# Developing an Integrated Drug Information System

# GAP Toolkit Module 1 Part I

## **Pre-publication version**

**UNDCP** Vienna International Centre Austria



United Nations New York, 2002 The contents of the *GAP Toolkit Module 1: Part I Developing an Integrated Drug Information System* was produced by the United Nations International Drug Control Programme as part of the activities conducted under the Global Assessment Programme on Drug Abuse (GAP).

For further information visit the GAP website at *www.undcp.org*, email *gap@undcp.org* or contact: Demand Reduction Section, UNDCP, P.O. Box 500, A-1400 Vienna, Austria.

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# Preface

*GAP Toolkit Module 1: Developing an Integrated Drug Information System* was prepared with the support of the United Nations International Drug Control Programme under the Global Assessment Programme on Drug Abuse (GAP). The main objective of GAP is to assist countries collect reliable and internationally comparable drug abuse data assists with building capacity at a local level to collect data that can guide demand reduction activities, and also to help improve cross-national, regional and global reporting on drug trends.

The GAP To support this process, the GAP Toolkit Module 1 "Developing an Integrated Information System" has been produced to assist UN member states to develop systems to collect drug information that are culturally appropriate and relevant to their country, and to support existing drug information systems to conform to internationally recognised standards of good practice, and focus on harmonization of drug abuse indicators.

Module 1 of the GAP Toolkit forms one component of a compendium of methodological guides that have been developed to support data collection activities. Other modules currently under development provide support in the following areas: school surveys, in-direct prevalence estimation techniques, data interpretation and management for policy formation, and basic data manipulation using SPSS.

Other GAP activities include provision of technical and financial support to the establishment of drug information systems and support and coordination of global data collection activities. For further information on GAP Toolkit Modules contact gap@undcp.org or visit the GAP website at www.undcp.org.

The philosophy behind the toolkit is to provide a practical and accessible guide to implementing data collection in core areas. The toolkit modules are designed to providing a starting point for the development of specific activities, referring the reader to more detailed information sources on specific issues, rather than being an end resource itself. GAP toolkits are based on principles of data collection that have been agreed upon by an international expert panel and endorsed by Member States of the United Nations. Models presented are based on existing working models that have been found effective, however, a key principle is that approaches have to be adapted to meet local needs and conditions. This module of the toolkit therefore provides specific examples to guide the reader on the nature of how general principles and models can be adapted to specific contexts, and is not intended to reflect the complete range or diversity of current drug information systems or data collection methods.

For further information visit the GAP website at *www.undcp.org*, email *gap@undcp.org* or contact: Demand Reduction Section, UNDCP, P.O. Box 500, A-1400 Vienna, Austria.

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# Abbreviations

AIDS	Acquired Immunodeficiency Syndrome
ARQ	Annual Reports Questionnaire
ATS	Amphetamine type stimulants
BRQ	Biennial Reports Questionnaire
CARIDIN	Caribbean Drug Information Network
CEWG	Community Epidemiology Work Group
CICAD	Inter-American Drug Abuse Control Commission (OAS)
DIRS	Drug Information Report System
EADIS	East African Drug Information System
EMCDDA	European Monitoring Centre for Drugs and Drug Addiction
ESPAD	The European School Survey Project on Alcohol and Other Drugs
GAP	Global Assessment Programme on Drug Abuse
GHB	Gamma-hydroxybutyrate
HBV	Hepatitis B virus
HCV	Hepatitis C virus
HIV	Human Immunodeficiency Virus
IDRS	Illicit Drug Reporting System
IDU	Injecting Drug Users
LSD	Lysergic Acid Diethylamide
RAS/RSA	Rapid Situation Assessment
UN	United Nations
UNDCP	United Nations International Drug Control Programme
SACENDU	South African Community Epidemiology Network on Drug Use
SADC	South African Development Community
SENDU	Southern African Community Epidemiology Network on Drug Use
SIDUC	Inter-American Uniform Drug Use Data System
WHO	World Health Organisation

# **1** General Introduction

#### Background

Although there are countries that can claim successes in controlling the demand for illicit drugs, abuse throughout the world continues to grow. In particular, illicit drug abuse in some developing countries has increased dramatically. However, knowledge of the scale of illicit drug use is still inadequate, and understanding of the patterns and trends limited.

To provide effective policies to reduce drug abuse, governments need data about when, where and why people use illicit drugs. Patterns of drug use transcend national borders as users in all regions of the world get access to a greater variety of drugs, and as social trends, particularly among young people, spread more rapidly than before via better communications. The globalization of drug abuse means that demand reduction policies also have to be global, as must the information system on which they rely.

In 1998 Member States of the UN adopted a Political Declaration<sup>1</sup> to eliminate or reduce significantly the supply and demand for illicit drugs by the year 2008. This is the first time that the international community has agreed on such specific drug control objectives. However, the systematic data that is needed to monitor and evaluate progress towards these goals are not yet available. For this reason, the UN General Assembly requested the United Nations International Drug Control Programme (UNDCP) to provide Member States with the assistance necessary to compile comparable data. UNDCP was asked to collect and analyse these data and report them to the UN Commission on Narcotic Drugs. As a response to this need UNDCP launched the Global Assessment Programme on Drug Abuse (GAP). GAP has been designed to:

- Support Member States to build the systems necessary for collecting reliable data to inform policy and action
- Encourage regional partnerships to share experiences and technical developments
- Facilitate a better understanding of global patterns and trends in drug abuse by encouraging the adoption of sound methods to collect comparable data.

These aims reflect the challenge posed in the Guiding Principles of the 1998 Political Declaration, which calls for:

"demand reduction programmes should be based on a regular assessment of the nature and magnitude of drug use and drug-related problems in the population... These assessments should be undertaken in a comprehensive, systematic and periodic manner, drawing on results of relevant studies, allowing for geographical considerations and using similar definitions, indicators and procedures to assess the drug situation."<sup>1</sup>

The main objective of the Global Assessment Programme on Drug Abuse (GAP) is to assist Member States build the capacity to collect internationally comparable drug abuse data and assess the magnitude and patterns of drug abuse at country, regional and global levels. Development of these national and regional information systems should not only assist with building capacity at a local level to collect data that can guide demand reduction activities, but also to improve crossnational, regional and global reporting on drug trends. To support this process, the GAP Toolkit Module 1 "Developing an Integrated Information System" has been produced to assist UN member states to develop systems to collect drug information that are culturally appropriate and relevant to their country, and to support existing drug information systems to conform to internationally recognised standards of good practice, and focus on harmonization of drug abuse indicators. Standardization of indicators and the wider adoption of sound methods for data collection will result in an enhanced analysis of trends in drug abuse in both the industrialized and developing world. For more information on GAP visit the GAP website at *www.undcp.org*, email

<sup>&</sup>lt;sup>1</sup> Special Session of the General Assembly Devoted to Countering the World Drug Problem Together, 8-10 June 1998.

*gap@undcp.org* or contact: Demand Reduction Section, UNDCP, P.O. Box 500, A-1400 Vienna, Austria.

# Principles and core indicators of data collection: the Lisbon consensus

Integral to efforts to improve international data on drug consumption is harmonization of data collection methods and activities. An important first step in achieving harmonization was taken in January 2000 with a joint meeting of representatives from international bodies, regional drug information networks, and other relevant technical experts. The purpose of this international expert forum was to discuss the principles, structures and indicators necessary for effective drug information systems. The meeting was hosted by the European Monitoring Centre on Drugs and Drug Addiction in Lisbon and was supported by UNDCP under the Global Assessment Programme on Drug Abuse. Particular consideration was given by the international expert panel to the development of a set of core epidemiological demand indicators were chosen as they address areas in which routine data collection was considered possible at least for some countries. They are not intended to provide a comprehensive information base for all policy questions, as areas that require dedicated research exercises are not suitable for inclusion in an ongoing information system. The identified core indicators and a discussion of their application follows:

#### Drug consumption among the general population

Drug consumption among the general population pertains to estimates of the prevalence and incidence estimates for drug consumption among the general population (those aged between 15-64 years). Understanding the level of drug consumption in any population is often the starting point for policy discussions. Generating general population prevalence and incidence estimates is therefore a key task of most drug information systems. Attention is often focused on prevalence estimation. However, incidence (new cases) levels are likely to be equally important for informing policy formation. In respect to both prevalence and incidence estimation it should be noted that this area does not lend itself to any single methodological solution. Whilst surveys provide one method for achieving estimates in this area, other estimation techniques. In many countries conducting national prevalence surveys may be currently not possible for reasons of cost, or because of methodological or practical difficulties.

#### Drug consumption among the youth population

Drug consumption among the youth population refers to estimates of the prevalence and incidence of drug consumption among youth (those aged between 15-24 years). Because drug consumption among young people is often a particular concern of policy makers, and because age cohorts of young people make a convenient sampling unit, estimates of drug consumption among the youth population form an important part of many drug information systems. School surveys have been used extensively to generate estimates in this area. However, because school attendance patterns vary between countries, and because surveys may exclude important sections of the youth population, other approaches may also be necessary.

#### High-risk drug abuse

High-risk drug abuse pertains to estimates of number of drug injectors and proportion engaging in high-risk behaviours and estimates of the number of daily users, regular or dependent abusers. Some drug taking behaviors are particularly associated with severe problems and as such merit attention. The most common data collected in this area are, the numbers of drug injectors, and the 'dependent' or very frequent users of drugs. Specific methods are needed to gain information on behaviours like injection as their hidden nature and low prevalence usually mean that they are poorly covered by general population estimates. In respect to drug injection and the transmission of infectious agents it is also necessary to collect information on rates of high risk injecting behaviours (equipment sharing).

#### Service utilization for drug problems

Service utilization refers to the number of individuals seeking help for a drug problem. Drug treatment registers are often used as a proxy indicator of treatment demand. This information is useful for analysis of service utilization and can be used as an indicator of trends in prevalence and patterns of high-risk drug consumption. These drug treatment registries may not be appropriate where general health and social services are the main providers of help. It should be remembered that across countries the scale, structure, and nature of services for those with drug problems vary greatly. Therefore, definitional clarity is particularly important in service utilization reporting, as is an understanding of the methodological and analytical issues pertinent to drawing conclusions from service populations to drug problems among the general population.

#### **Drug related morbidity**

Drug-related morbidity pertains to cases of disease directly or proportionally attributable to drug consumption, and in this context refers principally to HIV, HBV and HCV infection rates among drug injectors. Health costs are of obvious importance in informing policy development with regard to illicit drug consumption. Common measures include drug-related infections such as HIV, Hepatitis B, and Hepatitis C, and behavioural risk factors, among drug injectors. Conceptual problems do exist in this area and further development work is required. In particular, problems exist in estimating the contribution that drug consumption has made to cases of disease in which there are other additional attributed causes, and in calculating the proportion of cases in which drug use is the sole attributed cause when a number of possible causes exist.

#### **Drug related mortality**

Drug related mortality refers to the data on the deaths directly attributable to drug consumption. Whilst potentially useful and clearly important reliable data on this area is usually not widely available. Diagnostic criteria do exist to distinguish between psychiatric morbidity attributed to drug consumption and other psychiatric morbidity. However, this level of detail is often unavailable. There is also considerable debate about the potential of some illicit substances to cause psychiatric problems as well as the role of pre-existing psychiatric conditions in the development of drug problems. Regardless of the nature of the relationship between drug consumption and mental health problems, co-morbidity remains a major concern as elevated levels of drug consumption are often found among those with mental health problems. This area is currently poorly understood and requires further research elucidation.

#### **Principles for Data Collection**

In addition to gaining consensus on the core indicators of drug consumption, there was agreement on the principles that should under-pin data collection activities. The collection of meaningful data on drug consumption should be guided by the following broad principles:

- Data should be timely and relevant to the needs of policy makers and service providers.
- Whilst not sufficient in themselves for a comprehensive understanding of patterns of drug consumption, efforts to improve the comparability and quality of data at international level should focus on a limited number of indicators and a manageable priority core data set.
- Simple indicators of drug consumption must be subject to appropriate analysis before strategic conclusions can be drawn. Analysis and interpretation of basic statistical data is greatly enhanced when combined with research, both qualitative and quantitative, and with broader information on context.
- Multi-method and multi-source approaches are of particular benefit in the collection and analysis of data on drug consumption and its consequences.
- Data should be collected in accordance with sound scientific methodological principles to ensure reliability and validity.

- Methods need to be adaptable and sensitive to the different cultures and contexts in which they are to be employed.
- Data collection, analysis and reporting should be as consistent and comparable as possible in order to facilitate meaningful discussions of changes, similarities and differences in the drug phenomenon.
- Methods and sources of information should be clearly stated and open to review.
- Data collection and reporting should be in accordance with recognized standards of research ethics.
- Data collection should be feasible and cost-effective in the terms of the national context where it occurs.

#### Human Networks and Organizational Structures

It is recognized that the identification of good methods alone is not sufficient for improving data collection capacity. It is also necessary to develop appropriate networks and organizational structures to provide the infrastructure necessary to support data collection. To this end, there is a need for improved capacity to analyze and interpret information on drug consumption, and this depends on the application of good methods, human resources and the availability of appropriate This will require training and technical support, ongoing political support and resources. investment in this area to ensure sustainability and success of data collection systems. Throughout the guide we make reference to some of the regional and national systems that have been developed in this area. These systems and networks allow for a dialogue between scientists and policy makers that can ensure that data collection meets the needs of policy formation. While expenditure on data collection has to be cost effective given the resources available within a country, it also needs to be accepted that investment in data collection activities is both necessary and resource efficient in that it improves the development, targeting and evaluation of other demand reduction investments. In many countries we now find recognition by policy makers of the value of sound information as well as an appreciation of the infrastructure needed to provide this information. It is part of the purpose of this toolkit to summarize the lessons that have been learnt in this development process to assist countries that wish to adopt a strategic approach to developing their information resources.

The discussion paper arising from the 'Lisbon Consensus' meeting (E/CN.7/2000/CRP.3) was endorsed by UN Member States at the 43<sup>rd</sup> Session of the Commission on Narcotic Drugs in March 2000, and can be found on the GAP website (http://www.undcp.org /pdf/drug\_demand\_gap\_lisbon\_consensus.pdf).

#### Global mechanisms for data collection

Getting a comprehensive picture of the global patterns and trends in illicit drug consumption is not an easy task. At a Global level one mechanism exists that is designed to assemble an overview of the world drug abuse situation – The Annual Reports Questionnaire (ARQ). The ARQ is the mechanism used by Member States meet the obligations of the Drug Control Treaties to report on various aspects of the illicit drug problem to the Commission on Narcotic Drugs (CND). Further information can be found at www.undcp.org. Most pertinent to monitoring global patterns and trends in drug consumption is part 2 of the ARO, which can be found in the supporting material of this Toolkit Module. Part 2 of the ARQ has been adopted in a revised form from January 2002 to reflect the agreed core indicators of drug consumption (see above overview of indicators under **Principles** of Data collection or go to: http://www.undcp.org/pdf/drug demand gap lisbon consensus.pdf) and be sufficiently versatile to allow countries at different levels of data collection capacity to report. Specifically, the revised ARQ provides for global data collection on an agreed set of core drug consumption indicators using three levels of reporting: summary expert opinion, unstandardised or partial quantitative data, and standardised quantitative data. While the ARQ is only intended as a summary data set, it does provide a useful vehicle for encouraging the adoption of multi-source data collection methods and harmonized core indicators. The ARQ is not intended to be sufficient for all the needs of policy makers, but can provide a basic structure for data collection efforts. Countries that adopt the core measures found in the form also ensure that data collection exercises result in information that is compatible with international standards.

Currently, the a picture of the global drug situation is built upon ARQ data in conjunction with other published material on drug consumption, and relies heavily on data provided by national and regional level drug information systems. A copy of the most recent report on the world drug abuse situation can be found at http://undcp.org/cnd\_session\_45.html.

#### Summary

Reliable, accurate and up-to-date data on drug consumption is needed to guide the implementation of demand reduction activities, however, such data are lacking in many countries. Available data often varies in quality, methods of collection and is difficult to compare across countries and regions. Therefore, there is a pressing need in many countries to foster ongoing political commitment for the collection of data on drug consumption and its consequences; support the development of technical expertise for the sound collection and analysis of data; and establish and support human networks for the collection, analysis and dissemination of this data on drug consumption. This toolkit is a forerunner to the development of sound data collection activities, by supporting the development of human networks around which specific data collection activities can grow, while maximizing the utilization of existing information, local knowledge and available infrastructure. The toolkit is based on the principles for data collection that were identified in the Lisbon Consensus statement. The areas identified for inclusion in an ongoing routine data collection system reflect the core indicators of the ARQ.

#### Why collect drug abuse information?

Data on drug use and abuse answers key questions that enable an appropriate public health response from policy makers. It has been pointed out numerous occasions that for conscientious policy makers dealing with drug problems accurate data ought to be a fundamental element of sensible decision-making.

Policy-making decisions are all too often determined without consideration of epidemiological data. This data is not only useful to show that a nation or a region experiences a drug problem but the value of data related to drug use and abuse assists at all levels at which relevant health decisions have to be made.

At various levels records from clients may justify the plea for the financial aid to establish or improve a service. For example, records of the type of drugs used, type and frequency of sexual risk behaviour and the number of self-discharges in comparison to the previous year can provide in-depth information about the functioning of treatment services and systems. In addition they can pinpoint areas for improvement of the service.

At the community level data may help to identify trends within communities and enable policy makers to identify shortcomings at an early stage and be able to take appropriate counter measures. The early detection of crack cocaine consumption in a community where only marijuana use was known or new methods of use are highly relevant. This information provides a background for local strategies for prevention, treatment and control.

At the national level, strategies are increasingly focused on demand reduction, which must be based on reliable and valid epidemiological data. Furthermore, countries where national data is regularly collected are able to participate better in international discussions on drug issues. The regular assessment of the status of drug use and abuse can also serve as an early warning systems that will alert other countries, as new trends in drug abuse have the tendency to cross national borders and spread to neighbouring countries.

Finally at the global level drug use data helps to develop new global drug control policies. A global information system can facilitate the building of political resolve and spirit cooperation between industrialized and developing countries to combat the spread of illicit drug use, strengthening the common and shared responsibility to implement and evaluate global demand reduction strategies.

For further discussion of issues around drug epidemiology and policy refer to the *Bulletin on Narcotics*. Vol. LIV, No. 1, 2002, while further guidance on the interpretation of data for policy is provided under the GAP Toolkit (*http://www.undcp.org/drug\_demand\_gap\_m-toolkit.html*).

To inform current policies regarding interdiction, prevention and treatment by:

- Identifying existing drug use patterns—types of drugs available and types of drugs used by whom and in what ways
- Detecting new drugs being used or new methods of using existing drugs
- Monitoring changing trends in drug using patterns over time, over geographic area and across population groups

# **2** Description of an Integrated Drug Information System

#### Background

Drug abuse has become a global problem requiring more comprehensive international cooperation to reduce the availability of and demand for drugs. Although drug abuse is becoming an increasing problem for many countries, the experiences to address the problem have been largely those of the more affluent developed countries. Probably the most important lesson learned by these countries is that to understand their drug abuse problems and to be more efficient in addressing these problems a multi-source Integrated Drug Information System is essential. Such a system, if well designed, not only will provide information on the types of drugs being used and the characteristics of those using them but also will generate questions for other more focused studies to provide information that would serve to plan effective prevention and treatment programs.

In many parts of the world those responsible for responding to drug problems, at both at the city level and the national level, do not have access to centralized data systems that provide information regarding drug-using patterns. This Toolkit has been designed to assist researchers and administrators who wish to develop such data systems so that key questions about drug use in their countries can be addressed and appropriate decisions about programming interventions can be made. The challenge to those who wish to undertake the creation of a centralized data system to assess drug abuse/misuse is that in most countries the use of drugs is highly stigmatized. There may be laws against the possession and use of drugs making those who use them law-breakers and/or the general public may hold negative social attitudes towards those who use drugs. In these types of contexts, drug users often wish to hide their behaviors. In addition, the very nature of drug use, i.e., the variability in the types and qualities of drugs available, is dynamic and amorphous requiring timely assessments on a regular basis. Such conditions have made the assessment of drug use highly complex and multiple methods to collect information on drug use have been developed. To make information available that captures the drug use situation at any particular time as accurately as possible requires a number of data gathering activities. These may range from key informant interviews or conducting focus groups with drug users and professionals such as law enforcement officers or drug use treatment providers to large household surveys. Those researchers who conduct such studies describe these activities as the tiles within the true mosaic portrait of the drug using population. Each activity or tile provides a bit of information that describes drug use.

NOTE:

Drug use is a difficult and complex topic to monitor. All information sources have limitations and reflect only one aspect of the behaviour. Therefore, for a comprehensive understanding it is necessary to develop a multi-source or multi indicator system that can provide insight into the different aspects of the problem.

The approach that is recommended by the Toolkit is the development of an Integrated Drug Information System. Such a system includes an accumulation of a database made up of information from a variety of both "passive" sources such as existing reports or other databases and "active" sources such as population surveys. These data are reviewed by a group of drug abuse experts who are familiar with and interested in the local drug problem. These experts discuss the data that has been collected to interpret what the data suggest and what questions they can answer with them. The experts also specify gaps in the database, set priorities as to which gaps need to be closed and develop specifics about how to address these gaps. A summary of the data and the outcome of these discussions are prepared in a report that is disseminated to policy makers, program planners and practitioners and other researchers. The focus of this Toolkit is on local systems, i.e., information systems that consist of data for a city or county. When several cities within a country, or several countries within a region want to form a larger, system, such a system or network would consist of one representative from each of the local systems or networks. Each representative would present the findings from his/her network.

The Toolkit is written to help those interested in developing an Integrated Drug Information System at a local level. It is organized as a guide to a process of self-assessment and planning. It begins with a description of an ideal Integrated Drug Information System. This description is followed by a self-assessment process, called an "Information, Needs and Resources Analysis", that can be completed by an individual or, preferably, a group of individuals with an interest in drug use. The assessment is designed to determine what resources are available within the defined geopolitical area that can be incorporated into a data system and what resources are missing from having a complete system in place, and undertakes a strategic analysis of this information to formulate a strategic development plan. The next process outlined in the Toolkit assists in setting priorities among these gaps. Finally, the Toolkit offers step-by-step procedures to help address those gaps identified as being important. The Toolkit can be used by individuals or groups to conduct their own assessments or can be used in a formal training program. It is recognized that developing a comprehensive information system on patterns and trends in drug abuse will be a long-term endeavor. This module of the toolkit is designed to help the formulization of a development strategy, based on an analysis of existing resources, which is informed by local priorities and identifies realistic, short, medium and long-term goals.

Further guidelines on carrying out drug abuse epidemiology can be found on the GAP website, *http://undcp.org/drug\_demand\_gap.html*, and the World Health organization Guide to Drug Abuse Epidemiology, 2000 (http://www.who.int/substance\_abuse/pubs\_psychoactive\_drugs.htm).

#### To build a local system requires:

- a coordinator, someone with a strong interest in developing the system who is ideally knowledgeable about existing data sources and knows other drug abuse (e.g., drug abuse treatment providers, drug abuse researchers, drug abuse preventionists) and drug abuse-related professionals (e.g., mental health specialist, university researchers, law enforcement officers/data persons, and medical examiner/coroners).
- an interactive network of drug abuse and drug abuse-related professionals with access to
  existing data and who are committed to meet at least once a year for a full day; to bring their
  data to the meeting for discussion. This network is extremely important particularly when one
  is not sure what information is available or where to look for data.
- clarification of the objectives of the network:
  - identify existing drug abuse patterns within the defined geographic areas and periods of times covered by the data to be decided upon by the group
  - identify changes in drug abuse patterns over defined periods of time, including types of drugs, modes of administration and characteristics of drug users
  - monitor these changes to determine if they represent emergent drug problems
  - disseminate information to community agencies and interested professional groups.
- development of a standardized way of reporting information at the meeting
- stimulation of discussion of findings to address the objectives of the network
- development of a final report format
- development of a dissemination plan that includes a mailing list.

#### Drug abuse epidemiology and information systems

Key to knowing what data sources could be included into an information system is an understanding of the epidemiology of drug abuse. In general, epidemiology is an approach to organizing information regarding a health condition to identify what is the cause of the condition and how to reduce or eliminate its impact on the morbidity (those getting ill) and mortality (those dying) of both those affected by the condition and those vulnerable to becoming affected.

Epidemiologists will accept that a certain percentage of the population will experience some health conditions, for instance some children will not be inoculated for measles and therefore will contract measles or some children will be genetically predisposed to diabetes; however, when these percentages increase, or if affected groups evidence differing characteristics, epidemiologists become concerned. They then conduct analyses of existing data to generate hypotheses to explain these increases or changing characteristics. It is these hypotheses that form the core of epidemiological research. The findings from the studies addressing these hypotheses then become the basis for prevention interventions and research. Therefore, epidemiological studies include those that are referred to as descriptive — from which hypotheses are generated and those that are analytic — that address specific hypotheses. This Toolkit focuses on the first type of study, descriptive epidemiology.

Descriptive epidemiology serves to answer the "what" and "who" questions such as:

- what is the nature of the drug use problem in this population (what drugs are being used; how are they used; how frequently are they used)?
- to what extent is the general population using these drugs (what is the rate of new use within the past year, how many persons have been using drugs for more than one year)?
- who are the persons using these drugs (what are their characteristics, are both males and females using drugs, are youth using drugs)?
- what are the social, psychological and health problems associated with the use of these drugs and are they acute or short-term problems or are they chronic or long-term problems (do people who use drugs have more family problems, do they have difficulties keeping jobs, do they drop out of school)?

Because the field of epidemiology evolved from studies of persons with infectious diseases, epidemiologists are interested in rates of people who have the condition within defined populations within specific periods of time. Any changes in these rates over time would suggest a renewed epidemic. Therefore, it is important to be specific about the population base and the time period covered by the data one is studying. Are the data from one locale or are they from the whole country? Are the data available for only one year or are they collected every year? Answers to these questions begin to specify the drug-using problem. Systematic collection and review of data provides better evidence to support prevention and treatment efforts. This is the basis for an Integrated Drug Information System.

Networks are usually geographically based, i.e., city/country/province/state/nation/region. Often this geographic base is hierarchical, with city based systems being combined to form a state or national system, and combined at a country level to form a regional system., and so forth.

Monitoring of drug trends within a network is often done a sentinel fashion. That is, selected areas of a geographic region (e.g., city) and/or the drug using population (e.g., injectors, treatment attendees) are monitored through the systematic collection of data on key issues that warrant surveillance. For instance, in the United States, the community epidemiology work group consists of cities from across the United States including the Northeast, Southeast, Central, Northwest, Southwest and West regions, and Hawaii. Although certain drug patterns are consistent across cities there are preferences that are unique also. Methamphetamine use is more prevalent in San Diego and the west while crack cocaine is more prevalent in the northeast. Yet

with changing drug trafficking patterns, the use of methamphetamine is increasing in the central and northeast areas and crack cocaine is becoming a problem in the west in certain populations. Sentinel systems for a region allow monitoring of such changing trends. While a sentinel system does not provide data representative of the entire population of drug uses, it allows one to keep a watchful eye on trends in problematic drug use, or other pertinent drug use issues, in a cost-effective and convenient way.

Selected examples of regional and national level drug information systems are provided here, while descriptions of different drug information systems and related issues can be found in UNDCP (2002). *Global Workshop on Drug Information Systems: Methods, Activities and Future Opportunities, December 3-5 2001: Vienna, Austria. Meeting Proceedings.* UNDCP, Austria.

	Examples of Drug Information Systems
Regional systems/networks	The Pompidou Group of the Council of Europe http://www.coe.int/pompidou European Monitoring Centre for Drugs and Drug Addiction http://www.emcdda.org Inter-American Drug Abuse Control Commission (CICAD) and the Inter-American Uniform Drug Use Data System (SIDUC) http://www.cicad.oas.org/en/Observatory/Main.htm Caribbean Drug Information Network (CARIDIN) http://www.carec.org/projects/caridin_daess/caridin_daess.htm Southern African Development Community Epidemiology Network on Drug Use (SENDU) http://www.sadc.int/index.htm
National systems	Community Epidemiological Work Group (CEWG) http://165.112.78.61/CEWG/CEWGHome.html Illicit Drug Reporting System (IDRS) http://ndarc.med.unsw.edu.au/ndarc.nsf/website/IDRS South African Community Epidemiology Network on Drug Use (SACENDU) http://www.sahealthinfo.org/admodule/sacendu.htm Canadian Community Epidemiology Network on Drug Use (CCENDU) http://www.ccsa.ca/ccendu/index.htm Drug Information Report System (DIRS) in Mexico

## **Composition of an IDIS**

Any Integrated Drug Information System (IDIS) should consist of three components:

- (1) input,
- (2) interpretation, and
- (3) output.

An Integrated Drug Information System consists of data or input relative to measures of drug use within a population within a specified period of time, a review and interpretation of these data by local experts who know some aspect of the drug use problem, and a mechanism for reporting out the findings from these reviews and interpretations that reach other researchers, prevention and treatment providers and policy makers. This section will describe the structure and operation of an ideal system drawing on the experiences of successful systems. Table 1 provides selected examples of drug information systems and their internet contact details. For a review of these and other systems refer to the proceedings of the Global Workshop on Drug Information Systems: Activities Methods and Future *Opportunities* (see http://www.undcp.org/ drug demand gap datacollection.html#core).



# Input – Data Sources

An integrated information system can have the ability of addressing a number of important questions regarding drug using patterns and the characteristics of users that would assist prevention and treatment programming. The extent to which these questions are adequately and appropriately addressed depends on the types of data sources that are available.

The stigma associated with the use of drugs makes the development of an information system challenging. Although such stigma is not usually attached to other health conditions, collecting health information from the public is still quite difficult for in most cases a diagnosis is required. Therefore typical data sources in the area of health are medical files or population surveys. Persons who have health problems are likely to show up at a hospital, emergency department, or the offices of a medical practitioner. Their complaints are reviewed, tests run so that a diagnosis can be made and treatment initiated. Sometimes these diagnoses and the characteristics of the patients are reported to some central file such as a registry or insurance billing offices, sometimes if a serious infection is noted, reports are made to the local health department.

In population surveys, symptom lists are used to determine who in the survey may have certain health conditions. Information then is gathered as to whether the person sought medical care and received a diagnosis and was treated.

In many ways similar approaches are used to compile information regarding drug use. An understanding of problems associated with drug use assist in determining where and what kinds of information are available. This section will discuss the four major sources of data for drug use: existing data, population surveys, key informant interviews and other ethnographic approaches.

Data coming from existing databases and surveys are considered quantitative. As existing data generally are not direct measures of a problem, many people label them as being more qualitative. However, qualitative or ethnographic data more accurately reflect the context in which a behavior takes place. Although a tension exists between the quantitative and qualitative researchers, the nature of drug abuse epidemiology is such that both approaches are extremely important. Recognition of the significant contributions of qualitative research is underscored by the recent publication by the *European Monitoring Centre for Drugs and Drug Addiction* of the monograph, *Understanding and Responding to Drug Use: The Role of Qualitative Research (Fountain et al., 2000)*.

Summary of Methods			
Method	Advantages	Limitations	
General Surveys	Broad coverage	Validity and Representativeness	
	Trend data, if repeated	Expensive and training needed	
	Precision	May miss users of some drugs	
	Scientific standardized methods	May miss some "hidden" groups	
Special Population Surveys	Targeted coverage	Validity and representativeness	
	Information on users of specific drugs	Expensive and training needed	
	Information on "hidden" populations	Sampling difficult	
Existing Data	Readily available	Validity and representativeness	
	Inexpensive	Subject to collection bias	
	Can look at changes over time	"Known" users only	
Rapid Assessment Methodology	Rapid, inexpensive and multi- method	Validity and representativeness	
	Relevance to interventions	Training needed	
Key Informant Interviews, Focus Groups	Inexpensive	Validity and representativeness	
	"Hidden" populations	Training needed & access can be difficult	

#### **Existing Data**

To determine where to look for data on drug users, one must think about the natural history of drug use. We know that each drug does have a physiological effect on the user. Sometimes this effect is severe, sometimes it is mild. Many existing sources of data are based on records\_relating to the negative consequences of drug abuse (e.g., hospital admissions). It must be remembered that many more people experiment with drugs than go on to use them on a regular basis, and that this former group of experimental drug users is less likely to appear in these type of data sets. It is also the case that different drug types and consumption patters are differently associated with the likelihood of the individual experiencing problems. Most drugs are not used in their pure form and may be mixed with substances that are harmful. In addition, the way the drug is used can have health effects. For instance, injecting drugs particularly with unclean needles can cause emboli or clots, sepsis and other infections, such as transmission of HIV. Sometimes, the user will overdose on the drug and die. Also we know that as a user becomes more dependent on certain drugs they develop a tolerance for the drug and require higher and greater dosages to achieve the desired effects and to ward off withdrawal symptoms. Some of these individuals will seek treatment either by their own volition or though, their families, employers or the judicial system. Finally, drug users may violate local drug laws or get involved in illegal activities to support themselves and their drug use.

This review of the natural history of drug use suggests six potential sources for information on drug users: hospital admissions and emergency department logs; public health reports on infectious diseases, including HIV, Hepatitis B and C; poison control reports; medical examiners/coroners or other death records; drug use treatment admissions; and arrest reports

	•	hospital admissions and emergency department logs;
of lata	•	public health reports on infectious diseases, including HIV, Hepatitis B and C;
es c Jg d	•	poison control reports;
Typ istir	•	medical examiners/coroners or other death records;
ex a	•	drug use treatment admissions; and
	•	arrest reports

#### Other existing data sources

Other types of data that networks have utilized from law enforcement include drug *seizure information* such as amount and type of drugs seized over a specific period of time. In addition, information on the *street price of drugs* and the *quality/purity of street drugs* has been collected. There are obvious limitations as to how to use or interpret this information but, surprisingly, over time, price and quality of street drugs can take on significance particularly when used with other information gathered from more reliable sources.

#### Limitations

These are good sources of information but each also has certain limitations. Probably the greatest limitations to these sources are:

(1) they can include persons who may have used drugs only once;

- (2) they are not "population-based", i.e., prevalence and incidence rates of drug use for the general population cannot be directly calculated from these numbers;
- (3) as a drug user could appear in one or all of these records, one cannot consider each record independent of the others;
- (4) these records are sensitive to administrative and policy changes, e.g., if a city official, in response to public opinion, orders a crack-down on drug users, the numbers of arrests will increase; or the type of treatment available to drug users will influence the number that find it attractive; and
- (5) these records usually have not been prepared with the needs of a drug epidemiologist in mind and therefore may not contain the necessary information or be coded in a way that allows tracking of patterns of drug consumption.

#### Surveys

Two types of survey data are considered: general population surveys and surveys of special populations. What distinguishes surveys from existing data is that the former is an active data collection effort while the latter is more passive including data that are collected for other purposes such as documenting arrests, people coming into the emergency department for care or deaths.

<i>(</i> 0	•	General Population Surveys use standard survey and sampling techniques to assess drug use in the population as a whole.
ions	•	School Surveys access drug abuse within a particular age band or school grade.
ulat	•	Special Surveys:
ey Pop		<ul> <li>Focused surveys to assess drug use within a particular sub- population with a high risk of drug use, such as the homeless, sex workers, street children, or children excluded from school.</li> </ul>

 Surveys of drug users within the community who are usually not in touch with treatment or other services, which are used to explore behaviour of current drug users

#### **Population surveys**

Sur

General population surveys, if done well, can provide a great deal of information regarding the rate of existing drug use (*prevalence rates*) and the rate of new drug use (*incidence rates*), for commonly used drug types. That said, the high cost and technical resources required for a national household survey (e.g., large sample size requirements, need for an appropriate sampling framework, ensuring data confidentiality and quality of self-report data on illicit activities) make implementation cumbersome in resource poor settings.

The procedures used to select potential respondents to the survey will also determine how representative the responses are to the survey and the denominator for the rates that will be calculated from the data that are collected.

When conducted in a standard way over time, population surveys are able to provide not only prevalence and incidence rates but also patterns of use, trends in patterns of use and

characteristics of users, and correlates and consequences of drug use. Population surveys therefore can be valuable epidemiological tools.

Population surveys can be administered to a general population of residents within an area or of school students. Two examples of the application of general population surveys can be found at *http://www.emcdda.org/situation/themes/drug\_use\_general\_population.shtml* and *http://www.samhsa.gov/oas/oas.html*, while school surveys are discussed in the following subsection.

There are three major methods for conducting surveys:

- (1) *face-to-face* with an interviewer reading the questions and completing the answer sheet or being present when the respondent completes the answer sheet him/herself (self-administration);
- (2) *over the telephone* with either a live person asking the questions and completing the answer sheet or having a computer asking the questions and having the respondent indicate the response using the telephone pad numbers/letters; and
- (3) *through the mail* with the respondent completing the surveys and returning them through the post.

The third method has not been widely used at all as the rates of returned survey forms are generally very low. Studies have found that telephone interviews produce lower reported rates of drug use but the costs associated with telephone interviews are lower than the face-to-face approaches. Most surveys of drug use are administered face-to-face within a household or within a school. In schools the surveys are generally self-administered to whole classes within the classroom under the supervision of a trained research staff member.

It should be noted that while national level general population surveys can provide valuable information on the prevalence and incidence of commonly used drugs, they perform poorly in respect to the more problematic and stigmatized patterns of drug abuse, such drug injecting. Problematic drug use patterns tend to be "missed" by general population surveys because problematic drug users tend to concentrate in geographic clusters or "regions", are less likely to reside in conventional living settings (e.g., a proportion may be homeless, in hospitals etc.), may under-report on their illicit activities. Moreover, the low number of problematic drug users detected through household surveys and the lack of any detail obtained on their behaviour means that targeted surveys of problematic drug users are necessary to understand problematic drug using behaviour. With regard to estimating the size of problematic drug using populations, indirect methods of estimation are often preferred, the implementation of these methods being covered in Module II of the GAP Toolkit (*http://www.undcp.org/drug\_demand\_gap\_m-toolkit.html*) and discussed in the *EMCCDA Scientific Monograph Series No. 1 "Estimating the Prevalence of Problem Drug Use in Europe.* 

#### Household vs. School surveys for adolescents

In countries where both household or general population and school surveys are conducted, it has been shown that youngsters aged 12 to 17 tend to report lower rates of drug use when interviewed within the household than they do when surveyed in school. It is suggested that the difference is the greater anonymity that the classroom presents compared to the home where parents or guardians have a presence even if not proximal. However, the problem associated with school surveys is that young drug users are more often truant than their non-drug using peers and may be absent at the time the survey is conducted. There are always trade-offs when conducting this type of research.

Further information on school surveys can be obtained from the Monitoring the Future project (*http://monitoringthefuture.org*) and the European School Survey Project on Alcohol and Other Drugs (*Hibell et al., 2000. The 1999 ESPAD Report, Swedish Council for Information on Alcohol and Other Drugs and The Pompidou Group at the Council of Europe*).

#### Other population surveys

Other groups that may be surveyed are the homeless and street youth. Sampling techniques have been developed to ascertain an approximation of the total number of homeless and street youth (the denominator) so that both prevalence and incidence rates can be estimated. In addition it is possible to conduct surveys in those institutions from which existing data are also available. For instance, one could have staff interview incoming arrestees or emergency department patients. Again, sampling procedures can be applied to assure representation of the universe of arrestees or patients.

Surveys of drug users themselves are subset of population surveys, but they provide different information and rouse different methodological challenges due to the difficulty defining the parameters of the illicit drug using population. Surveys of drug users can provide in-depth information about low prevalence behaviours that are likely to be underrepresented in household or school surveys. While these surveys cannot in themselves be used to estimate prevalence, they can provide some of the information necessary for the estimation of prevalence using indirect methods. They are also often used in conjunction with a combination of other methods in rapid assessment methodology. As with household surveys, special population surveys can use face-toface, telephone or mailed interviews. However, the often itinerant or chaotic nature of some drug using populations generally precludes the use of the latter two techniques as they tend to result in very low response rates. Due to the hidden nature of illicit drug using populations, special consideration also has to be given to sampling methods used. The challenges presented by sampling a hidden population are often out-weighed by the information provided by these surveys, as even small-scale surveys of drug users can produce valuable results that would be difficult to generate by other means. For example, if heroin were being used by one percent of the population, even a very large sample of the general population, for example 10 000 people, would only generate a small sample of heroin users (i.e., 100, assuming that heroin users were adequately captured by the survey and prepared to take part) which may not be sufficient for a meaningful analysis to be conducted. Therefore, it is usually more cost-effective and practical to try and directly sample populations of problematic drug users through specialized surveys of community drug users.

For further information on specialized surveys of drug using populations and their application to drug information systems refer to *http://www.undcp.org/drug\_demand\_gap\_m-toolkit.html, Medina-Mora et al. (2000) WHO Guide to Drug Abuse Epidemiology,* the EMCCDA Scientific Monograph Series No. 1 "Estimating the Prevalence of Problem Drug Use in Europe, Handbook on snowball sampling (1997). Pompidou Group: Group of Epidemiology Experts in Drug Problem, Council of Europe, ", Hando et al. (1998) Addiction Research, 6, 97-113, and ODCCP guidelines on Drug Abuse Rapid Situation Assessments and Responses (1999).

#### Key Informant and other Ethnographic Methods

#### When to use qualitative data

Given the multiple roles of qualitative approaches, there are three situations in the development of an information system that would benefit greatly from key informant interviews or other ethnographic studies:

(1) when there are no existing data or very limited data available,

- (2) to augment data that are available, and
- (3) to interpret collected information.

For more detailed information on qualitative data collection refer to the *European Monitoring Centre for Drugs and Drug Addiction monograph, Understanding and Responding to Drug Use: The Role of Qualitative Research (Fountain et al., 2000).* 

	The use of key informant information and ethnographic studies are essential to understanding drug abuse patterns in any area and in any population. Rhodes (2000) points out that there are several important roles that ethnographic studies can play:		
	<ul> <li>reaching and researching hidden populations – using qualitative sampling methods such as snowball sampling that employ field workers and informants from the target population or others who have easy access;</li> </ul>		
collection	<ul> <li>understanding the experience and meaning of drug use – exploring the social meanings that drug users attach to their use of drugs and the social processes by which these meanings are created and reinforced, e.g., sharing injecting equipment is not just a behavior associated with the transmission of HIV or other viruses but it a social behavior that makes human connections and symbolizes trust and reciprocity;</li> </ul>		
Roles of tive Data C	• understanding the social contexts of drug use–specifying the interaction and interdependence of physical and social environment and drug using behaviors, e.g., the rules of a shooting gallery regarding the sale and rental of injecting equipment effect behaviors that place injectors at risk for infection;		
Qualita	<ul> <li>informing quantitative research – elaborating or "putting on the flesh" on quantitative information, e.g., understanding the many processes or steps in sharing injecting equipment such as the difference between 'front-loading' and 'back-loading';</li> </ul>		
	<ul> <li>complementing and questioning quantitative research – like the above, qualitative approaches remind us that it is the experiences of the drug users that we are attempting to understand in order to reach them not to be blinded by our own perspectives; and</li> </ul>		
	• developing effective intervention and policy responses-identifying processes and relevant contexts for reaching and engaging drug users into interventions that strive to address the needs and experiences of drug users.		
inc	Caution must be taken when using these approaches. Too often the interviewing of key informants, the use of focus groups, or of going into a group and making		
CAUTIO	observations seems far easier than collecting existing data or conducting a survey. However, qualitative research is science based and also requires training to make the information gathered meaningful and valid. All of these approaches are active, requiring data collection that is standardized but open-ended.		

#### **Key Informants**

Key informants can serve to *provide information when data are sparse*, to better characterize existing data and to *interpret the results of data analyses*.

Interviews with key informants and 'gate keepers' to the data and the populations of interest should be a part of the Integrated Drug Information System. These interviews describe the nature of the drug abuse problem within an area:

- what types of drugs are available,
- how they are used,
- what populations are using them and
- what are the significant consequences of their use.

They can also provide the *context* in which the existing data are collected, *describing biases in these data* as well as whether upward trends represent increased use or administrative changes in the data collection itself. In addition, asking for the key informants' interpretation of the data collected provides *further understanding of the meaning of the findings*.

As it was recommended to seek a variety of existing databases to reflect the natural history of drug abuse within a community, it is also important to select key informants representing these perspectives, and also to include drug users themselves. Interviews can be conducted individually or in a group, as is done with focus groups.

_ <u>t</u>	•	Treatment providers and/or treatment counselors
	•	Outreach workers and/or other people who work with substance abusers on the streets poison control reports
stec	•	General health workers, youth workers or community workers
gge Info	•	Law enforcement officers, customs officials
su (ey	•	Emergency/ambulance teams, hospital staff, emergency department staff
x	•	Infectious disease officers

 Active drug users representing diverse subpopulations defined by age, gender, socioeconomic status, ethnic groups or preferred drugs

#### Focus groups

Focus groups are another group approach to collecting information. These are composed of small group of individuals who have been recruited because of their knowledge about some aspect of the drug scene. Focus groups are sometime conducted with current drug users, recovering addicts, young people, or professional groups, like those working in drug treatment. Groups can be heterogeneous or homogeneous and must feel comfortable to freely discuss the topic of interest. The advantage of this technique is that a considerable insight into the topic in question can be gained quickly and cheaply. However, the quality of the information is critically dependent on having a good facilitator who will ask an open-ended question or make a statement to open discussion. The facilitator does not lead but guides the discussion making sure that all group members participate. Such facilitation requires a great deal of skill and training. The information from focus groups also has to be interpreted with caution, as it cannot be necessarily assumed to be generalisable beyond the membership of the group.

#### **Other Ethnographic Approaches**

Other ethnographic approaches can be used to collect information as well. These include contextual mapping used to characterize an area describing ethnic neighborhoods, placement of churches, dealing areas, site of social or health agencies, locations of bars, pubs or taverns. Use of ways to organize information, such as: free listing, pile sorts, network analyses, narration or sequencing of events or projective assessment techniques. All of these approaches provide the context of drug abuse patterns in an area.

NOTE:

All of these approaches are useful when an emergent drug abuse pattern is noted in an area. The question is whether this emergent pattern is "real" or is it an artifact of the data collection agency or methodology. Digging into how the pattern emerged, what consequences should be expected, and if it will grow and expand can be successfully explored with key informants and focus groups.

## Further information on data collection methods

Additional details regarding these data collection methods are included in the following section. When to use these methods and the advantages and disadvantages associated with each and solutions to the disadvantages are also presented.

NOTE:

When starting an information system in a country where existing data sources are not developed, key informants can still provide unstructured reports from their own experience. For example, in some African countries the initial network meeting received reports from treatment specialists, doctors, and community workers on the nature of the drug problem in their particular area. This provided valuable starting point for a discussing a more structured data collection exercises.

# Interpretation: Networks and Communication

#### Introduction

Integrated Drug Information Systems require as their core, a network of community-based agency representatives with an interest in public health and drug abuse, which form a communication network. The network members share a common goal: the elimination or reduction of drug abuse and its health and social consequences; and recognize that effective strategies need to be built on a sound evidence base. The role of the network is to provide this information and engage in a dialogue with policy makers on its implications for programming. In most cases, network members are those who have access to information or know where such information is available. The network members meet periodically, usually once or twice a year, and bring their data or information to the meeting to be reviewed, compared and discussed by the other members of the network. Members considered for the network include researchers as well as representatives of agencies that work with drug abusers, such as public health and other medical agencies and institutions, law enforcement agencies, drug abuse treatment programs, and sometimes local schools.

Such networks have many advantages:

- They are practical
- They are not costly

- They make good use of existing data and other information
- They have been used around the world quite effectively
- They provide immediate feedback
- They take advantage of many levels of expertise
- They provide comprehensive information that addresses[r6] the missions of multiple agencies
- They bring together professionals who would normally not interact
- They build an infrastructure to support further research

#### Organization of a Network and its Communication

#### Sponsorship of the network

The sponsorship of a network by an agency is advantageous as it puts that agency at the forefront of the issue and provides up-to-date information on the problem, particularly any emergent drug problem. Such sponsorship also has public relations opportunities to keep the public abreast of the problem and what actions the agency is taking to respond. Furthermore, once an emerging drug problem is identified, the sponsoring agency can take the lead in a community response to the problem.

#### National focal points

Most regional drug epidemiological networks, such those in Southern Africa, the European Union, the Americas and the Caribbean operate through a focal point system. One agency performs the role of a focal point for data collection for the country as a whole and is usually responsible for preparing a national report and presenting this in the regional forum. For national systems, nominating a focal point is highly recommended. It is also important to check that a focal point does not already exist for this kind of activity.

#### Who should form part of the network?

Initially at least, networks are best when they are small and the meetings are well - planned. Size is important as everyone in the network should have sufficient time to present their data and to allow full discussion. As indicated above, network members should be recruited from several different types of agencies so that multiple perspectives – legal, medical and social–are represented. If multiple geographic areas are represented, then time needs to be spent on making cross area comparisons.

#### Involving heads of agency

Although networks do not usually include agency directors or department heads, the successful networks begin by getting the support of these individuals. A meeting with agency officials or their representatives to talk about the network group would provide similar information and gain their cooperation. In this meeting, the purposes and advantages of the network, network membership including knowledge, skills and agency commitment in terms of manpower and accessing information could be discussed.

#### Hold an initial planning meeting

One of the outcomes of a meeting with heads of agency would be the structuring of a planning meeting. The planning meeting would bring together the agency representatives who may or may not become members of the network. The planning meeting would establish a common understanding of what the network purposes are, what agencies have data and therefore should have places in the network, what other groups should be included in the network and a plan made for sending out invitations to the next network meeting. The time and place for the first meeting and a meeting agenda also should be developed. Plans for at least one subsequent meeting would also be useful.

#### The first network meeting

The first meeting of the network is very important as it establishes whether there will be further such meetings. Clarifying the purpose of the network and each person's role should be emphasized during the course of the meeting. The first meeting should *identify known or potential sources of data and information*. It would be useful if the network had reports from other similar networks even from other countries for additional ideas. For those network members who brought information, time should be made for their presentation with follow-up discussion. *Plans for follow-up activities* such as accessing other data or making contacts with others and even inviting others to join the network must be well documented and assignments made to network members. The *network coordinators* will contact network members with

assignments to determine progress or if they need to give assistance. At the first meeting it will be important to decide how the information presented at the network meeting will be recorded, reported and disseminated. Finally, *dates, times and places for subsequent meetings must be decided*. Early on in the life of the network, it will be important for the group to decide on a *standardized format for presentations and reporting*.

# **Output: Reporting**

Successful information systems and networks are those that reach out to decision makers and program planners within their regions. What to report and in what format the report is made are significant to the life of an information system. Network reports should reflect issues that are of importance to network members. In general there are three reports that should be considered:

- (1) reports made during the network meeting,
- (2) reports on drug patterns, and
- (3) reports of drug patterns by geographic area.

#### Standardized Network Reporting

The importance of *standardized reporting formats* for the network members was mentioned above. Time given to each member presenting their information should be sufficient but not so long that any one person will dominate the meeting. Usually reports will mention how many individuals are represented by the data, what their characteristics are, at a minimum, age group, sex, ethnicity if relevant, and what drugs are used.

With standardization, comparisons can be made across data sets (e.g., comparing characteristics of arrestees to new admissions to drug abuse treatment) and across time. The latter is important for determining if there are changes or trends in the drug using population. For example, in the early 1990s reports from drug abuse treatment programs in some cities in the United States mentioned increased numbers of new admissions who were using heroin by snorting or inhaling it. This observation presaged an upsurge in the use of heroin that reached into school-aged populations.

In addition, networks that include representatives from a number of different communities will find that having standardized reporting makes comparisons across these geographic areas easier to do. Finally, standardized reporting and reports can be easily used by policy makers and others who have little time to review information. Standardization can be facilitated by the use of report data forms.

#### **Reports on Drug Patterns**

Reporting the data out to policy makers, program planners, practitioners, researchers and the public so that it is useful is very important. One approach is to summarize by drug category.

#### For instance:

"Indicators of methylenedioxymethamphetamine (MDMA or ecstasy) are increasing in the Smalltown Area. Use of the drug is spreading from raves and dance parties to high schools, colleges, and other social settings frequented by youth and young adults."

"Cocaine indicators have trended downward or stabilized in the past few years, as the negative consequences of crack use generated an awareness of its risks among potential users. Recent data show that indicators were stable or mixed in 12 areas, decreased in 6, and increased in 3".

More detailed information within drug category regarding the source of the information and the characteristics of the users can also be added.

For examples, see reports such as:

CEWG Epidemiologic Trends in Drug Abuse–Volume 1: Proceedings of the Community Epidemiology Work Group, June 2000;

Extended annual report on the state of the drugs problem in the European Union (1999), European Monitoring Centre for Drugs and Drug Addiction (EMCDDA).

Australian Drug Trends 2000. Findings from the Illicit Drug Reporting System (IDRS). National Drug and Alcohol Research Centre (NDARC) Monograph No. 47. University of New South Wales, Sydney, Australia.

Monitoring of Alcohol and Drug Abuse Trends in South Africa. Proceedings of SACENDU Report Back Meetings, March 2000.

Types of reports and target audiences			
Type of Report:	Content:	Audience:	
1) Meeting reports	Details of presentations	Network members and sponsors	
2) Policy reports	Executive summary and recommendations	Legislative members, programme planners, fiscal managers	
3) Mass media	Key findings	General public and community to public health and safety practitioners	
4) Publications	Research findings	Professionals in administration and research	

## Reports of Drug Use Patterns by Geographic Area

If data are available by geographic areas, for instance within a city or between cities, a report with sections focused simply on these geographic areas is useful. Comparisons across geographic areas are appropriate, particularly if similar data are collected and particularly when sufficient

data are available over time. Caution should be used, however, in interpreting these comparisons as the reasons for any differences or similarities found would require further investigation.

There are many ways to present data for geographic areas. The most useful organization for such presentation would be first to summarize the types of drugs used and by whom they are used, including source of data (e.g., cocaine use among women arrestees has risen over the last two years).

Both program planners and policy makers need a brief summary of the findings in the report, the interpretation of what the findings mean and a translation of how these findings impact interdiction and prevention and treatment practices. Therefore, no matter which reporting format is used, having an executive summary is extremely important.

#### Summary

This section provided an overview on the importance of having an Integrated Drug Information System and a description of the components of such a system. The following section provides guidelines on how to develop a drug information system. Before embarking on development of a drug information system, an audit of existing information and resources should be undertaken. This process is designed to help the user of this Toolkit to assess the availability of data for his/her region and, and based on this assessment, begin to plan the development of an Integrated Drug Information System. This process will ensure maximum utilization of existing resources and information, and therefore a more effective and efficient drug information system. A guide to undertaking such an initial assessment accompanies this Toolkit Module as Part II: *Information, Needs and Resources Analysis (INRA)*. Based on the findings of the INRA, the final section provides guidelines on How To:

- (1) establish a local network and communication system;
- (2) develop data sources and data base; and,
- (3) develop reporting formats and distribution systems.

# **3** Development of an Integrated Drug Information System

# Introduction

This section of the Toolkit presents guidelines or the "how to's" on establishing a network, on identifying data sources and establishing databases, and on writing reports. In addition, when databases are discussed, the advantages and disadvantages of each data element and approach are presented. Establishment of a drug information system should be guided by an initial assessment of what information is available, what human resources and infrastructure can be used to support the system, and some planning as to the purpose, nature, scope and structure of the initial network. A guide to undertaking such an initial assessment accompanies this Module as Part II: *Information, Needs and Resources Analysis (INRA).* The findings from the INRA will guide you in determining the baseline information and resources available for your information system.

# Establishing a Network

There are a number of steps that can be taken to establish a network. There are key features to a network. It SHOULD be:

- Comprehensive: including diversity with representation of a number of perspectives treatment, law enforcement, health, policy, research;
- Small enough to allow presentation of information and discussion of findings;
- Flexible enough to allow the inclusion of additional expertise;
- Lead by a coordinator who will organize meetings, agendas, and reporting; leadership could be rotated among network membership;
- Committed to meet on a regular basis at least once a year; preferably twice a year depending on the dynamic nature of the drug abuse problem.

In Section II, Inventory of Resources, you formed an ad hoc group of drug abuse experts to assist you in assessing the availability of relevant data to be included in the new Integrated Drug Information System that you and your colleagues are creating. In the course of this review, your group probably has identified additional members to include in your network. At some point in this process, it will be important for the network to examine what each current network member brings to the network in terms of skills and data, and to determine what components are missing. You should be thinking about both skills and data in these deliberations. In the skills area you may want research capabilities, public relations or communications expertise and political connections. When thinking about data it is important to think not only about what may exist but also about data that will be needed in the future.

*The first meeting is an extremely important one*. It is at this meeting that decisions will be set as to how the network will function. The following material is taken from pages 7 and 8 of the United States' National Institute on Drug Abuse publication, Assessing Drug Abuse Within and Across Communities (see resource list for reference).

"The first meeting is critical because it sets the stage for what the surveillance network will be, how it will function, and how it will be perceived by participants and others.

Two interrelated objectives should always be kept in mind:

- obtaining knowledge about drug abuse; and,
- developing and strengthening the work group.
Care should be taken to avoid common pitfalls that others have encountered in planning initial network meetings. Four principles should be observed:

- 1. **Start small.** Be selective in inviting individuals to attend. -It is easy to add individuals once the needs, sources have been identified, and to change individuals based on the strengths and interests of the members.
- Have clear, attainable objectives for the meeting. Avoid trying to overachieve at the beginning.
- Establish the agenda in coordination with other participants so they feel invested from the beginning.
- Give each participant a role to play and a contribution to make.

The first meeting should be organized to accomplish several objectives:

- Identify known and potential sources of data and information. Selected participants can be asked to describe particular data sets and to prepare and briefly present data from sources to which they have access.
- Review the types of data sources (indicators) accessed by other epidemiological networks to determine if they might be obtainable in your area. If they are, determine what steps should be taken to identify agencies and individuals who can provide access to each of these sources.
- Assign participants to follow up (after the meeting) and, if appropriate, make contacts to find out what types of data are available, how the data can be made available, and who is most knowledgeable about the data and the data sources.
- Determine how the information from the meetings should be recorded, reported, and disseminated, including to whom it should be sent. A full report with all the information will prove useful for agency planners, grant writers, and staff associated with the network member agencies. An executive summary that brings all the information together in a quick-reference format will prove very popular with the press and the general public.
- Identify current and potential sources of support for organizing and conducting the meeting, and producing and disseminating reports from the meeting. The full report should be based largely on the papers prepared and presented by participants along with data tables.

Surveillance networks need to remain focused on questions such as: What drugs are currently being used? Who is using them? Are drug use patterns changing from year to year? If so, how?"

#### **Network Parameters**

There are four essential parameters of a successful network: size and breadth, short meetings, an energetic coordinator, and meeting procedures report.

#### Size and breadth

Although broad representation is desired, it is also important that networks be small enough to allow discussion. Members should ideally include representatives from a variety of organizations with different perspectives on drug abuse in your area. The following areas are commonly represented in network meetings:

- drug abuse treatment
- medical examiner/coroner
- public health department biostatistician/planner
- university researcher or groups with access to survey data
- any outreach worker group that works with drug abusers on the street

Law enforcement

#### Short meetings

The members of the network group more than likely will be very busy people, therefore the meetings should be kept a short as possible. Sufficient time should be made for:

- Every participant with data and a data report to present his/her findings
- After each presentation or group of presentations; allow time for discussion of what the data show
- Follow up on issues that may have been raised at earlier meetings
- Discuss the agenda, date, time, and place of next meeting.

#### An energetic coordinator

Almost all successful networks have had an energetic coordinator who was thoroughly committed to the network process. Although once the networks are established they do not require a great deal of work, establishing the network does involve time devoted to contacting individuals, making up the agendas for meetings, keeping the meetings on time but still allowing participants to play their roles and overseeing the preparation of proceeding reports for dissemination. Anyone beginning a network must recognize, first, that the initial time s/he will devote to the network may be significant but, second, that once established much of the work can be designated and less time will be needed.

#### Meeting procedures report

Many networks fail because there are no meeting reports prepared. When this happens, participants have nothing to show their superiors, the network losses credibility, and interest in the network declines. The meeting reports do not have to be elaborate. They can consist of an executive summary, which is extremely important (see section on reports), and an appendix that includes all of the reports and tables submitted by network members. Their reports should follow this same format; an executive summary or narrative and tables.

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This section provided an overview on the importance of having an Integrated Drug Information System and a description of the components of such a system.

- Knowledge about their domain: health, research methods, treatment of drug abusers, crime, seizures
- Familiarity with others interested in drug abuse through their own or related agencies and organizations
- Skills—academic or research, political, policy, programmatic, planning, "frontlines/on the street"
- Access to data sources and understanding their limitations and strengths

## ★ It is very important to note here that networks are confronted by common problems that need to be addressed.

- Recognize that network members have their own interests; they have different training and different orientations. As such, they may not understand what is expected of them. It is therefore important that a specific format for their presentation at the network meetings be sent to all members of the network prior to the meeting.
- All of us get excited about our own areas and therefore when presenting data from these areas we often go off on tangents, keeping on schedule is very important. Therefore, all presenters must be told in advance of the meeting just how much time they will have to present. It will be difficult at first to keep presenters to their time allotment but the chair of the network must develop a system to let the presenters know how much time they have remaining and when their time is up to go on to introduce the next presenter.
- Turnover of network participants is often a problem. Finding interested members to take their places is sometimes a greater problem. Whoever coordinates the network should realize that recruitment sometimes is an ongoing task. That again is why, providing a report that is useful to the member agencies is important. If an agency finds that the network has worth, the agency will assign someone to work with the network. Keeping in contact with agency directors on a regular basis to thank them for their involvement with the network also is extremely helpful.
- Government/political support is also very important in many countries and having the support of the drug coordinator (if one exists) or a representative from the health ministry can be useful. However, it must also be remembered that the network should be a technical rather than a political forum and should be led by its technical members. This issue will vary greatly across countries. However the key point is for the network to be able to 'speak' to a policy audience whilst remaining a technical body. Having participation from the University and academic sectors is often very useful in ensuring this balance.

	Developmental stages of a drug information systems
	Systems usually start small, building on a couple of existing data sets that are easy to access and analyze. From there, other elements can be added to make the system stronger. If there is absolutely no data available to start with, getting touch with the right people who have contact with drug users and who know about the drug-using situation is a good starting point. Once a broad understanding of the situation is developed, other potential methods for collecting data or obtaining existing data will probably become clear. For example, these types of people can very easily form a key informant network that can provide updates on the drug situation. Below are some general examples of possible different stages during the development of a network and the different components and activities that may occur during these developmental stages.
tting started	<ul> <li>A meeting of key stakeholders with a discussion of the available data and potential data sources. This process can be done more formally through an Information, Resources and Needs Analysis (INRA) to guide the development of your network (see accompanying module).</li> <li>An analysis of some recent available existing data, possibly for:</li> <li>treatment demand data</li> <li>arrest data (i.e., possession and use of illicit drugs)</li> </ul>
Ge	<ul> <li>Review of any existing surveys of drug use (school surveys, specialized surveys, general population, rapid assessments)</li> <li>Expert opinion – e.g., gain the views of those working with drug users about the types of drug used and main drug problems and related-issues.</li> </ul>
Intermediate steps	<ul> <li>Once a network is established, the next step is to gradually improve the data sources. This may involve refining existing data sources or adding a new source of information. For example:</li> <li>Develop a standardized form for collecting treatment data</li> <li>Set up a key informant network or survey</li> <li>Hold regular (biannual or annual) meetings to analyze, interpret and discuss available data</li> <li>Publish a meeting report</li> </ul>
Further development	<ul> <li>Networks are a dynamic process and they need to grow and change along with other developments and changing patterns in drug consumption. Therefore it is important to always be considering how the network can further develop through additional activities. Some examples of additional activities that the system/network might undertake once it is up an running are:</li> <li>Conduct a school survey or undertake specialized research on a specific drug issue</li> <li>Develop a database for collating and analysing treatment data trends over time</li> <li>Expand the coverage of the data collection activities and/or network participation</li> <li>Hold a training seminar to develop technical skills, such as analysing and interpreting drug consumption data</li> <li>Engage in some inter-country or inter-regional collaboration by inviting participation from an neighbouring network/system</li> <li>Develop an regular reporting mechanism that serves the needs of a target</li> </ul>
	<ul> <li>Develop an regular reporting mechanism that serves the needs of a target audience (e.g., brief easy to read up-dates on drug trends to supplement meeting reports)</li> </ul>

# Identifying data sources and establishing data bases

Gaining access to information requires making and maintaining contacts with sources. The extent to which public organizations such as treatment agencies, hospitals, police departments will make their data or information available on request varies considerably between countries. Stressing that individuals will not be identified can help convince agencies to participate. However, agencies such as private hospitals, which are not obligated to provide information on request, may be difficult to access. In some parts of the world law enforcement agencies do not typically collaborate with health agencies and difficulties may arise in combining these different data sources. As you will want to get information from as many types of agencies as possible, it is important that you convince agency representatives that the inclusion of their information will benefit their agencies or at lest not be detrimental to their interests. Political support can also be very helpful, for example a letter from the Ministry of Health endorsing the network activities can open doors that would otherwise remain closed. Therefore, it is important to be fully prepared before contacting the agencies. It is important to talk about the agency YOU represent and the reason why your agency is interested in the network and how the information will be used and reported. You should also be clear that the project is one that addresses a public health problem and as such it is not necessary for you to have names or addresses of individuals who use drugs but their information is aggregated and quantified. This can be emphasized through a letter that may follow a telephone call or personal visit. If possible, copies of reports or portions of reports from other networks can be shared so the agency contact could see how such information can be used. In addition, of course, it is important to make an invitation to the agency contact to attend any network meeting. To maintain their interest, they should also be placed on the network's mailing list for reports and other materials.

data	•	Convince the agency that they can benefit from the exercise and/or that it will not be detrimental to them
es es	•	Fully explain activities of the network and for what purpose the data will be used
essir Jenci	•	Acknowledge the contribution of agencies and respect their data ownership by only using the information for agreed purposes
acc เ aç	•	Build up personal relationships of trust
or a 'om	•	Get political endorsement for the network activities
Tips f	•	Provide feedback and try to involve the agencies in the network activities where possible

Existing networks vary in their criteria for including data from a variety of sources into their databases. Most of these criteria reflect various levels of scientific rigor as well as availability. For instance, in some networks drug-abuse related arrest data are included while in others it is not. There are inherent biases with almost all available data sets (a discussion of these biases is presented below). For example, the mayor of a town may want to show how effective his administration is by directing the police to arrest all persons found in possession of marijuana. In this case, the data sets on arrests may show an increase in the proportion of marijuana-related arrests. This increase may or may not be associated with an increase in marijuana use in this particular town. On the other hand, including drug-related arrest data with the added knowledge of administrative directives or other artifacts associated with the collection of such data can be very helpful in the long-run as such data will be collected over time and there will be periods when directives will either inflate or deflate numbers. Networks that include arrest data understand these issues and have found that over time arrest data have been useful in understanding the drug problem in their communities. These data are particularly important for

detecting new drugs entering the community for it is often common for the more experienced drug users to have tried new drugs that become available.

In many cases, existing data may not be readily available. Records of drug use patterns may not be kept or those records that are available may be in the form of entries in logbooks or as case files. This will be a major challenge to each network. To make matters more complicated, it is possible that in most communities, there will be a mix of how data are maintained and access becomes difficult.

If data or reports are not available, there are two approaches that can be used to collect information for the network.

- 1. If records are available, it is possible to select a short period such as two-weeks each quarter and transfer the record data to network data forms. This transcription can be done by a network member or a member of the agency staff. In either situation, it is important that the transcription be reviewed for accuracy.
- 2. Another technique that can be used, particularly if record information is not available or if the record information does not include reference to the use of drugs, is to conduct face-to-face interviews with a sample of clients/patients. The sample could be consecutive cases presenting during a two-week period every quarter or some other acceptable approach.

These two approaches are detailed below.

## Focal points as a basis for a regional network – the Caribbean Drug Information Network (CARIDIN)

Most regional information systems recognize the value of establishing national focal points to ensure the continuity of activities. In the Caribbean, the CARIDIN network is based around focal points in each participating country. Focal points act as the national coordinators for information collection, represent the country in regional technical meetings, and prepare an annual national reports. As some Caribbean countries participate in both the CICAD/OAS monitoring activities for the Americas (SIDUC) and in the local Caribbean network having the same focal point both sets of activities ensures coordination and the best use of resources. Further synergy is ensured by adopting comparable measures so that the data collection tools used for network activities do not differ. Focal points provide a useful role by acting as a centre for communication between the different agencies engaged in data collection – they do not necessarily have to collect the data themselves.

## Description of available data

The following is a brief summary of the sources and types of existing data that are collected by networks. In collecting information from any source it is important to remember the following:

- 1. if there is a potential of identifying individuals, caution must be taken to protect them wherever possible by having the agency aggregate or summarize information;
- 2. staff within these agencies who have access to information that the network needs have other primary obligations and may not be cooperative in helping the network; and
- 3. although it may not appear as such, most agencies have limited resources and again may not be as interested in the network unless they can see that it could help them gain access to additional resources.

#### Existing agency data

#### Drug Use Treatment

One of the main indicators used, as a basis for most information systems is reports from specialized drug treatment services. As with health problems, when considering drug use treatment resources one must develop a list of places where drug users would go for treatment. These could be programs that specialize in the treatment of drug use and may be free-standing clinics or centers or they could be units of general psychiatric or medical clinics and hospitals. Treatment programs and medical and psychiatric hospital admission records would be good sources of information on drug use and drug users.

Advantages: As drug treatment programs focus on drug abuse, they are more likely to collect detailed information about what drugs are being used by their clients and how these drugs are used (e.g., injecting, snorting, smoking). In some cases, clients are even tested using urinalyses to determine their current use patterns. In addition, in many cases, drug treatment programs want to know what types of drug problems they may need to address in treatment and therefore may be more forthcoming with information particularly within a network that includes representatives of other types of agencies. Admission forms provide the best information about what drugs clients were using prior to coming into treatment.

**Disadvantages:** In many situations, treatment records include "drug of choice" or "primary drug problem" and may not ask about other drugs. Furthermore, it is important to get information from both publicly and privately funded treatment programs as clientele may use different types of drugs. As mentioned before, another disadvantage of drug treatment information is that those in treatment may not represent the current patterns of drug use; many treated users may be older and the drugs they use may not represent emerging patterns of use. Not all treatment admissions are self-motivated and may be referred from a number of other agencies including law enforcement for a number of non-drug use specific reasons and therefore there may be inherent biases in the treatment information. Another problem is distinguishing between new treatment demands and long time service users. As many drug users drop-out of treatment or relapse after receiving care drug services often have a disproportion number of long term and older repeat attendees. The characteristics of this group may be different to those new clients entering treatment for the first time. Much treatment reporting systems therefore try and distinguish between first and subsequent treatment demands. As some people will also visit more than one treatment service during a reporting period methods have also been developed to avoid the reduce the possibility of double counting. It is also important to remember that drug users typically seek help for a drug problem several years after they initiate their use. Therefore treatment data is considered a

'lagged indicator' of incidence. For example, when the UK drug treatment services started observing large numbers of heroin chasers seeking help in the mid to late 1980s the epidemic of new users was already 5 or 6 years old, having started at the beginning of the decade if not earlier. Another factor that will influence the usefulness of this kind of data is the level of development of treatment services with a country and the range of services on offer. This issue is also important when the scale or nature of treatment provision changes. Increased treatment demand may simply represent an increase in capacity or the development of new services that prove more attractive to those with drug problems. For example, the development of a new stimulant service may lead to increased reports of treatment demand by stimulant users – regardless of patterns of use among within the wider community

**Recommendations:** Understanding how people come to treatment and how information regarding drug use is recorded is important to understanding the data that are collected. Also it is important to show the treatment programs that their participation in the network may help them access additional resources as they can better document the drug abuse situation in their communities. A good example of a treatment reporting protocol that has been widely used in many cities is that of the Pompidou Group first treatment demand (*http://www.coe.int/pompidou*).

#### Treatment data collection – the SACENDU model

The South African Community Epidemiology Network on Drug Abuse (SACENDU) use treatment demand data as one of its core data sources for understanding patterns and trends in drug consumption in South Africa.

In this system, data are collected manually using a standard treatment data form, similar to that used by other systems like the Pompidou Group First Treatment Demand Format (see Exhibit 1). This form is manually completed for each patient and then posted to a coordinator for a designated geographic area, or province, who collates this data. The province coordinator then hosts a meeting with representatives from treatment agencies and other relevant information providers to discuss and interpret their data. A representative from each province then reports, along with other relevant data and/or information, to a national level forum to form a picture of what is happening in their province.

This system works well in South Africa as most of the designated sub-regions, or provinces, have sufficient specialized treatment centers for alcohol and other drug use but not so many that this manual system becomes cumbersome. Also, this manual system overcomes the need for computers and specialized data entry software at treatment centers – with a pencil and postal service being the minimum resources required for participation in the network.

The SACENDU system is now being expanded to other Southern African countries under the SADC network – SENDU – although the relatively low coverage of specialized treatment facilities in some of the Southern African countries has highlighted the need for capitalizing on existing data from non-specialized treatment facilities for drug users such as psychiatric hospitals and general health care settings.

For further information on this treatment reporting system visit the SACENDU web-site: (http://www.sahealthinfo.org/admodule/sacendu.htm).

#### Hospital Admissions and Emergency Department Logs

General hospital data can also be used to collect information on drug consumption but it is usually a more complicated and demanding task than working with specialized drug treatment centers. However, if specialized treatment centers do not exist or have very limited coverage in a country then hospital data, especially that from psychiatric hospitals may provide a good starting point for obtaining information on the types of drugs for which people are seeking help. Record keeping in hospitals varies greatly from country to country. In some countries, hospital admissions and discharges are reported centrally, so that hospitals will have this information available. Elsewhere no central records may be available. If the International Classification of Diseases is used to code the diagnosis associated with the hospital stay then this may allow the number of drug related admissions to be assessed.- However, unless drug use is the primary, secondary or contributing diagnosis it will not appear on these reports. In addition, the individual drug type may not be listed nor will other useful information necessarily be available, like route of administration.

Urgent or emergency medical care is generally provided in a facility for unscheduled services to persons whose conditions require immediate attention. These would include trauma cases as well as overdoses. In many countries, persons without access to medical services (such as those in poverty, new immigrants) will use emergency facilities for less urgent illnesses. Some emergency departments maintain admission logs that include reason for visits and outcomes of visits. However, if the involvement of drugs is not obvious, unless emergency department personnel ask about the use of drugs, there will be no record of such use available.

Advantages: There are a number of advantages for gathering information about drug users from hospitals and emergency departments. Drug abuse epidemiologists believe that when new drugs or new ways to use drugs occur, there will often be people who will have negative physical reactions to them and will either go on their own to the emergency departments or will be taken there by others. In addition, there are many drug users who will not use drug use treatment programs or be arrested who will use the medical care system. Obviously, the development of the health care system and the ease with which those with drug problems can access it greatly influences the potential of this information source. In countries with a tradition of medical reporting and where health care provision is good more potential will exist than for those countries in which access to medical provision is restricted.

**Disadvantages:** The major disadvantages of these resources are: (1) accessing the information and (2) once accessed, the completeness of the information available. As with all of the methods needed to gather information on drug use, particularly on a regular basis, a great deal of 'upfront' foot and mouth work needs to be done. Hospital and emergency department officials need to be convinced of the importance of collecting this information. It is suggested (National Institute on Drug Abuse, 1998) that such information allows local hospitals to document the expenditure of their resources for drug use treatment and will help the local medical community understand the health care needs of drug users so that improved strategies for medical care and for the treatment of drug use can be developed. If however even basic medical provision is restricted then it may be that priority is given to other health needs. Where medical staff are under extreme pressure and resources are limited they may simple not be able to engage in monitoring activities especially if these are not viewed as a priority. The resources available for health care also may influence the willingness of agencies to take part. For example, private hospitals may not wish to engage in what they see as extra work unless remuneration is made. Confidentiality policies can also make medical personal cautious or unwilling to provide information on their patients. This problem can usually be addressed by asking for data in aggregate form and by stressing that no personal identifiers are required and that individual data will be kept confidential. If data can be accessed it may be incomplete with information on patterns of use, drug type and route of administration missing or not collated in a standard fashion. These limitations in data quality can make meaningful analysis of the data difficult

**Recommendations:** Two major approaches have been used to collect this type of information. One way is to select time periods over the calendar year and make access to the hospital discharge logs (discharge is preferable to admission as during the hospital stay, diagnoses are made based on test results) or emergency logs, and either select a random sample of patients discharged or seen in the emergency department and abstract from their medical records. A second method is again to select time periods over the calendar year but have research staff available 24 hours to interview patients about their reasons for their visits and about their drug use. Costs in terms of manpower and training are involved with each approach. It will be important to make sure the times that are selected represent variations in season or climate, in special holidays etc., that the periods of data collection will be sufficient to be able to detect drug use, and that the denominator

of all patients and their visits be kept. This second method allows a standard reporting form to be used prospectively and therefore means that there is more chance that the descriptive information of interest can be collected.

#### Public Health Reports of Infectious Diseases

In many communities and countries there is a requirement to report diagnoses of infectious diseases including human immunodeficiency virus (HIV) infection or acquired immunodeficiency syndrome (AIDS); hepatitis A, B, C etc.; and, sexually transmitted diseases that appear at higher rates in drug using populations. For example, many countries participate in sentinel surveillance systems that continuously monitor sub-population groups, so pregnant women may be anonymously screened for HIV as a convenient sample to explore exposure in the broader community.

Advantages: Like the hospital and emergency department information, the advantage of these reporting systems is that they will include drug users that may not appear in drug use treatment or arrest databases. Furthermore, if it is noted that rates of drug users in these systems are increasing, as they have in many countries, particularly in developing countries, it will be important to target prevention and treatment efforts to limit the spread of infection.

**Disadvantages:** The problem that these systems pose is that most reporting forms do not require reporting drug use or if they do, this information is either missing or inaccurate.

**Recommendations:** It is important to work with those who have responsibility for the reporting requirements for these systems to convince them first to include information on the reporting forms about drug use and second to make sure that the information requested regarding drug use be appropriate and relevant. For instance, just asking about drug use is not helpful. Information is needed about types of drugs used, how drugs are used (e.g., injecting, snorting, smoking, swallowing), frequency of use of drugs, and length of time using drugs.

#### Poison Control Reports, forensic science and medical laboratories

Not every community has a central system for reports of poisonings. However, when these are available they can provide important information on both emergent drug use problems and existing use. Where poison control centers exist both medical personnel and the public report negative health effects of drugs and other substances. For instance, in the United States it has been the Poison Control Centers that brought the use of GHB (gamma-hydroxybutyrate) and its precursor GBL (gamma-butyrolactone) to the attention of the members of the Community Epidemiology Work Group. This drug is used along with MDMA (Ecstasy) in clubs and at dance parties such as raves and can cause death. Similarly in Europe, early warning system links reports from various sources, including forensic science laboratories, to assess the availability and risk of new drugs reported in any one member of the Union. Other routine data sources may arise from medical laboratories, such as screening of intoxicated drivers or sub-populations of drug users in treatment settings.

Advantages: The advantages of using the Poison Control Center reports are similar to the above: detecting emergent drug use problems and getting information on drug users that may not appear in other reporting systems.

**Disadvantages:** Clearly the disadvantages are similar to the other medical-based reporting systems: the reports are on drug use episodes and not necessarily on long-term drug users and may not have sufficient information regarding the specifics of drug use to understand what population is represented in the reports. The number of acute poisoning may be low and for some drug types negligible. In many countries forensic science systems are not sufficiently developed to provide consist poisons reports. Even where they are well developed, difficulties may still exist in correctly identifying the substance responsible for the poisoning especially when multiple substances are being consumed. When using medical toxicology data cases need to be deidentified or confidentiality assured, and sampling issues may present an obstacle for detecting

trends in particular drug types (e.g., tests on intoxicated drivers may over-represent stimulant drugs).

**Recommendations:** It is may be useful to work with the Poison Control Centers/forensic science laboratories to review and revise reporting forms to get the information on drug use that would be needed for the data system on drug users being developed.

#### Medical Examiners/Coroners Reports

In most locales, medical examiners and coroners are responsible for investigating sudden (unexpected) or violent deaths. As legal issues are at stake, they must be able to compile sufficient evidence to support their determination of cause of death. In many countries, their reports of cause of death are an important part of the nation's vital statistics. However, there is great variation in the training of medical examiners/coroners and in their level of expertise and interest in issues such as drug use. Medical examiners/coroners are not always trained medically or legally. The quality of reports of cause of death is therefore likely to vary between areas. For example, in a resent review the practice of medical examiners was found to vary so greatly between European Countries that meaningful comparisons could often not easily be made even where the same international diagnostic criteria's had been adopted. Furthermore, not all deaths are thoroughly investigated and even, in cases where all deaths are investigated, toxicological screens to determine the use of drugs are not always pursued. So it is important to know about these issues when accessing death reports. In addition, in most cases, death data are accessible to the public and special arrangements need to be made to gather this information. Drug users may die from a number of reasons. Cause of death may be directly linked to drug use, such as in drug poisoning or overdose. Or cause of death may be indirectly linked to drug use but to the lifestyle of a drug user such as homicide, suicide, and AIDS or other infection (sepsis, bacterial endocarditis). Or a drug user may die of natural causes and other diseases. Most drug use data systems include information of the direct and indirect causes of death but unless the information on drug use is collected, information for deaths among drug users due to natural causes or other diseases will not be included.

Advantages: This is another source of information, if toxicology or other screening is completed, on emergent drugs of abuse and of drug users that may not be found in the other data sources.

**Disadvantages:** There will be many deaths due to drug use and among drug users that will be missed. The lack of medical training, failure to conduct posthumous investigations and drug testing, and the limitations as to which deaths are referred to a medical examiner/coroner will impact who is reported in this system. The comparability of data on drug deaths between countries is low, and even within countries considerable variation may exist. Many drug users are consuming a range of substances, often including alcohol, and coroner's reports often only report on this in a summary fashion, i.e., 'opiate death'. It can also sometime be difficult to distinguish from deliberate poisonings (suicides) from accidental drug overdoses.

**Recommendations:** A thorough understanding of what deaths are referred to the offices of the medical examiner/coroner will clarify the limitations of these data. In addition, most communities have a central reporting system for deaths. It is important to remember that although all of these data sources have limitations, taken together, they can provide an excellent idea of drug use patterns within the population of the geographic area being considered. Arrangements can be made with the medical examiner/coroner to access their records or they can be made with the local public health agency that is responsible for vital statistics to gain access to reports on periodic basis. There are a number of technical resources on improving data quality and International standards are being developed in this area see EMCDDA web site for a review (http://www.emcdda.org).

#### Law Enforcement

In addition, the illegal nature of drug use in most countries will also place drug users at risk of arrest. Therefore, information from arrest records also provides information about people arrested for drug use crimes. In addition many law enforcement agencies seize drugs and in some cases, analyze the seized drugs as to type of drug and purity levels. Law enforcement agencies may also keep track of the street prices of drugs and have a better understanding as to how drugs are marketed.

Advantages: Law enforcement agencies have access to information that most other agencies do not such as price and purity. They also have the potential as with hospitals and medical examiners to have information on a broad range of population groups including members of the middle and upper socioeconomic classes as they may be called in cases domestic disputes and make arrests for driving under the influence of alcohol or drugs.

**Disadvantages:** As in the cases of the other agency data, law enforcement information is subject to administrative decisions. If there is great public concern about drug abuse, the police are more likely to step up their activities and arrest more drug abusers. Law enforcement agencies may also feel the need to "prove" their worth during times when budgets are being allocated and at those times more drug seizures may be made. In some countries law enforcement agencies do not typically cooperate with health and social agencies and may be reluctant to share their data. The categorization of arrest data may also be misleading. For instance, many jurisdictions have laws against possession and sales of drugs. Persons arrested for these reasons may not necessarily be drug users themselves. For this reason it is important to distinguish between charges related to the use of drugs, the selling of drugs and the trafficking of drugs. When seizure data is analyzed it is particularly important to distinguish between those drugs intended to be for sale within the country and those trafficking of drugs to be consumed elsewhere. Furthermore, drug use carries great social stigma and those from the higher socioeconomic groups may be less liable to arrest, able to have their arrest records expunged or have the reason for arrest altered.

**Recommendations:** Law enforcement agencies vary as to how they record arrest and seizure information. In some areas, specific individuals or divisions are responsible for maintaining data on arrests. As with all the other categories of agency-based data, it is important to understand how these data are recorded and to know what political or social pressures could be occurring that would influence what arrests are made.

Remember that the objective of the network is not only to define the characteristics of the drug abuse problem in the network's target area but also to identify emergent drug abuse patterns. For this reason, having data for sequential time periods, quarterly, semi-annually or annually, is very important. Interpretation of any changes that are observed must be cautiously made with a great deal of consideration of whether what is being observed is an artifact of some administrative decisions or of a real pattern change. For this reason, networks are encouraged to include information from a variety of agencies that at least include a health agency, a law enforcement agency and a drug abuse treatment program. If there appears to be some consistency across these agencies in an emergent pattern, the network members will be more confident about the trend they observe. Also having similar information from a number of geographic areas will further provide reinforcement.

#### Surveys

In general, there are three types of surveys that are available to networks: (1) general population, (2) student, and (3) special populations. General population surveys include either person-toperson, telephone or mailed interviews with a representative sample of the general population usually in households. They vary by age range and whether certain subgroups are over-sampled, i.e., whether the sample of persons being interviewed include larger numbers of groups than actually appear in the general population. For instance, a national household survey on drug abuse may over-sample specific ethnic groups to make sure the number of people representing these groups is sufficient to make estimates of drug use patterns for them. The general population survey can provide a good estimate of the number of persons in the population who use drugs at the time of survey (prevalence) for some drug types. They perform less well for more stigmatized and low prevalence behaviour (such as drug injecting or heroin use). While general population estimates may be cost effective and useful in large developed countries this is not always the case in the developing world. The value of this kind of exercise is particularly questionable in countries that lack a tradition of public polling or where suspicion of the authorities is high among the general public. The high cost of this kind of work and the technical sophistication of the sampling methods required also mean that investing in this kind of activity may not be costeffective at present for many countries in the developing world.

Student surveys provide information on drug use patterns among young people. As drug use is often initiated when people are in their teens, student surveys provide estimates of the incidence of drug use (new cases). These surveys are generally self-administered within the school setting. What ages are targeted for these surveys depend on a number of factors: what existing data and population surveys indicate are ages when drug use is initiated; what are the foci of drug abuse prevention programmes; and, of course, what are the reading and comprehension levels of the students. Usually student surveys are conducted with children 10 and older. Module III of the GAP toolkit gives guidelines on conducting school surveys. Increasing many countries in the world have conducted surveys of their student population and this data can be useful in making comparisons between countries (*http://www.undcp.org/drug\_demand\_gap\_m-toolkit.html*).

Special population surveys are generally conducted with well-defined population groups meeting certain inclusion (and exclusion) criteria. These may include the homeless or street children, users of specific drugs, representatives of special groups such as sex workers, or young people who attend nightclubs or dance events. These 'community' samples of drug consumers can provide rich data about the behaviour of this group, which is difficult to obtain by other means. However, interviewing drug users who are not in contact with services is a challenging endeavor. The primary challenge of special population surveys is estimating the denominator and the characteristics of the total population to allow that the sample surveyed is indeed representative. Further information on the application of special population surveys is provided in the resource list at the end of this section.

All surveys are most useful if they are conducted on a regular basis to allow trend analysis. Annual or biannual surveys using the same survey form, sampling approach and data collection methodology can lead to detection of up and down trends that influence the allocation of resources to either treatment or prevention services.

Advantages: There are several major advantages of surveys over other data collection methods. If well designed, surveys provide the information needed to develop incidence and prevalence rates with precision. They have broad coverage, including those populations of drug abusers who are able to maintain their habits without being arrested or hospitalized, perhaps seeking treatment from private clinics or practitioners. Other information can be added to a survey about the characteristics of drug users compared to non-drug users and about other factors that are of interest to those sponsoring the survey. When surveys are conducted on a regular basis, every year or every other year, it is possible to monitor trends across time.

Panel surveys (longitudinal, prospective studies), in which the same group of people are interviewed on a regular basis, have the potential of identifying risk and protective factors relative to initiation and involvement in drug abuse, documenting the progression of drug using behaviors, and specifying consequences of drug abuse and dependence.

**Disadvantages:** The major limitation of surveys is the failure to identify emergent drug use trends (if you don't ask you won't find out) and their poor performance with stigmatized and low prevalence behaviour. Furthermore, if only a general population survey is conducted without an

over-sample of young people, it will be difficult to ascertain new cases and information on the most affected populations (those that are arrested or live on the streets) will not be available.

The conduct of surveys requires special training and can be very expensive to complete. To be successful, a survey must have high response rates across subpopulations so that the results will not be biased in any way. School surveys are significantly cheaper and arguably more practical and technically straight forward to complete. School surveys are therefore usually a higher priority for information systems in developing countries than completing general population survey work. However, it must be remembered that: students will only be likely to report drug use if they are convinced that their answers are confidential and not result in any negative consequences; low frequency events will still require large samples to detect; and those young people who may be most at risk of using drugs may be absent (truants, non-attendees, etc.). Also, in some parts of the world education access is limited or many pupils may leave school at an early age, this again will compromise the usefulness of this kind of activity.

**Recommendations:** if the network is planning to use survey data, it will be important to know the following:

- The sample frame asking the question: What population does the group of respondents represent? Does it include children and adolescents? Adults and older people? Does it include men and women? Does it represent urban and non-urban groups? The way to determine the answers to these questions is to compare the proportions of the respondents within each of these descriptive categories to the proportions of the total population. For example: if the total population consists of 49% males and 51% females and the respondent population consists of 58% females and 42% males, we know that the survey slightly underestimates drug use rates for males.
- How large is the sample selected for the survey? Is it of sufficient size so that estimates of the rates of specific drugs categories of interest are stable? You may need a statistician to assist you in determining the answer to this question.
- What drug categories are included in the survey? Are these categories representative of drugs used in your community? Are these categories of interest to you and the network?
- What drug types are asked about, do they cover the areas of interest, and are the questions posed clear and meaningful way distinguishing between different types of psychotropic substance.
- Were all possible measures taken to reduce responses biases by making the respondents feel confident that their answers were confidential and not likely to lead to negative consequences for them or their communities?

#### School surveys – The SIDUC approach

School surveys are recognized as one of the easiest ways of making comparisons between countries. They are also relatively inexpensive and methodologically straightforward. This data source is often among the first that is systematically collected by new networks. A good example of this is the approach adopted by SIDUC – the Inter American Drug Use Data System. SIDUC is based upon a number of indicators but participating countries are encouraged to conduct a school survey as one of their early activities. A standardized method and short questionnaire is used ensure comparability of results and support is given more some of the more technical difficult activities such as drawing the sample. Tools also exist to allow the data to be easily entered and analyzed. In this way SIDUC is being successful in generating a comparable data set for countries in the region. As with other data sources, school survey data has its weaknesses and does not provide a full picture of the drug problem. Nonetheless this method does provide extremely useful data that can be relatively easily collected. By repeating the survey every few years using the same methods a data set that reflects changes over time can be assembled.

#### Qualitative data

Qualitative information can be used in a drug information system to complement and aid the interpretation of other data collected or alone where there is very limited other data available. The main methods of qualitative data used include focus groups, in-depth interviews, key informant surveys and more sophisticated ethnographic approaches. The incorporation of qualitative data into a drug information system will greatly aid the interpretation of trends in indicator data by providing more specific information on what drug trends represent. For example, rapid assessment approaches often incorporate qualitative methods along with existing data and specialized surveys on drug use to facilitate interpretation of the later sources. Qualitative information also serves an important function in providing information that cannot be pre-empted by a structured survey questionnaire or through existing data sources, and in doing this can act as a sensitive warning of new drug trends that may require further investigation. The richness of information provided on the broader context surrounding drug use (e.g., cultural, social, economic and demographic factors) can be helpful in understanding the antecedents and consequences of particular drug using behaviours. As such, qualitative information is very valuable when it comes to designing interventions in response a particular trend detected by a drug information system.

Advantages: One key advantage of qualitative data collection is that it does not depend on the availability of infrastructure relating to drug problems. That is, it is a viable form of data collection in situations where there are no specialized treatment agencies for drug dependence, where there is no routine toxicology for illicit drugs, or where coverage of services for drug-related morbidity are inadequate for monitoring purposes. Similarly, in a situation where there is minimal existing knowledge about the drug situation, qualitative methods are sufficiently flexible to provide a starting point for gathering information, which in turn can provide direction for further data collection activities (e.g., providing contact points for snowball samples of drug users). Another advantage is that some methods of qualitative data collection can be conducted with minimal cost and infrastructure and can be adapted to existing structures (e.g., key informant interviews can be conducted over the telephone to overcome geographic barriers, existing groups of people concerned with drug issues could be used to form the basis of focus group discussions).

**Disadvantages:** The open-ended or un-structured nature of data collected through these methods means that considerable time and expertise is often required for data analysis. Also, considerable training and experience is necessary to undertake some qualitative data collection (e.g., ethnography) so the applicability of these methods depends on the availability of human resources to support data collection. Obviously the applicability of these methods also depends on the availability of participants who have good knowledge of the drug use situation, and their willingness to disclose this information. Practicalities of interviewing people also need to be considered, such as social and cultural factors affecting the group dynamics within focus group discussions.

**Recommendations:** There needs to be clarity on the specific target group for the qualitative research and the questions that need to be answered from the research. Methods of qualitative data collection need to be adopted which are clear, transparent and appropriate given the available level of expertise and infrastructure to collect and analyze data (e.g., choice of software). Methods chosen need to accommodate the local social and cultural factors that may impinge on the quality of data collected. People from whom qualitative information is obtained should have adequate knowledge of the research question through contact or experience with drug users. Similarly, one should consider the impact of social and cultural factors on reporting in group situations (e.g., gender, ethnicity and status) and the method used for recording data (e.g., written

or tape-recordings) and methods should be chosen that minimize the adverse impact of these factors.

#### Using specialized surveys and key informants to monitor drug trends- the IDRS

Specialized surveys of drug users feature in most systems in an ad-hoc manner, where they are used to investigate issues highlighted by existing data, or are included where they already exist and provide relevant information. One system, namely the Illicit Drug Reporting System in Australia, undertakes specialized surveys of drug users part of its routine data collection – these data actually forming the core of this strategic early warning system.

The IDRS uses convenience samples of injecting drug users in capital cities as a sentinel population for monitoring trends in problematic forms of drug use. Annual self-report data from this group provides a barometer for trends in the type of drugs being injected, health-related issues (e.g. frequency of injection, HIV risk-taking behaviour, overdose) new forms of drug use, and changes in the availability and marketing of drugs.

Use of specialized surveys as a routine data source works well in Australia because there is a substantive population of injecting drug users who have broad exposure to the main drug classes types and who are often the first group to be exposed to changes in drug availability and shifts in patterns of drug consumption. Also, this group is readily accessible through the existing service providers and there is a strong technical infrastructure for researching this group. While this method provides a cost effective means for keeping a watchful eye on emergent drug trends in the Australian context, it would require considerable investment in countries where active survey research on populations of drug users was not commonplace. Nevertheless, this system provides an example of how specialized surveys can provide valuable information to assist with understanding trends in drug consumption.

Perhaps more relevant to developing regions is the supplementary data provided to the IDRS through the application of routine key informant surveys. The collection of qualitative data from "experts" who have regular contact with drug users through a semi-structured interview is inexpensive, requires minimal infrastructure, and has been successfully applied in developing regions. For example the expert opinions of school counselors have been incorporated into the routine data collection activities of the Seychelles through a semi-structured questionnaire on drug trends among youth. Similarly, key informant interviews were used in Pakistan to map intracountry variation in drug consumption patterns and service provision.

For more information on this system visit the IDRS web-site: http://ndarc.med.unsw.edu.au/ndarc.nsf/website/IDRS.

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- Coverage city, country, region
- Specification of drug categories
- Data resources
- Time period covered by data
- Characteristics of drug users provided by data
- Format of data—reports, hard copy in files, computerized

## **Definitions of Data Elements**

To be useful in making comparisons across time and space, usually information systems use standard definitions of data elements. The most common data elements and their definitions are presented below.

#### Incidence

The proportion of people within a defined population residing in a defined geographic area who are newly diagnosed as having a specified health condition or problem in a given time period; e.g., 5% of persons living in Country X were newly diagnosed with Condition Y in 1999, or 2% of persons aged 34 years and older residing in London reported having used marijuana for the first time in 2000.

#### Prevalence

The proportion of people within a defined population residing in a defined geographic area who are diagnosed as having a specified health condition or problem in a given time period (includes newly diagnosed cases or persons who newly initiated a problem behavior AND existing cases); e.g., 15% of persons living in Country X were diagnosed with Condition Y in 1999, or 10% of persons aged 34 years and older residing in London reported having used marijuana in 2000.

#### Data elements:

- Source of Data
- Types of Drugs Used
- Method of Use
- Proportion of People Using
   Drugs
- Who is Using These Drugs
- Age
- Gender
- Ethnicity

#### Time periods

In general, drug abuse researchers use four time periods when reporting about drug use in a population or subpopulation.

Lifetime - used a specific drug at least once in one's lifetime

Annual - used a specific drug at least once in the prior year (12 months)

Current - used a specific drug at least once in the prior month (30 days)

Daily - used a specific drug 20 or more times within the prior month

### **Drug categories**

As with time periods, drug abuse researchers generally report on the incidence and prevalence of drug use within a defined population for a specified time period by the following drug categories. These drug categories are fairly inclusive, yet we know that many populations within certain geographic areas may use drugs not listed below. These special categories are important and should be included in all reports on drug abuse.

Cannabis type - includes marijuana and hashish

**Opioids** – includes heroin, opium, and other opioids (e.g., morphine, fentanyl and buprenorphine)

Cocaine – includes powder (salt) cocaine, crack cocaine, and other forms of cocaine

Amphetamine type – includes amphetamine, methamphetamine and "ecstasy" type amphetamines

Sedatives and Tranquilizers - includes legally manufactured barbiturates and benzodiazepines

Hallucinogens – includes LSD, and other hallucinogens

**Solvents and inhalants** – includes a range of volatile substances such as gasoline/petrol, adhesives, aerosol products (e.g., paint sprays, air fresheners, analgesic sprays), anesthetics (e.g., nitrous oxide), cleaning agents, solvents, and "room odorizers" (e.g., amyl nitrite, butyl nitrite)

**Other drugs** – any illicit substances that do not fall within the above categories. For example, gamma-hydroxybutyrate, anabolic-androgenic steroids.

### Age categories

Using standardized age categories helps compare trends for different groups over time both across and between populations located in different cities, regions or countries. In most countries, drug use patterns vary across age groups with children using mostly inhalants and solvents or marijuana, for instance, while those in their 20s and 30s may use drugs such as heroin or cocaine. There are other "age"-related data elements that are of interest to drug abuse researchers. These elements are more likely captured through surveys where self-administered or face-to-face interviews are completed. In most data sets, age is collected as an open category and summarized according to reporting needs. Age groupings often referred to in summary statistics of drug data include:

Adults:	15-64 years
Youth:	15-24 years
Adolescents:	15-16 years

#### **Route of Administration**

The harmful consequences of drug abuse vary not only by drug type but also by the way the drug is consumed (route of administration). In particular, drug injecting is associated with the most severe consequences such as transmission of HIV infection, an increased risk of overdose, and an increased risk of drug dependence. Typical routes of administration include, oral consumption (eating/drinking/swallowing), sniffing or snorting (inhaling up the nose), smoking or inhaling sublimate (chasing the dragon) and injecting. Most information systems attempt to differentiate data on drug users according to route of administration especially for those drugs that can be injected. Injecting behaviour is often considered so important that a separate question will be used to ask about lifetime and current injecting experiences and possibly the extent to which the individual has shared injecting equipment with others.

## Establishing a data base

Information that is obtained by the network will appear in a variety of formats. It is important that one format for the presentation of survey and agency-based data be used by network members. This type of standardization will be helpful as the network maintains itself overtime. The problem with standardization is that it focuses on the lowest common denominator, i.e., those databases that have the least amount of information. It may be that separate formats are developed for each source of data. This means that the network may need to have formats specific for treatment, for law enforcement, for emergency departments etc.

When we talk about "existing" data we mean data that are available in the form of tables or graphs in reports or stored in data files that are computer accessible and can be made into tables. Putting data into tabular form enables a person to present information in a small amount of space. Tables present information, data, in an orderly fashion in rows (the horizontal lines) and columns (vertical lines). The intersection of a row and a column creates a cell.

When developing your database, make sure that confidentiality of the drug user is not violated.

See annex for further resources on ethical guidelines for epidemiology.

COLUMN 1	COLUMN 2	COLUMN 3	COLUMN N
CELL 1,1	CELL 1,2	CELL 1,3	CELL 1,N
CELL 2,1	CELL 2,2	CELL 2,3	CELL 2,N
CELL 3,1	CELL 3,2	CELL 3,3	CELL 3,N
CELL N,1	CELL N,2	CELL N,3	CELL N,N

The columns and rows represent different data items or characteristics. For example, column may represent drug category and the row may represent age groups. Then cell11 would represent column1-category and row1-age group. If column1 was "heroin" and row 1 was age group "under 17", then cell11 would be either a number or percent representing people using heroin who are under 17.

In available tables, the data presented in a cell is either a number or a percentage. If it is a percentage, it is important to note whether the 100% is the sum of percentages found in the rows or columns or of both rows and columns combined. Below are three tables that look at drug use by gender and age.

In the first table, we are looking at what percentage of male and female current users of illicit drugs are under 17 years of age, 17 to 24, 35 to 34 and 35 or older. The percentage then is: age group/gender, where the denominator equals the total number of males or females and the numerator equals the total number of males within each age group.

TABLE 1										
Distribution of current users of any illicit drug Gender by age (number and percentages)–1999										
				<u>/</u>	AGE GROU	<u>PS</u>				
	ALL AG	SES	<17		17- 24		25- 34		35+	
GENDER	<u>NO.</u>	%	NO.	%	NO.	%	NO.	%	NO.	%
MALES	350	100%	100	28.7%	% 175	50%	25	7.1%	50	14.2%
FEMALES	150	100%	30	20%	80	53.3%	6 15	10%	25	16.7%
TOTAL	500	100%	130	26%	255	51%	40	8%	75	15%

This table tells us that the distribution of males and females by age groupings is similar. Half of the male and the female drug users were aged 17 to 24. The next largest group for both males and females are those under 17, then those 35 and older and lastly, those 25 to 34.

Now let's turn this table around to determine what proportion of each age group were males and females using the same numbers. In table 2, the denominator (100%) will be the same for all age groups.

TABLE 2										
Distribution of current users of any illicit drug Age by gender (number and percentages)–1999										
				ļ	AGE GROU	IPS				
	ALL AG	SES	<17		17- 24		25- 34		35 -	+
GENDER	NO.	%	NO.	%	NO.	%	NO.	%	NO.	%
MALES FEMALES	350 150	70% 30%	100 30	76.9% 23.1%	6 175 6 80	68.6% 31.4%	625 615	62.5% 37.5%	650 625	66.7% 33.3%
TOTAL	500	100%	130	100%	255	100%	o 40	100%	5 75	100%

In table 2, we are interested knowing whether the gender distribution of drug users within each age group is similar to the overall distribution. We see that 70% of drug users are male and 30% are female. And in fact, males tend to dominate within each age group although there seems to be an over representation of males among those under 17.

TABLE 3								
Distribution of current users of any illicit drug by gender and age (number and percentages)–1999 Total drug users=500								
AGE GROUPS								
	<17		17- 2	24	25- 3	4	35 A	ND OLDER
<u>GENDER</u>	<u>NO.</u>	%	NO.	%	NO.	%	NO.	%
MALES	100	20%	175	35%	25	5%	50	10%
FEMALES	30	6%	80	16%	15	3%	25	5%

In table 3, we are looking at the distribution of all drug users by gender and age groups. So we see that 35% of all drug users are males between the ages of 17 and 24 followed by males under the age of 17 and then, females aged 17-24.

The data that are important to include in the database by reporting source include:

- Type of drug by mode of administration
- Age-actual age in years provided by the data source or converted from date of birth to date of report. (e.g., date of birth is January 22, 1964 and the date of admission to treatment is December 17, 2000= 36 years rounding up to the nearest age). For the network report, consistent age groups are used. To comply with the annual reports questionnaire and to make the age groupings comparable to other systems, use the following: children (12 and under), young teens (13-14), late teens (15-16), young adults (17-24), adults (25-34) and older adults (35 and older)
- Gender
- Ethnic group, if applicable

Examples of formats that are used to store data can be found in the appendix. Exhibits 1 and 2, below, used by the Pompidou Group of Epidemiology Experts in Drug Problems (Council of Europe, 1994) and the Community Epidemiology Work Group in the United States of America, provide good models for treatment data.

In addition to maintaining these charts in 'hard copy', it is possible to transfer the charts from hard copy to computer. In this way, when the network begins to accumulate data over time, it is possible to examine the data for trends. **Warning!** Interpretation of these trends must be cautiously made as there are many external factors such as those mentioned extensively above as disadvantages of using existing data and information that need to be considered. Trends may not actually represent changing patterns but administrative practices.

EXHIBIT 1 Form used for collecting treatment data								
1. City [ ][ ] 2.	Treatment	Centre [ ]	[ ] code i	][ ][ ][ ] number -type of centre	3. Client N	<b>0.</b> internal code		
A. TREATMENT CONTACT DET 4. Date of Treatment Demand [ ]  day	<b>AILS</b> []-[][]] <i>month</i>	-[ ][ ] year	<b>10. (a) Current Living Status</b> ( <i>circle</i> ) 1. alone 5. institution 2. with parental family6. temporary/homeless 3. with friends 8 other					
5. Type of Contact with This Centre	e (circle)		4. with partner 9. not known					
1. new client 2. Old client	9. not k	known	(b) Living with Drug Misusers (circle)					
6. (a) Ever Previously Treated, at <u>A</u> (circle)	<u>ny</u> Treatment	Centre	11	1. yes 2. n	o 9. not known			
1. never treated 2. previously trea	ted 9. not	known	11.	(a) Resident of City (	<i>circie)</i>			
(b) <u>If Previously Treated</u> , When I	ast? [ ][	][ ]	a	1. yes 2. II	Within City (specify	.)		
Number of months since left last treats (or enter code) 888, never previous	ment slv treated 9	999. not known		b) in cu of residence	(speed)	/ [][]		
<ul> <li>7. (a) In Contact with Other Treatment Centres (specify &amp; circle)</li> </ul>				(a) Nationality (speci	fy & circle code)	r , , , , , , , , , , , , , , , , ,		
1. yes     2. no       (b) Source of Referral (specify, and	known		1. national of 2. national of 9. not known	this country other country	I _ II _ II _ J			
		Ø	b) Ethnicity (specify)		[]			
1. self/family/friends5. s2. other drug treatment centre6. d3. general practitioner8. d4. hospital/other medical agency9. n	n/police	<ul> <li>13. Employment Status (circle code)</li> <li>1. regular employment</li> <li>2. unemployed/casual work</li> <li>8. other (specify)</li> </ul>						
<b>B. SOCIO-DEMOGRAPHIC INFO</b>	ORMATION		9. not known					
8. Sex (circle) 1. male 2. 1	female 9. not	known	14. (a) Highest Educational Level (specify)					
<b>9. (a) Age</b> [ ][ ] years <b>(b) Date of Birth</b> [ ][ ][ <i>day</i>	][ ][ ][ month	] year	(b) Age Left School [ ]] [ ] years (or enter code) 01. never went to school 88. still at school 99. not known					
C. PROBLEM DRUG USE								
(a) [ (	Drug Name write in)	(b) Route of Administrati (enter code)	f (c) Frequency Past Month (enter code) (d)Age at 1 <sup>st</sup> Use (years)			(e) Duration of Regular Use (years)		
15. Primary Drug								
16. Secondary (1)								
17 Secondary (2)								
18. Age 1st Used Any								
(b) Route: 1. inject, 2. smoke, 3. eat/drink (c) Frequency: 1. 1 per week or less, 2. 2	, 4. sniff, 9. not l 2-6 days per wee	known. k, 3. daily, 4. not u	sed pa	ist month, 9. not known.				
					et			
D. KISK BEHAVIOUK	7 )		20.	(b) <u>If Ever Inject</u>	ed, Age 1 <sup>st</sup> [ ][	) years		
19. (a) Currency Injecting ( <i>circle</i> ) (c) <u>If Ever Injected</u> , Ever Shared ( <i>circle</i> )								
(b) If Injecting, Shared Past Month (circle) 1. yes 2. no 8. not applicable (never injected) 9. not known								
1. yes 8. n 2. no 9. n	ot applicable (no ot known	ot injecting)	21.	HIV Status (circle,	)			
20. (a) Ever Injected (circle)			1. te 2. te	ested - positive 4. r ested - negative 9. r	never tested not known if tested			
1. yes 2. no 9. n	ot known		3. te	ested - results unknown				
Example of a treatment admission data collection form adapted from the Pompidou Group First T <u>reatment Demand Format. Council of Europe</u>								

EXHIBIT 2 Form used for collating treatment data										
Reporting Site										
СН	CHARACTERISTICS OF CLIENTS ADMITTED TO TREATMENT									
	FROM	TO		, 2001						
	Month	I	Month							
Total number of treatme	nt admissions:									
Alcohol only	Alcohol-in-	Heroin	Cocaine	Marijuana	Amphetamines					
Total N	Combination									
(Use to derive %) Gender:										
Male%	%	%	%	%	%					
Female%	%	%	%	0⁄_0	%					
Race/Ethnicity:										
White%	%	%	%	%	%					
Black%	%	%	%	%	%					
Hispanic%	%	%	%	%	%					
Age at Admission:										
17 & under%	%	%	%	%	%					
17-24%	%	%	%	%	%					
25-34%	%	%	%	%	%					
35 +%	%	%	%	%	%					
Route of Administration:										
Smoking%	%	%	%	%	%					
Sniffing%	%	%	%	%	%					
Injecting%	%	%	%	%	%					
Other%	0⁄_0	%	%	%	%					
Secondary Drug:										
Type of drug #										
%										
Example of a	treatment dat	a collation fo	rm adapted fr	om the Comn	nunity					
Epidemiology Working Group in the USA										

In the above exhibit, we are able to examine the characteristics of drug users within drug category. We can see what proportion of those admitted to treatment with a primary alcohol only problem are men, how many are under the age of 17 etc.. This is important information to have. The percentages that are calculated all use the total number of persons within each drug category (i.e., alcohol only, alcohol-in-combination, heroin, etc) as the denominator.

However, the network may want to address additional questions that would require the denominator to be a different one. For example, they may want to know what proportion of women admitted to treatment use alcohol. In this case the calculation would use the number of women admitted to treatment as the denominator and the numerator would be the number of women admitted to treatment with alcohol only (etc.) As their primary problem. So using the same information but changing the base, i.e., whether it is drug category or gender, provides answers to two different but very important questions. Exhibit 2 shows the tabular format that would provide the information where client/patient characteristic is the denominator.

## Network meetings and interpretation of the data

The network meetings are the most important component in any Integrated Drug Information System. It is here that the data are presented and discussed. It is the proceedings of the network meeting that forms the network report. There are three significant participants at these meetings: (1) the chair, (2) the network members and (3) a reporter.

In these proceedings, the chair of the network meeting has several major roles that must be played. The chair:

- Convenes the meeting and either develops the agenda or assigns this role to another network member
- Makes sure that all members keep on schedule
- Makes sure that each member has both the data in the appropriate format and has a written report
- Allows only a few minutes for questions after each individual report
- Discourages discussion of the data presented until after all presentations are completed
- Summarizes the key findings that were presented
- Encourages discussion of the findings
- Asks about other corroborating or additional information that is needed and assigns network members to access this information and to present it at the next meeting
- Assign someone to write a proceedings report that would include the discussion and establish a date when the draft is ready for review.
- Assign someone to disseminate the report
- Every so often, review the dissemination list with network members.

The importance for having short but lively network meeting was emphasized above. Each network member also has a significant role to play. The members bring to the meeting information in the form of data but also in the form of their own expertise and familiarity with drugs and drug users within their own "communities" whether treatment, outreach or law enforcement.

Once each network member has compiled the information from their data source in a standardized format, they need to write a presentation that: (a) summarizes the data, and, (b) discusses whether factors such as a police sweep or contamination of a widely distributed drug may have affected

the available data, i.e., increased arrests for cannabis possession or increased numbers of emergency department episodes for heroin use.

Once the network has a number of meetings and a database, the network members should include another section that looks at trends over time.

Although questions may be raised by network members during their presentations, it is probably more efficacious to save discussion till the end of the meeting. The chair or other person assigned to this task should listen and take notes of each presentation looking for cross-cutting findings or issues. For instance, the network member presenting information on arrests may mentioned that there appears to be an increase in arrests of young people for possession of heroin while the member presenting emergency department visits may note that more people under the age of 21 are being seen for heroin overdoses. These two observations when viewed individually may not signify any changes but together they suggest that more young people are involved with heroin.

When all the network members have presented, the chair or designee should present his/her observations. This should open the discussion about the data that was presented. The discussion does not have to be limited to these types of observations but should focus on the question, "what do these data tell us about drug use in our area?"

Having someone available to listen and take notes is very helpful to the group particularly to capture the questions and discussion on paper so that this information can also be included in the proceedings report.

For further information on interpretation of data from drug information networks refer to other GAP Toolkit Modules on data analysis and interpretation (http://www.undcp.org/drug\_demand\_gap\_m-toolkit.html).

## **Preparation of reports**

The above discussion emphasizes the need to clarify what questions your network is asking of the data and then preparing the data to accurately address the questions. The network may want to think of several types of reports. Certainly, the most important report is the one that summarizes the information discussed at the network meeting. In the introduction to this toolkit, a description of the Integrated Drug Information System discussed the importance of the network report, how it is disseminated and to whom it is disseminated. In that description it is suggested that the network report include an executive summary and a summary either by data source (agency) or by drug type. If more than one geographic area is represented in the network, a section by geographic area may be warranted.

The report would usually contain simple narrative summaries with some presentation of the data in table format (as shown below) or in graphic form. For instance, the data from tables 1 and 2 could be made into a bar chart. Figures 1 and 2 represent the data from tables 1 and 2. The data from table 3 are graphically presented as a pie chart in figure 3 where the entire circle represents all the current illicit drug users. Presentations such as these graphs are helpful to readers who have more difficulty reading tables. For this reason, graphs are used more often than tables in network reports.

#### FIGURE 1



#### DISTRIBUTION OF CURRENT USERS OF ANY ILLICIT DRUG: BY GENDER AND AGE GROUP-1999



#### DISTRIBUTION OF CURRENT USERS OF ANY ILLICIT DRUGS: GENDER BY AGE--1999

FIGURE 2

FIGURE 3



DISTRIBUTION OF CURRENT USERS OF ANY ILLICIT DRUG: AGE GROUP BY GENDER--1999

The size of the report depends on a number of factors: how many agencies are included, how many drugs are being considered, whether time trends are included, and how many geographic areas are represented in the network. The following is a suggested table of contents for two types of networks. The first network is one that just began in one geographic area. It has met only once and does not have complete agency representation. The second network has complete agency representation for a single geographic area and has met for three years. A third type of network is one that consists of representatives from multiple geographic networks.

#### New Network Report

Executive summary for "name of network": indicate authors and contact name, agency, address and telephone number and/or email address

- I. Goals and objectives of network
  - A. Define the long-term purpose of the Integrated Drug Information System
  - B. Specify the objective of the current meeting
  - C. Briefly describe future plans
- II. Brief description of the geographic area being represented by the network
  - A. Boundaries
  - B. Demographics of population residing in the geographic area
- III. List agencies represented at the meeting, specify chair
- IV. Brief narrative on types of drug patterns used in area; if noted during meeting, describe differences by reporting source
- V. Brief discussion on characteristics of drug users; if noted during meeting, describe differences by reporting source
- VI. Summary of discussion by network members about the findings

#### Network Report

- I Introduction
  - A. Objectives of the Integrated Drug Information System
  - B. Composition of network; agency representation
  - C. Dates and place of meeting
- II. Fuller description of geographic area

A. Total population size and demographics such as age, ethnicity, socioeconomic status

- B. Discuss factors that may influence drug use patterns in the city such as homeless populations, changes in drug laws, influx of new drugs, and increased prevention efforts
- III. Data sources and time periods covered
  - A. Source of data–describe where the data that is included in this report came from; agency and name of data (e.g., arrest information from precinct 'a')
  - B. Provide limitations of the data (e.g., arrest data came from only one of the ten precincts in the area)

- C. What is the time period covered by each data source i.e., January 1, 2000 through June 31, 2000
- D. Introduce the data sources with a listing that represents the sequencing of the data as they are presented; any results from special studies, key informant interviews or ethnographic studies should be presented last
- E. Data source presentations with exhibits/tables/graphs
- IV. Summary of network comments and discussion giving an overall interpretation of the data that was presented. Include gaps in data and plans being made to fill these gaps.
- V. Date, time and place of next meeting.

#### **Ongoing Network**

Follow the above outline but add trend data. Generally, the trend section is divided by types of drugs.

- I. Drugʻa'
  - A. Overall description of trends summarizing information from all sources of data
  - B. Trends by individual source of data; increases/decreases by specific population groups (e.g., gender, age, ethnicity); new modes of administration (e.g., intranasal use to injecting); new drugs of abuse
  - C. Special studies

#### Suggested National Report Format (see attached national report template and diskette)

Acknowledgements

• Owners of data, contributors, funding and support etc.

Executive summary or abstract

- Background (e.g., functions and structure of network, meeting etc)
- Summary of drug situation
- Recommendations

#### 1. Introduction

- Country or city information (demographics, politics etc.)
- Background to network (history and purpose, data sources, structure and coverage of network, integration of network with drug demand reduction, policy and other development activities etc.)
- 2. Information on drug consumption
  - Existing data sources
  - Survey data
  - Specialized/focused survey data
  - Overview of drug situation/trends (by drug type where possible)
- 4. Development proposal/future directions
  - Priority areas for future development
  - Identification of needs in order to address priority areas
  - Policy implications for drug demand reduction activities
- 5. Conclusion and recommendations

#### 6. References

• list of cited reports

#### Appendices

- Names and contact details of network participants
- Completed ARQ and/or regional reporting mechanism

#### Other issues related to collecting and interpreting data

#### **Ethical concerns**

Collecting data on drug consumption presents particular ethical challenges due to the illicit nature of drug-taking. Many countries have institutionalised procedures to protect the rights of participants in medical research, which are enforced through obligatory compliance with the World Medical Association Declaration of Helsinki, or locally developed ethical frameworks that are consistent with the Helsinki Declaration principles. The Helsinki Declaration can be found at *http://www.wma.net*. However, even the application of these general guidelines to drug abuse epidemiology presents particular ethical challenges. These challenges are detailed elsewhere, but the main themes centre around maintaining confidentiality and anonymity of drug users, obtaining 'informed consent' from drug using individuals (especially minors), and protecting the security and safety of both interviewers and interviewees where data collection involves face-to-face interviewing. Additional challenges remain for the application of general ethical principles to varied social and cultural settings, especially in countries where procedures for regulating the ethical parameters of medical research have not been institutionalised. For further discussion of

ethical principles relating to epidemiology refer to the World Health Organisation Publications on this topic (*http://www.who.int/dsa/cat98/ethic8.htm*). The specific application of ethical guidelines to drug abuse epidemiology is discussed by Fry and Hall, *Bulletin on Narcotics. Vol. LIV, No. 1, 2002.* An expansion of issues pertaining specifically to ethics in drug abuse epidemiology is planned under the GAP Toolkit (*http://www.undcp.org/drug\_demand\_gap\_m-toolkit.html*).

#### Gender

Available evidence suggests that gender differences in drug use vary between countries and regions, and are affected by factors such as the type of drug consumed, the pattern of drug use, the age of the user, and the regional and/or cultural setting. The reflection of gender differences in patterns of drug use, particularly those based on agency data, will be strongly affected by any gender differences in access to services (i.e., health data), in likelihood of being apprehended for drug-related crimes (i.e., arrest data), or likelihood of being recruited into surveys. Further, the cultural, social and economic context may differentially affect males and females ability and willingness to disclose and discuss drug use (e.g., social acceptability of use), or their drug use being picked up by routine data sources (e.g., abuse of prescription medications). If interventions are to be properly informed by data, then sound data on patterns of drug use in both males and females needs to be collected, analyzed and interpreted. In practical terms, this means disaggregating data by gender where possible and relevant. Gender differences in drug consumption patterns found in data collected must be interpreted in light of the potential biases in the data (e.g., differential access to service), as would be the case with interpreting drug-related indicator data in any situation. School-based surveys and general population surveys are a good way to get a rough idea of gender differences in drug consumption, although results from these will still be affected by social acceptability of drug use, and also may not provide good data on problem drug use: the data providing information on problem drug use often being biased for the reasons noted above. Where information on drug use is particularly scarce, a specialized survey on males or females alone, or analysis of existing data on services targeting either males or females, could provide a starting point for understanding the type of drug consumption patterns that are particular to either gender. For some notes on gender issues in drug consumption and related harms refer to http://www.nida.nih.gov/NIDA Notes/NNVol15N4/tearoff.html, and for an example of a gender-specific analysis of drug use see "Women and Drug Abuse: The Problem in India (2002), Ministry of Social Justice and Empowerment Government of India and UNDCP."

## **Concluding remarks**

Drug information systems have been found to be effective tools in many countries to monitor drug consumption. In most contexts they represent a cost-effect means of bringing together the available data and expertise on patterns and trends in drug consumption. These systems, which have been found effective in many developed regions, are also proving successful in developing regions. Without doubt, one of the key advantages of these systems is there ability to instigate communication and cooperation between different bodies with an interest in drug consumption. Providing a multi-disciplinary platform for the sharing and discussion of drug consumption data greatly enhances the capacity to develop data collection and the accurate interpretation of trends. Open dialogue between policy makers, researchers, epidemiologists and practitioners also provides a bridge for using data on drug consumption to guide policy and the implementation of demand reduction activities (i.e., treatment, prevention and reducing the adverse social and health consequences of drug consumption). This guide has provided a starting point for the development of such a system, emphasizing the key element of human networks. The following section provides a list of further resources to assist with development of a drug information system, while other modules of the GAP Toolkit provide further guidance on developing core data collection activities.

Finally, It is critically important to remember one point – developing an information system is a practical accomplishment the success of which is dependant on ensuring that the methods used are appropriate to the local conditions. This toolkit provides only a general guide based on what has been learnt from working elsewhere. These guidelines must be adapted to your own circumstances. Who to invite to participate in a network, what are the best information sources to use, and how to report them will vary between countries and even with them. Furthermore developing comprehensive information is a long-term endeavor. As such, the INRA guidelines provided here suggest a method for defining a development strategy complete with short, medium and long-term goals. One of the common observations of those working in this area that even when formal information sources are poor, considerable knowledge still exists and the insights gained from forming a network where different perceptions of the drug phenomenon can be shared can be considerable.

## Further reading and resources

Following is a list of selected relevant resources and further reading to assist in the development of a drug information system. Web-based resources are provided were possible. This list is not comprehensive, but is intended assist the reader by guiding them to a few key resources in followup to this Toolkit Module, and a base from where the reader can be exposed the broader body of literature on drug abuse epidemiology.

#### Examples of regional Drug Information Systems:

The Pompidou Group of the Council of Europe http://www.coe.int/pompidou

European Monitoring Centre for Drugs and Drug Addiction http://www.emcdda.org

Inter-American Drug Abuse Control Commission (CICAD) and the Inter-American Uniform Drug Use Data System (SIDUC) http://www.cicad.oas.org/en/Observatory/Main.htm

Caribbean Drug Information Network CARIDIN http://www.carec.org/projects/caridin daess.htm

Southern African Development Community Epidemiology Network on Drug Use SENDU http://www.sadc.int/index.htm

East African Drug Information System (EADIS) http://undcp.org/drug\_demand\_gap\_activities\_easternafrica.html

#### Examples of national drug information systems:

Community Epidemiological Work Group (CEWG) http://165.112.78.61/CEWG/CEWGHome.html

Illicit Drug Reporting System (IDRS) http://ndarc.med.unsw.edu.au/ndarc.nsf/website/IDRS

South African Community Epidemiology Network on Drug Use (SACENDU) http://www.sahealthinfo.org/admodule/sacendu.htm Canadian Community Epidemiology Network on Drug Use (CCENDU) http://www.ccsa.ca/ccendu/index.htm

#### Examples of regional and national reports from Drug Information Systems

**CEWG Reports** http://165.112.78.61/CEWG/Reports.html

EMCDDA Annual Report http://annualreport.emcdda.org/

Selected European national reports http://www.emcdda.org/infopoint/publications/national reports.shtml

South African Community Epidemiology Network on Drug Use (SACENDU) http://www.sahealthinfo.org/admodule/sacendu.htm

#### General guidelines on Drug Abuse Epidemiology

UNDCP Global Assessment Programme on Drug Abuse (GAP) Methodological Toolkit: The "GAP Toolkit" consists of interlinked resources on prevalence estimation, school surveys, data analysis and interpretation, ethics, and other core spheres of drug abuse data collection. Updates on guidelines available can be obtained by emailing gap@undcp.org, or writing to Global Assessment Programme, Demand Reduction Section, UNDCP, P.O. Box 500, A-1400 Vienna, Austria.

http://www.undcp.org/drug demand gap m-toolkit.html

Guide to Drug Abuse Epidemiology, 2000. http://www.who.int/substance abuse/pubs psychoactive drugs.htm

National Institute on Drug Abuse (1998). Assessing Drug Abuse within and across communities: Community Epidemiology Surveillance Networks on Drug Abuse. Department of Health and Human Services National Institutes of Health, Maryland.

#### Global mechanisms of data collection on drug abuse and related issues

UNDCP Global Assessment Programme on Drug Abuse (GAP) http://undcp.org/drug demand gap.html

Report by the Secretariat on the world situation with regard to drug abuse, in particular the spread of human immunodeficiency virus/acquired immunodeficiency syndrome (HIV/AIDS) through drug injection (E/CN.7/2002/2). Available in English, French, Spanish, Russian, Arabic and Chinese.

http://undcp.org/cnd session 45.html

Drug Information Systems: Principles, Structures and Indicators: http://www.undcp.org/pdf/drug demand gap lisbon consensus.pdf

Global Workshop on Drug Information Systems: Activities, Methods and Future Opportunities, December 3-5, Vienna. Meeting Proceeding. UNDCP, Austria. (Publication No. V-02-56298 -July 2002.)

http://undcp.org/drug demand gap.html

UNDCP Annual Reports Questionnaire Part II: Extent, Patterns and Trends of Drug Abuse http://undcp.org/drug\_demand\_gap\_datacollection.html http://undcp.org/cnd questionnaire arq.html

#### Surveys

General population surveys:

http://www.emcdda.org/situation/themes/drug use general population.shtml

http://www.samhsa.gov/oas/oas.html

#### School surveys:

GAP Methodological Toolkit Module on School Surveys http://www.undcp.org/drug demand gap m-toolkit.html

Monitoring the Future project : http://monitoringthefuture.org

Hibell et al., 2000. The 1999 ESPAD Report, Swedish Council for Information on Alcohol and Other Drugs and The Pompidou Group at the Council of Europe.

General survey issues and specialized surveys:

Journal of Drug Issues (2001). Substance use survey data collection methodologies and selected papers. Vol. 31, No. 3. Florida State University, Florida

*Handbook on snowball sampling* (1997). Pompidou Group: Group of Epidemiology Experts in Drug Problems. Council of Europe.

Medina-Mora et al. (2000) WHO Guide to Drug Abuse Epidemiology

*EMCCDA Scientific Monograph Series No. 1 "Estimating the Prevalence of Problem Drug Use in Europe,* 

#### Qualitative data collection

*European Monitoring Centre for Drugs and Drug Addiction* of the monograph, *Understanding and Responding to Drug Use: The Role of Qualitative Research (Fountain et al., 2000).* 

#### **Rapid Situation Assessment**

Rapid Assessment and Response http://www.rararchives.org/index.html

Rapid Assessment and Response Guide on Injecting Drug Use (IDU-RAR), 1998, and the Rapid Assessment and Response Guide on Psychoactive Substance Use among Especially Vulnerable Young People (EVYP-RAR), WHO/PSA and UNICEF in collaboration with UNDCP/UNAIDS, 1998

http://www.who.int/substance\_abuse/pubs\_psychoactive\_drugs.htm

Drug Abuse Rapid Situation Assessments and Responses (1999). United Nations Publication. Sales No. E.00.XI.12.

International Journal of Drug Policy. Special Issue: Rapid Assessment and Response (2000)

Bulletin on Narcotics. Special edition on rapid assessment of drug abuse RSAs in developing countries (1997-98), Vol. XLVIII Nos. I and 2. United Nations Publication V.00-56405. ISSN 0007-523X.

#### Ethics

Guidelines documents on ethics in epidemiology: http://www.who.int/dsa/cat98/ethic8.htm

The ethics of research related to healthcare in developing countries. Nuffield Council on Bioethics.

http://www.nuffieldbioethics.org/publications/pp\_000000013.asp

Fry and Hall (2002). An ethical framework for drug epidemiology – Identifying the issues. *Bulletin on Narcotics*. Vol. LIV, No. 1. UNDCP, Austria. http://undcp.org/bulletin on narcotics.html

World Medical Association Declaration Of Helsinki http://www.wma.net, or in English: http://www.wma.net/e/policy/17-c e.html

#### Gender

NIDA notes on gender issues in drug consumption and related harms *http://www.nida.nih.gov/NIDA Notes/NNVol15N4/tearoff.html* 

Women and Drug Abuse: The Problem in India (2002), Ministry of Social Justice and Empowerment Government of India and UNDCP.

Women and Drugs, Symposium, Prague, November 1993 [ISBN 92-871-2838-3] http://www.coe.int/T/E/Social%5FCohesion/pompidou%5Fgroup/5%2EPublications/List\_of\_pub lications/prague\_eng.asp#TopOfPage

#### Peer-reviewed journal articles on drug information systems

Bulletin on Narcotics. Vol. LIV, No. 1, 2002. Special edition on *Drug Abuse Epidemiology: Science and Practice*.

Griffiths, P., Vingoe, L., Hunt, N., Mounteney, J. and Hartnoll, R. (2000). Drug information systems, early warning and new drug trends: can drug monitoring systems become more sensitive to emerging trends in drug consumption? *Substance Use and Misuse*, *35*, 811-44.

Parry, C.D.H., Bhana, A., Pluddemann, A., Myers, B., Siegfried, N., Morojele, N.K., Flisher, A.J., & Kozel, N. (in press). The South African Community Epidemiology Network on Drug Use (SACENDU): Description, findings (1997-1999), and policy implications. *Addiction*, *97*.

Hando, J., Darke, S., O'Brien, S., Maher, L., Hall, W. (1998). The development of an early warning system to detect trends in illicit drug use in Australia: the Illicit Drug Reporting System. *Addiction Research, 6,* 97-113.

Darke, S., Kaye, S. and Topp, L. (2002). Cocaine use in New South Wales, Australia, 1996-2000: 5 year monitoring of trends in price purity, availability and use from the illicit drug reporting system. *Drug and Alcohol Dependence*, *67*, 81-88.
Darke, S., Topp, L., Kaye, S., Hall, W. (2002). Heroin use in New South Wales, Australia, 1996-2000: 5 year monitoring of trends in price, purity, availability and use from the Illicit Drug Reporting System (IDRS). *Addiction*, *97*, 179-186.

## Access to further academic journal articles online

http://www.ncbi.nlm.nih.gov/entrez/query.fcgi http://www.nlm.nih.gov/medlineplus/substanceabuse.html http://www.bireme.br/ www.healthinternetwork.net http://www.tandf.co.uk/addiction-abs/

## UNDCP material

The following material can be obtained from bookstores and distributors throughout the world. Consult your bookstore or write to: United Nations, Sales Section, New York or Geneva. Publications available in Arabic, Chinese, English, French, Russian and Spanish.

Terminology and Information on Drugs revised edition (1999). United Nations Publication. Sales No. E.99.XI.7.

Demand Reduction. A Glossary of Terms (2000). United Nations Publication. Sales No. E.00.XI.9.

Drug Abuse Rapid Situation Assessments and Responses (1999). United Nations Publication. Sales No. E.00.XI.12.

Political Declaration Guiding Principles of Drug Demand Reduction and Measures to Enhance International Cooperation to Counter the World Drug Problem. Special Session of the General Assembly Devoted to Countering the World Drug Problem Together, 8-10 June 1998. UNDCP, Austria. Publication No. V.98-58236.