implementers, it is impossible to overstate the importance of user-friendly data sets. With very simple guidance, it is possible for someone to be undertaking the types of analyses described in the five questions above within hours of being introduced to a coded data set and a statistical analysis package. Chapter 6 gives examples of rapid analysis of local programmes using standardised, recoded data sets.

A recoded data set in Stata format and a code book are provided to examiners with this document as an example.

In summary, monitoring programmes for the purpose of managing and improving them involves far more than just reporting standardised indicators. The process is not terribly complex, but it does require access to complete data sets that can easily be used to follow a simple sequence of questions – questions that relate the provision of services, to their use, and only then to outcomes.

#### A simple approach to programme monitoring: Key points

- The Back to Basics framework links HIV prevention and care programmes
  directly with three basic factors that determine the spread of HIV. Prevention
  programmes should state clearly how they expect to change those factors.
- Programme monitoring analysis should follow the stated logic of the programme, and should try to answer five questions: Does the programme exist? Is it reaching the target population? Is it making any difference? If not, why not? What should we do to improve the programme?
- This analysis, which links programme implementation data with outcome data, should be relatively easy to do with information from routine sources
- Good data management and user-friendly data sets will vastly increase the likelihood that programme monitoring will be used to improve performance.
- Innovations in this approach include: the systematic investigation of the links between programme provision, outcome and impact, analysis that meets local programme management needs, and analysis that can be used for immediate programme improvement.

# Chapter 6: Back to basics in the field

This work has proposed a simple framework for the analysis of HIV prevention interventions that can be used to identify specific behaviours or factors which determine where HIV transmission is most likely to be taking place. The same framework informs a question-driven approach to investigate how well prevention programmes are doing in targeting and changing those behaviours. In this chapter, examples are given of the use of the "Back to Basics" analytic approach in field situations, in the context of data use trainings in two disparate situations in Indonesia, as well as in the very different context of China.

As the steps to strengthen the surveillance system described in Chapter 2 began to improve the availability of high quality surveillance in Indonesia, attention began to turn to using the data appropriately. The extremely rapid decentralisation that took place from 2002 meant that Jakarta had relatively little influence over how HIV prevention priorities were set, and how money was spent. Major donors such as USAID (through the ASA programme) and AusAid tried increasingly to work with regional AIDS control commissions (KPAD), encouraging the use of local data to drive locally appropriate strategic plans for HIV prevention. P2M requested support from ASA in developing local skills for data analysis as well as for effective lobbying of local political bodies.

The major obstacle to better analysis and use of data at the central as well as the local level has been a chronic lack of human capacity. The statistics bureau (BPS) has staff trained in the mechanics of data analysis at the district level throughout Indonesia, but most of these people know nothing of HIV or HIV prevention programmes. Local health staff and programme implementers often have a strong instinctive understanding of the local risk landscape, but they have no technical skills in analysis. Recognising this, I worked with colleagues in the surveillance and M&E team at ASA to design a cooperative training in data use. At this stage, we had:

- high quality behavioural surveillance data in user-friendly recoded format
- reasonable quality HIV surveillance data in user-friendly SSHIV format

- high quality STI data with linked behavioural data in user-friendly recoded format<sup>15</sup>
- extensive programme monitoring data, still in fragmented spreadsheets
- a robust framework to guide epidemiological analysis
- a robust question sequence to guide programme analysis

It was our belief that if we introduced this set of information and tools to an appropriate team of people, they would quickly begin to use the tools together with their local knowledge to re-evaluate the current local response to HIV.

The analysis teams included public health officials responsible for HIV surveillance and prevention programmes, managers of specific HIV prevention services (including NGOs), programme officers from donor-funded programmes, and data analysts from BPS and, where appropriate, universities.

The local public health officials provided an initial assessment of the local epidemic. Prevention and care programme implementers were asked to describe existing programmes and the logic that underpinned them. A surprising proportion of programme managers were unable to state clearly how they expected their programme to lead to behaviour change, and some were unable even to articulate the target market for programme services. The data analysts (provided with combined, recoded data sets, a code book, a four-page introduction to key commands in the Stata software programme and half a day's training on Stata) eventually became the "data kitchen", serving up analysis requested of them by the programme implementers and managers.

In four days, participants were introduced to the "Back to Basics" analytic framework described in Chapter 3, and to the basics of programme monitoring described in Chapter 5. In addition, guidance was given on presenting data effectively to different audiences, and on communication of data to reach specific advocacy goals. The bulk of the time was spent in actual analysis of local data and discussion of implications for local programmes. At the end of the training, data were presented to a pre-determined audience, with the intention of achieving specific changes to programmes, according to the priorities that emerged during the analysis.

 $<sup>^{15}</sup>$  By 2005, this had been recoded to a common standard and mereged with the behavioural data sets

The following sections describe the results of this experience in two very different Indonesian settings – the major port city and sex industry hub of Surabaya, and the eastern-most ethnically Melanesian province of Papua. In addition, the use of the same tools in a radically different setting – a national training in the People's Republic of China – is described.

The "Back to Basics" framework was first used in a slightly different form in Surabaya, and has been progressively refined and modified since then, appearing in something like its present form in Guangdong nearly a year later. While a very crude spreadsheet was used in both Surabaya and Guangdong to give a rough idea of the proportion of exposed risk occurring in different behaviours, the full matrix used in the example in Chapter 4 had not been developed at the time of these field trainings.

# 1. Surabaya: Looking at local programme needs

Surabaya, in East Java, is the second largest city in Indonesia, with an official population of some 2.7 million. Many of East Java's 36 million inhabitants visit the city for trade and entertainment; because it is the nation's major port, it is a focal point for travellers from other parts of the country as well. The local AIDS commissions at both the provincial and the city level are relatively active; after the first provincial estimates of infection and risk populations were presented to the provincial parliament in 2003, the Surabaya government earmarked 600 million Rupiah (around US\$ 66,000) for HIV programmes, up from 150 million a year earlier. The provincial government increased its allocation for HIV to 2.4 billion in 2003 from 2 billion a year earlier. However there is considerable debate about how the money should be spent. The local legislature is dominated by conservative Islamic parties, and there have been frequent calls for a clampdown on Surabaya's vast sex and entertainment industry as a response to HIV.

There is anecdotal evidence, supported by police records, of a growing problem with drug injection in Surabaya, but there is no sentinel site for HIV surveillance among IDU in the city. The problem was largely ignored until behavioural surveillance data in 2002 revealed that 80 percent of the city's injectors visited sex workers – the highest recorded in any site worldwide. Fewer than one in 10 IDU used condoms consistently when buying sex.

After initial discussion of the Back to Basics framework, public health officials in Surabaya saw two major areas for analysis. The first was the interaction between drug injection and commercial and casual sex. It has always been assumed locally that the large, highly visible sex industry must be the major source of HIV transmission. After considering the three major factors on which the framework focuses, surveillance and prevention officials identified sex between injectors and non-injectors as a major potential source of unprotected sex between discordant partners -- they wanted a better understanding of the potential contribution of drug injectors to a wider epidemic.

The second area of interest was within the sex industry, in particular in the provision of services for sex workers. These services included condom promotion to reduce the probability that a sex act between infected and uninfected partners would lead to an exchange of body fluids, and STI screening and treatment to reduce the risk that HIV would be transmitted should such an exchange of body fluids between an infected and an uninfected person take place.

It was not possible to cover both areas of analysis (and all the training material) in the course of the four days available. Logically, it would make sense to tackle the first area first, because it would put the relative importance of sex worker interventions into perspective within the wider epidemic. However the second area was chosen because it was of immediate topical importance. The city parliament had recently renewed calls for the red light districts to be shut down, and the senior HIV prevention official attending the training (Bpk Gaguk of the Surabaya city health office) felt the need to prepare an informed response to this call. Some local politicians believed that the HIV problem could be solved by shutting down red light districts (known in Indonesia as "localisations"). Bpk Gaguk believed that where there is demand there will be supply; shutting down red light districts would simply put more sex workers on the streets. He further believed that it is harder to provide effective services for sex workers on the streets, and even for those in the karaoke bars and other entertainment spots outside Surabaya's well-defined red light districts. NGOs agreed with him – most of their services were provided for women in the red light districts.

A lot of the initial part of the analysis work was dedicated to demonstrating that these underlying assumptions were, in fact, correct. And indeed they were. Sex workers in red light districts were more likely to have condoms easily available to them, more likely to use condoms and more likely to use STI screening than sex workers elsewhere. But it was not until the analysis was broken down by venue – separating street based sex workers from others in institutions (such as bars and massage parlours) that the higher risk in street based sex workers became apparent.

The analysis went back to the "Back to Basics" approach. The full final presentation put together by the analysis team for presentation to the Surabaya legislature is provided in an English translation in PowerPoint format on the accompanying CD-ROM. Here I have extracted the slides which show the team's use of the analytic framework outlined in Chapter 3.

And sure enough, HIV among street based sex workers in Surabaya is rising even faster than in the red light districts

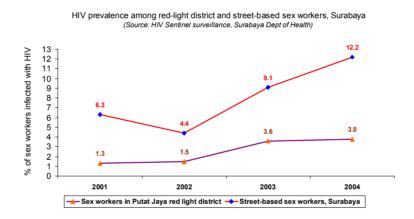
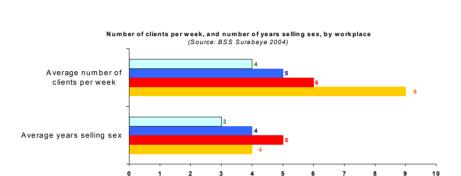


Figure 39: Slide showing analysis of who is most likely to be HIV-infected

The first step is to look at who is infected with HIV and who is not. As the slide reproduced in Figure 39 shows, HIV prevalence was higher among street based sex workers than among sex workers in the main red light district, and was rising faster.

<sup>16</sup> The training included a session on how to use Excel and Power Point software to make good graphics, and a session on how to build data into a compelling storyline which leads to clear recommendations. I have translated the slides from Indonesian to English, but have made no other changes to the presentations made by the analysis group. Electronic copies of the PowerPoint presentations are provided on the accompanying CD-ROM. Note that the "headlines" on the slides reproduced in the text here may appear somewhat irrelevant, since they have been taken out of the "story" sequence of the presentation.

The next question in the framework is: how likely is it that an infected person will have sex with an uninfected person? We know that street-based sex workers are more likely to be infected than those in red light districts. If the probability of the client being HIV-infected is the same for both groups of sex workers, then the likelihood of a discordant contact depends on sex worker HIV prevalence and on the number of partners they have.



Red-light district sex workers

Street sex workers have been on the job longest, and they sell pretty well...

Figure 40: Slide showing volume of contacts with potentially discordant clients

In fact, sex workers in brothels have more clients than those on the streets, although those on the streets have more clients than women in massage parlours or karaoke bars. The next question in the framework is: how likely is it that there will be an exchange of body fluids in sex between discordant partners?

| Massage parlour sex workers □ Karaoke bar sex workers

Street-based sex workers

As Figure 41 shows, condom use is considerably lower among street-based sex workers than among those in red light districts; indeed, street-based sex workers have the lowest condom use rate of any of the sex worker groups in Surabaya. So they are more likely to be infected with HIV than other sex workers, and more likely to be exposing their clients to that infection through unprotected sex.

# Knowledge, condom use and STI screening are lowest among street based sex workers

% of sex workers who know condoms prevent HIV, % using a condom with their most recent client, % who have have been screened for STI in the last month, by location (Source: Surabava BSS. 2004)

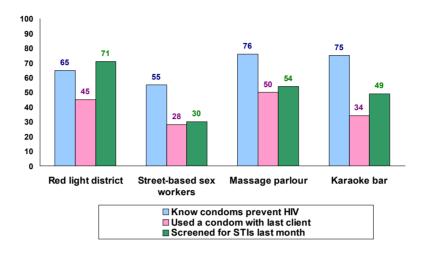
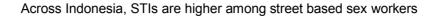


Figure 41: Slide showing likelihood of exchange of body fluids (pink bars)

The next question – how likely is it that HIV will be transmitted if there is an unprotected, discordant contact – is a more complex one. Some of the answers may be suggested in earlier figures. Figure 40 shows that street-based sex workers have been in the trade longer than others. This means that they have been potentially exposed to HIV for longer. At first glance it may also suggest that a higher proportion of infection in this group is established infection, and therefore less infectious. However if we look back to Figure 39, it appears from the steep growth in prevalence in street-based sex workers that a substantial proportion of current infections are newly acquired and may therefore be easily transmitted to sex partners if condoms are not used.

Figure 41 shows the proportion screened for STIs on a regular basis. Again, street-based sex workers are at the bottom of the table, with screening rates less than half that of red light district based sex workers. This may suggest that they have higher STI prevalence (although the analysis in Chapter 5 showed a disappointing correlation between screening and STI prevalence).

At the time of this analysis, no STI data were available for Surabaya. The analysis team therefore prepared a slide using data from other sites to suggest what the situation might be.



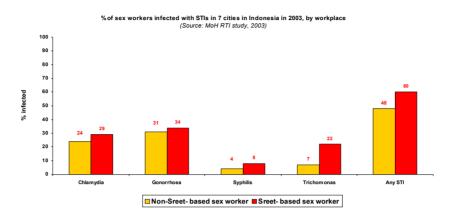


Figure 42: Slide showing likelihood of STI infection and consequent higher infectiousness in street-based sex workers

In fact, the second round of the RTI study which was conducted shortly after this analysis and did include Surabaya found virtually no difference between street-based and non street-based sex workers. In both groups, an astounding 70 percent tested positive for at least one of: gonorrhoea, chlamydia, trichomonas or syphilis.<sup>17</sup>

From the above "Back to Basics" analysis, the team concluded that street-based sex workers were both more likely to become infected with HIV than sex workers in red light districts, bars or massage parlours, and more likely to pass infection on to their clients.

The analysis (shown in Annex 1) went on to look for possible solutions. It identified an extremely inefficient use of NGO outreach services. In the red light district, condoms are almost universally available, where as only 55 percent of street-based sex workers had easy access to condoms. Yet over a third of sex workers in red light districts said they had been given condoms by outreach workers in the preceding three months, while not a single street-based sex worker reported receiving a condom.

<sup>&</sup>lt;sup>17</sup> These rates cannot be compared with those shown in Figure 42 because the tests were conducted by LCR in the Round 1 data shown in the figure, and by the more sensitive PCR in Round 2

<sup>&</sup>lt;sup>18</sup> Availability of condoms, and brands available, are independently recorded by BPS interviewers during behavioural surveillance

The analysis also showed that sex workers in red light districts were no more likely to go for STI screening if they had contact with outreach workers. Close to seven out of 10 reported recent screening even without outreach contact. But as Figure 43 shows, among street-based sex workers, outreach contact appeared to make a huge difference to the likelihood that a sex worker would get screened for STIs – only a tiny number of street-based sex workers reported any contact with outreach workers, but all of those who did went for screening.

Even without NGOs, sex workers in red light districts are screened for STIs. It's on the streets that NGOs have the potential to make the biggest difference

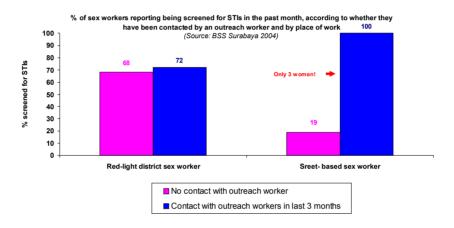


Figure 43: Slide showing analysis of effectiveness of outreach services in promoting STI screening and treatment

From this analysis, the team concluded that sex workers in red light districts in Surabaya are relatively well provided for in terms of prevention services, though improvement is needed. They recommended that NGO outreach services focus more closely on the under-served street-based sex worker population. And they warned that restricting access to red light districts might increase the number of sex workers on the streets, and therefore further undermine the already weak provision of services for this group.

The analysis shown here is not without its limitations. Most obviously, it does not anywhere address the question of the relative size of the sub-populations of sex workers. While it is true that street-based sex workers have higher HIV prevalence

and lower condom use than those in other venues, it is also highly likely that they are the smallest of all the populations. This is hard to assess accurately. The current estimate for Surabaya city is 5,200 sex workers, of whom 3,450 are direct sex workers (who only sell sex for a living). The rest are indirect sex workers – women who work in bars, discos or massage parlours and who may also sell sex. Both red light district based sex workers and street based sex workers are direct sex workers. In behavioural surveillance, samples are drawn separately for direct and indirect sex workers, but the proportions of sub-populations within each sample should be broadly representative of the proportions in the area covered by the mapping. Surabaya is one of the most difficult areas to map in Indonesia (it is one of the largest single districts). It is likely that sex worker estimates derived from mapping and listing underestimate the true figures, and that relative underestimation is greater for the more mobile and less visible street-based sex workers. That said, 16 percent of direct sex workers in behavioural surveillance in 2004/5 were street-based, not significantly higher than the 13 percent in 2002/3. So a back-of-the-envelope calculation of the absolute number of exposed, discordant contacts per month assuming the same level of prevalence in clients of both groups would be:

### **Red light district:**

3,450 direct sex workers x 84% in red light districts = 2898, x 3.8% HIV prev = 110 x 9 clients a week x 4 weeks = 3964 x 55% unprotected = **2180** 

### Street-based

3,450 direct sex workers x 16% on the street = 552, x 12.2% HIV prev = 67 x 6 clients a week x 4 weeks =  $1616 \times 72\%$  unprotected = 1164

In other words, among direct sex workers, two thirds of the unprotected, discordant contacts continue to be between red light district sex workers and their clients, with street based sex workers accounting for a third. This means that street-based sex workers are indeed punching above their numerical weight in terms of contribution to the risk of HIV transmission in Surabaya, but the brothels still outdo them in absolute episodes of unprotected, discordant sex.

This is important when planning the overall response to the current situation, and should probably have been included in the analysis. However it does not alter one of the main conclusions of the analysis: street based sex workers are already at higher

risk and harder to reach with prevention programmes. Closing down the red light districts could simply vastly increase the number of people with less access to prevention services and higher risk of exposure to HIV, and they would then be more likely to expose others to HIV.

Another limitation of this analysis is that it more or less treated STI screening as a programme outcome – the assumption being that if sex workers get screened and treated, STIs and therefore the risk of HIV transmission in any unprotected sex between an infected and an uninfected partner will fall. Although it did deal with discordancy and exposure, it did not push the analysis as far as it should have in order to demonstrate that the programme was producing a change at the level of the third of the "Basic" factors which directly influences the spread of HIV. As we saw in Chapter 5, the fact that sex workers are screened for STIs does not necessarily mean that they have lower STI rates than those not screened.

### Outcome of the Surabaya analysis

The Surabaya analysis was presented first to representatives of major donors, and then to the city and provincial AIDS control councils. It led to an immediate reorientation of NGO outreach services, away from duplication of government services in red light districts and towards greater focus on under-served populations in other areas, especially on the streets.

Talk of bulldozing red light districts has been dropped and a budget for continued service provision secured. The city AIDS control board has formed a sub-committee for data analysis which includes many of the members of the original analysis team: they have been charged with analysing the interaction between drug injection and sexual transmission of HIV in Surabaya. (Vidia Darmawi, ASA programme Surabaya, personal communication, April 2006)

# 2. Papua: Challenging misconceptions

Papua (formerly Irian Jaya), at Indonesia's eastern extremity, shares the island of New Guinea with the independent nation of Papua New Guinea. 19 Incorporated into Indonesia in 1969, it differs substantially from the rest of the nation. The Melanesian inhabitants, both Christian and animist, live largely in small communities in the mountainous interior that are only now becoming accessible as infrastructure improves. Low population density meant that Papua was chosen as a destination for resettlement of people, mainly Moslems, from the overcrowded island of Java in the transmigration programmes of the Suharto years. Javanese and other "newcomers" dominate the formal economy, and form the majority of the population in most larger towns. In addition, Javanese have been the main partners for the large multinational corporations that are stripping Papua of its natural resources. The province is home to the largest gold mine in the world, run by Freeport McMoRan, and has some of the world's largest stocks of copper and tropical hardwoods. Its fishing grounds are among the richest in Asia. Little of the profit from these extractive industries has been reinvested in Papua – health, education and infrastructure remain the poorest in Indonesia. This has caused resentment that has supported a low-grade resistance to rule from Jakarta for several decades.

The last few years have seen massive changes. Under a special autonomy law intended to defuse secessionist pressure, 70 percent of Papua's oil and gas revenue and 80 percent of other revenue now go straight into provincial coffers, making it suddenly one of the richest provinces in the nation. Much of the cash is making its way rapidly into the local economy thanks to generous spending by the now almost entirely Papuan political elite. This, and the rapidly rising wages at multinational companies such as Freeport, have changed daily life for many Papuans radically. Formerly isolated communities are now served by regular flights, market days are more common, and commodities, including alcohol, cigarettes and sex, are widely available to the increasing number of people with disposable cash.

<sup>&</sup>lt;sup>19</sup> There is an ongoing dispute about the administrative structure in Papua, its division into three provinces has been decreed by Jakarta, but has been ratified by only one of the two "additional" provinces. However no effective administrative structures are in place. I use the terms "Papua" and "province" to refer to the whole territory that was formerly Irian Jaya.

This all has a direct bearing on HIV. HIV appears to have been introduced to Papua by Thai fishermen visiting non-Papuan sex workers in the early 1990s. (Foley, Donegan et al. 2001) Papuan men buying sex carried the virus into their local communities. The pattern of spread has recently been not dissimilar to that seen in East Africa in the late 1980s. Men who have access to commercial sex and who are mobile have carried HIV between communities. Sexual networking between men and women within the community appears to vary by tribal group, but in many groups it has been substantial enough to produce an HIV epidemic driven by non-commercial heterosexual sex not seen elsewhere in Indonesia. (Butt, Numbery et al. 2002) Recent mobility and access to disposable income, and the consequent monetization of the economy, have created both a demand for commercial sex (in the form of men able to pay), and a ready supply (in the form of women willing to sell). The commercial sex sector splits into three broad categories: women from North Sulawesi and nearby provinces who sell sex in discos, bars and nightclubs to men willing to pay high prices, women from East Java who sell sex in red light districts at lower rates, and Papuan women based largely on the streets, who sell for the lowest rates and sometime barter.<sup>20</sup> Papuan men visit all three categories. It is comparatively rare for non-Papuan men to buy sex from Papuan sex workers.

Because of the presence of non-indigenous sex workers, and their role as a conduit of infection from Thai visitors to the Papuan population, it has been common for HIV to be presented in Papua as an infection of outsiders. Some political leaders have spoken of the disease as a genocide attempt, accusing Indonesian authorities of deliberately sending infected Javanese sex workers to Papua, to infect and kill off the local population. Indonesian officials, on the other hand, have sometimes implied that the epidemic is spreading rapidly in Papua because the (Christian and animist, dark-skinned) Papuans lack the moral restraint of other (largely Moslem, light-skinned) Indonesians. With this background of racism and political tension, it has been very difficult indeed to focus on the facts of the epidemic in Papua, and to plan prevention programmes that address the true risks.

<sup>20</sup> Direct sex workers in Papua report an average fee of 104,000 Rupiah (US\$ 11) from their most recent client, compared with a national average of Rp 93,000. Indirect sex workers in Papua report an average fee that is by far the highest of any commercial sex sub-sector in Indonesia: 660,000 Rupiah (close to US\$70), more than twice the average for indirect sex workers nationwide.

A first data use training was held in Papua in April 2005. Participants came from the department of health and the statistics offices of five of the province's vast and quite autonomous districts as well as the provincial level, while monitoring staff from NGOs working with sex workers, high risk male groups and young people also attended. Participants were a mixture of ethnic Papuans and other Indonesians.

After discussion of the Back to Basics framework, participants thought it important to start at the very beginning, focusing attention clearly on who is infected and who is not, and on the situations in which HIV-infected people might meet and have sex with uninfected people. The focus was exclusively sexual because at the time of the training there were no reports of injecting behaviour in Papua.

Analysis of newly-reported HIV cases showed a substantial shift over time from non-Papuans to Papuans. Public health officers were aware of the shift, but they had never analysed the data in this way before, and had trouble communicating the shift to Papuan leaders.

### And it's clear that HIV is not an "outsiders' disease"

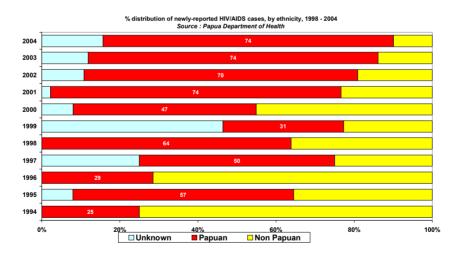


Figure 44: Slide showing the shift over time in the ethnicity of newly-reported HIV and AIDS cases in Papua

The graphic representation of the newly-analysed data, shown in Figure 44, is quite persuasive. Another slide (shown in the full final presentation on the accompanying CD-ROM) showed a similar shift in occupation among female cases over time; sex

workers dominated female cases from 1998 to 2001, but from 2002 to 2004, housewives predominate.

One of the reasons the Papua analysis relied on case reports to make these points is that there are no sentinel surveillance sites representing the general population. The 2004 national surveillance guidelines recommend sentinel sites at antenatal clinics in Papua, but this has not been implemented, largely because those accessing ANC services are largely non-Papuan Indonesians in more urbanised areas.

A handful of ad hoc population-based surveys have been carried out in Papua. But most of the HIV prevalence data continue to come from sex workers. So the next step of the analysis asked: how likely was it that the relatively highly infected sex worker population would have sex with men in the less infected "general population"?

# Percent of men who have bought sex in the last year, by occupational group and ethnicity Source: BSS 2004, Merauke youth 2003) 100 90 80 70 60 40 32 31 32 46 10 Moto-taxi drivers (Sorong) Port workers (Merauke) Civil servants (Jayapura) Unmarried youth, 15-24

The "low risk" populations aren't so low risk after all

Figure 45: Slide showing the interaction between sex workers and various male subpopulations

Behavioural surveillance in Papua includes some occupational groups at high risk (moto-taxi drivers, port workers), and others more representative of a wider population (unmarried youth in a random household sample, civil servants). Much of the analysis explored the differences in behaviour between ethnic Papuans and non-Papuans – in general, Papuan men reported slightly more risk than non-Papuans, while among women the difference was extremely marked.

The analysis team felt the need to explore potential reasons for the differences in behaviour which could be presented to policy-makers together with possible solutions. One factor emerged very clearly from the analysis: alcohol. As Figure 46 shows, both young men and young women who drank alcohol were far more likely to report unprotected sex than teetotallers; this held for both ethnic groups. Two thirds of young men and a fifth of young women report drinking alcohol, with no differences by ethnicity.

### What's fuelling all this risky sex in Papua, then?

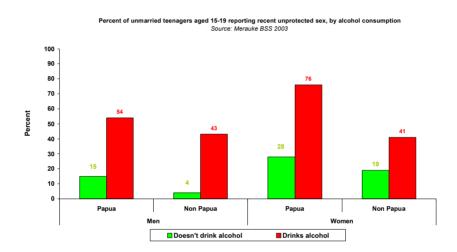


Figure 46: Slide showing association between alcohol consumption and unprotected sex in Papua

Although it is not possible to assess exactly the potential for discordant contacts in sexual networking in the general population Papua, the initial analysis suggests that it is indeed likely that there is substantial risk of HIV transmission in sex between young people. The analysis team therefore turned their attention to looking at the effectiveness of prevention programmes aimed at youth. According to programme managers, the youth programme focused on information about HIV and life skills training delivered through schools, the active involvement of religious leaders in supporting safe behaviour, and the promotion of abstinence until marriage.

The analysis of youth surveys in six sites found that fewer than one young person in 10 reported getting information on HIV from religious leaders in all but one site;

teachers reached substantially more people in every site but peaked at 53 percent coverage in Merauke. There is every indication that information is at best partial — with the exception of Merauke (which has a strong NGO and peer-outreach programme for young people), around a quarter of young people or less can name abstinence, mutual monogamy and condom use as ways of reducing the risk of HIV infection.

Analysis by main source of information, shown in Figure 47, suggests that religious leaders are least likely to impart full and correct knowledge about HIV to young people. Teachers also perform badly in Jayawijaya, the mountainous area which is home to the bulk of the ethnic Papuan population. In more urban, coastal Merauke, where non-ethnic Papuans are in the majority, knowledge is better across the board.



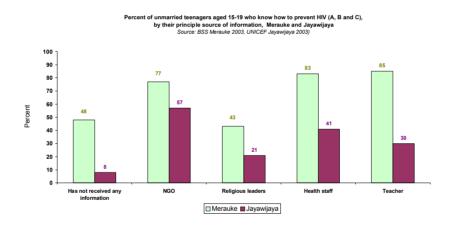


Figure 47: Slide showing HIV prevention knowledge among young people by source of information in two areas of Papua

The analysis went on to question the logic of a prevention programme that stops at imparting knowledge: analysis of behavioural data showed that over half of the young people choosing to have unprotected, premarital sex did so in the full knowledge that the behaviour carried a risk of HIV transmission.

Sex worker programmes were also analysed; the institutional approach taken in Merauke (modelled on Thailand's 100 percent condom programme) was found to be

far more successful than the individual outreach approach taken in the larger city of Jayapura; the latter neglected street-based sex workers as well as those in karaoke bars and other "indirect" venues.

### **Outcome of the Papua analysis**

On the final afternoon of the four day training and analysis session, participants invited the Deputy Head of the Papua Department of Health and several journalists to attend the presentation they had prepared. At the request of the deputy head of the health department, the results were also discussed with the Vice Governor of Papua that evening. They were later presented to the provincial AIDS control commission.

The following day, one of the major newspapers in Papua led its front page with a story about the threat of HIV in Papua, the dominance of infection and high risk behaviour in the indigenous population, and the need to go beyond information to provide prevention services for young people.

Merauke's institutional approach to sex worker programmes has now been adopted by other areas in Papua, and NGO activity has been refocused on outreach to ethnic Papuan sex workers on the streets.

The local health department initiated a second estimation and data analysis workshop in Papua in late 2005. The district of Mimika, which had not previously conducted behavioural surveillance, is planning to fund a first round of surveillance from its health budget in 2006. This should lead to continued improved understanding of the epidemic in Papua.

Efforts to improve routine sentinel surveillance in groups representative of the general population have not, so far, been successful.

# 3. China: Targeting programmes for greater effectiveness

The "Back to Basics" analysis framework has also been used in China, first within the confines of the China-UK programme, and then at a broader national level.<sup>21</sup> The

<sup>&</sup>lt;sup>21</sup> While based in Indonesia with Family Health International from 2001-2005, I also provided support for surveillance and programme monitoring to the UK DfID-funded China UK AIDS Prevention Programme, active in

China-UK programme is a DfID funded HIV prevention and care programme that was until very recently the largest HIV initiative in the country. It focused on providing services to populations considered to be at highest risk – mostly IDU, sex workers, their clients, and MSM – in Yunnan and Sichuan provinces, two of the provinces worst affected by HIV spread through sexual and drug-taking behaviour.<sup>22</sup>

In the early years, service provision was rather fragmented – prevention groups dealing with sex workers promoted condoms and STI screening and treatment, while those dealing with IDUs promoted the use of sterile needles through needle exchanges and the social marketing of safe injecting equipment. The programme also pioneered the use of behavioural surveillance in high risk sub-populations in China. The national second generation surveillance protocols issued by the National Centre for AIDS/STD Control, China Centre for Disease Control (NCAIDS/China CDC) in 2005, are based largely on those piloted by China-UK, while the questionnaires draw heavily on those developed over the course of this work in Indonesia, which were made available in Chinese translation.

Surveillance data showed HIV prevalence among IDU as low as 6 percent in one site in Sichuan, and 10 times higher in one site in Yunnan, with other sites in between. Among sex workers, however, HIV prevalence was universally low, never exceeding 1 percent. During a data analysis workshop looking at behavioural surveillance data from Sichuan and Yunnan provinces in 2004, participants learned to recode and combine data sets, using the methods developed in Indonesia. They then used the "Back to Basics" framework to identify the situations in which people who were HIV infected (largely IDU) were likely to have contact with people who were uninfected.

Participants in the analysis workshop included programme managers from China-UK at the national and the field implementation level, as well as programme managers from NCAIDS and from other donor-supported AIDS programmes. They were rather shocked at the findings from their own data, shown in Figure 48.<sup>23</sup>

Sichuan and Yunnan provinces, as well as to the Chinese government's National Centre for AIDS/STD Control (NCAIDS). Funded by UNAIDS, I was seconded to the Epidemiology Division at NCAIDS from September to November 2005 to provide support in HIV estimation and data analysis, using the methods developed in Indonesia. <sup>22</sup> Five other provinces have been badly affected by HIV as the result of unsafe plasma collection procedures between 1993 and 1996, but there is little evidence that the virus has continued to spread widely in those areas after the outbreaks were controlled.

<sup>&</sup>lt;sup>23</sup> Chinese authorities are extremely sensitive about the publication of data of any sort, so specific site names were not given in the "public" version of the analysis.

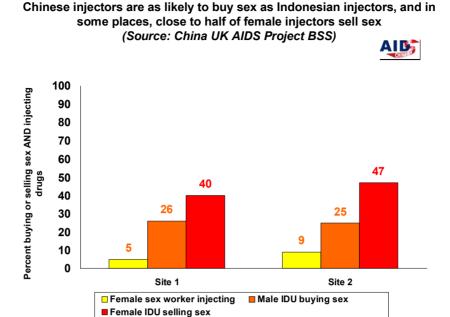


Figure 48: Slide showing the interaction between drug injection and commercial sex in sites in Sichuan and Yunnan provinces, China

The population sizes were taken into account in the analysis, and the interaction between drug injection and commercial sex clearly emerged as a major nexus for contact between people who were likely to be HIV infected and those more likely to be uninfected.

Participants then turned their attention to the likelihood of body fluids being exchanged in these discordant contacts. The data came from two separate sources — behavioural surveillance among drug injectors, and behavioural surveillance among female sex workers. Male IDU could be separated into men who bought sex and those who didn't -- Figure 49 shows condom use in commercial sex among those who reported being clients of sex workers. Female IDU could be separated into those who sold sex and those who didn't -- Figure 49 shows condom use with clients among those who report selling sex. Female sex workers could also be separated into those who inject drugs and those who don't — condom use with clients is shown separately for both sub-groups in Figure 49.

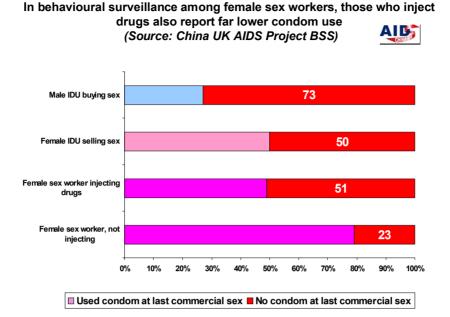


Figure 49: Slide showing levels of condom use in interactions between injectors and non-injectors, and between non-injecting sex workers and their clients

In summary, what Figure 49 shows is that among women selling sex, condom use is lowest among those who also inject drugs (the data from both the IDU sample and the sex worker sample are remarkably consistent on this point). In other words, those most likely to be infected with HIV are also most likely to be exchanging body fluids.

The analysis did not go on to look at client volume or frequency of sex, as would be desirable in a full "Back to Basics" analysis. However it raised enough alarm bells that a short presentation was prepared overnight for a meeting on HIV and drugs called by the central committee of the Communist Party, which was scheduled for the next day. The presentation, made by a staff member of US CDC who was already scheduled to be speaking at the meeting (given in full on the accompanying CD-ROM), highlighted the importance of focusing more prevention programming attention on female drug injectors who were likely to be selling sex. It received coverage from the influential national news agency Xinhua; the story, reproduced in the box below, also appeared in the Xinhua newspaper the next day, the final day of the analysis workshop.

As a result of this analysis, China-UK and other programmes targeting high risk populations focused more attention on trying to improve safe sex services for drug

injectors (and especially for female injectors), while including safe injecting awareness and referral services in programmes targeting female sex workers.

Female IDUs, key population for fighting AIDS in China: experts

BEIJING, June 24 (Xinhuanet) -- Female injection drug users (IDUs) are the key population to prevent HIV transmission from high-risk populations to the general population in China, said experts here Thursday on the sixth drug prohibition science popularization symposium & prevention and care for drug using and AIDS.

"Female IDUs may be at the highest risk of acquiring HIV and the highest risk of exposing others to HIV in China," said Bessie Lee, deputy director of US Centers for Disease Control (CDC) and Prevention Global AIDS Program, China.

According to statistics of CDC, in 2002 the three channels for China's HIV carriers to get the deadly virus are injection drug using, plasma collection and sexual transmission, covering 68 percent, 9.2 percent and 7.2 percent respectively of the total number of HIV carriers in China in 2002.

"The number of female drug users covers an percentage of 16.7 of the over one million drug users reported in China. In some regions, this percentage can even reach 40," said Cheng Feng, Country Director of Family Health International of the US in China.

"Many of them often collect money to buy drugs by offering sexual service. It makes this population a highly possible bridge connecting high-risk populations such as drug users to general population," said Cheng.

According to monitoring data offered by China-UK HIV/AIDS Prevention and Care Project, some 51 percent of female sexual workers injecting drugs do not use condoms normally.

"HIV routes for female sex workers who use drugs are from them to their male clients, then to low risk females, and then to low risk males. This is the secondary HIV transmission, which means HIV is transmitted from high risk populations to general population," said Bessie Lee.

"Now China is in the key phrase to prevent the secondary HIV transmission from spreading. How to realize this goal? The first is to focus priority attention on HIV prevention for female IDUs," said Lee.

"Next, to expand harm reduction of HIV by ways such as condom promotion and demand reduction for drug users," said Lee.

"And in the end, to offer anti-virus treatment for IDUs, especially females, to reduce risk of HIV transmission to male clients and other IDUs," said Lee.

"Now the Chinese government has begun to take measures including condom promotion and providing drug needles in regions of high outbreak of AIDS and drug using such as southwest Yunnan Province, which shows that the Chinese government has begun to take a positive and practical attitude in the prevention and care of China's AIDS and drug using," said Liu Zhimin, deputy director of National Institute of Drug Dependence (NIDD) of Beijing University.

There are nearly 900,000 HIV carriers reported in China.

Sparked by the Committee of Gao Shiqi Foundation of Science and Technology Development Foundation of China, the symposium was sponsored by NIDD, China Association for the advancement of International Friendship, Soong Ching Ling Foundation of Canada, Wujieping Medical Foundation, Lin Zexu Foundation of the U.S., China Institute for Popularization of Science and Technology, and the female mayors branch of Chinese Association for Mayors.

In late 2004 and 2005, the Chinese government greatly expanded its HIV and behavioural surveillance system. HIV prevention and care programmes were also radically expanded over that period. At the end of 2005, while on secondment to China CDC, I was asked to work with colleagues to lead a training in data analysis and use for provincial CDC staff. Programme managers from a variety of government and donor-funded HIV prevention programmes also participated.

The training began with a discussion of the Back to Basics framework, and of the principles of effective HIV prevention programme design and monitoring. Before these discussions, participants running prevention programmes had been asked to prepare presentations describing the rationale and logic of different prevention programme elements – only the government run methadone programme and the China-UK programme targeting the interaction between drug injection and commercial sex were able to articulate a clear rationale and logic which related to the

likelihood of interaction and exchange of body fluids between HIV infected and uninfected people, and the likelihood of HIV transmission in any such exchange.

Participants in this training came from several different provinces, with very different epidemic situations and data availability. It was necessary to choose a single area of focus for coherent analysis. It was decided to continue the analysis begun a year earlier of the interaction between drug injection and commercial sex, and to see whether the changes planned as a result of that first analysis workshop had had any effect.

The quantative, analytic and computing skills of the participants in the training in China were comparatively high.

# Programme logic

- Our programme aims to reach women who both sell sex and inject drugs.
- Entry points are finding injectors among sex workers as well as identifying female IDU who sell sex
- Outreach workers will distribute condoms to them, give skills training to promote condom negotiation and use, and refer to STI services.
- We will train doctors and support clinics providing quality STI services.
- Female injectors who sell sex will increase their use of condoms and STI screening and treatment.
- The risk of STI and HIV transmission will fall.

# Figure 50: Slide showing the programme logic described of a prevention programme aimed at the interaction between IDU and commercial sex

Participants were methodical in their approach, as well as in the presentation of results. The final presentation of the three-day training in China, (presented in translation on the accompanying CD-ROM) includes a clear statement of epidemiological background, programme logic (shown in Figure 50) and an analysis plan.

The analysis showed that condoms are being distributed and received by those at risk, and that condom use has risen substantially over time among women who both inject

drugs and sell sex. However skills training by outreach workers does not appear to be making all that much difference to condom use any more; condom use has become "normalised" at very high levels.

The analysis showed a much stronger correlation between contact with outreach workers and attendance for routine STI screening and treatment. As Figure 51 shows, sex workers who had contact with outreach workers were far more likely to attend STI screening and treatment facilities than those with no outreach contact, and the difference was especially marked among women who inject drugs as well as sell sex.

# And the outreach is more effective for injecting sex workers than for non-injectors

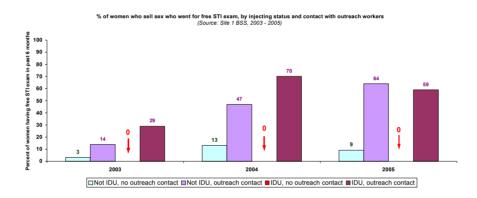


Figure 51: Slide showing correlation between outreach worker contact and STI screening among women who sell sex, by injecting status

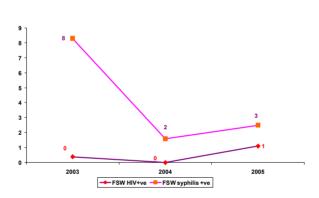
Of the injecting sex workers who were not contacted by outreach workers, not a single woman went for STI screening. Among those who did have outreach contact, over two thirds went for screening and treatment.

As we saw from the Indonesian data, it is worth questioning the assumption that more STI screening and treatment will lead to lower STI prevalence and therefore lower risk of transmitting HIV in any unprotected HIV-discordant sex. The only STI surveillance data routinely available in China are syphilis data – syphilis among sex workers in this site fell from 8 percent in 2003 to 2 percent the following year. However, routine programme monitoring data revealed weaknesses in the China-UK

programme's STI treatment facilities. The programme trained 40 doctors in STI management in the period covered by the analysis. Clinic data show that between them all they were treating an average of 59 women a month in project clinics – one and a half patients each per month.<sup>24</sup>

Overall, the analysis concluded that the programme had done quite well in achieving its goals of reducing the risk that HIV-infected female injectors would pass HIV on to non-injectors during commercial sex in the area under investigation (Sichuan province). Overall, syphilis dropped among female sex workers and HIV prevalence did not rise between 2003, before the programme re-design, and 2005.

The Chinese analysts went on to complete the cycle of a "Back to Basics" analysis. The first conclusion to the question analysts posed themselves: "Have we reached our programme goals?" is shown in Figure 52.



Yes! HIV among sex workers is not rising

Figure 52: Slide showing analysts' initial conclusions about achievements of HIV prevention programme goals

But the answer to the larger question: "Has the programme had any impact on the overall epidemic?" was less conclusive, as shown in Figure 53

<sup>&</sup>lt;sup>24</sup> Programme managers considering these data thought it highly likely that project-trained doctors were providing equivalent services outside of project clinics, in order to increase their income. They planned an enquiry after the training.

Yes! HIV among sex workers is not rising
Well maybe not. Are we missing an ongoing epidemic in IDU?

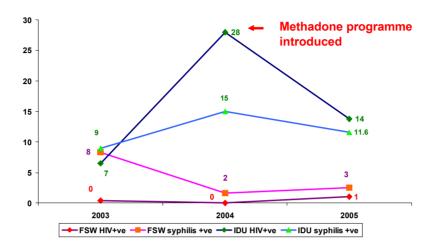


Figure 53: Slide showing analysts' final conclusions about achievements of HIV prevention programme goals

(In the Chinese presentation these are animated stages of the same slide).

Successful prevention programmes focusing on interaction between injectors and sex partners (especially commercial partners) may have contributed to preventing an expected extension of drug-driven infections into sexual networks, but spread through injection itself had been neglected. The analysis concluded with a strong recommendation to revisit programmes for drug injectors (an area that, at the start of this analysis, was considered to be "under control").

It was not possible to revisit the IDU data during the three day training, but this has happened since, as part of an extensive programme review. The training has since been extended to other provinces, and the Epidemiology Division at China CDC is providing support for this type of programme planning and evaluation analysis to the Global Fund and other large programmes which have requested assistance following the initial training.

### 4. Lessons learned in the field

The experiences of Surabaya, Papua and China – all quite different in terms of HIV epidemic background, institutional structure and human capacity -- provide a small window onto the use of the framework and analytic approach described in Chapters 3 and 5. Each of the analyses were produced in four days or less, and were the work of people who had never before been introduced to the framework, who often had limited experience in data analysis or programme monitoring, and who may never previously have seen the data sets or analysis software involved.

It is important to stress that these examples are a small drop in the ocean of analysis needs. However taken together, they suggest that a simple, clear analytical framework that focuses on the basic factors influencing the spread of HIV can indeed be useful in routine public health settings in developing countries, both to improve the understanding of a local HIV epidemic and to monitor the progress of prevention and care programmes.

A number of important provisos and lessons have emerged from the work so far, which might serve to inform future efforts.

## a Lesson 1: The right data, in the right format

Good analysis depends on good data. Data must be recent and appropriate to the questions being asked, and data from different sources must be available to the same analysts.

Chapter 1 discussed extensively the importance of surveillance and monitoring systems that produce data that can be used to analyse the HIV epidemic, the behaviours that spread it, and the programmes that seek to prevent it. Chapter 2 described the efforts undertaken in Indonesia as part of this work to develop and secure a national system that is capable of producing these data sustainably over time. The Indonesian surveillance system now routinely produces HIV sentinel surveillance, behavioural surveillance, population size estimation, STI surveillance and programme monitoring data; with the exception of STI surveillance these are all integrated into routine government-led activity. Without these data, it is not possible to undertake the kind of analysis described above.

It is important to stress that the format of the data is every bit as important as its simple existence. Data that are not easy to use will not get used. The paucity of the programme monitoring data in the analyses above is in large part because, at the time of the analyses, those data were stored in over a hundred Excel spreadsheets of inconsistent design. Groups working with the programme data could take several hours to analyse a single programme component and generate a single graph, while groups working with recoded, clearly labelled behavioural data could undertake analyses and generate graphs within a few minutes.

The availability of data from different sources is also fundamental. In some cases it proved extremely difficult to get different government agencies to cooperate in sharing data for analysis (sometimes even national and provincial units of the same agency refused to share data). Programme monitoring data are especially hard to access. We found that analysis teams including representatives from all the different organisations with data, as well as from organisations which may be "consumers" of data, were able to work together very cooperatively, and that more and more data emerged during the course of each analysis workshop. Formalising and sustaining this kind of teamwork in analysis may, however, prove difficult.

### b Lesson 2: Keep it structured

One of the greatest challenges in developing an analysis plan in all sites was getting participants to describe the logic of targeting, service delivery and desired outcome that underlay their HIV prevention and care programmes. Unlikely as it may seem, until the Back to Basics framework was discussed, even those participants in the training who were managing the implementation of prevention programmes or were responsible for service delivery were often unable to articulate why they were doing what they were doing.

Articulating what a prevention programme is expecting to achieve and how it is planning to achieve it is an inescapable first step in undertaking any analysis of whether prevention efforts are meeting their goals. It is essential to have the active participation of people who are able to define what a programme is trying to achieve, and how.

### c Lesson 3: Keep it concrete

Analysis of a local HIV epidemic and of prevention programmes is by definition specific to a given situation. The people involved in the analysis know the situation, and can often suggest possible routes of enquiry that point to locally specific problems which will have locally specific solutions.

This is important because there is a tendency to try to develop "generic" tools and indicators for epidemic analysis and programme monitoring, and "generic" data sets for training. This work has developed a simple framework that can be used to pinpoint priorities in virtually any epidemic situation, and a set of questions that can be used to investigate the association between programmes and outcomes for the purposes of programme management. Experience in the field suggests that people with different backgrounds and analytic capacities can easily use these frameworks to organise information about their own epidemic situation – information that was collected locally from people for whom programme managers seek to provide specific services. The process increases understanding of prevention and care priorities and of programme performance, and often points to necessary changes which are immediately actionable.

Locally relevant analyses that identify specific difficulties and propose specific solutions are generally welcomed by programme managers and by political decision-makers alike. In the examples described above where analysis results were communicated quickly to policy makers (through presentations) and to the public (through the press), immediate changes were made to programme implementation. In at least one of these cases, in China, follow-up analysis suggests that the programmes have contributed to a reduction in the risk of the sexual spread of HIV.

Trying to formalise this analysis process into a piece of software that can be downloaded from a website or into a manual with a series of "dummy tables" is unlikely to be productive.

### d Lesson 4: Mix and match

The insistence of Lesson 3 on using a simple framework to guide locally-specific thinking as the primary tool for programme analysis is not intended to discount the value of analytic or projection software. If the capacity to use some of the models

described in Chapter 1 exists locally, there is no reason that these models should not be used to further the analysis of programme effectiveness. Say, for example, that a "Back to Basics" analysis of unprotected, discordant contacts with a high probability of HIV transmission suggests that commercial sex is the major driver of an HIV epidemic locally. This being established, it may be a good idea to use the HIV Tools programme Sex Work to get a more sophisticated estimate of the cost and effectiveness of the outcomes of different sex worker programme approaches.

The use of more sophisticated projection software in conjunction with a "Back to Basics" analysis can help to overcome two of the most important constraints of the approach – firstly, its failure to take into account the relative costs of different prevention options, and secondly its inability to give an idea of the long-term consequences of different choices. In Jakarta, for example, the Back to Basics model was used to estimate the distribution of new HIV infections by risk behaviour over a single year, showing that at current, already high levels of prevalence among IDU, some 40 percent of HIV prevalence and 80 percent of incidence could be attributed to drug injection. (Pisani, Garnett et al. 2003) Then Asian Epidemic Model was used to project a "counterfactual" – the course of the epidemic without any IDU. The baseline model predicted 110,000 infections in Jakarta by 2010, 35,000 of them among IDU. Without any IDU epidemic at all, the Asian Epidemic Model showed that Jakarta could have expected as few as 2,000 HIV infections by the end of this decade. (Pisani, Setiawan et al. 2003) In other words, drug injection acted as a catalyst for a wider sexual epidemic – some 73,000 infections were sexually transmitted, but originated in the chain of infection with a drug injector. This kind of analysis, which cannot be provided by the simple "Back to Basics" approach, can provide powerful advocacy material supporting programme choices that are dictated by an analysis of exposure in the current situation.

### e Lesson 5: Human resources

The uses of the "Back to Basics" framework described above were the result of trainings and/or workshops, planned with external technical and financial support, and bringing together people from different institutions. However, to be truly useful to the local or national response, this type of analysis needs to be undertaken on a

routine basis. This means it needs to be institutionalised into a regular planning and evaluation cycle.

Realistically, the institutionalisation of analysis at any level (for example within a district government, or within a large, donor-funded prevention and care initiative) narrows the cross-section of people involved in the analysis. Most of the work will be done by epidemiologists and monitoring staff – and as Chapter 1 noted, the incentive structure is stacked against routine data analysis work even for these people in some countries. Programme implementers are even less likely to find the time to be involved in analysis on a routine basis. And yet the involvement of programme planners and implementers has proven critical, because without them to describe the programme logic and interpret findings, analysts may not know what questions to ask. Much more importantly, without the active participation of programme managers in the analysis process, it is very likely that the findings will get stranded in a report or on a slide, rather than being used to improve programme outcomes.

Analysis will not lead to improved programmes on a routine basis unless there are clear mechanisms through which programme implementers guide analysis, and the results of analysis in turn guide programme implementation.

# Chapter 7: The Back to Basics Framework: a critical review

The clamour for evidenced-based decision-making in health, and for results-based funding in development assistance, continues to grow in volume. This work has examined current practice in using evidence to plan and manage HIV prevention and care programmes; current practice has been found wanting. Chapter 1 proposed three main reasons for this:

- gaps in the evidence base
- weak incentives for basing programmes on evidence
- lack of a clear framework to translate evidence into programme decisions

In addition, many of the analytical tools available are inappropriate for use in routine public health settings.

The remainder of the work sought to address those issues in Indonesia, a country whose HIV epidemic is concentrated in sub-populations with high risk behaviour, by strengthening the surveillance system, developing a clear analytic framework for analysis of prevention priorities and programme success, and using the resulting data and analytic framework to improve HIV prevention efforts. Chapter 2 described a number of steps taken to reduce the gaps in the evidence base in the context of Indonesia's national surveillance and monitoring system. Chapter 3 proposed a framework through which surveillance data can be used, practically and effectively, to guide programme planning. The framework was used in Chapter 4 to investigate HIV prevention priorities in Jakarta, and to examine the actual and potential effects of different prevention efforts in terms of epidemic impact. The approach is extended in Chapter 5, with a set of simple questions which link programme implementation with outcomes and impact. The chapter demonstrates how these questions can be used to guide programme management on an ongoing basis. Both Chapters 4 and 5 use approaches that are easily communicated and are adaptable to different settings. Chapter 6 gives examples of the use of the proposed framework and the associated programme management questions in routine public health settings in three quite different situations.

To conclude this work, I summarise the advances represented by this work, examine the continuing challenges, and discuss the extent to which this approach is generalisable. Implications for policy and research are discussed.

# 1. Filling gaps in the evidence base

Chapter 1 described international recommendations for HIV-related surveillance in concentrated epidemics. Chapter 2 opened with a review of the state of the Indonesian surveillance system in 2001, prior to the start of this work. Nationally-led efforts were limited to HIV surveillance, using protocols that were unclear and inappropriate to the evolving epidemic. Decentralisation was undermining surveillance activity and disrupting data reporting. Behavioural and STI surveys existed but were not institutionalised; support from different donors with differing priorities led to duplication and fragmentation. None of the available data were used to guide HIV prevention policies, and data were not routinely published. There was no information on population size, and programme data were not available.

### a Advances achieved in surveillance system strengthening

In the course of this work, we achieved the following advances:

- Publication of existing data, and an established procedure for publication of a biennial national report on HIV
- Secured national funding for surveillance activities, and consolidation of donor support for a single, national surveillance system.
- Revision of national HIV surveillance protocols in line with the developing epidemic, and development of simple reporting and analysis software.
- Institutionalisation of behavioural surveillance under the Bureau of Statistics
   (BPS). Expansion of the system to cover over half of all provinces and all at-risks
   groups.
- Consolidation of data into a single, national, recoded data set which currently covers over 18,000 individuals at high risk for HIV transmission. As far as we

know, Indonesia was the first country to consolidate behavioural data to facilitate analysis.

- Development of methods to estimate the size of all populations at high risk for HIV, at the provincial and district level. As far as we know, Indonesia was the first country to develop methods and systems for comprehensive population size estimation at this level.
- Development of a single, web-based national data base for programme monitoring data, available at the implementation, management and policy levels as well as to the public This has involved agreement about programme management data collection between the Indonesian government and all major donors. As far as we know, Indonesia is the first country to develop a national programme management database.

### b Generalisability of the advances

A number of the advances described above have already been adopted globally or regionally.

- Questionnaires, field protocols and training materials developed by BPS to guide
  Indonesia's behavioural surveillance activities have been adapted for use in
  Malaysia. Translated into English and Chinese, they have been made available
  throughout Asia and have influenced the behavioural surveillance system in India,
  the Philippines and China.
- Population size estimation methods (and associated HIV estimation methods)
  developed in Indonesia were recommended by the UNAIDS Reference Group on
  HIV Estimates, Modelling and Projection as the basis of the global Gold
  Standard for estimates in concentrated epidemics with limited time series data.
  The methods have since been used in a number of countries, including China,
  Nepal and the Russian Federation and are currently being tried in India.
- The procedures and methods for management of behavioural surveillance data developed in Indonesia form the basis of the UNAIDS/WHO/CDC/FHI surveillance series guidelines on data management. They have been used in China, India, Cambodia and PDR Lao.

### c Continuing challenges

The biggest challenge in all areas of public health surveillance in Indonesia is the lack of human resources. During the course of the work described above, significant efforts were made to provide training to public health staff at the central as well as the provincial and district levels. Capacity has been secured for behavioural surveillance, largely because the quasi-autonomous statistics bureau has not been decentralised. It remains a highly centralised professional organisation, with well-established structures and facilities for training. By 2005, there were several dozen senior staff capable of providing advanced training in all aspects of behavioural surveillance, and many more capable of providing training in field procedures. BPS staff have clearly defined functions for which they receive extensive basic training, and turnover is relatively low.

The same is not true of the Ministry of Health. Many staff have multiple responsibilities for which they have had little or no formal training. Provincial governments are responsible for training district staff who actually implement surveillance activities, but they have no budget, system or capacity to provide such training. In the world's fourth most populous nation, there is not a single civil servant responsible exclusively for HIV surveillance. Training efforts have been undermined by extremely high staff turnover at all levels.

A further challenge is resurfacing in the form of increased donor pressure to demonstrate results attributable to specific programme efforts. From 2001 to 2005, a great deal of energy was invested in ensuring that the national surveillance system met the needs of all of the potential users of the data, so that all donors could invest in that system rather than fund separate data collection activities. UNAIDS is currently planning a Best Practice Collection case study of this experience, thought to be an important step towards turning the "Three Ones" ideal of a single national M&E framework into a reality. Since the completion of the work described here, however, several donor-funded programmes have proposed integrated behavioural and biological surveys in programme areas, some of which duplicate the regular national surveillance system. "We are totally confused by this," commented one senior P2M official. "Will their IBBS follow national protocols? What about sustainability ... and ethical issues? ...We already have a surveillance system – don't lets screw it up" (P2M official, e-mail communication, 11/04/06)

### d Implications for research

Inspection of exiting data suggests high levels of consistency within and between the various data sets. However it is clear that some important areas of information are under-represented in the data. Development of methods to reach some potentially important populations, such as the clients of high-end sex workers, is necessary. Existing data sets also present the opportunity for a fuller exploration of areas which have been much discussed but little quantified in surveillance. These include:

- the value of weighted analysis for populations such as sex workers. All analysis
  so far is unweighted because cluster information data for 2002 was judged to be
  poor. The introduction of Cluster Information Sheet software in 2004 allows for
  reliable weighting; data have been entered but not analysed.
- the potential bias introduced by use of different interviewers. Most behavioural surveillance included interviewers from BPS, the health department and NGOs; interviewers can be differentiated and responses compared.
- the potential bias introduced by the integration of behavioural and biological surveys. The RTI survey, which includes biomarkers, uses the same sample frame as behavioural surveillance, and an abbreviated version of the same questionnaire. Responses across the two surveys in the same populations can be compared.

In addition, systems research around the development and retention of human capacity within government systems is needed. This is discussed further in the section on incentives.

### e Policy implications

The advances described above suggest that the principles of Second Generation Surveillance can be implemented in large and administratively complex countries with concentrated epidemics. However certain important conditions apply.

 To be effective, surveillance must be nationally led from the central level. HIV surveillance systems provide a national public good and should be conducted using financial and human resources that are securely integrated into national systems and provided for by the central treasury, regardless of a nation's administrative structure.

- Donors and other interested parties will ultimately serve their own needs best by supporting a single, national system that provides high quality data in a form that is well managed, readily accessible and easy to analyse. Real or perceived demand for data showing changes attributable to a specific projects result in duplication, wasted opportunities, an exacerbation of human capacity constraints and under-investment in data quality. The opportunity costs of such duplication are extremely high.
- Investment in data management is as important as investment in data collection.
- Even with concerted donor support, no national system will be sustainable unless
  it includes structures and mechanisms that ensure adequate human capacity for
  implementation at all levels. Failure to invest in the systemic production of
  trained personnel in sufficient numbers will undermine all other efforts to
  improve public health surveillance systems.
- Surveillance systems must be coherent in design, so that different data sources
  complement one another and can be analysed together. It is critical to ensure that
  data from different sources are available to the same analysts.
- The components of Second Generation Surveillance proposed by UNAIDS/WHO should be extended in concentrated epidemics to include routine, systematic and data-based estimates of the size of populations at risk for HIV. Programme monitoring data is also an integral part of an HIV-related information system, and national authorities should assume responsibility for ensuring that these data are collected and reported in an acceptable format.

# 2. A clear framework to guide analysis

Chapter 3 of this work proposed a simple framework to guide the analysis of surveillance data in ways most likely to be useful to HIV programme planners and other decision-makers. The framework focuses on describing, in the context of a local epidemic, the three key factors which, in sequence, determine the spread of HIV:

- the likelihood that an HIV-infected person will have sex or take drugs with an uninfected person
- IF an HIV-infected person has sex or takes drugs with an uninfected person, the likelihood that body fluids will be exchanged
- IF body fluids are exchanged between an HIV-infected and an uninfected person, the likelihood that the virus will be transmitted and a new infection will occur

### a Advances made by the Back to Basics framework

This framework aims to put the epidemiology of HIV infection back at the heart of programme planning and analysis. It is based loosely on the components of the reproductive rate of infection originally described by May and Anderson in 1987. These are: the average rate at which new sexual partners are acquired, the average probability that infection is transmitted from an infected individual to a susceptible partner (per partner contact) and the average duration of infectiousness.

From the point of view of an analyst or policy maker wishing to use available data sources to improve the understanding of the local epidemic and to plan and monitor an appropriate response, this framework has three major limitations.

- It does not take into account the current state of the epidemic or distribution of infection
- It does not use data provided by routine surveillance systems
- It is not clearly related to programme effort

In addition, although the framework, expressed by the authors as:

$$R_0 = \beta c D$$

is elegant and simple, is not intuitively easy to understand.

The elements of the reproductive rate of infection were taken up again by Boerma and Weir in their paper of 2005. They were used to describe the biological pathways through which behavioural change might impact on HIV infection, in a proximate determinants model. This model also failed to take into account the epidemic state at the outset of the model. Programmes are included in the model, both as underlying

and as proximate determinants. However the authors observe that it is not possible to disentangle their effects on the biological determinants of infection.

The Back to Basics framework resolves many of these limitations. It contains the following innovations:

- The framework takes the current epidemic state as a starting point. This is a sine qua non for effective response planning.
- Most of the elements of the Back to Basics framework can be quantified using data from routine surveillance data.
- The elements of the reproductive rate of infection are deconstructed and laid out sequentially to guide effective planning. Discordancy is considered first, since if there is no discordancy there is no chance of HIV transmission. Then comes exposure to body fluids, also a prerequisite for transmission. Only then need we consider the other, more complex elements which are grouped with exposure in the other models as components of the efficiency of transmission per contact.
- The potential influence of different prevention and care programmes are mapped clearly on to the various stages of the Back to Basics framework.
- The Back to Basics framework is expressed as a series of simple questions which can be understood and discussed by programme implementers and policy makers at any level of analytic ability.
- Quantifying the framework with local data (as illustrated in Chapter 4) obliges analysts to consider the relative size of the various populations at risk, and focuses on the interaction between those populations.

The Back to Basics framework is essentially a tool for setting programme priorities. While frameworks for programme monitoring also exist, none relates programme implementation clearly to outcomes and impacts. Chapter 5 uses a simple question sequence to relate programme performance to outcomes within the Back to Basics framework. It contains the following innovations:

• A clear statement of programme goals and logic as a starting point for analysis

- A simple sequence of questions which follow programme logic. This allows
  analysts to pinpoint areas of strength and weakness, so that areas for programme
  improvement can easily be identified.
- A direct link between programme outcomes and impact on the epidemic; outcomes are examined for changes they make to any one of the three factors determining the spread of HIV expressed in the Back to Basics framework to focus
- Analysis based on data routinely available in national systems

### b Generalisability of the advances

The Back to Basics framework and the programme monitoring sequence have been used with programme managers and policy makers in a number of different situations, some of them described in Chapter 6. In every case, people of varied backgrounds and abilities have quickly grasped the principles involved, and have been able to use the framework to give coherence to an analysis of the local epidemic situation and local programmes.

The framework is currently available in three languages. Since the completion of this work, it has been used in a number of Indonesian provinces, and has been integrated into the training materials used by China CDC in training provincial staff. It is also used by China CDC staff to guide analysis performed at the request of the Global Fund and others. The framework has been used in teaching on HIV courses at Princeton University and the London School of Hygiene and Tropical Medicine.

The factors governing HIV transmission are universal, and the framework is therefore universally applicable, at least in theory. However, it is in my opinion less well suited for use as a public health planning tool in generalised epidemics. This is because issues of discordancy differ in concentrated and generalised epidemic. It remains true, of course, that the first requisite for HIV transmission is exposure between an infectious and a susceptible person. In concentrated epidemics, without knowing which individuals are infected, we can still use sentinel surveillance to identify sub-populations that are more or less likely to be infected with HIV. Evidence of mixing between those sub-populations is evidence of the potential for discordancy. In generalised epidemics, where infection is spread more evenly

throughout the general population this is less true. The framework does not currently capture the partner selection effects that are critical in determining the spread of HIV in generalised epidemics, as discussed below.

### c Continuing challenges

There are a number of areas that are not well described in the Back to Basics framework. Principle among them is partner selection (or network effects). This is particularly relevant in generalised epidemics, and in intra-population mixing in concentrated epidemics, especially between drug injectors and men who have sex with men. The quantified version of the Back to Basics framework shown in Chapter 4 essentially assumes random mixing in any given interaction. The likelihood that any given contact is discordant is calculated simply as the likelihood that one partner is infected (i.e. the population prevalence) times the likelihood that the other partner is uninfected (i.e. 1- the population prevalence). In truth, it is likely that there may be clustering of people of the same sero-status — uninfected people may choose to inject drugs or have sex only with other uninfected people. In Indonesia, rates of testing are currently so low that it seems unlikely that partner selection is a major factor in HIV prevention behaviour, but the situation may be different where testing is more widespread.

The Back to Basics framework suffers from other limitations. It can not be used to look at what might happen in the distant, or even the medium-term future. And it does not provide contextual explanations for why current behaviours are as they are. The intermediate effects of important structural changes such as legislation to facilitate prevention programmes or reduce discrimination will not be seen until they are translated into behaviours that actually change the basic factors affecting HIV transmission.

### d Implications for research

Some elements of the Back to Basics framework would benefit from better quantification. Methods to estimate partner selection effects from routine behavioural surveillance data would be an important step forward. In addition, little is currently known about the protective effects of some of the most easily achieved changes

affecting the risk of HIV transmission in concentrated epidemics, such as increases in the use of lubricants in anal sex and in bleaching of needles. The role of heightened infectiousness during primary HIV infection deserves further attention, both in terms of quantifying its effects and in developing potentially appropriate diagnostic tools and responses.

### e Implications for policy

The experiences described in Chapters 4 to 6 suggest that use of the Back to Basics framework and the associated programme monitoring approaches can be used in a wide variety of settings to prioritise HIV prevention and care policies and to improve the performance of prevention programmes in real time.

The framework begins from the current epidemic state and takes into account distribution of HIV infection, population size, levels and frequency of risk behaviour, as well as the relative risk of HIV transmission. It obliges decision-makers to specify how interventions are expected to impact on the epidemic, and allows analysts to look, at a glance, at the expected effect of different prevention programmes, at different levels of coverage. The Back to Basics framework and the associated programme management approach appear to have helped programme implementers to understand the goals of their programme, and articulate the way they seek to achieve those goals.

In theory, then, the framework can be used to choose the most effective HIV prevention and care approaches in a way that is transparent and easily understandable by all those potentially affected. Analysis using the Back to Basics framework will also highlight the inadequacy of any approaches which fail to address, on a sufficient scale, the behaviours most likely to be transmitting HIV in the local situation. Whether or not the framework is used in this way depends not on the technical feasibility, which has been proven during the course of this work, but on the perceived desirability. This is dealt with in the next section.

# 3. Incentive structures to promote evidence-based programming decisions

The sum of this work so far suggests that it is indeed possible to develop robust national surveillance and monitoring systems for HIV. It is possible, too, to use the data generated in a simple analytic framework to determine where HIV infection is most likely to be spreading, to investigate how well programmes are doing at reducing the risk, and to suggest changes which will lead to improved outcomes.

The next step is to institutionalise these elements so that they produce better analysis and better programme outcomes on an ongoing basis.

### a Assessment of efforts to institutionalise analysis

This work has identified many of the structural obstacles to institutionalisation of better data generation, analysis and use. They include:

- political disincentives to confront the major engines of HIV infection within national governments, including those in donor countries.
- lack of demand from funders to demonstrate that programmes are designed and managed to have the greatest possible impact on HIV transmission
- chronic shortage of human capacity in analysis and data use for programme planning and management

During the course of this work, we tried to increase capacity for analysis by creating an analysis unit attached to the HIV unit of P2M. The idea was accepted by the Director General of P2M and financing and training were made available. Four options were suggested for financing and staffing the analysis unit, including salary supplementation for P2M staff, creation of a paid secretariat for the surveillance and analysis working group, secondment of BPS staff and outsourcing to university staff physically located in P2M. However no institutional structure could be agreed.

A training curriculum was also offered to schools of public health, in order to introduce basic skills in surveillance and data analysis early on. This did not get off the ground, largely because of institutional inertia within the universities.

As an alternative, analysis teams were created at the local level, as described in Chapter 6. This was successful as far as it went, but it is not a sustainable solution. It has no built-in mechanisms for further training or replication, and members of the analysis teams, all of whom have other jobs, have no incentive to participate other than personal interest.

In short, this work made no major advances in institutionalising a culture of data analysis and data-based decision making.

#### b Implications for research

Several developing countries in Latin America and a few in Asia (most notably Thailand, and to a lesser extent the Philippines) have managed to build a credible and sustainable public health infrastructure with a certain depth of human capacity. More research into the mechanisms through which this has been achieved would be invaluable.

## c Policy implications

High quality data and clear analytical frameworks may produce good, data-based decision making in theory. But in the field of Public Health, a theory is of little value unless it can be turned in to practice. In the four years to 2005, despite concerted efforts from a number of partners, and excellent examples in practice, we failed to institutionalise a culture of data analysis and use. If this is to change, it is critical that governments, technical organisations and donors unite to confront the major structural constraints to better analysis. This means:

- creating demand for good analysis by requiring countries and organisations to follow a sound, epidemiologically based framework such as the Back to Basics framework in applying for grants and funding of HIV-related activities
- creating a culture of good programme management by requiring programme implementers to state their programme logic clearly. Implementers should then use a question-based analysis to see if programme logic is working, adjusting their approach as necessary without penalty. Programme managers should be

rewarded, rather than discouraged, for pointing out and correcting weaknesses in HIV prevention and care programmes.

• creating the capacity to meet those demands by finding a structurally appropriate way to provide training in analysis. That means finding the right people to train, and ensuring that those trained people end up in jobs that enable them to do the analysis, both because they are in the right institution and because they are adequately compensated for the work. This will not be achieved in a wave of multi-country workshops. It needs a long-term commitment that will create a depth of human capacity which can withstand the staff turnover and other pressures commonly seen in the civil service in developing countries.

#### 4. Conclusion

This work has succeeded in supporting the creation of a strong national surveillance system, which has become a model of its kind regionally. Many of the methods developed during the course of this work have been adopted internationally. I have further suggested a simple framework for analysis of HIV epidemics which focuses on the limited number of factors which determine the spread of the virus.

The work has demonstrated that the framework can be used both to increase understanding of the HIV epidemic and to monitor and suggest improvements to HIV prevention programmes. It has demonstrated that it is possible to use the framework with data generated by routine HIV surveillance and monitoring systems, working with public health staff in a number of different developing country settings. The process of analysis itself has forged links between people in different institutions at a local level. Participation in the process of analysis using this framework has provided clarity about programme objectives, and has helped people to articulate their achievements and the challenges they face.

The Back to Basics framework and the programme analysis questions are based on principles that are universally applicable in concentrated HIV epidemics and perhaps beyond. The constraints to its wider use are not technical – it has proven useful in numerous settings. Rather, they are structural. This work did not succeed in

institutionalising the type of analysis suggested in Indonesia (although in China, where human capacity is less of a constraint, the framework is now widely used).

Routine analysis that focuses HIV prevention programmes on the factors that will actually reduce the spread of the virus depends on increasing the demand for this type of analysis, and supply of those able to provide it.

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## **Acknowledgements**

Many people have contributed to this work. First among equals must be my Indonesian colleagues who worked hard and persistently to develop the national surveillance system into a model in the region. The team at the Ministry of Health's Directorate for Communicable Disease Control, and the sub-Directorate of HIV/AIDS – Haikin Rachmat, Saiful Jazan, Sigit Prihutomo, Fonny Silfanus, Bpk Slamet, Berton Suar and others, and especially the patient, ever-smiling and hardworking Naning Iswandono – led the charge. The Bureau of Statistics staff, ably led by Arizal Ahnaf and Happy Hardjo, were valiant in taking on new areas of research and enquiry. Their dedication to quality was an inspiration and an education to me, and they made it fun. Team members are too numerous to mention, but I would like especially to thank Mohammad Noor Farid and Sugih Hartono for many hours spent teaching me about data management.

The staff of the ASA programme worked closely with me to develop many of the ideas in this thesis, as well as the tools and training materials we used to put those ideas into practice. Aang Sutrisna, Kharisma Nugroho and Vidia Darmawi were very closely involved; it is to them that we owe what I believe to be the world's first live national HIV programme monitoring database, and to them that I owe much of my good humour. Terima kasih. Arwati Soepanto was a fount of wisdom and patience, and an invaluable guide to supporting innovation with government partners. Philippe Girault and Hari Purnomo taught me how to keep field work on track. Jim Johnson found resources to support every new venture that our team came up with. Thanks are especially due to Steve Wignall who led us all by example, with dedication, compassion, sound technical guidance and a healthy dose of ribald realism.

ASA staff and their partners inside and outside of government ran many of the programmes which contributed data which are used in the analysis; they were often working in difficult situations and to be commended for their dedication to trying to improve the lives of the people they served. To the tens of thousands of men, women and waria who have contributed their time, their frank responses and often their blood to allow surveillance staff to build up a clearer picture of the spread of HIV in Indonesia, I extend my warmest thanks. I hope and trust that the work we have done

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continues to contribute to an improvement in their occupational and recreational safety, and their enjoyment of life.

This work would not have been possible without the support of our colleagues at USAID, who provided far more than just the money that funded much of the systems development described. This work has described institutional constraints to good data analysis, particularly the disincentives to look critically at programmes for fear that those who hold the purse strings will be displeased. This was emphatically not the case in our own programme: Ratna Kurniawati, Joy Pollock, Molly Gingerich and Lisa Kramer all actively encouraged analysis that aimed to identify and solve problems. They also supported development of surveillance systems that served the broader national interest rather than narrow programme interests. Without their vision this work could not have been achieved.

Penny Miller shared the burden in supporting much of the early surveillance systems development. With characteristic tenacity she delved into the "too hard for now" basket and attacked the difficult and neglected tasks that I had left there. We were helped by Brad Otto in many of these.

Though this work focuses on Indonesia, the fruits of it were most recently tested in China. For this I would like to thank the staff of the epidemiology division of the National Center for HIV/AIDS/STD Control. Director Lu Fan provided me with opportunities that were extraordinary, not least the opportunity to work with his talented and dedicated staff. They are too numerous to thank individually, but special recognition must go to Wang Liyan and Chaganhuar. It was in midnight discussions with them that the current version of the Back to Basics framework came into being. My work in China was paid for by the UNAIDS Regional Support Team in Bangkok – thanks to Prasada Rao and Swarup Sarkar – with generous technical and moral support from Joel Rehnstrom and He Jinglin in the Beijing office.

In the international sphere I would like to acknowledge the contribution to the development of my ideas about surveillance and monitoring made by the "Geneva mafia" (many of whom are not in Geneva), notably: Ties Boerma, Michel Carael, Neff Walker, Tim Brown, Wiwat Peeratapanapokin, Peter Ghys, Txema Calleja, John Stover, John Novak, Deborah Rugg, Bernhard Schwartlander, Karen Staneki, David Wilson, Geoff Garnett, Cyril Pervilhac. I have argued stubbornly with most of

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you over many years, and I have always come off the wiser. Special thanks to Keith Hansen who took the time to read sections of this work and who consistently provided insightful and amusing comments.

Tobi Saidel and Steve Mills belong in the "Geneva mafia who have shaped my thinking" category, but fall too into the category of colleagues at FHI who have been supportive of this work, and generous in covering for me while I was more actively engaged in it. Others include Jeanine Bardon, Sara Hersey, Dimitri Prybylski, Nigoon Jitthai and Ganrawi Winnithana.

At the London School of Hygiene I have been fortunate to have two supervisors to keep my sometimes erratic meanderings on track: many, many thanks to both Jimmy Whitworth and Jim Todd, who have been patient and good-humoured about one change of tack after another. Judith Glynn has been very generous with her time, and I have also benefited from input from Simon Cousens, Charlotte Watts and Basia Zaba. A big thanks, too, to the ITD IT staff for keeping my access open across continents.

Finally, infinite thanks to Andrew Wilson and Claire Bolderson for refuge, encouragement and friendship, and to Jasper Winn for keeping me afloat and for distractions past and future.

The work described in this document was largely the result of support to the Indonesian surveillance system that was implemented by Family Health International's Aksi Stop AIDS programme and was funded by the United States Agency for International Development under cooperative agreement number 497-A-00-00-0038-00.

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