EMERGING DRUG PHENOMENA

A European manual on the Early Information Function for Emerging Drug Phenomena

Executive summary

This summary presents the main results of a European collaborative work on how to identify and understand early changes in drug use or new drugs more quickly than by using standard monitoring systems. It gives a general and theoretical overview of the dynamic process of an Early Information Function (EIF) for Emerging Drug Phenomena (EDP). This document is structured in three parts: firstly, a presentation of the context, objective and methods of the project; secondly, a synthesis of the results: the structure and operation of an Early Information Function for Emerging Drug Phenomena; and thirdly, the prospects for this issue.

I The project context, objective and method

In Europe, drug use is considered a high priority concern. In order to deal with the various issues related to drug use, consideration has been given to the implementation, development and improvement of monitoring systems (Drug Information Systems) as a means of obtaining operational knowledge on drugs and drug use. The creation in 1993 and subsequent development of the European Monitoring Centre for Drugs and Drug Addiction (EMCDDA), which is based on the development of a network of National Focal Points (REITOX), enabled the operation and linking of national Drug Information Systems (DIS) and an improvement in their compatibility. The information produced by a DIS must allow a better understanding of certain drug-related phenomena and facilitate decision-making at the policy-maker, professional and individual level.

At present, various models of DIS exist in European countries. Frequently, these are rooted in standard sources which provide interesting data but which often have a considerable time lag behind any actual changes in the drugs field. This lack of sensitivity is harmful to the early identification of changes or new phenomena related to drugs and drug use. Moreover, the fast circulation of new drugs and new patterns of use within Europe highlights the high probability of rapid changes in the drugs field. The need to identify these changes more quickly was perceived by various actors working in drug monitoring systems and led to the Euro-TREND project being promoted in 2002.

The main objective of Euro-TREND was to define and describe a possible common model of an Early Information Function (EIF) for Emerging Drug Phenomena (EDP) in order to make the Drug Information Systems in the participating countries more sensitive to EDP and more compatible with each other.

Within this context, several European countries (France, Germany, Greece, Netherlands, Portugal, Spain, and Sweden[1]) decided to participate in the Euro-TREND project which started at the beginning of 2002. The project was co-funded by the European Union and the participating countries. Two European agencies, the EMCDDA and the European Agency for the Evaluation of Medicinal Products (EMEA), contributed by following the process and participating in the general meetings.

The project was structured in six work phases. For each of these, except the last (drafting of the manual), the work was divided into three steps. First, a European Proposal was produced by a working party consisting of the coordination team and some of the coordinators from the participating countries. Secondly, this European Proposal was critically discussed at national level by experts who also had to put together a synthesis of their national situation in respect of the phase topic. Finally, a synthesis taking into account all the national reports was drawn up by the project coordination team and validated at the European level by all the participating countries and European agencies.

The manual produced, drawn up mainly on the basis of synthesis documents, tries to provide information on the description and working outline of what is called an Early Information Function (EIF) for Emerging Drug Phenomena (EDP), within a national or local/regional DIS.

II Project results

It was considered that a drug information system had to fulfil various functions. One of these, regarded as the central point of this project, is the Early Information Function for Emerging Drug Phenomena (EIF for EDP). This function needs quickly to identify, assess and categorize Emerging Drug Phenomena in order to allow the production of relevant information and its timely dissemination to target audiences.

Main Lines, Areas of Interest and Indicators

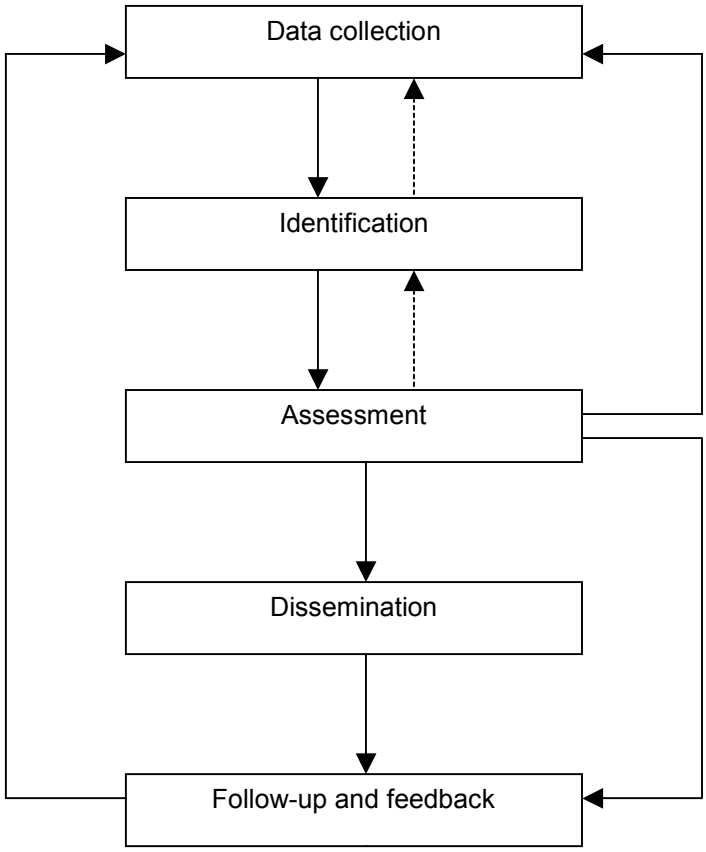
In order to work properly, an EIF needs first to focus on selected topics. To address this concern, a three-tier information structure was defined. This includes three main lines of inquiry (users, substances and settings). Each of these corresponds to different Areas of Interest which help to draw together the points that are considered most interesting (e.g. for the "user" main line of inquiry, the areas of interest include demographic characteristics, patterns of use and health consequences). Indicators are chosen for each area of interest. During the operational process of the EIF, information on these indicators will be collected and analysed.

[1] The corresponding institutions were: French Monitoring Centre for Drugs and Drug Addiction (OFDT, France), Institute for Therapy Research (IFT, Germany), University Mental Health Research Institute (UMHRI, Greece), Trimbos Institute (Netherlands), Drugs and Drug Addiction Institute (IDT, Portugal), University of Valladolid/Government Delegation for the National Plan on Drugs (UVA/DGPND, Spain), National Institute of Public Health (NIPH, Sweden).

Operational steps of an EIF

In order to make the EIF operational, a five-step dynamic model was developed. The steps identified are: data collection, identification, assessment, dissemination, and follow-up and feedback (see the following Figure).

The Early Information Function for Emerging Drug Phenomena: An outline of the operational steps



Data collection

Coordination of the data collection seems essential in order to make it fully operational. It has to address two key points: the elusive nature of drug use and the availability of resources. Data collection includes collecting, describing and storing as much relevant data as possible with as much detail as possible. It is a process that requires a variety of information sources (i.e., drug users, low-threshold facilities, health services, criminal justice settings, recreational nightlife settings, etc.), data collection professionals, data collection methods (i.e., population surveys, observations, interviews, focus groups, etc.) and instruments (i.e., questionnaires, interview guidelines, etc.). The many and varied data collection tools will allow the EIF to obtain information from different sources and by different methods which will facilitate the

identification step. Pre-existing general data collection tools that deal with the EIF's main lines of inquiry should be included and optimised to make them as functional as possible for EIF purposes. Where necessary, specific EIF tools will be developed. These tools will have to be robust and flexible and produce valid and reliable data.

Identification

The next step in the process leads to the identification of an emerging drug phenomenon (EDP). Various analyses of the data previously collected are necessary for the identification of an EDP. At the end of these analyses, all the available information for each chosen indicator is compared to discover any significant changes and possibly to identify an EDP.

Assessment

When an EDP is identified, it has to be described in as much detail as possible. It has to go through a standard assessment process which will use all the information already available on this EDP. Some EDP will be considered of high concern and thus meriting a specific assessment. Within this framework, four criteria are considered helpful for categorizing the EDP as a candidate for a specific assessment: diffusion potential, health consequences, social consequences and economic consequences. This categorization, along with other aspects (e.g., available resources, decision-maker interest, etc.), will help in deciding whether or not to undertake a specific assessment. It implies a more in-depth analysis and sometimes additional data collection, enabling a detailed description of the chosen EDP to be produced in a short time-span. All standard and specific assessments will end with a written report.

Dissemination

Once EDP are identified and assessed, a dissemination strategy must be designed. A great deal of information is available in the assessment reports produced and its dissemination to different target audiences must be carefully considered. This process implies definition of the purposes of the information dissemination (what do we want to do?), selection of the target audiences (who do we want to inform?) and selection of the dissemination methods (how do we want to disseminate?). Target audiences may belong to different sub-groups, such as policy-makers, professionals, information specialists and specific groups, or the general population. In general, the EIF has to provide an appropriate information format. The EIF team should be responsible for the production of recommendations on the purposes, target audiences and dissemination methods. Recommendations should be validated by a group of people appropriate to the national context. The results of the actual dissemination to the target audiences should permit the early reduction of a potentially harmful phenomenon.

Feedback and follow-up

To end the cycle and to begin a new one, feedback information will be sent by the EIF team to all those participating in the data collection, and a follow-up process will be carried out for all interesting topics. This implies that the new data collection period will have to continue to gather data on all topics of interest from the previous cycle.

The manual

The project outcomes have been laid down in the manual. In addition, this provides a description of concrete examples of national solutions for an EIF and a detailed overview on the sources and methods for data collection and dissemination. The national situation in the participating countries is described in an annex.

III Prospects

The development of an EIF within a drug information system complements the traditional monitoring of indicators and trends. A properly functioning EIF will be able to inform the target audiences in a shorter period of time, in order to promote actions aimed at reducing harm for users and the general population. The production of this information will be of less interest if it is not is linked to actions.

The heterogeneity of the DIS in the countries that participated in this project implies that the proposed model is sufficiently adaptable to cope with different national realities. Even though it is rooted in the previous experiences of the participating countries, this work remains a theoretical model of a possible EIF for EDP. It should be read critically and adapted in the light of national/local contexts and experiences. It is aimed at helping people who already participate in an EIF and people who are willing to implement and/or develop an EIF in their own country. Available information sources will vary from country to country. Available resources for an EIF will also vary and, thus, the volume of work will also change. The political structure of a country (federal or centralized) will certainly have an influence on the final design of a national EIF as well. In any case, the implementation of such a function is not a short-term process and it is necessary to have the time to be able to build a function that works properly.

It is worth stating that organising our work at two levels (national and European) allowed us to develop and strengthen the national groups of experts committed to this problem within the participating countries. It appears that this sort of group can be a firm cornerstone in the construction of an EIF.

The expected results should merit the investment. With the development of the European community and the acceleration of exchanges of people and knowledge, a collaboration between European countries is very necessary. A commonly shared model for an EIF will obviously facilitate the exchange of information on identified and assessed emerging drug phenomena and collection, analysis and dissemination techniques. New developing drugs, emerging patterns of use and emerging harms will be identified much earlier than with a standard monitoring system. It will allow earlier intervention and avoidance of the significant burden of suffering and expenditure in the care and law-enforcement fields.

The next stage in this work is due to address a variety of aspects:

- Adaptation of the EIF model to the different national realities in the participating countries and other interested European countries.
- Development of the process of exchanging information on EDP and on the technical aspects (data collection tools, analysis methods, dissemination methods) of the EIF among interested countries.
- The development of a European EIF for EDP, which implies not only exchanges of information but also the analysis and dissemination of information at the European level.
- Improvement and refinement of this model is obviously necessary. Although the practical experiences of the countries are an efficient way of improving the model, periodic discussion of the more theoretical aspects should help to refine it.