Establishing a national substance use treatment information system
A step-by-step guide

World Health Organization
Regional Office for the Eastern Mediterranean

Establishing a national substance use treatment information system
A step-by-step guide

World Health
Organization

Regional Office for the Eastern Mediterranean

Contents

Introduction

Overview

Substance use is a public health issue in the World Health Organization (WHO) Eastern Mediterranean Region. Substance use disorders account for a loss of four disability-adjusted life years (DALYs) per 1000 population and nine deaths per 100 000 population in the Region, compared with the loss of two DALYs per 1000 population and four deaths per 100 000 population globally (*1*).

Countries in the Region have developed a variety of treatment programmes and data collection systems. However, according to the *Atlas on substance use* (2010), around 57% of countries in the Region do not have a national data collection system for substance use care and treatment (*1*). Furthermore, the countries of the Region that have information systems have different ones, which makes it difficult to generate comparable data, and the existing systems are not necessarily capable of generating data that can be translated into the systematic information required for evidence-based decision/policy-making. This calls for action on the development of a standardized substance use treatment information system.

Substance use treatment information systems

The focus of this guide is to provide guidance on the development of a substance use treatment information system. The main objectives of a system are to generate information on:

- individual characteristics and patterns of substance use among people in contact with the substance use treatment system
- treatment estimates of problematic substance use
- the monitoring of treatment programmes.

Substance use treatment information systems are based on either "treatment episodes" or "case registration".

Reporting treatment episode

When the unit of measurement is a treatment episode, the period from the beginning of treatment to the termination of treatment is considered. Based on this approach, the number of treatment episodes an individual receives during a specified period of time is recorded and counted. Therefore, with this approach, double counting of an individual case can happen.

Reporting case registration

When the unit of measurement is an individual, usually the time period when the client engages with a treatment service is considered. The system does not count any individual more than once during this time period, thus avoiding double counting. Following this approach means that:

- treatment rates are measured
- individual characteristics of substance users can be captured
- the system is easier to run as it registers individuals at the starting point and does not track the treatment episode to its termination.

This guide, after assessment of the existing data collection efforts and resources in the Region and consultation with experts, both from within and outside the Region, uses case registration as the basis for a regional substance use treatment information system. The guidance provided focuses on identifying a core set of indicators and a minimum data set for capturing information for these core indicators

Aims of the guide

The aims of the guide are to:
- provide step-by-step guidance for countries on the establishment of a substance use treatment information system
- introduce a minimum data set as the basis for data collection to report on a core set of indicators
- support countries in setting up the proposed information system, contextualized according to national requirements.

The target audience for the guide is policy-makers, public health experts, and mental health and substance use specialists and other actors involved

in substance use management, programming and planning in:
- countries that have either not established an information system or have a fragmented one
- countries with already established data collection systems who can use the guide to improve their procedures on data collection and processing, and improve their reporting system in order to produce and disseminate comparable information.

The proposed system is also applicable for other countries and regions with similar socioeconomic contexts.

Structure of the guide

The guide introduces step-by-step guidance on setting up a substance use information system. The key steps are as follows.
- Step 1. Establish a coordinating body
- Step 2. Set up infrastructure
- Step 3. Determine data collection procedures
- Step 4. Develop data processing procedures
- Step 5. Analyse, monitor and report the data

The guide contains three annexes.
- Annex 1. A sample data collection form
- Annex 2. Signs and symptoms of dependence, intoxication (overdose) and withdrawal for commonly-used substances
- Annex 3. Guidance for developing a universal unique identifier code

Steps to set up a substance use treatment information system

Step 1. Establish a coordinating body

The establishment of a substance use treatment information system requires political commitment, administrative

support and technical capacity. Thus, a coordinating body is imperative to:

- advocate for, and mobilize, resources for political, financial and managerial support
- oversee and coordinate the establishment, implementation and maintenance of the system
- support development of the required technical capacity for establishment and maintenance of the system
- address challenges and barriers in the establishment and maintenance of the system.

Determine whether there is an existing body or group that could take on the role of the coordinating body such as national commissions and committees on substance use or expert associations or committees. Most countries of the Region have such an entity. Ensure that crucial stakeholders are part of the coordinating body.

The rules, procedures, responsibilities, functions and tasks for this coordinating body and its individual members should be well-defined and set out in the format of "terms of reference" and/or a "functional protocol", according to the local context. The outline of the functions of the coordinating body is explained in this manual and they are indicated throughout.

The suggested membership of the coordinating body includes representatives from:

- mental health/substance use units in the ministry of health
- major governmental organization(s) dealing with substance use
- nongovernmental organizations dealing with substance use
- substance use treatment experts/academia
- treatment centres/hospitals
- the private sector
- epidemiologists
- possibly the judiciary and law enforcement agencies/bodies.

According to local context and requirements, members can be added from other sectors and organizations, although it is better to avoid forming a large coordinating body.

Although the participation of representatives from the judiciary and law enforcement in the coordinating body may put its autonomy and independence at stake, in many countries of the Region, judicial and law enforcement bodies are considered key partners of ministries of health in policy/decision-making, as well as in providing services for substance use disorders. This needs to be taken into account in the selection of members of a coordinating body in a way that strikes a balance between maintaining its independence and practicality.

To facilitate administrative procedures, select a secretariat for the coordinating body, which may be:

- a unit in the ministry of health responsible for mental health and/or substance use-related activities
- an academic institution that specializes in substance use services.

It is recommended that the secretariat be a part of the health system.

To ensure the confidentiality of reporting procedures, it is advisable not to select the secretariat from:

- an anti-narcotic ministry
- substance use/drug control bodies
- the judiciary and/or law enforcement agencies/bodies.

Step 2. Set up infrastructure

Conduct a situation analysis

The coordinating body should designate sufficient time to collect the information that will provide the scaffolding for developing the structure for the information system including:

- studies and reports on substance use in the country
- existing or potential resources for implementation of the project, including data collection centres and data analysis bodies, and human and financial resources
- existing instruments for collecting data in the country.

Define catchment area

The coordinating body needs to decide on the geographical area in which substance use treatment data will be collected, known as the "catchment area".

The catchment area may encompass the entire country. Alternatively, due to limitations such as financial, logistical or human resources constraints, a smaller catchment area such as an individual province, district, subregion or even a single medical centre can be designated as the catchment area.

If a smaller catchment area is selected, it should represent the country as a whole in terms of the demographics of the population and environment (in terms of socioeconomic context, sex distribution, crime rates, substance use situation, geography and so on). This will avoid consequent substance use trend analyses being skewed.

It is recommended to start small to assess the stability of the system before scaling-up.

Define data collection centres

The eligible facilities for participating in data collection are those centres that people with substance use problems naturally attend to seek care and treatment.

The following centres are possible candidates:

- hospitals/emergency rooms
- specialized substance use treatment clinics (outpatient/inpatient)
- residential facilities for substance users
- primary health care settings.

The coordinating body should consider the local resources available when deciding on eligible centres. Within the context of this guidance, it is recommended to start with facilities specialized in providing services for people with substance use disorders

Identify a data processing organization

The coordinating body should identify a central body or organization, called here a lead organization, for entering, processing and analysing the data and producing systematic reports.

The coordinating body can select the lead organization from among these potential candidates:
- a research institution or university department (recommended)
- a substance use unit of the ministry of health
- a treatment facility (generally not recommended because of conflict of interest issues).

To ensure that people who use substances can trust the system, law enforcement and similar institutions should not be selected as the lead organization.

Depending on the extent of the catchment area, there might be intermediate levels between reporting/treatment facilities and the lead organization. For example, data can go from a treatment centre to district level and from there to the lead organization in the capital city. In such cases, due consideration needs to be given to the secure storage of data and to confidentiality.

Develop the data collection tool

A data collection tool is a form for collecting data about a specific episode that caused a patient to contact a centre providing care and treatment services for substance use disorders.

A data collection tool can be paper-based or electronic based, according to existing capacity.

The coordinating body should decide whether the format of the data collection form should be a hard copy or an electronic (soft) one.

The lead organization should take the lead in the development/adaptation of the data collection tool.

It is preferable not to introduce a new tool when a well-developed functioning data collection tool already exists. The lead organization needs to make sure that the minimum data set required for the current information system can be properly collected through the existing tools, possibly with some modification.

It is recommended that only items that can generate the data needed for the core indicators are included. A sample data collection form is presented in Annex 1, which can be adapted according to local requirements.

The form may be piloted for clear understanding of terms and coding rules.

Select/recruit staff

The coordinating body should decide which individuals/bodies are responsible for data collection and entry.

For data collection, someone who provides a service to people who use substances should be responsible. This can be a:
- psychiatrist
- general practitioner
- substance use treatment specialist
- nurse
- social worker
- clinical psychologist
- other health care worker.

For data entry, to avoid an extra burden on health facilities and enhance the precision of data entry, it is recommended that the lead organization or intermediate levels are responsible for extracting the data from the data collection tool and for data entry. In this situation, centres send the forms regularly to the lead organization or intermediate levels.

If the data collection body is involved in data entry, staff with the required technical capacity should be assigned to the task.

Staff training

It is the responsibility of the coordinating body to arrange training for the staff involved in data collection and data entry. The coordinating body can assign the training task to the lead organization.

The training should have three elements: the basics of substance use and related disorders, data flow and the data collection form.

The basics of substance use and related disorders

The staff should be familiar with:
- the concept of substance use
- various types of substances and their street names (with specific attention to the local context)
- characteristics of each substance, its physical and psychological effects, dependency, intoxication and withdrawal syndrome.

In Annex 2, a list of the signs and symptoms of dependence, intoxication and withdrawal for commonly-used substances is presented. The content is drawn from the ICD-10 diagnostic criteria and the mh-GAP intervention guide (*2, 3*).

Data flow

Staff members need to understand:
- the flow of data (where it is collected from and where it goes to)
- how to collect the data
- how to enter the data
- how to store the data

- how, and to whom, to send the collected data
- the frequency of sending the data.

Even if the centre is not involved in data entry, the staff should be familiarized with the data entry process.

Data collection form

Staff should have clear knowledge on:
- the data collection form
- detailed instructions for filling each item in the form
- troubleshooting procedures for difficulties faced when filling the form in.

A sample data collection form is presented in Annex 1.

Step 3. Determine data collection procedures

The unit of measurement in the proposed system is "cases" or individual clients.

A "case" is a person who has started substance use treatment in a calendar year (e.g. between 1 January and 31 December).

If a person has started treatment more than once during the reporting year, only the first treatment episode should be reported.

A person who contacts a treatment centre on behalf of a substance user, but who is not a substance user, should not be considered as a case.

A person with problems due to his/her personal relationship to a substance user, but who is not a substance user him/herself, should not be considered as a case.

Any structured intervention, whether pharmacological or non-pharmacological, in any setting, specifically aimed at addressing a person's substance use is considered "substance use treatment".

In this context, services for housing, education or relationships do not constitute treatment, even though support in these areas may be important elements of case management.

Services provided to a third party, such as those who present on behalf of the client (for example, a spouse or parents), should not be recorded as a treatment episode.

Recording the data is supposed to be performed during the time of visit, unless the patient or the person accompanying him/her are not capable of providing the required information or some investigations are needed (for example, when the patient has a decreased level of consciousness or the person accompanying the patient has no knowledge about his/her situation such as in police referrals).

The coordinating body should ensure that data collection centres have copies of the data collection form or know where to access it. For example, the centres can obtain the form through a central database or website or can ask for the hard copies to be mailed to them. When the system is paper-based, it is recommended that data collection forms be attached with a carbon copy. The centres need to send the original form to the lead organization and keep the copy in a secure place at the centre.

How to collect data

In this section, instructions for filling the data collection form are presented. These instructions are in accordance with the defined items for a minimum data set that are recommended to be included in all data collection exercises. Please refer to the sample form in Annex 1.

Each piece of information that needs to be recorded in the form is termed an "item".

In this guide, a core set of indicators is introduced. These core indicators are to be reported on at the regional level; however, the coordinating body at the national level may wish to develop an expanded list of indicators to meet local needs.

The form is divided into nine sections, each with several items.

Section 1. Identifier codes

Master identification (ID) code. This item is for the use of the lead organization and will not be filled out by the data collection bodies.

1.1 Form code. Each form should have a code to be filled in by the data collection/treatment bodies for further cross-checks and monitoring.

1.2 Patient unique anonymous ID. A unique identifier, which will allow duplicates to be removed when data are reported. This should fulfil all requirements to guarantee protection of personal identity.

1.3 Staff ID number. The person who fills in the form should include the number of his/her job ID card in the form. This helps for monitoring the process and providing feedback to staff.

1.4 Catchment area name/code. The coordinating body/lead organization should assign codes to catchment areas. This code depends on the extent of the catchment area. If it is the whole country, then the coordinating body/lead organization assigns a code to each city and the assigned person for data collection includes the name of the city and its code in each form. If the area is limited to a city, different districts receive a number.

1.5 Centre name/code. The coordinating body/lead organization should assign codes to each centre participating in data collection to help identify/double check the type of facility.

1.6 Waiting period for admission. The average number of days a patient has to wait to attend a treatment centre for clinical assessment of his/her substance use disorder. This can be calculated as the number of the days between the first contact (in person or by phone) with the centre and the date of the appointment.

1.7 Date of first clinical assessment. The date of clinical assessment is recorded as month/day/year or day/month/year. In each case, the order should be clearly mentioned in the form. If, for any reason, some data are not available and the form is supposed to be completed later, the staff should put the date of the assessment, not the date of completion of the form.

Section 2. Demographic data

2.1 Age. Fill in the age of the client as declared. There is no need to ask for a certificate or ID, or about the month of birth. Include the age as "years".

2.2 Sex. Fill in whether the event registered is related to a man or women. In case of transgender clients, mark "other" and give an explanation if it is a change from male to female or vice versa.

Ethnicity is not included in the form as it is not applicable in most countries of the Region. However, the coordinating body should decide on including this item based on the local context.

Other demographic data are not included as the core items in the minimum data set. Individual countries may wish to add other items as part of an expanded data set.

Section 3. Source of referral

In this section, the source of referral for the current contact with the treatment centre needs to be mentioned.

3.1 Self or individual. Either the patient has made the contact based on his or her free will (self-referral) or on the request of another individual (for example, a friend or family member).

3.2 Health system. Referrals made by other health facilities. These can be public, private or nongovernment organizations, such as community health services, primary health care facilities, private hospitals/centres, needle-syringe

programmes, workplace-based services, health facilities within schools, higher education and industry, self-help groups like Narcotics Anonymous, and faith-based organizations that provide health services.

3.3 Criminal justice system. Referrals made by court and law enforcement agencies for substance use treatment.

3.4 Other. Referrals made by any other services.

Section 4. Type of substance(s) involved in current treatment episode

The coordinating body has to decide on the substances that the information system will report on. The general groups of illicit substance are listed below, but each country may decide to modify the general group based on local needs.

4.1 Opioids (opium, heroin, morphine, methadone, codeine, etc.)

4.2 Cannabinoids (marijuana, pot, grass, hash, etc.)

4.3 Amphetamine-type stimulants (speed, diet pills, ecstasy, methylphenidate, khat, etc.)

4.4 Cocaine (coke, crack, etc.)

4.5 Hallucinogens (LSD, acid, mushrooms, PCP, special K, mescaline, psilocybin, etc.)

4.6 Solvents (nitrous, glues, petrol, paint thinner gases, aerosols, paint thinners, etc.)

4.7 Sedatives or hypnotics

4.8 Alcohol

4.9 Other. If staff members are not sure of the category of a substance, it should be indicated in the "Other" section. This category is for substances that are not specifically named but are reported to the system.

4.10 Number of days the primary substance was used in the last 28 days.

The data collection form allows for registry of primary substance and non-primary substances. The primary substance is the substance responsible for the current contact with the treatment centre. All the other substances are to be registered as non-primary.

If a patient has used more than one substance, but it is not clear which substance is responsible for the current treatment episode, mark all the substances in the data collection form in the non-primary column.

It should be noted that the system is primarily for substance use disorders excluding alcohol; however, the system allows for registry of alcohol as a non-primary substance.

Polysubstance use is not recorded as an item; however, if no substance can be recorded as the primary substance responsible for the current contact, this can be coded as polysubstance use during the analysis stage.

When no primary substance is identified for the current contact, the number of days of use of all the reported substances needs to be registered.

Section 5. Route of administration of primary substance involved in the current treatment episode

This item needs to be registered only for the primary substance of use.

5.1 Oral
5.2 Injecting (intravenous and intramuscular)
5.3 Smoking
5.4 Inhaling
5.5 Snorting
5.6 Unknown

If the patient takes the primary substance in more than one way (for example, by both smoking and injecting heroin), the staff member needs to tick all the relevant options in the data collection form.

Section 6. History

6.1 Age of first use of primary substance (years). The age in years when the client started using the substance identified as primary in the current treatment episode for the first time.

6.2 Is this the first ever treatment episode? This records if the patient has ever been enrolled in any treatment programme for substance use disorders before the current treatment episode.

Section 7. Pattern of use (injection and sharing equipment)

7.1 History of injecting over the lifetime. This item asks whether the person has injected any substances over their lifetime. The injection history can be related to the substances involved in the current contact or a substance that the client is not using anymore.

7.2 History of injecting equipment shared over the lifetime. This item includes sharing needle and syringes, or any object used us a needle, for injection, as well as shared pots or other containers. Re-use of one's own equipment is not registered as sharing.

7.3 Any sharing of injecting equipment during the last 28 days. Sharing of injecting equipment, either for the primary substance or any other substances, during the last 28 days should be registered here.

Section 8. Treatment setting planned for the current treatment episode

In this section the staff should register the setting that is planned for provision of treatment within the current treatment episode. This could be as an outpatient, inpatient or in a long term residential setting. There is always the possibility that the treatment setting changes over time; however, if the system does not track the treatment episode, only what is planned at the beginning will be indicated.

8.1 Inpatient
8.2 Outpatient
8.3 Residential

In this document, the term "treatment" refers to structured pharmacological and/or non-pharmacological interventions planned for the current treatment contact.

Section 9. Opioid maintenance treatment

When opioid substitution treatment (OST) is part of the treatment plan it needs to be registered. By OST, an open-ended long term treatment with opioid

agonists is meant. Any treatment with opioid agonists on a dose reduction basis cannot be considered as OST.

9.1 Opioid maintenance treatment planned for the current treatment episode. If the client is already enrolled in a maintenance treatment, it should not be registered here.

9.2 Type of medication to be used for maintenance treatment. The staff should register whether the maintenance treatment is based on using methadone or buprenorphine.

Step 4. Develop data processing procedures

The coordinating body should decide on how the data will be entered, processed and stored.

Data entry

The coordinating body decides the starting point of data entry. The starting point for data entry needs to be the same for all the centres involved in data collection. It is recommended that the lead organization take responsibility for data entry. Therefore, the data collection centres need to send the completed data collection forms to the lead organization.

Someone in the centre should be assigned for collecting the forms and sending them to the lead organization according to the standards defined for protection of the security of data.

It has to be decided how often the forms will be sent to the lead organization. It is preferable to have a regular time interval such as at the end of each month.

The hard copies will be collected and sent to the lead organization and carbon copies of the forms will be kept in a secure place within the centre.

The lead organization receives individual data forms from the centres.

According to the local context, an intermediate level may be involved between the centres and the lead organization. The body that performs this task receives the forms from the centres in its catchment area and sends them to the lead organization. This intermediate body should also monitor the timeliness of data flow within the system to avoid any delay.

Standardized input procedures

The lead organization is responsible for the development of the standardized data entry software/template.

The database can be in Microsoft Excel or SPSS format. However, the Microsoft Excel template is simpler and easier to manage. Each registered client and his/her associated identifier code must occupy one row of the database.

Each data item should be assigned a variable name and each variable should occupy one column in the data file.

- A "variable" is defined as the characteristic (or item) you are recording, such as the sex, age, type of substance and so on.
- Variables should be assigned names that are concise (or abbreviated) and that can be easily interpreted, for example, the "type of substance" variable can be given the name "TOS".
- The names of some variables such as "age" or "sex" may not require alteration.

Data quality

There should be a mechanism for systematic checking of data, such as periodically checking 5% of all entered cases on a monthly basis to ensure that all cases have been entered properly.

Double check the database with a "backup" copy of the electronic database and with individual hard copies of the cases.

Data should be checked to ensure that it is all of the following.

- Correct. Some ways to assure the correctness of data include checking for: age (too high or too low), incompatibility between the route of administration and the substance (such as injection for marijuana), and inappropriateness of the registered substance and attributed setting for treatment (such as opioid maintenance for cannabis use).
- Devoid of missing fields. The system can be designed not to allow incomplete registration either automatically or semi-automatically.
- Devoid of duplicate cases (the same event entered twice).

Central storage of data

The master file will contain the data for registered cases from all data collection sites encompassing the entire country or catchment area.

Each registered case in the master file will be given a unique "master identification code". Since form numbers will be autonomously assigned by each local subregion or medical centre, there may be duplicate use of form numbers. The master identification code keeps track of how many cases have been registered in the entire country or catchment area and prevents confusion due to the potential overlap or duplicate use of form numbers from different data collection sites.

Thus, in the master file, each registered case will have two identification codes:
- the form code, assigned when the case was first registered at the local level
- the master identification code, to avoid confusion due to form code overlap as each form will have this second unique identification number.

The lead organization must be in charge of compilation, verification, maintenance and ensuring the security of the master file.

Security of data

The centre needs to send the forms in sealed packages and to store carbon copies of the original forms in a secure place to ensure confidentiality.

The lead organization should save a backup copy of the electronic version of the data files on an external hard-drive or to a secure network. The backup copies should be maintained and updated regularly (preferably every three month). Backup copies should also be kept secure.

The coordinating body should develop clear instructions and required mechanisms for storage of forms. For example, it might be required that all treatment centres be equipped with shelves that can be locked.

Step 5. Analyse, monitor and report the data

Analysis

Use statistical methods to analyse registered data. Statistical software, such as Microsoft Excel, Epi Info or statistic packages such as STATA, SPSS and SAS, can be used for analysis purposes. As the data formats are compatible and relatively easy to export (see, for instance, Stat/Transfer), it is advised to use resources that are already available in central institutions. However, a unified format of coding the variables should be agreed for the Region so that further analysis is possible.

Table 1 proposes a core and expanded set of indicators. However, it is strongly recommended to limit data collection to the core set of indicators at the early stages of implementation of the system and before the development of the required capacity.

Table 1. Proposed core and expanded set of indicators

Category	Indicators
Demographic	Number of admissions total: broken down by gender, age and primary substance
	Number of individual patients total: broken down by gender, age and primary substance
Substance of use	Number of admissions and individual patients according to primary and non-primary substance of use (rate admission/case)
	Number of admissions and individual patients disaggregated by frequency of use of individual primary substances (admission rate/case)
	Number of admissions and individual patients disaggregated by route of primary substance administration (admission rate/case)
	Number of admissions and individual patients disaggregated by age of first use of primary substance (admission rate/case)
	Admissions and cases with a history of substance injection during past 12 months (admission rate/case)
Treatment episode	Number and percentage of admissions by service setting
	Number and percentage of individual patients started OST
	Number and percentage of individual patients started OST by the type of medication
	Number and percentage of admissions by prior treatment episode
	Number and percentage of admissions according to waiting period for receiving the treatment (intervals)
	Number and percentage of admissions disaggregated by sources of referral
	Mean and average waiting times by gender, WHO age intervals, type of substance and type of facility
Expanded set of indicators (optional)	Frequency of alcohol use (as a secondary substance) and possibly other substance(s) of national interest
	Difference in characteristics (age, gender, waiting period, onset of use, etc.) of users with specific secondary substances (such as alcohol) and without them
	Average and median number of admissions per substance and route
	Years of onset of substance use (frequencies)

The admission and individual case rates are reported as an absolute number and per 100 000 population (15–64) of the relevant catchment area (city, province, country, region).

Monitoring and reporting

Under the supervision of the coordinating body, the lead organization should establish a system for checking the quality of data and monitoring the reporting process.

The coordinating body, with the technical support of the lead organization, should define reporting lines and feedback loops. They should communicate these procedures clearly with staff in data collection centres and in the lead organization.

The reporting should be bi-directional, which means the lead organization/coordinating body both receive data and provide facilities with prepared reports.

The feedback loop should also be designed as a mutual way for giving and receiving feedback between the lead organization and the coordinating body on the one side and data collection centres on the other.

The monitoring system is responsible for:
- regular checks for completeness, consistency, correctness and timeliness of the reports sent by facilities
- regular feedback to data-collecting staff and making them more involved in the system
- receiving feedback from staff involved in data collection
- tracking changes to detect any problems with reporting activities
- ad-hoc alerts for major issues including interruption of data flow.

The monitoring and reporting system has the following products:
- regular reports (e.g. quarterly) for participating treatment centres containing summary tables of the compiled data and specific points regarding each centre
- regular briefs for policy/decision-making levels containing brief explanations together with simple summary tables
- annual reports containing detailed tables and explaining trends and any observed changes.

Reporting data

The coordinating body should identify key policy/decision-making bodies that will clear the report(s) for publishing.

The coordinating body should also share the final report(s) with data collection centres and the lead organization.

The coordinating body should identify key persons/entities for sharing the final document(s) with from:
- the ministry of health
- substance use control organizations
- academia
- the judiciary and police force
- the media
- the private sector
- specialized associations
- patient and family associations.

Each and every information system has inevitable constraints and sources of bias that place limitations on the conclusions that can be reached. For example, an increase in the number of young people seeking treatment may indicate increasing incidence of substance use problems in the population or may reflect a successful attempt to intervene at an

earlier stage of the problem. Therefore, the recipients of information based on substance use treatment data should be made aware of such limitations.

Where data are to be published in the public domain or are targeted at an audience otherwise unfamiliar with the analytical methods, there is a possibility that published figures might be open to misinterpretation. Therefore, as far as possible, publications should highlight which conclusions may reasonably be drawn, and which may be inappropriate (*4*).

References

1. Atlas on substance use: resources for the prevention and treatment of substance use disorders. Geneva: World Health Organization; 2010 (http://www.who.int/substance_abuse/activities/atlas/en/, accessed 24 June 2014).

2. The ICD-10 classification of mental and behavioural disorders. Diagnostic criteria for research. Second edition. Geneva: World Health Organization; 2003 (http://www.who.int/classifications/icd/icdonlineversions/en/index.html, accessed 24 June 2014).

3. MhGAP intervention guide for mental, neurological and substance use disorders in non-specialized health settings. Geneva: World Health Organization; 2010 (http://whqlibdoc.who.int/publications/2010/9789241548069_eng.pdf, accessed 24 June 2014).

4. Guidance for the measurement of drug treatment demand. Toolkit module 8. Vienna: United Nations Office on Drugs and Crime; 2006 (http://www.unodc.org/documents/GAP/Module%208_English_06-52819_Ebook_Final.pdf, accessed 24 June 2014).

Annex 1. Sample data collection form

Master ID code (to be filled at the central level):

1.1 Form code (to be filled at the data collection centre):	1.2 Patient's unique anonymous ID:		
1.3. Staff ID as used at facility:	1.4 Catchment area name: Catchment area code:		
1.5 Centre name: Centre code:	1.6 Waiting period for admission:	Number of Days	

1.7 Date of first clinical assessment:	Day	Month	Year

2.1 Age (years):	2.2 Sex: 1 Male ☐ 2 Female ☐ 9 Other ☐

3. Source of referral
3.1 Self or individual ☐   3.2 Health system ☐   3.3 Criminal justice system ☐
3.4 Other ☐   Please specify: _____

4. Type of substance(s) involved in current treatment episode	Primary	Non-primary	Specify the name of the substance	5. Route of administration of primary substance involved in current treatment episode	Please tick
4.1 Opioids				5.1 Oral	
4.2 Cannabinoids				5.2 Injecting	
4.3 Amphetamine-type stimulants (ATS)				5.3 Smoking	
4.4 Cocaine				5.4 Inhaling	
4.5 Hallucinogens				5.5 Snorting	
4.6 Solvents				5.6 Unknown	
4.7 Sedatives/hypnotics				**6. History** 6.1 Age of first use of primary substance (years):_____ 6.2 Is this the first ever treatment episode? Yes ☐ No ☐	
4.8 Alcohol					
4.9 Other					
4.10 Number of days the primary substance was used in the last 28 days:					

7. Pattern of use (injection and sharing equipment)
7.1 History of injecting over the lifetime: Yes ☐   No ☐
7.2 History of injecting equipment shared over the lifetime: Yes ☐   No ☐
7.3 Any sharing of injecting equipment during the last 28 days: Yes ☐   No ☐

8. Treatment setting planned for the current treatment episode 8.1 Inpatient ☐ 8.2 Outpatient ☐ 8.3 Residential ☐	9. Opioid maintenance treatment 9.1 Opioid maintenance treatment planned for the current treatment episode: Yes ☐ No ☐ 9.2 Type of medication to be used for maintenance treatment: Methadone: ☐ Buprenorphine: ☐
Remarks	

Annex 2. Signs and symptoms of dependence, intoxication (overdose) and withdrawal for commonly-used substances

Substance dependence
- Strong desire or sense of compulsion to take substances
- Difficulties in controlling substance use in terms of its onset, termination or levels of use
- A physiological withdrawal state when substance use has ceased or been reduced, as shown by the characteristic substance-withdrawal syndrome; or use of the same (or a closely-related) substance with the intention of relieving or avoiding withdrawal symptoms
- Evidence of tolerance, such that increased doses of the substance are required in order to achieve effects originally produced by lower doses
- Progressive neglect of alternative pleasures or interests because of substance use, increased amount of time necessary to obtain or take substance or to recover from its effects
- Substance use persisting, despite clear evidence of overtly harmful consequences

Opioid intoxication (overdose)
- Slow movement
- Decreased attention
- Slurred speech
- Sleepiness
- Slow respiratory rate
- Pinpoint pupils
- Unresponsive or minimally responsive to environment/coma in severe cases

Opioid withdrawal (recent ceasing or reducing of substance with a history of dependence and/or recent heavy use)
- Muscle aches and pains, abdominal cramps, headaches
- Nausea, vomiting, diarrhoea
- Dilated pupils
- Raised pulse and blood pressure
- Yawning, runny eyes and nose, piloerection ("gooseflesh")
- Anxiety, restlessness

Stimulant intoxication (overdose)
- Excited, racing thoughts, disordered thinking, paranoia, grandiose beliefs
- Aggressive, erratic or violent behaviour
- Repetitive stereotyped behaviour
- Auditory, visual and tactile hallucination
- Raised pulse and blood pressure
- Dilated pupils

Stimulant withdrawal (recent ceasing or reducing of substance with a history of dependence and/or recent heavy use)

- Slowed down thoughts and movements
- Lethargy and fatigue
- Increased appetite
- Oversleeping or not sleeping
- Unpleasant dreams
- Dilated pupils

Cocaine intoxication (overdose)

- Excited, racing thoughts, disordered thinking, paranoia, grandiose beliefs
- Aggressive, erratic or violent behaviour
- Repetitive stereotyped behaviour
- Auditory, visual and tactile hallucination
- Raised pulse and blood pressure
- Dilated pupils

Cocaine withdrawal (recent ceasing or reducing of substance with a history of dependence and/or recent heavy use)

- Excited, racing thoughts, disordered thinking, paranoia, grandiose beliefs
- Aggressive, erratic or violent behaviour
- Repetitive stereotyped behaviour
- Auditory, visual and tactile hallucination
- Raised pulse and blood pressure
- Dilated pupils

Cannabinoids intoxication (overdose)

- Excitement, anxiety, suspiciousness or paranoia
- A sense of time passing very slowly
- Decreased attention
- Not able to show timely reaction to what is happening around
- Increased appetite
- Red eye
- Dry mouth
- Raised pulse

Cannabinoids withdrawal

- Can happen after cessation of cannabinoid use after long time use with a high dose, but there is no well-defined syndrome for cannabinoids withdrawal

Hallucinogen intoxication (overdose)
- Anxiety and feeling fear without any reason
- Paranoia or having the feeling that either the people or the world around you is not real
- Auditory, visual and tactile hallucination
- Impulsivity and hyperactivity
- Decreased attention
- Tremor
- Raised pulse rate
- Blurred vision
- Dilated pupils

Hallucinogen withdrawal
- There is no recognized hallucinogen withdrawal state

Solvents intoxication (overdose)
- Indifference to the surrounding environment, decreased attention and impaired memory
- Slowed movements
- Aggressive behaviour or talking
- Difficulty in standing, walking and talking
- Blurred vision and double vision
- Stupor or coma
- Muscle weakness
- Involuntary eye movements

Solvents withdrawal
- There is no recognized solvent withdrawal state

Sedative or hypnotic intoxication
- Elevated mood or indifference
- Reduced attention
- Difficulty in standing, talking and speaking
- Aggressive behaviour or talking
- Anterograde amnesia (loss of the ability to create new memories after getting intoxicated)
- Involuntary eye movements
- Stupor or coma
- Red skin lesions and blisters

Sedative or hypnotic withdrawal
- Tremor of tongue, eyelids and outstretched hands
- Headache, nausea and vomiting
- Raised heart rate, postural hypotension (sudden fall of blood pressure when standing up or stretching)
- Agitated movement or malaise and weakness
- Paranoid ideation
- Convulsion

Annex 3. Guidance for developing a universal unique identifier code

What is a universal unique identifier?

A universal unique identifier relates to the right of individuals to have their data protected during collection, storage, transfer and use, in order to prevent unauthorized disclosure of that information to third parties.

A unique identifier is the one that can never be associated with an individual or entity other than the particular person or entity to whom it is assigned.

Unique identifiers enable all data collected within a facility to be correctly attributed to a specific person/entity. In addition, where persons receive services from a number of different facilities, relevant information can be shared and linked across service sites to improve coordination and strengthen monitoring and evaluation.

Characteristics of an identifier

Ideally, an identifier for an individual patient should be:
- unique
- ubiquitous and available for every person
- unchanging, for instance eye colour, date of birth, genotype
- uncomplicated and easy to recall or record
- non-controversial, not involving the collection or dissemination of sensitive personal data
- easily and inexpensively accessible.

Development of unique identifiers

Health systems that are beginning to build identifier systems should ideally choose identifier schema that will allow for incremental changes over time, such as the conversion of paper records into electronic systems.

Development of unique identifier systems should incorporate specific steps in development to preserve and protect records on the one hand and ensure their ready accessibility for appropriate use on the other. In no instance should government departments/entities have the right to obtain access to identifiable information without due process. This is of particular importance in countries of the Region where substance use is considered a criminal act and treatment facilities are either run by law enforcement agencies, or law enforcement agencies have official or unofficial access to treatment files.

The unique identifier should be assigned by an issuing authority that can ensure that numbers once issued will not be reissued. The issuing authority in the proposed substance use treatment information system is the coordination body which performs this task through the lead organization.

The unique identifier should be a sufficiently large number in order to cover an entire population for the life time of that population, typically 9–12 characters. The desired longevity of a patient identifier affects the design of the identifier schema and is an important

input for developing an overall identifier strategy. However, it should be noted that the increased identifier length, and thus increased longevity, must be balanced against the fact that longer identifiers increase complexity, raise the likelihood of recording errors and reduce patients' ability to remember their identifiers.

Potential approaches to uniquely identifying patients include the following.

- *Biometric identifiers* such as fingerprints, voice scanning, retinal scanning or iris scanning. These identifiers are highly specific but very expensive and subject to false non-matches due to hardware or procedural failures. They may also raise privacy and security concerns for sensitive data such as related to substance use.
- *Patient matching algorithms*, which combine multiple patient attributes, such as date of birth, mother's maiden name and other common identifiers, to create an individual identifier. This approach leverages available information and does not require expensive hardware or the generation of a unique identifier that a patient may lose or forget. However, such algorithms are not foolproof due to the possibility of duplication or false positives, and their accuracy varies with data quality. A simple model of this kind is a coding system used in some countries of central Asia that consists of:
  - first two letters of mother´s first name
  - first two letters of father´s first name

  - gender (single letter M/F or number 1/2)
  - year of birth (last two digits).

  Unlike some other systems, this model contains no identifying information about name, date of birth or place of residence.

- *National identification numbers* are used by some countries of the Region as the unique identifier for registry in the substance use treatment system. This approach is simple and reliable; however, this might compromise the safety and security of data given that in some countries of the Region treatment facilities are either run by law enforcement agencies, or law enforcement agencies have official or unofficial access to treatment files. This in turn can affect the acceptability and accessibility of the treatment system for substance users who may wish to avoid the system to protect their identity, especially where substance use is illegal or they may have lost their ID cards.

Confidentiality and consent

Different countries apply different approaches in obtaining consent while registering the patients and collecting data related to the unique identifier. These include the following.

- *Full explicit consent*. This approach requires the patient's clearly expressed consent each time personally identifiable information is to be used. This approach is the most respectful of individual

autonomy, but it is also costly and burdensome for providers and patients. Full explicit consent is normally required in the course of medical research, but is not usually demanded for routine care or public health surveillance.

- *Opt-in*. The patient provides explicit consent during the initial contact and "opts-in" to allow additional, appropriate use of personal information. The patient reserves the right to "opt-out" – or prevent the further use of information – at any point. This approach favours autonomous decision-making, but may result in incomplete information as some patients may elect not to opt-in.

- *Opt-out*. Consent is assumed unless the patient explicitly opts-out. This approach is respectful of individual autonomy but, like opt-in, may result in incomplete information as a result of patients who opt-out.
- *No consent*. Under this approach, information is held in trust with assurances of confidentiality. Even where individual consent is not obtained, individuals should nevertheless be notified or informed that their personal data may be shared with others, but only in a format where the data are no longer personally identifiable.

This guide provides step-by-step guidance on the development of a national substance use treatment information system. The goal is to generate data on the individual characteristics and patterns of substance use among people in contact with the substance use treatment system, enabling treatment estimates of problematic substance use and the monitoring of treatment programmes. It introduces a minimum data set as the basis for data collection based on a core set of indicators. The guide is for policy-makers, public health experts, mental health and substance use specialists, and all others involved in substance use management, programming and planning. It will be useful in countries that wish to establish a substance use treatment information system or want to improve their current system.