EMCDDA DOCUMENTS ON IMPROVING COMPARABILITY - DRUG-RELATED INFECTIOUS DISEASES

1. Draft guidelines key indicator infections
2. Infection Indicator Map
3. Standard table 09-INFECTIONS-2000

EMCDDA / 2000

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Draft guidelines for developing the Key Indicator: Infectious Diseases in Injecting Drug Users

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1. Status of this document

This document contains the draft guidelines on the key indicator 'infectious diseases' that the EMCDDA has agreed to provide to the Focal Points by the end of January 2000. These first draft guidelines are intended to provide a framework indicating the direction of future work. An expanded version will be provided before 15 April 2000. This will include the updated standard tables for reporting data on infectious diseases, which also form part of the general guidelines for reporting epidemiological data for the national reports.

Developing a key indicator at European level may take several years. This document does not intend to change the current data collection on infectious diseases in injecting drug users (IDUs) drastically, but it envisages a gradual process of improvement of the present work, at the country and EU levels. This will be achieved by investigating the currently available data and data sources more in depth, and examining, and, if possible, mobilising potential sources for future data collection on infectious diseases among IDUs. The first activities expected from the Focal Points mainly entail identification of key experts, exploratory mapping of potential data sources and some strategic reflection on the key indicator at national level.

The Scottish Centre for Infection and Environmental Health (SCIEH) and the Centre for Drugs Misuse Research (CDMR), University of Glasgow, have recently been contracted to assist the Focal Points and the EMCDDA in improving the comparability, timeliness, quality and coverage of data collected on hepatitis B/C and HIV in IDUs in the EU.

2. Purpose of the key indicator

Drug related infectious diseases (hepatitis B/C and HIV), is one of five key epidemiological indicators used by the EMCDDA to determine the prevalence and health consequences of drug use. Infectious diseases are among the most serious health consequences of injecting drug use, and may lead to important health care costs in the near future. IDUs may also act as 'core groups' or pockets of infection that pose a continuous threat of spread to the general population.

The purpose of the key indicator is:

1) to measure levels of infection (prevalence rates = infection rates = % infected) in drug using populations and subgroups, and
2) to monitor trends over time (increases or decreases in prevalence, infections in new subgroups of IDUs, changes in prevalence among young or new IDUs which

may give some indication of changes in incidence in these IDUs).

The framework presented in this document proposes to regard existing data (sources) as a set of 'infection indicators', each potentially providing a prevalence rate in a specific population or subgroup of IDUs.

3. Current situation

Existing data that is recent, and as representative as possible on hepatitis B/C and HIV (studies, routine data) is collected through the REITOX national Focal Points. Data on reported AIDS cases are obtained from EuroAIDS/EuroHIV (the former Centre for the Epidemiological Monitoring of AIDS, Saint-Maurice). AIDS data are however becoming less useful to monitor trends in infection, as the long incubation time from HIV infection to AIDS is lengthened even more by recent improvements in treatment. In the future, data on HIV notifications in IDUs can possibly be obtained from EuroHIV, as centralised reporting is currently being implemented in Europe. However, the interpretation of notified cases to assess epidemiological trends is often difficult.

The EMCDDA currently collects recent data on prevalence rates of infection (% infected) with hepatitis B and C and HIV among IDUs. It is important that work at national or European level should not be duplicated between the EMCDDA and EuroHIV. At present close collaboration with EuroAIDS/EuroHIV exists. On the basis of further discussion, the EMCDDA intends to complement the work of EuroHIV specifically for IDUs, by adding data on hepatitis B and C, and providing data on HIV where these can be more easily collected through the Reitox network of national Focal Points (e.g. data from drugs treatment or overdose deaths).

For the Centre's 1999 Annual Report, all countries were able to provide some indication of more or less recent HIV infection rates in IDUs (all data were for 1996-1998 except one estimate for 1995). Although most sources had a large geographical coverage (two countries could only provide local data), data sources were clearly not comparable across countries. Regarding hepatitis B and C, the situation was worse, as data were more often out of date (1994-1998) or of questionable quality (e.g. self-reported test results) or had only local coverage.

In general, the data collected by the EMCDDA are still not comparable between individual countries nor of sufficient quality to permit reliable conclusions at country level (with some exceptions). However, at the EU level they indicate very high rates of infection with hepatitis B and C and suggest large variation in HIV infection rates.

4. Work done by EMCDDA and results achieved

During 1999, a project co-ordinated by the CDMR and SCIEH appraised the EMCDDA/Reitox data collection and undertook a review of published European studies. The project demonstrated that complete and comparable information on hepatitis B and C for Europe’s injecting population was not available, and suggested

five options to improve surveillance at the European level. The options are described in full detail in the EMCDDA report 'CT.98.EP.15'

Options for Future Surveillance (as proposed in project CT.98.EP.15):
Option1. Improving the collection of existing data by assisting the Focal Points to identify existing and new sources of information in their respective countries and advising on the interpretation of such data.
Option 2. Funding a specific institution to have the remit to undertake the collation of available hepatitis B/C and HIV information relating to IDUs in the EU
Option 3. The collation of information on diagnosed infections from public health laboratories throughout the EU. Within some countries, however, it may not be possible to obtain data from all laboratories, therefore, sentinel surveillance systems may be more appropriate.
Option 4. Using community-wide sampling of drug injecting populations in specific localities to put national information in context. The EMCDDA could fund a pilot study in which the feasibility of applying a common protocol in five or more European cities is assessed.
Option 5. The provision of direct support and training to the Reitox Focal Points for undertaking community-wide surveys in their respective countries.

In the long term, community wide sampling would appear to be the best method for establishing prevalence and incidence in injecting populations. However, community-wide surveys are costly, and while support and training for undertaking them could be provided, identification and procurement of funding (either in part or in whole) from relevant authorities and/or other EU sources would be necessary.

The option which would appear to be the most practical in the short term, would be option 1. Improving the collection of existing data would be less costly and the project group (CDMR and SCIEH) is prepared to assist the Focal Points in improving the collation and reporting of data to the EMCDDA. Improving the collation of data in each country would of course be a collaborative process between the project group, EMCDDA and representatives from the Focal Points in each country.

5. Next steps, developing 'indicators of infection' from existing data sources

For the immediate future, the Focal Points are expected to start work on option 1, i.e. to improve the collection of existing data. Comparability throughout the EU may be improved by collating data from specific sources within each country, such as data from overdose deaths, drugs treatment, prisoners or arrestees, needle/syringe exchanges, STD clinics, pregnant women, public health laboratories or existing studies. Each of these sources, or 'indicators of infection', will be subject to different forms of bias and can therefore not easily be used to estimate national (or regional/local) prevalence of infections among IDUs.
However, adopting an indicator-approach would have several advantages:

1) The information from one data source can be valid and give important insight for that same data source, even if this source is biased as an estimate of national prevalence in IDUs in general (e.g. it can be important to know infection rates of IDUs in treatment per se)

2) Within a country, combining information from different sources may give useful insight on the spread of infections in IDUs in general, even if each of the individual sources is biased. This would depend on the level of divergence in prevalence between the different data sources (at country or region/city level).
3) While countries cannot easily be compared across the EU because of different data sources, if more sources become available countries might be compared per data source. For example by comparing infection rates in drug deaths between countries or comparing self-reported HIV test results from treatment centres between countries.
4) Developing a set of indicators of infection would be complementary to the future option of developing a European system of sentinel surveillance (repeated in-depth local studies). The first could provide data of lower quality but with higher geographical coverage, while the second would provide data of high quality but low coverage. The Focal Points might in the near future be asked to participate on a voluntary basis in a proposal for sentinel surveillance, but that is not within the scope of this document nor a core task for 2000.

6. Proposed data sources for developing indicators of infection rates

Below follow the proposed data-sources for infection indicators of rates of infection with HIV and hepatitis B and C. It is not expected that the Focal Points cover all these sources in the first year, as this will be easier in some countries than in others. The work could rather start as an exploratory mapping exercise by the national reference group for the key indicator infectious diseases.

Standards will be developed across all sources (as far as this is possible) relating to: age groups, information on injecting history (e.g. year of first injection, injection in last 6 months), drugs injected, preferred method of blood or saliva sampling, preferred laboratory markers and tests of infection/carriage, detail of geographic breakdown, etc.

Possible data sources are:

1. *Overdose deaths (+non-fatal emergencies)*

2. *Drugs treatment*

3. *Needle exchanges*

4. *Prisons / arrests*

5. *STD clinics*

6. *Pregnant women*

7. *(Public health) Laboratories*

8. *Special studies / sentinel surveillance*

Currently not recommended as a data source to work on are *notifications,* given the potentially large problems in obtaining reliable data and the very different nature in comparison with the other sources (incomplete absolute numbers rather than rates). Notifications for HIV are currently being implemented at a European scale by EuroHIV, and might in the future be centrally obtained from them. For hepatitis C, a recent European project concluded that national notification systems are not comparable between EU countries, mainly because of lack of a standard case definition (Nalpas et al. 1998).

7. Tasks of Focal Points for 2000

- To actively correspond with SCIEH, CDMR and EMCDDA in order to clarify any questions on data on infectious diseases in the standard tables and national reports that will be used to prepare the EMCDDA 2000 and 2001 Annual Reports and Statistical Compendium.

- To actively collaborate with SCIEH, CDMR and EMCDDA in activities meant to improve the key indicator 'infectious diseases'. This will include (delegated) participation in a EU technical meeting on improving the key indicator.

- To provide a first orientative work plan by 31/3/00, including the following elements:

1) Names of some experts who are in key positions for most of the proposed infection indicators. These experts together with the Focal Point will form the expert working group (reference group) on the key indicator 'infectious diseases'.
2) Name and contact details of technical responsible for the key indicator infectious diseases at the Focal Point. It is highly recommended that this person have some professional experience in the field of infectious diseases.
3) Name and contact details of the person who will be chairing the expert group. This should not necessarily be the responsible at the Focal Point. It is recommended that the most experienced individual in the expert group be the chair, and that this person will be representing the expert group (including the Focal Point) at the international technical meetings on implementation of the key indicator. Good dominion of English is important.
4) A short report (if possible not more than one page) of the activities planned, which should include a first meeting of the expert group before end of June 2000 (date that first progress report is due), plus a time table of the planned activities.

8. General Time Table

1 February - 'draft guidelines' available from EMCDDA (=current document)

31 March - orientative work plan to EMCDDA

15 April - updated guidelines available from EMCDDA

30 June - first progress report including report of first meeting of expert group

15 September - full statistical tables (including update of previous years) to EMCDDA

30 November - second progress report, including targets for 2001

9. Contact details

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References

European Monitoring Centre for Drugs and Drug Addiction. Project to improve the data quality for surveillance of hepatitis B/C and HIV infection in injecting drug users in the EU. (CT.98.EP.15) Lisbon: EMCDDA, 1999.

European Monitoring Centre for Drugs and Drug Addiction. 1999 Extended Annual Report on the State of the Drugs Problem in the European Union. Lisbon: EMCDDA, 1999.

Nalpas B, Desenclos JC, Delarocque-Astagneau E, Drucker J. State of epidemiological knowledge and national management of hepatitis C virus infection in the European Community, 1996. Eur J Public Health 1998; 8: 305-312.

Technical annex.

Proposed data-sources for developing indicators of infection rates

Below follow the proposed data-sources for infection indicators of rates of infection with HIV and hepatitis B and C, with some comments on potential biases and other issues. Biases are likely to vary by country and/or data source, and should be evaluated with the relevant national experts.

Standards will be developed across all sources as far as this is possible relating to: age groups, information on injecting history (e.g. year of first injection, sampling would probably be limited to those who injected recently e.g. in last 6 months), drugs injected, preferred method of blood or saliva sampling, preferred laboratory markers and tests of infection/carriage, detail of geographic breakdown, etc.

It is not expected that the Focal Points cover all these sources in the first year, as this will be easier in some countries than in others. The work could rather start as an exploratory mapping exercise (sources, availability, practical obstacles in obtaining the data etc.) by the national reference group for the key indicator infectious diseases.

1. *Overdose deaths (+non-fatal emergencies)*
   This data source largely refers to injecting drug users and is therefore potentially very useful. Possibly national or at least regional samples could be obtained. These would probably include young drug users not in treatment. Overdose deaths could possibly over-represent irregular, in-experienced users, but an over-representation of older IDUs has also been found. Suicides related to a positive HIV status could result in bias as well. In most countries overdose deaths are related to opiate use, in some countries however mostly include amphetamine injectors. For this data source the national experts currently involved in the key indicator 'drug-related deaths' should be informed/contacted.

2. *Drugs treatment*
   These data may refer to older drug users with a longer injecting career resulting in prevalence being biased upwards. Outbreaks among IDUs could be less well detected by this source given that treatment (e.g. methadone) is expected to reduce injecting. It should be examined if obtaining treatment is (officially or unofficially) related to HIV status. Often these data refer to self-reported test results, it should be investigated if these can be confirmed from medical records. It would be necessary to limit data to current injectors (e.g. last 6 months). If possible, it would be important to use data from first treatment demands only, as this would give results closer to prevalence in IDUs not in treatment. For this data source the national experts currently involved in the key indicator 'treatment demand' should be informed/contacted.

3. *Needle exchanges*
   This data source specifically attracts current IDUs and is therefore potentially useful. High risk IDUs might possibly be over-represented, but on the other hand needle-exchanges are expected to reduce infections. In several studies of needle

exchanges the highest infection rates were found among the non-consistent attenders. This infection indicator might, in conjunction with other information, also give some feedback on the effectiveness of the protection by a needle exchange programme in the target population.

4. *Prisons / arrests*
   This is an important data source that is getting increased attention. However there may be specific data quality problems, e.g. individuals may have strong reasons to hide their injecting history. Ethical issues are important to consider, given the nature of the data. It would be necessary to limit data to current injectors (e.g. last 6 months). These data often include younger IDUs that are not in treatment. A European network on HIV and hepatitis prevention in prisons exists which might be willing to provide data to the FPs.

5. *STD clinics*
   A European network exists which might be willing to provide data on IDUs among attenders of sexually transmitted diseases (STD) clinics. These data could also be collected centrally. IDUs who attend STD clinics are likely to have a higher risk of sexually acquired infections of HIV or hepatitis B (hepatitis C is difficult to transmit sexually), but prevalence would be expected to depend more heavily on their patterns of injection.

6. *Pregnant Women*
   In several countries pregnant women are screened for HIV and sometimes for hepatitis B and C. These data usually contain information on risk factors for infection including IDU. The data could be useful if limited to prevalence rates in pregnant women who report having ever injected drugs. Prevalence rates in young pregnant women could give an indication of prevalence (incidence) in current injectors.

7. *(Public health) Laboratories*
   This data source would be developed more in-depth in a separate proposal (see option 3 in section 4). However, if data are readily available to the FPs these should be collected and reported. Data from laboratories are likely to have very little background information, e.g. whether the infection was related to IDU might be unknown. For HIV and hepatitis B, data on IDU-status would be necessary. For hepatitis C, if prevalence of antibodies in the general population could be monitored by age and gender this could indicate pockets of high risk individuals most probably infected by IDU (e.g. by looking at infection rates in those under age 25). It would be important to obtain person-based prevalence rates (% persons infected) and not test-based rates (% positive tests), and at least to collect age and gender. Also, it would be important to have data on positive as well as negative test results in order to calculate rates. Data from laboratories could potentially have large geographical coverage.

8. *Special studies / sentinel surveillance*
   This data source would be developed more in-depth in a separate proposal (see option 4 in section 4). However, if data are readily available to the FPs these should be collected and reported. Repeated studies or sentinel surveillance will provide the highest quality data, although it is relatively labour intensive and costly, and can therefore only have low coverage (e.g. one or a few cities per country). This high quality data is however very important to understand why infections continue to occur and to validate the trends observed in the other sources.

Notifications of known cases:
Currently not recommended as a data source to work on are *notifications,* given the potentially large problems in obtaining reliable data and the very different nature in comparison with the other sources (incomplete absolute numbers rather than rates). Notifications for HIV are currently being implemented at a European scale by EuroHIV, and might in the future be centrally obtained from them. For hepatitis C, a recent European project concluded that national notification systems are not comparable between EU countries, mainly because of lack of a standard case definition (Nalpas et al. 1998).

Problems with notifications include: a) very important levels of under-reporting which may not be constant over time, b) mostly only acute cases are recorded in the case of hepatitis B and C while many of these infections occur asymptomatically, c) they give no prevalence rates but only incomplete absolute numbers. However, they may be used to follow the composition of the patient population over time (age, gender, geographic area) and to detect new outbreaks (e.g. the recent HIV outbreak in Finland was mainly detected through the notification of known infections).

Current or past infection and vaccination:
For hepatitis C and HIV, seropositivity for antibodies mostly indicates current infection (for HIV always). For hepatitis B this indicates either past infection or vaccination. Therefore, in the case of hepatitis B the proportion not positive for antibodies indicates the proportion of the population at risk of infection, or in other words the potential for vaccination. For hepatitis B, besides reporting the prevalence against any antibodies (anti-HBs and anti-HBc) as has been done up to present, the prevalence of chronic or acute infections, indicated by seropositivity for surface antigen (HBsAg), would be important to report separately, if these data are available. Only chronic or acute infections can lead to further spread.

INFECTION INDICATOR MAP

European Monitoring Centre for Drugs and Drug Addiction

Country:……

For each indicator of infection (= data source, see EMCDDA guidelines), please answer the following questions as far as possible:

OVERDOSE DEATHS (+NON-FATAL EMERGENCIES)

1. Does data from this source exist from 1998 onwards?
   HIV [ ] HBV [ ] HCV [ ] No [ ]
2. Is the data routinely available or from a special study?
   Routine [ ] Special study [ ]
3. Can (injecting) drug users be distinguished?
   Drug users [ ] Ever injectors [ ] Current injectors [ ] No [ ]
4. What percent of IDUs (in the same area) are probably covered by the source? [ ]
5. What percent of IDUs in the source are probably being tested? [ ]
6. What is the geographical coverage of the data?
   Whole country [ ] Two or more regions/cities of the country [ ]
   Only one region/city of the country [ ] Other (e.g. rural) [ ]
7. Is the data available in the format of the standard reporting table? Yes [ ] No [ ]
   Please specify most important differences……
8. Are stored samples available which potentially could be tested? Yes [ ] No [ ]
9. Are data collected anonymously? Yes [ ] No [ ]
10. If no tests are being performed, could these technically be done if funding were available?
    Yes [ ] No [ ]
11. Who is the owner of the source (institution, contact person)?
    ……
12. Is the owner happy for the data to be provided to the EMCDDA? Yes [ ] No [ ]

Any other comments?

DRUGS TREATMENT DATA

1. Does data from this source exist from 1998 onwards?

   HIV [ ] HBV [ ] HCV [ ] No [ ]

2. Is the data routinely available or from a special study?

   Routine [ ] Special study [ ]

3. Can (injecting) drug users be distinguished?

   Drug users [ ] Ever injectors [ ] Current injectors [ ] No [ ]

4. What percent of IDUs (in the same area) are probably covered by the source? [ ]

5. What percent of IDUs in the source are probably being tested? [ ]

6. What is the geographical coverage of the data?

   Whole country [ ] Two or more regions/cities of the country [ ]

   Only one region/city of the country [ ] Other (e.g. rural) [ ]

7. Is the data available in the format of the standard reporting table? Yes [ ] No [ ]

   Please specify most important differences……

8. Are stored samples available which potentially could be tested? Yes [ ] No [ ]

9. Are data collected anonymously? Yes [ ] No [ ]

10. If no tests are being performed, could these technically be done if funding were available?

    Yes [ ] No [ ]

11. Who is the owner of the source (institution, contact person)?

    ……

12. Is the owner happy for the data to be provided to the EMCDDA? Yes [ ] No [ ]

Any other comments?

NEEDLE EXCHANGE DATA (AND OTHER LOW-THRESHOLD SERVICES)

1. Does data from this source exist from 1998 onwards?

   HIV [ ] HBV [ ] HCV [ ] No [ ]

2. Is the data routinely available or from a special study?

   Routine [ ] Special study [ ]

3. Can (injecting) drug users be distinguished?

   Drug users [ ] Ever injectors [ ] Current injectors [ ] No [ ]

4. What percent of IDUs (in the same area) are probably covered by the source? [ ]

5. What percent of IDUs in the source are probably being tested? [ ]

6. What is the geographical coverage of the data?

   Whole country [ ] Two or more regions/cities of the country [ ]

   Only one region/city of the country [ ] Other (e.g. rural) [ ]

7. Is the data available in the format of the standard reporting table? Yes [ ] No [ ]

   Please specify most important differences……

8. Are stored samples available which potentially could be tested? Yes [ ] No [ ]

9. Are data collected anonymously? Yes [ ] No [ ]

10. If no tests are being performed, could these technically be done if funding were available?

    Yes [ ] No [ ]

11. Who is the owner of the source (institution, contact person)?

    ……

12. Is the owner happy for the data to be provided to the EMCDDA? Yes [ ] No [ ]

Any other comments?

PRISONS / ARRESTS DATA

1. Does data from this source exist from 1998 onwards?

   HIV [ ] HBV [ ] HCV [ ] No [ ]

2. Is the data routinely available or from a special study?

   Routine [ ] Special study [ ]

3. Can (injecting) drug users be distinguished?

   Drug users [ ] Ever injectors [ ] Current injectors [ ] No [ ]

4. What percent of IDUs (in the same area) are probably covered by the source? [ ]

5. What percent of IDUs in the source are probably being tested? [ ]

6. What is the geographical coverage of the data?

   Whole country [ ] Two or more regions/cities of the country [ ]

   Only one region/city of the country [ ] Other (e.g. rural) [ ]

7. Is the data available in the format of the standard reporting table? Yes [ ] No [ ]

   Please specify most important differences……

8. Are stored samples available which potentially could be tested? Yes [ ] No [ ]

9. Are data collected anonymously? Yes [ ] No [ ]

10. If no tests are being performed, could these technically be done if funding were available?

    Yes [ ] No [ ]

11. Who is the owner of the source (institution, contact person)?

    ……

12. Is the owner happy for the data to be provided to the EMCDDA? Yes [ ] No [ ]

Any other comments?

STD CLINIC DATA (AND HOSPITAL DATA)

1. Does data from this source exist from 1998 onwards?

   HIV [ ] HBV [ ] HCV [ ] No [ ]

2. Is the data routinely available or from a special study?

   Routine [ ] Special study [ ]

3. Can (injecting) drug users be distinguished?

   Drug users [ ] Ever injectors [ ] Current injectors [ ] No [ ]

4. What percent of IDUs (in the same area) are probably covered by the source? [ ]

5. What percent of IDUs in the source are probably being tested? [ ]

6. What is the geographical coverage of the data?

   Whole country [ ] Two or more regions/cities of the country [ ]

   Only one region/city of the country [ ] Other (e.g. rural) [ ]

7. Is the data available in the format of the standard reporting table? Yes [ ] No [ ]

   Please specify most important differences……

8. Are stored samples available which potentially could be tested? Yes [ ] No [ ]

9. Are data collected anonymously? Yes [ ] No [ ]

10. If no tests are being performed, could these technically be done if funding were available?

    Yes [ ] No [ ]

11. Who is the owner of the source (institution, contact person)?

    ……

12. Is the owner happy for the data to be provided to the EMCDDA? Yes [ ] No [ ]

Any other comments?

PREGNANT WOMEN DATA

1. Does data from this source exist from 1998 onwards?

   HIV [ ] HBV [ ] HCV [ ] No [ ]

2. Is the data routinely available or from a special study?

   Routine [ ] Special study [ ]

3. Can (injecting) drug users be distinguished?

   Drug users [ ] Ever injectors [ ] Current injectors [ ] No [ ]

4. What percent of IDUs (in the same area) are probably covered by the source? [ ]

5. What percent of IDUs in the source are probably being tested? [ ]

6. What is the geographical coverage of the data?

   Whole country [ ] Two or more regions/cities of the country [ ]

   Only one region/city of the country [ ] Other (e.g. rural) [ ]

7. Is the data available in the format of the standard reporting table? Yes [ ] No [ ]

   Please specify most important differences……

8. Are stored samples available which potentially could be tested? Yes [ ] No [ ]

9. Are data collected anonymously? Yes [ ] No [ ]

10. If no tests are being performed, could these technically be done if funding were available?

    Yes [ ] No [ ]

11. Who is the owner of the source (institution, contact person)?

    ……

12. Is the owner happy for the data to be provided to the EMCDDA? Yes [ ] No [ ]

Any other comments?

(PUBLIC HEALTH) LABORATORIES DATA

1. Does data from this source exist from 1998 onwards?

   HIV [ ] HBV [ ] HCV [ ] No [ ]

2. Is the data routinely available or from a special study?

   Routine [ ] Special study [ ]

3. Can (injecting) drug users be distinguished?

   Drug users [ ] Ever injectors [ ] Current injectors [ ] No [ ]

4. What percent of IDUs (in the same area) are probably covered by the source? [ ]

5. What percent of IDUs in the source are probably being tested? [ ]

6. What is the geographical coverage of the data?

   Whole country [ ] Two or more regions/cities of the country [ ]

   Only one region/city of the country [ ] Other (e.g. rural) [ ]

7. Is the data available in the format of the standard reporting table? Yes [ ] No [ ]

   Please specify most important differences……

8. Are stored samples available which potentially could be tested? Yes [ ] No [ ]

9. Are data collected anonymously? Yes [ ] No [ ]

10. If no tests are being performed, could these technically be done if funding were available?

    Yes [ ] No [ ]

11. Who is the owner of the source (institution, contact person)?

    ……

12. Is the owner happy for the data to be provided to the EMCDDA? Yes [ ] No [ ]

Any other comments?

SPECIAL STUDIES / SENTINEL SURVEILLANCE DATA

1. Does data from this source exist from 1998 onwards?

   HIV [ ] HBV [ ] HCV [ ] No [ ]

2. Is the data routinely available or from a special study?

   Routine [ ] Special study [ ]

3. Can (injecting) drug users be distinguished?

   Drug users [ ] Ever injectors [ ] Current injectors [ ] No [ ]

4. What percent of IDUs (in the same area) are probably covered by the source? [ ]

5. What percent of IDUs in the source are probably being tested? [ ]

6. What is the geographical coverage of the data?

   Whole country [ ] Two or more regions/cities of the country [ ]

   Only one region/city of the country [ ] Other (e.g. rural) [ ]

7. Is the data available in the format of the standard reporting table? Yes [ ] No [ ]

   Please specify most important differences……

8. Are stored samples available which potentially could be tested? Yes [ ] No [ ]

9. Are data collected anonymously? Yes [ ] No [ ]

10. If no tests are being performed, could these technically be done if funding were available?

    Yes [ ] No [ ]

11. Who is the owner of the source (institution, contact person)?

    ……

12. Is the owner happy for the data to be provided to the EMCDDA? Yes [ ] No [ ]

Any other comments?

THANK YOU

Please return, preferably in electronic format and by email, to:

Dr Avril Taylor, SCIEH, Clifton House, Clifton Place, Glasgow G3 7LN, Scotland

<Avril.Taylor@scieh.csa.scot.nhs.uk>

Prevalence of hepatitis B/C and HIV infection among recent injecting drug users in EU Countries (Version 10.04.00)

Country _____ **Date** _____

1 Definition of injectors (Note: if possible data for current injectors only)

Ever ○ Current (i.e. injected in last 12 months) ○

1a When did they start injecting [*Indicate all that apply*]

<2 years ago ☐ 2 or more years ago ☐ Not known ☐

2 Gender Males only ○ Females only ○ Both ○ Not known ○

3 Age range from _____ to _____ years Not known ☐

4 Recruitment area (Geographical Coverage) [*Indicate only one*]

The whole country ○ Two or more regions / cities ○

Only one region / city ○ Other (e.g. rural) ○ Not known ○

4a If the geographical coverage is the whole country or two or more regions / cities, can the data be provided for each individual region / city or other area

Yes ○ No ○

5 Data source(s) [*Tick all that apply*]

Overdose deaths and/or non-fatal emergencies	☐	STD clinics	☐
Drug Treatment Centres	☐	Pregnant women	☐
Needle Exchanges	☐	Hospitals	☐
Low threshold services	☐	Prisons	☐
(Public Health) Laboratories	☐	Arrests	☐
Other ☐ Specify _____		Not Know	☐

6 Method of data collection Exhaustive (all eligible individuals) ○ Sampling ○

6a Describe the sampling method: _____

7 The study is conducted: Only once ○ Periodically ○ Continuously ○

7a Define precisely the timescale or the periodicity / frequency of the study: _____

8a If the data are self-reported
Specify what was reported *[tick one or more]:* HBV ☐ HCV ☐ HIV ☐

8b If the data are clinical diagnoses
Specify what was tested for *[tick one or more]:*

HBsAg	☐				
antiHBc	☐				
antiHBs	☐	HCV Ab	☐	HIV Ab	☐

9 Specimen tested Serum ☐ Saliva ☐

Form completed by

Name	
Institution	
City	

PLEASE GO TO PAGE 2 OF THIS WORKBOOK

Results for geographical area

Indicate the geographical area described in question 3. If data for sub-areas are available - in particular for capital cities or major urban areas, complete a separate copy of this page for each region/city or other area

What virus was reported (from 8a) **What marker was tested for (from 8b)**

If data for more than one test is available use a separate copy of this page for each set of results

In Row 1: Indicate the total sample size of injectors.
In Row 2: Indicate the number of individuals who tested positive only.
In Row 3: Indicate the total number of individuals who tested positive or negative for the test indicated above.
In Row 4: Indicate the percentage who tested positive (row 2 divided by row 3).

Row	Year	1991	1992	1993	1994	1995	1996	1997	1998	1999	2000
1	Total sample size of injectors (IDUs)										
2	No. of IDUs with a positive test result										
3	Total no. of IDUs tested										
4	Percentage infected										

IF AVAILABLE
In Rows 5–13: Indicate the percentage of the sub-groups that are infected, then the number who were positive and the total number tested for each of the sub-groups described.

Row	Year	1991		1992		1993		1994		1995		1996		1997		1998		1999		2000	
5	**MALES** percent infected																				
5a	Number Positive ¦ Number Tested																				
6	**FEMALES** percent infected																				
6a	Number Positive ¦ Number Tested																				
7	**IDUS AGE < 25** percent infected																				
7a	Number Positive ¦ Number Tested																				
8	**IDUS AGE 25 - 34** percent infected																				
8a	Number Positive ¦ Number Tested																				
9	**IDUS AGE > 34** percent infected																				
9a	Number Positive ¦ Number Tested																				
10	**RECENT ONSET IDU (see note)** percent																				
10a	Number Positive ¦ Number Tested																				
11	**LONGER TERM IDU (see note)** percent																				
11a	Number Positive ¦ Number Tested																				
12	**OPIATE USING IDU** percent infected																				
12a	Number Positive ¦ Number Tested																				
13	**NON-OPIATE USING IDU** percent																				
13a	Number Positive ¦ Number Tested																				

14 Additional Information / comments

14 Principle Investigator's Name:

15 Principal Investigator's Institution:

16 Complete Bibliographic Reference

Prevalence of Hepatitis B/C and HIV infection among recent injecting drug users in EU Countries

INSTRUCTIONS FOR COMPLETING THE FORMS ON PREVALENCE DATA

Page 1

Q1. Injectors must be described as ever or current.

Q1a. For current IDUs, if available, indicate when they started injecting i.e. less than or more than 2 years ago.

Q2 Indicate if the IDU population are males only, females only or includes both males and females.

Q3. If available, indicate the age range of the IDU population.

Q4. Describe the geographical coverage to which the results relate. If results are available for more than one sub-areas, i.e. regions within a country and/or cities within a region, please complete a separate result form for each region or city.

Q4a. If the geographical coverage is less than 2 regions/cities, tick the "not applicable" box.

Q5. Please tick all types of sources from which data has been collected

Q6. If all IDUs at a treatment centre had provided information on test results this would be "exhaustive". If only a proportion had provided this information this would be "sampling".

Q6a. The following are examples of sampling schemes:
Random selection using random numbers
Systematic sampling e.g. alternate patients, alternate days, every tenth patient etc.
Consecutive sampling e.g. the first 200 IDUs attending a clinic at the beginning of every month

Q7. Cross sectional surveys may be conducted *only* once or may be repeated *periodically*. A study that is carried out without interruption (e.g. in a continuous surveillance system), is conducted *continuously*.

Q6a. For once only studies, please provide the timescale of the studies e.g. March 1995 - February 1996.
For periodic studies, please provide the frequency of such studies e.g. conducted every 2 years.
For continuous studies, please state when study began.

Q7. A positive test result may be obtained by self reports or screening. If a positive result was identified through screening, tick which test(s) was used.

Page 2

Results

Where possible, results should be provided in 12 month periods (i.e. from 1st Jan to 31st Dec) in each year. Data obtained from a continuous surveillance system should be broken down into 12 month periods. For studies which cover more than 1 year (e.g. June 1996 - Sept. 1998), if possible, provide results for each separate year (i.e. 1996, 1997, 1998), If this is not possible, provide the complete set of results in the column which corresponds to the final year of the study i.e. 1998. If data for sub-areas are available, complete a separate form for each region/city or other area. Likewise if data for more than one test is available use a separate form for each set of results. Please make extra copies of page 2.

Recent injectors refer to those who began injecting less than 2 years previous. Longer-term injectors refer to those who have been injecting for 2 or more years

Study bibliography

If the data has been published either as a report or an article, indicate the most recent publication. For journal articles the following information should be included: (a) the last names of the authors, followed by their initials, (b) title of the article with the same spelling and accent marks as in the original, (c) the journal title, (d) the year of publication, (e) the volume number, and (f) the first and last page numbers. For a report include: (a) the authors (as before), (b) the title of the report, (c) the publishing place, (d) the publishers, (e) the year of publication and (f) the report number if possible. For unpublished data please provide the name of the source and their affiliated institution. Examples of the correct format are as follows:

1.Fretz C, Jaulmes D, Mor-Klaren I. Blood donors and HCV antibodies: serology and epidemiology. Progress in Liver Disease 1995, 96: 4-10

2.Ehata T, Omata M, Yokusuda O, Hosoda K, Ohto M. Nature of the HCV virus. London, Churchill. 1998, 76.