

---

**EMCDDA Project CT.03.ENL.209**

**FINAL REPORT & PROPOSED OUTLINE GLOBAL TOOLKIT  
FOR THE MEASUREMENT OF DRUG TREATMENT DEMAND**

**BACKGROUND MATERIAL FOR THE DEVELOPMENT OF A TOOLKIT ON DATA  
COLLECTION REGARDING DRUG TREATMENT DEMAND IN THE EUROPEAN  
MEMBER STATES AND IN THE ACCEDING AND CANDIDATE COUNTRIES**

**INCLUDING MEETING REPORT OF THE GLOBAL WORKSHOP ON TREATMENT  
DEMAND INDICATORS VIENNA INTERNATIONAL CENTRE, DECEMBER 2003**

---



European Monitoring Centre  
for Drugs and Drug Addiction



UNITED NATIONS  
*Office on Drugs and Crime*



Global Assessment Programme  
on Drug Abuse

**Project Team:**

Michael Donmall (Author)	National Drug Evidence Centre, Manchester, UK
Linda Montanari	EMCDDA, Portugal
Stefano Berterame	UNODC, Austria

**Meeting Participants:**

Stefano Berterame	UNODC, Austria
Luis Caris	CICAD, Chile
Michael Donmall	National Drug Evidence Centre, UK
Leigh Henderson	SAMHSA, USA
Douglas Ken-Garfield	CAREC, Republic of Trinidad and Tobago
Peter Lawrinson	National Drug and Alcohol Research Centre, Australia
Riku Lehtovuori	UNODC, Austria
Jean Long	Pompidou Group, Ireland
Linda Montanari	EMCDDA, Portugal
Visweswaran Navaratnam	National Centre for Drug Research, Malaysia
Kamran Niaz	UNODC, Turkey
Isidore S. Obot	WHO, Switzerland
Charles Parry	SENDU, South Africa
Luis Royuela Morales	Plan Nacional sobre Drogas, Spain
Brian Rush	Centre for Addiction and Mental Health, Canada
Bela Studnikova	Drug Epidemiology Headquarters, Czech Republic
Fayzel Sulliman	Dr Idrice Goomany Centre Mauritius
Juana Tomas-Rossello	UNODC, Austria
Matthew Warner-Smith	UNODC, Egypt

## GLOSSARY

AA	Alcoholics Anonymous
CAREC	
CICAD	
DASIS	Drug & Alcohol Services Information System
EMCDDA	European Monitoring Centre for Drugs and Drug Addiction
GAP	Global Assessment Programme on Drug Abuse
INRA	Information, Needs and Resources Assessment
MENDU	
NA	Narcotics Anonymous
NDTMS	National Drug Treatment Monitoring System (UK)
NSSATS	
OAS	
PG	Pompidou Group
SACENDU	
SAMSHA	
SEIT	Spanish State Information System on Drug Abuse
SENDU	
TEDS	
TDI	Treatment Demand Indicator
UNODC	United Nations Office on Drugs and Crime
WHO	World Health Organisation

Others<sup>1</sup>

---

<sup>1</sup> List to be populated/ expanded in the next phase of work

## CONTENTS

### Part 1: FINAL REPORT ON GLOBAL WORKSHOP, VIENNA 2003

1.1	Background and Introduction .....	5
1.2	Reasons for Collecting Treatment Data .....	7
1.3	What kind of data should be included? .....	10
1.4	How to ensure quality of collected data.....	15
1.5	How to collect treatment data.....	17
1.6	Features of the Toolkit .....	21

### Part 2: PROPOSED TOOLKIT STRUCTURE

1	Introduction .....	23
2	Overview: reasons for collecting drug treatment data.....	23
3	Building your foundation .....	23
4	Data to be collected .....	23
5	Implementing a Treatment Demand Indicator System.....	24
6	Analysing and Reporting on the Results .....	24
7	Maintenance & Evaluation.....	24
	<i>Glossary</i> .....	24
	<i>Bibliography</i> .....	24
	Appendix.....	24
A	Sample Materials .....	24
B	Frequently Asked Questions (FAQs) .....	24
C	Links to relevant Web Addresses .....	24
D	Key Toolkit Markers (PowerPoint) .....	24

**Part 1: FINAL REPORT ON GLOBAL WORKSHOP, VIENNA 2003**

---

## 1.1 Background and Introduction

---

Most countries, aware of problems of addiction and their effect on individuals and on society, have implemented, are in the process of implementing or are planning to implement drug information systems attached to treatment facilities. The collection of treatment demand data is an important element in building a national drug information system.

The Treatment Demand Indicator (TDI) is one of the five Key Epidemiological Indicators identified by the EMCDDA and has the objective to collect data on the number and characteristics of people seeking treatment from specialised drug services in Europe. Based on a joint EMCDDA-Pompidou Group Protocol<sup>2</sup>, the TDI allows the EMCDDA to collect information in a harmonised way in all European countries.

Considerable progress that has been made in defining and implementing the Treatment Demand Indicator (TDI) Protocol, Core Item List and associated Guidance across all European countries. The TDI, which incorporates thinking and practice from the Pompidou Group, has potential for wider application.

The GAP project was initiated in 1999 with the objective of improving the global information base on patterns and trends in drug consumption. In 1998 the Special Session on Drugs of the UN General Assembly adopted a series of goals and a declaration on the guiding principles of drug demand reduction. One of the principles is that demand reduction activities should be based on a regular assessment of the drug abuse situation. Furthermore, the Political Declaration adopted at the Special Session commits government to achieve significant and measurable results in the field of demand reduction by 2008.

Monitoring progress towards this goal required reliable and systematic data on drug consumption that was unavailable at global level. To overcome this problem GAP was launched to:

- Assist governments in compiling reliable and internationally comparable data;
- Collect, summarize and analyze data from governments and report them to the Commission on Narcotic Drugs.

At a national level GAP has provided support in carrying out INRA (Information, Needs and Resources Assessment) and other activities with the objective of building sustainable drug information systems.

At a regional level GAP has supported the establishment of information systems, encouraged networking among countries and provided training.

At a global level the objective of GAP has been to disseminate methodological developments and best practices, to harmonize indicators and to improve reporting standards and increase the quality and coverage of the global information base.

---

<sup>2</sup> [http://www.emcdda.eu.int/multimedia/project\\_reports/situation/treatment\\_indicator\\_report.pdf](http://www.emcdda.eu.int/multimedia/project_reports/situation/treatment_indicator_report.pdf)

One of the crucial elements in the harmonization has been to identify core indicators. An international consensus was reached in 2000 at an EMCDDA meeting in Lisbon during which a number of indicators were agreed including service utilization for drug problems or *demand for treatment*.

Following a TDI meeting in Lisbon in June 2003, a joint initiative was established between EMCDDA and UNODC whose aim is to define **a practical and workable toolkit for all countries that will significantly assist data harmonization and allow for comparative international work essential for policy and practice development.**

The use of a single information model by many countries that may have different traditions and policies provides a significant challenge. In such a large exercise there is bound to be variation in quality and comparability, and issues such as agency coverage, geographical coverage, client coverage and case definition are crucial.

Clarity is important at an organisational level (in terms of definitions for example), the system must be perceived to be useable and useful for implementation to be successful, and interpretive feedback is necessary to ensure effective communication between all the people involved.

In order to achieve this, particularly in the context of increasing numbers of participating countries, it is helpful to recognize **common issues that require structured guidance so that some degree of consistency can be achieved over a wide area.** At the same time it is important to recognize the possibility that certain aspects of the developed system may require clarification, particularly in specific country contexts.

Definitional issues are also very important, particularly in terms of what is meant by treatment itself, how to define cases and episodes of use, and in understanding the strengths and limitations of a core data set. Technical matters concerning double counting, quality control/assurance, and practical matters concerning data capture need examination, taking into account the experience of the existing country systems.

The process of development and implementation of national systems is also vital in the context of local, national and international information needs, as is the way in which these different requirements might be integrated, for example through analysis and dissemination of results.

These issues can potentially be addressed through the process of developing a **toolkit** that is dynamic enough to account for increased understanding and changing needs.

The overall aim of this initiative is to develop a harmonized response amongst participant countries in the method and practice of data collection that will assess the extent and nature of demand for treatment by problem drug users. It has therefore first been important to undertake a collaborative exercise that gives opportunity for all relevant stakeholders to share information and expectations in relation to the implementation and development of a treatment demand indicator in their country.

The **Global Workshop on Treatment Demand Indicators, Vienna 2003** is the first step towards the production of a module on treatment demand data collection worldwide.

The meeting, held at the Vienna International Centre in December 2003, provided the opportunity for countries and international organisations, to discuss and share experiences of the practical implementation/ application of Treatment Information Systems, and to explore the basic rationale behind the collection of treatment demand information, its role and utility, as well as its strengths and limitations as an epidemiological tool and in performance management, and to define in broad terms the requirements of a toolkit for use in implementation and development.

This report presents a review of issues discussed at that meeting and includes a proposed structure for such a toolkit.

Presenters' slides were distributed to participants at the meeting and have not been included here, although elements of some have been incorporated where particularly relevant to the principles of toolkit development.

The structure of the following sections in Part 1 incorporates the main substance of the meeting.

---

## 1.2 Reasons for Collecting Treatment Data

---

### *The role of treatment data for epidemiology and/or performance management purposes*

In the context of increasing substance problems worldwide, countries need to assess the extent and nature of problems in their communities. The imperative to establish information systems may be driven by specific political and/ or socio-medical needs, but there is widespread agreement over the aims of such an activity, which include:

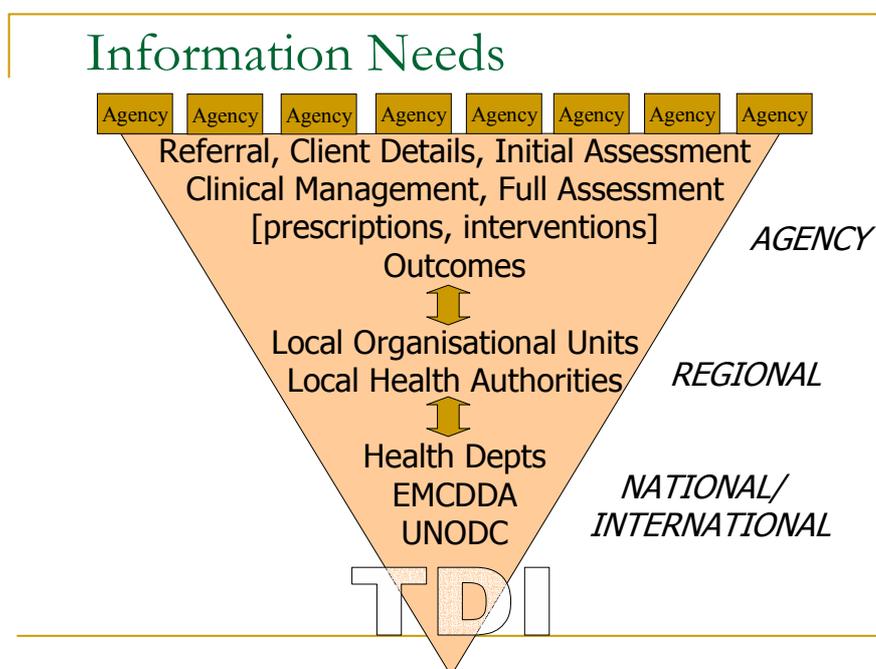
- ❖ Identifying patterns of drug use
  - Assessing the size and nature of the problem
  - Identification of geographic/ organisational differences
  - Assessing risk behaviour
  - Identifying specific sub-groups (eg young people, social groups, users of certain drugs etc)
  - Determining population rates
- ❖ Estimates of treated incidence and prevalence
  - How many new drug users present for treatment
  - How many drug users are currently in treatment
  - Changes and trends over time
- ❖ Indirect indication of trends in problem drug use
  - Utilising data with other techniques such as capture, re-capture (CRC) methods to estimate the size of the drug using population
- ❖ Comparisons at regional, national and international levels
- ❖ Performance management
  - Service utilisation
  - Lag from use to treatment
  - Treatment effectiveness and outcomes
  - Cost effectiveness
  - Information for identified targets eg waiting times, increases in numbers in treatment, increases in criminal justice referrals, reduction in risk taking behaviour such as injecting/ sharing
  - Quality assurance
  - Clinical audit
- ❖ Special investigations
  - Questions to be answered
  - Research and Evaluation

## The Need for Information

In considering the uses of information about problem drug users, it is important to distinguish the different levels of need for such data. It is quite apparent, for example, that local treatment facilities are likely to require very detailed patient level information for the development of individual treatment and care plans. Local administrators by contrast have different needs, perhaps connected to service utilisation and cost effectiveness (including making the case for investing in treatment), while regional or national governments will require policy level and strategic data.

It should be recognised that a single information system is very unlikely to be able to satisfy all these needs and any that tries to do so is likely to fail. There is a tendency, once a system is in place, for interested parties to believe that it will answer all their questions. However, it is possible (and this is the challenge), to devise a system that would both inform policy and provide some epidemiological information. In this connection it should be borne in mind that information needs, especially in terms of policy, change over time.

The diagram below illustrates these different levels of information need.



© Donmall, 2003

Of course it may not always be convenient or even necessary to systematize each level across a country or between countries. It is important to recognise that each country will be at a different stage of development and therefore it is best to focus first on the essential information and to harmonise that wherever possible, prior to expansion of the system for other purposes. In this way a modular approach can be adopted that reflects the reality and pragmatism of each country.

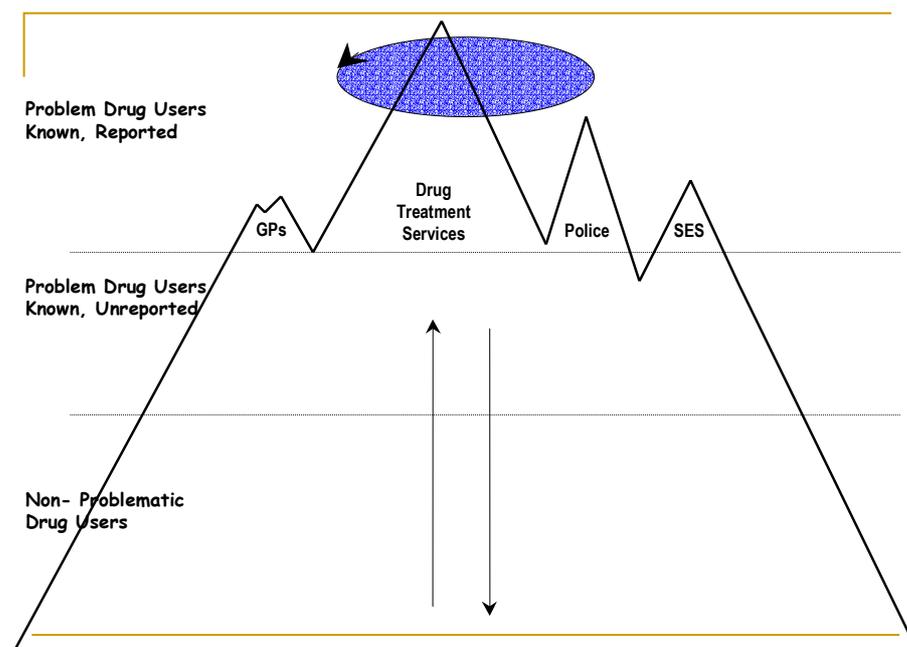
It is essential to involve practitioners in data system development and in the implementation process, to be clear about the utility of data at all levels, and to provide feed-back to all key stakeholders which in turn stimulates increased motivation for participants.

Types of Data and their Purposes/Levels			
Purpose/Level	Level of Use	Type of Data	Examples of Instruments
<b>EPIDEMIOLOGICAL</b>			
Indirect indicator of trends		Minimum data set	TDI (EMCDDA/PG) MDS(Australia)
Patterns	International	Episode/client number and profile	TEDS (USA)
Basis for other methodologies	National		SIDUC
<b>STRATEGY/POLICY DEVELOPMENT/SERVICE PLANNING</b>			
Client number and profile	National	Minimum data set	TDI (EMCDDA/PG)
Geographical distribution	Regional	Waiting lists	MDS(Australia)
Service utilisation (also other health and social services)	Local	Client flow	TEDS (USA)
Monitoring of achievement of strategic goals		Discharge	???
<b>SERVICE MANAGEMENT AND QUALITY ASSURANCE</b>			
Financing	Regional	Minimum data set	TDI (EMCDDA/PG)
Target monitoring	Local	Waiting lists	MDS(Australia)
Service utilisation	Service	Client flow/referral	TEDS (USA)
Monitoring clients and outcomes		Treatment activities	UFDS (USA)
		Discharge	
		Retention rates	
		Basic outcomes	
		Vulnerability factors	
<b>SERVICE EVALUATION AND RESEARCH</b>			
Client/service matching	All	Client satisfaction	ASI/DENS (USA)
Treatment outcomes		Outcome indicators	EURO-ASI
Cost effectiveness		Retention rates	MAP (UK)
Comparison of treatment modalities			BTOM (AUS)
<b>CLINICAL PURPOSES</b>			
Client assessment and diagnosis	Treatment system/network	DSM /ICD Criteria	ASI/DENS (USA)
Screening and triage	Centre	Stage of change	EURO-ASI
Individual client treatment planning		Problem severity in different areas	MAP (UK)
Client progress assessment		Treatment services provided	BTOM (AUS)

## The Limitations of Treatment Demand Data

In considering the strengths of treatment demand data and its potential uses, it is also important to be realistic about what can be achieved with the data that are collected in the Core Data Set, and to recognise the inherent limitations. For example:

- ❖ Data rely on compliance from treatment facilities
- ❖ Drug users not included:
  - Those not reported by treatment facilities
  - Those presented to facilities not participating in the reporting system
  - Those not presenting to any treatment facility (especially for example where treatment is psychiatry-led and there is stigma related to mental illness)
  - Those not yet experiencing problems with their drug use
- ❖ Inconsistencies
  - Within and between systems – in terms of case definitions, data definitions etc
  - Clarity required over which items can be harmonized across systems
  - Not all countries have individual data
  - Not all countries collect full data set
  - Variable extent of treatment systems and different organisation and financing
  - Variable frequency of reporting
- ❖ Treatment episodes on their own cannot be considered as a proxy of prevalence.
- ❖ Treatment Demand Data have limited value for performance management



© Donmall, 2000

Whatever the uses to which the data will ultimately be put, it is vital that all parties are realistic as to:

- a) initial aims of the data collection
- b) what can be achieved within the given social/ political/ developmental context
- c) timescale for development

A useful starting point is the Treatment Demand Indicator of the EMCDDA as an epidemiological indicator. The aim here is to provide a toolkit that helps countries to implement the TDI, to develop existing system where necessary and to draw together data from the system so as to better understand the global drug misuse situation. It is vital to consider the core items and components and not be too ambitious; the priority must be to make the system useable, practical and useful for countries at whatever level of development.

---

### 1.3 What kind of data should be included?

---

#### The Core Item List

It is important to be sensitive to national level issues – for example where drug treatment is ‘organised’ by police or where there is a national notification system to the authorities. These situations raise different issues to situations in which treatment is medically or socially led, or run by organisations such as NA and AA. The data to be included may also be affected by local ethical legislation regarding confidentiality, where it is not possible, for example, to collect information on dates of birth or initials. It should also be recognised that not in all countries/ communities is it possible to collect dates of birth as these (a) may not be relevant or (b) not even known by individuals themselves in some rural communities. Such considerations affect the way in which treatment is delivered, and the way in which information can be collected.

Nevertheless there is now widespread agreement over the core essential data categories that are desirable in order to build a reliable and comparable system. These can be summarised as follows, but see TDI Protocol for more detailed description of items and codes.

### ***Information on Drug Users***

#### Socio-demographic

- Gender
- Age/ Date of Birth
- Education
- Employment
- Living status
- Ethnicity
- Nationality

### ***Drug Use Patterns***

- Drug Types – classification of drugs
- Primary Drug
- Secondary Drugs/ Other drugs used – in combination, at different times
- Frequency
- Method of Use - injecting

### ***Injecting Risk Behaviour***

- Injecting – ever, current
- Sharing
- ??HIV and other blood borne infections status/ testing

### ***Treatment Data***

- Type of treatment services
- New/ former client differentiation
- Sources of referral

Many countries are already collecting core information. Many countries collect additional data for specific purposes. When harmonising systems it may only be possible to use what donor systems can provide. It may be better to accommodate differences rather than spend huge effort in trying to achieve exactly the same definitions. However, where the toolkit is being use by countries without existing systems, then there is the opportunity to make recommendations as to the core data set with definitions and possible options. In the toolkit there may be justification for a chapter on additional systems – although the main focus must not be lost.

### **Definitions**

Whilst there is general consensus around the data categories, there is less consensus around the definition of certain items, in particular treatment itself and the inclusion of alcohol. There is a need to define treatment modalities and to arrive at clear boundaries and inclusion criteria. One view is that there is no point in defining treatment, as this cannot be imposed on a country because of wide variations in treatment provision.

An inventory of facilities is a useful first step to understanding the range and distribution of services in a country. When a system is established this can then also be used to monitor sources of information.

In particular, guidance is needed on the following:

- ❖ Treatment – what are the limits? Religious counselling, herbal therapy and other non-Western therapies?
- ❖ Definition of current use
- ❖ Inclusion/ exclusion criteria
- ❖ Dual diagnosis

- ❖ Treatment episodes and re-admission
- ❖ Treatment demand
- ❖ Case definitions
- ❖ What is current use? Past month or past year.
- ❖ Issue of alcohol - as public health issue is more important than illicit drugs in many countries

### Guiding Principles

- 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
- Methods need to be adaptable and sensitive to different cultures and contexts
- Data collection, analysis and reporting should be as consistent as possible
- 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
- Clarity over when to collect the information (start of treatment, in treatment, cessation of treatment, post treatment) is required
- It is best to obtain *both* episode *and* individual data

It will be useful for the toolkit to provide an overview of the essential elements of representative reporting systems in tabular form, for example:

Overview of reporting systems			
	TDI	TEDS	NMDS
No. items	20	20 (15)	21
Unit of measurement	"case" <sup>1</sup>	Treatment admission <sup>2</sup>	Treatment episode (TE) <sup>3</sup>
Reporting	First case recorded	admissions (discharge)	closed TEs
Reporting time points	annual?	Monthly (from states)	Annual (from states)
Collation	Collate at national level?	Collate at state level	Collated at jurisdictional level

<sup>1</sup> person who starts Tx for their drug use at a Tx centre during the calendar year (only first Tx demand is counted in calendar year)

<sup>2</sup> formal acceptance of a client into substance abuse Tx

<sup>3</sup> period of contact, with defined dates of commencement and cessation, between a client and Tx provider

Comparing (inter)national data sets			
Item list	TDI	TEDS (MDS)	NMDS
Treatment (Tx)	<ul style="list-style-type: none"> <li>•Treatment centre type</li> <li>•Date of Tx month</li> <li>•Date of Tx year</li> <li>•Ever previously treated</li> <li>•Source of referral</li> </ul>	<ul style="list-style-type: none"> <li>•Provider ID</li> <li>•Type of service</li> <li>•Date of admission</li> <li>•No. prior TEs</li> <li>•Source of referral</li> <li>•Client transaction type (initial admission or transfer)</li> </ul>	<ul style="list-style-type: none"> <li>•Establishment ID</li> <li>•Geographical location</li> <li>•Tx delivery setting</li> <li>•Date of Tx commence</li> <li>•Date of Tx cessation</li> <li>•Reason for cessation</li> <li>•Source of referral</li> <li>•Main Tx type</li> <li>•Other Tx types</li> </ul>

## Comparing (inter)national data sets

Item list	TDI	TEDS	NMDS
Client	<ul style="list-style-type: none"> <li>•Age</li> <li>•Year of birth</li> <li>•Gender</li>   <li>•Nationality</li> <li>•Highest education</li> <li>•Labour status</li>   <li>•Living status (with whom)</li> <li>•Living status (where)</li> </ul>	<ul style="list-style-type: none"> <li>•Date of birth</li> <li>•Sex</li> <li>•Race</li> <li>•Ethnicity</li>   <li>•Education</li> <li>•Employment status</li> <li>•Co-dependent/ Collateral</li> <li>•Client identifier</li> </ul>	<ul style="list-style-type: none"> <li>•Date of birth</li> <li>•Sex</li> <li>•Indigenous status</li> <li>•Preferred language</li> <li>•Country of birth</li>   <li>•Client type</li> <li>•Person identifier</li> </ul>

## Comparing (inter)national data sets

Item list	TDI	TEDS	NMDS
Drug use	<ul style="list-style-type: none"> <li>•Primary drug*</li> <li>•Secondary drugs (current)</li>   <li>•Route of admin*</li>   <li>•Injecting drug use</li> <li>•Frequency of use*</li> <li>•Age at first use*</li> <li>•Substitution treatment*</li> </ul>	<ul style="list-style-type: none"> <li>•Primary substance<sup>1</sup></li> <li>•Secondary substance<sup>2</sup></li>   <li>•Tertiary substance<sup>3</sup></li> <li>•Usual route of admin<sup>123</sup></li>   <li>•Frequency of use<sup>123</sup></li> <li>•Age at first use<sup>123</sup></li> <li>•Opioid replacement therapy</li> </ul>	<ul style="list-style-type: none"> <li>•Principle drug of concern*</li> <li>•Other drugs of concern</li>   <li>•Method of use*</li>   <li>•Injecting drug use</li> </ul>

## Scope of reporting systems

		TDI	TEDS	NMDS
Agencies	included	Any agency that provides "treatment" to people with drug problems	Any substance abuse treatment unit receiving public funds	Publicly funded govt. & NGO AODTS
	excluded	<ul style="list-style-type: none"> <li>•NSP only</li> <li>•Hospital emergency rooms, health or social care facilities which drug misusers contact for non-drug problems</li> </ul>	Variations between states	<ul style="list-style-type: none"> <li>•Private / GPs</li> <li>•Accommodation</li> <li>•NSP, MSIC</li> <li>•Correctional</li> <li>•AOD psych units, inpatient only</li> <li>•Methadone, bup</li> </ul>

## Scope of reporting systems

		TDI	TEDS	NMDS
Clients	included	Any person who starts treatment for their drug use at a treatment centre	Publicly or privately funded clients receiving Tx from any agency receiving public funds	<ul style="list-style-type: none"> <li>Assessed &amp; accepted for Tx for problem from AODTS</li> <li>Other person's AOD problem</li> </ul>
	excluded	<ul style="list-style-type: none"> <li>Persons in contact with Tx centre on behalf of drug user</li> <li>Persons with problems due to relationship with drug user</li> </ul>	Variations between states	<ul style="list-style-type: none"> <li>M/BMT only</li> <li>Information only (not assessed)</li> <li>Clients from excluded agencies</li> </ul>

## Scope of reporting systems

		TDI	TEDS	NMDS
Drugs	included			Australian Bureau of Statistics (ABS) listing
	excluded	<ul style="list-style-type: none"> <li>Primary tobacco</li> <li>Primary alcohol</li> <li>Medicinal use</li> </ul>	tobacco	<ul style="list-style-type: none"> <li>Methadone, etc used in substitution therapy</li> </ul>

Ideally, the process required to implement a new national system should include the following:

- Review available collection systems and international literature
- Audit current data collection practices
- Consult widely with key stakeholders
- Undertake feasibility study
- Standardise definitions
- Determine scope of the collection
- Define data collection and reporting platforms (paper-based, electronic)
- Consider data conversion/ mapping
- Identify responsibility & roles for organisations and individuals

Key issues may be considered to be:

- Methodologically sound collection (best) practices
- Minimising additional burden on staff (consistent with clinical practice)
- Standardisation of definitions
- Training
- Resources
- Institutional support
- Political will
- Cultural acceptability
- Confidentiality/privacy
- Ethical issues
- Data quality/missing data/missing agencies

---

## 1.4 How to ensure quality of collected data

---

The issue of data quality runs through each of the sections rather than just in section 1.4.

### Harmonization of methods

Progress on harmonization has already taken place within European Member states in the implementation of TDI. This is a process that takes time. The 'parent' systems, independently developed in Germany (1980), Netherlands (1986), UK (1986) and Spain (1987), alongside the Pompidou Group Protocol (1996) brought considerable experience and provided a model for the TDI Protocol (2000) that includes both a core item list and associated guidelines. Although progress has been made, there is still work to be done in order to make these data truly comparable.

Recent (2002-3) assessment of TDI data quality across the 15 EU member states shows:

1. Treatment information is not available from all the EU countries.
2. More information is needed regarding the availability and use of drug treatment facilities.
3. Eleven countries report data for outpatient treatment centres, but the coverage of these centres is higher than 70% in only five of these countries.
4. Not all EU countries are covering the entire core set of items of the TDI protocol.
5. The level of control of double counting is not the same in all EU countries, ranging from none at all, to control at a regional or national level.

The overall message to take from this is that inconsistencies persist even between countries with relatively comparable levels of development, culture and expertise. This is largely due to two facts:

1. Most countries were not starting from scratch with the development of TDI but already had systems/ infrastructure in place.
2. Countries differ in their service provision, infrastructure and available resources.

The same is true, but to a much greater extent, when considering any global harmonization, and the more complicated a system that is proposed, the less consistency there will be.

*The data set must be modest and achievable, and implementation must be pragmatic and flexible.* Such a pragmatic approach will accept that there will be different ways of dealing with issues such as double counting. It is nevertheless useful to describe and document examples of good practice. It is also important to make people aware that the decisions people make will affect what can be done with the data. Issues of compliance can be addressed by linking agency funding to data numbers, so long as there is faith that the numbers generated by the system reflect reality.

### Internal validation

Simple quality checks are needed at country level, with different levels and methods of checking possible at region, areas or agencies. Clearly more is possible at an agency and regional level, including highlighting common mistakes on the forms, although the check-back process with treatment facilities can be extremely time-consuming and not always realistically productive. Use of 'skip and fill' validation procedures can be helpful within a software solution in order, for example, to check for internal inconsistencies such as non-injectors who are identified as sharing needles/ syringes.

Validation of the data has to be on the basis of the data available. It may be important to consider contextual information in order to understand the results.

Case studies could be valuable within the toolkit to demonstrate examples of good practice.

### **Training**

It is important to invest time and resources in training form-fillers as well as those processing and analysing data, so that the value and utility of the data set is understood. Once identified, errors should be fed back to the person(s) completing the form, and measures put in place to ensure, (a) that errors are corrected and (b) that the likelihood of repeat errors is minimised.

### **Episodes**

Where episodes are reported for profile analysis, the first episode in a time period should be considered so as to avoid multiple counts. When people use different facilities, they should only be counted once if analysing descriptive profiles (such as the percentage of injectors), but multiple times if analysing service utilisation (for example). *The type of analysis and the way in which episodes or individuals are considered depends on the questions being asked.*

### **Ethics**

Good practice dictates that: each client should be asked to consent on the fact that data are included in the database and reassured that it is anonymous; that it is confidential; that it will not be possible to link the person to the data. There is a duty to measure what you set out to measure; data should be valid; should do no harm to people; data should be published and utilised so used to improve services for drug misusers. There is always a balance between risks and responsibilities.

The reasons for data collection should be clear to all parties. It is also important to recognise that whatever the legality/ ethical issues regarding permission from the clients themselves, treatment facility workers are often particularly keen advocates of their clients' confidentiality. This may present an unreasonable barrier even if all other controls are properly in place.

If recommendations are made regarding informed consent, follow-up and monitoring of these recommendations should be carried out.

It is not enough to say that a project has *UN approval*. In countries where there are clear regulations/ laws, these should of course be followed. Data Protection Act regulations should also be followed to help ensure that identifiable information is protected. The issue of what constitutes identifiable data is relevant here. Wherever possible, the protocols for data collection should go to the relevant country/ regional ethics committees. In the absence of such ethics committees consideration should be given to their establishment. *The question of how it is possible to ensure that ethical issues are considered in countries that do not respect human rights is a very important one.*

There should be clarity and transparency over the uses to which the data will be put. In some countries it is recognised that there are increasing calls for the sharing of information with Criminal Justice Service. This is a potentially dangerous situation in terms of client confidentiality. The relationship between the treatment services and criminal justice services may be critical.

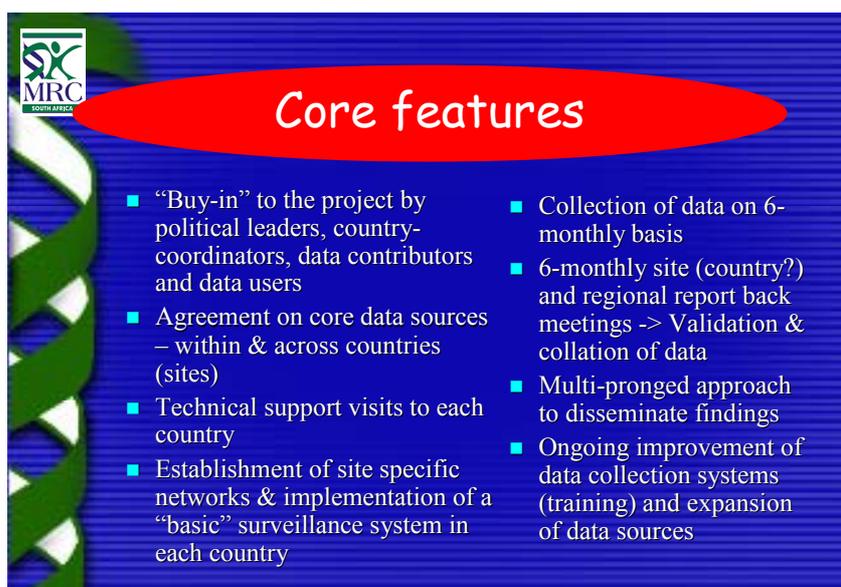
There is already a toolkit on ethical matters that may be useful. Reference should also be made to the International Epidemiological Association rules on ethical issues. There may be a distinction between public health surveillance and research.

There should be an ethical review of the data protocol in the toolkit. The issues of security of data should also be considered.

## 1.5 How to collect treatment data

### *Developing/Setting-up a national treatment data information system*

In this section, consideration is given to the practical aspects of introducing a data collection system on drug misuse. Here the experience of participants who have already implemented systems is crucial and it is envisaged that the toolkit will include many examples of good practice from around the world. For example:



**Core features**

- “Buy-in” to the project by political leaders, country-coordinators, data contributors and data users
- Agreement on core data sources – within & across countries (sites)
- Technical support visits to each country
- Establishment of site specific networks & implementation of a “basic” surveillance system in each country
- Collection of data on 6-monthly basis
- 6-monthly site (country?) and regional report back meetings -> Validation & collation of data
- Multi-pronged approach to disseminate findings
- Ongoing improvement of data collection systems (training) and expansion of data sources

The development of a treatment demand information system is a long term commitment. It may be useful to view this in developmental terms of childhood, adolescence and adulthood. In the childhood phase there is much learning to be done, skills to be acquired and identity to be established; *this is the phase of planning, defining and development*. In the adolescent phase there should be readiness to change, recognising that requirements do not stand still, that technologies change and that new indicators may be developed; *this is the phase of flexibility and modification*. In the adult phase the system is established, fully up and running, and standardized, in some countries there will be a high level of IT sophistication, in others a simpler solution; *this is the phase of results and feedback in which the utility of the system is truly demonstrated*.

For development worldwide it should be recognised that these phases will be moved through at different speeds because of different constraints. In most countries it will be important to go through the developmental process as this is how (compliance) relationships are formed within the country that create the healthy adult. On the other hand, it may not always be necessary for all countries to go through all the phases of development, for example to develop protocols from the start, as lessons can be learnt from others. This is where the usefulness of the toolkit is most demonstrated – as a way of sharing expertise and best practice, thus learning from each others’ experience.

Several critical phases can be identified in establishing an information system. This might include, for example:

1. Planning, development & implementation
2. Data collection
3. Data reporting
4. Review & consolidation

## **Phase 1: Planning, development & implementation**

### **Coverage**

The value of establishing an inventory of treatment facilities has already been mentioned. It is considered to be essential to have an up-to-date and accurate perception of the number and range of services provided in any area so that these can be targeted for participation in treatment monitoring. The publication of a facility list has proved very popular in one country and is considered to have helped with agency compliance when used to generate information on the system's percentage treatment centre coverage.

### **People Issues**

When considering and/ or developing an information system it is vital that all stakeholders be part of the discussion and decision making process; this should include clinicians and clinical managers. 'Buy-in' to the process is essential; this can be helped by one-to-one meetings with key personnel, although this may be a very time-consuming process. Both a simultaneous 'top-down' and 'bottom-up' approach is likely to be the most successful, in which key clinical practitioners and other local individuals are encouraged, motivated and 'signed-up' to the initiative at the same time as key policy makers give it their support and mobilise funding.

It is most helpful to have a motivator to lead the initiative. Skill requirements should be well defined and there should be management structures that account for staff absences.

For practitioners, data collection should be part of the job description. However, the issue of form fatigue may be important. In some countries there is a danger that many questionnaires are sent to clinicians asking the same or very similar questions. Sensitivity is required to address this.

### **Location and ownership**

The location of the data collection exercise should be considered in the country context and clear leadership within one organisation should be identified. Regular meetings of a multi-disciplinary steering group are important. Clear ownership of information is essential.

### **Technical Issues**

#### **Definitions**

The rationale as to why it is important to include each category, should be brief and clear, and associated with unambiguous working definitions. See earlier sections.

#### **Procedures**

Where forms are used these should be designed to be simple, user-friendly, 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 beginning and a system check for those who have the system running, incorporating for example:

- Data submission (paper/disks/electronic/web)
- 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 issues and how they are being handled

Training materials should be developed based on the above along with an evaluation plan for the training process itself.

### **Technology**

Hardware and software should be provided that take account of the need for simplicity and ease of use, security and data back up, and straightforward export facilities in a number of formats (for use with SPSS for example or Epiinfo, EpiData). Data processing software should be written in standardised packages such as Access, dBase etc. and should include internal validation and control checks.

### **Evaluation Plan**

It may be valuable to develop strategies for system failure. It is certainly valuable to devise qualitative and quantitative feedback so that performance can be assessed and reviewed.

### **Planning for use of the data**

This can take place once the early stages of implementation have been achieved. The precise uses to which the data will be put depend on need, as has already been stated. Uses will also be dependent upon available technology and expertise. There will be different kinds of reports for policy makers, the media, evaluators, researchers etc. Some reports may use supplementary sources such as census data in conjunction with treatment demand data – to present population rates, for example.

## ***Phase 2: Data collection***

### **Data Capture**

Regular contact with treatment facilities and key stakeholders including visits, phone calls, newsletters, etc., is helpful in order to encourage attention to detail and quality control in data capture, as well as to receive feedback comments on operability, clarity, data volume and other identified constraints.

### **Data Processing**

A logging system that monitors and acknowledges data arrival from each source alongside a record of necessary data processing queries and anomalies that derive from validation procedures and error checking, is also useful.

Difficulties at any level should be fully documented, along with discussions held with contributors and other stakeholders, and including any managerial issues that emerge.

## ***Phase 3: Data Reporting***

It would be useful if the toolkit could make recommendations as to the best possible indicators (eg % of people under the age of 20 years) and provide examples of how these can be used.

Several different types of report can be distinguished, including:

### **Routine Feedback**

Monthly or other interval reports of data derived from the system should be provided to all key stakeholders – particularly contributory agencies/ facilities. These may or may not take the form of tables of data and/ or commentary. There may be a need for more detail and less commentary at a treatment facility level, with increasing commentary and interpretation but fewer data tables at an area/ regional or country level, and even fewer at an international level

Feedback to staff at monitoring level ('one's own staff') is also important so as to encourage interest and motivation. Something of value must be returned to them if they are to make the effort to provide data in the first place.

### **Policy Documents**

These may take the form of delivery of tables of key performance indicator data to satisfy specific defined policy requirements, or may be longer discursive reports about a particular issue, depending on the local/ national requirements and priorities.

### **Research Publications**

It may be important to publish in recognised journals or other scientific publications in order for the system and data to be valued and recognised as making an important contribution to current thinking and policy formation at a national level.

It may be considered that a variety of reporting methods and styles is important – some written specifically for the lay audience, heavy on graphics for example, others with more complex data analyses suitable for an ‘epidemiological’ audience. So called ‘hot spot maps’ are almost always helpful, so long as an attempt is made to explain the reasons for the observed differences.

### **Interpretation**

Every effort should be made to ensure that data are interpreted accurately and appropriately. For example, caution should be used in interpreting apparent increases in the size of the problem that may be artefacts due to improvements in data capture or bringing people into treatment. Increases in the numbers of treatment facilities may also have a dramatic effect on numbers and throughput. Furthermore, changes in the wider political context (e.g. legislation) could influence the increase or decrease in treatment demand. Other data should be used to corroborate findings (e.g. other indicators) and qualitative information utilised to provide context (e.g. qualitative research, anecdotal information, stakeholders interviews, etc.).

Consideration should be given to distribution of all this feedback material.

## ***Phase 4: Review and Consolidation***

There should be a recognised loop back from all the above processes to evaluation and review. In this way the system is dynamic, clarifying purpose and rationale, adapting to changing needs, and best utilising data.

In circumstances where it is difficult to convince people that the system is necessary, there is really only one solution: the data must be demonstrated to be of value – ideally at both a practical and a policy level.

Methods for communication should periodically be reviewed so as to update tools and take advantage of new technology eg web-based reporting. Lists of contacts (perhaps from the inventory, if implemented) for distribution of results should also be reviewed from time to time as staff and facilities change rapidly. Feedback on content and quality of reports should also be sought at local, regional and national levels.

After a while it will become important to innovate the way in which data are presented in order to keep it fresh and interesting.

### ***Integration of TD data from local to national to international level***

#### **Units of data collection**

There are advantages and disadvantages of data analysis at small area level. For example, on the positive side it may be easier to validate and interpret data, and it may be more straightforward to derive accurate denominator information and the data may be perceived as being locally relevant (important, as it is the local personnel who make the system work). On

the negative side, the data may be too locally specific and less generalisable to other areas and the local focus may result in a greater pressure to maximize all data sources, some of which may be difficult to access.

At a wide area level, it may be advantageous to take 'the bigger picture' and not to be caught up with local detail and idiosyncrasies. There may also be positive policy advantages in terms of 'big picture' funding. At a practical level, a more skilled human resource may be available in the wider area. However, set against this the system may be more difficult to maintain in order to keep data providers motivated, to get people to come to meetings etc., and country-wide data may mask important regional differences making the findings less relevant for sub-areas.

### **Pooling of data from different sources**

It should be remembered that, even within a country context, the treatment centres themselves may differ substantially and that this may result in an imbalance and lack of comparability across regions or countries. This may be the case for example where countries or regions hold contrasting drug policies with regard to treatment, or where centres are predominantly specialist alcohol/ drug treatment facilities as against generic psychiatric centres. Other differences include state versus private treatment; detoxification versus maintenance regimes; social interventions versus medical interventions; size and resourcing levels; demographic, religious and other constraints.

In order to accommodate these differences (and others not mentioned here), it may be advantageous to include as many distinct centres as possible, to always provide information on the number of clients per centre and as full a description of each centre as possible, to indicate if there have been changes as compared to previous reporting periods, and to report data appropriately to the purposes required (eg it may be necessary to disaggregate data in the analysis by drug, gender, type of centre, etc.).

*The most critical way round some of these inherent problems is a) to provide qualitative, contextual information about the data being reported and b) to tailor the analysis to the purpose or question under investigation.*

---

## **1.6 Features of the Toolkit**

---

### **Aims and General Features**

The aim of the toolkit is clear: to provide countries with the framework capability to develop and harmonise a data collection system on problem drug users presenting for treatment.

A clear statement of purpose to this effect should be produced, giving clarity of purpose and the basic rationale as to why it is important, and including examples of use.

The toolkit should take the reader through step by step. Solutions will of course be country specific, but it should still be possible to make broad recommendations on the basis of current experience.

Most importantly it should provide a checklist for new systems starting up but also a checklist for systems that are already running. For example, a prerequisite is to define treatment. "There will be many variations across the world, but if you are just starting out, then this is what we recommend".

The aim is not to produce a document with all the definitions, justifications etc., as this would then constitute a Data Manual/ Dictionary. *The toolkit is mainly a process oriented guide rather than a technical manual.* It should cross-refer to existing manuals, guidelines etc.

**Readership**

*It is generally agreed that the readership consists primarily of those responsible for setting or currently operating local monitoring systems and those responsible for inter-regional and national systems.*

It is most important that the toolkit caters for all levels of skill and understanding, with an emphasis on basic level implementation, making as few assumptions as possible.

**Format**

The document should be reader friendly and sufficiently concise and 'handy' so as to make it portable and easy to use. It should be written straightforwardly in non-technical, non-jargon language, so as to communicate effectively with as wide a readership as possible.

There should be a glossary with abbreviations, where used. Case studies should be included in box inserts and charts and graphics should be utilised where possible instead of over-lengthy text.

Key icons can be used to 'sign-post' the document in order to help with accessibility. A clear matrix should be provided that identifies specific EMCDDA/ TDI requirements.

An appendix should give references, links to other sites, and should include specific sections giving examples of good practice and 'Frequently Asked Questions' (FAQs)

Consideration should be given to the production of a web version of the toolkit, A Cd-rom version and a training version should be provided in PowerPoint/ overhead slide format.

Consideration should also be given to distribution and dissemination strategy, including distribution of flyers, forums/ networking, and other issues of training.

Consideration should also be given to the issues of evaluating the effectiveness of the toolkit itself.

## **Part 2: PROPOSED TOOLKIT STRUCTURE**

Following the Global Workshop in Vienna and using material gathered from contributors at that meeting, the toolkit structure below is proposed. This will be taken further during the next phase of this project when it is envisaged that an editorial group will co-ordinate contributions to the final publication, incorporating material from the above meeting report.

An attempt has been made to be sufficiently inclusive so as to make sure that nothing is left out, at the same time as removing obvious duplication. The structure should be considered to be provisional at this stage.

### **Framework**

---

#### **1 Introduction**

- 1.1 Aim
- 1.2 Readership
- 1.3 Main Features & Roadmap

#### **2 Overview: reasons for collecting drug treatment data**

- 2.1 Why a system of treatment data collection is useful
  - For epidemiological and/or performance management
  - As an indirect indicator of trends in problem drug use
  - For identifying patterns of drug use
  - As a basis for other methodologies (eg incidence)
  - For policy and advocacy
  - To identify patterns of use of services
  - For plans and service evaluation
  - Other purposes
- 2.2 Limitations

#### **3 Building your foundation**

- 3.1 Scoping – comparison between systems
- 3.2 Information, Needs and Resources Assessment (INRA)
- 3.3 Organisational Issues
  - Gaining political support
  - Identifying stakeholders
  - Location
  - Funding
- 3.4 Inventory of services & describe treatment system

#### **4 Data to be collected**

- 4.1 Guiding principles
- 4.2 The core item list
- 4.3 Core Definitions
  - Case definition
  - Treatment, treatment demand, type, episode
  - Item definitions and valid codes
- 4.4 Core information requirement at a global level
- 4.5 Case Studies

---

## Implementation

---

### **5 Implementing a Treatment Demand Indicator System**

- 5.1 Planning and development
  - People/ network issues
  - Procedures
  - Technical Issues
  - Ethical Issues
  - Planning use of data
- 5.2 Data collection
  - Establishing process
  - Data checking, validation & ongoing audit
- 5.3 Data quality & Coverage
- 5.5 Case Studies

---

## Dissemination

---

### **6 Analysing and Reporting on the Results**

- 6.1 Data Analysis & Interpretation
- 6.2 Reporting
- 6.3 Case Studies

---

## Conclusions

---

### **7 Maintenance & Evaluation**

- 7.1 Maintenance
- 7.2 Evaluation

### ***Glossary***

### ***Bibliography***

### **Appendix**

---

#### **A Sample Materials**

- Data collection sheets
- Reports
- Validation rules

#### **B Frequently Asked Questions (FAQs)**

#### **C Links to relevant Web Addresses**

#### **D Key Toolkit Markers (PowerPoint)**