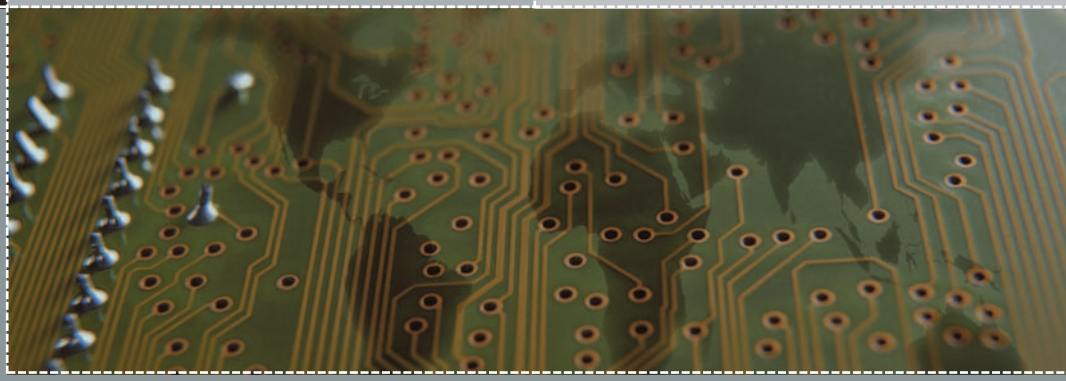
Global Assessment Programme on Drug Abuse (GAP)

Toolkit Module 8



Guidance for the measurement of drug treatment demand

Guidance for
the measurement of
drug treatment demand

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UNITED NATIONS
Office on Drugs and Crime

European Monitoring Centre
for Drugs and Drug Addiction

UNITED NATIONS OFFICE ON DRUGS AND CRIME
Vienna

Guidance for the measurement of drug treatment demand

Global Assessment Programme on Drug Abuse

in collaboration with

the European Monitoring Centre for Drugs and Drug Addiction

Toolkit Module 8

UNITED NATIONS
New York, 2006

Foreword

In most countries, people who are dependent on drugs are stigmatized and excluded from mainstream society. But these people should not be shut out. That will only exacerbate the problem. They should be helped through treatment. It is the only way to get them back into society, free of addiction.

In a sense, a rise in the number of people seeking treatment is a good sign. While it is a leading indicator of drug abuse, it is also a cry for help. And that is the first step towards overcoming drug dependence.

It is therefore essential that when people seek treatment, they find proper care. Without it, they risk further drug dependence and social isolation.

Treatment relies on information. At the individual level, a health expert needs to be informed about the profile of his subject in order to have a clear picture of his/her problem and to design the treatment and rehabilitation accordingly.

More generally, the data collected contributes to our greater understanding of trends and patterns of drug dependency, which can increase our understanding of the nature and the extent of the problem and, as a result, improve the impact and efficiency of treatment services.

In order to assist countries enhance their drug abuse information systems, the United Nations Office on Drugs and Crime, the European Monitoring Centre for Drugs and Drug Addiction, together with experts from other international organizations and national drug information systems, have produced this *Toolkit Module 8—Guidance for the measurement of drug treatment demand*. This module, building also on the *Joint Pompidou Group—EMCDDA Treatment Demand Indicator Protocol*, provides experts and practitioners in the field of treatment services with concrete guidelines for establishing and managing systems for the collection of treatment demand data.

The aim is to improve common standards for data collection and monitoring. This should enable a more uniform approach around the world, provide a clearer picture of drug trends and facilitate comparative analysis. The evidence that is collected should improve our capacity to measure drug treatment demand and respond accordingly with effective demand reduction programmes and projects.

This a shared interest of the European Monitoring Centre for Drugs and Drug Addiction and the United Nations Office on Drugs and Crime, which are mandated by our respective member States and governing bodies to collect and analyse information on the drug problem. We hope that this latest joint project will contribute to improving the analysis of the drug situation and help to identify effective approaches to drug treatment and rehabilitation.

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Acknowledgements

GAP Toolkit Module 8: Guidance for the measurement of drug treatment demand was produced by the Global Assessment Programme on Drug Abuse (GAP) of the United Nations Office on Drugs and Crime (UNODC) and the European Monitoring Centre for Drugs and Drug Addiction (EMCDDA), together with experts from other international organizations and national drug information systems. Both organizations would like to thank the distinguished experts for their contribution to this publication.

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UNODC and EMCDDA would like to express their gratitude to all the institutions and expert networks that kindly provided examples of methods, tools and related material and assistance for the compiling of *Toolkit Module 8*. Particular thanks are due to the European Expert Group on Treatment Demand Indicator, which provided valuable feedback during various stages of the publication.

UNODC would like to acknowledge the support of the Governments of Austria, Canada, France, Germany, Italy, Netherlands, Sweden and the United Kingdom of Great Britain and Northern Ireland, whose financial contributions made the publication of *Toolkit Module 8* possible

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Introduction

Chapter I

A. Aim

Although data on demand for drug abuse treatment are commonly available in many countries, there is an overall lack of standardization with regard to data coverage, concepts, methods and tools, which makes cross-national comparisons and identification of client characteristics and their needs in different national and regional settings very difficult. In order to assist countries in compiling comparable data on drug treatment demand, the present Treatment Demand Indicator (TDI) Global Toolkit has been prepared for inclusion as *Module 8* of the Epidemiological Toolkit of the Global Assessment Programme on Drug Abuse (GAP) of the United Nations Office on Drugs and Crime (UNODC). The module has been developed in collaboration with the European Monitoring Centre for Drugs and Drug Addiction (EMCDDA), building on the work of the Pompidou Group and incorporating the experience of major ongoing treatment information systems.

GAP improves the global information base on patterns and trends in drug consumption by helping Member States to build the systems necessary for collecting reliable data to inform policy and action; encouraging sharing of experience and technical developments through regional partnerships; and encouraging the adoption of sound methods to collect comparable data.

The GAP Epidemiological Toolkit is intended to help States Members of the United Nations to develop drug information systems that are culturally appropriate and relevant, to ensure that existing drug information systems conform to internationally recognized standards of good practice and to focus on the harmonization of drug abuse indicators. Other modules provide support in the following areas:

- Development of an integrated drug information system
- Indirect prevalence estimation techniques
- School surveys
- Data interpretation and management for policy formation

- Basic data analysis using a statistical software package for the social sciences
- Focus assessment studies using qualitative research methods
- Ethical issues

Other GAP activities include providing technical and financial support to establish drug information systems and support for and coordination of global data collection activities. For further information on GAP Epidemiological Toolkit modules, contact GAP by electronic mail (e-mail) at gap@unodc.org, visit the website of the UNODC at www.unodc.org or contact the Office at P.O. Box 500, 1400 Vienna, Austria.

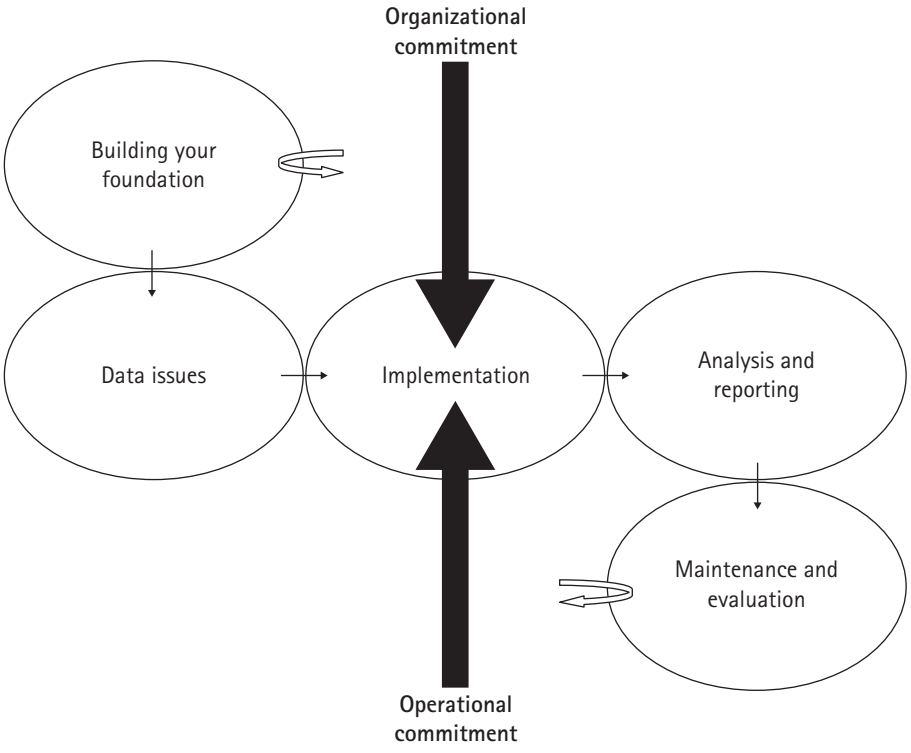
For further information on EMCDDA TDI methodology and results please consult the following website: http://www.emcdda.eu.int/?nnodeid=1420.

B. General approach

In order to implement an information system for drugs, it is essential to approach the issue both from an operational perspective and from an organizational perspective.

1. Operational perspective

This is the ground level, practical or "bottom-up" approach, in which treatment providers, agencies and services are helped to understand the need for and value of such a system, are signed up to the initiative and become committed to it because they can perceive its value and utility.



2. Organizational perspective

This is the "top-down" or political approach, in which key individuals and organizations are either driving the initiative because of their own policy needs or are persuaded to adopt the system for the greater good. Either way there should be the political will for such a development that percolates down through the various organizational tiers and allows it to happen.

3. Sequential stages

The above diagram shows the logical stages that such a development must follow if it is to be successful. These stages correspond to chapters III-VII in the Toolkit itself as follows:

I. Introduction

II. Reasons for collecting drug treatment data

III. Building your foundation

IV. Data issues

V. Implementation

VI. Analysis and reporting

VII. Maintenance and evaluation

Chapter II

Reasons for collecting drug treatment data

A. Why a system of treatment data collection is useful: main purposes

Treatment reporting systems were first introduced during the 1960s and 1970s and many European countries developed and/or standardized systems during the 1990s [1]. In many countries, they represent the most substantial and long-standing available source of information about drug use.

Knowledge about the number and characteristics of drug users who seek help and the treatment that they receive is valuable to a variety of audiences. It must underpin the planning and management of the treatment system and inform the commissioning of treatment services. It may also assist with the process of need assessment, offer data for research and provide epidemiological indicators of drug problems in the wider community. Ultimately, it should be part of the evidence base within a national information system, to inform and develop drug policy.

1. Epidemiological purposes

Information concerning people treated for drug problems is very useful for epidemiologists, who undoubtedly benefit from systematically collected drug treatment data in better understanding the drug problem, its extent, patterns and trends. Such data collection must be systematic, in particular because data need to be compiled from a number of different types of facility providing drug treatment services. Disease registries are an established feature of research in other areas of epidemiology and properly designed treatment surveillance systems should serve a similar function in drug misuse epidemiology.

Treated drug users represent a visible part of the, often elusive, population that experiences problems associated with drug use. As such, information about identified cases might provide a "window" onto an otherwise hidden drug problem. It might indicate what sections of

the population are most affected by drug problems, the types of problem that are experienced and the levels of associated morbidity. Most important, it should provide information to answer questions about the level of treatment demand and patterns of service utilization.

Where privacy legislation permits, it is advantageous if treatment data can allow case linkage. This will reduce the extent of multiple counting in situations where drug users may be known to multiple services. It may also enable case linkage with recording systems that monitor drug users' other institutional contacts. For example, it may facilitate longitudinal tracking of clients between the health and criminal justice system and can enable other methodologies such as capture-recapture to be applied to data from the system. In many countries treatment data include details of clients' initials, date of birth and gender, referred to as an "attributor" code [2], which are suitable for the purposes of case linkage.

For identifying patterns of drug use

In many countries where these data have not previously been collected, it will be valuable to establish basic patterns of drug use in the first instance. Such information will include the drugs most commonly reported, their route of use and the age groups mainly affected—information that has not hitherto been available. The importance of such basic information should not be underestimated. As the systems become more sophisticated, more detailed and specific data collection and research questions can be implemented.

As an indirect indicator of trends in problem drug use

Drug users' behaviour may often attract social and legal sanctions; hence, the population that experiences drug problems is often elusive, or "hidden". As a result, it is usually necessary to rely on indirect indicators of underlying changes in that population. Where information is collected systematically and case and data definitions are held constant over time, treatment data may provide one such indirect indicator.

Changes in the size or composition of the population that seeks help may indicate changes in the size or composition of the population experiencing drug problems. For example, an increase in the use of stimulants might be reflected in increasing numbers of stimulant users seeking help. It is helpful if data collection can identify cases that have sought treatment for the very first time (*first treatment demand*), as these may sometimes be most representative of the underlying, untreated population. An increase in the number of first demands for treatment may indicate that the incidence of drug problems has increased. The appearance of new drugs of misuse, new routes of administration or a change in the characteristics of a particular subgroup may indicate that changes have taken place in the untreated population.

It is essential, however, to remember the service-dependent nature of treatment data, as changing patterns among the treated population may be a consequence of changes in the pattern of service provision, rather than of changes in the underlying population.

As a basis for other methodologies

A treatment surveillance system may provide ready access to data suitable for estimation methodologies. For example, where data items suitable for case linkage are collected, it can provide samples for use in capture-recapture prevalence studies. Capture-recapture ascertains the extent to which lists of known cases have been sampled from an underlying population. It does this by comparing the overlap between known samples and, on that basis, estimates the size of the unsampled part of the population. The method is recommended by EMCDDA as a method to obtain prevalence estimates at the local level [3] and has been applied in numerous studies of drug use prevalence [4-35]. Although its use in epidemiology has been criticized [36], it is a well-tried and efficient method of obtaining useful and credible estimates of the prevalence of problem drug use.

Where time-series data about persons seeking treatment are available, these may provide a suitable basis on which to generate indicators of the incidence of certain types of drug use within the population. Using lag-correction techniques, it is possible to produce indicators of incidence trends within the population, accounting for those who have not yet sought help for their drug problem [37-39]. Lag-correction combines information about observed incidence among diagnosed cases with information about the observed delay between onset and diagnosis in order to produce incidence estimates for those who have not yet sought help.

Management purposes

Those responsible for planning, managing and commissioning treatment services need to be able to assess the performance of those services. A treatment surveillance system can provide an objective and external source of information that enables comparison between similar types of service and monitoring of changes in service performance over time.

As national understanding of the need for drug services develops, it is likely that national and local targets will be set and figures evaluated against these targets. (See, for example, local delivery plans and public service agreements for England at http://www.ndtms.net/LocalDeliveryPlan.aspx and http://www.ndtms.net.)

Performance management is likely to require an information system that can provide more detailed information about the treatment process and its outcomes, in order to answer such questions as: How long do clients wait before treatment commences? How long does the treatment last? In what situation are the clients when the treatment is completed?

Perhaps the most fundamental question in performance management concerns the degree to which treatment agencies engage with, and retain, their target population. Used in conjunction with other sources of information, treatment data may answer such fundamental questions. For example, where methods such as capture-recapture (see below) have been applied to obtain prevalence estimates, these may be combined with information about the size of the population that accesses services to provide a public health indicator of coverage by services of their target population [32,40].

For policy and advocacy

Information about persons with known drug problems may provide essential information for policymakers to take broad decisions about the need for prevention interventions, treatment services, ongoing aftercare and control.

To identify patterns of use of services

Once the system is fully up and running, and when it is possible to combine treatment demand data with other national data sets, it should be possible to identify shortfalls in service provision across a geographical/organizational area.

For service evaluation

Countries will find that data from treatment information systems are much in demand for a range of research and evaluative work around treatment uptake, retention and effectiveness.

Other purposes

These include providing information for students, the media and general public.

To be useful for any of these, data collection must be systematic. It should involve case and data definitions that are consistent between agencies, geographical regions and over time. Without consistent systematic data collection, there are severe problems in combining the information gathered by different agencies even at the city or regional levels. Such problems are amplified at the national and international levels. Furthermore, if case and data definitions are subject to frequent change, then soon it becomes difficult to discern trends in the information that is available.

When systematic data collection and aggregation are routine, they provide a central reference point for those needing to investigate treatment data and allow consistent publication of aggregate statistics. Although the level of detail required by the various audiences for treatment information will differ, a skillfully designed system should provide a cost-effective way of pooling the information that most, if not all, treatment agencies will already gather for clinical management and accountability purposes.

B. Limitations

Some limitations of treatment data should be recognized. Firstly, the data will be affected by the degree to which agencies comply with data requirements. Even where there is a legal requirement to contribute data, health professionals have not always been willing to comply with that requirement [41]. Where compliance rests on goodwill alone, it is inevitable that treatment systems will under-record. In some circumstances, under-reporting may simply be a consequence of administrative burden or a change in key personnel. In others, there may be a basic unwillingness on the part of an agency to open its treatment activities to external scrutiny, or concern about the possible disclosure of patient information. In either case, it is desirable that mechanisms to audit reporting completeness are put in place so as to allow the degree of under-recording to be quantified, understood and, subsequently, minimized.

Sources of bias and external influence may sometimes place limitations on the conclusions that can be reached. For example, as already suggested, although an increase in the number of persons seeking treatment may indicate an increase in prevalence, it may alternatively indicate an increase in treatment capacity or throughput. Equally, an increase in the number of young people seeking treatment may indicate increasing incidence of drug problems in the population, or may reflect a successful attempt to intervene at an earlier stage in drug users' "career". The data generated by treatment agencies are service-dependent, that is to say, as well as reflecting the size and composition of the population that experiences drug problems, they also reflect the agencies' attempts to attract that population into therapeutic contact.

Furthermore, because treatment agencies may cater for the needs of particular types of client, treatment data may not capture information about specific subgroups that arise within the population. For example, where services cater primarily for the needs of opiate users, an increase in problematic use of cocaine within the community may not necessarily result in increased demands for cocaine treatment.

It is also important to note that it may take some time for changes in the underlying population to be reflected in the treated population. For example, treatment data may not immediately reflect changes in the incidence of use, because of the lag between onset of use and first treatment demand.

Definitions of the problems associated with drug use are, to a degree, socially, culturally and politically, as well as medically defined. Treatment provision that is concerned largely with addressing the medical consequences of addiction may access a very different population of drug users than provision that is focused primarily on the social or public health of a community.

Recipients of information based on drug treatment data should be made aware of such limitations. This is most important where data are to be published in the public

domain or are targeted at an audience otherwise unfamiliar with the methods. If there is a possibility that published figures might be open to misinterpretation, then, as far as possible, publications should highlight which conclusions may reasonably be drawn, and which may be inappropriate.

Chapter III

Building your foundation

As a first step towards introducing a drug treatment demand information system, it is useful to carry out a three-stage exercise in order to establish a baseline of existing information and resources, as follows: needs assessment, organizational assessment and an inventory of treatment facilities. This is sometimes called an information, needs and resources assessment (INRA).*

A. Needs assessment

Sufficient time should be allocated to the following background work:

(a) Identify key stakeholders who will be the recipients of feedback from these initial processes;

(b) Document the kind and nature of information that currently exists on drug misuse in the country;

(c) Make an inventory of instruments collecting data;

(d) Conduct an audit of existing drug misuse studies and reports;

(e) Identify which important questions cannot be answered with existing information;

(f) Determine the potential that exists for developing ongoing surveillance and monitoring activities;

(g) Identify the resources that are to be made available to the project along with an indication of expected timescale for development;

(h) Identify priority areas for national assessment as well as for future data collection and document the necessary accompanying infrastructure, technical support and training needs;

Having carried out such an audit, it will be important for key stakeholders to analyse the information gained in three ways:

Firstly, available data sources on drug misuse are analysed individually to assess their utility and to determine areas of common purpose and content, where they exist, so as to minimize duplication.

*A good example of an INRA report can be found at www.un.org.tr/unic/docs/INRA_Turkey_Eng.pdf

Secondly, information from the analysis of data sources is assimilated with information on available resources to form a framework for the development of the system.

Thirdly, strategic goals are set for the development of the proposed information system.

Once strategic goals have been set, the following tasks are recommended:

(a) Identify key individuals and institutions that are best placed to contribute to a national drug misuse epidemiological network;

(b) Develop a coordinated information network including linkage and information-sharing, and a reporting mechanism among the different professionals and institutions involved in drug control;

(c) Address the issue of training for selected personnel in drug misuse epidemiology, especially with regard to guidelines on developing core indicators, data management and analysis, as well as data capture at the clinical level.

(d) Address infrastructure needs such as staff provision, a skills base for the development of templates for data collection for the indicators, provision of database software and computers, and support.

The above section was adapted from United Nations source material [42].

B. Organizational Issues

1. Gaining political and senior management support

The need to gain political support has already been mentioned. Throughout this development phase it is very important to involve relevant authorities at all levels. Key personnel at the government and local government levels, as well as senior executives of relevant organizations such as health and social services, should be personally contacted and the purposes and procedures explained to them. In the case of health services it may be valuable to gain the support of senior medical and nursing staff. Professional groups can be somewhat protective of their own discipline and not easily influenced by the need for additional requirements on their staff. However, without their support it will be difficult to move to the implementation phase.

Where possible, official sanction should be sought that can then be used to assist in the implementation process.

The organization responsible for introduction and implementation of a TDI should be aware of political constraints that may arise when social data are published at the national or international level.

2. Identifying stakeholders

Stakeholders' needs will vary according to their area of work. Some will be concerned with evaluation and performance, some will be most concerned with clinical implications, while others will be more concerned with issues of epidemiology and research.

It will be important to attempt to balance these various needs through open and realistic discussion about the potential for, and limitations of, the proposed new information system.

All stakeholders should be identified and their expectations of the new system should be managed and realistic. Experience shows that unrealistic expectations lead to dissatisfaction and rapid decline in data contributions.

Motivation will contribute strongly to achieving successful implementation. In order to encourage the key parties in the field to participate, it is important to motivate them towards the objectives and necessity of data collection.

Most importantly, clear information about the use of the data at all levels is important in order to get parties to cooperate during implementation of the information system and for its persistence.

3. Location

The organization responsible for implementation, data collection, analysis and management should be identified early. It is often sensible to appoint an organization that will act as objective collector and processor of the data. The organization must be in close contact with the treatment facilities and related organizations that have to supply the data and should be steered by the persons in charge of this policy area within the Government. Clear agreements should be made in relation to the expected scope and activity of the organization, including roles and responsibilities concerning such things as data protection/privacy, quality control and feedback.

One option may be for the "lead organization" to be one of the treatment organizations themselves, in particular in the early stages of development. This situation would need to be very carefully handled so as to maintain data integrity and perceived impartiality. In this case it would usually be important to agree on a plan to hand over the operation of the information system to an independent third party when fully operational.

4. Funding

Adequate funding and accountability should be established for the whole project. Resources should be made available for all operational aspects as well as for training at the central and peripheral levels. Resources may also need to be provided to contributing agencies in order to facilitate the data collection and upload/download processes.

C. Inventory of services and description of the treatment system

In order to be able to interpret the data properly, an overview of all treatment organizations and the services they provide within a country is indispensable. This is a far from trivial task and a classification structure appropriate for the treatment system will need to be developed or adapted. It should cover the widest range of treatment facilities and helping organizations that engage with drug misusers. This overview will help to identify issues of coverage and reliability. It also allows for stratification of data according to the specific nature and content of the available treatments and services.

D. Ethical issues

Four general ethical principles of research/information-gathering on human subjects pertain:

(a) Autonomy;

(b) Beneficence;

(c) Non-maleficence;

(d) Justice.

The principle of **autonomy** is better known as informed consent. Informed consent comprises three components: information, understanding and consent. It should be given without external pressure and without unreasonable inducements. It is ideal if a neutral party obtains consent rather than the main treatment provider. Non-participation or withdrawal of consent should not result in disadvantage for the client. Consent is not required if the data are already in the public domain, but the definition of "public domain" varies from country to country. It is not necessarily the case in each country that informed consent will be required for the collection and collation of routine anonymized treatment data.

The principles of **beneficence** (do good) and **non-maleficence** (do no harm) are often combined. The ultimate aim of epidemiological research is to increase peoples' opportunities to choose options that enhance their health. There is also a moral obligation to cause "no harm" to those who participate in research studies or surveillance systems. The risk of harm associated with an epidemiological surveillance system is low, although breach of an individual's privacy is a risk. Data stored in a surveillance system should only have personal identifiers if absolutely necessary and access to databases should be restricted to a "need-to-know" basis. The storage of, and access to, identifiable data should follow procedures that prevent disclosure. When analysing the data pertaining to small numbers of subjects, care should be taken in case an individual can be identified. People who participate in a surveillance system should be presented with summary reports on a regular basis. The reports need to be disseminated in an easy-to-assimilate format (such as a newsletter) and can be used by participants for advocacy purposes.

A conflict of interest (**justice**) arises when the researcher or sponsor has or appears to have a vested interest that may influence the interpretation of the results. Prior to implementing a surveillance system, the lead team should identify possible conflicts of interest and implement strategies to deal with them. Conflicts of interest are more commonly associated with industry- and government-sponsored research. All results are the intellectual property right of the parent organization and their independence must be maintained at all times. Prior to publication, it is good practice to ensure that results are peer-reviewed by at least one independent expert. The results should be released to the media and public at the same time.

A drug treatment reporting system requires a protocol and its primary objectives are:

(a) To state the current situation and justify the need for the proposed reporting system and outline its potential outcomes;

(b) To establish the appropriateness and validity of the proposed methods;

(c) To demonstrate the feasibility considering staff and client participation, as well as training and resource requirements;

(d) To confirm that the principal investigator has the capability to implement the system successfully.

The protocol will be used to obtain permission and resources as well as to guide the implementation of the surveillance system. It will be a key document when evaluating the validity and usefulness of such a system.

In order to comply with ethical considerations, it is necessary to write a detailed study protocol outlining the current situation and rationale for the proposed reporting system. This protocol will present:

- The objectives of the drug treatment reporting system;
- The methods employed to collect, enter, store, validate and analyse the data;
- Data protection issues pertaining to the specific country and procedures to address them;
- Ethical considerations (consent, confidentiality and use of data) and the actions taken to address each of them (such as client and service provider information forms, procedures to store and access data, procedures to review pending publications);
- The implementation plan, justifying human and financial resources and structures;
- The outputs expected from the reporting system.

E. Technical standards

Data transfer and supply should meet the required safety standards for such sensitive files. This may entail file protection measures, line security, access security, user

authorization and similar (sending protocols, hash totals, encryption, decryption, virtual private network (VPN) and public key infrastructure (PKI).

Choices have to be made within the technical and legal possibilities available in a country. A framework for standardizing security can be found in:

International and national standards in healthcare information security

International Standards Organization

The International Standards Organization (ISO) work on information security and the relation to healthcare can be best described with the following scheme:

ISO roadmap

Requirements	→	*Guidelines*	→	*Specific standards*
Integral security		Risk assessment		Banking
Management system		Risk treatment		Health care (ISO 27799)
(ISMS)BS17799.2		Quality assurance (ISO 17799)		

European Standards Organization

The European Standards Organization (CEN) and ISO agreed to exchange work items in order to propel the convergence of European and worldwide standards. This agreement is known as the Vienna Agreement. CEN/TC 251 is responsible for the topic "healthcare informatics". Important (pre-)standards are ENV13606 (Electronic healthcare record communication) and ENV13608 (Security for healthcare communication).

In addition, national standardization commissions exist in many countries that make implementation protocols for international standardization.

F. Security management

Information security has multiple dimensions. When collecting national information on treatment demand the focus is on three of these:

1. Privacy enhancing technology

The collection of drug treatment information should be protected by a pseudo-anonymization procedure. Personal identifiable information should be encrypted with a one-way algorithm in order to prevent linkage of information to identifiable persons.

2. Transport security

Message encryption is used during transport of the data to a national database. A simple encryption procedure as a password-protected WinZip© file may be sufficient if the data have already been subjected to the encryption algorithm and cannot be used to trace identifiable individuals.

3. Storage security

Special protocols should be established and hardware/software solutions implemented to prevent illegal remote and local access to terminals with a connection to the treatment data.

Chapter IV

Data issues

A. Introduction

Many countries have already developed national data collection on the activities and characteristics of drug and/or alcohol treatment services and their clients.

In order to aggregate and compare such data across nations it is necessary to identify a core set of common data items and to harmonize methodologies of data collection. The complexity of such an endeavour should not be underestimated. Although it may be relatively easy to derive a brief item list, the task of harmonizing the scope of collections and achieving consensus on a basic set of definitions, such as what constitutes treatment and drug use, is considerably more challenging.

In the development of this Toolkit, a comparison of several national and provincial minimum data collections on treatment supply indicators from treatment services was undertaken in order to identify a common set of data items. The Treatment Episode Data Set (TEDS) of the United States of America, the European TDI, the Australian National Minimum Data Set (NMDS) and data sets from Canada and Southern Africa were chosen for the comparison. It should be noted that the European TDI is itself derived from the experience of several established European systems and follows also the experience of the Pompidou Group [43, 44].

Common items forming the basis of a core data set relate to client characteristics, treatment characteristics and patterns of drug use. Major differences between the collections include the unit of measurement, for example, client registration (European Union), treatment registration (United States) or treatment episode (Australia); reporting rules and time-points for data collection. These systems also differ in the range of agencies, clients, activities and drugs included in the data collection. The similarities and differences between these and other data collection systems are not presented here. Instead, this Toolkit limits itself to the key practical issues that would need to be addressed in order for an internationally consistent data set to be derived.

B. Guiding principles

The least burden possible should be placed on treatment service staff who will be responsible for collecting the data. This may be achieved if the following are observed:

- Every attempt should be made to utilize, and/or adapt, pre-existing data collection systems. Countries with data collection systems already in place will be more amenable to participating in an international collection if the data can be extracted from their systems without the need for fundamental changes in scope, definitions or item list.
- Countries lacking a data collection system can be provided with a template for items and methodologies of collection, one that is modest but has the capacity to be expanded upon to suit local requirements for data.
- Consideration should be given to how data are routinely collected at the treatment centres in order to ensure that: *(a)* wherever possible, duplication of data collection is avoided and *(b)* both the process of data collection and the data itself are clinically useful, and every attempt is made to integrate data collection into routine clinical practice.
- Differences in scope and definitions should, within reason, be able to be accommodated as long as they are clearly identified and documented.

Additional considerations:

- Collection should focus on a limited number of indicators and a manageable core data set.
- Data should be collected in accordance with sound scientific methodological principles to ensure reliability and validity.
- Collection methods need to be adaptable and sensitive to different cultures and contexts while retaining consistency.
- Item and concept definitions should be standardized, along with the scope of collection and reporting period.
- Data collection and reporting processes should be ethical and ensure that the client's confidentiality and privacy is protected.
- Data collection should be feasible and cost-effective.
- The roles and responsibilities of both the organization and the individuals working within it should be clearly identified, understood and accepted.
- Contact must be established and maintained with agencies to promote compliance and assist with local implementation issues.
- Support needs to be engendered at all levels of service administration and delivery.
- Feedback must be provided in a timely fashion to agencies collecting the data and at the local, regional and national administrative levels.

C. Recommended core international data set

Based on the review of key international information systems noted earlier, there is now widespread agreement over the core essential data categories that are desirable in order to build a useful, reliable and comparable system. These are presented in summary form in the table below. It is envisaged that this set of items could potentially form the basis of a core international data set.

Core item set derived from comparison of data sets

Client	*Drug use (last 30 days)*	*Treatment*
• Attributor[a]	• Primary drug	• Treatment centre type
• Age/date of birth	• Secondary drugs	• Date of treatment start
• Gender	• Method of use[b]	• Source of referral
• Race/ethnicity	• Frequency of use[b]	• Prior treatment episodes
• Living status	• Age of first use[b]	
• Employment status		

[a]Attributor (initials + date of birth + gender), or equivalent method, to minimize multiple counts.
[b]For primary drug or each drug, if possible.

These items should be considered to be the "lowest common denominator" data set. Adoption of this data set would place a minimal (or no) extra burden on countries that are presently collecting national treatment data and provide a modest set of items for collection in countries without existing systems.

It should be noted that there will always be contextual differences between national approaches to problems of drug misuse, including whether treatment services are led primarily by medical, social or legal constraints, and it is important to be sensitive to these and other national/local issues.

D. Unit of measurement, concept and item definition

Apart from deriving a set of items for the core collection it is necessary to decide upon the unit of measurement for the data collection, for example, whether it is to be based on *client registration* or *treatment episode*. Secondly, a consensus is required on definitions of essential concepts, such as what constitutes "treatment", when treatment is said to commence, what is the definition of "client" and what is meant by "drug use"? Lastly, the items should be defined and their data fields, if not harmonized exactly, need to be able to be mapped to a common set of codes. Such crosswalk methodology can be outlined in a data dictionary. This would be the subject of later development. The key to success in international collection is to ensure that data collected from different countries can be crosswalked to a common set of acceptable codes.

While there is no clear agreement on the meaning of all concepts/definitions across countries, and there will be many variations globally, if a country is just starting out, the recommendations below may act as a useful guide.

1. Unit of measurement

The most pragmatic approach is to adopt client/case registration as the most basic unit of measurement in a manner similar to that currently used in the TDI collected in the European Union. That is:

Client/case registration

A client/case is a person who starts treatment for their drug use in a treatment centre during the calendar year, 1 January–31 December.

In order to minimize multiple counts of clients attending several different agencies within the same year, for the purpose of national TDI-type reporting, only the last treatment provided to a client is counted in any year and treatments continuing from previous years are not counted in the later years. This applies to any time period or geographical area chosen (see chapter VI, Analysis and reporting, and also refer to the TDI, Standard protocol 2.0. (http://www.emcdda.eu.int/?nnodeid=1420 and link to the European Monitoring Centre for Drugs and Drug Addiction/Joint Pompidou Group–EMCDDA Treatment demand indicator Standard protocol 2.0, under "Protocol and methodological reports")). Adopting this approach allows for episode-based systems to be "mapped" and counted in equivalent terms to client-based registrations.

The choice between treatment episode and client/case registration:

(a) *Treatment episodes* are generally regarded as being for the period from the beginning of treatment (for a drug (or alcohol) problem) to the termination of treatment (discharge). Establishing a discharge date is critical since, without this, it is difficult to delineate the end of a treatment episode, short of defining an arbitrary cut off point, for example, six months;

(b) *Client/case registration* is generally regarded as being from the point in time when the client engages with a treatment service (see below). It should be noted that client registration, at the individual level, underestimates the true burden placed on the treatment system as it is known that clients can access many services in the course of a year. A discharge date and reason for discharge is a basic requirement for any move towards examining treatment outcome. However, client/case registration provides a reasonably straightforward start and can be upgraded to an episode-based system subsequent to initial development.

2. What is treatment?

As the scope and nature of treatments provided for people with drug problems vary enormously between countries, it is important to adopt a sufficiently broad definition of treatment and its commencement that is interpretable and acceptable across a wide area.

Drug treatment

Drug treatment is considered to be any structured intervention aimed specifically at addressing a person's drug use.

Although a drug user's problems may be very wide ranging, *treatment* addresses a person's drug use itself. Examples include stabilization or reduction of drug use, maintenance or abstinence regimes, behavioural therapy, medical or psychological interventions and so on. In this context, help with related problems of housing, education or relationships, for example, do not constitute *treatment*, even though support in these areas may be important adjuncts to treatment.

3. What agencies should be included in the collection?

In many countries, specialized drug treatment facilities provide most of the treatment places, although it should be noted that drug users will, of course, be seen in a number of other generic contexts (e.g. at the family doctor's) or other specialist medical facilities (e.g. a psychiatric department). In countries where no specialist drug facilities exist, problem drug users will often be seen primarily in general medical and/or social help contexts. It is important to include all locations in which drug users are treated in a structured intervention for their drug use.

Self-help groups such as Narcotics Anonymous or Alcoholics Anonymous are not normally considered to constitute *structured* treatment and should therefore normally be excluded.

Treatment centres

A treatment centre is any agency that provides treatment to people with drug problems. Treatment usually takes place at specialized facilities for drug users, but may sometimes occur in generic contexts such as general practice. One treatment centre may provide more than one treatment programme or service.

Treatment centres can be based within structures that are medical or non-medical, governmental or non-governmental, public or private, specialized or non-specialized. They include inpatient detoxification units, outpatient clinics, drug substitution programmes (maintenance or shorter-term, detoxification (or "detox")), therapeutic communities, counselling and advice centres, street agencies, crisis centres, drug treatment programmes in prisons and special services for drug users provided within general health or social care facilities.

It should be noted that the following are usually excluded: hospital emergency rooms or general health/social care facilities that drug misusers contact primarily for help with problems other than with drugs and programmes concerned exclusively with making syringes/needles available or disseminating information, unless these activities are part of a wider range of services offered to help people with drug problems.

4. When does treatment commence?

Some flexibility is required here to reflect different clinical practice. In some situations, clients are triaged prior to decisions being made about their treatment; in others, client assessment represents the start of the treatment process; in yet others, prescribing is considered to be the start of treatment.

Start of treatment

This is the first formalized service contact when assessment and/or treatment occurs with the treatment provider and typically involves formal registration of the person into the treatment centre. This includes structured assessment leading towards a treatment plan.

5. Who are the clients?

Client definition

A client is a problem drug user who starts treatment for drug use at a treatment centre. This excludes persons in contact with a treatment centre on behalf of drug users and persons with problems that relate only to their relationship to a drug user.

The system should count as clients, only problem drug users in treatment and not third-party clients (presenting on behalf of someone else) or those making enquiries for advice and information alone. However, if the treatment information system is already mandated to include such third-party clients, it is vital that the system is capable of identifying these and excluding them from the analyses.

6. *Which drugs are included?*

Drug definition

Any drug of misuse excluding alcohol or tobacco.

OR

All drugs of misuse, including alcohol and tobacco, as long as these can subsequently be excluded if necessary from further analyses.

The concept of drug misuse often excludes the use of alcohol and tobacco, even though use of these may result in far greater health problems and burdens for society. Cultural and societal issues influence the way in which drugs are viewed and approached and vary from one country to another, as do the laws that make drugs legal or illegal. The inclusion or exclusion of alcohol or tobacco from an information system is largely a decision driven by policy and resources. There is no intrinsic reason why these drugs may not be included in data collection, even though it should be noted that the questions in most drug treatment core item lists do not specifically address alcohol or tobacco problems.

It is very important that all systems should be capable of *excluding* users of only alcohol and tobacco from their data sets, so that international analyses and comparisons can be made between data sets.

The misuse of prescription drugs resulting in problems for an individual should be included.

Chapter V

Implementation

Once the implementation phase is reached, it is assumed that all background work has been accomplished. Implementation is then practical by nature.

> ***Involving people***
>
> The cooperation of those to be involved in a drug data information system is crucial to its success. Individuals must be enabled to carry out their functions by means of support, training and resources. Three phases are necessary: identification, development and field work.

A. Identification phase

It is suggested that the following be identified:

- Suppliers of information
- Host organization(s)
- Other key stakeholders
- Software/hardware needs
- Lines of communication
- Lines of accountability
- Processes
- Training needs
- Feedback loops

B. Development phase

Alongside the above, or shortly after, a phase of development is essential so that all materials and structural elements are in place before attempting to start up the new system. This is particularly

important if confidence in the new system is to be built up from the start. Support and cooperation, in particular from clinical treatment facilities, will very soon be lost if the system is not clearly thought through and practically acceptable. It has often been found to be useful to carry out field testing of the instruments (schedules, documentation, etc.) to ensure that they are understandable and correctly interpreted.

It is suggested that the following be developed:

- Implementation plan and timescale
- Data capture/analysis software
- Data handbook and dictionary
- Written materials
  - Letters to stakeholders
  - Publicity material
  - Logos and so on
  - Data collection sheets
  - Practical guidelines
- Protocols for data capture, delivery and feedback
- Training resources
- Pilot testing and revision

Where forms are used they should be designed to be simple, user-friendly and, preferably, one-page instruments. It is most important to be relatively modest at first and not try to collect everything that might eventually be needed. There is a need for pragmatism and realism.

Policy and procedures should be published as a manual. This acts as an instruction manual for those implementing a system for the first time and a subsequent check for those who have a system already running. The manual should include at least the following:

- Data submission (paper/disks/electronic/web-based)
- Deadlines and incentive/enforcement practices
- Data entry, including logical checks
- Feedback loop back to treatment facilities to report on, and correct, errors and inconsistencies
- Data analysis plan (with dummy tables)
- Tailored, multi-level reporting plan
- Summary of ethical and security issues and how they are being handled

C. Fieldwork phase

A programme of initiation and training should be implemented. All key stakeholders should be contacted in person, either by letter or face to face, and considerable efforts made to ensure full understanding and support for the initiative. Adequate time should be allocated to this exercise.

These initial contacts should be followed up by regular contact with treatment facilities and key stakeholders, including visits, phone calls, newsletters and so on. This is helpful in order to encourage attention to detail and quality control in data capture, as well as to receive feedback on operability, clarity, data volume and other identified issues.

Chapter VI

Analysis and reporting

A. Introduction

In order to convert collected data into useful feedback it is necessary to prepare the data for analysis and to decide appropriate forms of feedback for the audiences concerned. Data will need to be cleaned and validated, appropriate software employed, reporting priorities selected, case definitions clarified and appropriate levels of reporting detail agreed.

1. Audience

Treatment demand indicators should provide multiple levels of feedback appropriate to different audiences. These are likely to include provider services, commissioning organizations, national government bodies and, where appropriate, international organizations. Reporting to existing international systems may have established procedures to be adhered to. In some instances it may be appropriate to adhere to the same methods as those used for international reporting, but to tailor analysis to specific and local needs in others. The rest of this chapter will concentrate on a common range of options that will face anyone needing to analyse a drug treatment data set.

2. Case definitions

A treatment demand indicator is not designed to measure the full extent of activity between drug services and their clients. Within a single service over a particular time period, an individual client may experience multiple episodes and multiple modalities, or treatment regimes, within those episodes. In the same time period a client may also, of course, make treatment demands at more than one centre. A separate episode may be recorded each time an individual presents to a centre. For each aspect of reporting a decision needs to be made as to whether the individual or the episode is the most appropriate basis for analysis. Once this decision has been made, careful consideration should be given as to how to define and extract data about the individual or episode from the available dataset.

Individuals

It is general practice to report on client characteristics (such as gender, ethnicity, age and drug use) at the level of the individual. That is, only one case for each individual within the appropriate time period is used for analysis. On this basis a systematic prioritization of cases must be employed. The options for this are listed below:

(a) Earliest episode within the time period;

(b) Latest episode within the time period;

(c) Aggregation of each episode into a single case (only appropriate for certain fields)

It is generally considered most appropriate to report on the latest case for an individual within a time period as this represents the most up-to-date report of that client's status and activity. Client details such as living status, employment status and drug use may of course change over time and the most recent status is likely to be the most appropriate. Whichever method is adopted, the limitations must be made clear to the data recipient so as to avoid misinterpretation.

Consider, for example, a group of 10 clients who make a treatment demand early in the reporting period with a primary heroin problem. Five of these clients also seek treatment a second time, later in the period, with a primary cannabis problem. The "latest episode" methodology will report five individuals with primary heroin problems and five individuals with primary cannabis problems. Another method of reporting (aggregation of cases) would report that 10 individuals reported a primary heroin problem and five reported a primary cannabis problem, but that the two groups are not mutually exclusive. A national demand indicator will clearly involve a much greater degree of complexity, but this simple example shows how important it is to consider which method of interpretation of the data is appropriate.

Age will of course change over individual episodes and with the likely interest and emphasis on reports made by the young, there will be circumstances in which it is the characteristics displayed at the earliest episode by an individual that will be considered the most appropriate to consider. Similarly, if researchers are interested in newly emerging drug use, the earlier episode in a time period may be of most interest, in particular if the client is new, at this point, to the treatment system.

A mixture of these methodologies may be appropriate for specific contexts/ audiences, though it is generally recommended that, for clarity and ease of interpretation, a single method is employed throughout a single report. Any deviation from a standard methodology should always be accompanied by very clear guidance and explanation.

For those characteristics which do not generally change (gender, ethnicity), it is possible to populate missing data from other cases by selecting the latest valid response

to the field, or variable, from within the time period. For example, if the "latest episode" methodology is employed and gender is missing but present in the previous episode, then the information may be imported from the previous episode. Even where the field/variable may legitimately change, it is often still valid to select the latest positive response in cases of missing data.

Episodes

Treatment episode characteristics, such as the type of agency or source of referral, may be more usefully reported on at the episode level. Again, there is more than one way of interpreting these data; at the treatment centre level it is often more appropriate to represent the totality of demand rather than just the number of individual clients.

B. Data preparation

Good analysis starts with a thorough routine of data cleaning and validation. This is likely to involve identifying erroneous, or potentially erroneous, data and seeking to confirm/edit the data or to delete the appropriate case(s). The computer system for data entry may not allow a case to be entered if any key fields are missing (so-called "internal validation"). If this is not the case, then missing items need to be identified before any analysis can begin. Some other common checks may include the following:

- Age too high or too low
- Route of administration not compatible with drug (e.g. cannabis; inject)
- Age of first use greater than current age

Depending on the data collected there may be hundreds of such internal validation checks. These can absorb a considerable amount of time between data collection and reporting, especially where agencies need to be contacted to correct the data provided. Therefore, it is vital to implement a consistent and automated/semi-automated system of data validation for the attention of data-processing staff.

1. Recoding categories

It is best to collect data with a high level of detail, but to recode those data into manageable categories for the purposes of much reporting. For example, several hundred individual drug categories may be recorded at source that will need recoding into groups for any manageable level of reporting. These groups can be as broad or specific as required, for example, opiates/stimulants or heroin/methadone/other opiates/cocaine/amphetamine/other stimulants. Categories should be flexible enough to change over time in order to reflect changes within the reported population. An example of this would be the emergence of crack cocaine as a separate category

to "cocaine" as a result of its growth in use in the United Kingdom of Great Britain and Northern Ireland throughout the 1990s. It will still be essential to analyse drug use at the smallest possible level of detail in order to monitor the use of very specific drugs.

Age groups will also need to be created for ease of reporting and these should be split into categories of five years to allow for classification that accords with country needs and is flexible enough to allow recoding for comparison with other international data.

In recoding specific data into broader groups it should always be possible to "reverse engineer" the process so as not to lose any detail in the available data.

2. Calculation of key fields

In many databases age is not collected, but rather calculated from date of birth. For a treatment demand indicator, age should be calculated as the time between date of birth and date of treatment demand. This provides a greater level of accuracy than simply collecting age in the original data. It is reliant on both date of birth and date of treatment demand being present, although without these it would be impossible to define an individual (based on attributor) within a time period.

C. Data analyses and reporting

1. Suggested analyses

Chapter II gives a good indication of the depth of uses of a treatment demand indicator, especially ones established over many years. The total scope of possible analyses is too great to cover here, but certain fundamental reporting needs are likely to be held in common by different countries. Clearly the central role of a TDI will be to report on the nature and extent of drug use that is reported to treatment agencies alongside an assessment of how these demands differ between subsets of client characteristics. A bare minimum of reporting (for each time period and area of residence or treatment provision) should include:

(a) The number of individuals making treatment demands: probably the most central figure to any TDI, indicating the number of people who both match the criteria of problem drug user and have sought treatment for their problem;

(b) The number of treatment demands made by those individuals: many individuals make multiple demands over time and across services or service provision areas, and this figure describes the level of demands made of those services;

(c) The types of agency to which demands are made: as services are commissioned to meet need, it is essential to understand the level of demand made to each service type and the nature of the problems presented to them;

(d) The numbers reporting primary use of each drug: the primary drug of use can be the drug causing the most problems at the point of making a treatment demand and/or the drug for which the client sought treatment (its exact definition is a training issue for participating agencies). Either way it is the clearest indication of the nature of the problems being presented to which services need to respond;

(e) The numbers reporting any use of each drug: drugs other than the primary drug of use may or may not be problematic in their use. As such, although they may not be such a direct indicator of the nature of demands made to services, they are still a vital indicator of wider drug use and potential unmet need;

(f) Levels of injecting: the injecting of drugs can both indicate the "advanced" nature of an individual's drugs use and create public health concerns regarding the spread of blood-borne diseases. As such, "injecting" is a vital reporting indicator. Localized assessment of this factor can also provide a direct indication of clean injecting equipment service provision needs;

(g) The number of individuals previously/not previously treated: this allows for the monitoring of the level of demand made by the (previously) hidden population and can indicate any emerging trends in drug use and client characteristics. It may eventually be used to indicate epidemics or stable populations (see chapter II);

(h) The gender of reported individuals: males and females may have a different range of problems, have different service needs and present to services at different ages and to differing degrees. All these factors represent important reporting needs;

(i) The ethnicity of reported individuals: ethnicity is a similar case to gender representing a window into monitoring the equity of service provision within diverse communities;

(j) The age groups of reported individuals: younger individuals may have different treatment needs and any difference in the nature of their treatment demands may indicate emerging trends.

This list is far from exhaustive as any number of combinations of reported data may be required by different key stakeholders at different times. Indeed it is a general principle that all data collected should be utilized and reported at some stage if it is justifiable that it is collected in the first place. However, it is essential to formulate consistent and standardized reporting that can be compared over time and expanded upon as appropriate. The above list provides for an assessment of the nature and levels of demand and how these may change over time. Descriptors *(a)—(f)* above should be analysed by age, gender, ethnicity, whether previously treated and area of residence/treatment in order to provide for the most obvious and needed comparisons. The majority of basic information requirements and monitoring towards targets is likely to be provided within this minimal reporting system.

2. Trends

It will be important to record and report on changes in these basic descriptors over time. This can be used to assess changes in the nature and extent of demands and their progress towards any set targets. It is most common to report on changes between annual periods. Changes over shorter periods can be assessed, although these may be particularly subject to seasonal changes or other short-term fluctuations. For commissioning purposes, it is generally desirable to be able to analyse data on the basis of fiscal (financial) periods, usually 1 April to 31 March. However, reporting systems should be equipped to report over both calendar years and fiscal years.

Caution should be taken not to simply compare one period of data with the previous one without assessing the significance of these changes within the context of longer-term trends.

3. Area of treatment provision and client residence

Commissioning bodies are likely to need to know both about the level of treatment demands within their area and the level of treatment demands made by residents of their area, as the two are unlikely to be identical. Analyses may need to be reported at either one of these levels and may also need to describe the amount of crossover between the two.

4. Levels of interpretation

It is usually beneficial to include some level of interpretation of the analysed data in any report. Inclusion of appropriate interpretation is likely to improve any feedback report as it can provide a commentary on, and insight into, the descriptive frequency data tables. At the national and regional levels, this may involve comparisons between administrative or commissioning areas whereas reporting at the local, or even at the individual agency level, may involve issues of specific and detailed local interest.

Whenever data are interpreted, care should be taken to consider the potential influence of bias that may be introduced by issues of coverage. If, for example, particular sub-populations have declined to participate in data collection because of issues of informed consent, or if particular significant treatment centres have not participated, this will affect the total data captured by the system and available for analysis and interpretation.

5. Anonymity

Reporting from a TDI should be conducted at a number of levels, most commonly at the national, regional, commissioning area and agency levels. Though all reports

at a level above that of the agency should be in summary, aggregated format without client identification, care should still be taken over potential identification when reporting on a small number of cases, especially if the reports are to be publicly available. All reporting should be useful and fair and should never jeopardize the anonymity of the client, or present an impression that anonymity is not taken extremely seriously. Reporting on the drug use of a small number of clients with certain characteristics within a certain area of residence, although not directly identifiable, may be considered inappropriate. A general rule is to consider any reported subgroup of less than 10 individuals to be inappropriate, although rules are not internationally set on this and careful decisions must be made at the local level.

6. Caveats/limits of data

All analyses and reports must be accompanied with clear descriptions of exactly what the data can and cannot be legitimately interpreted to say. In particular, it must be made clear that data relate to those individuals reporting problematic drug use to treatment services and not to the whole drug using population, and that any measure of new demands made to agencies does not represent the full extent of all demands experienced by treatment services.

Changes in service provision may have a significant impact on the throughput of certain groups of people, for example, the implementation of a service for a type of drug use behaviour not formerly catered for. These changes in service provision may result in proportional changes in characteristics of the treated population and should therefore be interpreted in context, that is, they may reflect changes in the population seeking treatment, rather than changes in the underlying problem drug-using population.

7. Feedback/quality monitoring

It is essential to include within the feedback loop those agencies which provide the source data both so as to give feedback analyses of their own data contribution and to allow them to see how their contribution compares with others within appropriate geographical or commissioning areas. This also provides an excellent opportunity to report on levels of data completion and quality within provider agencies and to place relevant stress on their importance.

Regular reports, at monthly or other intervals, of data derived from the system should be provided to all key stakeholders, in particular contributory agencies/treatment facilities. These may take the form of tables of data with or without detailed commentary, according to need and the resources available. More detail and less commentary may be more appropriate at the treatment facility level, with increasing commentary and interpretation but fewer data tables at the area/regional or national/international level. Feedback to staff at the data capture level is also critical as

a way of encouraging interest and motivation. Significant value must be returned to agency staff if they are to make the effort to provide data in the first place.

8. Ad hoc requests

Systematic reporting structures cannot answer all the questions that the data may raise. It is most likely that essential questions will be answered for the majority of stakeholders but that further in-depth questioning will be needed by a significant minority. It is, of course, difficult to predict the nature and level of these additional requirements. However, it is wise to ensure that the analytical capacity exists to deal with them when they arise. Caution should be taken to ensure that such ad hoc requests do not interfere (in human resource terms) with the business of providing a standardized reporting system. Clear guidance must be provided in assessing the appropriateness and priority of each request, bearing in mind that not all forms of analysis should be made available to all who request them.

9. Handling missing cases

Missing data raises a number of issues, including the need to provide feedback to agencies on the requirement for as complete a set of data about each individual as possible and the need for caution in analysing and reporting data. If certain key fields are missing, such as elements of the attributor (initials, date of birth, gender) or reporting agency, then the case/record may need to be excluded from analyses or even deleted if there is no chance of further completing that record.

Although some level of missing data is inevitable, the extent can affect the validity of interpretation. The preferred method of handling missing data in tables of analysis is to provide valid percentages (i.e. the number of *valid responses* as the denominator in calculations, not the total number of cases) and to report on the level of missing data. This combination allows the reader to view percentages that total 100 per cent and to make some judgement on the extent to which they can be taken as representing the population within the entire data set.

10. Expanded data collection and analyses

This chapter has concentrated on some of the potential analyses of data from a system designed to measure treatment demand. Some thought should also be given to the possibilities that arise from a system capable of recording every treatment episode and including start and end point data. Information of this quality can both summarize treatment demand and provide a wealth of information such as the nature and level of treatment actually received, the length of contact with services (including levels of retention and attrition within episodes) and total client loads over any time period/organizational area.

Maintenance and evaluation

Chapter VII

It is valuable to update the inventory of service provision on a regular basis for inclusion in the reporting system. This can be achieved through systematic and routine contact with all treatment facilities. It may be most practical and useful to organize this on a regional or other small area basis.

A logging system that monitors and acknowledges data arrival from each source, alongside a record of data-processing queries and anomalies that derive from validation procedures and error checking, is also useful. Difficulties at any level should be fully documented, as should discussions held with contributors and other stakeholders. Managerial issues that emerge should be included. A rolling programme of contact and feedback to and from stakeholders should be established. These may take the form of twice-yearly meetings of key personnel, with peer update and review sessions and themed expert input.

Evaluation is a continuous process that should identify gaps between objectives and results. An evaluation of treatment demand indicators/data should also aim: *(a)* to improve collected data; and *(b)* to improve and revise the indicator, if necessary.

A. Internal validity

Checks should be made to ensure compliance to protocols and guidelines for data capture, data processing and data analysis. Internally valid data will demonstrate correct case definition, correct use of coding frames, avoidance or at least minimization of double counting and acceptable levels of data completeness, avoiding extensive missing data values. Where data are missing and values (whether of text, numeric or date fields) are out of acceptable range or inaccurately coded, measures should be made to improve data quality.

It may be that practical improvements in data capture, for example, improvements to data forms or provision of electronic data capture

via computer, will be necessary following review of operational methods and will greatly improve data quality and validity.

Providing feedback reports to individual providers of the data that show outliers or incorrect entries is one strategy to gradually improve data submissions over time.

Some items of the database will need to be internally consistent. For example, dates (birth, age of first use of drugs, date of start of treatment) should be sequential and sensible, and certain items of drug data such as route of administration and whether a drug is said to have ever been injected.

Attributors

Many countries utilize the basic personal details of a person—that is, their names' initials, date of birth and gender—to produce an *attributor code* that has sufficient uniqueness without the practical possibility of real identification of the individual. Commonly the first initial of the first name and the first initial of the last or family name are used alongside the date of birth and gender, although considerable variation is possible here according to country tradition.

The main purpose of such an attributor is to be able to link records and to minimize duplication of records. This becomes very important when considering data across years or even within years where it is possible that a person visits more than one treatment service. For epidemiological purposes, although it is sometimes useful to count episodes of care, in particular, for example, in work on performance management, it is essential to be able to distinguish individuals—for example in order to present valid percentages of users of heroin or numbers of males/females.

In order to do this, internal checks can be set up that identify exact matches and that identify close matches. These are sometimes referred to as, "hard" and "soft" matches. Ideally, close matches should be checked for accuracy, but in most cases this will not be practical. There will be much variation across countries in the possibilities and/or legality of such data matching and it is not the purpose of this Toolkit to be proscriptive as to method. It is, however, important to be able to distinguish individuals from repeat episodes within an acceptable level of error.

B. External validity

As most surveillance systems rely on self-report, it would be ideal to verify the data by reference to external testing, such as urine analysis, saliva analysis or analysis of hair. However, this is more likely to be the subject of research rather than surveillance. Therefore most systems rely on other recorded indicators, such as population surveys, mortality indicators, emergency room information and local intelligence. Feedback from treatment services themselves is perhaps the best and most

straightforward method of verification. For this purpose it may be useful to compare cases reported to the indicator with cases selected from a sample of clinical records from the treatment centres. In this way it is possible to check the centre and client coverage over a period of time, as well as case definition and the methodological guidelines, and thus provide evidence for the sensitivity, specificity and predictive capability of the indicator.

Contextual and qualitative information is also important to better understand and interpret treatment data. Gathering relevant information about service availability, accessibility, use and characteristics can support the external validation.

The issue of completeness of data capture, that is, to what extent all expected individuals are recorded by the system, is also important, as is the coverage of treatment facilities themselves.

A cycle of maintenance and evaluation should be established to monitor all such issues of data quality and validation, and regular reports back to all key stakeholders should be made available. In this way the data will be seen to be of increasing value, and confidence will be built up that will enable proper utilization of the data in decision-making processes that improve service provision and community responses to issues of drug misuse.

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