UNAIDS/WHO
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Case study on estimating HIV infection in a concentrated epidemic: Lessons from Indonesia

World Health Organization

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Acknowledgements

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1. Introduction

Indonesia's 13,000 sprawling islands are home to over 210 million people. In the late 1980s and through most of the 1990s, it seemed as though the country might be spared the worst of the HIV epidemic that had begun to make significant inroads into some other South-East Asian nations, such as Cambodia, Myanmar and Thailand. But, by the year 2000, the surveillance system was beginning to record rises in HIV prevalence in a number of population groups with risky sexual and drug-taking behaviour.

Previous efforts to estimate the impact of HIV in Indonesia produced numbers that ranged wildly from a few thousand to several million, with little information about the distribution of infection either across the country or among people with different forms of risky behaviour. The principal weaknesses of these earlier estimates is that they were developed by one or two individuals from outside Indonesia, and were based on very limited data.

Recognizing the importance of improving the scope and quality of information to inform decision-making about HIV prevention and care, the Indonesian Government in May 2001 strongly endorsed the principles of second-generation surveillance for HIV, as recommended by the World Health Organization and UNAIDS[1]. Second-generation surveillance concentrates surveillance resources among those whose behaviours are most likely to be contributing to the spread of HIV—the human immunodeficiency virus that causes AIDS. Information from behavioural and biological surveillance activities is used to improve understanding of the HIV epidemic: where is infection currently concentrated, and who is likely to be at risk in the future, if there is no change in existing behaviour?

Newly-available information from the second-generation surveillance system provided an opportunity for Indonesia to make more reliable estimates of the number of people infected with HIV. In 2002, the Ministry of Health began a process that led to vastly more informative estimates of the number of people at risk of contracting HIV in Indonesia, and the number currently infected with the virus. The technical details of the estimates have been published in Indonesian and English[2]. This document focuses on the process that the country undertook in developing its estimates, discussing some of the challenges faced, the decisions made and the lessons learned. UNAIDS thanks Indonesia for sharing its experiences, and hopes that other countries with HIV epidemics concentrated in populations with high-risk behaviour will benefit by adopting a similar estimation process.

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[1] UNAIDS/WHO (2000) *Guidelines for second generation HIV surveillance*, Geneva.

[2] Indonesian Ministry of Health (2003) *National estimates of adult HIV infection, Indonesia 2002*, Jakarta.

2. Why make national estimates of HIV infection?

Before discussing the Indonesian experience specifically, it may be worth making some general observations about the purposes of estimating HIV infection. It is sometimes felt that we already know what drives HIV; we should spend less time worrying about numbers and more time worrying about programmes that will limit the spread of the virus and its impact. But the truth is that HIV epidemics are dynamic. What is true in one country is not necessarily true in another, and what was true two years ago may no longer be true this year. Public health officials must regularly monitor the data, evaluating information about HIV and risk behaviour to see if things are changing over time. This process of evaluation, which stands at the core of the estimation process, leads to a better understanding of who is infected with HIV and who is at risk at any given time. And that enhanced understanding leads, in turn, to better advocacy and better programme planning—the two fundamental reasons for making reliable estimates of HIV infection.

'Advocacy', in the current context, means lobbying for resources for HIV prevention and care. As the international community begins to come to terms with the threat the HIV epidemic poses to development, more and more resources are being made available to counter that threat. Many of the resources are earmarked for countries that already have a very high level of HIV prevalence, and therefore a large number of people needing care. But resources are also available for countries where effective prevention is still possible. In both cases, countries need to have credible, data-based estimates of how many people are already living with HIV, and how many are potentially at risk of contracting HIV infection because they engage in high-risk behaviours.

Effective international lobbying may depend on a country's own leaders being convinced that HIV is a real challenge in their own national context, and in many countries this is not yet the case. The first audience for advocacy based on solid national estimates of HIV infection and risk, then, is very often the cabinet or president's office of the country making the estimates.

The national government will certainly be the first audience for estimates in the context of programme planning. A country will move forward faster if its health and development efforts are prioritized so that they achieve the greatest impact for the amount of money and human resources invested. But effective prioritization is only possible where information is readily available to guide the choices that must be made. Good national estimates based on reliable data provide information on who is most likely to be infected with HIV, who is most likely to be at risk of infection, and which behaviours are putting them at risk. Information on the distribution of these people, both geographically and by age, can also be provided through a strong estimation process. All this information is necessary to help plan HIV-prevention-and-care interventions that will have the greatest impact on the spread of HIV and the welfare of those affected.

A third benefit of national estimates is rarely considered but worth noting. A good estimation process such as that followed by Indonesia and described in this document brings together widely diverse actors who may not previously have had much contact. Lively discussion and data-sharing between institutions previously suspicious of one another, such as law enforcement authorities and nongovernmental organizations (NGOs), can forge relationships that lead to greatly improved HIV-prevention programming.

Finally, a note of realism: international institutions have their own needs and mandates. Providing information on HIV infection and risk for countries worldwide is a core activity of UNAIDS and its cosponsoring organizations. UNAIDS recognizes that data-driven estimation processes undertaken at the national level are likely to produce far better estimates than can be produced with limited data in the headquarters of an international institution. When a country undertakes such a process and documents its methods, assumptions and results, which it shares with international institutions, the national estimate will almost always be used as the official estimate by the international agency. This improves the information available internationally, and also avoids the confusion that arises when international institutions publish estimates that differ from those made by national governments.

3. The difficulties posed by concentrated epidemics

In recent years, a great deal of international attention has been concentrated on HIV epidemics in East and Southern Africa, where very high proportions of the adult population are infected with HIV. In these long-running epidemics, where the virus is spread largely via sex between men and women in the general population, estimating the numbers of people infected with HIV is relatively simple. The prevalence of HIV among pregnant women attending antenatal clinics is, after some adjustments for age, sex and urban and rural distribution of the population, applied to all adults in the country to get a national estimate of people living with HIV.

In countries where the bulk of HIV infections are concentrated within populations whose behaviour puts them at especially high risk of contracting and passing on the virus, estimates based on prevalence among women at antenatal clinics may be very inaccurate. Men who have sex with men and male drug injectors do not get pregnant, so if they make up a large proportion of those infected with HIV, antenatal-based estimates will miss a significant part of the epidemic. Some types of heterosexually-driven epidemics are also not well captured by antenatal-based estimates. The latter assume that infection is spread relatively equally between men and women in the general population, while, in some countries, a relatively large number of male clients buy sex from a relatively small number of female sex workers. The result is usually that more men are infected than women, especially in the early stages of an epidemic. In addition, professional sex workers are usually more likely than other women to be infertile or to be using contraceptives. This means that estimates based on infection in pregnant women will not accurately reflect the true levels of HIV infection in countries where the epidemic is driven largely by commercial sex between men and women.

Those wishing to make accurate estimates of HIV infection in concentrated epidemics therefore have to take a different approach. They have first to decide which population groups are likely to be most at risk of contracting HIV in their national situation because of their sexual or drug-taking behaviour. They then have to estimate how many people in the country engage in each of those high-risk behaviours. They must consider whether anyone else is exposed to HIV infection by those who engage in those behaviours, even though the former do not themselves engage in any high-risk behaviour. They may also wish to consider whether a significant number of people who once engaged in high-risk behaviour (and may have been infected with HIV at that time) have since moved out of those groups—for example, by leaving sex work, or by giving up drug injection. Certainly, they must have an idea of the prevalence of HIV infection in each of the population groups at high risk.

As the Indonesian example illustrates, the strength of a national estimate of HIV infection in a concentrated epidemic depends largely on the extent to which the HIV surveillance system provides information on the levels of risky behaviour, HIV infection and number of people in each of the population groups potentially exposed to the virus.

4. Challenges faced by Indonesia

Indonesia is a vast country that is undergoing very rapid political, social and economic change. Recent changes in population mobility and behaviour have probably contributed to the spread of HIV, while changes in administrative structures have created challenges as well as opportunities in tracking changing behaviours and patterns of infection. Some of the challenges faced by Indonesia, and currently shared by many other countries considering how to improve their understanding of their national HIV epidemics, are described below.

4.1 Different forms of high-risk behaviour

Indonesia is home to over 210 million people, of many different cultures and ethnic groups. The majority of the population is Muslim, but substantial minorities practise most other major religions. Monogamous marriage and close relations with an extended family are the norm. But, as might be expected from such a diverse population, virtually every human behaviour can be found, and this includes sexual and drug-taking practices that carry a high risk of HIV infection. Drug injectors, heterosexuals with high partner turn-over (most commonly, sex workers and their clients) and men who have sex with men are found in virtually every society; these are the most common population groups at risk of contracting HIV and almost every country with a concentrated epidemic will need to track behaviour and infection in these groups. But countries should also be aware of other groups at high risk in their own socioeconomic and cultural circumstances. In some countries, these may include migrant workers or groups exposed to nosocomial infection; in others, they may include transgender sex workers or street children. The groups in which the bulk of exposure to HIV occurs in Indonesia are briefly described here.

Injecting drug users

The use of illegal drugs has grown rapidly in Indonesia in recent years, particularly among young people. Among secondary-school boys in the capital Jakarta included in the national surveillance system, one in three admitted to using illegal drugs, and one in 40 had already begun injecting drugs. Sentinel surveillance among injecting drug users (IDUs) in Jakarta shows that HIV prevalence has risen rapidly since the late 1990s; by 2001, one injector in two was infected with HIV. Nine out of 10 injectors were male, and almost all were in their teens or twenties.

Commercial sex workers

Most men in Indonesia have sex only with their wives. However, a substantial minority, including many of the country's mobile population of sailors, transport workers and migrant labourers, occasionally buy sex. Most buy sex from female sex workers. Transvestite sex workers, known as *waria,* also sell sex to men who consider themselves heterosexual. Female and *waria* sex workers meet the demand of male clients from one end of the archipelago to the other. Recent surveillance data suggest that HIV infection is around 10 times higher in transvestite than in female sex workers (the latter being a far larger group) but HIV prevalence is rising steeply in female sex workers in many parts of the country.

Men who have sex with men

In addition to sex between *waria* and their male clients, other types of male-male sex exist in Indonesia. In large urban areas, men can buy sex from male sex workers. In recent years, an openly 'gay' scene has begun to emerge in the capital and other large cities. Male-male sex continues to be highly stigmatized, and surveillance in male sex workers and gay men only began in 2002 in Jakarta. HIV infection is already higher in these population groups than it is among female sex workers.

Other 'exposed' populations

An expanding behavioural surveillance system has provided information that has led Indonesian public health officials to conclude that populations at risk of HIV do not fit into neat boxes. Many people engage in more than one type of risky behaviour. For example, many drug injectors also buy sex from female sex workers, while many men who sell sex to other men also buy sex from women. In addition, many people who do not fit in to any of the population groups defined above may also be exposed to HIV infection because they have sex with spouses, girlfriends or boyfriends who do engage in risky behaviour.

Many of the behaviours described above are engaged in only by small minorities of Indonesia's vast population. Public health officials cannot afford to ignore any one of these behaviours because the groups interact, meaning that rising HIV rates in one population group at risk could easily translate into a wider epidemic in other groups.

4.2 Unknown numbers engaging in risky behaviour

To make a reliable estimate of the number of people infected with HIV, we need to know not only the rate of HIV prevalence within the group but also the absolute size of the group. Surveillance systems have, until now, concentrated largely on generating the first part of this equation: they allow us to say with confidence that, of 300 drug injectors tested, 108 individuals were

infected with HIV, or, in other words, that HIV prevalence among drug injectors is in the range of 36%. But virtually no country has developed detailed estimates of the number of people in each of the population groups at risk of contracting HIV.

Indonesia recognized that good estimates of the size of populations at risk of HIV stand at the core of reliable estimates of the number of people infected. But the country had to start virtually from scratch in estimating the size of each of these populations. This process is described in greater detail later in this document, but it is worth mentioning that, by involving people with access to a wide variety of data, it was possible to produce data-based estimates for most populations using existing data sources and simple multiplier methods.

4.3 Huge geographical diversity

Indonesia stretches for some 5,000 kilometres along the equator—roughly the distance from London to Moscow. Over 40% of the population lives in urban areas, including huge agglomerations such as the greater Jakarta area, which is home to around 12 million people. At the other end of the spectrum are vast and sparsely populated provinces such as Papua, where just 2 million people live in an area larger than Germany, Belgium and the Netherlands combined. In between are bustling trading centres such as Makassar in South Sulawesi, busy tourist islands such as Bali or Batam, the densely populated rural areas of Java and the vast and relatively empty rainforests of Sumatra and Kalimantan.

This physical diversity is matched by a diversity of culture and, thus, behaviour. Current information suggests that drug injection is more common in the crowded, largely urbanized islands of Western Indonesia, while anthropological data suggest that sexual networking is more extensive in some islands than in others. Infrastructure varies vastly, too, with some areas remaining relatively isolated, and others woven into tight networks of national and international migration. Even if behaviour were the same throughout Indonesia, the differences in infrastructure mean that HIV will be introduced at different times in different parts of the country, and spread at different rates. The idea of developing a single national estimate of HIV infection to encompass the vastly different realities of Indonesia was a daunting one.

4.4 A decentralizing government structure

Partly because of tensions inherent in the geographical, cultural and economic diversity of the country, Indonesia has, in the last two years, undergone a very rapid process of decentralization. This has many advantages, some of which will be described later in this document. But it also creates challenges for administrative systems. Data-collection systems that were once centrally mandated and implemented are increasingly being devolved to the district level, where limited human resources and competing claims on resources sometimes undermine activities such as data collection, which are seen as non-essential.

Like many decentralizing countries, Indonesia faces the challenge of maintaining standards and quality in public-health-information systems, while still meeting the information needs of local policy-makers.

5. Deciding on a process

At the time that Indonesia's Ministry of Health decided to undertake a new national estimation process for HIV infections in 2002, there were few examples to follow from other large countries with concentrated epidemics. The HIV/AIDS sub-directorate within the Directorate General for Communicable Disease Control and Environmental Health (known locally by the acronym P2M) had to make some fundamental decisions about a process before they could even begin to develop estimates. The questions that arose are discussed in this section.

5.1 Who should be involved?

Previous estimates had been made by a small handful of epidemiologists and other experts within the Ministry of Health, usually with the guidance of a specialist on a short visit from overseas. The resulting estimates were often roundly criticized by Indonesians in other sectors—in particular, people living with AIDS, members of communities at risk and the nongovernmental organizations that work to meet their needs.

The Ministry of Health felt it was important to include these partners in the new estimation process for several reasons—most importantly because of the invaluable knowledge that they contribute. Affected communities often have a very good idea of the dynamics and the distribution of risky behaviours, have frequently been involved in research surrounding those behaviours and sometimes have access to information and data that have been collected outside the government system.

In addition, it was recognized that many government departments other than the health ministry may have important insights and information to contribute. The Department of Social Affairs deals actively with sex workers, transvestites and drug users, and collects data on each of these populations, for example, and the National AIDS Commission is also actively involved with populations engaging in risky behaviour. In recent years, the surveillance system has recorded a sharp rise in HIV among prisoners, and it was felt that the prison service might have knowledge not routinely available to public health officials. In addition, the department of transport has information about mobile populations, and the police, the military and the drug enforcement agencies have information that can be used in indirect estimation techniques in order to obtain stronger estimates of the size of populations at risk of HIV.

Most information about HIV and STI prevalence and risky behaviours in Indonesia comes from the sentinel surveillance system, run by the Ministry of Health and implemented in partnership with the Central Bureau of Statistics. But the health ministry recognized that related research was also available from other sources, including the ministry's own research institute, universities, and prevention-and-care programmes.

The Indonesian Ministry of Health could have chosen to exclude any information that did not come from the 'official' HIV surveillance system, or from 'official' government sources. Instead, the ministry chose to cast its net as widely as possible, seeking inputs from the widest possible cross-section of sources. It was felt that open discussion of all available data from all sources would act as a sort of 'peer review' process; estimates could be made using multiple methods and multiple data sources, and the most robust could ultimately be selected for use in the estimation process.

Key lessons and decisions

- Include the widest possible range of partners in the estimation process
- Use data from all available sources, after critical discussion of their quality

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5.2 What steps are needed?

It was clear from the start that reliable estimates for population size and HIV infection in a number of different population groups could not be made by a few people in a single afternoon. A more extensive process would be necessary, covering a number of separate steps. Some of these could be foreseen from the start. As the leader of the whole process, the Ministry of Health decided on the following steps:

- Introduce the idea of the estimation process to all possible partners.

- Discuss possible methods and data sources, and agree on ground rules.

- Make a decision about the groups and geographic scope to be included in the estimates.

- Prepare the necessary tools, including data collation and spreadsheets.

- Hold small technical meetings to review and improve estimates for each population group.

- Present draft estimates to a wide group of interested partners at the national and international level.

- Seek input, revise estimates and finalize.

- Carefully document process and assumptions.

- Publish estimates.

In practice, several of these steps could be combined into multi-day meetings, or could be performed simultaneously. From start to finish, this process took three (hardworking!) weeks. The steps are discussed in the following chapter.

Key lessons and decisions

- Follow a multi-step process at the national level, including a broad spectrum of experience and opinion
- Seek international opinion in the final stages
- Document and publish results

6. The process in practice

6.1 Introducing the idea of the estimation process

A multi-stage estimation process had never before been attempted in Indonesia, let alone one that included such a wide range of partners. Many of the partners involved, such as organizations of people living with HIV, drug treatment hospitals or transvestite sex-worker organizations deal with HIV as a routine part of their work and lives. But many, such as the Department of Transport or the prison authorities, do not often have cause to think directly about the epidemic. The first important step, then, was to introduce the idea of the estimation process, explain its purposes and expected outcome, and explain the role that each of the participants could play.

Because of the complex nature of the Indonesian administrative structure, this happened in several steps. First, the Ministry of Health's Sub-Directorate for HIV convened a meeting of all potential partners at the national level in Jakarta. At this meeting, it was decided that, for the first year, the process would be implemented at the central level, as discussed below. However, it was also recognized that the goal over time was to shift implementation to the provincial and district levels, where decision-making about HIV programming is increasingly taking place. In order to prepare for this eventual shift, the process was, from the start, introduced to the heads of the provincial health offices and of the provincial AIDS control boards. Inputs that would help improve the quality of estimates were solicited and welcomed. Many provincial public-health authorities were enthusiastic about the process, and look forward to more active involvement in the future.

Key lessons and decisions

- Clarify objectives, roles and expected outcomes at the start
- Ensure that opportunities for feedback between the provincial and central level are built in from the start, as a preparation for a more decentralized process in the future

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6.2 Discussing possible methods and data sources

Once the idea of estimates had been introduced in the Jakarta meeting, the discussion turned directly to possible methods. The overall method was clear from the start and the group chose to do the following:

- Define the geographic scope of the estimates
- Define which population groups should be included in the estimates
- Estimate the size of each of those population groups
- Estimate HIV prevalence in each of those population groups
- Multiply the population group size by the population group HIV prevalence to get an estimate of the number of people living with HIV in that population group
- Add up the resulting estimates for a single estimate of the total number of people living with HIV.

As long as the HIV and behavioural surveillance system are focusing on the right behaviours and are providing good-quality data, most of these steps are technically fairly straightforward, although not without controversy.

At what geographic level should the estimates be made?

Previous national estimates in Indonesia had always been made at the national level, with a single assumption about the size of high-risk populations and prevalence in those groups. As the second-generation surveillance system improved, it became increasingly clear that both HIV prevalence and risky behaviour varied quite widely throughout the country.

A single national estimate also ignores the fact that, in a country with 30 provinces and over 340 districts, decisions about funding priorities and service delivery are increasingly being made at the provincial and district level. Because of the high levels of mobility in the population, it would be very difficult indeed to make separate estimates for each district but making estimates at the provincial level was a possibility.

The pros and cons of this were discussed. Weighing against provincial estimates was the added complication of the task, and the still-patchy coverage of data collection, both in terms of HIV surveillance and in terms of inputs that would help estimate the size of populations at risk. In favour of provincial estimates was the fact that estimates should be available at the level where they are most likely to be used in decision-making and to improve programming, and that level is no longer the national level. In addition, it was decided that, in future, the estimation process itself would ideally be implemented at the provincial level. It therefore made sense to set up the estimation process so that the single national estimate was, in fact, an aggregation of a number of provincial estimates.

While it was recognized that some provinces with poor data-collection and surveillance systems might be somewhat misrepresented within the national estimates, it was none the less decided that the advantages of provincial-level estimates outweighed the disadvantages. Time and budget did not, however, allow for a full estimation process to be carried out simultaneously in the first year. In addition, it was hoped that the first year's experience would yield important lessons and perhaps a standard protocol that could more easily be followed at the provincial level in subsequent years. It was therefore decided that the estimates would be made by province, but that, for at least the first year, the process of estimation would actually be undertaken at the central level.

Having decided to make estimates by province, a further decision was needed: what should be done about provinces where no data were available, or where data were only very sparse? Most provinces provide basic data from which estimates of population sizes could be made. Indonesia's relatively strong surveillance system also provides at least some HIV prevalence data for the majority of the country's 30 provinces. At the time the 2002 estimates were made, behavioural data were available for eight provinces. Even with this relatively rich data base, however, many gaps were apparent. It was decided that those gaps would be filled temporarily by assuming that HIV prevalence and behaviour in a given province were similar to those in the province geographically, economically and culturally most similar, for which data were available (2).

As might be expected, the process of examining data at the provincial level highlighted some important gaps in national data-collection systems, and provided an opportunity to plan for more comprehensive data collection in priority areas in the future.

Key lessons and decisions

- Estimates would be made by province, and aggregated for a national number
- Implementation of the estimation process would be undertaken at the national level, at least initially
- Missing data would be imputed from similar provinces, while improved data-collection efforts would be encouraged at the local level

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Which population groups should be included?

Estimates of the number of people living with HIV in Indonesia made in 2001 had included only three population groups: female sex workers, clients of female sex workers, and drug injectors. In addition, a catch-all category of 'general population' was included to capture all other potential exposure.

The standard UNAIDS spreadsheet for estimates in concentrated epidemics was more detailed (see www.unaids.org for more information on the Workbook method). In addition to the populations identified in the WHO-led estimation process in Indonesia in 2001, the UNAIDS spreadsheet includes men who have sex with men, and male and female STI patients—categories meant to represent heterosexuals with higher-than-average-risk behaviour.

With the increasing amount of surveillance data available in Indonesia by mid-2002, it was felt that neither of these approaches adequately captured the diversity of the epidemic. In addition, participants in the estimation process felt that the estimates provided an opportunity to make an important advocacy point: that millions of Indonesians are exposed (or potentially exposed) to HIV not as a result of their own behaviour but because of the risky behaviour of their partners.

Another factor that came into the discussions was the situations that made people particularly vulnerable to exposure to the virus, such as being in prison or living on the streets. The more traditional epidemiologists in the debate began by dismissing this approach, saying that people were not at risk of infection because they were in prison, for example, but because they were using drugs or having anal sex with other prisoners, and would therefore be captured in the estimates of drug injectors or men who have sex with men. Those who focused more on prevention-and-care programmes disagreed, arguing that many of the people exposed to HIV in prison had not engaged in any risky behaviour before entering prison. This was confirmed by participants both from the IDU community and from the prison service, and the group was ultimately included. The debate about whether to include migrants as an exposure category, on the other hand, went the other way. While it was ultimately recognized that people away from home are more likely to engage in risky behaviour, it is virtually impossible to define a migrant in the Indonesian context, where mobility within and between islands is the norm. It was also felt that these populations are adequately represented within other population groups, such as men who buy sex, for whom solid data are available. Migrants were not, therefore, included as a separate exposure category.

What about the general population?

The final debate revolved around the general population. Although HIV was first reported in Indonesia over a decade ago, the surveillance system only began to register any significant rise in infection in any high-risk population at the very end of the 1990s. This means that the epidemic is still very new. It is almost certain that the virus is already spreading beyond those directly engaging in risky behaviours to their regular sexual partners, and these groups are included as 'exposure'

groups in the national estimates. But because all indications are that non-commercial sexual networking among men and women in the general population is extremely limited in Indonesia, it is not likely that the virus has yet spread widely beyond these exposure groups. The participants in the estimation process recognized that this will change over time—for example, as women who were infected by a client while selling sex leave sex work and get married. The risk of HIV transmission between ex-sex workers and their husbands, or ex-clients and their wives, or ex-drug injectors and their sexual partners, will not be captured in the existing estimation method, and it will be necessary to change the methods to account for these exposures, possibly adding a 'general population' category in the future. In many countries with epidemics that are driven largely by identifiably risky behaviour now or in the past, this is already necessary. In Cambodia, for example, the 2002 estimation process concluded that around 45% of HIV transmission is now taking place within marriage. In most of these couples, the woman or man was exposed to HIV through commercial sex (either as a sex worker or a client), but many do not currently engage in any identifiable 'risky behaviour'. In other words, they would not be included in our estimates of 'exposed populations'.

Every country will have to make its own decision about how to handle transmission of HIV beyond people with identifiable risky behaviour and their sexual partners. In Indonesia, it was decided that, in 2002, the epidemic was sufficiently new that virtually all infection would be captured in the defined exposure categories, and that therefore no 'general population' element would be included in the current estimates. Transmission to the 'low-risk' sexual partners of individuals with high-risk behaviour could be estimated from HIV, STI and behavioural data collected from the people with high-risk behaviour, using information about the number of partners and frequency of sex, and assumptions about HIV-transmission probabilities.

The list of exposure categories finally included in the Indonesian national estimates was as follows:

- Injecting drug users
- Regular partners of injecting drug users
- Female sex workers
- Clients of female sex workers
- Wives/regular partners of clients of female sex workers
- Male sex workers
- Male clients of male sex workers
- Wives/regular female partners of male sex workers

- *Waria* (transvestite) sex workers
- Clients of *waria* sex workers
- 'Husbands'/regular male partners of *waria* sex workers
- Gay men
- Prisoners
- Street children

Key lessons and decisions

- Define population groups on the basis of potential exposure
- Include those who are exposed through the risky behaviour of their regular partners
- Include those who only engage in risky behaviour because of their current status—e.g., as prisoners
- Exclude a 'general population' category because Indonesia's epidemic is so recent that little transmission is yet taking place outside identifiable exposure categories

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How should we estimate the size of the exposed populations?

The second step in the agreed method—estimating the size of population groups at risk—was one with which Indonesia had little experience. In recognition of this, the country had, earlier in the year, hosted a meeting of other Asian countries to discuss methods and share experiences in this area. Guidelines on methods to estimate the size of populations at risk of contracting HIV have been informed by this meeting[3]. A summary of this meeting, describing methods commonly used in population size estimation, was presented to the Jakarta estimates meeting by a senior P2M official. The methods presented included census and survey methods, multiplier methods using existing data sources, nomination methods and capture-recapture methods. An official from the Central Bureau of Statistics then summarized the data-collection methods commonly used in Indonesia, and described some of the existing data sources that may be used in estimating the sizes of populations.

Much lively discussion ensued. Many participants had come to the meeting with data in hand, but, as discussions progressed, many new sources of data were identified. Some clear gaps were also identified, but it was thought that many of these could be filled with existing data. In part because time and money were limited, it was decided that multiplier methods using existing data sources would be used wherever possible. Specific multiplier methods were discussed for the major exposure categories (drug injection and com-

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[3] FHI/Impact/USAID/UNAIDS/WHO/UNDCP (2003) *Estimating the size of populations at risk for HIV. Issues and methods.* Updated July 2003. Geneva.

mercial sex), and problems and data gaps were identified. Individual participants were asked to develop the methods further, while others were charged with tracking down particular pieces of information that would increase the accuracy of the estimates made using that method.

How should we estimate HIV prevalence in exposed populations?

It was clear from the start that the key source of information for making estimates of HIV prevalence would be the national surveillance system. However, other sources of HIV data were also known, and not all were immediately available. Individuals volunteered to follow up on specific sources of data (such as HIV surveillance in the military or studies of transvestite and male sex workers and gay men in Jakarta), which were not at the time included in the national surveillance data base.

For some exposure populations, such as the wives of clients of sex workers, there was no HIV prevalence data available at all. In these cases, some participants volunteered to check the scientific literature on transmission probabilities, and to try to calculate a likely prevalence, given the prevalence in the partner group and the known patterns of sexual behaviour.

6.3 Deciding on the ground rules

Estimating the number of people with high-risk behaviour, the number of people exposed to HIV and the number of people living with HIV can be a highly political activity, with different actors having different agendas. Activists working on behalf of people living with AIDS may have an interest in seeing high estimates of the number infected, for example, while some national programme officials fearing they will be accused of failure if figures are high would prefer to see low estimates. NGOs working with injection drug users may favour estimates that emphasize the importance of injecting as a route of transmission, while sex-worker organizations would rather stress the role of commercial sex.

To minimize the effect of these competing agendas, the Indonesian Ministry of Health adopted the most inclusive process possible. Everyone would have a chance to contribute their opinions, and all information would be considered and discussed. In addition, the leaders of the process suggested two ground rules, which participants agreed to abide by. The first was that all inputs would be based, as far as possible, on measured data. The source of the data, and any

assumptions that were not based on data, had to be clearly stated. Any discrepancies would be resolved by discussion, and where they could not be resolved, 'high' and 'low' figures could be used, with the reasons for the choices again clearly stated.

The second ground rule was that participants would not look at the results of the estimation process as it progressed. Participants would agree on the methods, agree on data sources and assumptions and the inputs these led to. Having agreed on the methods and the inputs, participants in the estimation process would be bound to accept the result. Because all data-entry was done on provincial spreadsheets, it was possible to avoid looking at the final draft estimate until all assumptions and inputs had been agreed and entered.

Another issue on which an 'executive decision' had to be made was when to finish the process. Data collection is an on-going business, and the very process of developing an inclusive national estimate often results in more and more data sources coming to light. Sometimes these take time to collect or collate; sometimes important information is still in the laboratory or not yet fully analysed at the time estimates are made. It is always tempting to hold up the publication of the estimates until one more data source is available, or one more input verified. This is not feasible. Ultimately, a cut-off date must be set, and estimates must be accepted as the best possible with the data available at that time.

This does carry the danger that future estimates will change, not only because the epidemic is dynamic, but also because data sources have improved. This can cause confusion among policy-makers as well as the general public, because people have a habit of interpreting even small rises or falls as trends, and trends in HIV prevalence are almost always newsworthy. There are two ways of minimizing the confusion associated with improving data sources. The first is to be very clear about the limitations of any estimation process at the time the estimates are published. In publishing the estimates, Indonesia issued an extremely detailed technical document that listed all of the methods, inputs and assumptions, and gave a detailed account of the weaknesses of the estimates. This means that future estimates will be able to explain changes due to better data more easily. The second way of minimizing the confusion is to calculate 'parallel' sets of estimates in future years, one using only the data sources previously available, the other using the full range of currently available data. This serves to illustrate to what extent changes in data sources have affected estimates. It is important to note that this is only possible if there has been a rigorous documentation of what data sources were used for each round of estimates.

The process in practice

Key lessons and decisions

- All inputs would be based on measured data, where possible
- All data sources and assumptions would be clearly stated
- Participants would agree on methods and inputs, but would then be bound to accept the resulting estimates
- A cut-off date was set for final best estimates for 2002

6.4 Setting up the spreadsheets

Once decisions had been made about the geographical scope of the estimates and the groups to be included, it was possible to set up spreadsheets to actually make the estimates. With 30 provinces and 14 exposure groups, this proved to be a time-consuming business. One of the lessons learned by the Indonesian team is that it is worth investing time and energy to get the spreadsheets right at the start.

Indonesia made one 'master' workbook that had separate spreadsheets for each of the country's 30 provinces. The national estimates spreadsheet simply aggregated the totals estimated to be infected with HIV for all of the provinces. The HIV prevalence estimates were entered directly onto the provincial spreadsheets for each of the exposure populations. However, the estimates of the size of each of the exposure populations, which were far more complex to calculate, were computed on separate spreadsheets and simply linked into the master workbook.

The most common temptation in this elaborate process was to cut corners: to exclude procedures in the estimates because available data were too sparse to justify them, for example. This is almost always a mistake. More elaborate spreadsheets can use 'national' default values where data are not yet available, but have the advantage of highlighting exactly where the data gaps are, and where better data collection would be most worthwhile. Data *will* improve over time: if the spreadsheets are already set up to cope with the ideal situation, new data can be plugged in as they become available. If corners have been cut, it may be necessary to start again from scratch or to revise all the spreadsheets to accommodate new information. Besides being cumbersome to do, changing the way spreadsheets are structured from one year to the next makes it very hard to explain changes in estimates that result from improved data collection. This increases the danger that changing estimates will be seized upon as 'trends', even when there is no evidence of substantial change in the direction of the epidemic.

In the very early days, the Indonesian team kept the assumptions sheets separate from the estimates sheets, merely cutting and pasting any changed totals in population estimates into the provincial sheets in the master workbook. This proved to be a very bad idea. It became impossible to keep track of changes as improved data sources came in and assumptions changed. In the end, the team went back and changed all of the spreadsheets so that they were linked automatically to the master workbook. This way, any changes in assumptions at the provincial level were automatically reflected in updated estimates at the national level.

This document refers to a 'team' working on spreadsheets, but herein lies another lesson. At first, the task of entering data into spreadsheets was divided up between several team members. But, again, it became impossible to keep track of which was the latest version of which sheet, what was linked to what, etc. It was strongly recommendation that, for the future, a single individual and a single computer be designated as the repository of all the spreadsheets throughout the entire process of estimation. Once the cut-off date has been reached and the estimates are considered final, these spreadsheets can be locked and distributed widely. Distributing draft versions causes confusion and leads to errors in the estimates.

Key lessons and decisions

- Make spreadsheets as comprehensive as possible from the start, so they do not have to be reconstructed as data improve
- Link inputs to outputs automatically, wherever possible
- Designate a single person to be responsible for spreadsheets

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6.5 Technical working groups

Once the initial process had been explained to all participants, general methods had been discussed, essential decisions has been taken and broad data sources identified, Indonesia chose to designate small technical working groups for major exposure populations. These small groups included people directly involved with that particular population group or behaviour, and those having access to secondary or related information about those groups. These small working groups were informal and very productive. People who had not previously cooperated in their work (for example, NGOs and law enforcement authorities dealing with drug injectors) found common ground, and engaged in very productive debate. People were generous with their data and, indeed, went to great effort to seek inputs from colleagues around the country in order to improve their contribution and the resulting estimates.

In no case was it impossible to reach agreement on inputs (although high and low estimates were often made for a given population). Encouragingly, many of the links forged during the work of the technical groups have led to ongoing cooperation in HIV-prevention-and-care programming.

The technical working groups did the bulk of the work of specifying the inputs and assumptions for the groups they were concerned with, and of reviewing the resulting spreadsheets. A core team from the Ministry of Health's P2M then combined these sheets into the draft national estimate.

6.6 Getting a second opinion

Once a draft national estimate was prepared, it was presented to a meeting of national and international experts. Many of the national participants had been engaged in the estimation process from the start, but some participants were senior political and institutional figures whose suggestions might be expected to enrich the final result. The meeting also gave those who had been in only one of the technical working groups the chance to comment on the results presented by the other groups.

Input was also sought from international contributors whose global perspective might add to the final result, and who might suggest improvements for future rounds of surveillance. Consultants from UNAIDS and the World Health Organization made valuable contributions and suggestions, as well as requesting the documentation of the process described in this document.

It was anticipated that this final meeting would be something of a 'rubber-stamp' exercise, with partici-pants endorsing the process with little discussion. This was not the case. Meeting participants engaged very actively in debate about the process, the methods and the assumptions. Cross-fertilization of ideas between different participants led to many valuable suggestions for improvements. Most of those improvements could be made immediately, and many aspects of the estimates were revised overnight, so that estimates presented at the start of the second day of the meeting reflected much of the first day's discussion. A few of the suggestions had longer-term implications and were noted to inform and improve future rounds of estimates.

At the end of the meeting, participants reached a consensus about the current estimate of HIV infection for the provinces and nation of Indonesia, and recommended that it be adopted as the formal national estimate by the Ministry of Health. The Director of Communicable Disease Control, who was present throughout the final meeting, accepted this recommendation, but requested that the estimation team prepare a full documentation of all the methods, inputs and assumptions for approval and publication by the Ministry of Health. In retrospect, it would have been more helpful to prepare the bulk of this documentation before the final meeting.

Key lessons and decisions

- Provide participants with comprehensive documentation of the methods and processes used
- Be ready to incorporate new ideas and make changes in the estimates at the last minute
- Document improvements requested for future rounds of estimates

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7. The way forward: building on a strong foundation

The 2002 round of HIV estimates included several 'firsts' for Indonesia. It was the first time the country had attempted to conduct a truly inclusive estimation process for HIV infection. It was the first time these estimates had been made by province, and by potential exposure category rather than 'risk group'. It was the first time Indonesia (or, indeed, any country) had made estimates based on comprehensive, data-based estimates of the number of people in those exposure categories.

The process was very productive at the national level. It brought together many people who had not previously collaborated, and allowed them to share information and develop cooperative relationships. And it greatly increased understanding of the HIV epidemic within the country. It is fair to say that all of the participants in the process, including those who are extremely well-informed about the HIV epidemic, discovered by following this rigorous process that some commonly-held assumptions were not borne out by the available data. Important, but previously under-recognized, opportunities for HIV-prevention programming were highlighted, and advocacy opportunities identified. The process was also well received internationally. With so much that was new and uncharted, however, it is inevitable that some mistakes were made and lessons learned for future improvements. Most of these have been discussed already in this document, but a few major points are summarized again here.

7.1 Improving inputs

Estimates are only as good as the information on which they are based. Indonesia's surveillance system is relatively strong and improving annually. It covers most of the major population groups at risk of HIV in Indonesia, including female, transvestite and male sex workers, injection drug users, men who have sex with men, and men in occupational cohorts likely to be clients of sex workers. However, some of these groups are covered only inconsistently, and some geographic areas supply virtually no data. Continued improvements to the national surveillance system, especially in terms of consistency of coverage of key groups in key sites, will lead to better inputs and better data.

In estimating the size of exposure groups, multiplier methods were used. These methods are described in detail elsewhere, but, in most cases, some kind of population register was combined with information from behavioural surveillance to arrive at an estimate. In the process of making this first round of estimates, weaknesses were identified on both sides of the equation. First, the methods used in arriving at the population registers are not always clear, nor is it clear whether they are up to date—an important consideration in Indonesia's rapidly-changing socioeconomic landscape. There are also concerns, expressed earlier, about the effect of decentralization on the timeliness and quality of data collection in the future.

Secondly, the information available from behavioural surveillance can not always be used effectively to provide multipliers for population-based registers. For example, early behavioural surveillance survey (BSS) questionnaires ask drug injectors whether they have ever been in treatment, but not whether they have been in treatment for a specified time period, such as the last year, which is what would be needed for a multiplier. These limitations are relatively easy to fix: the current round of BSS questionnaires in use in Indonesia have already been modified to provide information more useful for population-size estimation.

7.2 Decentralizing the estimation process

The issue of decentralization has been referred to many times throughout this document. In this first round, estimates were made by province, but they were made at the central level. Efforts were made to contact provincial partners and to get their input, and provincial data recorded at the central level were used where direct input from the provinces was not available. It is clear, however, that more district- and provincial-level involvement in the estimation process will lead eventually to better estimates. This is partly because local participants are more aware of what data are available, are better placed to make judgements about the quality of the data, and are uniquely placed to fill the necessary gaps with improved data collection. It is also partly because local policy-makers must decide what to do about the resulting estimates. The better their understanding of who is infected and who is at risk in their area, the better equipped they are to respond appropriately. It is hoped that the process will be decentralized in the near future, and the process followed at the national level has already been introduced to health department and AIDS control officials nationwide.

The decentralization of the estimation process will not be without challenges. While reliable estimates at the provincial and district levels where decision-making takes place are clearly needed, it is still important to have consistent national estimates that are comparable over time. It is also important that methods

used locally be consistent and comparable across provinces. And it must be recognized that political pressure to influence the outcome of the estimation process may be stronger at the district and provincial level than at the national level. All of these factors mean that strong national oversight and guidance in maintaining data standards and consistent methodology will be necessary as the decentralization of estimates evolves. They mean, also, that careful documentation of methods, assumptions, inputs and results will be more important than ever.

7.3 Faster dissemination of results: an agreed approval process

The 2002 estimation process in Indonesia included a final national review meeting where draft estimates were discussed and where a recommendation that they be approved nationally was made. Virtually no documentation of methods, assumptions or inputs was available at the time of the meeting, however. In addition, no advance preparations had been put in place for formal approval of the results by the Minister of Health, the cabinet or other authorities.

The preparation of the necessary documentation and the formal approval process took several weeks, and resulted in a considerable delay in the final publication of the results of the estimation process. Since this was the first time such methods had been used in the national estimation process, it was appropriate that very careful oversight of the process and results be exercised by the Ministry of Health. Greater anticipation and preparation of documentation, and an approval process on an agreed timetable negotiated beforehand with the Minister's office, would have minimized the delay in the formal dissemination of the results. An agreed timetable would also have allowed the estimates team to anticipate the date of the final dissemination more exactly, to prepare materials and to plan the dissemination to the press, the public and policy-makers more appropriately.

7.4 Better use of the results: short-term projections

The product of the estimation process—detailed estimates of the number of people potentially exposed to HIV and the number already infected, by risky behaviour and by province—represents a huge step forward in Indonesia's understanding of its epidemic. The provincial-level estimates have already been presented to local policy-makers and widely discussed in several provinces. In some cases, they have led to a complete rethink of HIV-prevention-and-care activities.

The Ministry of Health recognizes, however, that the estimates could be used even more fully to inform policy. At the final review meeting, international partners presented modelling and short-term projection methods that might be used in conjunction with the estimates data to investigate the course of the epidemic in the immediate future, and to pinpoint critical prevention activities. Training in these methods is being planned, and it is anticipated that Indonesia will have the capacity to make more comprehensive use of the estimation data by the time the next round of estimates is completed.

Conclusion

Few countries with epidemics concentrated in populations with high-risk behaviour have been able to make robust estimates of the size of populations at risk of HIV and of the number of people infected with the virus. Indonesia's experience demonstrates that it is possible to make such estimates in a huge, geographically, culturally and epidemiologically diverse country. The first round of the estimation process was not perfect, but it has left the country far more confident in its understanding of the HIV epidemic than ever before. The lessons learned in this ground-breaking province-based estimation process point the way to even more reliable estimates in future years. Indonesia and its international partners sincerely hope that other nations will be able to learn from, and build on, this experience and look forward to sharing experiences with other nations in the future.

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Case study on estimating HIV infection in a concentrated epidemic: Lessons from Indonesia.

Second-generation surveillance concentrates surveillance resources among those whose behaviours are most likely to be contributing to the spread of HIV. Information from behavioural and biological surveillance activities is used to improve understanding of the HIV epidemic: where is infection currently concentrated, and who is likely to be at risk in the future, if there is no change in existing behaviour?

Newly-available information from the second-generation surveillance system provided an opportunity for Indonesia to make more reliable estimates of the number of people infected with HIV. In 2002, the Indonesian Ministry of Health began a process that led to vastly more informative estimates of the number of people at risk of contracting HIV in Indonesia, and the number currently infected with the virus. This document focuses on the process that the country undertook in developing its estimates, discussing some of the challenges faced, the decisions made and the lessons learned.

Indonesia's experience demonstrates that it is possible to make such estimates in a huge, geographically, culturally and epidemiologically diverse country. Other countries with HIV epidemics concentrated in populations with high-risk behaviour can benefit from Indonesia's experience by adopting a similar estimation process.

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