CHAPTER 8

REPORTING SYSTEMS[1]

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[1] This chapter revises Rootman, I., and Hughes, P.G. (1980). Drug Abuse Reporting System, WHO Offset Publication No. 55, WHO, Geneva. Some of the original text from the publication is included in this chapter.

CONTENTS

1. Introduction

This chapter revises Rootman, I., and Hughes, P.G. (1980). Drug Abuse Reporting System, WHO Offset Publication No. 55, WHO, Geneva. Much of the original text is still relevant and is therefore included. However, since the original publication in 1980, there have been significant advances in technology, such as the use of personal computers for the collection, management and analysis of data, as well as developments in the nature and types of reporting systems operating. This chapter has been updated to reflect these changes. The original publication described three types of reporting systems: event reporting, case-reporting, and case registries. A significant development since the original publication has been the emergence of a fourth type of system referred to as "aggregate". As no published reference currently catalogues and describes these aggregate systems, an attempt has been made here to do so, albeit briefly. The original publication provided examples of specific types of systems to illustrate how systems are operationalized in different political, social, and cultural contexts. Likewise, in the process of revising this chapter, representatives from reporting systems around the world were contacted to obtain current examples of all four types of systems in various stages of development from long established systems to very new ones. An attempt has been made, where appropriate, to illustrate how reporting systems develop and change over time, thus historical information is included in the discussion of some systems.

Reporting systems are an important aspect of the overall effort countries can make to assess population levels and characteristics of drug abuse. They can supplement data obtained from surveys and special population studies (see Chapter 5 and 7). A large number of countries have some sort of reporting system relevant to drug abuse. For example, 22 of 43 countries reviewed by Porter et al. (1986) required some reporting of drug dependent persons. In some cases, systems are focused only on drug abusers but in others they are more general and may relate to the mentally ill or to infectious diseases such as hepatitis or HIV/AIDS. In the latter cases drug abusers are expected to be only a part of the total cases registered. Reporting systems may be national or local and they may contain a large number of cases or only a few. Also, reporting systems may relate to events, i.e., something a drug user is doing such as being arrested or admitted to treatment or to drug abusers themselves.

Reporting systems are helpful in:

- determining the prevalence of drug users in contact with reporting agencies, as well as their characteristics and drug use history
- studying drug use habits and the changes over time in these
- determining how many drug users are entering various kinds of services and how many others may require these
- assessing new efforts to prevent and manage drug use.
- identifying new groups at high risk

- identifying new drugs of abuse and emerging drug problems

Reporting systems, especially national systems, can be expensive and technically complex as they deal with many cases. Decision-makers and professional personnel responsible for implementing them should be aware of their uses and limitations. This chapter attempts to provide the necessary background information for planners and administrators by reviewing the different types of reporting systems, their benefits, and limitations. It also describes the steps in the development of reporting systems, the problems most frequently encountered and their possible solutions.

A number of countries have developed national reporting systems including the Drug Abuse Warning Network (USA), the Drugs of Addiction Notification System (Australia), and the Central Registry for Drug Addicts (Hong Kong). In Europe, of the 15 Member States of the European Union, eleven countries have specialised reporting systems on drug treatment and eight countries have registers of drug users. A national integrated data system has been established in Malaysia. Mynmar has a national registration systems for heroin users. Decision-makers in these countries felt that the usefulness of drug-abuse reporting systems outweighed their cost and complexity. While it may not be appropriate or practical for all countries to have national reporting systems, it can be extremely useful to have one or more cities within a country where local systems are set up to monitor drug trends and whose representatives meet periodically. Such drug abuse epidemiology city based networks have become increasingly common. Section 2.4 describes and provides examples of city based reporting systems. The decision to organise a reporting system for drug abuse in a country should be taken on a clear understanding of its likely benefits and costs in terms of human and material resources.

1.1 The Objective of Reporting Systems

Reporting systems typically gather information on drug users who have come to the notice of a physician or some institution, hospital or social agency, the police or criminal justice, because of their drug abuse or some characteristic related to abuse. National reporting systems probably have different objectives than local ones. Porter et al. (1986) in their review of national registers concluded that such systems have the objectives of i. controlling and measuring drug use, ii. monitoring illicit drug traffic, iii. identifying trends in drug abuse and abuser characteristics and iv. evaluating treatment programs. Local registers or reporting systems are usually oriented to studying the characteristics of those in treatment (Arroyave et al. 1973) and making sure that they do not get duplicate prescriptions. The objectives of reporting systems should be to contribute to the total volume of information on drug abuse in a given locale. Ultimately, the purpose of such systems is to provide the means to monitor drug abuse and to provide information useful in prevention and management efforts. Generally, reporting systems identify drug abusers who have some problem with their abuse such that they need treatment or appear in the criminal justice system. They therefore tend to identify heavy users with problems rather than light or infrequent users. The latter are best identified in surveys of general or special populations.

The objectives in creating new reporting systems should be to gain information on problem or heavy drug users rather than all types of users.

1.2 Definitions of Reporting Systems

Reporting systems for drug use generally refer to those data gathering efforts which get information on drug abuse from institutions or agencies that see drug abusers in their usual work. These systems tend to last for long periods and to produce data on a monthly or yearly basis. The usual agencies that contribute to drug abuse reporting systems are treatment facilities, physicians and hospitals as well as welfare and criminal justice systems. In most of the countries surveyed by Porter et al. (1986) physicians were required to report that a person was addicted to drugs or is making non-therapeutic use of drugs. A further element in the definitions of reporting system is that they have some defined geographic coverage, whether that is a whole country or a small area of the country. Different terms are used for reporting systems. Some refer to registration or notification while others are warning networks. Although alcohol and tobacco are dependence-producing substances, this chapter will focus primarily on reporting systems for other drugs.

1.3 Role of Reporting Systems

Reporting systems have as their role contributing to the total picture needed of drug abuse in a country or locale. They contribute information for heavy users primarily, as few infrequent users will come to the notice of physicians, police or other agencies likely to provide information to such systems. Reporting systems should not be created to collect and store information on drug abuse. Their role should be to make that information widely available to the general public and to those who make decisions about drug abuse interventions. That group includes health planners and decision makers as well as people who run treatment and prevention facilities. An important role of reporting systems is to make regular reports on trends in drug abuse habits such as new drugs becoming available, new methods of drug administration and new types of users involved in drug abuse. As a minimum, yearly reports should be made, but if the situation is changing rapidly or new drugs are appearing, more frequent reports will be needed.

1.4 Characteristics of Reporting Systems

Reporting systems should constitute procedure for gaining reliable and valid information about what is happening in some segment of the drug abuse situation whether it be hospital admissions, arrests, specialised treatment or only notice by a physician that a person is dependent to drugs. Good reporting systems require clear definitions of what or who is to be reported and under what circumstances. They require reporting procedures and definitions that are simple and easy to understand for those that are to make reports.

In a good reporting system reports are sent one by one or at fixed intervals to a central body for collation, analysis, and presentation. This body may be a university research team, a government agency, or some other group. Every good system requires systematic reporting procedures, i.e., explicit procedures for ensuring that reports are submitted in an appropriate form to a designated person or persons as well as for checking and analysis. The reporting system is then responsible for making yearly or other reports on their data and for providing feedback to those who send in the reports.

As mentioned, reporting systems have one main advantage in that they give information on heavier users of drugs - a group often missed by surveys. This is an important group, since it comprises the casualties of drug use which consume most of the treatment and rehabilitation resources. Another advantage is that reporting systems can be built on existing record systems and so use data already being collected by treatment or enforcement agencies.

2. Types of Reporting Systems

Drug-abuse reporting systems vary considerably, though they have the common characteristics of central pooling of data and systematic reporting procedures. This chapter reviews examples of four main types of systems: event-reporting systems, case-reporting systems, case registers and aggregate systems.

Although all reporting systems are based on reports of "events" such as the treatment of a drug abuser, a death, or the prescription of a drug, these reports can be handled in various ways. For example, they can be received, analysed, and presented as single unconnected events. Some systems count only the number of drug-related hospitalisations, arrests, seizures, deaths, prescriptions, HIV/AIDS or serum hepatitis cases treated during a given period. The total number of these reported events (with the exception of deaths) will greatly exceed the number of individuals in contact with the reporting agencies during that time, because the same individual may be treated more than once for the same problem and be in contact with more than one agency. Thus, one individual may account for several event reports during the period concerned. Event-reporting systems, then, report only events and do not reveal the total number of individuals involved.

Alternatively, systems can be constructed to link different events for the same individual in the same reporting institution. For example, two hospitalisations for the same individual within a given reporting agency represent only one case. If the same individual were reported by two reporting institutions, he would be considered as two cases. Systems enabling multiple events for the same individual in the same institution to be identified as a single case are called case-reporting systems.

Systems may be created to link events that occur in different settings for the same individual. Thus, reports on a person who is arrested, is hospitalised, and visits a clinic, may be brought together

and analysed as the related experiences of one individual with different reporting institutions. An individual who is reported separately by several institutions can be identified as one case rather than several cases. Systems capable of doing this are called case registers.

Aggregate reporting systems use information from all available sources for a given area including hospitalisations, deaths, case registers and case reports.

Table 1 illustrates the differences between the different types of systems. It shows hypothetical contacts of 2 individuals with 5 different institutions over a period of 1 year from drug-related events. If an event-reporting system were in existence, 10 separate events could be reported by the 5 institutions. With a case-reporting system, 7 cases could be described, person 1 having had one or more contacts with 3 reporting institutions and person 2 with 4 reporting institutions. However, if a case register were in existence, only 2 individuals could be described. Because 10 drug-related events, 7 drug-user case reports, and 2 drug users are different entities, it is important to maintain these distinctions in describing drug-abuse reporting systems.

While case registers are capable of describing individuals in contact with a variety of institutions, they can also describe cases in contact with single institutions as well as unique events. That is, a case register can do everything that event-reporting and case-reporting systems can do. Similarly, case-reporting systems can describe events as well as cases. Event-reporting systems, however, cannot go beyond the reporting of single events. Thus, case registers have the greater flexibility and analytical capability, and event reporting systems have the least. The typology presented here is not rigid. Aggregate systems combine elements of all three types.

A distinction should be made between systems that are "specialised" for the exclusive use of drug abuse programmes and those that are "non specialised" - i.e., systems that monitor a wider range of phenomena (such as crime, HIV/AIDS or mental disorders) but permit the monitoring of some aspect of drug abuse. The decision to establish a specialised or a non-specialised system has significant administrative, financial, and policy implications. For this reason, examples of both specialised and non-specialised systems will be presented for each of the major types of reporting system.

2.1 Event Reporting Systems

A variety of event reporting systems have been developed and some examples are described here.

2.1.1 Specialised Type

The Drug Abuse Working Network (DAWN), USA.

Table 1: Differences Between Types of Reporting System

Chronology of events	**Month**											
Source of Report	J	F	M	A	M	J	J	A	S	O	N	D
Hospital A	Person 1 Hospitalised			Person 2 hospitalised			Person 2 hospitalised			Person 2 hospitalised		
Police Department B					Person 1 arrested			Person 2 arrested			Person 2 arrested	
Clinic C									Person 1 treated			
Hospital D	Person 2 Hospitalised											
Police Department E			Person 2 arrested									

Collation of events

Event -reporting system	Case-reporting system	Case register	Aggregate System
5 hospitalisations 4 arrests 1 clinic admission 10 events	Hospital A reports 2 cases Hospital D reports 1 case Police Dept. B reports 2 cases Police Dept. E reports 1 case Clinic C reports 1 case 7 cases	3 events reported for individual 1 7 events reported for individual 2 2 individuals	All events under event, case reporting and case registers.

Source: Richman A. (Personal communication to Rootman I) Reported in Rootman I and Hughes P.H. Drug Abuse Reporting Systems. World Health Organization, Geneva 1980.

The DAWN system was one of the first drug abuse event systems developed. It has been one of the most useful reporting systems in the USA and a large amount of research has been done on the data. The DAWN system was originated by the Drug Enforcement Administration (DEA) with the first data collection in 1973. It was taken over by the National Institute on Drug Abuse (NIDA) in 1980 and since 1992 has been run by the Substance Abuse and Mental Health Services Administration (SAMSHA). Copies of the forms currently used are shown in the Annex.

The major objectives of DAWN are:

- To identify substances associated with drug abuse episodes that are reported by DAWN-affiliated facilities;
- To monitor drug abuse patterns and trends and to detect new abuse entities and new drug combinations;
- To assess health hazards associated with drug abuse; and
- To provide data for national, State, and local drug abuse policy and program planning.

DAWN provides information on emergency department (ED) episodes (referred to as "events" earlier in this chapter) related to drug abuse and information from medical examiners on drug related deaths.

Drug related ED episodes reported to DAWN involve drug overdose as well as the chronic effects of habitual drug usage or unexpected reactions. Reported episodes also include persons who are seeking detox, in withdrawal, and/or have experienced an accident or injury due to nonmedical drug use. Up to four different substances can be specified for each episode. The only ED cases reported are those in which the patient admits taking drugs or the hospital staff identify drug use related to the symptoms presented. Each report includes demographic information about the patient and circumstances of the episode. Data collected from participating facilities do not constitute a random sample prior to 1988. However, back weighting techniques have been applied to the data for 1978-87.

In the first year of data collection (1973) DAWN used a random probability sample within some metropolitan census areas. In subsequent years, facilities within the original areas, as well as others added were selected for participation as a sample of convenience. Facilities participating in DAWN were added and dropped over the years nonrandomly. In 1986 NIDA began recruiting emergency department facilities for a statistical sample that would permit inferences beyond the facilities sampled. By 1988 a nationally representative panel was in place, as well as representative over-samples of hospitals in 21 major metropolitan areas. Since 1988, the sample redesign provides national and local estimates. Now 21 major metropolitan areas are included.

At each participating institution, a trained reporter or alternate is responsible for completing a standard form for each drug-abuse event occurring during the reporting period. Completed forms are sent regularly to the data-processing centre, where they are checked for missing or false information and inconsistencies. Any problems are followed up by project monitors either by telephone or by visits. This process is facilitated by the fact that reporters are often trained by the monitors. The data are then prepared for computer processing, tabulated, and analysed.

The medical examiner (ME) data is also extensive. In 1994, DAWN data were collected from ME facilities in 42 metropolitan areas. An episode report is submitted for each drug abuse death

encountered by a DAWN ME. Each report of drug abuse ME case includes demographic information about the deceased and information about the circumstances of death. A designated reporter in each participating facility is responsible for identifying deaths related to drug abuse and recording and submitting data on each case. On a weekly basis, the total number of deaths handled by MEs and the number of cases related to drug abuse are entered into a reporting log. The relevant details of each drug abuse death are transferred from the official facility record onto DAWN data collection forms (Annex 1).

Several types of DAWN reports are produced regularly. These include annual reports, semi-annual reports, and summary reports for each participating city. National estimates of drug-related deaths and emergency department visits for the most abused drugs in the USA are regularly available. This information is of obvious importance to planners in documenting the large number of deaths related to specific drugs and drug combinations.

The information emerging from the DAWN system has been used by DEA in its enforcement, compliance, and scheduling activities. In addition, other federal, state, local, and private organisations concerned with drug abuse have used the information in their programmes. These organisations pinpoint the specific drugs that are causing serious public health problems and for which additional controls may be required, and they warn physicians and medical societies to exert additional caution in their use of some drugs.

The following definitions have been used in DAWN:

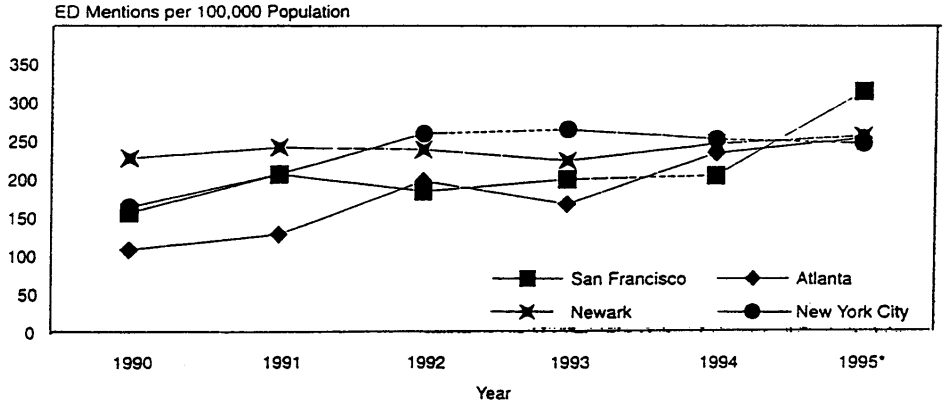
Drug abuse. The nonmedical use of a substance for any of the following reasons: psychic effects, dependence, or suicide attempt/gesture, i.e., the use of: i. prescription drugs in a manner which is inconsistent with accepted medical practice, or ii. over-the-counter drugs (OTC) contrary to approved labelling, or iii. any other substance (heroin, marijuana, glue, aerosols, etc.) for the reasons above.

Drug-abuse death. Either i. drug-induced, involving a drug "over-dose" where a toxic level is found or suspected, or ii. drug-related where, the drug usage is a contributory factor but not the sole cause (i.e., accidents, diseased state, withdrawal syndrome, etc.).

Figure 1 shows the trend in the rates of cocaine-related episodes per 100,000 population for selected cities (NIDA, 1997a). A wide city by city variation can be seen.

FIGURE 1: RATES OF COCAINE-RELATED EPISODES PER 100 000 POPULATION FOR SELECTED U.S. CITIES

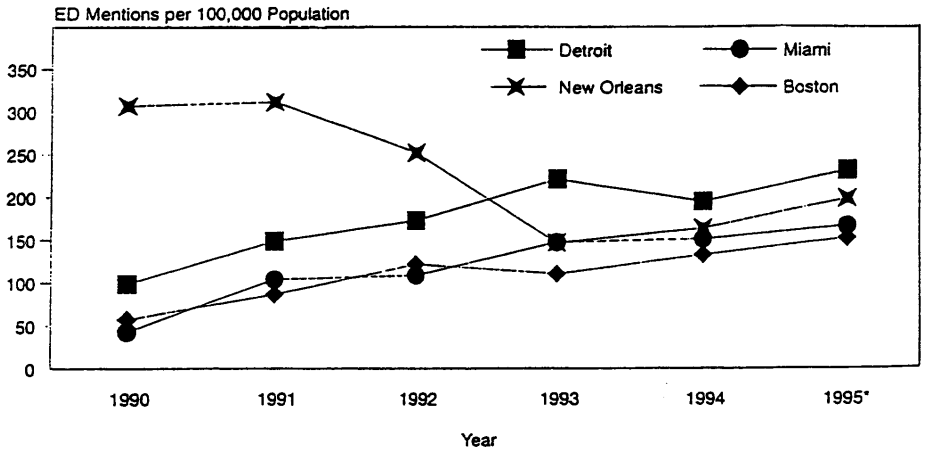
Exhibit 3. Annual trends in cocaine/crack ED mentions per 100,000 population in four top-ranking cities, 1990–95*



*Preliminary estimates

DATA SOURCE: SAMSHA, Drug Abuse Warning Network, October 1996 files

Exhibit 4. Annual trends in cocaine/crack ED mentions per 100,000 population in selected cities, 1990–95*



*Preliminary estimates

DATA SOURCE: SAMSHA, Drug Abuse Warning Network, October 1996 files

Exhibits Source: National Institute on Drug Abuse. *Epidemiologic Trends in Drug Abuse, Volume 1, Highlights and Executive Summary, Community Epidemiology Work Group, December, 1996*, NIH Publication No. 97-4204, Rockville MD: USDHHS, National Institutes of Health, 1997a, p.17.

The DAWN system was one of the first in the USA to give an early warning that cocaine and crack use were increasing in the 1980's. Although DAWN is an excellent example of a specialised drug-abuse-event reporting system, it has limitations characteristic of event-reporting systems. For example, the system does not produce an unduplicated count of individuals coming in contact with emergency departments, since the same person may be counted more than once. Moreover, the system does not permit follow-up of cases beyond the initial contact.

DAWN has other limitations arising out of its unique design and not necessarily characteristic of all event-reporting systems. First, the large number of reporting facilities involved, and their geographic dispersion, make it difficult to maintain quality control on the data submitted. Secondly, the definition of a "drug abuse death" is not without problems. A person might die of liver failure or other long-term effects of intravenous heroin use, even though the drug was not found at autopsy. It can be extremely difficult to determine when use of a drug "contributes" to death. Thirdly, the cost of the system is considerable and is feasible only in a technically advanced country. It should also be noted that the DAWN system provides no information on alcohol abuse unless it is associated with the use of some other drug. DAWN might require considerable modification in less developed countries or in smaller countries where the cost would have to be borne by a smaller population.

Some specific problems with DAWN reporting have been noted in the research literature. Brookoff et al. (1993) showed that cocaine related trauma was under-reported in one hospital by a large margin. Also, DAWN data report as many as 6 times as many deaths from cocaine as reported in vital statistics records (Pollock et al., 1991). It should be noted that this may not be a problem with DAWN, but rather with the vital statistics. Probably, the DAWN data are more accurate but there are many problems in defining a cocaine-related death especially where other drugs may be involved and the cause of death is unclear or multiply determined. These problems have not been clearly resolved as yet in the DAWN system.

Current forms used for DAWN Medical Examiner and Emergency Department Report are given in Annex 1 and 2 respectively.

Despite its limitations, the DAWN system illustrates the characteristics of specialised drug-abuse-event reporting system and provides a model for possible use in other settings. In some countries it will be more feasible to have fewer hospitals included, perhaps only those in a few large cities with drug testing laboratories. In such circumstances, it may be more justifiable to develop event-reporting systems based on other institutions, such as poison-control centres, or law-enforcement agencies. The latter are a cheap and useful basis for establishing an event-reporting system, since enforcement agencies are commonly in contact with drug abusers and often collect information about them that could be systematised and made part of the reporting systems described in the next section. However, they do not deal with health related problems and may be less useful in planning health services.

Recent data from DAWN are given in USDHHS (1994, 1996) and instruction guides in

USDHHS (1991 a, b).

2.1.2 Non-specialised Type

Uniform Crime Reporting System, Canada

In 1962, Statistics Canada, the national central statistical agency, collaborated with the Canadian police forces to establish a Uniform Crime Reporting System. This system is based on monthly reports submitted to the agency by police forces using a standard form developed by Statistics Canada with the co-operation of the Canadian Association of Chiefs of Police. The form requests information on offences, including violations of federal drug statutes, reported or known to the police. Since 1971, drug offences have been covered by four subclassifications: i. addicting, opiate-like drugs; ii. cannabis (marijuana); iii. controlled drugs; and iv. restricted drugs.

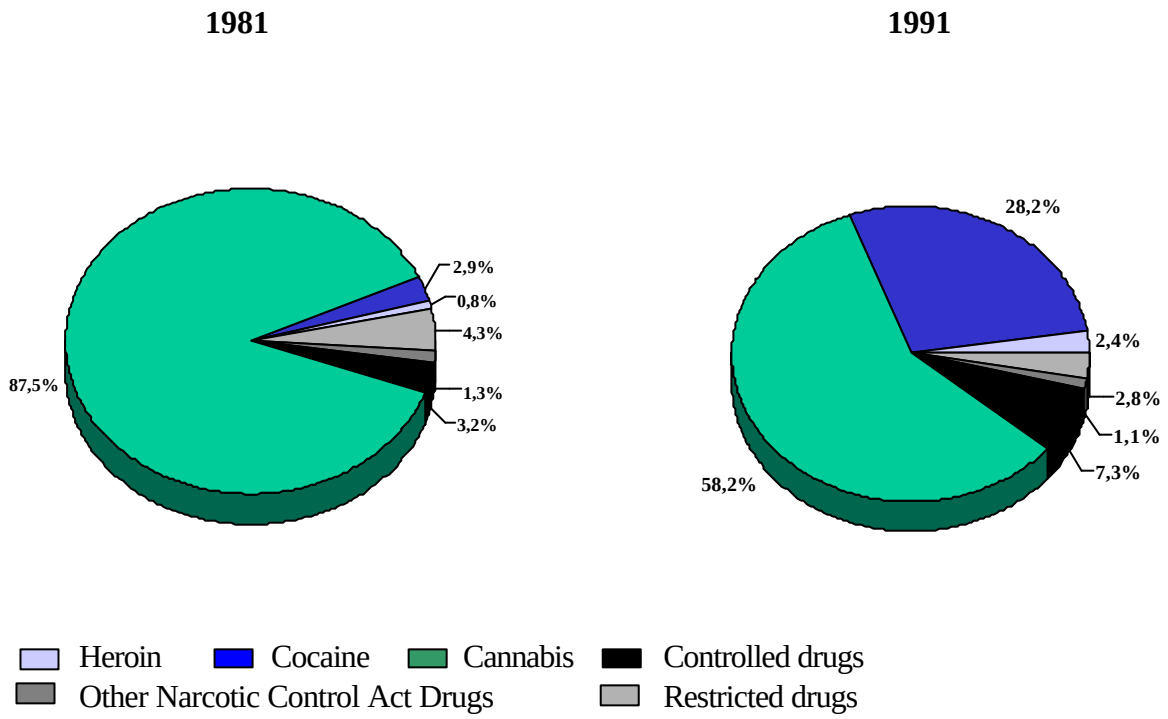
The summarised data reports are submitted to Statistics Canada monthly by police agencies in the country by means of the form or computer printouts or tapes in the same format. Statistics Canada checks for accuracy and uniformity of reporting, collates and tabulates the data, and publishes tables. The data for 1981 to 1991 (Figure 2) showed that there was a very large increase in the proportion of cocaine related offences - from 2.9% to 28.2% - and a decrease in cannabis offences - from 87.6% to 58.3%. The potential usefulness of this system was demonstrated by these data which showed that the drug abuse scene had changed greatly in Canada over 10 years from 1981 to 1991 and that cocaine became the second most important drug after cannabis. One cannot be sure from these data alone whether there was actually more cocaine use, since the arrests may be caused by various factors, including the zeal with which enforcement is carried out. However, the system has been useful to police, policy-makers, and the public, especially when it agrees with data from other sources.

The system has the limitations of event-reporting systems - i.e., it does not produce an unduplicated count of individuals, since a person may be reported more than once. The problem with the system is that it indicates reports on drug use known to the police. Not all of these result in arrests and sometimes the data on known violations of drug laws is subjective. Drug arrest data have also been very useful to planners in Japan in describing trends in drug abuse. Arrest data for 1969 to 1991 are shown in Figure 3. Again these data should not be considered alone, but along with other data (for example treatment data) and never considered outside the context in which the data were collected.

Most countries seem to collect data on drug related arrests and those data can be seen as a reporting system in the terms defined here. In some cases improvements could be made to arrest reports by including data on the characteristics of arrestees.

Figure 2:

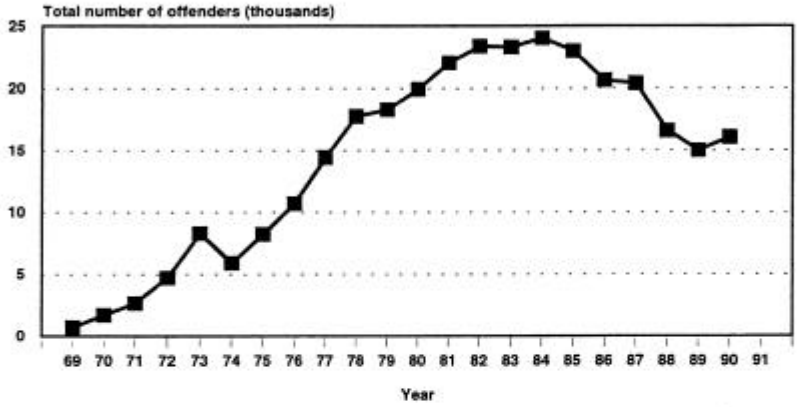
Federal Stature Drug Offences by Type
Canada, 1981 and 1991



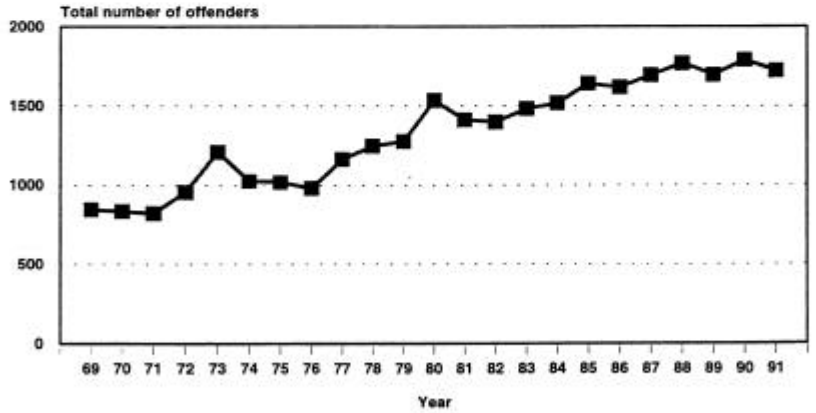
Note: Due to rounding procedure, percentage may not aggregate to 100%

Figure 3
Trends of Drug Offenses in Japan
Number of Offenders by Narcotic Regulation Laws

Violation of stimulant control law (1969 - 1991)



Narcotic offenders (narcotics, opium, cannabis) (1969 - 1991)



Also, information on the accuracy of arrest reports may be necessary. Further, drug arrests may not result always in a conviction and hence they tend to over-report drug activity. Another consideration is that arrest reports reflect police activity and not necessarily levels of drug use or abuse in society. Correlations between surveyed levels of drug use in Canada, for example, do not correlate well with drug arrests (Smart and Adlaf, 1989).

Non-specialised event-reporting systems can be extremely useful to policy-makers concerned with drug abuse and should be considered among the alternatives when systems are being selected. Although we have chosen to present enforcement-based systems as examples, health-based systems - e.g., serum hepatitis monitoring - might also be considered. Similarly, many countries already use the International Classification of Diseases (ICD) to code and report deaths. Some of these codes pertain to drug-related deaths and can be used as at least a crude measure of the extent of such deaths in a country (WHO, 1993).

Another example of health-care based system is the National Eye Trauma System Registry in the United States which has been used to examine the role of alcohol and drugs in trauma events. Alcohol was a factor in 48% and illicit drugs in 6% of eye injuries (Dannenberg et al, 1992).

2.2 Case-reporting Systems

2.2.1 Specialised type

First Treatment Demand - the Pompidou Group - Council of Europe

In member countries of the Council of Europe's Pompidou Group institutions which have contact with substance users seeking help or treatment are a valuable source of data on patterns and trends of substance use. These "demands" for help or treatment can provide data on the number and demographic profile of those seeking help or treatment. Such information provides a direct measure of the uptake of services. In addition these data can provide an indirect indicator of substance use trends. By collecting data on those seeking treatment for the first time and comparing it with those who have previously been treated can provide some indication of new trends in substance use. Data collected over a period of time can provide information on trends in substance use, identify changes in behaviour (e.g. injecting, syringe sharing) and provide one source for capture-recapture prevalence estimates.

These data have their limitations in that: they can reflect the relative availability or attractiveness of certain types of treatment; given the elapsed time between first drug use and first treatment demand they have their own inertia; substance users can make demands on different institutions so a distinction between treatment episodes and individuals seeking treatment should be made. Double counting is a common cause of over estimating the number of individuals seeking treatment. For this reason case record forms should have a unique identifier to prevent double-counting. It should be

noted that substance users seeking treatment represent only a small proportion of all users and mainly those experiencing problems with their use.

A protocol for this indicator has been developed by the Expert Epidemiology Group of the Pompidou Group (The Council of Europe's Co-operation Group to Combat Drug Abuse and Illicit Trafficking in Drugs). This provides a framework for the routine collection and reporting of comparable core data on the profile and size of drug using populations who contact treatment centres in different cities. The protocol includes: objectives; definitions (including those for drug classification and treatment); items for a minimum core data set; instructions for recording and coding data (including a model data collection instrument); and standardised output tables for collating and presenting the information. The model data collection instrument used can be found in Annex 2 to Chapter 3 on Existing Information Sources.

Treatment Episode Data System (TEDS) - USA

TEDS, formerly called the Client Data System, is a reporting system that collects information on individual admissions to substance abuse treatment programs that administer public funds. It is a State-based administrative system used both by the States and the Substance Abuse and Mental Health Services Administration (SAMHSA) to monitor access to publicly funded treatment. TEDS was initiated by the National Institute on Drug Abuse (NIDA) and the National Institute on Alcohol Abuse and Alcoholism (NIAAA). In 1992, responsibility for TEDS passed to the (then) newly constituted SAMHSA.

All clinics and/or programs receiving any State Alcohol and/or Drug Agency (including Federal Block Grants) funds for the provision of alcohol or drug treatment services must report Client data. At the State's option, data will be accepted on other programs such as private programs. TEDS has a minimum (required reporting) data set and a supplemental (optional reporting) data set. The Minimum Data Set includes primary, secondary, and tertiary drugs used, their routes of administration, frequency of use and the age at which use began, as well as the source of referral for treatment, type of service received, number of prior treatments, and standard demographic information. The Optional Data Set includes health insurance, expected source of payment, primary source of income, pregnancy and veteran status, additional psychiatric problems and DSM III-R diagnosis, and more detailed data on criminal justice referral and status of those not in the labour force.

System for Registry of Information on Drugs (SRID) - Mexico

The overall goal of this system is to define drug abuse trends in Mexico. In the first phase only Mexico City is covered but eventually the system will be national in scope. The data are drawn from "hospitals, drug abuse treatment centres, homes for minors, and reformatories "(Ortiz, 1990). There are two special evaluation periods for 30 days per year (June and November). The SRID

questionnaire is applied to all drug abuse cases seen in the reporting institutions. Training is given to those who fill in the questionnaire, which can be administered in about 5 minutes.

Drug Treatment Reporting System - England, UK

Since 1992 data from fourteen regional drug misuse data bases have been combined into a national drug treatment reporting system. The data are collected at a regional level from a range of specialist and non-specialist drug treatment and welfare agencies in both the public and private sectors. Every six months summaries of these data are provided to the governments Department of Health which co-ordinates the system. Participation in the system is voluntary so coverage varies, but the data are collected to a common format. From 1996 a wider range of data, broadly comparable with that collected by the Pompidou Groups First Treatment Demand Protocol (see above), has been provided.

Reported Users of Narcotic and Hallucinogenic Drugs - Canada

Some reporting systems turn out not to be very useful and are eventually discarded. This is true of the Bureau of Dangerous Drugs (1987) reports on known illicit drug users (Table 3). The system was begun in 1965. It includes data from pharmacies, treatments centres and police. The drugs reported were narcotics, cocaine and hallucinogens. Most reports came from the police who gathered information on drug users during their regular activities. It seemed necessary only for some agency to report that a person was a drug user. No arrest was necessary nor was it ever clear what criteria were used. Police reports to the system diminished in the 1980's. The Bureau of Dangerous Drugs admitted in 1987 that "the determination of an individual's drug use is subjective and circumstantial and as such the accuracy of the data may suffer." There was no validation of the reports received. Also, human rights issues arose because of the keeping of sensitive records on individuals when those records were admittedly not very accurate. The Bureau stopped reporting the data on known users in 1987. The data were not often used by researchers or planners and the loss was not very great. Experience with this system shows that to be useful a reporting system should have a clear definition of how cases are to be defined and registered and some method of checking for accuracy. They should also offer some confidentiality for those whose names are included.

Specialised case-reporting systems can be extremely useful for persons working in the drug-abuse field at several levels. However, they have certain limitations. For example, it is not possible on the basis of reported data alone to follow up on cohort of admissions to determine what contacts have been made with other agencies, the mortality rate, or treatment status on anniversary dates. Some systems may also have unique limitations, such as a continuous change in the composition of reporting clinics owing to the creation of new clinics and the closing of old ones. Finally, these systems are expensive to operate. Planners in other countries may therefore wish to consider the use of non-specialised case-reporting systems as an alternative.

2.2.2 Non-specialised Type

The National Mental Health Reporting Programme - Indonesia

Work to develop this non-specialised case reporting system was started in 1968 as a co-operative venture between the Directorate of Mental Health, Ministry of Health, Indonesia, and the International Committee Against Mental Illness. It was established on a national basis in 1972 (Salan, 1978). Information on all patients admitted to 35 mental care institutions in Indonesia was recorded on a 10-page multiple-choice questionnaire known as the General Purpose Psychiatric Questionnaire. Demographic data were entered, as well as data on psychiatric history, criminality, diagnosis, prognosis, and use of selected drugs. A clinical report printed by the computer for each patient and was mailed to each hospital for further use. In addition, periodic statistical reports were produced from the computer tapes.

The information obtained from this system has enabled policy-makers to monitor some of the dimensions of drug abuse in the country. In particular, it has helped them to identify at an early stage a serious outbreak of morphine and heroin use among middle-class and upper-class young people in the major cities during the early 1970s. Although only a portion of the total numbers involved sought treatment in mental hospitals, the reporting systems permitted planners to observe quickly their age, sex, socio-economic status, and drug-using patterns, and the geographical regions involved. A national prevention, treatment, and law-enforcement programme was thus initiated at an early stage in the course of the epidemic.

While a case-reporting system of this type provides useful information to planners, it does not permit conclusions to be reached on drug abusers outside hospitals. As a non-specialised mental-health reporting system, it cannot be expected to obtain as much information on drug abuse as a specialised system would. Finally, a case-reporting system takes up 10-15 minutes of a physician's time to provide a diagnosis and other observations on each patient; thus it requires better trained professional personnel than most specialised drug-abuse reporting systems. Despite these limitations, the National Mental Health Reporting Programme of Indonesia provides one of the few international examples of a reporting system that detected a serious national drug-abuse epidemic at an early stage, and monitored what would appear to be a successful response by the Government to control it.

HIV/AIDS and other Infectious Disease Registers – World-wide.

Data on drug-related infectious diseases can provide: an indicator of trends in the prevalence of drug-related infectious diseases, mainly amongst injecting drug users; and at times, an indirect indicator of drug-injecting incidence. Possible sources include: notifications to public health authorities; infectious disease hospitals or units; hospital statistics on discharge diagnoses; public health laboratories; sentinel surveillance records; and national AIDs prevention and control

programmes.

Injecting drug use is a known risk factor for certain infectious diseases such as hepatitis B, C and D, endocarditis and AIDS. Data on the prevalence of these conditions or their markers amongst population of IDUs are useful for identifying the need for prophylactic measures, such as hepatitis B vaccination or risk-reduction education, and for monitoring the impact of these measures.

Data on trends in the incidence of drug-related cases of acute hepatitis B have also sometimes been used as an indirect indicator of the incidence of new drug injectors. As was discussed in Chapter 3, data on hepatitis B need to be interpreted with caution for the following reasons: 1. In some countries, there may be widespread prevalence of hepatitis B which is unrelated to injection drug use, 2. Hepatitis B vaccination campaigns and important changes in risk behaviour on the part of drug injectors in response to AIDS, may make the interpretation of this indicator is difficult in some countries, 3. Interpretation is confused by the increase in hepatitis C in some drug-injecting populations, and 4. Information on the risk factors involved is often lacking.

If data on risk factors are available (drug injection versus other factors such as homosexual activity or blood transfusion) and the aforementioned circumstances which could affect the population prevalence have been considered, then epidemic increases in drug-related cases of hepatitis B, non A – non B or C may point to an increased incidence of drug-injecting amongst previously unexposed populations. The converse is not true. A low number of drug-related cases of hepatitis does not necessarily mean a low incidence rate of injecting. Hepatitis A is not a good indicator of drug use.

The rate of HIV-seropositivity amongst injecting drug users varies greatly among countries. Similarly, rapid changes over time are sometimes observed. This means that data on HIV cannot be used as an indicator in trends in drug injection, though of course they are very relevant to identifying the need for interventions aimed at limiting the spread of HIV.

Data on infectious diseases can be obtained through public health surveillance systems and laboratories, and through hospital discharge statistics, though they may be unreliable due to missing information on risk behaviours. National and regional AIDS reporting systems may be more reliable.

Most countries in the world have a national system for registering known HIV or AIDS cases (Dickens, 1988; National Academy of Sciences, 1986; WHO/EURO, 1993). In most countries AIDS is notifiable but AIDS related complex is not (Dickens, 1988). Some states in the USA require the reporting of HIV positive tests but some do not. The proportion of AIDS cases related to intravenous drug use varies from one country to another. However, in many countries the information on AIDS is very useful in tracking changes in intravenous drug use and its consequences. AIDS registers have been used in a variety of countries (Smart, 1991; Kaldor et al., 1993; Diez et al., 1992; WHO/EURO, 1993) to study the characteristics of intravenous drug abusers affected with the disease. Also, regional centres for monitoring AIDS have been developed in all parts of the world. Table 2 shows the increase in AIDS cases among injection drug users in Europe between

1987 and 1992.

Table 2:AIDS Cases Among Injecting Drug Users in Europe

Reported Cases of AIDS Among Injecting Drug Users						Percentage Increase in Number of Cases				
1987	1988	1989	1990	1991	1992**	1987/88	88/89	89/90	90/91	91/92***
N %	N %	N %	N %	N %	N %					
1941	3691	5007	5853	6355	3635					
27.2	34.6	35.8	35.9	38.4	38.3	90.1	35.6	16.8	8.5	NA

* From the European Centre for the Epidemiological Monitoring of AIDS: WHO-EC Collaborating Centre on AIDS; Paris, France. AIDS Surveillance in Europe, Quarterly Report No. 35

** January 1 to September 30

*** Data for 91/92 are not comparable since data for 1992 includes only those for the period January September.

Drug Use Forecasting Program (DUF) and Arrestee Drug Abuse Monitoring (ADAM) Program USA.

DUF, which began in 1987, monitored the level of drug use among male and female arrestees in 23 cities in the USA (National Institute of Justice, 1997). Each quarter, trained local DUF staff obtained voluntary and anonymous urine specimens and interviews from adult arrestees and juvenile arrestees/ detainees who have had in a booking facility for no more than 48 hours in the participating locales. The data collected include the current charge, self reported drug use, voluntary urine specimen, and the need for treatment for drug dependence. This was the first system to provide objective measures of drug use among arrestees.

The target population was all arrestees charged with major offences, excluding minor offences such as vagrancy, traffic violations, etc. This system used the criminal justice system in a unique and creative way to monitor drug use in a high risk population. Other countries could devise some similar systems, perhaps with fewer sites. These systems monitor a heavy drug using group which is probably often missed in surveys.

In 1995, the National Institute of Justice proposed the development, in stages, of the Arrestee Drug Abuse Monitoring (ADAM) Program to replace DUF. ADAM includes many of DUFs features but also includes an expansion to 75 sites, the establishment of an annual outreach program to nearby and outlying arrestee populations, development of local co-ordinating councils, and the redesign of the data collection and sampling methodology. The development of ADAM illustrates the evolving, rather than static, nature of many drug abuse reporting systems.

2.3 Case Registers

A study of 43 countries' legislation by Porter et al. (1986) found that 21 countries had compulsory reporting provisions for alcohol or drug dependence. Of those 21 countries 17 required reporting of drug dependent persons, i.e. Myanmar (Burma), Colombia, Cyprus, Finland, France, Hong Kong, Indonesia, Italy, Japan, Malaysia, Mexico, Norway, Philippines, Senegal, Singapore, Somalia, Sweden, Switzerland (St. Galen), Tunisia, United Kingdom, and Zambia. Also, three countries (Finland, Norway and Switzerland) require the reporting of some types of alcohol dependent persons and only one country (Sweden) requires the reporting of both. It is impossible here to describe all types of registers and how they function. This chapter confines itself to describing a few of the longest running systems for which information is available. As stated earlier most systems require physicians to notify known or suspected addicts. However, some registers are voluntary e.g. the Hong Kong Central Registry of Drug Addicts and at least one requires self registry (Myanmar).

2.3.1 Specialised Type

The Addicts Index - United Kingdom

Doctors have been required to notify addict patients to the Chief Medical Officer at the United Kingdom Home Office since 1968. The Misuse of Drugs Regulations of 1973 required all doctors to notify the Home Office of persons whom they suspect of addiction to 14 drugs, including heroin, morphine, methadone, and cocaine. Notification was required if the person is addicted or dependent on drugs. Since 1997, there is no legal requirement anymore for a doctor to notify the Home Office if the person is addicted or dependent on drugs. Notifications are however still recommended. The three major sources of notification are clinicians at drug-treatment centres, general practitioners, and prison medical officers. When any of these people is confronted by a person wanting a legal opiate prescription, who claims to be using an opiate, who shows evidence of recent needle marks and/or provides a urine test which is opiate positive, the doctor should submit to the Home Office the required written notification. Before submitting a notification, the doctor may, and usually does, telephone the Home Office to inquire if the patient is already known to them. The notification includes the following information: patient's name, address, sex, date of birth, National Health Service number, date of attendance, and name(s) of drug(s) concerned. Doctors are not required to submit names of people receiving drugs for medical purposes, i.e. treating organic disease. In addition to information obtained from formal notifications, information of a variable nature is often obtained from police reports, Home Office inspectors, or other sources.

When a valid notification is received, the person's name is entered in a nominal index. The purpose of this index is to provide a way of checking immediately whether a person is already known to the Home Office in connection with drugs of addiction or whether he is a confirmed addict. In an attempt to confirm the case, the Regional Medical Officer then visits the notifying doctor.

Where notification comes from a treatment centre or prison medical officer no confirmation is sought. When a case is confirmed it is entered into the addicts' index. On receipt of subsequent notifications, the particulars are checked and personal files and index cards are updated to include any changes. If no notification is received on an individual for 18 months, his card is removed from the addicts' index. Cards of persons who are known to have died are removed from the index immediately. By law, the information in the index is confidential, except that any doctor may ask for information about a patient under his care. Only after the identity of the inquirer is verified is the requested information released.

Procedures are followed to eliminate duplicate countingi- e.g., the counting of the same individual as two or more addicts. Specifically, doctors may check with the Home Office before submitting a report, in order to determine whether or not a patient is already known. In addition, the reports that are received are carefully checked (name, date of birth, and any other particulars) against those for individuals already listed. However, the doctor is usually required to submit a formal notification even if the patient is already known to the Home Office.

On the basis of the information in the addicts' index, the Home Office prepares regular tabulations of known addicts and of "new addicts" (or those not previously notified to the Home Office). The tabulations have been used to monitor changes in the number and characteristics of known addicts, determine clinic attendance patterns, and prepare reports for international agencies. In addition, the index has been used for other purposes, including enforcement, treatment, planning and research.

The potential usefulness of data based on the addicts' index is illustrated by Table 3 which shows the number of persons newly notified to the Home Office as addicts, according to the source of notification, 1989-1991. As can be seen, the number of new cases increased during that time as did the number of renotified addicts. This information is very useful to policy makers planning changes in treatment programs and the UK register has been often used for such purposes. Also, the system has been used to provide regional data bases for the United Kingdom and hence more local data is now available (Mott et al., 1993).

Table 3: United Kingdom Addict Notification Summary Statistics

United Kingdom	Percent Change				
	1989	1990	1991	1990	1991
New drug addicts reported	5,639	6,923	8,007	23	16
Renotified drug addicts	9,146	10,832	12,813	18	10
All drug addicts reported	14,785	17,755	20,820	20	17
heroin	12,484	14,497	15,086	16	4
methadone	2,951	4,992	7,997	69	60
cocaine	888	1,085	1,525	22	41
Average age	28.9	28.8	29.2		
Deaths of previously notified addicts	302	331		10	

Like the other systems described, this system has certain limitations. In particular, it is not possible, by means of the addicts' index, to determine the precise number of "addicts" in the community, since the index includes only the persons coming to its attention. Thus, as suggested by Blumberg, (1974) there may be a substantial number of reasonably regular users unknown to the Home Office. For example, an intensive case-finding study carried out in Oxford (Arroyave et al., 1973) revealed that 20% of 63 "certain" cases of opiate use had not been notified to the Home Office, and that none of the 111 "very probably, probably, or suspected" cases had been notified. A similar study in Crawley, a town of about 60,000 people near London, showed a rate of 8.5 per 1000 confirmed cases of heroin addiction compared with a rate of 1.4 predicted by the addicts' index (Mott and Rathod, 1976).

Despite the requirement that all addicts should be notified in the United Kingdom, many of these seeking treatment are not. The study by Smart and Ogborne (1974) showed that 10-15% of those in therapeutic communities were never notified. As well, 46% of those seeking treatment were not notified by the attending physician. This probably occurred because they did not remain in treatment and physicians were reluctant to notify those who they were not actually treating. More recently Mott et al. (1993) showed that 7% of addicts reported to a local addict database were not reported to the Home Office.

Another possible limitation of the Home Office addicts' index is that the practice of "confirming" addicts before they are included in the index may well exclude some early cases. Visits by regional medical officers to notifying doctors to confirm cases may also be impracticable when more than a handful of "addicts" is involved. Finally, the "removal" of cases from the index, as opposed to an internal analytical procedure for considering certain individuals "inactive" if they have not reported within a specified period, may be a limiting factor.

Central Registry of Drug Abuse (CRDA) - Hong Kong.

The CRDA began its operations in 1976 and has become an invaluable monitoring system for drug abuse in Hong Kong (Wat, 1985). The CRDA uses a wide variety of reporting sources including Law enforcement agencies, welfare agencies, general hospitals and clinics, and specialised addiction agencies. All agencies are requested to report all addicts or suspected addicts which are known to them. Considerable efforts are made to catch errors in reporting. Also, many efforts are made to eliminate duplicates, a difficult job in Hong Kong where many last names are the same. Reliability checks are also made using age of first use and reported age.

The Register of Drug Addicts - Western Australia.

Under the Drugs of Addiction Notification Regulations of 1980 medical practitioners in Western Australia are required to notify drug addicts to the Public Health Department. The law requires that known and suspected addicts be reported. A person is deemed to be addicted to drugs if he is periodically or chronically intoxicated by, has a desire or craving to take drugs, or has a psychic or physical dependence. These definitions seem relatively broad compared to those for other registers but no work has been published on the types of addicts notified in the system. Cases are removed from the system after five years if no further notification has been received.

The National Drug Abuse Monitoring System - Malaysia.

This system is one of the largest and most comprehensive anywhere in the world. It includes events monitoring, case reporting and a case register for addicts. Events include arrests and seizures as well as hospital admissions (Navaratnam and Foong, 1989). The goals of the system are:

(a) To provide current epidemiological information on drug abuse in the country and to update such information;
(b) To identify trends in the nature of drug abuse over time and variations between geographical locations;
(c) To provide relevant information for effective planning, evaluation and management of drug abuse programmes.

A standardised instrument was developed for collecting data. Core information included:

(a) Administrative details (reporting agency, identification card number of each individual);
(b) Background characteristics of each individual (including ethnic affiliation, sex, age, marital status, date of birth, educational level attained, occupation and monthly income);
(c) Pattern and history of drug use (age of initiation, types of drugs used in the past and

at present, duration of use, daily expenditure, source of drugs, reasons for use and discontinuing use);

(d) Treatment experience;

(e) Criminal history (past arrests, convictions and imprisonment);

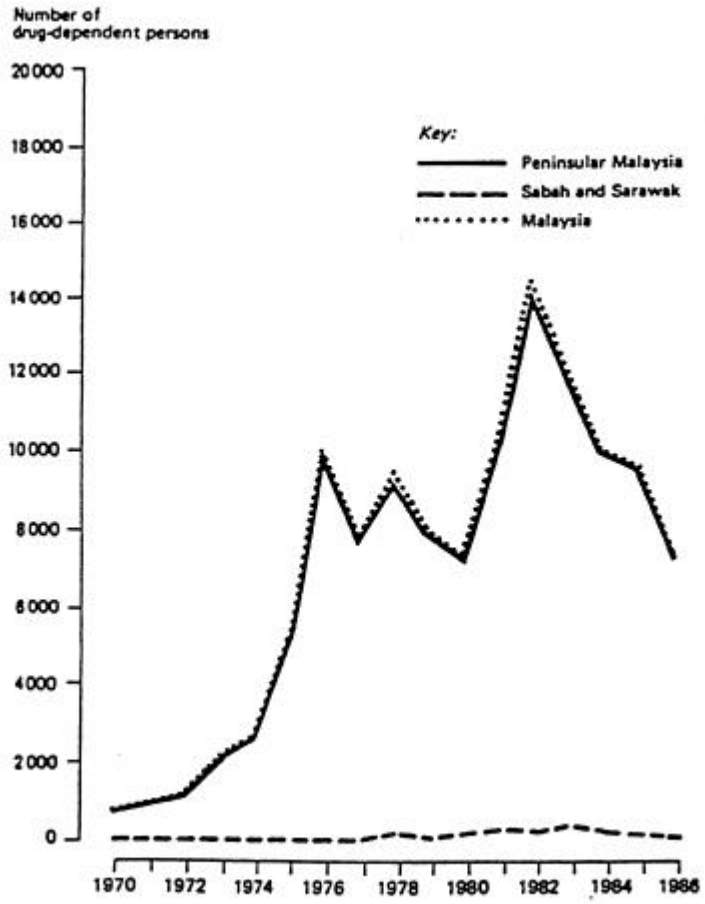
(f) Drug-related crimes (type of drug and amount seized, type of crime committed and criminal status of the addict).

According to Navaratnam and Foong: (1989) "Data from the system are useful for epidemiological research and for the planning of drug abuse prevention, control, treatment and rehabilitation. Information from the system is used for assessing the extent, distribution and pattern of the drug abuse problem in Malaysia.

Data on the socio-demographic characteristics of drug-dependent persons, the type and pattern of drug abuse, the severity of the drug problem and variations in drug abuse activities between regions, together with other relevant data, have been found to facilitate programme planning and policy-making in the field of drug abuse control."

An example of the data produced by the monitoring system in Malaysia is shown in Figure 4. It can be seen that there are marked regional differences as well as a decline in the later years. In general, case registers are an important part of epidemiological monitoring systems. They may be too expensive for some countries with small drug problems or problems not involving the serious drugs of dependence. For example, if a country had mainly problems with cannabis or khat, it may decide against a case register as relatively few users will need treatment or become dependent.

Figure 4: Trends in reported incidence of drug dependent person 1970-1986, Malaysia



Source: Navaratnam, V and K. Foong (1989). *Development and Application of a System for Monitoring Drug Abuse: The Malaysian Experience.* Bulletin on Narcotics, Vol XLI, Nos. 1 and 2, p. 59.

2.3.2 Non-specialised Type

Psychiatric Patients Register, Australia

An example of a psychiatric case register that can identify drug abusers is to be found in the State of Victoria, Australia. This register has been in operation since 1961, when all residents of psychiatric institutions in Victoria were given a permanent identification number. All subsequent patients have also been allotted a number. Information on each patient consists of a summary record, which is updated after each contact with a psychiatric institution, and chronologically recorded reports of all contacts with psychiatric inpatient, day-care, and outpatient institutions. The

data are collated by computer with confidentiality safeguards built in. The computer data base consists of an active file containing all data on patients under care in a given year and a historical file on all other patients (Medinfo, 1977).

Although not designed specifically to monitor drug abuse, this register and others like it have the potential of being used for this purpose, since they use the ICD codes to classify diagnoses. The ICD provides specific code numbers on drug dependence and nondependent abuse of drugs, and subcodes are provided for the major types of dependence-producing drugs.

An example of the use of a psychiatric case register for purposes of drug-abuse programme planning comes from Israel, where data on abusers of alcohol and drugs were analysed to detect localities with varying abuse patterns. The analyses were used as a basis for preliminary planning estimates and programme evaluation (Israel, 1977).

Such non-specialised case registers have all the limitations of specialised registers. In addition they have limitations arising out of their non-specialised nature - e.g., the amount and quality of information obtained on drug abuse are limited because of competing priorities and the data obtained may also not be comparable with drug-abuse data obtained from other sources.

2.4 Aggregate Systems

These systems use data from a variety of reporting mechanisms and typically include data from event registers such as hospital admissions, and death reports as well as case reporting and case register systems. Usually these systems examine all available drug abuse indicators for a given area, usually a large metropolitan area. Many aggregate systems report data at the city level and are thus referred to as multi-city systems. These multi-city systems often form “networks” or “work groups” of individuals representing the participating cities. These networks meet periodically to monitor drug trends and to provide a forum for discussion and interpretation of the data at the local level as well as within larger national and, in some cases, regional contexts.

Community Epidemiology Working Group (CEWG) - USA.

The Community Epidemiology Work Group (CEWG) is a network of researchers from 21 major metropolitan areas of the United States and selected foreign countries. It meets semi-annually to discuss the current epidemiology of drug abuse in specific geographic areas. The primary mission of the CEWG is to provide ongoing city-level surveillance of drug abuse, principally through collection and analysis of outcome and consequence data. Since its establishment in 1976, the CEWG has provided ongoing descriptive information regarding the nature and patterns of drug abuse, emerging trends, and characteristics of the vulnerable population. The number of cities has increased over time, as well as the amount of data gathered for each city (NIDA, 1999).

To assess drug abuse patterns and trends, data from a variety of health and other drug abuse

indicator sources are used including the following for each city:

- **Drug-related deaths** reported by (1) medical examiner (ME) offices to Drug Abuse Warning Network (DAWN), (2) local coroner/ME offices, and (3) State public health agencies
- **Drug-related emergency room (ER) episodes** (estimated mentions and estimated mentions per 100,000 population) reported to DAWN
- **Primary substance of abuse** reported by clients at admission to treatment programs
- **Arrestee urinalysis results** based on data collected by the Drug Use Forecasting (DUF) System of the National Institute of Justice and by local criminal justice agencies
- **Seizure, price, purity, prescription/distribution, and arrest data** obtained from the Drug Enforcement Administration (DEA) and from State and local law enforcement agencies
- **Other city-specific data** gathered from ethnographic research, surveys, criminal justice and correctional sources, public health sources, and other sources unique to local areas

Although the major aim of the CEWG is to describe data at the city level comparisons are made of what is found in the whole country. Caution is advised in making such comparisons for death, treatment, and arrest data, however, comparisons are necessary. Figure 5 shows a comparison of heroin treatment admissions in twenty cities in the USA. It can be seen that there are very large differences in treatment admissions across cities. Similar comparisons can be made for other drugs.

The CEWG has many advantages. It brings researchers together to talk about common problems. It produces regular reports on the data gathered. Clearly it produces data useful to local planners in the cities participating. The method has been copied in several countries and regions such as Mexico, Central America and South and East Asia. Also state wide CEWG have developed in several states in the USA. Recent data on CEWG are available NIDA (1999).

It might be perceived that a limitation of the CEWG is that not all cities are included; however, the strength of the multi-city model is that data is interpreted within its local context as well as with respect to national trends. This provides a data driven basis for planning and action at the local level which is for more difficult, if at all possible, with national systems. It can also alert public health officials in neighbouring locations of regional drug abuse issues and emerging trends, thus the impact of the data presented extends beyond the boundaries of the reporting city. A guide for local Community Epidemiology Work Groups has been developed by the United States National Institute on Drug Abuse (NIDA) as a resource for state, county, city and local community agencies and organisations that are interested in developing drug abuse epidemiology work groups although developed for the U.S., may also be of relevance to other countries. (NIDA, 1998).

South African Community Epidemiology Network on Drug Use (SACENDU)

The CEWG has represented an important model, much copied in other places. Epidemiological work groups on drug abuse, modelled on the CEWG have been established or are under development in a number of countries and regions of the world. In South Africa, for example, the South African Community Epidemiology Network on Drug Use (SACENDU), collects, collates and interprets data from multiple sources. Currently established in three cities Cape Town, Durban and Port Elizabeth, there are plans to extend the network to Johannesburg, Pretoria and other cities in other countries of the region (SACENDU, 1997).

The Multi-city Study of Drug Misuse in Europe.

This comparative epidemiological study began in 1983 under the auspices of the Pompidou Group (Council of Europe) within the Epidemiology Expert Working Group.

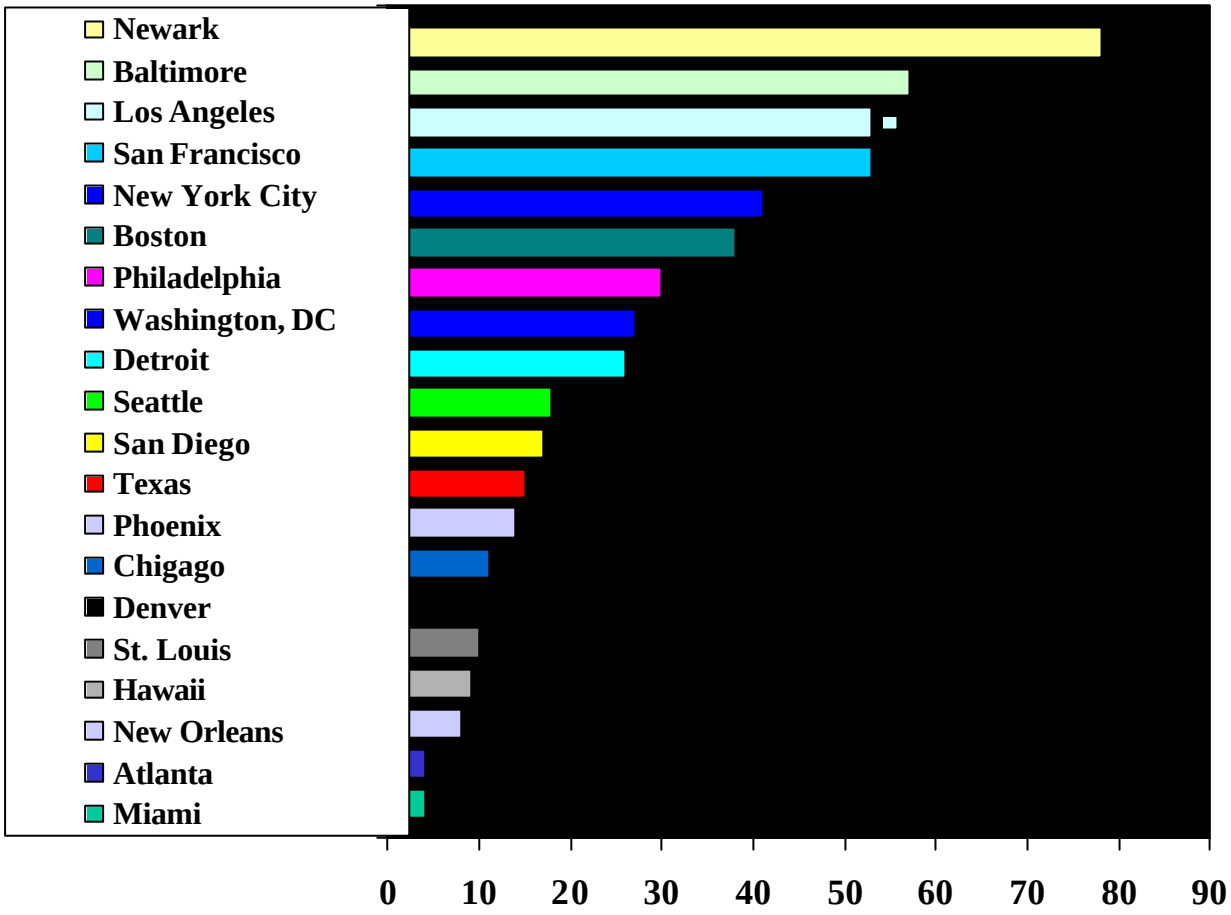
The main objectives of the Multi-City Study are the following:

- Review and summarise the available data on drug misuse in the participating cities.
- Critically examine the degree to which indicators are consistent and comparable between cities.
- Assess the benefits of using such indicators to measure and interpret the extent and changing patterns of drug misuse.
- Compare trends and prevalence between cities.
- Make recommendations in order to improve comparability or elaboration of the indicators.
- Develop methodologies and survey instruments in order to improve data collection.

The first report (a, 1987) contained data on drug misuse in seven major European cities up to the year 1985, but was mainly aimed at a providing a critical methodological review of indicators and at making recommendations for improving their quality and comparability.

Figure 5: Treatment admission for heroin in 20 selected U.S. cities

Exhibit 11: Heroin as a percentage of primary drugs of abuse among treatment admissions[a] in reporting CEWG areas 1996[b]



[a] Total admissions number excluded alcohol-only but includes alcohol-in-combination.
[b] Calendar year 1996, except for the following: State fiscal year 1996 in Chicago, Newark, New York City, Phoenix, San Francisco; 1995 in Baltimore and Washington, DC;10/96-12/96 in Los Angeles;and 7/96-3/97 in Miami

Source: National Institute on Drug Abuse. *Epidemiologic Trends in Drug Abuse, Volume 1: Highlights and Executive Summary, Community Epidemiology Work Group, June, 1997*, NIH Publication No. 98-4207, Rockville, MD: USDHHS, National Institutes of Health, 1997b, p. 28.

The second report (b,1994) focused on trends in drug misuse over the 1980s, and especially from 1985 to 1991, covering already thirteen cities. Since then, city reports have been updated on an annual basis, using a comparable framework, so as to provide a contemporary picture of trends in drug misuse across Europe. The main trends are summarised yearly in a synthesis of updates. It is intended to produce a full European Multi-City synthesis, based on complete city-reports, every five years.

The main indicators covered are first treatment demand, hospital admissions, drug-related deaths, police arrests, imprisonment, drug seizures, price/purity and survey data. Methodological development has concentrated on treatment data, police data, non-fatal emergencies and survey instruments.

Since 1992, the Pompidou Group implements a specialised epidemiological training programme for Central and Eastern European countries ("Information systems and applied epidemiology of drug misuse"), involving members of the Epidemiology Expert Working Group as lecturers. The Multi-City Study, presented as an example of the work of this Group, awake the interest of the Eastern experts, and subsequently a pilot-project (December 1994-May 1996) was launched. The concept, guidelines and multi-sectorial approach of Multi city data-collection were applied in nine cities of the region, testing its value as an epidemiological information system. The encouraging results make the extension of the network to further cities seem likely.

Epidemiological Surveillance System of Addictions (SISVEA)

This system, designed and co-ordinated by the General Directorate of Epidemiology (DGE) of Ministry of Health of Mexico, was installed in 1990 with the main objective to create and consolidate a continuous information system that could update the available information on drug use in Mexico. The information gathered from 1991 to 1995 serves as baseline in the epidemiological understanding of drug consumption. In addition, it is used as a reference for planners and decision-makers on different programmes which involve prevention, rehabilitation and treatment of substance abuse. Since then it has identified changes in consumption patterns, risk groups, new drugs and factors associated with the use and abuse of alcohol tobacco, medical and illicit drugs.

In order to accomplish the above mentioned objectives, a series of strategies were proposed. The first one is a network that includes continuous information generated routinely by institutions at different levels: drug treatment centres, medical coroner services and law enforcement agencies. The resulting information is concentrated at city, state and national level. The characteristics of the information flow are defined by each institution according to its infrastructure. This process results in proposals regarding the analytical level (city, state or regional) of data included in the SISVEA.

The second strategy, generates information which expresses the individual and social consequences of morbidity associated to the use and abuse of drugs. The process of this strategy works through the establishment of a network of sentinel posts, which include both: epidemiological surveillance sites located in high risk areas and key sites to detect the problem through its health and social consequences. These sites are mainly located in emergency rooms, psychiatric hospitals, primary health care units and detoxification and drug treatment centres, among others. The number and location of sentinel posts in each selected city is determined on the information collected and in co-ordination with the corresponding authorities in this field. Each sentinel post provides information about users of addictive substances, these data are collected during six weeks, twice a year.

The third strategy includes data that are collected through two types of methodologies. The first one is the development of population studies, in which probabilistic and non probabilistic surveys are considered and the second one is the development of qualitative studies. Among the former it is possible to assess, the prevalence of tobacco, alcohol and other drugs, to give information on the geographic, demographic and temporal issues related to the consumption of drugs, and therefore permit to study trends and changes in patterns of drugs abuse. The second category of studies relates to specific risk populations, such as juvenile infractors, IVD users, postnatal morbidity outcomes associated with the use of tobacco and alcohol during pregnancy, dropout of school population, among others.

SISVEA has been continuously evolving, and at present, it works on the basis of five indicators:

- Consumption of tobacco, alcohol, medical and illegal drugs
- Morbidity and injuries from external causes
- Mortality rates among drug users
- Law enforcement data
- Drug consumption among the general population and specific risk groups.

To support the activities of data gathering a specific software called Epi-Adicciones was developed, and is currently used in 14 cities that are at the moment part of the system.

Asian Multi city Epidemiology Study on Drug Abuse

The Asian Multi city Epidemiology Study on Drug Abuse was initiated in 1993 to respond to regional and policy needs on issues concerning drug abuse. Conceptually this programme is based on the Community Epidemiology Work Group (CEWG) project implemented by NIDA in USA. The major aim of the programme is to develop and utilise common drug abuse indicators in selected cities to assess and compare the changing pattern of the extent and nature of the problem, within the context of cultural and socio-political frameworks, thus facilitating better interpretation and understanding of the data. This is likely to help in implementation of effective treatment and

preventive intervention services. The Drug Abuse Indicative Report Form used in this study includes general population demographic indicators, drug treatment indicators, law enforcement indicators, health indicators and social indicators.

The Asian Epidemiology Work Group (AEWG) now consists of 22 cities and a city-based surveillance system has already been developed in ten cities. These cities gather drug indicator data on a quarterly basis. The Centre for Drug Research, University Sains, Malaysia, co-ordinates the programme, compiles and analyses data biennially. The initial report from the AEWG is available (Navaratnam, Leng, 1994, Navaratnam & Kin, 1996).

State Information System on Drug Abuse (SEIT). Spain

Spain's State Information System on Drug Abuse (SEIT) was established as a national reporting system in 1987. It integrates data on three drug use indicators: treatment demand; non-fatal hospital emergencies and deaths due to acute reactions to drug use (overdoses or poisonings). It collects data from a range of different sources including: private and public out-patient treatment centres; emergency rooms from a national sample of hospitals and pathology and toxicology units in major cities. The system monitors trends in the prevalence, patterns and health consequences of illicit drug use (until 1995 opiates and cocaine, from 1996 all illicit drugs). The national system was developed from existing regional systems. A protocol was agreed, with a set of common data collection methodologies and indicators, by those responsible for the regional systems. The results are published annually in a common format together with additional data from surveys, law enforcement statistics, HIV/AIDS data and ad hoc research studies.

International Epidemiology Work Group on Drug Abuse (IEWG)

Since 1994, an international work group consisting of representatives of most national and regional networks as well as representatives of regional and international organisations with responsibilities pertaining to drug abuse, has met annually. The mission of the IEWG is to provide a scientific/technical work group, linking national and regional surveillance activities using a multi-city model, for the exchange and interpretation of information on international drug use in order to enhance the international monitoring of drug trends, to identify emerging public health issues, and to strengthen and facilitate the development of drug abuse epidemiological surveillance research. Specific objectives of the IEWG are to:

- provide international drug abuse surveillance
- inform policy and program planners at national, regional and global levels
- offer opportunity and context for the development of exploratory and hypothesis driven drug abuse research
- help strengthen data gathering including promulgation of new technologies
- elucidate strengths and limitations of epidemiological data

- serve as a training resource, particularly for the development of new networks

International Drug Abuse Assessment System (IDAAS). United Nations

Any State party to the international drug control treaties of 1961, 1971 and 1988 has a treaty obligation to supply the Secretary-General with information on narcotic drugs, psychotropic substances and precursors. While there is no such obligation for non-parties to the relevant treaties, their co-operation is encouraged. Since 1947 an annual reports questionnaire (ARQ) has been used to collect data. The content of the questionnaire is decided by the Commission on Narcotic Drugs. It has been amended several times in order to accommodate different data requirements.

The response rates from governments as well as the quality of data has not been considered optimal. With this in mind, the Commission on Narcotic Drugs at its tenth special session in February 1988 adopted a resolution on the establishment of an International Drug Abuse Assessment System (IDAAS). The resolution stated that IDAAS, to be developed by the then Division of Narcotic Drugs, should aim at improving the overall quality of information submitted to the Commission on extent, patterns and trends of drug abuse world-wide.

The current annual reports questionnaire consists of three parts:

Part I concerns legal and administrative measures, Part II drug abuse and Part III illicit traffic. Part II forms the basis of the IDAAS. It contains three sections, Section 1 on the Extent, Patterns of Trends of Drug Abuse, Section 2 on Education, Workplace, Leisure time, Community and Media Activities and Section 3 on Treatment and Rehabilitation.

The Annual Reports Questionnaire (ARQ) is sent once a year (in December) to the Member States. The deadline for submitting such reports has been set by the General Assembly to 30 June the following year, but many countries do not reply until later in the year.

The ARQs are filed, together with attached annexes, in country boxes. ARQ information is also stored electronically. The intention is to merge information on demand and supply into a shared data base.

One of the main objectives of the ARQ information analysis, which takes place between June and December every year, is the preparation of a global report ("Extent, patterns and trends on drug abuse") for the Commission on Narcotic Drugs. The ARQ information is also used, together with other sources of information, to produce Country Drug Profiles, Country Programme Frameworks and, upon request by recipient or donor countries, other reports for policy-making or programmatic purposes.

Countries vary in their capability to collect data on the drug abuse situation. Many Government authorities find it difficult to fully complete the annual reports questionnaire. In recognition of this - and in response to a request by the Commission on Narcotic Drugs to simplify

the questionnaire - UNDCP has identified a number of minimum questions to be answered. Accordingly, a simplified reporting system was introduced in 1994 and will be tried for a period of two reporting years (1994 and 1995).

2.5 Advantages and Limitations of Each Type

Some of the advantages and limitations of the four types of reporting system have already been mentioned. However, it is useful to review and summarise them in one place to aid planners in making appropriate choices. Each type of system will be discussed separately, followed by a summary of its relative merits.

2.5.1 Event-reporting Systems

One potential advantage of these systems is that they can alert programme staff and policy-makers to emerging drug-abuse phenomena such as new adverse reactions to drugs, new routes of administration, the use of new combinations of drugs, and new substances abused. For example, the DAWN system developed an "Emergence Index" for monitoring and appearance of new drugs.

The direct costs should be lower for event-reporting systems than those for a case-reporting system or case register, since less collation and matching of reports is required. Matching names can be very difficult especially in societies where many names are similar or people do not know birthdays. Costs are lower if only aggregate rather than individual data are received from reporting agencies. Where this is done, the cost per case of pooling the data should be lower than with the other types of system. On the other hand, the costs of collation are passed on to the local agencies, and this may raise the indirect costs.

A third potential advantage of an event-reporting system is that confidentiality problems can be dealt with relatively easily. This is especially true if aggregate data are reported, which means that no identifying information has to be passed on to the central agency. Finally, an event-reporting system may entail fewer maintenance problems than other types of systems, because it may not require as highly trained and specialised staff as case registers or case reporting systems do.

Of course, the major limitation of an event-reporting system is that it is not possible to determine how many individuals are involved in a given set of events - i.e., individuals are not identified in the reports, so it is not possible to determine whether several hundred reports involve several hundred drug users or a small number of individuals who are reported many times. It is also extremely difficult to determine whether one is dealing with a new or an old group of drug abusers, and this makes it difficult to design intervention efforts.

Another limitation is that event-reporting systems do not provide follow-up information or reports, so that it is not possible to determine the outcome of particular contacts. With the DAWN

system, for example, the immediate outcome of an emergency-room visit may be ascertained, but there is no provision for following up the individual subsequently. In arrest based systems it is possible to determine immediate outcome at the aggregate level, but not for particular individuals, i.e., we can get data on sentencing but not for individuals.

Another limitation of event-reporting systems is that it is usually not possible to directly link information obtained from different types of institution. For example, information from the emergency room about a particular episode cannot be linked with data from the coroner about the same episode. This makes it difficult to develop a coherent picture of related events, and the consistency of information from one source cannot be checked against that obtained from another. However, aggregate systems can examine several types of related events at the aggregate level, e.g. trends in cocaine deaths overdoses and treatment admissions in a given area are examined by the CEWG in the United States.

The validity and reliability of data in event-reporting systems may be less certain than those of data obtained from other systems. The central agency cannot check the consistency or accuracy of individual or aggregate reports on the basis of the information it receives. Special studies are therefore required if information on reliability and validity is needed.

A fifth limitation of an event-reporting system is that it may be less useful in scientific research than the other two types of system. This is due to the tendency to obtain less information than with the other systems. In addition, when data are reported, data analysis is limited by the number of variables, at hand. If there are few variables less analysis is possible.

2.5.2 Case-reporting Systems

One advantage of such a system is its potential for describing the characteristics of persons who develop particular types of drug problem. This enhances the ability of such systems to identify high-risk groups.

Another advantage that a case-reporting system has over an event-reporting system is that it is better able to determine outcomes for individuals. Such outcomes are generally limited, however, to one set of events, such as those occurring during a hospital admission. Thus, it is not as effective as a case register is permitting a cohort of admissions to be followed for subsequent contacts with other agencies, their mortality, or treatment status on anniversary dates.

A case-reporting system may not be as efficient as an event-reporting system in quickly alerting planners to changing patterns of drug abuse, but it may be more helpful in interpreting the meaning of changes by virtue of collecting more information on the individuals involved. For the same reasons, a case-reporting system may have an advantage over an event-reporting system in terms of the validity and reliability of the information collected, since it is possible to conduct more

checks when more information is available.

2.5.3 Case Registers.

As indicated earlier, case registers have greater analytical capability and flexibility than either of the other types of system - i.e., they can analyse and present data in terms of events, cases, or individuals. However, the major problem with case registers is defining a case and making sure that all cases are registered. Case registers are capable of following an individual's contacts with various agencies. This gives policy-makers a better opportunity to determine the impact of treatment and enforcement agencies on subsequent drug use and other activities of those reported.

Because registers usually obtain information from several sources and are capable of linking it to individuals, they are more capable than the two other types of system are of checking the reliability and validity of the data that they receive. For these reasons, case registers are more likely than case-reporting or event-reporting systems to facilitate scientific research. On the other hand, registers may have more problems in maintaining confidentiality than the other two types of system. They also need better trained and specialised staff over a long period. They also entail higher direct costs, because of the need to link all reports for each individual for a longer time.

2.5.4 Summary comparison

Table 4 summarises the relative strengths of the three types of system. Each system type has been ranked as 1, 2, 3 or 4 depending on its relative strength in a number of dimensions. Event-reporting systems appear to be the most advantageous in terms of early warning, direct costs, confidentiality, and system maintenance. Case registers appear to be the most advantageous in terms of analytical capability, flexibility, follow-up, interpretation, validity checking, reliability checking, research, and estimating incidence and prevalence. Case-reporting systems seem to fall in between in all dimensions. These ratings may be of some use to planners wishing to choose between types of system. Aggregate systems use all three of the above approaches. The major advantage is that they make use of all data available in a given area. They therefore have all the advantages of the three major systems and may give a better picture of what is happening than a system which relies on or reports primarily one type of data.

2.5.5 Specialised versus Non-specialised

Finally, the distinction between specialised and non-specialised reporting systems should be kept in mind by the planner. To develop a comprehensive reporting system exclusively for drug abuse may be quite expensive and, when drug abuse declines, it may not be possible to justify the continued expense. On the other hand, a specialised system has the advantage that it can be designed to meet the exclusive needs of drug-abuse programmes. The system can be shaped to give the planners of drug-abuse programmes the type of information they need.

Non-specialised reporting systems are less expensive because the costs are shared with one or more agencies. They are also more likely to survive when drug abuse receives a lower priority for government funds. The problem with the non-specialised system, however, is that it is not often possible to ensure comparability with other systems for collecting drug-abuse data. Only a limited number of items on drug abuse is generally permitted, since the system must serve the needs of other users as well. The planner must weigh, in his individual setting, whether the compromises and advantages of the non-specialised system counterbalance the advantages and disadvantages and the higher economic cost of the specialised system.

Table 4: Relative Strengths* of Four Types of Reporting System on a Number of Dimensions

	Event-Reporting Systems	Case-Reporting Systems	Case Registers	Aggregate Systems
Early warning	**1**	**2**	**3**	**1**
Direct costs	**1**	**2**	**3**	**2**
Confidentiality	**1**	**2**	**3**	**1**
Maintenance problems	**1**	**2**	**3**	**3**
Analytical capability	**3**	**2**	**1**	**1**
Flexibility	**3**	**2**	**1**	**1**
Follow-up	**3**	**2**	**1**	**1**
Interpretation	**3**	**2**	**1**	**1**
Validity checking	**3**	**2**	**1**	**4**
Reliability checking	**3**	**2**	**1**	**4**
Research	**3**	**2**	**1**	**1**

* 1 = Excellent; 2 = Very Good; 3 = Good; 4 = Fair

3. Stages in the Development of Reporting Systems

Considerations in the development of certain reporting systems have been discussed in other WHO publications (Brooke, 1974; Porter et al. 1986). In order not to duplicate those efforts, the present text emphasises considerations unique to drug-abuse reporting systems. This will be done in terms of four stages of development through which a reporting system should pass: i. initial planning, ii. design, iii. testing, and iv. implementation. Each of these stages consists of relatively distinctive activities, outlined in Figure 6.

Although these stages are not the only way to conceptualise the process, they provide a framework for discussing the development of reporting systems. Accordingly, they will provide the basis for this chapter. It should also be noted that, in practice, the stages and activities do not always follow the sequence in which they appear below.

3.1 Initial Planning

The first stage in planning is to review what reporting systems already exist to see whether they are adequate (see chapter 3). If they are not then perhaps some minor change or updating is necessary. Only if there are no systems or totally antiquated ones with no hope of rejuvenation should a new one be proposed. A comprehensive review should include those who will use the system for planning as well as those who might contribute to it. Reporting systems should be planned, keeping in mind all types of existing systems, surveys and special studies.

As this chapter has demonstrated, there are drug abuse reporting systems operating in many countries. It might be useful to obtain more detailed information on some of these systems either by obtaining reports or by directly contacting the co-ordinating agencies in order to review and learn from the experience of developing and implementing reporting systems in other countries. It might also be useful to inquire whether technical assistance in conceptualising, planning and implementing a reporting system might be available though an international, regional, or national organisation.

3.1.2 Identification of Need

Recognition of the need for drug-abuse reporting systems and the decision to implement one generally involve a complex political and technical process. The decision to set up such a system is often made when the government is confronted with an acute drug-abuse epidemic or has to deal with serious endemic drug-abuse. One reason for anxiety on the part of policy-makers and administrators in these circumstances is that drug abuse is often furtive and frightening. There is an urgent need to expose the real dimensions of the problem, so that it can be contained. Despite the crisis atmosphere that often prevails, a technical group should review the need for a reporting system and consider alternative data-collecting possibilities, taking into account relative costs as well as resources and expertise available.

Most specialised drug-abuse reporting systems exist in countries where the abuse of heroin, opium, or intravenous stimulants are a dominant part of the drug problem. This is merely an observation and does not suggest that, for other drug problems, surveys or other data-collecting activities are preferable. However, the decision to develop a drug-abuse reporting system is a serious one and is not to be made lightly or in the absence of a serious drug problem in society. Certainly societies in which drug abuse is not a serious social and public health problem may find less expensive and more practical mechanisms for assessing it.

3.1.3 Clarification of Purposes

Given the diversity of institutions and disciplines involved, it is not surprising that reporting systems differ greatly in the purposes for which they were established. Much depends on the agency that first identifies the need for a new system; a health agency may be more interested in improving intervention efforts; and a researcher may be interested in understanding some aspects of drug abuse in order to make a contribution to knowledge. These purposes are necessarily reflected in the choice of a particular system, in formulating its objectives, and in other aspects of the development of the system. Thus, in developing any kind of system, one of the first steps is to determine who identified the need and what the purposes of the system are. In some circumstances, where more than one type of agency is involved - e.g., agencies concerned with health, enforcement, and welfare - there may be conflicting purposes.

For instance, a health agency may wish to establish a reporting system to plan more effective treatment programs, whereas an enforcement agency may seek to identify those addicts in contact with agencies, in order to place them under surveillance. It is necessary to make such potentially conflicting purposes explicit; otherwise, impossible demands may be made on the system. The purpose of the reporting system should be clarified and agreement should be reached on their order of priority. Disagreement may necessitate the choice of an approach other than a reporting system or perhaps a variety of systems serving different purposes.

3.1.4 Determination of objectives

Once agreement has been reached on purposes, it is possible to begin to determine the objectives. Reporting systems are particularly suitable for attaining the following objectives;

- to determine the incidence, prevalence, and characteristics of drug users in contact with reporting institutions;
- to measure continuously the trends in prevalence of use and its serious consequences;
- to determine and describe groups at risk of those consequences;
- to determine how and to what extent community agencies are used to deal with drug abuse; and
- to assess existing efforts to prevent and treat drug abuse.

While all reporting systems can fulfil each of these objectives to some extent, some systems can fulfil some objectives better than others. Those involved in the planning process should agree on the order of importance of objectives.

3.1.5 Choosing the Type of System

Once agreement has been achieved on the objectives, it is possible to choose the system that would be most appropriate to attain those objectives. How it is chosen will also be determined by the number and types of institutions in contact with the drug-using population. In the United Kingdom, for example, all addicts have a right to medical treatment for their addiction, there is uniform coverage of the population with medical services, and the addict is in no way punished when he applies for treatment. Physicians may be expected, under these conditions, to be in contact with a large proportion of the drug-using population, and are thus an obvious institutional base for a reporting system.

Figure 6: Stages in the development of reporting systems

I. **Initial Planning**

Initiating the review
Identification of need
Clarification of purposes
Determination of objectives
Choosing the type of system
Determining feasibility
Soliciting agency cooperation

II. **Design**

Specification of objectives
Specification of outputs
Selection of data items
Design of forms
Development of instructions
Selection of reporting agencies
Establishing reporting criteria
Development of reporting procedures
Development of data-processing procedures
Development of quality-checking procedures
Development of analysis procedures

III. **Testing**

Pr-pilot testing
Pilot studies

IV: Implementation

Obtaining and maintaining agency participation
Training personnel
Maintaining the system

Reporting and interpreting data
Changing the system

In other countries there may be too few physicians or medical coverage may be too uneven for such a system to be feasible. In some, law-enforcement agencies may be the institution in contact with the greater proportion of the drug-using population. It may already have a uniform system for reporting events and drug seizures, which would provide a logical basis for drug-abuse reporting. Elsewhere, there may be well-developed national systems by which coroners report deaths, health services report cases of AIDS and hepatitis, and rehabilitation services for addicts may be provided by a welfare ministry. These national systems could be combined to establish a case register. In rural areas of some developing countries there may be a weak health infrastructure, so that consistent reporting may not be feasible at all. In short, planners must examine the institutional infrastructure (if any) in the communities where drug use is a problem and the existing pattern of institutional contacts with the drug-using population. The type and structure of the reporting system may then become obvious.

Other considerations also enter into the choice of a system. These include the availability of funds and skilled personnel, the geographical area to be covered, the expected number of reports, and the legislative context. For example, if funds and skilled personnel are limited, there is a large geographical area to be covered, a large number of reports are expected, and the legislative context does not permit the identification of individuals, a case register may not be possible, even though it might best achieve the stated objectives. In such cases, planners may have to choose a case- or event-reporting system instead. If, on the other hand, the opposite conditions prevail, a case register may be the optimum choice. Combinations of conditions must be weighed and an appropriate decision reached.

Most types of systems likely to be needed already exist and planners can get a good idea of how costly they are and how feasible by contacting people in other countries who operate systems. In some cases, a non-specialised system might be the optimum choice. This is particularly true when resources for controlling drug abuse are scarce, and where such a system already exists and could be adapted.

3.1.6 Determining Feasibility

To determine the feasibility of establishing a reporting system or one of a particular type, it is sometimes desirable to carry out a study. For example, in 1975, the Victoria Mental Health Authority, Australia, surveyed relevant agencies to determine whether it was feasible to establish a register of drug users. In addition to providing preliminary data on drug users coming to the attention of authorities in Victoria, the study found that:

> *"the majority of agencies would co-operate fully if the confidentiality of the register was guaranteed by law; and if the recording for the register was built into the internal statistical system of the agencies involved. The survey also showed that data available were sufficient for the major purposes of the*

register." (Quoted in Rootman and Hughes, 1980).
This survey helped the authorities to determine how to proceed.

3.1.7 Soliciting Agency Co-operation

At this stage in the development of a reporting system, it is important to solicit the Cupertino of potential participating agencies. This is not only to determine the feasibility of establishing a system, but also to ensure that the system will be compatible with the practices of participating agencies and to determine what kind of feedback would be useful for the agencies to obtain from the system. As observed by a consultant to the Hong Kong register, "it is vital to have close contact with reporting agencies through all stages of development". In his opinion, "the Hong Kong register would not have become as successful if the participating agencies had not been actively involved in the new system from its initial proposal stage up to the implementation and operation of the system" (Quoted in Rootman and Hughes, 1980). Thus, during the initial stage, it is extremely important for planners to lay the foundation for the kind of collaboration needed with participating agencies through all stages of system development. In doing so, it is important for planners to spend considerable time on meeting with agency personnel to determine their concerns, their methods of operation, and the ways in which a reporting system could be of most benefit to them. Lastly, it is important to give agency personnel regular reports on what interesting questions the system has been able to answer.

Agency co-operation in large scale systems may depend upon payment for the data collection. If a large amount of effort is required payment is more likely to be necessary to get consistent data.

3.2 Design

3.2.1 Specification of Objectives

One of the first steps - perhaps most important - in designing a reporting system is the more detailed specification of its objectives. The importance of stating these objectives in achievable terms is illustrated by the experience of one drug-abuse register, which found that its originally stated objectives were not achievable. As a result, it was necessary to develop a completely new system based on reformulated and achievable objectives. Certainly all reporting systems go through a trial-and-error period, and mistakes are inevitable. Nevertheless, it is important to spend time on formulating realistic objectives in the early stages of designing such a system, in order to make it as efficient as possible.

An example of what is required is the following statement of objectives for the Central Registry of Drug Addicts in Hong Kong:

- to identify trends in the nature of addiction and the addict population in Hong Kong

over time;

- to describe certain characteristics of the reported addict population and to contrast these characteristics among addicts reported from specific sources;
- to provide information regarding the course of addiction and the impact of contact with different reporting sources (e.g., law enforcement agencies and treatment agencies).

An important objective of the system should be to get as much internationally and nationally comparable data as possible. It is recommended that whatever system is developed, it be constructed to contain the core drug use and socio-demographic data described in Chapter 6. For some event reporting systems only limited core data may be available but for case reporting and case registers most should be available.

3.2.2 Specification of Outputs

It is important, at the design stage, to begin specifying types of reports and data tables to be derived from the system. This will produce a concrete picture of what might realistically be expected from any particular system, and will indicate whether the objectives can be achieved. Consideration should be given to different reports for different audiences, some detailed and technically sophisticated and some simpler and more based on the main results of interest to planners.

The value of producing tabular shells may be illustrated by the consultant's report on the Hong Kong register. A number of tables were presented to illustrate what could be produced by the proposed system. Such tables allowed the Hong Kong authorities to determine quickly whether the proposed system would produce the information they required. The discussions that followed permitted the consultant and other technical personnel to identify more clearly the data to be collected by the system.

It may be extremely useful, if not essential, to involve experienced staff or consultants at this point. This is especially true if they are able to provide long-term assistance in the analysis of data and preparation of reports.

3.2.3 Selection of Data Items

It is important in designing a system to select carefully the data items to be collected. In doing so, it is necessary for planners to determine explicitly what each item will be used for. Of course, it is not possible to anticipate all potential uses of items of information, but the major ones can usually be determined. Those who are most likely to use the reports for planning should be consulted at an early stage on what reports they need. As stated above the core items described in Chapter 6 should be included wherever possible.

3.2.4 Design of Forms

Once the data requirements have been identified, it is possible to begin designing the forms to be used in the system. The object should be to make standard forms suitable for collecting the basic data required, which are straightforward, and simple to complete. In designing forms, an attempt should be made to relate them to the basic record-keeping of the reporting agencies, rather than have two separate, unrelated pieces of paper. In some cases agencies may report data on computer printouts using software provided by the central storage group. Transmission of data or reports by facsimile also be feasible in some countries. If that system is used forms should be kept as short as possible to minimise costs.

Technology for reporting of agencies to a central system is developing rapidly. It is possible in some countries to use a computer network to have every reporting agency report to a central computer. Also, interactive voice response systems using touch-tone telephones and a key pad are practical in many developed countries. For example, the Drug Abuse Reporting Treatment System in Ontario uses such a system. About 226 treatment agencies report daily or weekly on patient loads and space availability to a central agency which matches waiting drug abuse clients to available space in treatment agencies.

There is some merit in keeping all forms short and using the minimum number. However, core and optional sections can be created that allow each agency to contribute and some to contribute more than others. System planners should avoid having different formats in different agencies as collating them will be a problem.

Any data collected should be capable of being processed by computers. Hard copy forms must be pre-coded so they can be typed into the computer or scanned. Interactive voice systems or computer networking assures that only pre-coded data is entered thus saving time.

For some systems, particularly case registers, certain identifying data are required for linking records. In addition to the name, date of birth, mother's first name, and other personal identifiers, national identity-card number are being used in some countries. The collection of such information is, of course, contingent on legal provisions and requires the privacy and confidentiality of both clients and records to be protected.

3.2.5 Development of Instructions

Concurrently with the designing of forms, it is desirable to develop detailed instructions for filling them in. These instructions should be designed and then reviewed with the people who are likely to be completing the forms. There is no point in preparing complex instructions suitable for a highly trained researcher if the forms are to be completed by someone with an elementary school education. Of course, each system will have to design its own instructions according to its own

characteristics. The instructions may be made available as a manual to accompany the forms. In general, though, it is desirable for the forms to be comprehensible enough to make separate instructions unnecessary, and for all essential instructions to be printed on the form itself. Training should be made available for all agency staff who are to report data into the system. This training may be very brief if filling in a short form is required. However, the more technologically sophisticated the task the more time for training is needed. Those who do the reporting should be encouraged to report problems and not cover them up. They should also have someone always available in the central office whom they can call about problems in reporting data.

If reports are mailed they may be lost. Duplicate forms on specially treated paper can be used but these may be expensive. Carbon copies and photocopying are cheaper. Agencies should be asked to keep copies of reports using whatever method is most feasible.

3.2.6 Selection of reporting agencies

During the design stage it is important to decide which agencies should participate in the system. In addition to the fundamental consideration of identifying agencies in contact with drug users, the selection depends on other factors, including the type of system being designed, the resources available, the geographical coverage, and the likelihood that agencies will be willing to co-operate. Sometimes all government agencies receiving funding must comply or perhaps all physicians are obligated by law to report cases. Even if there is an obligation those expected to report cases should be encouraged to participate voluntarily and in the best possible way. This can be best done by making the system relevant to their interests.

Systems may cover all agencies of a particular type or only those who volunteer. If the latter is the case then they may not be representative. The DAWN system after many years of voluntary participation by hospitals changed to sample a representative group of hospitals. In voluntary systems the number of agencies increases over time as new agencies are added. This can make it very difficult to examine trends. Sometimes trends can be examined by keeping a subset of agencies that have reported in each year of the system.

3.2.7 Establishing Criteria for Reporting

It is necessary to establish the criteria to be used for determining whether or not a case should be reported. For example, should all cases coming to the attention of participating agencies be reported, or only certain cases? If it is the latter, how should these cases be distinguished? The former Director of the New York City Registry argued that there was merit in "over inclusiveness". He added that: "If one really wants to get some idea of the natural history of addictions, I think all suspected cases, and not just confirmed cases should be included". (Quoted in Rootman and Hughes, 1980). There is a case, too, for including confirmed and suspected cases in separate files and for keeping first notifications separately from previous ones.

Once criteria have been established, it is desirable to develop a set of instructions that clearly define them for participating agencies. The Addicts Index in the United Kingdom, the Hong Kong Registry, and Malaysian Registries, as described in section 2.3.1, provide samples of clear and specific criteria for reporting, including a list of the drugs, abusers of which are to be reported. It is important that reporting agencies should apply the same criteria consistently.

3.2.8 Development of Reporting Procedures

When designing reporting procedures, it is often useful to examine existing procedures in the agencies likely to participate in the system. If too many agencies are involved, a sample of agencies representing the various types may be sufficient. In this way, it is possible to determine when it would be most convenient for agencies to report, whether the reporting system could be integrated easily into the agency's own procedures, and whether the agency is likely to be capable of reporting accurately and efficiently with its own staff. On the basis of this information, it should be possible to design procedures that are satisfactory for both the agency and the reporting system. It may, of course, be necessary to modify these procedures on the basis of feedback from the agencies and subsequent experience, but making them explicit at this point is desirable. This can be done by producing a set of instructions written as clearly and simply as possible, bearing in mind those likely to be following them.

Careful consideration must be given to any changes in reporting requirements. For example, if criteria were changed so that "suspected" as well as "confirmed" abusers are to be reported the apparent number of cases would increase without the real number of cases changing. No changes should be made in reporting criteria before deciding how that will affect trend data.

3.2.9 Development of Data Processing Procedures

During the design stage careful consideration must be given to how data will be prepared and analysed. In almost all systems computer storage and analysis will be needed. Low cost personal computers are available now in most countries. Programs are readily available for storing and analysing data. Programs such as SPSS are available widely and these are powerful enough to analyse almost all kinds of reporting system data.

Drug abuse reporting systems are likely to expand quickly and overwhelm any effort to handle data manually. There may be a few local registries with only a few cases that can be handled with edge punch cards or hard copies. However, it is strongly recommended that reporting systems use computers for storage, table preparation and for producing reports. Their speed and reliability are likely to be repaid many times over hand systems.

It is useful to develop a flow chart to show the stages in data preparation. The Charts in Figure 7 show how the case register in Hong Kong functions to enter the data and match cases.

3.2.10 Development of Quality Checking Procedures

It is also important at this stage to develop procedures for auditing and checking the quality of the reports submitted. Each report should be checked for completeness, consistency, and out-of-range responses (e.g., when a response of 4 is given to a question where the only possible answers are 1, 2, or 3). In addition, there should be procedures to keep track of the flow of reports in order to detect quickly any malfunction or interruption in flow. Procedures might also be designed to check periodically a sample of reports against the agency's record for a particular case. Some reports will need to be returned to agencies for correction or be discarded.

3.2.11 Development of Analysis Procedures

Early attention should be given to how the data should be analysed. For any report simple tables showing rates and number of cases cross-tabulated against age and sex are necessary. Also, some geographical distribution of cases will be of interest. These procedures require only easy-to-learn software programs. If multi-variate analyses are required then the statistical package programs should be used. The most common of these are SPSS, SAS and BMD. More sophisticated analyses may be of more interest to research scientists than to health planners. The priority in any analysis program should be to do the analyses first that planners of treatment and prevention programmes can use.

Attention should be paid to the interesting ways in which data can be presented. Complex tables are difficult to read. Graphs and other visual displays should be used more than tables. Some examples are in Figure 8. Easy to use programs such as Harvard Graphics and Statistics can be learned in a few days by those who know English and are familiar with computers.

This covers the main activities that must take place during the design phase of any reporting system. There may be other activities as well, depending on the type of system under consideration. In any case, it should be apparent that the design stage is critical in the successful development of any reporting system, and that the more effort is devoted during this stage, the more likely is the success of the system.

3.3 Testing

3.3.1 Pre-pilot Testing

Before carrying out a full-scale pilot study, attempts should be made to test the components of the system as they are developed. For example, the forms might be tested by asking staff equivalent to those who will eventually be completing them to fill them in and comment on any problems. Similarly, attempts might be made to test the adequacy of data preparation and

processing procedures by using fictitious data. Many other ways can be found to test the adequacy of the various components of the system prior to the actual pilot study.

3.3.2 Pilot Studies

Before implementing any reporting system, it should be tested under real conditions or as close to them as possible. This may be done in various ways including tests of individual components and tests of the system as a whole through a pilot study using potential participating agencies. This is frequently carried out in a single target community or in a limited number of communities. It permits forms, instructions, reporting procedures, and any other elements that may involve problems to be modified.

The pilot study will also familiarise the participating agencies with the procedures required, will permit them to suggest modifications to suit their own needs, and may increase their commitment to the continuation of the system. At the minimum, it will help to determine their willingness to co-operate. It may also result in improving the design of the system. Pilot testing should be part of the plan from the beginning. It may not be possible to involve all potential reporting agencies in the pilot study, but an attempt should be made to include at least one agency of each type.

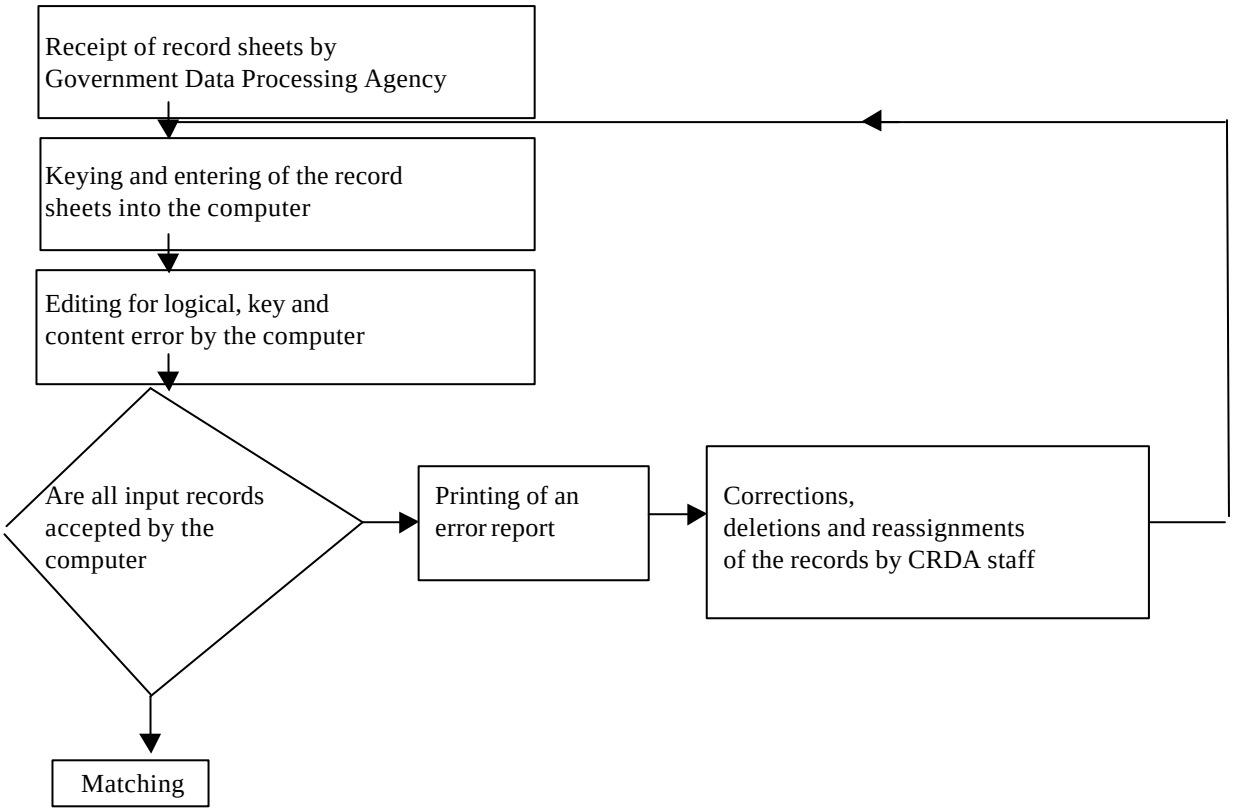
3.4 Implementation

3.4.1 Obtaining and Maintaining Agency Participation.

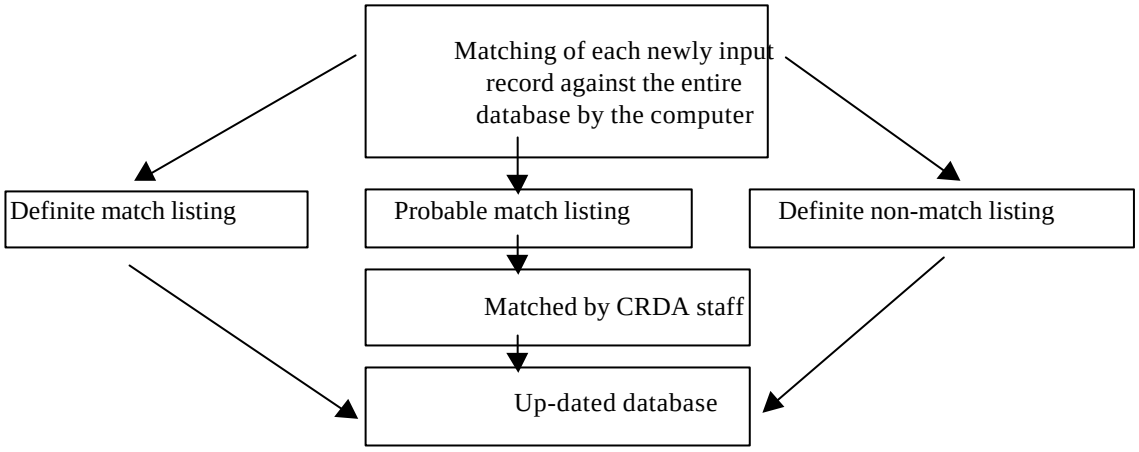
One of the first steps in implementation after pilot testing is to solicit the participation of new agencies and to confirm that those already participating will continue to do so. This is critical because the quality of agency participation will determine the quality of the data produced by the system. Thus, considerable effort should be devoted to obtaining and maintaining agency participation. This includes explaining the purpose of the system and its forms and procedures, as well as soliciting comments and recommendations. It is helpful to provide the participating agencies with as many incentives as possible. These might include regular feedback of data received from them, sending them copies of completed forms for their own record systems, and providing them with consultation. It is also helpful to assure participating agencies that they are not violating their clients' ethical or legal rights, since provisions exist for protecting the confidentiality of reported information. Because the collecting and reporting of data utilise the resources of participating agencies, informal and voluntary arrangements with these are successful for limited periods.

Figure 7

Flowchart for Phase 1: Editing in the data processing system of the Central Registry of Drug Abuse



Flowchart for Phase 2: Matching in the data processing system of the Central Registry of Drug Abuse



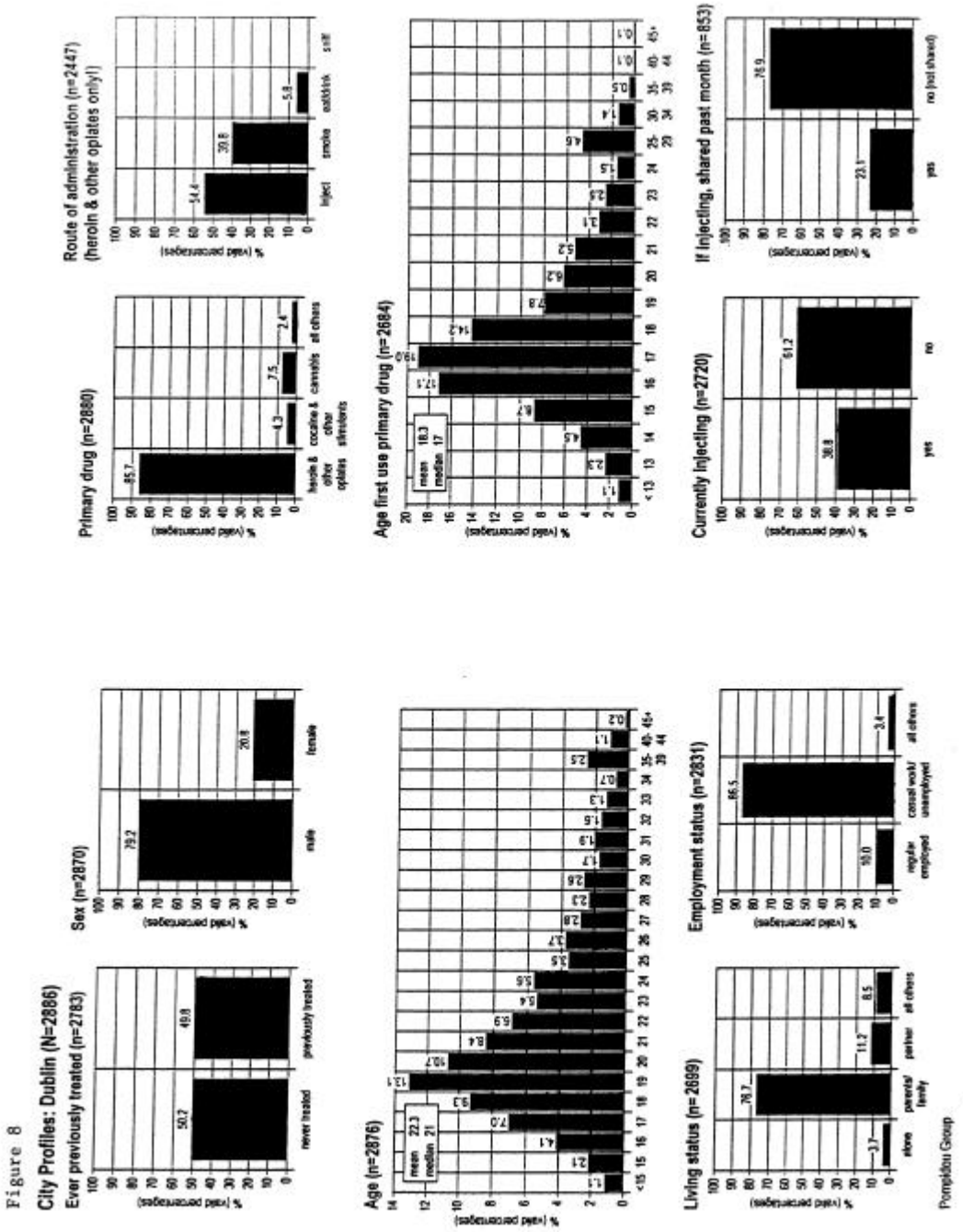

City Profiles: Dublin (N=2866)
Ever previously treated (n=2783)
never treated
previously treated
50.2
49.8
Sex (n=2870)
male
female
79.2
20.8
Age (n=2876)
mean 22.3
median 21
Primary drug (n=2880)
heroin & other opiates
cocaine & other stimulants
cannabis
all others
85.7
4.3
7.5
2.4
Route of administration (n=2447)
(heroin & other opiates only!)
inject
smoke
eat/drink
sniff
54.4
39.8
5.8
Age first use primary drug (n=2684)
mean 18.3
median 17
Currently injecting (n=2720)
yes
no
38.8
61.2
If injecting, shared past month (n=853)
yes
no (not shared)
23.1
76.9
Employment status (n=2831)
regular employed
casual work/ unemployed
all others
10.0
86.5
3.4
Living status (n=2699)
alone
parental family
partner
all others
3.7
79.7
11.7
8.5
% (valid percentages)
Pompidou Group

Figure 8

To ensure the long-term participation of the agencies, it may be necessary to obtain a legislative mandate or a directive from a high government official, or to provide payment.

3.4.2 Training personnel

Once participation has been agreed upon, it is necessary to train personnel who will be responsible for running the system. Such training includes a detailed review of forms and procedures and could be accomplished in various ways, including workshops, individual instruction sessions, and practical sessions. Training will be needed for new agency staff and when any changes in the system are made.

3.4.3 Maintaining the System

The next step is to provide the participating agencies with a sufficient number of forms and instruction materials to operate the system and to establish an official starting date. Agencies might, however, be encouraged to begin earlier if they wish to gain experience with the system. The early period of operation is likely to be difficult, since many unforeseen problems may be expected. Such problems should be accepted as inevitable and dealt with as quickly and efficiently as possible. Those involved should be encouraged to identify and report problems at an early stage.

3.4.4 Reporting and Interpreting Data

It is important that systems should produce reports regularly since such reports justify the existence of the system. Reports may take a variety of forms. For example, the DAWN system has produced quarterly reports, annual reports, an instruction manual, and special tabulations and publications in scientific and professional journals. In producing such reports, it is desirable to keep in mind the readership to which the report is directed since different groups of reader may require different types of information presented in different ways. However, in all cases, the information should be interpreted fairly with due regard to the necessary qualifications. In addition, a description of the system and its advantages and limitations may help readers to make their own assessments.

In addition to routine statistical reports, significant changes in drug-use patterns and other important trends need to be communicated to key administrators and policy makers. It is also desirable, in operating a reporting system, to arrange for sponsoring and participating agencies to receive interpretative reviews of their data regularly. This will encourage continuing support for the system and enable it to be modified to meet newly perceived needs. Such reviews should be designed in order to be understandable to people who may not have experience in the analysis and interpretation of data. Slides and transparencies showing graphs and charts are often helpful.

3.4.5 Changing the System

Despite careful planning and pilot testing, a number of flaws in the system are likely to be identified in the early years of implementation, and it may be necessary to introduce modifications. Periodic reviews can be the basis for introducing such modifications. The reviews would include extensive discussions with participating agencies, which may well have pertinent suggestions for improving the operation and usefulness of the system.

DAWN provides an example of a system that was modified in many ways as experience accumulated. However, an effort was made to retain the essential aspects of the system, so that comparability was possible. Some systems will also outlive their usefulness and must be abandoned as with the known drug user statistics in Canada. Planners of reporting systems should be prepared to make changes as required. It is preferable to make as few changes as possible, since they reduce the continuity of the system, make comparisons more difficult and may result in operational problems.

3.5 Special Considerations Pertaining to Types of Reporting

So far, only issues that relate to all reporting systems have been reviewed. There are, of course, some considerations that pertain only to specific types of system.

3.5.1 Event-reporting systems

One consideration that is unique to event-reporting systems is whether to report on an individual basis, as is done in the DAWN system, or on an aggregate basis as with arrest systems. Aggregate reporting has the possible advantage of lower cost, but the probable disadvantage of less opportunity to check the data. The choice of approach will depend on the relative importance of these and other factors, such as confidentiality requirements and the willingness and ability of agencies to submit individual or aggregate reports.

3.5.2 Case-reporting Systems

One special consideration in a case-reporting system is the need to allot the same case-identification number to all reports for a specific individual from the same agency (readmission, re-arrest, etc.). To do this, the agency should maintain a confidential list allowing cross-reference between case-report numbers and individuals. Other solutions may also be possible, depending on circumstances.

A second consideration is the desirability of developing ways of estimating the duplication of reports between agencies. There is no easy solution to this problem, but presenting data from different sources separately may be helpful.

3.5.3 Case Registers

Addict registers have a number of dangers, including the possibility of jeopardising the right of drug users to obtain confidential medical care. They also provide for possible misinterpretation and/or misuse of data by the ill-informed or unscrupulous. As we saw earlier, most case registers have problems with under-reporting, even the notification system used in the United Kingdom has such problems.

Newman and Cates (1976) have discussed the problems in matching cases to provide an unduplicated file where each abuser is counted only once. In this regard, they argue that "an appropriately protected addict registry should never be permitted to be used against the interests of anyone listed: the ex-addict, current addict and non-addict all must be safeguarded by identical, complete guarantee of anonymity". However, the requirement of confidentiality reduces the potential usefulness of the register. Specifically, "it cannot help police catch suspected criminals; it cannot locate probationers or parolees who have absconded; it cannot prevent multiple simultaneous registration in treatment programs; it cannot accommodate researchers who wish to 'track' individual addicts; it cannot be used to prevent gun licenses (or medical licenses) from being issued to known or suspected addicts". Arguing that these limitations are an indispensable price that must be paid if a registry is to exist at all, they suggest that protection can best be ensured by involving outside agencies and individuals in overseeing the registry.

4. Common Problems and their solutions

Problems are bound to arise in the development of any drug abuse reporting system. These include ethical and legal problems; administrative problems; and technical problems. This chapter discusses some of the common problems and their solution, in order that planners can take them into account during the early stages of system development.

4.1 Ethical and Legal Problems

4.1.1 Consequences for reported individuals

Although reporting systems may have positive consequences for individuals, such as giving them access to treatment, they may have adverse consequences as well. These may include loss of job, loss of freedom, and stigma. For example, in some countries, reporting is part of a formal registration system in which the individual must participate in treatment or face the risk of imprisonment or fines. Where there are adverse consequences of being reported, drug abusers may decide not to use available treatment services that may be of benefit to them. This is a consideration that should be taken into account in planning a system, for it may be that the benefits of the system may not be worth the adverse consequences to the individual.

Some systems, by their very nature, have fewer consequences for the individual. In particular, event-reporting systems, in which individuals are not identified in any way, are likely to have fewer adverse consequences. On the other hand, case registers, which require some system of linking records from various sources, have potential for the most serious consequences. However, even these systems can be designed in such a way as to minimise the negative impact on the individual. For example, the New York City Narcotics Register developed safeguards to protect the registry from being used against the interests of anyone listed. Chief among these was an unwavering policy of guaranteeing complete anonymity.

4.1.2 Confidentiality

The key to avoiding the adverse consequences of reporting systems for individuals is in the protection of confidentiality. In effect, this means not disclosing the information in the system for any other purpose than that required by law or allowed voluntarily by the person registered.

Some countries such as the USA and Canada have regulations regarding the confidentiality of records of drug-abuse patients. These regulations state that the medical records of such patients are not to be released without the specific authorisation of the patient. This authorisation must be in writing; must include the names of the facility and of the patient; must designate the person to whom (or organisation to which) the information is to be released; must state the purpose for the disclosure, as well as the nature or extent of the information to be disclosed; must give the date of the consent; and must include a statement regarding the duration of the authorisation.

There are many safeguards that can be introduced to protect the confidentiality of information in reporting systems, in addition to ensuring informed consent. These include the coding of identifying information, careful training of reporting-system staff, and releasing information in aggregate form only. Full consideration should be given to the development of such safeguards in the planning of any reporting system, and they should be protected by government codes or regulations or by special legislation.

4.1.3 Compulsory Reporting

A number of the systems described here require agencies or institutions to report. Such a requirement may be backed up by the law, by the threat of withdrawing funds, or by other means. In Mynmar individuals are required to report themselves.

Although compulsory reporting is intended to produce more and better reports, it may have the opposite effect and lead to a reduction in coverage where individuals fear the consequences of reporting. It may also lead to a reduction in the quality of the information, either the drug users or the staff of the reporting agencies purposely falsifying information in order to protect themselves or their clients.

There are other ways of increasing the quality and coverage of reporting without making it mandatory. If agencies obtain benefits, such as feedback of useful information, improvement of their record system, and staff development, they may be more likely to report and to do so accurately. In addition, the effort expended in introducing the system and training staff to participate may be of benefit. Where such an approach is practical and feasible, it is to be preferred to the use of compulsion.

4.1.4 Enabling Legislation

Some countries have legislation enabling government agencies to collect statistical information. For example, in Canada, the Statistics Act enables the national statistical agency, Statistics Canada, to collect such information. In addition, this Act provides safeguards to protect the confidentiality of the information collected. Specifically, statistical information may not be released if the particulars are related to any individual. Severe penalties are provided for a breach of confidentiality by employees of the agency.

If such legislation exists in a country, it may be desirable, where practicable, to give the responsibility of developing and implementing drug-abuse reporting systems to the agencies covered by such legislation. If, however, such legislation does not exist, or if it cannot be construed to apply to drug-abuse reporting systems, it may be necessary to provide it. Thus, planners should give some attention to the need for such legislation in the early stages of system development. The legislation should be designed to make the legal status of the reporting system clear and to guarantee confidentiality.

4.2 Administrative Problems

4.2.1 Pooling of Enforcement and Treatment Data

Because of the illegal nature of the use of certain drugs, law-enforcement sources of data are often more significant with respect to drug use than to other health phenomena, such as psychiatric illness. Thus, in the development of any drug-abuse reporting system, it is necessary to consider using enforcement and other types of agencies as sources of information. It may even be desirable to consider developing systems that pool both enforcement and medical data.

Such undertakings, however, face certain problems. For one, the expectations of enforcement agencies from a reporting system may conflict with those of other agencies. This would occur if, for example, a law-enforcement agency requested a list of drug users names in order to make arrests or investigations. Another problem may be that, in some societies, the police may be prohibited by law or regulations from providing information to other agencies, and therefore may not be able to participate in reporting systems.

A third problem may be that very different types of data are collected by enforcement and other types of agencies, making it difficult to collate information from the different sources. This problem may be overcome by recognising, as was the case in Malaysia, that the information needs of various agencies differ. Law-enforcement and treatment-agency forms were designed to share certain core-data items, but the former contained an additional set of items to meet the special information needs of law-enforcement agencies. The analysis of these data items thus provided an additional incentive for the participation of law enforcement agencies in the system.

Additional mechanisms can be developed to overcome other impediments to joint reporting systems. For example, information about individuals may be reported by the use of code numbers; information might also be reported in aggregate form only. It might also be possible to locate the responsibility for maintaining the processing data in a "neutral" agency in order to avoid the objections that might arise if it were located exclusively in a health, welfare, or law-enforcement institution.

4.2.2 Location

An important administrative question is which agency should have primary responsibility for maintaining the reporting system. This decision may have significant implications for the success of the system, since the institutional location may determine the willingness of agencies to co-operate, the amount of resources and effort invested in the system, and the access to required information. For example, if a system is located in a law-enforcement agency, health and welfare agencies may not be willing to provide information because of the fear of consequences for their clients. One argument for locating the system in a health agency is that the confidentiality of records might be better protected. But enforcement agencies may have difficulty in providing information to health agencies because of their own safeguards against the release of information. In addition, a health department is concerned with a wide range of other pressing health issues, and may not always be able to give a specialised reporting system the priority it requires.

For these reasons, it has been argued that the best location for a system is a neutral institution, such as a national drug-abuse co-ordinating body, which would permit the Co-operation of a wide range of agencies. However, it is not always possible to find an appropriate neutral body willing and able to house a drug-abuse reporting system. It may also be that a neutral body is not the best location for a system in some circumstances, such as when the objectives are of primary concern to only one agency.

Thus, in locating a system, it is important for planners to consider the purposes for which it is being established as well as the capability of the particular institution to absorb the system and to enhance its opportunity for success.

4.2.3 Changes in Reporting Agencies

If reporting systems continue for long periods, there are bound to be changes in the number and perhaps even type of agencies participating in the system. Such changes do not give rise to problems if reports focus on only one point in time. However, to examine changes over time might present a problem, since such changes might be attributable merely to changes in the number and type of reporting agencies. One way to deal with this problem is to report findings according to the type of agency. Another is to report findings only for agencies that have remained in the system during the period in question.

4.2.4 Changes in Institutional Practices

In addition to changes in the number and type of agencies, institutional practices may also change. For example, there may be changes in police activity or enforcement practices. There may also be changes in the policies of treatment agencies that might result in the admission of more or fewer people with different conditions. These changes should be included in any reports on the data from reporting systems. One way to deal with such problems is to monitor institutional practices and policies closely so that data may be interpreted properly. Continuous working relationships with reporting agencies may be helpful in this regard, as may be a network of informed observers. Another way is to examine independent sources of information in order to discover any discrepancies in the trends.

The point to be stressed with respect to changes both in the number and type of reporting agencies and in institutional practices is that the planner should be careful in interpreting data from reporting systems, since such data may reflect changes in reporting agencies to a greater extent than they reflect changes in drug-use patterns.

4.2.5 Cost

This is important in countries where resources are particularly limited and where the allocation of funds and personnel must be seen in the context of other national priorities.

Fully developed specialised drug-abuse reporting systems will be expensive. However, there are ways of reducing the cost in order to tailor the system to available resources. For example, it is possible to reduce the size of the system by sampling the reporting agencies, taking one or a few of each type or sampling only one type of agency such as emergency wards. Costs may also be reduced by limiting the information required to a few basic elements, reducing the frequency of information requests, using pre-coded forms, and applying new low-cost computer technology.

As indicated by the examples cited earlier, it is also possible to reduce costs by integrating drug-abuse information into more general-purpose information systems, such as HIV/AIDS, crime-

reporting, poison-control and psychiatric reporting systems. It is advisable to discourage the establishment of new specialised systems when existing and less expensive systems may be used unless very clear reasons exist. Because of the difficulties encountered in gathering information on an illicit and hidden activity, the many different agencies that interact with the drug-abusing population, and the sometimes urgent need for comprehensive information, a case can be made for specialised systems that integrate enforcement, health, welfare, and other institutional sources of information.

It should be stressed, however, that no country should develop a system that it cannot afford. The challenge to the planner is to develop the system that best satisfies the explicitly determined and real information needs with the resources available.

4.3 Technical problems

4.3.1 Duplicate Cases

A major problem with case-reporting systems and case registers is identifying duplications of cases and individuals reported. The problem is greater with drug abuse than with many other conditions, because drug users often falsify their names or use aliases in order to avoid prosecution for previous crimes and sometimes in order to obtain drugs from more than one treatment programme. Although this double or multiple counting can never be totally eliminated, there are a number of ways to reduce it.

Chief among these is to develop systematic procedures for matching. For example, the Hong Kong register matches every incoming record to the computer data base on a number of variables including identity card number, name or alias, month and year of birth, and sex. Currently, 25 different combinations of these variables are used (Wat, 1985). Similarly, the New Jersey register cross-classified each registrant according to all known aliases and the mother's maiden name if available (Lavenhar, et al., 1975). In addition, the register rearranges cases according to the date of birth, generating a listing of all registrants with an identical birth date. Further comparisons are then made according to sex, birthplace, parents' birthplace, race, educational level, and religious affiliation. This allows for the identification of suspected duplications and their subsequent confirmation and correction.

Although the procedures that have been noted so far are sophisticated, it may not be necessary to develop such approaches for all reporting systems. Some may be small enough to require only manual checking and matching. In such cases, it is helpful to have well-trained staff who have been with the system for a considerable time. Other systems may simply require the assignment of code number by reporting agencies.

No matter what the procedures employed, however, it is important for planners to define them precisely and use them consistently. Rules should be established regarding the latitude in

spelling, the use of phonetic codes for names, the degree of discrepancies in dates of birth, unique personal identifiers, or combinations of identifiers. These procedures or rules should be checked subjectively from time to time by persons who have a good memory and are sensitive to clues.

4.3.2 Reliability

A common problem with reporting systems is the difficulty of ensuring that the information collected is reliable and that it is collected and reported consistently. Reliability differs from validity, which refers to the extent to which the information is true. If information is not reliable, it is unlikely to be valid, and it is therefore important that reporting systems should assess the reliability of their information on a regular basis. Such assessment may be carried out through continuous checking. For example, the internal consistency tests performed by computer can ensure that reported data are consistent with one another, and - to give two simple examples - each discharge date may be checked to determine if it is after the admission date and the year of birth may be checked to determine if it is after the admission date, and the year of birth may be checked to see if it precedes the year of admission.

Assessment may also take the form of a special study - e.g., the one carried out by the New Jersey register, which compared the first two reports submitted on 1000 registrants and found a high degree of consistency in the reporting of basic demographic characteristics, such as age, race, and date of birth, but lower consistency on recall of items such as the age of onset of drug abuse. As a partial remedy for discrepancies in addicts' responses to questions about age at first heroin use, the authors of the latter study suggested that "treatment agencies might consider obtaining this information some time after admission when better rapport with the patient has been established". They also thought that it might be worthwhile "to attempt to confirm the response by asking for the corresponding year of first drug use, first drug-related arrest, dates of addiction treatment, and other relevant questions which would lend support to the stated age of onset." (Newman and Cates, 1977).

In general, the point to be made is that one cannot assume that the information used by reporting systems is reliable. Therefore system operators must be continuously vigilant against lapses in reliability and must design ways to determine the extent and nature of such lapses. On the other hand, it should be stressed that a certain degree of unreliability in reporting systems may be tolerable. The critical question is how much can be tolerated. This decision must be made by system planners and operators, and obviously depends on the objectives of the particular system.

4.3.3 Validity

As mentioned, validity refers to the extent to which information collected is true. This is a major problem for all types of reporting system, but particularly drug abuse systems, where drug users may consciously attempt to mislead authorities by supplying incorrect answers, partly out of the

fear of consequences.

Unfortunately, this is a problem that defies complete solution, but there are some steps that can be taken - e.g., as is suggested by Lavenhar and his colleagues (1975) with the New Jersey register: "In some instances, it is possible to verify responses by checking with external sources, i.e. previous arrests and convictions can be compared with police records".

Another approach is the use of special studies, as in the case of reliability - e.g., the study carried out in the United Kingdom to determine the validity of addict notifications (Mott and Mac Millan, 1978). Two representative samples of males first notified as addicts during 1969 were followed up for 5 years, using records of prescriptions for opiates, renotifications, and convictions for drug offences as evidence of a valid notification. The general conclusion was that "the interpretation of the Notification of Addicts Regulations may depend as much upon the setting and circumstances in which doctors see their patients as on their clinical judgement of a 'notifiable' case of addiction". This conclusion certainly suggests the need for caution in assuming the validity of data obtained from reporting systems, and emphasises the need for continuous vigilance.

Finally, if resources are available, consideration might be given to carrying out some independent tests of the validity of data obtained through reporting systems. For example, it may be possible to see how many of those dying of heroin overdoses or arrested for heroin related offences are in a register for addicts. If most addict arrests or deaths are of people registered in the system that suggests validity for it. It may also be possible to ask addicts in countries where there are registries whether they are in the registry and how long after being addicted they were registered. If addicts do not become registered for many years that suggests a weakness in the reporting system.

4.3.4 Computers

There are now few technical problems in using computers in reporting systems. All large and medium sized systems use desk top personal computers or large mainframes. Personal computers are much cheaper than in the past and costs decline each year. Use of various computer driven data systems was discussed earlier. When deciding what system to adopt planners should consult local experts on the best and most feasible systems to use.

4.3.5 Estimation

Although no reporting system can measure the exact number of drug users or addiction in the population, such a system may be extremely useful in estimating numbers, as indicated in a report by Greene (1974). This author identified several direct and indirect methods of estimating the prevalence of heroin use, many of which are based on data obtained from reporting systems. He pointed out that each of the techniques "has inherent limitations which must be borne in mind when the results are interpreted", and he described these limitations in detail. Also, Greene recommended that "multiple methods be used in a given locality in order to establish a reasonable range of prevalence estimates".

An example of such a range, established by means of the "indicator dilution" method, might be as follows:

If a field study of street heroin addicts found that 50% were known to the community case register and 5000 such individuals were recorded in the register, an estimate of 10,000 street heroin addicts might be advanced for that community. One could look for other data sources that, at least theoretically, should be drawn from the entire addict population, such as heroin overdose deaths. In this hypothetical community one might, for example, find that a proportion of heroin overdose deaths were known to the local drug register in a particular year. This would suggest a total heroin addict population of:

$$\frac{\text{total addicts}}{\text{registered addicts}} = \frac{\text{total addicts who died}}{\text{registered addicts who died}}$$

Baden (1970) has estimated the number of heroin addicts in New York City by multiplying the number of heroin overdose deaths by 100. This estimation was made because Baden found that overdose death records indicated that they were 1% of the registered addicts.

Also, Schreckengort (1983) developed a systems' dynamic model of the heroin supply market based on international supply data and the likely number of users.

Capture - recapture methods have also been used (see Brodsky, 1985 for a review). A "capture" is the occurrence of a name in a file of known drug users. A recapture is a recurrence in a successive year. The usual models have mathematical adjustments for the number of deaths and the likelihood of recurrence. The results are multiplied by the proportion of addicted arrestees, assumed to be the same as the proportion of addicted narcotic treatment admissions.

4.3.6 Other

Reporting systems often experience other technical problems as well. These include under reporting, dropping of inactive cases, and delays in reporting.

Under-reporting may result from a number of problems, including the tendency of agency personnel not to complete or send in forms for pertinent events, and an excessive interval between the occurrence of the key event and its reporting. The first problem can often be solved by proper training and encouragement of responsible personnel (which may include giving bonuses for good reporting and providing regular feedback). A delay in reporting may be due to administrative facts, such as the need to wait until court action is completed.

Dropping of inactive case is mainly a problem for case registers. It can be solved by a number of means including linkage with other data sources, such as death, treatment agencies or

immigration records. If this cannot be done, it may be possible periodically to match samples of names from other sources, such as coroners' records, to obtain a rough idea of the proportion of inactive cases. Another, perhaps more practical way of dealing with this problem is to place greater emphasis on new cases in reports based on the system, since such cases are more likely to be active. Finally, as is done in some registers, notably the United Kingdom register, cases that are not heard from for a fixed period of time are placed on an inactive file. They can be brought back into the system if they are notified again. Another problem is around deaths of those on case registers. The register may not routinely hear of such deaths. In the United Kingdom's registry the staff routinely search death notices and remove any known dead cases from the files. Registers should establish some rule about when to drop inactive cases or put them in an inactive file.

Delays in reporting are undesirable, since policy-makers tend to require up-to-the-minute information. Every attempt should be made to design and operate systems in such a way as to ensure maximum promptitude in reporting. At the same time, up-to-the-minute information is not always possible to obtain and, even if it is, may not be accurate. Thus, there is sometimes a need to delay the release of information. Perhaps planners should explain to policy-makers that it is not always possible to provide accurate up-to-the-minute information and that they may have to be satisfied with less frequent reports, while assuring them that every attempt will be made to report promptly.

5. Conclusion

We have described different types of drug-abuse reporting system, given examples of each, and discussed major issues and problems in their development. The selection of the most appropriate epidemiological data-gathering approach for a community depends on a variety of factors, including the existence or non-existence of agencies that could report, their willingness to do so, the resources available, and perhaps, most important, the objectives of the planners. Reporting systems may be ideal in certain circumstances, while other epidemiological approaches may be preferable in others. The unique role of reporting systems will be summarised here, and the chapter will conclude with a discussion of some possible future directions for the development of drug-abuse reporting systems.

5.1 Role of Reporting Systems

5.1.1 Necessary Conditions for Reporting Systems

Certain conditions must be present before it is possible to establish a successful drug-abuse reporting system. First, it is necessary to have institutions that are in contact with drug users. Where such an institutional network does not exist, it is pointless to even consider establishing a reporting system.

Secondly, where such institutions exist, there must be willingness to participate in the reporting system. Otherwise, it may be expected that the coverage and the quality of information will not be sufficient to justify the expense of establishing the system.

Thirdly, the problem of drug abuse must be sufficiently serious to justify establishing a system. A reporting system would generally not be indicated in a community where the drug problem was primarily cannabis use, even though use of that drug might be extensive. On the other hand, a reporting system might be considered for a community with a relatively small but rapidly spreading problem of heroin, cocaine, or amphetamine abuse.

Finally, it is advantageous if the participating institutions have existing record systems and staff who are experienced in these systems. If such institutions are willing to co-operate, it will be much easier for a new system to be introduced or for the existing system to be modified.

Unless these conditions are met, it is unlikely that a reporting system can be successfully established and planners may be advised to consider other approaches. If, however, all the conditions are fulfilled, a reporting system may be the most practical and useful approach for achieving certain objectives, discussed in the next section.

5.1.2 Advantages of Reporting Systems

A reporting system is one of the best ways of measuring continuously the level and consequences of drug use. It might be argued that the most serious consequences come to the attention of emergency rooms, treatment programmes, the police, and medical examiners, and are therefore more likely to be monitored by a reporting system than by other approaches, such as a general population survey. Thus, reporting systems can be very effective in identifying groups that are at high risk for drug-related disabilities. The information they provide permits appropriate targets to be identified. Reporting systems are particularly suitable for determining the extent and nature of utilisation of community agencies, and monitoring trends in such utilisation. That is, if decision-makers need to determine the number and characteristics of people in contact with treatment or enforcement agencies as a consequence of their drug use, particularly on a regular basis, some sort of reporting system would be desirable. Among other things, this will permit planners to determine the resources that are being expended for treatment or enforcement in relation to the number of drug users. Such a system may also allow decision-makers to determine the overall availability of care for drug-related disabilities as well as the relative accessibility of treatment.

Reporting systems are also appropriate for the continuous evaluation of intervention efforts. This is particularly true of case-reporting systems and case registers, which are capable of following patients up as well as determining the impact of changes in the demand for treatment.

Reporting systems may also accomplish other objectives, such as determining the sequence and direction of contacts with community agencies. However, the purpose is not as important as those noted above. If a community or a government wishes to achieve any of these objectives, serious consideration should be given to the possibility of establishing a reporting system.

5.1.3 Weaknesses of Reporting Systems

It is generally expected of reporting systems that they will provide reliable information on the total number of drug users in the population. But reporting systems, by their very nature, can identify only the portion of the drug-using population that comes to their attention, and only the case-register type of system develops an unduplicated list of this population. Even this list represents an unknown and varying fraction of the total population of drug users. Except in rare circumstances where the vast majority of drug users are identified by a reporting system, it is unrealistic to expect that these data alone can be extrapolated to the total number of drug users in the population.

Case registers identify an important segment of the drug-using population: those that come to the public attention because of serious problems, a desire for treatment, or law-enforcement activity. Thus, case registers keep track of at least a minimum number of drug users in the community as well as their characteristics, and this is of considerable use to planners.

As indicated earlier, a case register can be used to provide estimates of the total number of drug users in a community by several methods. For the perfectionist, the resulting estimates may not be satisfactory because they may rely on too many unwarranted assumptions. However, if the limitations of such estimates are clearly explained to administrators and policy-makers, they are likely to be extremely useful and to show the practical value of reporting systems. Another limitation of reporting systems is that they may not be the preferred approach when planners are interested in determining drug-abuse patterns at one point in time only. Other approaches, such as analysis of existing data, intensive case-findings, or interviews with knowledgeable informants, may be less costly and just as useful. Such approaches may also be preferred when the necessary conditions for reporting systems are absent, for example, in the very early stages in the development of a drug-abuse control programme.

5.2 Future Directions

5.2.1 Integration of Data Systems

One direction in which some countries are moving is towards integrated data systems. An excellent example of such a trend is found in Malaysia, where a National Integrated Data System on drug abuse has been established. In the initial phase, existing agency records were used as the source of information, but, in the second phase, a uniform case-reporting record was used by nineteen reporting units including drug-treatment, rehabilitation, and psychiatric facilities.

Subsequently, enforcement agencies were included in the system, as well as private physicians, customs officers and laboratories carrying out analyses of drugs obtained in the street. The system has been facilitated by the assignment of an official identification number to all citizens by the Government of Malaysia. The confidentiality of information given by a reported individual is protected by legal safeguards. The system is making it possible gradually to accumulate data on all drug abusers identified by treatment and law-enforcement agencies. It also identifies new trends, such as the emergence of morphine abuse in some areas in lieu of heroin abuse.

Another approach taken in both the CEWG in the USA and the multi-city study in Europe is to integrate all available data for a large city. This means that all data from hospitals, enforcement agencies and registers is collated for a number of cities. Separate reports are made for those cities but an overall picture can still be obtained. A regional approach is also being taken in Europe with the establishment of the European drug abuse observatory and some regional reporting centres.

5.3 Relevance to Developing Countries

Many planners will ask if reporting systems are not too sophisticated and expensive for developing countries, which have other competing priorities. However, a number of developing countries have either recently implemented or are planning reporting systems. The need for a reporting system is not based on whether or not the planner finds himself in an affluent country. The primary consideration appears to be that the country has a serious, large-scale or rapidly spreading problem of drug abuse, often of the opium, heroin, or stimulant-drug type. The spread of heroin abuse to thousands of adolescents and young adults in Malaysia was judged by planners and policy-makers as a threat to national socio-economic development justifying resources for an effective programme of drug-abuse prevention and control, including a national reporting system.

While this chapter has been written to be of assistance to planners in developed as well as developing countries, several special issues deserve mention, from the perspective of the latter.

5.3.1 Special Issues

If drug-abuse reporting is of sufficient priority to be established in a developing country, planners will need to determine at the outset if there is an adequate institutional infrastructure, particularly in rural areas where there may be large numbers of drug users. If there are no appropriate institutions for contacting and intervening in community drug-abuse problems, a reporting system - at least on a national level - may not be feasible.

The planners should take care to develop a reporting system that does not require highly trained personnel. The data-reporting form must be very simple, clearly understandable, and suitable for completion by staff with the minimum of education and formal training. Where possible, the system should be integrated with other national information systems, or at least compatible with them.

5.3.2 Use of Computers

In 4.3.4 there is a discussion of the role of computers in reporting systems. If there are many reports and data items, additional reports need to be included as the analysis proceeds, if the record system needs to be constantly brought up to date, and if previously reported data are to be included in future analyses, then the use of a computer is essential. Only for the smallest local registers is hand computing feasible.

Another economic factor is the cost of developing computer programmes to analyse the data. While these may be expensive, the cost of developing them is incurred only once, and they may be used time and again. Costs for such computers are falling and they are even cheaper when purchased in large numbers.

Many recent developments in computer technology are applicable in the establishment of data systems concerning drug abuse. Such developments are particularly useful in developing countries because of their relatively low cost. Thus, personal computers, which have now become widely available, theoretically permit the local entry and processing of considerable amounts of data at low cost and require only a standard electrical outlet as a power source. Consequently, they might be useful in field projects, such as often exist in drug-abuse research. Software for drug abuse systems is readily available.

Planners must take into account the rapid developments in this field, which generally have tended to reduce the cost of automatic data-processing systems and to make them more accessible. Therefore, before they implement a system, they should examine the alternatives and relative costs for data-processing methods in the country concerned. They should also examine the long-term benefits of using equipment compatible with existing computer systems in the country. In the long run, this will reduce costs by making repairs and servicing less expensive.

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ANNEX 1

FORM NUMBER
5591667

DEPARTMENT OF HEALTH AND HUMAN SERVICES
PUBLIC HEALTH SERVICE
SUBSTANCE ABUSE AND MENTAL HEALTH SERVICES ADMINISTRATION

FORM APPROVED:
OMB NO. 0930-0078
Expires 3/31/97

DRUG ABUSE WARNING NETWORK (DAWN)
MEDICAL EXAMINER REPORT

1. PROVIDER NUMBER

2. CROSS REFERENCE *(Facility Use Only)*

3. DATE OF DEATH — Month / Day / Year

INFORMATION ON DECEASED

4. AGE *(Must be 00-97 yrs.)*

5. SEX
1 ☐ Male
2 ☐ Female

6. RACE
1 ☐ White, not of Hispanic Origin
2 ☐ Black, not of Hispanic Origin
3 ☐ Hispanic
4 ☐ American Indian or Alaskan Native
5 ☐ Asian or Pacific Islander
6 ☐ Unknown
7 ☐ Other *(Specify)* _____

7. DECEDENT'S HOME ZIP CODE
(Otherwise mark [X] one response)
1 ☐ Unknown 2 ☐ No Fixed Address

8. CAUSE OF DEATH *(See reverse side)*

A. Was this a DRUG-INDUCED CASE (e.g., the drug[s] directly caused the death as documented in County records such as the death certificate and/or autopsy findings)?
1 ☐ Yes ☐ No

B.1 If not drug induced, please select one of the following DRUG-RELATED CASE categories:
2 ☐ Drug Abuse in Combination with Physiological Condition
3 ☐ Drug Abuse in Combination with External Physical Event
4 ☐ Drug Abuse-Caused Medical Disorder (Whether abuse is past or present)

B.2 Please mark (X) confirmed if the drug-related case in B.1 is based on a documented conclusion in County records (e.g., death certificate states that drug abuse contributed to the death but was not the primary cause):
☐ Confirmed
Please mark (X) presumed if the drug-related case in B.1 is based on positive toxicology (e.g., presence of illicit substances or legal drugs exceeding therapeutic levels) – OR – on other documentation of past or present substance abuse that may be related to the cause of death.
☐ Presumed

9. MANNER OF DEATH
1 ☐ Accidental/Unexpected
2 ☐ Suicide
3 ☐ Homicide
4 ☐ Undetermined
5 ☐ Natural

10. FACTORS SUPPORTING DAWN CASE DETERMINATION *(Mark [X] for all that apply.)*
1 ☐ Death Certificate
2 ☐ Toxicological Laboratory Report
3 ☐ Autopsy
4 ☐ Inspection of Scene of Death
5 ☐ External Physical Signs
6 ☐ Statement of Hospital/Family/Friends
7 ☐ Other *(Specify)* _____

DRUG/SUBSTANCE INFORMATION

11. ALCOHOL INVOLVED *(Mark [X] one response)*
1 ☐ Yes (If YES, please note concentration _____) 2 ☐ No

12. LIST EACH DRUG/SUBSTANCE NAME IN ONE OF THE SPACES BELOW

	SAMHSA USE ONLY	
1	[redacted]	[redacted]
2		
3		
4		
5		
6		

For each non-alcohol substance listed above, mark [X] one response in each data item below.

13. ROUTE OF ADMINISTRATION

		SUBSTANCES 1	2	3	4	5	6
Oral	01						
Injection	02						
Inhaled	03						
Smoked *(Includes Freebase)*	04						
Sniffed, Snorted	05						
Unknown	06						
Other	07						

14. LAB TEST USED TO IDENTIFY DRUG

DRUG #	FINDINGS *(List test methods, specimen, and findings for each drug listed)*

15. CODED REMARKS
(If case involves an IV drug user with HIV+/AIDS, please write "HIV+" or "AIDS" in the first four spaces below.)

SMA 100-7
REV. 4/94

SELECTED REPORTING GUIDELINES AND INSTRUCTIONS DRUG ABUSE WARNING NETWORK (DAWN) MEDICAL EXAMINER REPORT

I. General

The following abbreviated guidelines and instructions highlight critical reporting items. Please refer to the detailed instructions found in the Instruction Manual for Medical Examiners for further information.

II. Reporting Guidelines

Report data on all decedents whose death was induced by or related to drug abuse. For DAWN, drug abuse is defined as the use of any illegal drug or the nonmedical use of a legal drug where the reason for taking the substance was for: psychic effects, dependence, suicide, or homicide. Further discussion and examples can be found in the DAWN ME Instruction Manual.

III. Abbreviated Instructions for Completing Selected Items

Data Item #7 - Decedent's Home Zip Code

Use *"no fixed address"* for the homeless (even if stayed at a shelter) and for prisoners who expired.

Data Item #8 - Cause of Death

This data item has two parts, parts A and B. Part A requires a selection of "YES" or "NO" to indicate whether the case is a confirmed drug-induced death. If the response to part A is "YES", go on to Item 9 (manner of Death.) If the answer to part A is "NO", parts B. 1 and B. 2 require a response.

A. Mark [X] if the case is a confirmed drug-induced death (e.g., the drug(s) directly caused the death).

B1. Mark [X] if the case is a drug-related death, such as a death caused by sepsis in which the decedent had a history of IV drug use and the injection site is indicated as the source of the infection that resulted in sepsis death.

B2. Mark *"Confirmed"* if County records substantiate the conclusion that the death is related to drug abuse (e.g., drug abuse is noted as a contributing cause on the death certificate); or

Mark *"Presumed" if* case involves a death from a gunshot wound in which toxicological findings indicate recent illicit drug use. The two may be related but there is insufficient evidence for legal certification of drug relationship cause.

Data Item #10 - Factors Supporting DAWN Case Determination

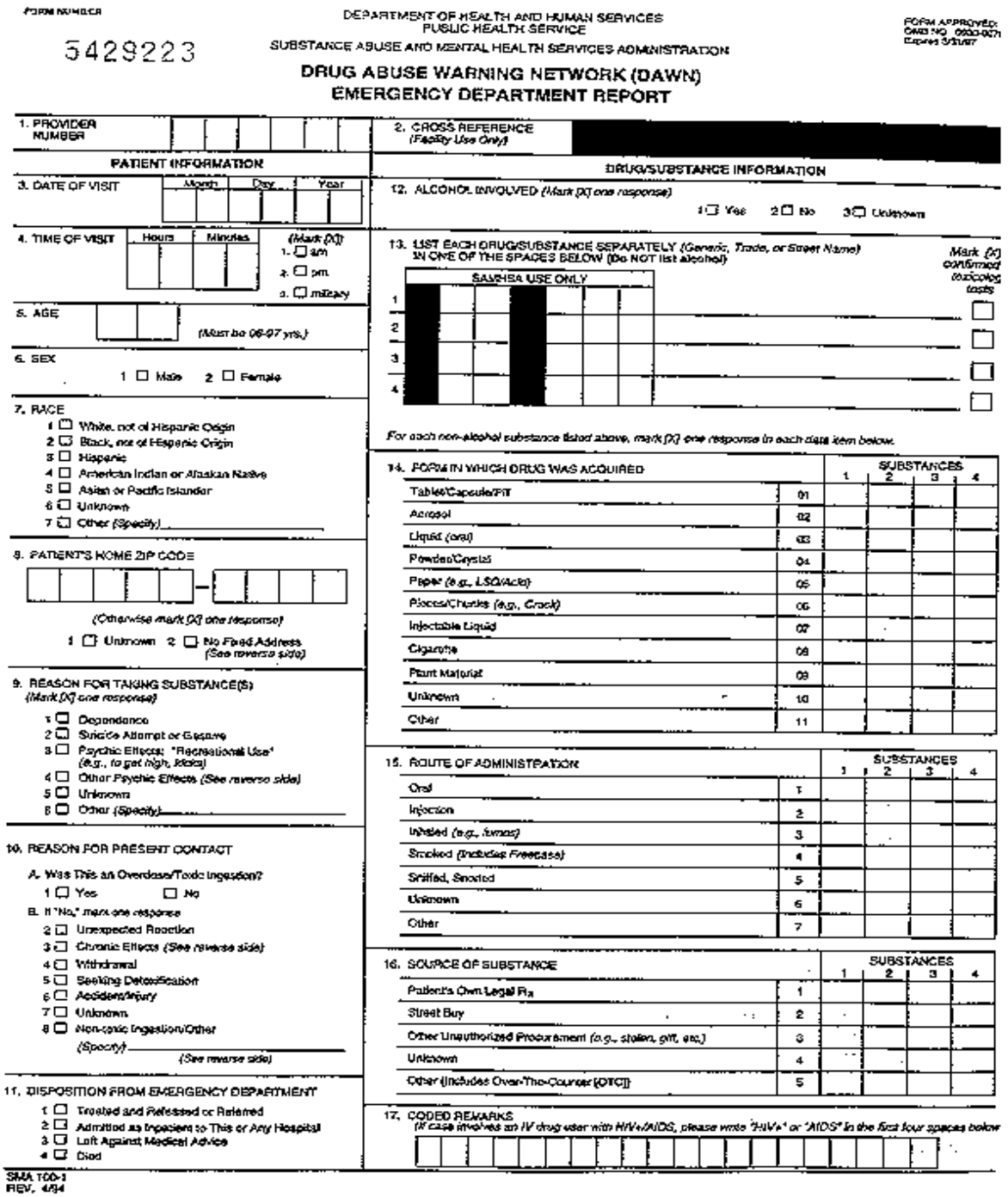
Mark with an [X] all items that were reviewed in order to determine if this case meets DAWN criteria.

Data Item #15 - Coded Remarks

Please be certain to write "HIV+" or "AIDS" in the first four blocks if the decendent was a confirmed IV drug user.

SMA 100-2 (BACK)
REV. 4/94

ANNEX 2



FORM NUMBER
5429223

DEPARTMENT OF HEALTH AND HUMAN SERVICES
PUBLIC HEALTH SERVICE
SUBSTANCE ABUSE AND MENTAL HEALTH SERVICES ADMINISTRATION

FORM APPROVED
OMB NO. 0930-0078
Expires 5/31/97

DRUG ABUSE WARNING NETWORK (DAWN)
EMERGENCY DEPARTMENT REPORT

1. PROVIDER NUMBER

2. CROSS REFERENCE (Facility Use Only)

PATIENT INFORMATION

3. DATE OF VISIT — Month / Day / Year

4. TIME OF VISIT — Hours / Minutes (Mark [X]) 1. ☐ am 2. ☐ pm 3. ☐ military

5. AGE (Must be 06-97 yrs.)

6. SEX
1 ☐ Male 2 ☐ Female

7. RACE
1 ☐ White, not of Hispanic Origin
2 ☐ Black, not of Hispanic Origin
3 ☐ Hispanic
4 ☐ American Indian or Alaskan Native
5 ☐ Asian or Pacific Islander
6 ☐ Unknown
7 ☐ Other (Specify) _____

8. PATIENT'S HOME ZIP CODE
(Otherwise mark [X] one response)
1 ☐ Unknown 2 ☐ No Fixed Address (See reverse side)

9. REASON FOR TAKING SUBSTANCE(S) (Mark [X] one response)
1 ☐ Dependence
2 ☐ Suicide Attempt or Gesture
3 ☐ Psychic Effects: "Recreational Use" (e.g., to get high, relax)
4 ☐ Other Psychic Effects (See reverse side)
5 ☐ Unknown
6 ☐ Other (Specify) _____

10. REASON FOR PRESENT CONTACT
A. Was This an Overdose/Toxic Ingestion?
1 ☐ Yes ☐ No
B. If "No," mark one response
2 ☐ Unexpected Reaction
3 ☐ Chronic Effects (See reverse side)
4 ☐ Withdrawal
5 ☐ Seeking Detoxification
6 ☐ Accident/Injury
7 ☐ Unknown
8 ☐ Non-toxic Ingestion/Other
(Specify) _____ (See reverse side)

11. DISPOSITION FROM EMERGENCY DEPARTMENT
1 ☐ Treated and Released or Retained
2 ☐ Admitted as Inpatient to This or Any Hospital
3 ☐ Left Against Medical Advice
4 ☐ Died

SMA TOD-1
REV. 4/94

DRUG/SUBSTANCE INFORMATION

12. ALCOHOL INVOLVED (Mark [X] one response)
1 ☐ Yes 2 ☐ No 3 ☐ Unknown

13. LIST EACH DRUG/SUBSTANCE SEPARATELY (Generic, Trade, or Street Name) IN ONE OF THE SPACES BELOW (Do NOT list alcohol)

	SAMHSA USE ONLY	Mark [X] confirmed toxicology tests
1		☐
2		☐
3		☐
4		☐

For each non-alcohol substance listed above, mark [X] one response in each data item below.

14. FORM IN WHICH DRUG WAS ACQUIRED		SUBSTANCES 1	2	3	4
Tablet/Capsule/Pill	01				
Aerosol	02				
Liquid (oral)	03				
Powder/Crystal	04				
Paper (e.g., LSD/Acid)	05				
Pieces/Chunks (e.g., Crack)	06				
Injectable Liquid	07				
Cigarette	08				
Plant Material	09				
Unknown	10				
Other	11				

15. ROUTE OF ADMINISTRATION		SUBSTANCES 1	2	3	4
Oral	1				
Injection	2				
Inhaled (e.g., fumes)	3				
Smoked (Includes Freebase)	4				
Sniffed, Snorted	5				
Unknown	6				
Other	7				

16. SOURCE OF SUBSTANCE		SUBSTANCES 1	2	3	4
Patient's Own Legal Rx	1				
Street Buy	2				
Other Unauthorized Procurement (e.g., stolen, gift, etc.)	3				
Unknown	4				
Other (Includes Over-The-Counter [OTC])	5				

17. CODED REMARKS
(If case involves an IV drug user with HIV+/AIDS, please write "HIV+" or "AIDS" in the first four spaces below)

SELECTED REPORTING GUIDELINES AND INSTRUCTIONS
DRUG ABUSE WARNING NETWORK (DAWN)
EMERGENCY DEPARTMENT REPORT

I. General

The following abbreviated guidelines and instructions highlight critical reporting items. Please refer to the detailed instructions found in the Instruction Manual for Emergency Departments for further information.

II. Reporting Guidelines

Report data on all patients seen in the emergency department for problems induced by or related to drug abuse. For DAWN, drug abuse is defined as the use of any illegal drug or the *nonmedical use* of a legal drug where the reason for taking the substance was for: psychic effects, dependence, or suicide attempt or gesture.

Detailed discussion of the "nonmedical" use definition and other case selection criteria can be found in Chapter II, Case Identification Guidelines, of the Instruction Manual for Emergency Departments.

III. Abbreviated Instructions for Completing Selected Items

Data Item #8 - Patient's Home Zip Code

Use *"no fixed address"* for the homeless (even if staying at a shelter) and for prisoners brought into the hospital.

Data Item #9 - Reason for Taking Substance(s)

The response categories are: Dependence, Suicide Attempt or Gesture, Psychic Effects: "Recreational Use," Other Psychic Effects, Unknown, and Other (Specify). The definitions are as follows:

1. *Dependence* - A physiological or psychological condition characterized by a compulsion to take the drug on a continuous or periodic basis in order to experience its effects or to avoid the discomfort of its absence (i.e., to avoid withdrawal).

2. *Suicide Attempt or Gesture* - Successful or unsuccessful actions(s) taken for the purpose of self-destruction or to gain attention.

3. *Psychic Effects: "Recreational Use"* - Use of drug(s) for experimentation or to enhance social situations or conditions. Examples of common patient responses are: "just wanted to know what it felt like," "wanted to have fun," or "to get high."

4. *Other Psychic Effects* - Use of drug(s) to improve, enhance, or make better any mental, emotional, physical state. Examples of common patient responses concerning this self-applied medication are: "needed to relax," "wasn't feeling well," "to stay awake," "depression," "anxiety," "lose weight," "fight with boyfriend/mate."

5. *Unknown* - Should be used only if information is unobtainable or unavailable.

6. *Other* (Specify) - Should be used only when the *Reason for Taking the Substance* cannot be classified into the categories above. Write the appropriate reason in the space provided.

Data Item #10 - Reason for Present Contact

This data item has two parts, parts A and B. Part A requires a selection of "YES" or "NO" to indicate whether the case is an Overdose/Toxic Ingestion. If the response to part A is "NO," part B requires a response.

3. *Chronic Effects* - Includes Hepatitis, Abscess, Cellulitis, Tremors, and AIDS contracted by IV drug abuse (see manual for additional examples).

8. *Non-Toxic Ingestion/Other* (Specify) - Should be used only when *Reason for Present Contact* cannot be classified into the categories above. (For example, police bring patient in for toxicological testing related to commission of a crime or parents force a child to come in to be checked because of strange behavior.) If *Other*, write reason in space provided.

Data Item #17 - Coded Remarks

Please be certain to write "HIV+" or "AIDS" in the first four blocks if the patient is a confirmed IV drug user.

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CHAPTER 9

REPORTING AND APPLICATION OF RESULTS

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CONTENTS

1. Introduction

The presentation, dissemination and application of the results are key components of any epidemiological study. It is important to think about these questions from the beginning and to involve, at an early stage, the key figures who will subsequently use the results and, wherever possible, the target communities.

Epidemiological studies can provide the scientific foundation for understanding substance use and can be utilised to further public health goals. Often both these objectives are served by epidemiology, but to a varying extent. These two objectives and their relative importance for a particular study need to be clearly recognised at the beginning of the study. This helps in planning so that the necessary information is collected, but beyond this it helps in presenting the results in a manner that is best suited for achieving the objectives of the study. Research should meet the criteria of sound scientific method and relevance for decision making.

There are potential conflicts related to varying orientations of researchers and decision-makers. One is the differing perception of time frame. Research often takes time and decision-makers do not like to wait. Often because of pressing needs they want results immediately. A compromise needs to be reached so that necessary results are available within a mutually acceptable time-frame, though further analyses may take more time. Another area requiring attention is the level of complexity used in presenting results. Decision-makers often want results that are stated as simple facts. Researchers being aware of all the limitations of interpreting results, present these in a form that often raises more questions than it answers. It is important that results of any epidemiological research be presented in a simple form that can be easily understood and used by decision-makers, though details can be presented in the larger report or publication for more scientifically inclined readership.

How to transform knowledge into action is one of the main challenges for epidemiology and public health. The World Health Organization (1986), has proposed a model to build bridges between researchers and decision makers with the use of "decision-linked research". The essence of this approach is to facilitate interactions in order to increase the probability that decisions are made on the basis of valid and reliable information for the benefit of society including the researchers themselves. A "primary link" exists when interaction occurs before the project is initiated, the starting point is then a diagnosis of needs for decision making. This type of interaction is more typical of problem oriented research. The "secondary link" occurs when the project begins under the initiative of a researcher, more typical of projects oriented to increase the knowledge. Communication is possible with decision makers at any phase of the research process, the earlier it is established, the better it usually is.

Pathmanathan (1992), suggests a path for linking research results with policy making when, as most often occurs, "the research process is initiated by researchers who design and implement

studies on the basis of individual interests, sources of funding currently available and on their own perception of what might be useful for decision makers". According to him, "findings may subsequently be examined for relevance; pertinent information might be brought to the attention of the decision makers; efforts might follow to determine if and how the information could help in decision making". "Increasing the volume of this type of research, will raise the probability that at least some of the findings will filter through to the appropriate decision makers, be perceived by them as relevant, and be incorporated to the decision-making process". In order to ensure applicability of research findings, studies ideally need to address priority problems, be multidisciplinary in nature, participatory, timely (results should be available when needed), cost-effective, useful for administrators, decision makers and the community, and include an evaluation component aimed at the improvement of the conditions of the problem that ultimately lead to better health.

Much of the debate regarding applicability of results has considered communication between epidemiologists and researchers with policy makers or decision takers, but in the applicability of research findings there is another very important actor, the community, or more broadly the population from which the data were drawn and that should ultimately benefit from the research and decisions based on findings. It is well known that many policy initiatives will impact the community only if the people in that community are aware and agree with the benefit of the measures.

Some research designs facilitate the link between researchers and the community, and between research and action (so called "action research"). This is the case with some qualitative methods, discussed in more detail in chapter 4 of this guide. If the information is gathered in the form of a group discussion on the aspects of the problem that affect the community, sensitisation takes place even during the data-gathering stage. This can be further enhanced by providing these groups, with the results of the study and recommendations for action.

A useful strategy that has been recommended by WHO (1982) is to provide feedback to the community on the research results and to discuss the findings and possible solutions. An experiment of this nature was undertaken as part of the WHO Community Responses to Alcohol Related Problems multinational project (WHO, 1982). The community was gathered in different groups and research results were discussed. As a consequence not only very enriching additional information was gathered but specific actions were undertaken by different groups. This initiative functioned as a community mobilisation strategy. Since the early 1980s community participation has become more central to planning and initiating studies and feeding back and applying the results. Community participation in drug abuse epidemiology has a longer history in some countries. In the United States, for example, the Community Epidemiology Work Group (CEWG) model of the National Institute on Drug Abuse (NIDA), which is described in Chapter 8, is a very useful strategy for engaging community participation in the collection, reporting, dissemination and utilisation of drug abuse epidemiology surveillance data. Local CEWGs can be established at any level: national, State, county, city, and community or neighbourhood, and are composed of individual members who are in a position to contribute and assess information about drug use in specific areas or communities.

NIDA has developed a guide to the development of local community epidemiology workgroups (NIDA 1998) and the model has been replicated in other countries. In South Africa, for example, the South African Community Epidemiology Network on Drug Use (SACENDU), collects, collates and interprets data from multiple sources. Currently established in three South African cities Cape Town, Durban and Port Elizabeth, there are plans to extend the network to Johannesburg, Pretoria and other cities in other countries of the region (SACENDU, 1997).

Rapid Assessment and Response Methods for substance use being developed by the World Health Organization provide methods for rapidly collected and assessing information to inform decisions about practical interventions. Such methods are orientated to action rather than contemplation and are of direct relevance to interventions. In addition to providing answers to epidemiological questions the method can also be viewed as a tool for developing local capacity at the community level for developing interventions (WHO, forthcoming; WHO & UNAIDS, forthcoming).

2. Reporting of the Results

Reporting the results generally involves the preparation of a written report which provides details of methods, results, conclusions and recommendations, and an executive summary of the main results. It is especially important that the summary gives a clear account of the major conclusions in a way that can be understood and used by busy ministers or officials. How the results are presented depends on: the objectives of the study and how the results are to be used; the nature of the material (e.g., survey, routine statistics, synthesis of data from different studies and sources, ethnographic study); and the target audience(s).

The results can be presented in a variety of formats, depending on the goal and target audience. These various formats include:

1. full report, recommendations & annexes;
2. executive summary;
3. feedback to participating agencies;
4. publication in professional or specialist journals;
5. general release to public, media etc.;
6. presentations to committees, meetings, conferences etc.

2.1 Objectives of the study

It is essential that the objectives of the study are clearly defined at the outset, during the planning of the research. The objectives determine both the content of the report and way in which the results are disseminated and applied. The specific objectives could be, for example:

- assessment of the nature and extent of drug use and drug related problems identification of the major drugs involved and the characteristics of those groups most at risk ;
- assessment of the health and social consequences of drug use;
- assessment of the attitudes, knowledge and perceptions regarding drug use in specific populations.

The context or purpose of the study should also be carefully considered during the planning stage. Again this will determine the structure of the report and way in which the results are disseminated and applied. The context within which the study aims to achieve these specific objectives may be that of:

- a short-term needs assessment or rapid situation assessment;
- a broad or longer term policy development;
- planning programmes in specific areas:
    - education & prevention,
    - treatment & rehabilitation,
    - public health programmes.
- identifying problems and un-met needs in the community;
- evaluation of:
    - policy;
    - specific programmes (e.g. a school prevention programme);
- setting up a reporting and monitoring system.

2.2 Audience for the results

The audience will also determine how the results are reported. Different forms of presentation will often be appropriate for each target audience. Possible audiences include:

- ministers and senior government officials;
- local administrators and other officials;
- professionals and organisations working in the field;
- agencies and others who participated in the study;
- funding agencies (governmental, private etc.);
- the media and general public;
- scientific research community;
- international organisations.

2.2.1 Ministers and senior government officials

Ministers and senior government officials need information for formulating policy and decision-making, though they also use it for a variety of other reasons (making speeches, justifying their policies, reassuring or warning the public etc.). However they rarely have time to read a long report, identify the most important findings or derive recommendations. It is thus important to prepare a summary which does this for them. The main departments concerned are likely to be the Ministries of Health, Social Welfare and Education, Justice, and Home Affairs, though others may also be involved. In some countries, there are Interministerial Commissions set up to co-ordinate responses to drugs and drug-related problems.

National governments need rather general information that gives an overview of broad patterns, trends and regional variations to help them develop and assess the overall direction of policies. They also often require information on the impact of specific types of interventions (e.g. in primary prevention, treatment or public health) so as to develop recommendations based on successful examples of "good practice" in order to improve the quality of practice and training in prevention, treatment and rehabilitation.

2.2.2 Local administrators and other officials

Local administrators or specialised government officials are more likely to have responsibility for drawing up briefings or for implementing actions in the fields of education, prevention, treatment, and rehabilitation. They therefore need more concrete, detailed results and recommendations that enable them to plan, justify or evaluate policies and programmes.

Local circumstances often vary considerably according to the profile and traditions of local communities; the number and type of local services; and the local patterns of drug use and supply. Even within a city, large differences can be found, both between areas, and over time. Thus local information needs to be more sensitive, flexible, rapid and specific than at national level. The type of information needed at national as opposed to local level depends on the degree of centralisation or decentralisation in policy making and service provision.

2.2.3 Professionals and organisations working in the field

The extent to which the target audience includes professionals and organisations working in different aspects of the drug field (education, prevention, treatment, social welfare etc.) will clearly depend on the focus of the study. A particularly important group are those agencies or groups that participate in data collection. Feedback to them is a valuable way of maintaining their involvement, not only in data collection but also in the implementation of new programmes in the fields of prevention, treatment or rehabilitation. In many countries, non-governmental and community based organisations play an important role and it is essential to include them as an important audience.

2.2.4 Funding agencies

Funding agencies, both governmental and non-governmental, are a major audience. Funding sources may have reporting requirements in order to provide justification for expenditure on this as opposed to other activities. It may be useful to prepare a separate summary or short version of the report which emphasises this aspect. Furthermore, by demonstrating research productivity and the value of the research endeavour, researchers can help to establish credibility with funding sources which could strengthen the justification for possible future funding.

2.2.5 The media and general public

The general public is often a more diffuse audience than the groups above. Whilst drugs is an issue that arouses concern or curiosity, especially in the media, their role as an audience for the results cannot be defined in general terms. For example, the presentation of a report which recommends setting up treatment centres in particular communities, or developing community-based prevention programmes will need considerable thought and discussion in terms of local circumstances. It is generally inadvisable to release results through the media before they have been presented and discussed with the relevant parties.

2.2.6 The scientific community

Depending on the nature and objectives of the research, the investigator may consider developing a paper for publication in a scientific journal. This provides a mechanism for communicating results to other researchers and contributes to the greater body of knowledge in this field. Establishing a publication record helps to establish the investigator as a credible researcher. This may lead to opportunities for research collaboration and can strengthen future applications for research support.

2.2.7 International organisations

At the international level, information is needed to assist the development of policies concerning regional or inter-regional issues, and to enable countries within the same region to share experiences and to learn from the successes and failures of others. Collaboration is helped by the adoption of agreed, standard criteria, though progress can be made if differences in definitions are made clear. There is great value in utilising comparable methodologies to assess the nature and extent of drug use, drug addiction and their consequences, since this allows the situation in different countries to be compared. Examples of city-based national and regional reporting systems and networks and of international reporting systems are discussed in Chapter 8 (Reporting systems).

The emphasis in this chapter is on reporting and applying results within a country, either at national or local level. Reports may of course be prepared for international organisations such as the

United Nations International Drug Control Programme (UNDCP) or WHO, either as part of a reporting system or in order to obtain funding. In most cases, there are specific guidelines for presenting such reports.

2.3 Structure of the Report

One outcome of any study or assessment should be a full report which includes the relevant elements in the following suggested structure. Each element in the report is further elaborated below.

2.3.1 Executive summary

This is a very important element of the report. Many people, including senior decision-makers, may well not read the full report. Others will read the summary first in order to decide whether the main body of the report contains relevant information. The summary should therefore provide in a clear and succinct fashion and only the most significant information. Technical language should be avoided, and statistical details kept to the essential minimum. A very limited number of graphs (as appropriate) may be included in the summary. The following element should also be included in the executive summary:

- key results (graphical presentation optional),
- note any important or unexpected findings,
- state briefly the most likely explanations for the results (in the context of the study site and population),
- stress the limits of generalisability,
- clearly caution about causal inference,
- major recommendations.

On a practical note, it is often easier to write the executive summary, after the main report has been finalised.

2.3.2 Introduction

The introduction to the report should be preceded by a Table of Contents which will help readers to quickly find the information they are most interested in. The introduction should include the following elements:

- an overview of the study, including background and significance,
- a review/synopsis of key studies on the research topic and existing data (if available),
- clearly stated aims and objectives of this study,
- acknowledgements and identification of collaborators and participating institutions, as appropriate.

2.3.3 Methods

- a brief description of study location (including demographic data and reasons for selection of location),
- an overview of the research method(s) and reasons for approach chosen,
- a description of sources of information
- sampling frame and sampling procedure, including discussion of any weighting (where appropriate),
- instrument development and piloting (data collection protocols and other relevant documentation in an annex),
- training of interviewers (where appropriate),
- methods of data collection,
- data management and analysis,
- ethical issues, including confidentiality.

2.3.4 Results

- response rates (where appropriate)
- characteristics of sample
- presentation of results in an appropriate form (this clearly varies with the type of study)
- the main results (if quantitative) should be presented either graphically or in tables in the text. More detailed data tables should be in an annex.

2.3.5. Discussion, Conclusions and Recommendations

- limitations of methods,
- interpretation of results in terms of objectives,
- implications for planning, services, policy etc.,
- future information needs,
- recommendations.

2.3.6. Bibliography/ references

A bibliography and/ or references should be provided. A list of references are those works cited elsewhere in the text of the report as sources of data or other information. It may include unpublished documents, provided that these are available to interested readers. A bibliography is a list of published works relevant to the subject matter of the report and recommended for further reading. A standard referencing system should be used (for example the Harvard system).

2.3.7. Annexes

- instruments and documentation on data collection protocols
- detailed statistical tables (where appropriate)

2.4 Other methods of reporting results

While a written report, following the structure suggested above, is one way in which results can be reported, there are other methods that should be considered to ensure that the information is provided to the broadest audience. A written report alone will often not be sufficient to ensure best use is made of the results.

2.4.1 Feedback to participating agencies

This is an important aspect of the presentation of the results that is often overlooked. Not only is it a matter of courtesy to those who have played a vital role in providing information, but it can also be a very valuable way of motivating them to continue to participate in continued monitoring or in other activities that follow on from the study. It also enables them to contribute to the discussion of how the results should be interpreted and of what the implications might be. The feedback can take several forms, depending on what is appropriate in the circumstances: by sending them a draft of the report, or the sections of it which are relevant to their contribution, and asking them for their comments; by visiting them to describe the results (only possible if the number of agencies is not too large); or by organising a feedback meeting to which all the participating agencies are invited.

2.4.2 Publication in professional journals

The preparation of an article for publication is likely to be left until after the final report has been completed. However, if there is time, it is worth considering at an earlier stage what sort of publication might be envisaged and what could be included, so that this can be taken into account when carrying out data analysis. Different journals have different target audiences and different guidelines for submitting manuscripts, so it is essential to pay attention to these before starting work on an article. The form, content and style of a scientific article differ from that required for a final report of a project. Usually it is necessary to focus on aspects that are of wider interest above and beyond the immediate local needs for which the study was carried out. For investigators who are inexperienced in the task of preparing articles for scientific journals, it is worth discussing this with someone who has experience, for example at a university or department of epidemiology. When submitting an article to an international journal, it is very important to ensure that the language is checked, if possible by a native speaker of the language of the journal concerned.

2.4.3 General release

Issues concerning drugs are often of concern to the wider public, including parents, teachers, and the media. However, this is also a sensitive topic that raises anxiety and that tends to be reported and discussed in sensational and often inaccurate terms. Thus it is important to balance the need to disseminate information and the need to ensure that releasing it is not counter-productive. Managing the general release of information will vary considerably depending on local circumstances. It is important that information is not prematurely released until it has been checked for accuracy. It is also important that the identities of individuals and, where appropriate, agencies are not made public unless their prior consent has been obtained.

2.4.4 Presentations to committees, meetings and conferences

If the results of the study are to have an impact and be used by policy makers, professionals and other audiences, then close attention should be paid to how best to disseminate the findings and discuss their implications with the relevant actors. This will depend on the objectives of the study and on local conditions. In many cases, the audiences for these presentations will not be specialised researchers, and in some cases will not have detailed knowledge of the drug field. It is therefore necessary to prepare these presentations carefully, taking account of the interests and level of experience of the audience. It is often important to explain clearly the purpose and main objectives of the study, to concentrate on the most important findings, to be open about the limitations of the data, whilst avoiding methodological detail or technical jargon, and to allow sufficient time to discuss the meaning and implications of the data. Visual aids can be very helpful, but detailed tables of results should be avoided, and the temptation to present complex information should be resisted. The guiding principle should be the question "What are the two or three priority points that the audience should remember after the presentation?"

3. Issues in preparation of a Report

Several issues arise in the course of preparing a report. Some of the more important of these include the following:

3.1 Interpretation

Statistical measures only quantify the extent of drug use or of drug problems. It is essential to interpret those data to the extent that is appropriate and in the context in which they were collected. Over interpretation of findings based on a small sample is a mistake that is often committed. Similarly, it should always be remembered that a statistically significant correlation shows only an association and does not necessarily indicate causality. For example, high prevalence of substance use among the unemployed may be interpreted in a variety of ways. It may indicate

unemployment as a cause for substance use, substance use as a cause for unemployment or both being caused by a common third factor. In practice, causation's to phenomena like substance use are very complex, usually not amenable to interpretation based on association alone.

The setting and context of the study should also be important determinants for interpretation of findings. This includes the local culture, the nature of the health, social and enforcement structures, the history and tradition of drug use in the society or in communities within it and the processes by which the data were collected. In this respect, it is of great value to include qualitative data as well as figures. These data refer not only to the context described above, but also to accounts obtained from drug users, and other significant informants in contact with them, concerning their perceptions of the drug scene, beliefs about drug use and drug problems, attitudes towards treatment, and so on. This enables the statistical data to be applied to policies and interventions in more appropriate and relevant fashion.

3.2 Confidentiality and referral

The report must respect the agreements reached with the responding individuals and agencies regarding confidentiality. Ordinarily, in a population survey report, there will be no need to identify individuals, but results analysed for separate regions or subpopulations may create some difficulties, like identification of these as drug regions or populations. If these results are considered useful, they need to be presented but taking the relevant people into confidence on this issue is desirable.

The issue of confidentiality is even more crucial in studies using information from key individuals and agencies. Whether these individuals and agencies would agree to be identified in the report, should be clearly discussed at the beginning of the study. Any promise of confidentiality, must be respected in all reports. If there is an overriding reason for findings from an agency to be identified separately, the reasons must be communicated to the agency and a fresh negotiated agreement reached.

These issues are not only important as ethical considerations, but may also be crucial for maintaining a close working alliance with key individuals and agencies for further epidemiological studies.

3.3 Presentation

The way of presenting information in the report including the use of tables and charts should be guided by the target readership. Charts, diagrams and other visual displays are preferable for all readers but they often can present only the summary data. Detailed results need tables, but complex tables must be avoided except for serious scientific publications.

An attempt must be made to present broad and general findings visually and detailed results in tabular form. The text should only highlight, interpret and discuss the results presented rather than repeat what is already available in charts and tables.

While the above scheme may work well for quantitative results, variations need to be made for qualitative data. Presentation of the latter often requires textual description, but even here, an attempt should be made to identify information that can be categorised and presented in a tabular or chart format for easier comprehension and better retention.

4. Application of the Results

There are several issues related to the role of the researcher in facilitating the use of research results. For optimal utilisation of research into policy it may be necessary for researchers and academicians to focus on priority drug problems in the country; for research managers to advocate, promote and support development and drug abuse epidemiology; for policy makers and high level managers to better appreciate what drug epidemiology is and use it to improve decision-making; and for health workers, service providers and mid-level managers to better develop a capacity for critical thinking and use epidemiological information in problem solving.

The production of reports should take into consideration the information required by the decision maker. For each type of decision a different set of information may be required. For example, allocating resources for treatment services may need information on a number of people using substances in a dependent or harmful way, the prevalence of health and social adverse consequences related to this practice (i.e. cirrhosis, cardiac conditions, suicide, HIV etc.) by regions. But if the focus is on the prevention of the problem in relatively untouched populations, the variable for the study should be degree of experimentation and use of drugs. Sometimes adequate data are available but frequently these are not analysed or interpreted to provide meaningful information to be used in decision-making.

The type of information that may be needed also depends on the existing state of knowledge of a problem. If, for example, there is a suspicion that the use of a new substance is expanding, (i.e. MDMA "ecstasy" in formerly non using groups), we need to know what is the problem; if a problem exists but there is little information about it, (i.e. reasons for the epidemic increase of the use of stimulants and sources of acquisition), we need to know what are the characteristics of the problem; if there is some evidence that certain factors may be contributing to the problem (i.e. increased availability of cocaine) and others may be the result of the problem (i.e. normalisation of use or social tolerance toward users), the research project should be directed to learn more about the relationship between the characteristics associated with the problem; if association has been established then the research should address the issue of cause or contribution, (i.e. study of risk and protective factors and consequences).

Applicability is enhanced if the researcher can identify areas of concern, prioritise the problems, formulate a research protocol that addresses the concerns of decision makers, and present the results answering to these concerns, considering degree of familiarity of the decision maker with the research process. The part of the report that includes the recommendations is crucial, they should follow logically from the discussion of the findings. They may be summarised according to the groups toward which they are directed. For example, "policy makers" - health, transportation, social welfare, labour, commerce, etc. - managers, staff, community. It is useful to add to the findings of the study being reported, supportive information from other sources and available information on other related factors. They should be discussed with all the persons involved, before the final report is finished. A summary of main recommendations may be added to the summary.

Pathmanathan (1992), suggests the use of techniques of social marketing to promote the use of research findings. According to him marketing in a research institute has four major elements: i. analysing the target group and "product"; ii. planning the development of the "product", defining its value, promotion and distribution; iii. organising strategies to link researchers with potential research users and iv. controlling the demand of the product. The "product" might be the research results, the methods developed, the human sources trained, the recommendations or public policy implications. These "products" might vary for different potential users (i.e. funding agencies, universities, health managers, etc.). The demand of the "product" deals with the dissemination of results and the availability of reports for satisfying potential demand, this issues is often forgotten when planning a survey and estimating costs for funding purposes.

An important source of increasing awareness of a problem and support the need of trustable information is communicating results to media. As in many cases the interests of the media (insure audience) and of researchers (objectively communicate findings) do not always match, it is advisable to prepare a written report in an adequate format for use by the mass media.

It is useful to draw a plan of action to ensure that the data do not end in a report with little or no impact on decision makers. Varkevisser et al., (1991) recommend the consideration of the following questions: *which recommendations can be implemented without further authorisation or extra support?; How can you proceed with the implementation?; for which recommendations is the support of the authorities required?; in what ways can you encourage this support?* The applicability of possible results and recommendations will greatly depend on factors like support from authorities, availability of resources and perception of the needs of data for making decisions. Thus it is useful to clarify the viewpoints of managers, health care workers and researchers in relation to the problem. When actions require planning by several parties, a workshop where parties can discuss the findings and alternatives can lead to commitment of the different parties to work together.

When participants are in direct positions of managerial responsibility, or higher level decision

makers have been involved, recommendations are more likely to be implemented soon after the studies are completed. Political acceptability of recommendations is also useful. If authorities invited share the interest and support recommendations, the chance that the results of the study can be implemented are increased.

5. Epidemiology and Public Health

Chapter 2 of this guide (Defining the Problem) discusses some of the reasons why an epidemiological inquiry may be initiated, reviews key drug abuse research questions and identifies methods appropriate for the investigation of specific questions. The remainder of this chapter illustrates how the information obtained from drug abuse epidemiology research can serve as a basis for community education and action, and program development; and, can contribute to specific public health objectives. By using the so-called "epidemiological triad" of agent, host and environment, it is possible to plan comprehensive public health actions. Using this paradigm the target might be defined as substance use, dependence, morbidity, mortality or social problems, where substance use plays an important role (i.e. cirrhosis, accidents, cancer, violence, etc.). By defining actions pertaining to the agent or substances, the host or individual user and the environment it is possible to link biomedical, clinical, epidemiological, social and services research findings. It is also possible to define actions at the different levels of prevention (primary, secondary or tertiary) and through the analysis of risks, suggest different actions in type or intensity, according to the level of risk or vulnerability in the individual.

Some examples are provided here on how, based on information from epidemiological surveys, public health actions may be planned for the three levels of prevention and the three elements of the "epidemiological triad".

Example I. Level: Agent/ primary prevention.

Aims: i. control of availability. and ii. reduction in the level of risk of the agent.

i. surveys are an invaluable tool for gaining knowledge on the regions of the country where different types of drugs are available and used. Persons interviewed may be asked to provide their perceived availability of substances, the occasions where different drugs have been offered to them, their knowledge on peer use, the places where they get the drugs, etc.

ii. an example of this type of contribution may be drawn from studies on special populations that inhalants in Mexico, by asking the users on type of substances used. It was possible to examine samples to track highly intoxicant components and regulate their distribution and eliminate from the mixtures sold in small outlets, that were the main source for the minors. These observations also lead to important biomedical and clinical research that

evaluated the psychotropic and toxic effect of various components and mixtures and to a regulation that prohibits that solvents are sold to underage youth.

Other contributions are the study of attitudes and use of beverages with low or non alcohol content, filter tipped cigarettes, etc.

Example II. Level: Host/primary prevention.

Aims: i. promotion of moderate drinking and of low risk; ii) prevention of risk of experimenting and using substances (tobacco and other drugs); iii) control of passive exposure to tobacco.

i. A basis for this intervention is the knowledge on patterns of drinking of different type of beverages and in different subgroups of the population, in different circumstances (i.e. while with children) and occasions (i.e. before driving or at work) drawn from epidemiological surveys. Other variables of interest are the degree of knowledge on alcohol metabolism, intoxication levels, levels of risks, norms and attitudes, social barriers to moderate drinking etc.

ii. Epidemiological surveys can provide information on the factors that differentiate users from non users, those that quit using after experimenting and those that continue using, those that turn to heavy or dysfunctional users. Risk factors (i.e. presence of alcohol in the family, history of conduct disorders) can be identified and their influence can be studied in presence of other individual or environmental factors.

iii. Surveys can also provide useful information on passive exposure to tobacco and norms and barriers toward the regulation aimed at providing safe places; degree of awareness of the risks and acceptability of imposing restrictions as forbidding tobacco use in public places.

In all three cases, surveys can also help to evaluate education campaigns and effect of regulations on knowledge (i.e. awareness of risks associated with different levels of alcohol exposure) attitudes (i.e. agreement on the benefits of restrictions) and behaviour (i.e. use of security belts, avoid drinking before or while driving).

Example III. Level: Host/secondary prevention.

Aim: Early identification and treatment, harm prevention.

Surveys can help identify individuals at risk due to their drinking habits at an early stage before they start to present problems, barriers for seeking help and knowledge of places where they can seek help.

Example IV. Level: Host/Tertiary prevention:

Aim: Treatment and rehabilitation, prevention of consequences.

Estimation of needs for planning of services is one of the important uses of Epidemiology. Complementary information on patterns of service utilisation, role of self help groups and other alternatives for treatment and specially the reasons for not using services, cultural barriers, accessibility, lack of information etc. may also be very useful in planning substance abuse services. Qualitative approaches aimed at studying hard to reach groups are specially useful for the study of users who do not attend treatment.

Example V. Level: Environment/primary/secondary prevention.

Aims: Strengthen social controls that limit use of tobacco and drugs. Modification of social norms that favour alcohol misuse.

Epidemiological Sociology (Dufour, 1995) has proved to be very useful in gaining knowledge about social norms and attitudes that influence behaviour and problems, an interesting example of this approach is the WHO Community Responses to Alcohol Related Problems (1981). By including in the study reasons for drinking, getting drunk or abstaining; quantity of alcohol that is acceptable for different groups of the population, mainly defined by age and sex; and for drinking in different circumstances (before driving, at home, after work, etc.) and by comparing responses given in different cultures (Roizen, 1981) it was possible to identify areas that deserved special attention for intervention.

Other examples are the questions used in the "Monitoring the Future Surveys" undertaken in the US (Johnston et al., 1995), and used also in other countries such as Mexico (Medina-Mora et al., 1995a) among students, that study social tolerance or peer approval toward use that have proven to have predictive value over experimentation and drug use. Variables that measure social acceptability or rejection of different type of users are also useful to assess social factors that limit or promote misuse.

Example VI. Level: Environment/tertiary prevention.

Aim: Strengthening of social networks for support of addicts and their families.

Qualitative studies that approach social networks can be very useful in the study of their role in supporting vulnerable groups specially spouses and other members of families of users, and thus used as a tool for treatment and rehabilitation.

6. Relevance of Data to Different Objectives

Different types of data are relevant to different objectives. For example, surveys of the knowledge and attitudes of school children about drugs may help to design prevention programmes, but they do not help plan services for narcotic addicts. The purposes for which information is collected, and the sorts of knowledge which are particularly important for those purposes may be summarised as follows:

- to describe the nature and extent of drug use:
  - incidence and prevalence;
  - types of drugs used, availability and sources;
  - profile of populations involved;
  - trends over time.

- to plan health and social services for drug problems:
  - number and type of existing services;
  - extent and nature of problem use and consequences;
  - pattern of risk-behaviours (injecting, sharing etc.),
  - patterns of help-seeking and service utilisation;
  - profiles of treated and untreated populations;
  - differentiation of range of needs and whether met.

- to develop prevention and education strategies:
  - current prevention resources and activities;
  - use patterns in the population and subgroups at higher risk;
  - knowledge and attitudes regarding drugs;
  - analytical epidemiology (aetiology and risk factors);
  - dynamics of drug initiation and continued use.

- to project future trends:
  - epidemic and econometric modelling;
  - early warning systems.

- to evaluate public health interventions:
  - process or outcome measures of treatment programmes;
  - changes in attitude, behaviour etc. in prevention programmes;
  - baseline measures or relevant measures in control groups;
  - short term and/or long term measures;
  - assessment of contribution of intervention(s) to changes.

7. The use of epidemiological data: some examples

The following illustrates some uses of epidemiological data.

7.1 Assessing and developing prevention programmes for young people.

Chapter 2 of this guide (Defining the Problem) introduces epidemiology as a tool for answering key questions related to drug abuse. A point is made that carefully planned epidemiological studies can provide a picture of the nature and extent of drug abuse in specific populations and can be used as a basis for developing drug abuse prevention intervention strategies and programs. Johnston (1991) describes how surveys designed to assess the nature and extent of drug abuse in special populations, such as students, can provide information useful to drug abuse prevention. Such studies can:

1. define the drug related problem that needs to be prevented;
2. indicate the ages at which such use is initiated or problems are occurring;
3. identify the subgroups of the population most at risk in terms of their demographic and lifestyle characteristics;
4. provide information on a changing backdrop against which the effects of a specific prevention efforts should be assessed;
5. identify certain key intervening variables such as attitudes and beliefs;
6. inform on behavioural and moral norms with regard to drug use among young people and other groups, that can be used in the prevention programs or massive campaigns;
7. evaluate the extent to which major classes of prevention programs are reaching targeted segments of the population and the subjective opinions of those populations as to the helpfulness and effects of the interventions;
8. provide a picture of the combined effectiveness of all forces in the society that tend to reduce drug use or abuse, including those that are planned programs, more spontaneous efforts of groups or individuals and other historical events.

While survey data can provide some information relevant for drug abuse prevention, a broader range of epidemiological studies and methodological approaches are necessary to investigate factors and processes associated with initiation and maintenance of drug use, and to evaluate the effectiveness of specific prevention interventions. The experience of the National Institute on Drug Abuse (NIDA) provides an example of how epidemiological research has been used to help practitioners in the United States plan more effective prevention programs based on research evidence about what works. The results of more than twenty years of research have helped to identify the important factors that put young people at risk for, or protect them from, drug abuse, and have helped to evaluate the effectiveness of various prevention approaches. Research has shown that no one program will eliminate all drug abuse. There are a variety of effective approaches to drug abuse prevention which focus on risk and preventive factors within the individual,

peer group, school, family and community. Experience indicates that drug abuse prevention efforts are most effective when they are comprehensive and multi-faceted, and when they focus on reducing the factors which place individuals at risk, and on strengthening factors which protect individuals against drug abuse. Effective prevention approaches are tailored to the needs of each at-risk target group and are designed with input from those groups (NIDA 1997).

To assist people working in prevention from communities throughout the United States, NIDA sponsored the National Conference on Drug Abuse Prevention Research: Putting Research to Work for the Community in September, 1996. This conference convened government officials, researchers, program planners, and community based practitioners from throughout the country. In conjunction with this effort, NIDA produced, Preventing Drug Use Among Children and Adolescents: A Research Based Guide (Sloboda and David 1997). The NIDA Guide was the result of collaboration involving NIDA staff, drug abuse prevention leaders, and NIDA-supported prevention scientists. Specific questions were solicited from State and local drug abuse prevention practitioners and key leaders in national prevention organisations. The answers were developed in consultation with prevention scientists.

The Guide is presented in question and answer format and provides an overview of the research on the origins and pathways of drug abuse, the basic principles derived from effective drug abuse prevention research, and the application of research results to the prevention of drug use among young people. The following principles for the prevention of drug use among children and adolescents have been derived from research in the United States (Sloboda and David 1997):

Prevention Programs should be designed to enhance "protective factors" and move toward reversing or reducing known "risk factors".
Prevention programs should target all forms of drug abuse, including the use of tobacco, alcohol, marijuana, and inhalants.
Prevention programs should include skills to resist drugs when offered, strengthen personal commitments against drug use, and increase social competency (e.g., in communications, peer relationships, self-efficacy, and assertiveness), in conjunction with reinforcement of attitudes against drug use.
Prevention programs for adolescents should include interactive methods, such as peer discussion groups, rather than didactic teaching techniques alone.
Prevention programs should include a parents or care givers component that reinforces what the children are learning.
Prevention programs should be long-term, over the school career with repeat interventions to reinforce the original prevention goals.
Family-focused prevention efforts have a greater impact than strategies that focus on parents only or children only.
Community programs that include media campaigns and policy changes, such as new regulations that restrict access to alcohol, tobacco, or other drugs, are more effective when they are

accompanied by school and family interventions.

Community programs need to strengthen norms against drug use in all drug abuse prevention settings, including the family, the school, and the community.
Schools offer opportunities to reach all populations and also serve as important settings for specific sub-populations at risk for drug abuse, such as children with behaviour problems or leaning disabilities, and those who are potential dropouts.
Prevention programming should be adapted to address the specific nature of the drug abuse problem in the local community.
The higher the level of risk of the target population, the more intensive the prevention effort must be and the earlier it must begin.
Prevention programs should be age-specific, developmentally appropriate, and culturally sensitive.
Effective prevention programs are cost effective. Resources spent on drug use prevention can serve to lower costs within communities for drug abuse treatment and counselling.

The publication of the Guide was followed by the development of a more detailed set of instructional materials derived from research findings, the Drug Abuse Prevention Research Dissemination and Applications (RDA) materials, which were designed to help practitioners plan and implement more effective prevention programs. The RDA materials provide practitioners with the information they need to prepare their communities for prevention programming and to select and implement drug abuse prevention strategies that effectively address the needs of their local communities. The audience for theses documents includes prevention program administrators, prevention specialists, policy makers, community volunteers, community activists, parents, teachers, counsellors, and other individuals who have an interest in drug abuse and its prevention (NIDA 1997).

7.2 Developing interventions in the workplace.

Another example of utilisation of results from epidemiological surveys comes from a joint ILO/ WHO/ UNDCP multinational project (Fauske, 1993). It is based in two research results: i. The observation that most persons with drug/abuse dependence were in fact employed (Robins, 1992, Medina-Mora et al., 1991), turned the attention to the need of conducting prevention/intervention research in the work place. ii. The evidence from various surveys suggest that the bulk of many harmful consequences occur among moderate users (Makela, 1992).

This project using the red light paradigm is aimed at keeping the non-risk workers, (safe patterns of alcohol use green zone), at this level, identifying workers at risk (yellow zone) and modifying their patterns of use, and channelizing heavy users (red zone) to treatment. One of the main components of the project is the participation of the companies human resources department. The research orientation is decided by the decision maker and the researcher acts as consultant and advisor to the manager. This model has ensured the appropriation of the prevention program by companies.

8. Possible misinterpretation and misuse of epidemiological data

A final note is included considering that caution must be kept in mind to avoid misinterpretation of findings and possible misuses, when data are used by decision makers or other persons not familiar with the technical aspects of this work. This is mostly unintended, but sometimes can be deliberate towards achieving specific aims.

Interpretation of epidemiological data must consider issues associated with the extent of the problem, its significance in relation to other public health problems and its vulnerability or degree to which it can be modified with public health policy.

One common misinterpretation is a poor understanding of the epidemiology of drug use, limiting its scope to the traditional model of infectious diseases, thus focusing on the control of the agent or drugs and on isolating the individual from the agent as the main goal. More appropriately, the model should focus on the interaction between an individual with varied degrees of vulnerability and the environment (Kozel et al., 1992), thus making more emphasis on demand reduction.

Data obtained from surveys can also be misused, often with important implications. Common examples of this include:

i. oversimplifying the problem, considering a general category "drugs" when there are important differences between drugs, their effects and characteristics of users;
ii. not distinguishing between use and dependence and thus incorrectly characterising the nature of the problem and limiting the value of the data for needs assessment and targeting of interventions;
iii. failing to understand the concept of risk and attributing casual links between variables;
iv. generalising results to a different setting or group of the population;
v. using instruments or definitions without assessing cultural appropriateness and introducing adaptations, as necessary;
vi. attributing significance to changes in prevalence rates without considering confidence intervals or using significance tests;

9. Conclusion

Reporting and application of results are crucial steps in any epidemiological research. Close attention to these right from the beginning of the research proposal is needed to ensure that the effort, time and money used in the research contributes meaningfully to the development of sound public health action and to the furtherance of our scientific knowledge base.

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CHAPTER 10

FIELD ASSESSMENT OF MODEL CORE QUESTIONNAIRE

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1. Introduction and background on the NIDA/WHO Expert Revision

This chapter provides a detailed description of the field assessment project and research protocol used to produce a cross-culturally applicable model core questionnaire suitable for use in drug abuse epidemiology research. The model questionnaire is intended to be a multi-purpose instrument including core standardised questions relating to drug use that can be administered with minimal training and supervision to a range of different target populations, and which can be utilised in both interviewer administered and self administered formats (see Annexes 7 and 8). The questionnaire is not a diagnostic instrument. This protocol and summary findings from the field assessment are directly applicable to the development of parallel questionnaires for other language and cultural groups. The primary objective of this project has been to assess the cross cultural utility of the draft model core questionnaire that was compiled according to the specifications of the Initial Consultation Group for the Revision of the WHO Manuals on Drug Abuse Epidemiology Project. Additional revisions were recommended by the field assessment site Principal Investigators during a field assessment preparation meeting, October, 1994. The field assessment focused on key cross-cultural issues related to questionnaire development such as: language, concepts conveyed, and topics covered. The field assessment at six sites (one in each of the six WHO regions) utilised systematically applied qualitative research methods.

The field assessment phase described here is one part of the NIDA/WHO expert revision of the WHO Offset Publications on drug abuse epidemiology, originally produced in 1980 and 1981. An Initial Consultation Group (ICG) of international experts in drug abuse epidemiology was convened in November, 1992, to review existing publications and develop recommendations for the implementation of the revision project. The ICG recommended the creation of a consolidated manual, to include detailed guidelines for the compilation of a model core questionnaires for drug abuse data collection. The specifications for the proposed questionnaire were constructed to be consistent with the standards for drug abuse information reporting set by the United Nations International Drug Abuse Assessment System (IDAAS). The key agreements and recommendations emerging from the ICG are as follows:

- It was agreed that valid substance abuse questionnaires already exist and many questions have been used in different cultural settings as, for example, in studies conducted in the United States, Mexico, and by the Pompidou Group in Europe. The questionnaires used in these studies were reviewed by the group and it was recommended that the final document should utilise the existing technology and not attempt to develop new questions.

- It was recommended that questions be identified from the existing valid questionnaires and complied into a model "core" questionnaire which would cover areas identified as key for assessment by the ICG. The ICG provided guidelines for the compilation (including content, structure, and formats) of the model questionnaire. It was agreed that the model questionnaire should be developed so that it could be utilised in both interviewer administered and self

administered formats. It was further recommended that the simple question format utilised in the questionnaire presented/ in the original WHO Offset Publication 50 be retained.

- It was stressed that the questionnaire should be clearly identified as a "model" which, if utilised appropriately, could generate data consistent with current recognised international standards. In order for the model questionnaire to be utilised appropriately, the ICG stressed that it must be carefully reviewed and evaluated relative to the specific social and cultural context in which it would be used, with adaptations incorporated where necessary.

- It was recommended that a field assessment be used to illustrate the process of review and revision involved in questionnaire adaptation. This would include the identification of specific questions and topical areas which the field assessment indicates may require local adaptation.

2. Design Elements for the Field Assessment Project

The primary objective of the field assessment was to evaluate the cross cultural utility of the draft model core questionnaire compiled according to the recommendations of the I CG. The cross-cultural field assessments were subsequently designed to meet the conditions and requirements set out by the ICG. The group designing the field assessment created the following set of objectives to achieve these goals.

i) Assess the linguistic and cultural applicability of the core questions for local language and cultural variation

Linguistic differences (problems in translation and conceptual transfer between cultures) constitute some of the primary cross-cultural barriers to adoption of a core questionnaire. The primary method used to meet this technological transfer objective is the translation/back translation protocol. It was used to assess each question and to locate specific conceptual problems in the questionnaires. Each field site identified questions which posed problems in the process of translation and noted the type and severity of translation problems encountered. This allowed cross-site comparisons to be made for each core question.

ii) Identify potentially threatening questions and potentially culturally sensitive questions

Since drug use and drug abuse are morally and legally interdicted in many cultures, it was necessary to assess the questions in the core questionnaire for their sensitivity to data distortion stemming from cultural barriers to accurately answering the questions. Focus group interviews were used to identify sensitive or threatening questions, in order to determine how the wording could be

made less threatening, or to identify other approaches to collecting this type of data. The recommendations were designed to identify the differences between misinformation resulting from question ambiguity, which may be identified during the translation process, as compared with deliberately false answers caused by sensitive or threatening questions, which were identified through qualitative cultural analysis of the focus group interview data.

iii) Identify whether and to what extent the questions address the range of drugs and drug using behaviours specific to the social and cultural context.

Changing patterns and trends in local drug use have been identified world-wide. It was felt that some mechanism should be included in the field assessment to determine the most current configuration of drug use, and the most current information on attitudes towards illicit drugs. Free listing data collection and focus group interviews were used to collect the data needed to meet this objective. These two qualitative techniques allowed the sites to conduct a cultural domain exploration of the types and the range of drug use in the local cultures, and to determine the need for extended coverage of the drugs surveyed in the core questionnaire.

iv) Assist in the development of annotations for the questionnaires, particularly regarding specific issues and topical areas which may require local adaptations

The overall field assessment data collection process was designed to collect direct, culturally sensitive, data that would allow field based examples of both cross-cultural problems and cross-culturally comparable questions to be identified and presented as a guideline for the use of the core questionnaire. Focus group data, the methodological questionnaire, and the field assessment summary reports (including translation issues, results of focus group, and free listings) were used to construct the annotations.

v) Obtain the input/recommendations from field investigators regarding methodological issues in the development of annotated model self administered and interviewer administered questionnaires

The Principal Investigators were chosen for their expertise in alcohol and drug research at both an international and local level. These individuals constituted an expert panel on the methodological issues associated with the construction of the model questionnaire. They were consequently asked to respond to methodological questions which arose during the development of the model core questionnaire, based on the field assessment data collected by their site, and their experience with constructing cross-culturally applicable epidemiological instruments.

3. Methodology

The cross-cultural field assessment of the core questionnaire required the use of several systematic qualitative data collection techniques. Research Centres in six culturally different locations (Egypt, Greece, India, Mexico, Malaysia and Zimbabwe) agreed to participate in the field assessment. The data provided by each site included: i. an initial information assessment that provided contextual information about the culture and drug use in the local area, ii. data collected through the translation/back translation protocol, iii. data collected using the freelisting protocol, iv. focus group interview data, and v. the Principal Investigator methodological questionnaire. This common format allowed for successful cross-site comparison of qualitative data, in addition to generating excellent data for individual site modification of the core questionnaire as a cross-culturally valid instrument.

3.1 Initial Information Assessment

Each field site was asked to provide descriptive information on the local area and country; and, a brief description of substances used and patterns of use within the country, drawing on existing sources of information such as government reports, research literature, and special studies such as the WHO Cultural Applicability Research (CAR) Project. The initial information assessment consisted of a secondary data and literature review that provided information about the demographics, cultural parameters, and key issues pertaining to drug abuse at the local site. This information was gathered and summarised prior to or during the process of translation and served as a useful background for the process of translating and adapting the questions. These data provided important cross-cultural, contextual, and comparative information for the field assessment. Field sites were also asked to provide a brief description of official social policies related to the use of drugs, (i.e., which are legal, illegal, restricted by age or other condition) and a brief description of cultural values associated with each drug (a positive or negative view of use). A standard reporting format was utilised to facilitate the consistency of reporting this information across the six field sites. The completed initial assessments provided a standardised framework across the participating sites for the interpretation and comparison of findings.

3.2 Translation/Back Translation

Each site translated the self administered and interviewer administered core questionnaires into one major local language. Standard translation/back translation methods were used to produce an acceptable language version of the questionnaires. A small systematic data collection module was added to record the type and severity of translation problems encountered. This information was used to identify the cross-cultural, or cumulative, issues relating to the translation process and the linguistic issues relating to the core questionnaire, as well as site specific issues. The original questions for the English version of the questionnaire were chosen to be as simple, clear, and concise

as possible, based on the use of questions that had previously been used in studies in which they had been tested for validity and reliability.

One of the difficult issues that the translation protocol had to accommodate was the use of colloquial or specialised language in the original questionnaire. In some cases, linguistic research had to be conducted prior to the development of the translated instrument, to determine appropriate replacements in the second language for the colloquial terms, or for special terms used by sub-populations, such as local names for drugs. In a number of cases it was necessary to provide multiple terms or variants, to cover regional and/or dialectical differences in the words used in the questionnaire. Alternately, the colloquialisms were identified and replaced in the original questionnaire with terms that are more generally understood. These more generic terms could then be translated into the second language using generally understood terminology in that language. One note of caution to this approach is that it may make any prior validity and reliability studies on the original questionnaire invalid for purposes of comparison, since the original questionnaire has been modified. The protocol used for the translation/back translation process is included in Annex1.

3.3 Focus Groups

The focus group protocol, coupled with the focus group training in Athens, provided a standardised process for collecting and analysing interactive qualitative data at each of the sites. Several conditions related to the conduct of the focus groups were agreed upon by the Principle Investigators. Participants were given a copy of the translated Self Administered core questionnaire before the focus group discussions, so they could review it prior to the discussions. It was made clear to participants that they would not be asked to answer the questions in the questionnaire and that no information on their own use of substances would be collected, rather that they were helping to determine the cultural applicability of the questions. Appropriate flip charts/posters were prepared with the questions from the questionnaire sections, for use in the focus groups. This allowed the moderators to provide a point of reference for discussion on specific sections and specific questions, and it provided a reference for reading and reviewing questions for non-literate participants.

A minimum of six focus groups were conducted at each Centre, Each group included approximately 6-10 participants and lasted for approximately 2 hours. The Principle Investigator Group jointly designed the focus group questions to address the cross cultural applicability of the core questionnaires and to identity other issues related to the development of those instruments.

Focus Group discussions at each site were lead by a moderator and followed the content of the Focus Groups Guide Questions developed for the project. During the Athens Field Assessment Training Meeting, the Principle Investigators agreed to select comparable focus groups and to recruit individuals for those groups so that there would be at least one group discussion at each site where the participants were drawn from the following groups of respondents:

- health and social research professionals
- youth and adolescents
- members of the culture who have or have had alcohol or drug problems or who use alcohol or other drugs heavily
- treatment providers

The common focus group protocol used at all sites is provided in Annex 1 at the end of this chapter. Annex 1 also contains the focus group guide questions and examples of data collection forms.

3.4 Free Listings

The free listing data collection method is used in many different contexts where it is important to rapidly explore the content, limits, and the meaning of an important cultural domain, such as drug use in a particular culture. The data can be collected either as an interview, or as a self-administered listing exercise.

In the case of this study, it was important to do a site by site assessment of the types of drugs that were in use in each location, and to explore the meaning of those drugs in the local culture. Each site was requested to follow a systematic free listing protocol, as described in Annex 2. The focus group participants were asked to complete a free listing exercise as one special part of the data collection process, as a "warm-up" exercise prior to the focus group discussion. This exercise used a simple question format, such as "What are all of the types of drugs that are used in this region" The consolidated data, or listings, from each of the informants allows a thorough exploration of the elements (both the most salient drugs and the variety of drugs) in this cultural domain. These listings often identify new substances that are being abused, as well as providing an excellent, linguistically relevant, set of drugs that can be included in epidemiological surveys. The free listing protocol used at each of the Centres is in Annex 2 of this chapter.

3.5 Methodological Questions

The Principal Investigators were asked to respond to a series of methodological questions which arose during the process of developing the model core questionnaires. In addition, some of these questions were embedded in the focus group data collection and analysis, as well. The questionnaire contained a series of open ended questions in which the P.I. was asked to discuss the methodological issues for their culture and research area, and to provide a rationale for their recommendations. The questions were divided into general issues and section specific questions for the core instrument. These questions are included in Annex 3.

4. Multi-site Co-ordination

The successful application of these methods required both support to individual sites, and cross-site co-ordination. This co-ordination was undertaken by PSA/WHO Geneva staff. The process included i. establishing common personnel requirements, ii. cross site co-ordination, and iii. the implementation of quality control mechanisms. It was recommend that each site select appropriate personnel, in addition to the Principal Investigator, including one or more focus group moderators (one may be the Principal Investigator), up to four bilingual translators, and a social scientist for consultation in qualitative analyses.

The field testing was managed and co-ordinated at two levels. At the country level, the Principal Investigator was responsible for the implementation of all the activities and the overall supervision of the project. The Principal Investigator also ensured adherence to the testing plan schedule. At an international level, WHO/PSA project staff liaised with the Principal Investigators in the participating centres to ensure that the scheduled activities were undertaken in a timely manner, by maintaining regular contact with field site Principal Investigators and responding to problems which arose.

WHO/PSA project staff periodically contacted field centres regarding the progress of the studies and problems encountered. To generate the highest possible quality data and to assure consistency in application of methods across sites, the data collection phase was preceded by a centralised 3 day training workshop for Principal Investigators. During the workshop, field centres discussed and agreed upon the use of common reporting formats to facilitate and standardise the reporting of information to enable systematic detailed comparison of results across sites.

5. Summary of Results from the Field Assessment Project.

The field assessment allowed the project team to evaluate all of the objectives set out for this project by the initial expert group and the field assessment group. It allowed the project to evaluate the cross-cultural applicability of the model core instrument. The appended annotated instruments (Annexes 6, 7 and 8) are the primary products of the combined expert group and field assessment process. These instruments provide the basic questions; note where local variability may improve the overall quality of the data; and provide examples of how changes can be made to the basic questions, along with the rationale for making those changes.

The majority of core questions do not pose cross cultural validity and reliability problems. Some questions are more appropriate in one form for some cultures, as opposed to another form for others, but remain solidly comparable. In a few cases, specific questions pose problems for some individual cultures that they do not pose for others. In the case where these questions are identified

as locally problematic, but broadly applicable, the field assessment process allowed reasonable substitution (or in some cases, elimination) for these questions. The following sections provide examples of the results of the field assessment, as reported by the six participating sites.

5.1 Translation/Back Translation Procedures

The translation/back translation process was successfully completed at all six sites and produced key information on the applicability of the core instruments. Several areas of translation difficulties or complexities were identified by at least half of the sites, while other areas were more strictly localised. In many cases, the problems were not in finding suitable words to translate from English to the local language, the problems were caused by differences in social conditions and structures (family, living arrangements), by local interpretations of words and phrases, or by the difference in attitudes towards providing certain types of information in the culture. The summary statement from the Greek site exemplifies the experience of most of the sites:

"The translation back translation process showed that there were problems in the applicability of certain terms and items in the Greek cultural context".

These difficulties included: the frequency questions (for example some sites proposed alternative coding frames for asking about the frequency of drug use based on the number of times a drug had been used rather than on the number of days); some questions relating to social relationships (in some countries the concept of "living together" is not recognised); and other socio-demographic questions such as those relating to education and occupation.. Other sites had similar findings, and at the same time, found that most of the questions and the translations went well and could be modified to accommodate the differences in cultural context.

In at least two cases, Malaysia and Mexico, one of the key translation problems was not the content of the questions, but their length and complexity once they had been translated. The resulting questions caused some confusion that could be eliminated by simplifying the question once it was translated. Some additional confusion was caused by some of the few remaining colloquialisms left in the English version. For example, the phrase "on the street" (in the context of where respondents were living) was not easily translated, even when the meaning was clear in English. In Malaysia, it was not possible to find generic terms for some social relationships, like spouse, and the term had to be translated into either husband (suami) or wife (isteri). It was also difficult to find some local equivalents of the drugs listed in the questionnaire. Another example of the concepts that are taken for granted in some cultures, but not of equal importance, or equal ease for translation, in others were found most frequently in the demographic section of the questionnaires. The Egyptian site noted that the ethnic minority groups in Egypt are very small, and are not a standard part of epidemiological surveys. They also noted the significant difference in attitude present in the construction of questions about alcohol, from the alcohol consuming cultures, compared with the

conditions that arise in Islamic countries where alcohol is forbidden. The wording of those questions, with the implied acceptance of alcohol as a legal substance, may cause some differences in the ways that the data are both collected and interpreted, cross-culturally. They also noted that, for local use, they had to eliminate the word "ever" because it can take on several different meaning when translated into Arabic. Translating the questions without the word caused no problems, since in Arabic one can deny or reject something in our language without using the word "ever".

The Indian site also noted some of the special difficulties of cross-cultural applicability of the demographic questions. They found problems with the list of types of residences that were provided, with some of the labels of relationships, and also with the question on age. This highlighted some of the differences found between literate and non-literate conditions. As the researchers state

"Nearly 50 percent of our people are illiterates and do not remember their date of birth. They may not even know their exact age. It is quite often experienced that they ask the interviewer to guess their age and record it. Thus, this the item may not elicit the right response".

This site also noted that even where the same word is used, such as school, it may not have the same meaning, or may be divided differently than assumed in the original questionnaire. In this case, school means the first 10 years of education, and College is reserved for education beyond that level. If someone is asked how many years of school they have completed, they may answer 10, and may fail to add the additional years of schooling that they received in College, thus providing an inaccurate picture of their educational achievement. This clearly illustrates the need for questions that are sensitive to local variations in the schooling/ education systems.

One of the common issues that were brought to light by the translation/back translation protocol were the "hidden assumptions" of the English version of the questionnaire. There are relatively standard measurements for alcoholic beverages in English speaking cultures. While some variation occurs, the size of containers, and the social processes for consuming drinks remain relatively comparable. In contrast, the Zimbabwe Centre noted that there was a serious problem with the question "how much did you drink", since: "it is difficult to measure how much we drink here especially if it is a local brew like Scud, as this is shared by several people from one cup when drinking". Sharing a continuous round of local brew cannot be calculated in the same way as pouring glasses from a pitcher as is a common drinking practice in the United States. Given the importance of these local brews, and the difference in their consumption compared with commercial or "clear beers". the site recommended that there be a distinction between these and other beverages, and that the measurement of consumption be modified to fit the type of information that individuals could provide about these drinking occasions.

Each site indicated that the translation/ back translation process went well. In most cases the translation problems were relatively minor, and could be accommodated by a localisation of terms, by an explanation of what was desired, or by modifying the instrument to fit local social conditions that were not anticipated in the English language versions of the questions.

5.2 Free listing

The free listing protocol produced both expected and unexpected results for the field sites. The expected results were the successful listing, linguistic exploration, and identification of the variety and range of drugs that were being used in the local culture. The unexpected results were the discovery of drugs and other substances that were not formerly identified by the field sites as having the potential for abuse, or substances that were not formerly identified as being in use in that culture. This turned out to be a highly efficient and effective method for rapidly assessing the nature and extent of drug use in the cultures. In some cases, the free listing exercise was important because it pointed out key linguistic differences between different segments of the society. In Malaysia and Egypt the researchers noted that the health professionals and those providing drug related services had some knowledge of both scientific and street names for drugs, while former and current drug users tended to only know the street names and could not distinguish the drugs they were using by the generic terms used in the survey instrument. This would lead to under-reporting of drug use if the street and the scientific names were not both provided in the survey instrument. This exercise was also useful in demonstrating differing levels of both exposure to drugs and drug terminology, and knowledge about those drugs in different segments of the population.

The free-listing protocol was also successful in providing important information for localising the questionnaires. As a brief example, the question asking about all alcoholic beverages produced the following list from a single focus group conducted among social and health professionals in Zimbabwe : scud (local brew), Don Juan, wines, chibuku (local brew), beers, 7 days (local brew), chihwani day (local brew), vinyu (local be originally from Mozambique), skokiyana (local brew), methylated spirit. Even a short analysis of these data points out the existence of two different alcohol beverage production and consumption systems (local versus wider commercial production), which leads to a clearer understanding of alcohol consumption in that culture. The same condition was also true of the other sites and allowed key substances (such as Beedi smoking in India) to make the questionnaire both more comprehensive and more sensitive to local cultural conditions.

5.3 Focus Group Data

The focus group data identified both the strengths and the weaknesses of the core questionnaire. This process allows the group to discuss, negotiate, and to arrive at either a strong or a weak consensus on the issues being explored. These discussions provided important additions to the free listing questions, provided linguistic explanations for the difficulties encountered in the

translation/back translation process, and provided additional evidence to support the methodological recommendations provided by the field site Principle Investigators.

One of the most thorough discussions carried out at each of the sites was related to the sensitivity of the questions in the questionnaire, both in terms of producing cultural embarrassment or discomfort, and in terms of the likelihood that people would not answer the question honestly. The Egyptian site reported on some extensive discussions regarding the place of alcohol use, and abuse, in an Islamic society, and the acceptability of some forms of recreational drug use at celebrations that would not otherwise be allowed. The Malaysia site provided the view that: The only major barrier (in using the questionnaire) was the whole focus of study, specifically to identify extent of illicit drug use. Because of the legal sanctions against illicit drug use, the issue of obtaining reliable information from respondents always pose as a potential conflict for the study. This has to be given considerable thought and attention in the design of the study. These examples help clarify some of the issues of both social embarrassment caused by some of the questions, as well as addressing the issue of reliability of the data. Another area of questioning that produced discussions of social reluctance to answer was in the area of the demographic question on marital status. One of the options is the phrase, "living as a couple. While some of the discussants felt this might be allowed, they also noted it was something that people preferred not to recognise formally, since it went against local religious custom. This type of response could consequently cause problems with the data collected in the instrument.

The focus groups were also very useful in determining where there might be confusion or ambiguity in the wording of the questions. For example, in Egypt the term "unpaid work" was felt to be potentially derogatory or negative towards people who provide critical support of the family, at home, but are unpaid. In another example, the Malaysian site was able to determine that the term "tranquillizer" was unknown in major segments of the drug using population, and the focus group respondents were not able to determine which local drugs, if any, fall into this category. Thus, questions either generically about tranquillisers, or about specific tranquilliser would be difficult to answer.

The focus groups also confirmed the difficulties that were uncovered in the translation/back translation protocol, in terms of the variations in housing and social relationship categories, problems with age determination, ethnic group labels and descriptions, issues on the necessary labels for standard sized beverage containers, and even problems with the listing for the sizes of towns and cities in the instruments. They noted the need to simplify some of the questions, and noted a number of issues (lifetime use, social consequences of use, and cultural values and rationales for use, in particular) that they felt should be added to the core instrument. The priority placed on including these issues varied from site to site and in some cases from focus group to focus groups. These discussion were particularly valuable in producing the annotations for the core questionnaire. Whilst standardised questions across countries and cultures are highly desirable to enable comparability, the

questions must be sensitive to local variations. Focus groups are one way in which local definitions and coding frames can be constructed.

5.4 Methodological Questionnaire

The results of the methodological questionnaire fall in the two categories of general issues and section specific issues. Within the general category, two questions were addressed. The first relates to the collection of data on the frequency of drug use, and the second requests recommendations for questions of local importance not listed in the core questionnaire, which would be important to add for research in the local cultures.

The cross cultural differences in the way that time is understood and described in various languages and cultures caused differences in the preferences at each site on the way the standard question requesting information on the frequency of use of drugs is worded. In some groups, it is clearer to the individual to ask the number of "times" drugs have been used, in others, the number of "occasions" drugs have been used in the past thirty days. This issue is complicated by the difference in preference to use 30 days, versus one month as the best frame of reference for recent drug use. These preference fall in at least four combinations: occasions in the past 30 days versus the past month, and times in the past 30 days versus past month. The overall cross-site assessment of these differences is that any of the four combinations provides sufficiently equivalent information to allow a judgement to be made in relation to the frequency of drug use in each particular culture, and that the actual format used in one culture is dependent on the social usage of these time frames.

The field assessment centres recommended the addition of a number of questions to the core interview. These fell into several categories. The first was some form of question on lifetime use, or lifetime frequency of use of each drug. This question was recommended in order to distinguish between individuals who are temporary experimenters from those who have a longer and more severe pattern of drug use. A question on the age of first use was included in the model core questionnaire, however this does not provide information on continuity of use or pattern of use since that first use. Other sites recommended the addition of questions that explored the motivation for drug use, again with the rationale that it would be important to distinguish infrequent and experimental users from those who have a more severe dependence on drugs. It was also felt at several sites that it was important to be able to distinguish between the non-medical use of prescribed or medically available drugs, from the use of illegal or interdicted drugs in that culture. This is further complicated by the fact that in some countries, "prescription" drugs are often sold without prescriptions. At least two of the sites felt that it would be important to include questions in the core questionnaire that gather data on the perceptions and attitudes of the respondents to drugs and drug issues, and to add a small section on the consequences of drug use, in order to provide information for drug policy development for the nation. While the recommendations for the wording of these questions varied by site, the rationales for including each of these areas of information in the

core questionnaire, or certainly in the final questionnaire developed for each site, were uniform in their justification of the importance of this type of information being asked in epidemiological surveys.

The section specific recommendations were more diverse from site to site, than the general recommendations, often reflecting local concerns and priorities. There were a number of issues raised including: the diversity of use, attitudes towards use, consequences of use, and legal processes in the local cultures. Most of these issues were appropriately accommodated through translation, and through the ability of each centre to interpret the research findings in a way that made them cross-culturally applicable. The following information provides some examples of the section by section recommendations.

The demographic section produced by far the most common and most difficult issues for cross-cultural applicability. The differences centred on core cultural processes that, by their very nature are highly diverse. These include local categories for educational attainment, methods for reporting age, occupational categories, residence patterns, issues about ethnic identification and gender identification, as well as marital (or family) status. A small number of examples are helpful. In terms of residence, one site noted, "In the response set for the item "Where do you presently live (most of the last 12 months)?" the item hut or shack (temporary dwelling) is important" to capture information that is appropriate for rural or low socio-economic population.

The Mexican site noted that "the questions on residence lacks options such as shelters or street" which are often important in urban settings. For several sites, it was felt that asking respondents about illegal income was threatening, and for others, any requests for information on income of any sort were problematic. There were also a number of occupational categories that were recommended for inclusion in the questionnaire. Since these occupations have a strong relationship to socio-economic status, this type of addition may provide a significant improvement in the data base, if they are accommodated.

There were also recommendations for additions to the demographic section. At least two sites recommending adding additional information on respondents living arrangements, both in terms of the number and the social relationships to the respondents (i.e., number of people respondent lives with, and the numbers who are family, etc.). At least one site recommended adding a question to identify the respondents religion, and another recommended adding a question on the number of rooms in the respondents home (again as a proxy for socio-economic status).

The sites noted that the primary list of drugs found in the questionnaire were focused on those for which there is a significant level of international trafficking, and that many of those drugs are found in very low percentages in the local culture. While there was strong agreement that the so called "international drugs" should be surveyed, it was also noted that each of the sites should add locally significant elements of drug use as well, both to capture local use patterns, and to suggest

forms of use that may be present in other countries, but are not captured by the current lists. Some local examples of substances and behaviours recommended for inclusion were: betel nut chewing, snake bite addictions, and Beedi cigarettes, to name a few. In most cases this information can be gathered by adding locally relevant drugs to the questionnaire.

As a second issue, almost all of the sites made recommendations to modify the language used in the questionnaire in regard to the local cultural differences in prescription versus non-prescription use of drugs, and the illegal versus legal use of drugs. There are significant differences among the sites in terms of the drugs that are legal and those that are interdicted for use. In some cases, alcohol is legal, and in others it is not, as one example. And there is the problem of "quasi legal versus legal or illegal drugs". In some cases there are laws that restrict the use of substances, most often plants such as ganga or hallucinogenic mushrooms, but there is such an extensive local history of use of these substances that they become defacto legal substances in some social settings. Finally, there is extensive variation in the types of control that are placed on the distribution of pharmaceuticals in each area. Many of these manufactured drugs have both medical uses, and non-medical abuses. The core questionnaire attempts to capture both the non-medical uses of legal drugs, and the illegal uses of interdicted drugs. In some cases, the cross-cultural variation at the various sites necessitates locally specific wording to accomplish this task. For example, one site noted, "In our country, "over-the-counter drug" is a difficult concept. A sizeable number of prescription drugs (like antibiotics, tranquillisers, smooth muscle-relaxants) are sold without doctors prescriptions. Because of the ignorance of people, and poor enforcement of laws related to drug sales, it is difficult to differentiate over the counter drugs and prescription drugs. Another site reported "All legal drugs (inclusive of controlled drugs) are available over the counter. Thus it is necessary to specify the types of drugs being referred to". However, in general the use of culturally appropriate translation protocols were highly successful in overcoming these issues and allowed the field sites to produce appropriate core questionnaires.

6. Conclusions

This project included the use of four qualitative research techniques for the investigation of the cross-cultural applicability of the core epidemiological questionnaire recommended by this study. The four methods (translation/back translation with assessment, free listing, focus group interviews, and qualitative methodological questionnaires) complement each other and provide both overlapping, and unique data sets. The overlap was a deliberate and successful attempt to "triangulate" the key issues and findings. This is one form of qualitative research reliability and validity testing. In the case of this project, the triangulation provided in depth confirmation of the primary findings from at least three methodological approaches in the course of the project. At the same time, each method covered sufficiently unique information that the overall coverage of all of the key issues was much broader than would have been possible using only one of the research techniques.

The final results of the cross cultural applicability study were incorporated into the questionnaire and associated annotations. However, the process itself has proven to be highly successful in producing a standardised, cross-culturally comparable, drug and alcohol epidemiological survey questionnaire that can also be successfully made appropriate for local conditions that may not apply internationally, but are very important for the development of appropriate drug and alcohol policy. This combination of global and local applicability make the overall process, in both its past and future applications, a success.

ANNEX 1

TRANSLATION/BACK TRANSLATION PROTOCOL

Procedures for Translation

The ideal situation is to have a minimum of two individuals independently complete the original translation of the questionnaire into the second language. Each translator should have appropriate knowledge of the group or population who are to be asked the questions in the questionnaires (e.g. children of certain ages, adults, people from sub-groups within the culture, or a broad general audience), to increase the probability that the language level (reading or interview vocabulary) used in the questionnaire will match closely with the language level in the targeted group.

During the translation process, the translators should record any difficulties they had in finding equivalent concepts or words for each question; they should record the fact that no problems were encountered for specific questions as well. The translators should also record each instance where there were alternative choices for a word or phrase, and a brief reason for their choice, over the other choices.

Once the questionnaires have been independently translated, they were exchanged, so that each translator has the opportunity to review the other translations. Either one member of the group, or the whole group should summarise the issues discovered in the translation process. This initial translation summary should identify each question, or part of a question where there were differences in word choice or structural elements in each of the questionnaires. At this point the translators should meet in a group and discuss the areas of difference. The purpose of this meeting is to determine the best consensual agreement on the wording for each question. This meeting also provides the opportunity to identify any significant cultural conditions that would prevent individuals from answering the questions in a meaningful way.

5.1 Translation/Back Translation ProceduresThe translation/back translation process was successfully compleor back translation is identical to the model for translation from the original language. Two or more people (who did not participate in the original translation) independently translate the instrument from the second language back to the first.

After the back translators independently translate the instrument, differences in wording among the translations should be recorded and discussed, to determine if the versions are significantly different in meaning when compared with the original wording.

Once the differences are discussed and the appropriate wording of the back translation

agreed upon, the bilingual-bicultural panel should be reconvened. In this session, the panel members should compare the original questionnaire with the back translated questionnaire. If significant differences in wording for a particular question have surfaced through this process, then the translation has probably altered the meaning of the question beyond acceptable variation. It is not unusual for most of the questions to be stable in the two languages, with a small number showing problems of varying degrees. These problem questions can be dealt with independently through either elimination, if that is feasible, or through additional attempts at translation and back translation until a successful transfer of meaning is achieved.

ANNEX 2

FOCUS GROUP RESEARCH PROTOCOL

Complete focus group data collection involves three primary activity periods in which information should be recorded to assure the preservation and the highest quality analysis of the focus group interview data. The first includes the selection of the group members and the selection of the site for a focus group. The second is the focus group session, and the third consists of all of the post focus group endeavours (field notes, debriefing, data management). Proper data collection and data management at each stage helps assure accurate analysis of the data. Examples of data collection and focus group data management forms are included at the end of this annex. They are intended as illustrations or examples, and are not the only forms for this type of data collection and management and local adaptations may be necessary to improve the utility of these forms for use in the field assessment process.

i) Group participant identification activities

Prior to the formation of a focus group, it is very useful to record (and later analyse) focus group participant lists. These data include basic demographic information about the potential and actual participants, how they were contacted, and their reaction to the invitation to participate. This information acts as a quality control data set, as well as identifying any problems that arise when certain population segments might be either over-represented or missing from the focus group participant lists. The primary areas for both process and evaluation data collection include:

- a contact list that lists the individuals contacted about the group, and the rationale for the selection of each potential participant. This information can be recorded in the **Pre-Session Contact Log**, Part 1;

- a log of all communications with the individuals on the initial contact list, including their response to the contact. This information is recorded in the **Pre-Session Contact Log**, Part 2;

- a preliminary participant list, including key characteristics which lead to an individual's selection for group. This information is used for reminders and follow up contacts, and to provide the moderators with a list of individuals who will be attending the focus group. This information is recorded on the **Initial Participant List**.

ii) Location development activities

The quality and the conditions that exist within the space that is used for the focus group can

have either a positive or deleterious effect on its success. Projects normally record data about the site to provide both quality control information and to record any problems with the data collection that might be caused by the physical environment. Key issues for the choice of a research location include the following:

- Selecting a location that is appropriate for high quality sound recording and comfortable interviewing. Information about the location is recorded in the **Location Record**. This provides the moderators with valuable information to help them design the proper setting for the interview in that location.

- It is also necessary to assure that there will be no interference from external activities at the time of the focus group. Noisy activities in the same building or outside the room, as well as interruptions from outsiders can make recording during the focus group either difficult or impossible.

iii) Focus Group Data Recording Activities

The actual interviews must be either audio or video recorded for analysis. In addition, it is valuable to record ancillary information about the focus group process, such as speaker information, overall quality of the interview, etc.. The following information is normally collected for each focus group:

- a record of all focus group participants; including names, addresses, note late arrivals, note relationships to other participants, etc. This information is recorded in the **Participant Log for Focus Group Session**. Some of the information for this form can be collected directly from each of the participants when they complete the **Focus Group Participant Form** at the end of the focus group session. However, the additional comments made by the moderator about each person's participation can be very important information about the focus group which will assist in the analysis of the data.

- a focus group session log for each focus group which includes the start time, a list of questions asked, notes of the time when each major question is asked, and a record of major probe questions used. In addition, the moderator should sketch actual arrangement (physical location) of participants in the session. All of this data can be recorded in the **Post Session Field Note Log**.

- The entire focus group session should be audio-recorded from start to finish. It is best to use at least two tape recorders at all times, to avoid loss of data.

- It is very useful to have an assistant moderator take notes during the session. These include sequential notes on who is speaking, notes of questions for the moderator to follow-up later in the session, notes on the "tone" of the session and any problem areas that occur and what their

resolution or lack of resolution were.

- The focus group is conducted according to a set of Guide Questions. The questions used in the field assessment are included at the end of this annex. They are intended as illustrative examples of the type of questions that can be asked.

Each guide question has a number of probes for eliciting the required information. The early questions are used to introduce the subject and to provide some useful contextual information. Subsequent questions allow for an in depth exploration of the subject.

iv. Post-Session Activities

To assure that the final analysis is appropriate to the subject matter and to the quality of each of the focus groups, the following set of information that should be recorded as part of the data collection activities following each focus group:

- The moderator should record a set of post focus group session notes either as individual notes from the moderator and assistant, or as an audio recording of a post-session debriefing on the focus group. These notes should include an overall assessment of the session, its strengths and weaknesses, notes on key issues that were raised, notes on potential cultural domains to explore with further sessions and one-on-one interviews, as well as notes about individual participants and their contributions.

- Each tape recorded during the session should be marked with appropriate identification information (date, place, moderator, interview, etc.) and logged in the **Master Log - Focus Group Tapes**. It is highly recommended that each tape be duplicated to prevent loss of data.

- The moderator should collect all of the **Focus Group Participant Forms** from participants.

- The ideal circumstance is to have the moderator and any other researchers present complete a post session debriefing and record any potentially useful information about the session. This information can be recorded in the **Post Session Field Note Log**.

- The audio tapes should be transcribed as soon as possible after the session, so that the moderator can help resolve any problem areas. All of the information about the audio tapes should be recorded on the **Focus Group Data Management Check List**.

- Finally, we have found it useful to maintain a master log of all of the focus sessions conducted. It makes it easier to locate the information for a particular session. This information is maintained on the **Focus Group Master Log**.

Models for each of the above data collection forms are attached at the end of this annex.

The following section contains the actual focus group questions and question guide used at each of the Field Assessment sites (after suitable translation) for this study.

FOCUS GROUPS GUIDE QUESTIONS

The following questions were used in the field assessment. They are intended as illustrative examples theses focus group guide questions relate to the model core questionnaire.

TOPIC I

We are trying to develop a set of questions that will help us understand drug use and drug abuse in this society.

Would you please tell us about all of the different ways that drugs are used in this society?

What are the illegal and the legal uses of drugs?

Who uses drugs and why do they use them?

QUESTIONS IN THE NEXT TWO SECTIONS ARE ASSISTED BY HAVING LARGE POSTERS, FLIP-CHARTS OR OVERHEADS LISTING THE QUESTIONS FOR EACH SECTION SO THAT PARTICIPANTS CAN REFER TO THE ACTUAL QUESTIONS DURING DISCUSSIONS. MODERATORS SHOULD ALSO READ OUT EACH OF THE QUESTIONS TO ENSURE THAT ALL PARTICIPANTS, INCLUDING THOSE WITH POOR LITERACY, UNDERSTAND THE QUESTIONS. PROBE QUESTIONS SHOULD BE USED FOR EACH OF THE MODEL QUESTIONNAIRE SECTIONS.

TOPIC II

What are the barriers that might make it difficult for people to answer or might make people not want to answer the questions in our questionnaire?

Probes:

Would any of these questions (in this section) offend people? If so which questions and why?

Are any of these questions (in this section) asked in the wrong way? If so which questions and why?

Are any of these questions ambiguous (i.e. they could be answered in more than one way)?

If so, what are the different ways they could be answered that would cause confusion about them?

Are any of these questions confusing? If so, which ones?

TOPIC III

In some cases, it may be difficult for people to honestly answer the questions we want to ask about drug use.

We would like for each of you to tell us the types of questions that you feel people will have a difficult time answering honestly about drug use in the society.

Probes:

Are there types of questions that people are likely to lie about?

Why will they lie about these subjects?

Are there types of information that people are likely to exaggerate, and why?

Are there types of information that people are likely to forget to tell us about, and why?

Are there types of information that people are going to be embarrassed to talk about, and why?

Are there realistic dangers of legal sanctions for any behaviours subjects could report on the survey?

The focus groups were successfully conducted at each of the six sites, using this protocol and the question guide, above. This data was analysed using standard qualitative analysis processes, and reporting, in accordance with the format established for the project (described below). Collecting data from these specific groups allowed the researchers to conduct a direct comparison of the focus group results across the six sites. In addition, it was decided that each site could select two additional target groups for focus group interviews. These additional groups allowed the site to collect focus group data from additional populations that were especially important in that location. These groups were designed to be composed of individuals who would provide additional cultural information for the local site, but were not necessarily matched with groups at the other sites. These population groups included those based on: age gender, social class, ethnicity, religion, drug of choice or another specific population characteristic defined by the unique circumstances of the particular field site. All of the focus groups participants were asked to review the questionnaires for purposes of discussion, prior to the focus group interview.

FOCUS GROUP: PRE-SESSION CONTACT LOG

I. Part 1: Initial contact list, including rationale for selection

Name Phone Address
Rationale

1.
2.
3.
4.
5.
6.
7.
8.
9.

II. Part 2: Contact Log

Name Date(s) Contacted
Remarks

EXAMPLE ONLY

FOCUS GROUP: INITIAL PARTICIPANT LIST

Moderator: Session Date:

Participant List

Name Phone
Rationale

FOCUS GROUP: LOCATION RECORD

Moderator: Date:

Session Information:

a. session information (topic, general group information)

b. session date:

c. session location (exact location of both building and room)

d. sketch of physical space, with location of individual participants, moderator, and others noted.

FOCUS GROUP: PARTICIPANT LOG FOR FOCUS GROUP SESSION

Moderator: Session Date:

Participant List

Name Comments

1.
2.
3.
4.
5.

FOCUS GROUP PARTICIPANT FORM

Name
_____

Address
_____

Age_____
Sex_____

Relationship to any other member of focus group (relative, work, recreation, etc.:

Name: Type of Relationship:

Would you like to make any comments about the focus group?

FOCUS GROUP: POST SESSION FIELD NOTE LOG

Moderator: Date:

Session Location:

Session Participants:

Session Topics (attach question and probe sheet)

General impressions and overall assessment of the session:

Key issues that were raised:

Notes about individual participants and their contributions:

Notes on potential cultural domains to explore with further sessions and one on one interviews:

Comments and Speculations:

FOCUS GROUP: DATA MANAGEMENT CHECK LIST

Focus Group_____ Date Conducted_____ Location _____

Moderator _____Asst. Moderator _____

Description of Group:

Data List:

1. Tapes

Original Recordings Duplicates Date

a. microcassettes ID s _____
b. minicassettes ID s _____

2. Data Logs

Log Received Date

____Pre-Session Participant Log

____Focus Group Location Log

____Group Participant Log

____Post Session Field Note Log

____Observer field notes

3. Transcriptions

Tape Number Date Transcribed Comments

FOCUS GROUP: MASTER LOG -- FOCUS GROUP TAPE CASSETTES

Focus Group	Tape type	Tape

ANNEX 3

FREE LISTING PROTOCOL

1. Introduction

The free listing technique utilises the knowledge of cultural experts; individuals who have information about the particular area of culture under study. This protocol will allow each site to use exploratory ethnographic research techniques to compare alcohol and drug conditions in several cultures. The protocol can be carried out with a small number of respondents for each task. It is recommended that at least 15 individuals be asked to create these lists, for each important segment of the population that is to be studied (e.g. male and female, drug users, treatment personnel, etc.). However, the actual number of respondents will be limited by the size of the focus groups that are conducted at each site.

2. Free Listing Procedures

Each individual is asked to name as many items as they can recall, for the particular cultural domain which is being investigated.

It is a best to ask for an initial list, and then to ask once or twice more for the person to think of anything else that should be added. When the respondent does not have anything else to add, the list is complete.

Combining all of the lists together produces a composite list for each domain. The lists may contain single words, phrases, or short descriptions. The composite lists should include a list of the items (including synonyms for items), information on the number of times each item in the domain was listed by separate respondents, the total number of individuals who provided the original list, the total of the number of individual items listed (including all duplicate items), and a listing of the percent of the total number of respondents who mentioned each particular item. This provides a comprehensive list, and a measure of the salience of each item.

3. Free Listing Questions

Two types of free listing questions should be asked by each site. These questions can provide important information for both the translation/back translations, and for the cross cultural applicability discussion in each site report.

All sites should ask participants:

1. Please list all of the substances that are used in this society by people who want to alter the way they feel (get high, forget their problems, etc.). (This question is asked in a general way to be flexible enough to include alcohol).

2. What are the different names which people use to refer to?

(Regarding Q.2, free listings can be used to elicit street names for specific drugs; this information can be used to check or enhance the translation of the questions which require identification of local terminology. Each site should determine for which substances they will ask this question).

OPTIONAL FREELISTINGS

The following are a list of free listing questions from which field sites may choose an additional question if they wish. **This is not required.**

It is recommended that a total of no more than 3 different free listing questions be asked (question 2 is considered one question even though it may be asked about several drugs).

1. What are all of the harmful consequences of using drugs?

Alternatives:

2. What are all of the harmful consequences of using (where each site asks about alcohol, tobacco, and one other drug)?

3. What are all of the characteristics that identify someone who is using drugs.

Probes:

a. Are these the same or different characteristics as those of someone who needs to be treated for problems associated with their substance use.

b. Are the characteristics different for different drugs?
If so, what are the most important characteristics that go with each drug?

4. What are the legal consequences of using drugs in this society? (Alternative, choose 3 drugs and ask consequences of each)

5. What are the health consequences of using drugs?

6. What are the consequences to the family, if someone is using drugs?

7. What are all of the consequences to society that are caused by people who use drugs?

The Freelisting Data Collection form to be found at the end of this annex provided as an example of one way in which the data can be collected for this type of analysis.

Free Listing Data Collection Form_____ Free Listing

Site: _____ Interviewer: _____ ID_____

Demographics:

Sex _____ Age _____ Educational Level _____

Occupation _____

Free Listing Data:

ANNEX 4

METHODOLOGICAL QUESTIONNAIRE

I. General issues:

A. The first questions relate to the local options for determining the frequency of drug use per 30 days (ALCOHOL and OTHER DRUGS).

"Days" is the response unit which was recommended by the Initial Consultation Group; however, "occasions" is more frequently used (Pompidou surveys, Monitoring the Future Survey), as well as "times".

Is there a standard way of framing this question in research in your country?

How would you recommend framing this question/ response?

B. Two additional general questions are included to reduce the chance that any important "core" questions are not missed.

Are there any general categories of questions which you would consider to be "core" which are not included in this model "core" questionnaire?

If so, please identify and provide examples of how you ask those questions in your country.

II. Section specific issues:

SECTION 1: SOCIO-DEMOGRAPHICS

C. *Questions pertaining to residence, employment, work, and income were obtained from two questionnaires designed for international use (WHO Publication #60 and UN Manual on Drug Abuse Assessment). They include categories which were considered cross culturally applicable and have been used widely.*

Given your research experience in your country, would these questions be appropriate for your country?

If not, how would the questions be modified?

D. Should all the questions included be considered as core? If not, which should be eliminated?

E. Are there socio-demographic questions which you would consider to be core (internationally) which are not included? If so, please identify.

SECTION 2: ALCOHOL USE

F. Regarding the time interval for the question on five or more drinks in a row if you regularly use this question in your research, do you use a 2 week or 30 day time frame?

SECTION 3: OTHER DRUG USE

G. *For non-medical use of medical drugs:*

Is it appropriate to use the phrase "without a doctor or a health worker telling you to do so"? How do you phrase this question in your country?

In your research, how do you exclude "over the counter" drugs?

Do you find the annotation referring to questions on non-medical use of drugs helpful (that is, p. 6, Annotated Guide, "Any use without a doctor's prescription, in greater amounts or more often or for any reason other than a doctor said you should take them such as for kicks, to get high, to feel good, or for curiosity about the pill's effect."?

H. Do you think that a consistently coded response to a mode of administration question would be useful in identifying new, unanticipated ways that drugs are being used; or, could it confuse the respondent?

I. Are there changes you would make to a proposed list of core drugs included in the Self Administered Questionnaire?

By core we mean a minimal set of drugs which would be recommended to be included in most if not all questionnaires on drug abuse. This would serve the purpose of encouraging researchers to obtain information on drugs which are used in many countries, ever if the researchers do not think all of the drugs are currently used in their country. Given the rapidly evolving international drug trafficking situation, this approach could be valuable in identifying use substances which are new to a country.

SECTION 4: DRUG INJECTION/SHARED NEEDLES AND INJECTING EQUIPMENT

J. Are there standard ways in which drug injection questions and sharing of injection equipment

questions are asked in your country?

During the field assessment, these questions were analysed for cross-site trends as well as for information for the annotations for the core questionnaire, using standard qualitative analysis techniques.

ANNEX 5

FIELD ASSESSMENT GUIDELINES FOR DATA ANALYSIS AND REPORTING

Participating field sites provided a description of local drug issues and cultural information about each site. In addition, each site conducted a local analysis of the translation/back translation, focus group, free listing, and methodological questionnaire data.

Preparation of Final Reports

Field sites were asked to prepare a summary report in English. Standardised formats for presenting information on the translation process, free listing exercises, and focus group discussions were provided in a Field Procedure Guide to lessen the reporting burden on field sites and to facilitate the cross site analysis of findings.

OUTLINE FOR TRANSLATION/BACK TRANSLATION REPORT

The report for the translation/back translation process consists of three parts. The first part is an introduction and overall discussion of the issues encountered in the translation/back translation process. The second part is a question by question identification of any problems, modifications, ambiguities, or culturally inapplicable conditions that were associated with each question. The third section consists of a copy of the original questionnaire, a copy of the translated questionnaire, and a copy of the back translated questionnaire.

Section I: Introduction

A. A narrative description of the process used in translation/back translation, including any changes from the initial protocol.

B. Identification and acknowledgement of the individuals who conducted the translation, the back translation, and the bilingual/bicultural panel.

C. A description of any cross cultural applicability conditions or issues that were encountered in the process that would be important to understanding the results of the questionnaire when it is used in its translated format

Section II: Question by Question Analysis

The specific problems encountered in translating each question should be identified in this section. These problems may include lack of a particular word or term in the local language, differences in the way that a phrase or concept would be understood in the local language, or any other problem in making the question cross cultural applicable.

Section III: Original, Translated, and Back Translated Questionnaires

OUTLINE FOR FREE LISTING REPORT

The report on the free listing data includes an introduction that contains the actual question used to compile the free list, a rationale for the question, a composite table of each free listing and a discussion of the ways that the free lists can be used to understand the cross cultural applicability of the model instrument.

I. Introduction

This section describes the characteristics of each group that provided free listing information (age, gender, socio-economic status, etc.), the question used to compile the list and a rationale for the question (why this question or cultural domain was chosen for data collection.

II. Free Listing Data

This section consists of tables and brief discussions of each table. One table should identify the composite summary of all of the domain items listed for a particular question. If there are culturally important variations in the lists, by gender, age, occupation, social status, etc., then segmented free listing summaries should also be presented, as well.

III. Discussion

This section provides a summary of the contribution the data makes to understanding the cross cultural applicability of the core instrument.

FOCUS GROUPS

There are two primary levels of qualitative data analysis that were considered appropriate for this project: descriptive and relational analyses. Descriptive analysis describes the findings of focus groups by summarising each set of ideas discussed by the informants, as well as using quotations to illustrate each point. This provides readers with the clearest possible understanding of the issues from the point of view of the respondents. In this analysis the purpose is to look for similarities, the emergence of patterns, and to recognise variations on themes in the data. In cases where most participants say very similar things, the summary of answers will be brief, but when there

is considerable variation, the descriptive summary will be more extensive. Care must be taken not to overly generalise or selectively choose information, but to accurately report on the findings.

The first descriptive analysis should be an attempt to represent the overall position of the respondents on each question or issue. For example, the description of knowledge of respondents about the availability of substances may read, "approximately half of the 24 respondents knew where they could obtain prescription medicaments from a non-medical source...".

Once the broad description is provided, it is usually desirable to show the range and depth of any variation. This is called a *relational* analysis. A relational analysis seeks to find how the most common variations on ideas or themes are predominantly associated with important subgroups in the population, such as differences between males and females, experts and lay persons, or different social or economic groups. The major points of qualitative data analysis used in this study include the following: :

i. Note the major themes of each focus group in relation to the problem being explored and highlight them. You may decide what are important themes you will be looking for but, it is important to be ready to recognise categories, themes, issues, explanations and beliefs that begin to emerge from the information supplied by those interviewed.

ii. Data from each focus group should be carefully read over and the issues extracted and put in the different categories.

iii. Identify each category by a code. For example, information related to the methods of using drugs may be coded as "1" or information related to the side effects of drugs as "2". How the categories are coded is the responsibility of the researcher. There will be overlapping of codes. There may, for example, be information that fits into 2 or more categories; in this case, put this information in all the necessary categories.

iv. It is important that through-out the analysis the codes remain the same. It is essential that a key to all the codes be available. The codes and the key may be modified as the data require.

v. Once all the data (all of the information in the interviews) is coded, it may be compared. What are the most common categories of information to emerge from the data collection. Who seemed to know what kind of information? What were the most important issues to one group as compared to another group?

vi. An analysis of the data should also begin to create a category for vocabulary which is used within the context of substance use, e.g. local names for drugs, terminology for those who sell substance, words used to describe different levels of use, methods of use or effects of substances on

people and words used to describe excessive use and health hazards.

vii. Once the general patterns are described a picture of how many times each has been mentioned, or prevailing beliefs, attitudes and explanations referred to will be available, and then conclusions may be drawn from this. Meanwhile issues that appear to be unique can be noted for further follow-up.

FIELD ASSESSMENT RESULTS SUMMARY REPORT FORMAT

A comprehensive comparative report summarising the findings from the participating sites was prepared by each individual site, in order to produce a comprehensive, cross site analysis. The following information was provided to each site to assist in the analysis and the production of these reports.

Introduction

Each centre's report should provide a brief overview of the study and its background. This will include any acknowledgements, list of participants/ collaborators, key studies previously conducted on the topic in the country, a description of any traditional or historical ways that drugs may have been used, broad characteristics of the culture which may have an impact on the use of drugs, the channels of supply of various substances, and the demand for products and sources of important information.

Method

This section is concerned with how the study was carried out. It describes what methods were used in the study: e.g. what was measured, methods used to manage the data, problems in the translation process and/or in carrying out the protocol and so on. The essential material is specified by the following subheadings:

a. *Choice of Focus Group Participants*

Briefly mention how the participants were selected, the areas from which they were drawn and any interesting aspects which you consider to be relevant to the study, describing those characteristics that are likely to affect the outcome of the study.

b. *Ethics*

If certain ethical practices were required, provide a brief explanation, e.g. that a consent form was used, as well as any special data protection practices.

c. Data Recording

Give an account of the process used to record the data.

d. Data Management

Describe very briefly the manner in which the data was managed.

e. Data Analysis

The approach used to analyse the data should be noted.

f. Results

The objective of this section is to present a summary of the data relevant to the study, to communicate information about the results of any significant findings and report any interesting variations, themes or points. Appendices may be referred to here, as appropriate.

g. Discussion, Conclusions and Recommendations

This section should develop from concrete findings and end with an assessment of implications of the findings, with special emphasis on their relevance to your country. Investigators may refer here to responses to methodological questions posed in the study. Discuss any limitations the study might have uncovered. If you encountered problems with the study, say what they are and how to avoid them, e.g. culture-specific language.

h. Reference List

Provide details of references referred to in the report.

ANNEX 6

ANNOTATED GUIDE TO THE MODEL CORE QUESTIONNAIRES FOR THE GUIDE TO DRUG ABUSE EPIDEMIOLOGY

The model core questionnaires in Annex 7 and 8 result from the field assessment described in this chapter. These are intended to be multi-purpose model instruments with core standardized questions relating to substance use that can be administered with minimal training and supervision to a range of different target populations (general populations; students; street youth; drug and other substance users seeking treatment) in a range of different settings (schools; prisons; drug and other substance treatment and advice centres; in the community; and on the streets). The intent of including model questionnaires in this guide is to provide a guide to the construction of culturally appropriate questionnaires which can be used to generate core data on substance use which are consistent with current recognized international standards. These model questionnaires are not diagnostic instruments. Questions addressing issues relevant for specific populations can be added to the core sections identified here.

The core questions only address demographic variables and measures of substance use. Other measures should be given serious consideration for inclusion. The field assessment revealed a range of measures considered important in the local context. These included questions on: knowledge, attitudes and behaviour related to drug use; demographic and individual characteristics associated with increased risk of drug use; and health and social consequences of drug use. Some these measures are discussed in Chapter 6.

This instrument is intended to revise and update the "Non-Student Drug Use Survey Questionnaire" included in WHO Offset Publication No. 60 (WHO, 1981) and the "Youth Survey Questionnaire" included in WHO Offset Publication No. 50 (WHO,1981). The questions have been compiled from these two early WHO questionnaires, as well as other more recent questionnaires which have been validated and used in several countries. These questions were then assessed as part of the field assessment and further modified.

It is not intended that these instruments should be used in isolation from, or the data interpreted without, an understanding of the context in which the data were collected. Other indicators from other sources should also be used. It is the intention that these data will form a part of a much broader picture of the extent of and patterns and trends in alcohol, tobacco, and other drug use.

Key areas of investigation are offered followed by some possible basic standard questions for eliciting that information. These questions and, where appropriate, alternative questions were reviewed during the field assessment.

SECTION 1 Eligibility check
SECTION 2 Socio demographics
SECTION 3 Cigarette and other tobacco use
SECTION 4 Alcohol use
SECTION 5 Other drug use
SECTION 6 Drug injection and equipment

This annotated guide and model core questionnaires should be used by researchers, field investigators and other potential users of the model in the construction of a questionnaire appropriate for their own specific cultural and social context. Further discussion regarding the selection of variables and measures can be found in Chapter 6.

NOTES ON SECTION 1: FRONT SHEET/ELIGIBILITY CHECK

This section includes:

- a reminder to the interviewer (for personal interview format) about the criteria for inclusion depending on the target population - or possibly a check list of inclusion criteria (eligibility check);

- a reminder about confidentiality, ethics, and informed consent;

- a written statement to be read to the respondent (for personal interview format) or read by the respondent (for self administered format) which explains the purpose of the questionnaire, confidentiality, informed consent, and the right of refusal (an example of such a statement is given). Care should be taken in the wording of the statement. For example the field assessment revealed that the word "sincerely" was preferred to "honestly" that appeared in the original statement;.

- a brief reminder about how to code/complete the questionnaire (depending on whether it is personal interview or self administered) for example, how to code missing data, non-response, refusal, non-applicable data and how to follow instructions and filters;

- a unique identifying number which safeguards confidentiality and anonymity but prevents double counting (S1.1);

- country/city/area code (S1.2);

- the date the interview was carried out (S1.3);

- where the interview is being carried out (e.g., in a treatment centre (type), in a school, on the street, in a bar, in a prison, in the home, etc.) (S1.4);
- interviewer's initials (S1.5) (Interview Administered Format only);
- interviewers should be reminded to thank respondents for their participation.

NOTE: The field assessment did not test questionnaire administration; it examined language, topics and concepts. Field sites were asked only to construct a front sheet and statement comparable to that included in the model questionnaire.

NOTES ON SECTION 2: SOCIODEMOGRAPHICS

This section gathers the baseline data needed to describe the study sample. It should have an introductory statement (an example is given). The variables covered by these questions have been recommended as a minimum core data set.

Special consideration should be made for the following variables/questions in using and translating the model questionnaire:

Sex: The formulation '*Is the respondent male or female*?" Was preferred or are you male or female (S2.1).

Age: There are different questions which can be used to obtain data on age. Field sites should select the most appropriate wording for the question for their context. The field assessment revealed some difficulties with this apparently straight forward question. The concept of "birthday" is not cross culturally applicable and should not be used. The preferred formulation for this question was: '*How old are you*?" In some of the countries in which the questionnaire was field assessed people do not know their age (S2.2).

Ethnicity: Coding of responses will depend on which main ethnic groups that exist in the study region. Field investigators should establish the main ethnic groupings in constructing and translating the question and response classification. The field assessment revealed some difficulties with this question, including the lack of clearly defined ethnic groups or the basis for such a classification. Ethnicity can be a sensitive topic (S2.3).

Housing: A question of this kind is extremely useful in establishing socio-economic status. Must be sensitive to local variations in housing and living conditions. The field assessment revealed extensive variations in housing and living conditions and that the classification originally suggested was inappropriate.

For example the word "apartment" used in the field assessed classification is rarely used outside the United States. Field investigators should establish the main types of housing and living conditions in constructing and translating the question and response classification (S2.4).

Education: Must be sensitive to local variations in schooling/education systems (such as the "grade" systems in some countries) and include "levels" of education (eg primary, secondary and tertiary). Should also allow for a ? never went to school response. The term "school" in many countries refers only to primary and secondary levels of education and should be avoided. The preferred formulation for this question was: '*How many years of formal education have you completed*?"(S2.5-S2.6)

Employment: Must be sensitive to local variations in employment and work practices and sources of income. There may also be a need to differentiate between the unemployed and the never employed and regular and irregular work. The field assessment revealed a great deal of variation with regard to classifying employment. An open question could be considered, though a closed frame facilitates analysis and comparison (S2.7-S2.8).

Rural/Urb: Field Investigators should consider the appropriateness of the population size coding for their context in translating the question. The field assessment revealed that the suggested classification was inappropriate. The population figures provided in the original questionnaire were not useful. The preferred formulation for this question was "Rural or village" "City or town" (S2.9).

Marital: Field investigators should review this question in light of their research experience within their country. A range of different terminologies and sensitivities were revealed by this question during the field assessment. The category "living as a couple" included in the draft that was field assessed was seen as problematic in some countries (S2.10).

Main source of income: Field investigators should consider the appropriateness of the response coding for their context. The category of illegal income may be problematic in some contexts. The field assessment revealed that the suggested classification was inappropriate, particularly "public assistance" which is unknown outside of certain countries (S2.11).

Variations in questions for interviewer administered format and self administered format

Self administered model format: This format has been designed to **avoid skip patterns.** Each question requires a response; responses are coded accordingly. The field assessment however revealed that skip patterns were preferred to avoid unnecessary repetition.

Interviewer administered model format: This section includes one "skip". A "no" response to S2.7 leads the interviewer to S2.9. May be problematic in that they may not be followed properly by interviewers who are unfamiliar with questionnaires. This could result in questions being missed. In the self administered format the skip pattern has been left out.

NOTES OF SECTION 3: CIGARETTES AND OTHER TOBACCO USE

Tobacco use needs to be defined according to local variations. In some areas tobacco products other than manufactured cigarettes are commonly used - hand rolled cigarettes, "beedis", cigars and pipes, but also chewing tobacco, snuff and other "smokeless" tobacco products. In other countries these other tobacco products are unknown and could be excluded from the questionnaire. Tobacco chewing is common in some countries but unknown in others, for example. Local patterns of tobacco use and local names for tobacco products should be determined during the field assessment of the questionnaire. A free listing exercise of the type described elsewhere in this chapter may be useful in this respect and is recommended. During the process of translation, field investigators should consider the appropriateness and completeness of the questions identified in this section for their context:

Questions S3.1 to S3.5 refer to manufactured cigarettes and hand rolled cigarettes. In some countries beedis are the most commonly smoked cigarettes and should be asked about here.
Questions S3.6 to S3.8 refer to tobacco products other than cigarettes which are smoked; for example, cigars and pipe tobacco.

Questions S3.9 to S3.10 refer to tobacco products which are not smoked; for example, snuff or chewing tobacco. These products are common in many countries, yet in others practically unknown and could be excluded. Local names should be used as examples of these products.

Question S3.11 is widely used by the WHO Tobacco or Health Program. Again local names should be used.

<u>Variations in questions for interviewer administered format and self administered format</u>

Self administered model format: This format has been designed to **avoid skip patterns.** Each question requires a response; responses are coded accordingly.

Interviewer administered model format: This format **includes skip patterns**.

NOTES ON SECTION 4: ALCOHOL USE

The opening statement should be sensitive to local custom, laws and religious attitudes to alcohol use. Alcohol should be defined according to local variation (including beer, wine, spirits, traditional or local brews) and this section introduced with an opening statement such as the example given. Researchers should establish the main types of alcoholic drinks prior to framing this question. In some cultures alcohol is not morally or legally sanctioned.

Local patterns of alcohol use and local names for alcoholic drinks should be determined during the field assessment of the questionnaire. A ? free listing exercise of the type described elsewhere in this chapter may be useful in this respect and is recommended.

The term "alcoholic drink" may not be appropriate in all English speaking contexts; the term "alcoholic beverage" may be preferred.

The term "drinks in a row" may not be understood or translatable. Researchers should establish the terminology to be used for their linguistic and cultural context.

Having established whether or not the respondent drinks alcohol a basic measure of frequency of drinking and amount of alcohol is needed. "A standard drink" should be locally defined. It may be extremely difficult to determine a standard drink, however the local definition should be carefully recorded.

Variations in questions for interviewer administered format and self administered format

Self administered model format: This format has been designed to **avoid skip patterns.** Each question requires a response; responses are coded accordingly. Frequency of use in the past 30 days may have an open ended response where the respondent fills in the appropriate number of days alcohol was drunk or may have a closed coded response as identified in the model questionnaire.

Interviewer administered model format: This format **includes skip patterns** and an open ended question for frequency of use during the past 30 days.

NOTES ON SECTION 5: OTHER DRUG USE

Drug classification and coverage in questionnaires

There will be much local variation in the types of drugs used, the ways in which they are used and in the local/colloquial (street/slang) names for the drugs. Field investigators should establish the main types of drugs used, local names, etc., in constructing this section of the questionnaire.

Examples and descriptions should be included to communicate clearly to respondents the type of drug to which the question refers. It is useful to provide a brief introduction to each sub-section dealing with each specific type of drug clarifying the nature and e type of drug. Examples derived from existing validated self administered questionnaires are included in the model.

Classifying drugs and developing a coding structure for the many types of substances is problematic. Drug use is a dynamic phenomenon with new substances being used and manufactured in different countries and regions all the time. Local patterns of drug use and local names for drugs should be determined during the field assessment of the questionnaire. A ? free listing exercise of the type described elsewhere in this chapter may be useful in this respect and is recommended.

For these reasons, a **core list** of substances is suggested with local variations added as necessary. This could be based on the ICD-10 Classification of Mental and Behavioural Disorders (F10-19 Mental and behavioural disorders due to psychoactive substance use). Some drugs included in the model questionnaires may not be used or appropriate in the local context and can be excluded. Other drugs should be included if their use is common.

The core drug classification list from the Council of Europe's Pompidou Group (Epidemiology Experts in Drug Problems) is a good example of a classification which covers the main drug classes (see also Annex IV: page 1: Drug treatment reporting systems and the first treatment demand indicator, Council of Europe, 1994 for a full classification). The following list has been adapted from that list (see also Chapter 6).

1. Heroin and other opiate/opioid type drugs (heroin, opium, methadone, morphine, etc.) ICD F11 PGDC 100-188. Note that heroin and opium have been classified separately in the model questionnaire.

2. Central nervous system stimulants (cocaine, amphetamines, methamphetamine, MDMA, other amphetamine-type stimulants etc.) ICD F14-F15 PGDC 200-288. Note that cocaine has been classified on its own in the model questionnaire.

3. Hypnotics and sedatives (barbiturates, benzodiazepines, etc.) ICD F13 300-388. Note that benzodiazepines have been classified on their own as tranquillizers in the model questionnaire. Other sedatives and hypnotics (including barbiturates and methaqualone) are classified together.

4. Hallucinogens (LSD, PCP, mushroom, peyote, etc.) F16 400-488

5. Volatile inhalants (glues, butane, solvents, petrol, nitrites, aerosols, etc.) F18 500-588

6. Cannabis (marijuana, herbal, resin, oil, etc.) ICD F12 600-688

7. Alcohol (dealt with in SECTION 3) ICD F10 700

8. Other psychoactive drugs ICD F19 800-888

This section includes inhalants (volatile solvents and aerosols, etc.,) and also the non-medical use of pharmaceuticals (e.g., benzodiazepines, buprenorphine, etc.) and other drugs which can be used under the direction of a doctor, but are not used in this way. The field assessment revealed that this type of use was common.

It may be necessary to further sub-divide categories of substances where appropriate to their context (e.g. have a separate question on use of "crack" or 'basuco" which would distinguish it from other forms of cocaine use or a question on MDMA ? Ecstasy to distinquish it from other amphetamine-type stimulants). Additional substances should be added as appropriate to the local context. Substances which are unknown in the local context should be omitted.

Some of these drugs (e.g. benzodiazepines) can be used for legitimate medical reasons so a distinction between medical and non-medical use is made. Non-medical use could be defined in the following terms:

Any use without a doctor's prescription or direction; in greater amounts or more often or for any reason other than a doctor said you should take them, such as for kicks, to get high, to feel different or for curiosity about the pills' effect.

Certain drugs are also used in the treatment of drug related problems (most commonly methadone and tranquillizers, but also other opioids, such as buprenorphine and other drugs) and, as an option where these drugs are commonly used in this way, should be dealt with separately. Prescribed drugs (such as methadone) should be defined in an understandable way; for example, *"Methadone given (sold) to you by a doctor as part of your treatment"*.

Some drugs are commonly used in combination with others. These combinations should be included (eg. heroin and cocaine together).

Core Questions

The same pattern of questions is recommended to be followed for each drug included in the study. Measures should be obtained for:

i. use in lifetime;
ii. use in past 12 months;
iii. use in past 30 days.

A measure of frequency of use should be obtained for the past 30 days. No consensus was reached during the field assessment regarding the best measure of frequency although quantities of drug used and number of occasions of use were suggested. Some Centres preferred to use "last month" rather than "last 30 days". Two possible solutions related to the number of days on which drugs were used in the past 30 days are proposed in the model.

A general question on route of administration including consistent response coding for **each** drug can be useful in identifying new ways in which drugs are being used. In some cases where it is clear that a drug is not used in a particular way (eg cannabis is rarely, if ever, injected) may necessitate some revision to coding frame (see also Chapter 6 for further discussion of this point).

Variations in questions for interviewer administered format and self administered format

Self administered model format: This format has been designed to **avoid skip patterns.** Each question requires a response; responses are coded accordingly. Frequency of use of the past 30 days may have an open ended response where the respondent fills in the appropriate number or may have a closed coded response as identified in the model questionnaire.

This format also includes a recommended **minimum core list of substances** which researchers would be encouraged to include in their research.

Interviewer administered model format: This format **includes skip patterns**. A response coding is provided for frequency of use during the past 30 days; however, this questions may also use an open ended response.

A model grid is provided in the model questionnaire to facilitate the recording of information obtained by personal interview. This grid is provided as an example and is not intended to either be an exhaustive listing or a list which would be appropriate for every context. A grid should not be used in the self administered format or by untrained interviewers because of the possibility of mis-coded responses.

NOTES ON SECTION 6: DRUG INJECTION AND SHARED USE OF INJECTING EQUIPMENT

Due to concern about infectious disease transmission, particularly HIV transmission, through use and sharing of contaminated needles/syringes and contaminated injecting equipment, is its

recommended that a minimal set of basic questions pertaining to these behaviours be included. These questions should be asked of those who have already indicated that they have injected a drug in Section 5. Model questions may be particularly problematic on this topic because of different practices, behaviours, and equipment associated with drug injection in different contexts.

It is recommended that the following core information be collected:

Drug injection:

i. "ever" injected
ii. age first injected
iii. recency (last time injected)
iv. which drugs have been injected

Shared use of injecting equipment:

i. personal use of injecting equipment which has been used by someone else (indicating risk of infection)
ii. whether the respondent is aware of any one else using injecting equipment which the respondent has used (indicating risk of transmission)

Field investigators should use their knowledge of injecting practices in their country in framing appropriate questions to elicit the data for this section. This includes the process involved in preparation and injection of drugs, in order to establish a definition of the concept of shared used (or "sharing" of) injecting equipment. Two things should be taken into consideration:

The concept of "used" equipment need to be understood.

The distinction between "accepting or borrowing" used equipment (risk of infection) and "passing on or lending" used equipment (risk of transmission).

The focus group discussions with treatment providers, researchers, and drug users should be used to assess the appropriateness of the questions and revise as necessary.

The questions listed in the model questionnaire provide a guide to the types of questions to be asked to elicit the core data and examples of ways in which these questions have been asked in drug use surveys (from U.S. National Household Survey on Drug Abuse questionnaire). **Field investigators should adapt the questions (or add questions), as appropriate, and include description of injecting and sharing which are appropriate for their context.**

In some cultures self administered therapeutic injections are common, eg of vitamins, insulin, antibiotics, etc. These should be differentiated from other injecting drug use.

Variations in questions for interviewer administered format and self administered format

Self administered model format: Each question requires a response; responses are coded accordingly.

Interviewer administered model format: Respondents answering "no" to S6.1 will skip the remainder of the questions in this section.

ANNEX 7

WHO MODEL CORE QUESTIONNAIRE SELF ADMINISTERED FORMAT

SECTION 1: FRONT SHEET/ ELIGIBILITY CHECK

The following questions are about your use of substances such as alcohol, tobacco and other drugs. Your answers to these questions will help us find out about what substances people are using these days. The information that you give is confidential and you do not have to answer the questions if you do not want to. The information you provide is of vital importance, so try to answer as sincerely and accurately as possible. This is not a test, there are no ? right or wrong answers. What you tell us is completely confidential and only the researchers will have access to the form. Your name or address will never be linked to any of the information you provide.

S1.1 Interview Number (***PRECODED***) ___ ___ ___ ___

S1.2 Country/city/area code (***PRECODED***) ___ ___ __ ___

S1.3 (***WRITE IN***) Today's date Day Month Year
__ __ __ __ __

S1.4 Where are you completing this Questionnaire? (***Please CIRCLE ONE CODE***)

1. In a school
2. In a home
3. On the street
4. In a prison
5. In a treatment centre (***WRITE IN TYPE***) _____
6. Other location (***WRITE IN TYPE***) _____

SECTION 2: SOCIODEMOGRAPHICS

The following questions are about you - These questions are only asked to help us analyse the results of the study. The information that you give is confidential and you do not have to answer the questions if you do not want to. Your help is of vital importance to our research.

S2.1 Are you male or female? (***PLEASE CIRCLE ONE CODE***)

1. male
2. female

S2.2 How old are you?

_____ years (***WRITE IN***)

S2.3 (**Option**) Which of the following ethnic groups do you consider yourself to be a member of?

RESPONSE CODED AS LOCALLY APPROPRIATE FOR EACH SITE

S2.4 Where are you currently living?

RESPONSE CODE AS LOCALLY APPROPRIATE FOR EACH SITE

S2.5 How many years of formal education have you completed?

_____ years (***WRITE IN NUMBER OF YEARS***)

S2.6 For most of the last 12 months were you a full-time or part-time student? (***CIRCLE ONE CODE***)

1. No - not a student
2. Yes - part-time
3. Yes - full-time

S2.7 For most of the past 12 months were you working on a paid job full-time or part time? (***CIRCLE ONE CODE***)

1. No - not working
2. Yes - part-time
3. Yes - full-time

S2.8 If working, what type of work do you do? (***WRITE IN TYPE OF WORK***)

_____

_____

S2.9 During most of the past 12 months, have you been living mostly in a rural area or village or in town, or in a city? (***CIRCLE ONE CODE***)

1. Rural area (or village)
2. Town
3. City
4. Other (***WRITE IN***) _____

S2.10 Which of the following best describes your current marital status? (***CIRCLE ONE CODE***)

1. Married
2. Widowed
3. Divorced or separated
4. Living as couple - may be inappropriate in some cultures
5. Never married/single

S2.11 Did you receive money from any of the following during the last 30 days? (***CIRCLE CODES***)

0. No source of money
1. Salary and wages from a job (including self employment)
2. Welfare, government assistance, insurance, charities
3. Spouse or family
4. Friends
5. Illegal income - may be inappropriate in some cultures
6. Other (specify)_____

SECTION 3: CIGARETTES AND OTHER TOBACCO USE

The following questions are about cigarettes and other tobacco use.

S3.1 Have you ever smoked cigarettes (including hand rolled cigarettes)?

1. No - Never smoked cigarettes
2. Yes - Once or twice only
3. Yes - Occasionally, but not regularly
4. Yes - Regularly in the past
5. Yes - Regularly now

S3.2 How old were you when you first smoked a cigarette?

_____ years old (***WRITE IN***) WRITE IN 00 IF NEVER SMOKED A CIGARETTE

S3.3 How many cigarettes a day did you smoke in the past 30 days (or past month)? (***CIRCLE ONE CODE***)

1. None at all
2. Less than 1 cigarette per day
3. 1-5 cigarettes per day
4. 6-15 cigarettes per day
5. 16-25 cigarettes per day
6. 26-35 cigarettes per day
7. Over 35 cigarettes per day

S3.4 Have you ever smoked cigarettes daily for 6 months or more? (***CIRCLE ONE CODE***)

1. No
2. Yes

S3.5 For how many years did you smoke cigarettes daily?

_____ years (***WRITE IN***) WRITE IN 00 IF NEVER SMOKED CIGARETTES DAILY

S3.6 Have you ever smoked any form of tobacco other than cigarettes (e.g. cigars, pipe tobacco, etc.)?

1. No - Never
2. Yes - Once or twice only
3. Yes - Occasionally, but not regularly
4. Yes - regularly in the past
5. Yes - Regularly now

S3.7 How old were you when your first smoked any form of tobacco other than cigarettes?

_____ years old (***WRITE IN***) WRITE IN 00 IF NEVER SMOKED ANY FORM
TOBACCO OTHER THAN CIGARETTES

S3.8 Have you ever smoked a tobacco product other than cigarettes daily for 6 months or more?

1. No
2. Yes

S3.9 Have you ever used chewing tobacco, snuff or other smokeless tobacco? (Use local examples eg jarda and pan masala India) - ***Only ask where this practice exists*** (***CIRCLE ONE CODE***)

1. No - Never
2. Yes - Once or twice only
3. Yes - Occasionally, but not regularly
4. Yes - Regularly in the past
5. Yes - Regularly now

S3.10 How old were you when you first used chewing tobacco, snuff or other smokeless tobacco?

_____ years old (WRITE IN)WRITE IN 00 = IF NEVER USED CHEWING TOBACCO, SNUFF OR OTHER SMOKELESS TOBACCO

S3.11 How many of these have you smoked (or used) on average per day in the in the past 30 days? (IF NONE WRITE IN 00). ***Use local names for these or similar***

Manufactured cigarettes	_____
Hand-rolled cigarettes	_____
Pipefuls of tobacco	_____
Cigars or cigarillos	_____
Beedis/goza/hookahs	_____
Pinches of snuff/quids of tobacco	_____

SECTION 4: ALCOHOL USE

The following questions are about alcoholic drinks, that is beers, wines, spirits *(such as give local examples)* and local (traditional) drinks (such as *give local examples eg: samsu Malaysia, tepache Mexico, arack India and scud Zimbabwe*).

S4.1 Have you ever had an alcoholic drink?

1. No
2. Yes

S4.2 About how old were you the first time you had an alcoholic drink? (Do not include childhood or medicinal sips).

_____ years old (WRITE IN)WRITE IN 00 = IF NEVER HAD AN ALCOHOLIC DRINK

S4.3 When did you last have an alcoholic drink?

0. Never had an alcoholic drink
1. Today
2. Yesterday
3. In the past week
4. In the past 30 days
5. More than 30 days ago, but less than 12 months ago
6. More than 12 months ago

S4.4 On how many days in the past 30 days have you had an alcoholic drink?

_____ days (WRITE IN)

S4.5 Think back over the last 30 days, how many times have you had five or more drinks in a row? (A drink is (local definition eg ? copas Mexico) (CIRCLE ONE CODE)

0. None
1. Once
2. Twice
3. 3 - 5 times
4. 6 - 9 times
5. 10 or more times

S4.6 On the days that you drank during the last 30 days, about how many drinks did you usually have a day?

Usual number of drinks: _____(WRITE IN) WRITE IN 00 = IF YOU DID NOT HAVE ANY ALCOHOLIC DRINKS IN LAST 30 DAYS.

SECTION 5: OTHER DRUG USE

Tranquillizers

The following questions are about **tranquillizers** which are sometimes prescribed by doctors to calm people down, or relax their muscles. Librium, Rohypnol, Diazepam and Valium are tranquillizers (give local examples as appropriate). They are sometimes called (give local examples).

S5.1a Have you ever taken tranquillizers without a doctor telling you to do so?

1. No
2. Yes

S5.1b How old were you when you first took tranquillizers without a doctor telling you to do so?

_____ years old (WRITE IN)WRITE IN 00 = IF YOU HAVE NEVER TAKEN TRANQUILLIZERS WITHOUT A DOCTOR'S INSTRUCTIONS

S5.1c Have you taken tranquillizers in the past 12 months without a doctor telling you to do so?

1. No
2. Yes

S5.1d On how many days in the past month (past 30 days) have you taken tranquillizers without a doctor telling you to do so?

0. None
1. On 1-2 days
2. On 3-5 days
3. On 6-9 days
4. On 10-19 days
5. On 20 or more days

OR_____days (WRITE IN NUMBER OF DAYS)WRITE IN OO = IF YOU DID NOT TAKE ANY TRANQUILLIZERS IN THE PAST 30 DAYS WITHOUT A DOCTOR? S INSTRUCTIONS

S5.1e In what ways have you taken tranquillizers in the past 30 days?
(CIRCLE ALL THE WAYS YOU HAVE USED IT)

1 Eating/Swallowing
2. Injecting
3. Other ways_____(WRITE IN)

S5.1f If you have ever taken tranquillizers, write in the types used below:

_____
_____
_____

Sedatives and Hypnotics

The following questions are about **sedatives and hypnotics** including **barbiturates** which are sometimes prescribed by doctors to help people to sleep or to relax and methaqualone (Mandrax). They are sometimes called (give local examples).

S5.2a Have you ever taken sedatives without a doctor telling you to do so?

1. No
2. Yes

S5.2b How old were you when you first took sedatives without a doctor telling you to do so?

_____ years old (WRITE IN) WRITE IN 00 = IF YOU HAVE NEVER TAKEN SEDATIVES WITHOUT A DOCTOR'S INSTRUCTIONS

S5.2c Have you taken sedatives within the past 12 months without a doctor telling you to do so

1. No
2. Yes

S5.2d On how many days during the past 30 days have you taken sedatives without a doctor telling you to do so?

0. None
1. On 1-2 days
2. On 3-5 days
3. On 6-9 days

4. On 10-19 days
5. On 20 or more days

OR_____days (WRITE IN) WRITE IN OO = IF YOU DID NOT TAKE ANY SEDATIVES IN THE PAST 30 DAYS WITHOUT A DOCTOR? S INSTRUCTIONS.

5.2e What ways have you taken sedatives in the past 30 days?(CIRCLE ALL THE WAYS YOU HAVE USED IT)

1. Eating/Swallowing
2. Injecting
3. Other ways_____(WRITE IN)

S5.2f If you have ever taken sedatives, write in the types used below:

_____
_____
_____

Amphetamines and amphetamine type stimulants

The following questions are about **amphetamines** or **stimulants** which can be prescribed by doctors to help people lose weight or to give people more energy. They are sometimes called (give local examples, eg max Egypt, speed) and also include: methamphetamine, MDMA (ecstasy) and other amphetamine analogues.

S5.3a Have you ever taken amphetamines or other stimulants without a doctor telling you to do so?

1. No
2. Yes

S5.3b How old were you when you first took amphetamines or other stimulants without a doctor telling you to do so?

_____ years old (WRITE IN) WRITE IN 00 = IF YOU HAVE NEVER TAKEN AMPHETAMINES OR OTHER STIMULANTS WITHOUT A DOCTOR'S INSTRUCTIONS

S5.3c Have you taken amphetamines or other stimulants in the past 12 months without a doctor telling you to do so?

1. No

2. Yes

S5.3d On how many days in the past 30 days have you taken any amphetamines without a doctor telling you to do so

0. None
1. On 1-2 days
2. On 3-5 days
3. On 6-9 days
4. On 10-19 days
5. On 20 or more days

OR _____days (WRITE IN NUMBER OF DAYS) WRITE IN 00 = IF YOU DID NOT TAKE ANY AMPHETAMINES OR OTHER STIMULANTS IN THE PAST 30 DAYS WITHOUT A DOCTOR'S INSTRUCTIONS.

S5.3e In what ways have you taken amphetamines or other stimulants in the past 30 days? (CIRCLE ALL THE WAYS YOU HAVE USED THEM)

1. Eating/Swallowing
2. Smoking
3. Sniffing
4. Injecting
5. Other ways_____ (WRITE IN)

S5.3f If you have ever taken amphetamines or other stimulants, write in the types used below:

_____
_____
_____

Cannabis

The following questions are about **cannabis** such as marijuana, hashish, (give local examples as appropriate, eg ganja, bhangi, bango, marihuana, grass).

S5.4a Have you ever used/tried cannabis?

1. No
2. Yes

S5.4b How old were you when you first used cannabis?

_____ years old (WRITE IN) WRITE IN OO = IF YOU HAVE NEVER USED CANNABIS

S5.4c Have you used cannabis in the past 12 months?

1. No
2. Yes

S5.4d On how many days in the past 30 days have you used cannabis?

0. None
1. On 1-2 days
2. On 3-5 days
3. On 6-9 days
4. On 10-19 days
5. On 20 or more days

OR_____days (WRITE IN)WRITE IN OO = IF YOU HAVE NEVER USED CANNABIS

S5.4e In what ways have you used cannabis in the past 30 days?(CIRCLE ALL THE WAYS YOU HAVE USED IT)

1. Eating/Swallowing
2. Smoking
3. Other ways_____(WRITE IN)

Hallucinogens

The following questions are about **hallucinogens** such as LSD, mescaline, peyote, psilocybin mushrooms, (give local examples, e.g. myzepete Zimbabwe, mescaline Mexico, acid etc.)

S5.5a Have you ever used/tried hallucinogens?

1. No
2. Yes

S5.5b How old were you when you first used hallucinogens?

_____ years old (WRITE IN) WRITE IN 00 = IF YOU HAVE NEVER USED HALLUCINOGENS

S5.5c Have you used hallucinogens in the past 12 months?

1. No
2. Yes

S5.5d On how many days in the past 30 days have you used hallucinogens?

0. None
1. On 1-2 days
2. On 3-5 days
3. On 6-9 days
4. On 10-19 days
5. On 20 or more days

OR_____days (WRITE IN) WRITE IN OO = IF YOU DID NOT USE ANY HALLUCINOGENS IN THE PAST 30 DAYS

S5.5e In what ways have you used hallucinogens in the past 30 days? (CIRCLE ALL THE WAYS YOU HAVE USED THEM)

1. Eating/Swallowing
2. Smoking
3. Sniffing
4. Injecting
5. Other ways_____ (WRITE IN)

S5.5f If you have ever used hallucinogens, write in the types used below

_____
_____

<u>Cocaine</u>

The following questions are about **cocaine**, including all the different forms of cocaine such as powder, "crack," free base, and coca paste. Cocaine is sometimes called (give local examples, eg coke, snow, nieve, etc.).

S5.6a Have you ever used/tried cocaine?

1. No
2. Yes

S5.6b How old were you when you first used cocaine?

_____ years old (WRITE IN) WRITE IN OO = IF YOU HAVE NEVER USED COCAINE

S5.6c Have you used cocaine in the past 12 months?

1. No
2. Yes

S5.6d On how many days in the past 30 days have you used cocaine?

0. None
1. On 1-2 days
2. On 3-5 days
3. On 6-9 days
4. On 10-19 days
5. On 20 or more days

OR_____ days (WRITE IN) WRITE IN OO = IF YOU DID NOT USE ANY COCAINE IN THE PAST 30 DAYS

S5.6e In what ways have you used cocaine in the past 30 days?
(CIRCLE ALL THE WAYS YOU HAVE USED IT)

1. Eating/Swallowing
2. Smoking
3. Sniffing
4. Injecting
5. Other ways_____ (WRITE IN)

S5.6f If you have ever used cocaine, write in the used below (e.g., powder, crack free base, coca paste, etc.)

_____
_____

Heroin

The following questions are about **heroin**. Heroin is sometimes called (give local examples, e.g. brown sugar, etc.).

S5.7a Have you ever used/tried heroin?

1. No
2. Yes

S5.7b How old were you when you first used heroin?

_____ years old (WRITE IN) WRITE IN 00 = IF YOU HAVE NEVER USED HEROIN

S5.7c Have you used heroin in the past 12 months?

1. No
2. Yes

S5.7d On how many days in the past 30 days have you used heroin?

0. None
1. On 1-2 days
2. On 3-5 days
3. On 6-9 days
4. On 10-19 days
5. On 20 or more days

OR_____ days (WRITE IN) WRITE IN OO = IF YOU DID NOT USE ANY HEROIN IN THE PAST 30 DAYS

S5.7e In what ways have you used heroin in the past 30 days?
(CIRCLE ALL THE WAYS YOU HAVE USED IT)

1. Eating/Swallowing
2. Smoking
3. Sniffing
4. Injecting
5. Other ways_____ (WRITE IN)

Opium

S5.8a Have you ever used/tried opium?

1. No
2. Yes

S5.8b How old were you when you first used opium?

_____ years old (WRITE IN) WRITE IN OO = IF YOU HAVE NEVER USED OPIUM

S5.8c Have you used opium in the past 12 months?

1. No
2. Yes

S5.8d On how many days in the past 30 days have you used opium?

0. None
1. On 1-2 days
2. On 3-5 days
3. On 6-9 days
4. On 10-19 days
5. On 20 or more days

OR_____days (WRITE IN)WRITE IN OO = IF YOU DID NOT USE ANY OPIUM IN THE PAST 30 DAYS

S5.8e In what ways have you used opium in the past 30 days?
(CIRCLE ALL THE WAYS YOU HAVE USED IT)

1. Eating/Swallowing
2. Smoking
3. Other ways_____ (WRITE IN)

Other Opiate Type Drugs

The following questions about certain other opiate/opiod type drugs which doctors sometimes prescribe to relieve seven pain prevent coughing, or to control diarrhea. These drugs include

morphine, codeine, demerol, talwin, and laudanum (give local examples as appropriate, eg. Tidigesic India.

S5.9a Have ever taken any opiate drugs without a doctor telling you to do so:

1. No
2. Yes

S5.9b How old were you when you first took any of these opiate drugs without a doctor telling you to do so?

_____ years old (WRITE IN) WRITE IN OO = IF YOU HAVE NEVER TAKEN ANY OF THESE OPIATE TYPE DRUGS WITHOUT A DOCTOR? S INSTRUCTIONS.

S5.9c Have you taken of these opiate drugs in the past 12 months without a doctor telling you to do so?

1. No
2. Yes

S5.9d On how many days in the past 30 days have you used other opiate type drugs?

0. None
1. On 1-2 days
2. On 3-5 days
3. On 6-9 days
4. On 10-19 days
5. On 20 or more days

OR_____ days (WRITE IN)WRITE IN OO = IF YOU DID NOT TAKE ANY OF THESE OPIATE TYPE DRUGS IN THE PAST 30 DAYS

S5.9e In what ways have you taken any of these opiate drugs in the past 30 days?
(CIRCLE ALL THE WAYS YOU HAVE TAKEN IT)

1. Eating/Swallowing
2. Smoking
3. Sniffing
4. Injecting
5. Other ways _____ (WRITE IN)

S5.9f If you have even taken any of these opiate drugs, write in the types used below:

_____
_____
_____

Volatile Inhalants

The following questions are about **volatile inhalants** (such as fluids and gases, aerosol sprays, glue, etc.) that people sniff or breath in to get high or feel different.

S5.10a Have you ever sniffed glue, or breathed the contents of aerosol spray cans, or inhaled any other gases, sprays, or fumes from substances such as liquids in order to get high?

1. No
2. Yes

S5.10b How old were you when you first sniffed or inhaled something to get high?

_____years old (WRITE IN) WRITE IN 00 = IF YOU HAVE NEVER SNIFFED OR INHALED SOMETHING TO GET HIGH

S5.10c Have you sniffed or inhaled something to get high in the last 12 months?

1. No
2. Yes

S5.10d On how many days in the past 30 days have you sniffed or inhaled something to get high?

0. None
1. On 1-2 days
2. On 3-5 days
3. On 6-9 days
4. On 10-19 days
5. On 20 or more days

OR_____days (WRITE IN) WRITE IN OO = IF YOU HAVE NOT SNIFFED OR INHALED SOMETHING TO GET HIGH IN THE PAST 30 DAYS

S5.10e If you have ever sniffed or inhaled something to get high, write in the types of things sniffed or inhaled below

_____

_____
_____

S5.10f Are there other drugs not mentioned above that you have used in the past 12 months without a doctor telling you to do so?

1. No
2. Yes

If yes, please write the names of those drugs

_____
_____
_____

SECTION 6: DRUG INJECTION/SHARED USE OF INJECTING EQUIPMENT

The following questions are about injecting drugs. By this we mean (describe local practices)

S6.1 Have you ever used a needle to get any drug injected under your skin, into a muscle, or into a vein without a doctor or health worker telling you to do so?

1. No
2. Yes

S6.2 When was the most recent time you used any drug with a needle without a doctor or health worker telling you to do so?

1. Today
2. Yesterday
3. In the past week
4. In the past 30 days
5. More than 30 days and less than 12 months ago
6. More than 12 months ago
7. Have NEVER used a drug with a needle without a doctor's instructions

S6.3 Which drugs have you ever used with a needle without a doctor telling you to do so?

_____
_____
_____

"Sharing a needle" means using a needle for injecting drugs when you know or suspect that the needle has been used by someone else. It also means someone else injecting drugs with a needle you have used. (this is just an example; field investigators should define "sharing" as appropriate for their context)

S6.4 Have you ever used a needle for injecting drugs when you knew or suspected that the needle had been used by someone else?

1. No
2. Yes

S6.5 Has someone else ever injected drugs with a needle after you used the needle?

1. No
2 Yes

ANNEX 8

WHO MODEL CORE QUESTIONNAIRE INTERVIEWER ADMINISTERED FORMAT

SECTION 1: FRONT SHEET/ELIGIBILITY CHECK

READ OUT: "I would like to ask you some questions about your use of substances such as alcohol, tobacco and other drugs. Your answers to these questions will help us find out about what substances people are using these days. The information that you give is confidential and you do not have to answer the questions if you do not want to. The information you provide is of vital importance, so try to answer as sincerely and accurately as possible. This is not a test, there are no "right or wrong" answers. What you tell us is completely confidential and only the researchers will have access to the form. Your name or address will never be linked to any of the information you provide".

"If you do not understand the questions please tell me. If there is anything else you would like to know please ask me".

INTERVIEWER TO COMPLETE

S1.1 Interview Number (***PRECODED***) ___ ___ ___ ___

S1.2 Country/city/area code (***PRECODED***) ___ ___ ___ ___

S1.3 Date of interview (***WRITE IN***) Day ___ Month ____ Year ___

S1.4 Where are you completing this Questionnaire ***(CIRCLE ONE CODE***)?

1. In a school
2. In a home
3. On the street
4. In a prison
5. In a treatment centre (***WRITE IN TYPE***)_____
6. Other location (***WRITE IN TYPE***)_____

SECTION 2: SOCIO-DEMOGRAPHICS

READ OUT: "The following questions are about you - These questions are only asked to help us analyse the results of the study. The information that you give is confidential and you do not have to answer the questions if you do not want to. Your help is of vital importance to our research".

S2.1 Is the respondent male or female? (***AS OBSERVED BY INTERVIEWER***)

1. male
2. female

S2.2 How old are you?_____years (***WRITE IN***)

S2.3 **(OPTION)** Which of the following ethnic groups do you consider yourself to be a member of?

RESPONSE CODED AS LOCALLY APPROPRIATE (***SHOW PROMPT CARD LISTING MAIN ETHNIC GROUPS AND ENTER CODE***)

_____

S2.4 Where are you currently living?

RESPONSE CODED AS LOCALLY APPROPRIATE (***SHOW PROMPT CARD LISTING MAIN TYPES OF RESIDENCE AND ENTER CODE***)

_____

S2.5 How many years of formal education have you completed?

_____ years (***WRITE IN***)

S2.6 For most of the last 12 months were you a full-time or part-time student (***CIRCLE ONE CODE***)?

1. No - not a student
2. Yes - part-time
3. Yes - full-time

S2.7 For most of the past 12 months were you working on a paid job full-time or part time (***CIRCLE ONE CODE***)?

1. No - not working----------**GO TO S2.9**
2. Yes - part-time
3. Yes - full-time

S2.8 (IF WORKING) What type of work do you do (***WRITE IN TYPE OF WORK***)?

_____

S2.9 During most of the past 12 months, have you been living mostly in a rural area or village, in a town or in a city (***CIRCLE ONE CODE***)?

1. Rural area or village
2. Town
3. City
4. Other (WRITE IN _____)

S2.10 Which of the following best describes your current marital status? (***READ LIST AND CIRCLE ONE CODE***)

1. Married
2. Widowed
3. Divorced or separated
4. Living as couple - may be inappropriate in some cultures
5. Never married/single

S2.11 Did you receive money from any of the following during the last 30 days? (***READ LIST AND CIRCLE ONE CODE***)

0. No source of money
1. Salary or wages from a job (including self employment)
2. Welfare, government assistance, insurance, charities
3. Spouse or family
4. Friends
5. Illegal income - may be inappropriate in some cultures
6. Other (specify)_____

SECTION 3: CIGARETTES AND OTHER TOBACCO USE

READ OUT: The following questions are about cigarettes and other tobacco use.

S3.1 Have you ever smoked cigarettes (including hand rolled cigarettes/ beedis)? (***CIRCLE ONE CODE***)

1. No - Never smoked cigarettes----------**GO TO S3.6**
2. Yes - Once or twice only
3. Yes - Occasionally, but not regularly
4. Yes - Regularly in the past
5. Yes - Regularly now

S3.2 How old were you when you first smoked a cigarette?

_____ years old (***WRITE IN***)

S3.3 How many cigarettes a day did you smoke in the past 30 days (past month)? (***CIRCLE ONE CODE***)

1. None at all
2. Less than 1 cigarette per day
3. 1-5 cigarettes per day
4. 6-15 cigarettes per day
5. 16-25 cigarettes per day
6. 26-35 cigarettes per day
7. over 35 cigarettes per day

S3.4 Have you ever smoked cigarettes daily for 6 months or more? (***CIRCLE ONE CODE***)

1. No----------**GO TO S3.6**
2. Yes

S3.5 For how many years did you/have you smoke(d) cigarettes daily?

_____ years (***WRITE IN***) 00 = NEVER SMOKED CIGARETTES DAILY

S3.6 Have you ever smoked any form of tobacco other than cigarettes (e.g. cigars or pipe tobacco, etc)? (***CIRCLE ONE CODE***)

1. No - Never ----------**GO TO S3.9**
2. Yes - Once or twice only
3. Yes - Occasionally, but not regularly
4. Yes - Regularly in the past
5. Yes - Regularly now

S3.7 How old were you when your first smoked any form of tobacco other than cigarettes?

_____ years old (***WRITE IN***)00 = NEVER SMOKED ANY FORM OF TOBACCO OTHER THAN CIGARETTES

S3.8 Have you ever smoked any form of tobacco other than cigarettes daily for 6 months or more (***CIRCLE ONE CODE***)?

1. No
2. Yes

S3.9 Have you ever used chewing tobacco, snuff or other smokeless tobacco (use local examples eg "jarda" and "pan masala" India)? ***Only ask where this practice exists.***
(***CIRCLE ONE CODE***)

1. No - Never----------**GO TO S3.11**
2. Yes - Once or twice only
3. Yes - Occasionally, but not regularly
4. Yes - Regularly in the past
5. Yes - Regularly now

S3.10 How old were you when you first used chewing tobacco, snuff or other smokeless tobacco?

_____ years old (***WRITE IN***) 00 = NEVER USED CHEWING TOBACCO, SNUFF OR
OTHER SMOKELESS TOBACCO

S3.11 How many of these have you smoked (or used) on average per day in the past 30 days? (IF NONE WRITE 00). ***Use local names for these or similar.***

Manufactured/brand cigarettes _____
Hand-rolled cigarettes _____
Pipefuls of tobacco _____
Cigars or cigarillos _____
Beedis/goza/hookahs _____
Pinches of snuff _____
Quids of tobacco _____

SECTION 4: ALCOHOL USE

The following questions are about alcoholic drinks, that is beers, wines, spirits *(such as give local examples*) and local (traditional) drinks *(such as give local examples eg: "samsu" Malaysia, "tepache" Mexico, "arrack" India, sud Zimbabwe).*

S4.1 Have you ever had an alcoholic drink (***CIRCLE ONE CODE***)?

1. No----------**GO TO S5.1**
2. Yes

S4.2 About how old were you the first time you had an alcoholic drink? (Do not include childhood or medicinal sips)

_____years old (WRITE IN) 00 = NEVER HAD AN ALCOHOLIC DRINK

S4.3 When did you last have an alcoholic drink (***CIRCLE ONE CODE***)?

1. Today
2. Yesterday
3. In the past week
4. In the past 30 days
5. More than 30 days (month) ago, but less than 12 months ago------**GO TO S5.1**
6. More than 12 months ago----------**GO TO S5.1**

S4.4 On how many days in the past 30 days (past month) have you had an alcoholic drink?

_____days (***WRITE IN***)

S4.5 Think back over the last or 30 day, how many times have you had five or more drinks in a row? (A drink is (local definition eg "copas" Mexico)) (***CIRCLE ONE CODE***)

0. None
1. Once
2. Twice
3. 3 -5 times
4. 6 - 9 times
5. 10 or more times

S4.6 On the days that you drank during the last 30 days, about how many drinks did you usually have a day?

Usual number of drinks: _____ (***WRITE IN***) 00 = DID NOT HAVE ANY ALCOHOLIC DRINKS IN LAST 30 DAYS

SECTION 5: OTHER DRUG USE

READ OUT: "Now I am going to ask you some questions about drugs you may have used or tried. For each drug I mention, I am going to ask you if you have ever at any time used the drug. I am then going to ask you how old you were when you first used it. Then when the last time was that you used the drug, how often you have used the drug in the past thirty days and how you have used the drug".

FOR EACH DRUG ASK:

S5.1 Have you ever used/tried (***NAME DRUG,*** E.G. cannabis such as marijuana, hashish, grass, bhang, ganja, etc.)?

[IF NEVER USED CODE AGE FIRST USE 00 AND **GO TO NEXT DRUG**]

[IF EVER USED GO TO **S5.2**]

S5.2 How old were you when you first used (***NAME DRUG***)? [***WRITE IN AGE FIRST USED***]

S5.3 Have you used any (***NAME DRUG***) in the past 12 months? [**IF NO GO TO NEXT DRUG**]

S5.4 On how many days in the past 30 days have you used any (***NAME DRUG***)? [***CIRCLE ONLY ONE CODE FOR EACH DRUG AS FOLLOWS***]

0. No, did not use it in past 30 days----------**GO TO NEXT DRUG**
1. On 1-2 days
2. On 3-5 days
3. On 6-9 days
4. On 10-19 days
5. On 20 or more days

OR_____ days (***WRITE IN NUMBER OF DAYS***)

S5.5 In what ways have you used (***NAME DRUG***) in the past 30 days? [***CIRCLE CODES FOR EACH DRUG AS FOLLOWS***]

1. Eating/Swallowing
2. Smoking/"chasing"
3. Sniffing/"snorting"
4. Injecting
4. Other ways_____) (WRITE IN)

5.6 Are there other drugs not mentioned that you have used in the past 12 months without a doctor telling you to do so?(***CIRCLE ONE CODE***)

1. No
2. Yes

[IF YES, ASK THE NAMES OF THOSE DRUGS AND WRITE BELOW]

_____
_____
_____

SECTION 6: DRUG INJECTION/SHARED USE OF INJECTING EQUIPMENT

READ OUT: The following questions are about injecting drugs. By this we mean (*describe local practices*)

S6.1 Have you ever used a needle to get any drug injected under your skin, into a muscle, or into a vein without a doctor or health worker telling you to do so (***CIRCLE ONE CODE***)?

1. No----------**GO TO END**
2. Yes

S6.3 How old were you when you first used any drug with a needle without a doctor or health worker telling you to do so?

_____ years old (***WRITE IN***)00 = NEVER INJECTED A DRUG

S6.4 When was the most recent time you used any drug with a needle without a doctor or health worker telling you to do so (***CIRCLE ONE CODE***)?

1. Today
2. Yesterday
3. In the past week
4. In the past 30 days
5. More than 30 days and less than 12 months ago
6. More than 12 months ago
7. Have never used a drug with a needle without a doctor or health worker's instructions

S6.5 Which drugs have you ever used with a needle without a doctor or health worker telling you to do so? (***WRITE IN RESPONSE***)

_____
_____
_____

"Sharing a needle" means using a needle for injecting drugs when you know or suspect that the needle has been used by someone else. It also means someone else injecting drugs with a needle you have used. (this is just an example; field investigators should define "sharing" as appropriate for their context).

S6.6 Have you ever used a needle for injecting drugs when you knew or suspected that the needle had been used by someone else (***CIRCLE ONE CODE***)?

1. No
2. Yes

S6.7 Has someone else ever injected drugs with a needle after you used the needle (***CIRCLE ONE CODE***)?

1. No
2. Yes