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Original article

2nd-generation HIV surveillance and injecting drug use: uncovering the epidemiological ice-berg

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Summary

Objectives: HIV/AIDS surveillance methods are under revision as the diversity of HIV epidemics is becoming more apparent. The so called "2nd generation surveillance (SGS) systems" aim to enhance surveillance by broadening the range of indicators to prevalence, behaviors and correlates, for a better understanding and a more complete and timely awareness of evolving epidemics.
Methods: Concepts of HIV SGS are reviewed with a special focus on injecting drug users, a major at-risk and hard to reach group in Europe, a region with mainly low or concentrated epidemics.
Results: The scope of HIV/AIDS surveillance needs to be broadened following principles of SGS. Specifically for IDUs we propose including hepatitis C data as indicator for injecting risk in routine systems like those monitoring sexually transmitted infections and information on knowledge and attitudes as potential major determinants of risk behavior.
Conclusions: The suggested approach should lead to more complete and timely information for public health interventions, however there is a clear need for comparative validation studies to assess the validity, reliability and cost-effectiveness of traditional and enhanced HIV/AIDS surveillance systems.

Keywords: HIV – Hepatitis C – Surveillance – Epidemiology – Drug injecting – Substance abuse.

Currently, infectious disease surveillance methods are in a process of change from the traditional exclusive focus on case reporting towards more comprehensive or enhanced systems that timely information and encompass a wider range of data sources, including sentinal surveillance and indicators such as risk determinants, behavior and prevention indicators (Krämer et al. 2003) (Reintjes et al. 2001) (Mellmann et al. 2006) (Wiessing et al. 2006). Surveillance systems for HIV/Aids epidemics remain at the centre of attention. Methods traditionally used to monitor HIV (e. g. sentinel studies in pregnant women or STI patients) have proven to be important in early heterosexual epidemics, but are less helpful in situations where HIV is concentrated in population sub-groups at higher risk. Current surveillance methods are particularly poor where vulnerable populations with high-risk behaviors exist on the margins of society, which may not or insufficiently be reached by traditional health care and data collection systems. At the same time the diversity of HIV epidemics around the world is becoming ever more apparent, ranging from massive general population based epidemics in some regions to epidemics that are still low level or concentrated in high-risk groups in other areas (UNAIDS 2004). This reveals a need for interpreting and developing current uniform recommendations in a more flexible way, adapting them on a case-by-case basis to the existing diversity of epidemiological situations.

Injecting drug users (IDUs) are disproportionately affected by HIV and other infections and require special attention. In regions of the world with low level or concentrated HIV epidemics, notably in Eastern Europe but also in several EU countries, they are among the groups at highest risk both in terms of their proportion infected as in absolute numbers of infections, causing high costs to society (EMCDDA 2004; Semaille et al. 2003; Godfrey et al. 2002; Porter et al. 2003; Postma et al. 2001; Jager et al. 2004). One in three HIV-infected individuals in Europe and the US has hepatitis C co-infection (Rockstroh 2004) and is likely to have injected drugs. Traditional HIV surveillance systems often provide insufficient information to reliably follow trends in marginalized high risk groups such as IDUs. Also they do not generally include the monitoring of determinants of acquiring HIV and other blood borne diseases, such as injecting or sexual risk behavior, or knowledge, atti-

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tudes and contact with prevention, which are important to get a better understanding and a more complete and timely picture of evolving epidemics. The term "2nd generation surveillance" (SGS) was developed by UNAIDS to describe a family of data collection systems aimed at enhancing the understanding of the factors involved in emerging epidemics, and allowing a better targeting of public health programs to prevent HIV and other infections, that extend beyond surveillance systems that use only HIV case reporting or seroprevalence based methods. Efforts are being made to build on existing systems, strengthening their explanatory power and making better use of the information they generate (UNAIDS/WHO 2002).

The aim of this paper is to review concepts and potential additional components of HIV/AIDS SGS, with a special focus on injecting drug users, a major at-risk and hard to reach group in Europe, a region experiencing mainly low and concentrated epidemics.

2nd generation HIV surveillance

The main objectives of SGS are to monitor trends over time based on basic principles of disease surveillance (AIDS-case surveillance and HIV sero-surveillance) combined with STI surveillance and risk behavior surveillance, in order to provide essential data needed for the development of interventions and the evaluation of their impact. This provides a more comprehensive understanding of the epidemic. WHO bases the Principles of SGS and their aims on the following aspects (UNAIDS/WHO 2000):

- *Surveillance systems should be appropriate to the epidemic state*

Recognizing the heterogeneity of HIV epidemics around the world, SGS should meet different surveillance needs in different epidemic states. Surveillance systems are designed to answer the needs of a particular country situation at a particular point in its epidemic evolution. For example, in countries with low level epidemics, including low prevalence in IDUs, one might focus on early indicators of injecting risk behavior such as self-reported behavior from studies or routine sources (e. g. admissions to drug treatment) and trends in hepatitis B and C levels (from screening or notifications). In countries with concentrated epidemics however, one would also need to pay attention to the transmission from high-risk groups to low risk individuals.

- *Surveillance systems should be dynamic, changing with the needs of the epidemic*

HIV epidemics evolve differently in various situations. SGS systems aim to follow this evolution. While some components such as HIV case reporting are clearly basic and should be maintained over time, SGS should flexibly adapt to new and evolving situations by adding or discontinuing specific components according to key priorities. For example specific studies in specific at risk groups can be implemented depending on early warning signals indicating increased risk in those groups, or signals of potentially decreasing validity of the core surveillance components that may call for one-off or repeated validation studies.

- *Surveillance systems should focus resources where they can provide most useful information*

This will often mean tracking behavior and infection in subpopulations whose members are at high risk of contracting or passing on HIV infection. The surveillance strategy for different high-risk groups will vary according to the epidemic state and potentially available data systems, and may again shift over time. For example, several countries in the European Union (EU) have national level routine data available on IDUs from screening in drug services. Here it would be cost-effective to use these already existing data and data systems for monitoring and surveillance, in addition to the mostly already available national HIV case reporting that may cover different sub-populations of IDUs. Using such combinations of different data systems, and especially combining case reporting with prevalence monitoring, is currently being recommended for surveillance among IDUs in the EU (EMCDDA 2002; EMCDDA 2004; Jager et al. 2004, Wiessing et al. 2006).

- *Behavioral data should be used to guide biological data collection and explain trends in HIV infection*

In low-level epidemics where there are still few HIV infections, behavioral surveillance can indicate what sub-groups of specific populations are at highest risk. Once HIV incidence is increasing having information on risk behaviors helps understanding how to focus prevention messages and how to provide appropriate prevention services. In IDUs another important variable is the age of first injection. From this, one can estimate the average number of years injecting in the IDU population, to help the interpretation of prevalence data. It is also possible to follow prevalence among new injectors as a proxy indicator of incidence, in addition to monitoring overall prevalence (EMCDDA 2004, 2006).

- *Biological and behavioral data should be used to validate one another*

Two sets of data pointing in the same direction make a more convincing case than just behavioral data or HIV prevalence alone. For example, as hepatitis C infection is currently almost exclusively caused by injecting drug use, rising levels

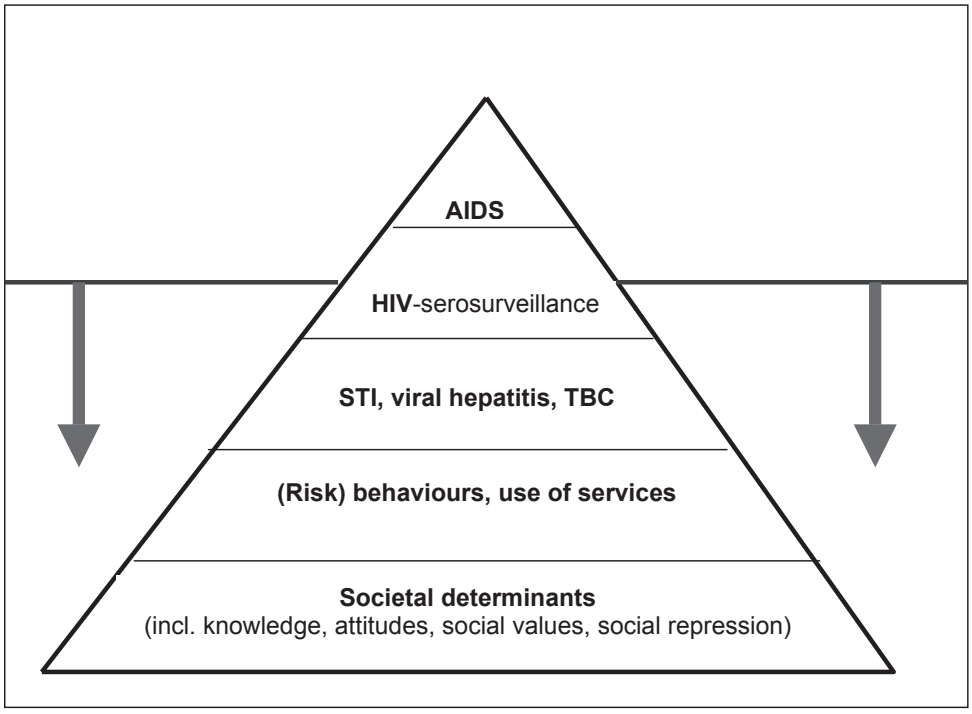

Figure 1 Disclosing the surveillance Ice-berg; Components of 2nd generation HIV surveillance representing aspects of an epidemic. 'Lowering the water line' will give a more complete picture of an epidemic.

of hepatitis C infection can form an early warning signal for increases in injecting risk behavior, as has been reported from the UK (Judd et al. 2003; Hope et al. 2004).

- *Information from other sources should be integrated into HIV surveillance systems*

Where other sources of information exist that might contribute information on sexual or drug-taking behavior or exposure to HIV, these should be integrated into HIV/AIDS surveillance systems wherever possible. For example rising trends in STI data among specific risk groups may indicate increasing sexual risk behaviour that may in turn lead to increased HIV transmission.

- *Information generated by surveillance must be used to design and promote preventative interventions, to plan for impact and to measure change*

For example the number of needles exchanged in a prevention program for IDUs or the number of sex workers treated for STI can give an indication of prevention performance. On the basis of this it will be possible to estimate coverage and potential impact of interventions on the epidemic situation in risk groups (Holtgrave 1998; Jager et al. 2004). The needs of end users should be taken into account when building up SGS systems, and data should wherever possible be packaged to meet those needs. This indicates that effective coordination between surveillance and prevention programs and between those and specialized (e. g. drug) services, are crucial.

Classical components for the collection of information for SGS systems are AIDS and HIV case reporting, HIV serosurveillance, STI surveillance and Behavioral surveillance. Other sources of information may also be important. In the case of IDUs it should be considered adding surveillance of other blood borne infections such as viral hepatitis, or data on needle and syringe programs, to this standard package. For example, by routinely asking injecting drug users entering drug treatment for the first time where they obtained their clean needles and syringes, one can continuously monitor the reach of such prevention services and obtain specialized data on this risk group.

Disclosing the epidemiological ice-berg

Figure 1 shows an iceberg as a metaphor for the conceptual framework of (enhanced) SGS. Traditional surveillance structures focus on counting clinical cases, thus only looking at the top of the epidemiological 'ice-berg'. As AIDS has a long latency period after the original infection with HIV, the information gained reflected only transmission patterns of the past. To get a timelier picture HIV-case reporting has already been incorporated in many (but not all) national surveillance systems in Europe. The aim of SGS is to broaden the scope with additional data and information that will help to better

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Table 1 Traditional HIV surveillance, SGS and additional components for enhanced SGS among IDUs

	Traditional HIV surveillance	SGS	Enhanced SGS	Comments
AIDS case reporting	x	x	x	
HIV case reporting	x	x	x	
HIV (UA) repeated prevalence studies	x	x	x	Among IDUs UA = unlinked anonymous.
Behavioural studies		x	x	Among IDUs
Knowledge and attitudes			x	Among IDUs
Hepatitis C (and B) data			x	notifications and prevalence, with IDU status and laboratory confirmation
STI data	x (sometimes)	x	x	With IDU status and/or from drug user specific settings, laboratory confirmed
Prevention indicators			x	e. g. needles exchanged nationally
Treatment indicators			x	e. g. national HAART coverage
Data from prisons			x	With IDU status. E. g. seroprevalence, behaviour etc among IDUs in prisons
Data from drug treatment centres			x	With IDU status
Data from public health laboratories	x	x	x	Only of use if with IDU status
Population size estimates			x	Indicators of prevalence, incidence of IDU, national and locally

Note: the use of and investment in indicators should be allowed to vary to some extent, according to data availability and relevance for the national epidemiological situation

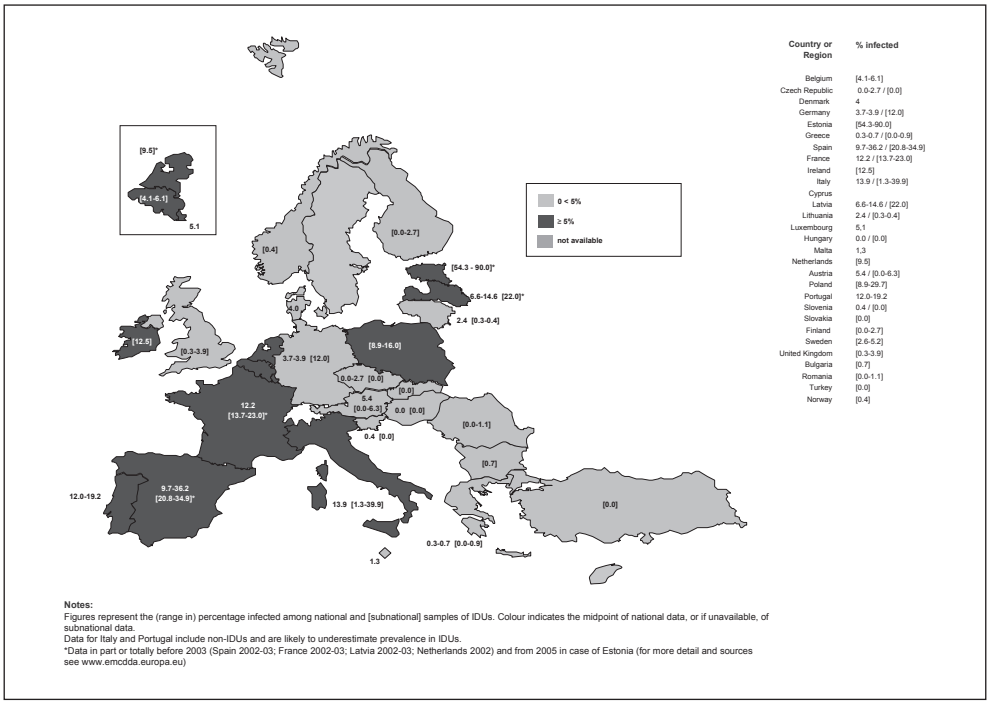
understand the epidemic process and thus to assist prevention and care. For example by including repeated serobehavioral surveys in specific risk groups and by using STI data as a component of HIV surveillance. We propose going even further and to include indicators of risk, determinants and prevention, that may be different for the different groups at high risk, such as for example adding data on hepatitis C infection to gauge injecting risk behavior among IDUs or data on needles and syringes distributed to estimate coverage of prevention services (see Tab. 1).

Data on current developments especially in Eastern Europe and central Asia indicate dramatic changes and a close association of injecting drug use and HIV transmission. The scenarios for HIV surveillance can also be applied to the surveillance of hepatitis C. Prevalence of hepatitis C infection in injecting drug users is high overall in the European Union, while HIV shows more marked variation between countries in prevalence and trends (Wiessing et al. 2004, 2006; EMCDDA 2006). Figure 2 shows the different geographic patterns in the prevalence of HIV and hepatitis C in IDUs. The challenges for effective surveillance systems are similar and in the case of IDUs efforts should be combined. Risky injecting behavior is the main underlying determinant for the spread of both HIV and hepatitis in IDUs, and having more specific data will allow a view into high risk activities currently taking place. Behaviors are influenced by societal determinants as social values, knowledge, repression and attitudes and these can be seen as the underlying risk of infection even in the (temporary) absence of virus in the population. For effective surveillance it is crucial to obtain a more complete picture of determinants and indicator data. Using the classic metaphor, a key aim of SGS is to lower the water line of the epidemiological ice-berg.

Discussion

With the establishment of SGS systems, data collection is becoming more focused on the populations most at risk of becoming newly infected with HIV, such as high risk populations (including IDUs) or young people at the start of their sexual lives. This means, comparing information on HIV prevalence and on the behaviors that spread it will help to give an informative picture of changes in the epidemic over time. This can include using potential proxy indicators of risk behaviors such as hepatitis B (as an indicator for sexual and injecting risk) and hepatitis C data (indicating injecting risk). The appropriate use of sources of information other than only AIDS case or HIV case reporting data (e. g. sentinel surveillance, regular reproductive health surveys, regular surveys on behaviors, knowledge and attitudes, etc.) is important to increase understanding of the HIV/AIDS epidemic.

Data use should vary according to the epidemic state. Where HIV is uncommon, biomedical surveillance (hepatitis C and STI) and behavioral data may provide early warnings of a possible increased risk of an epidemic. Where HIV is concen-

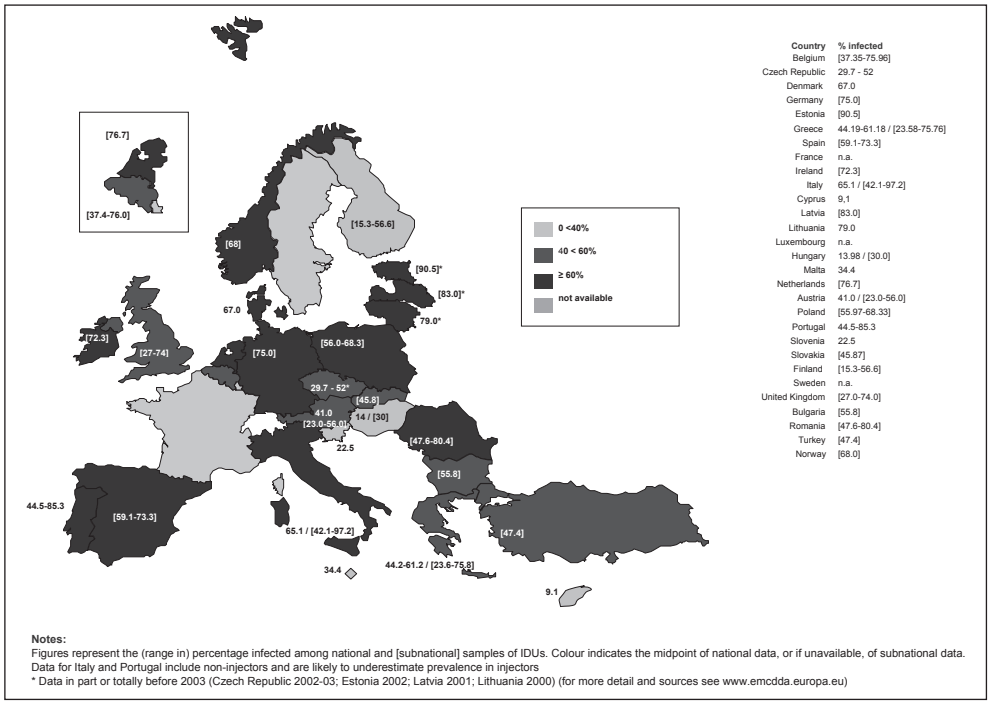


Country or Region	% infected
Belgium	[4.1-6.1]
Czech Republic	0.0-2.7 / [0.0]
Denmark	4
Germany	3.7-3.9 / [12.0]
Estonia	[54.3-90.0]
Greece	0.3-0.7 / [0.0-0.9]
Spain	9.7-36.2 / [20.8-34.9]
France	12.2 / [13.7-23.0]
Ireland	[12.5]
Italy	13.9 / [1.3-39.9]
Cyprus	
Latvia	6.6-14.6 / [22.0]
Lithuania	2.4 / [0.3-0.4]
Luxembourg	5,1
Hungary	0.0 / [0.0]
Malta	1,3
Netherlands	[9.5]
Austria	5.4 / [0.0-6.3]
Poland	[8.9-29.7]
Portugal	12.0-19.2
Slovenia	0.4 / [0.0]
Slovakia	[0.0]
Finland	[0.0-2.7]
Sweden	[2.6-5.2]
United Kingdom	[0.3-3.9]
Bulgaria	[0.7]
Romania	[0.0-1.1]
Turkey	[0.0]
Norway	[0.4]

Notes:
Figures represent the (range in) percentage infected among national and [subnational] samples of IDUs. Colour indicates the midpoint of national data, or if unavailable, of subnational data.
Data for Italy and Portugal include non-IDUs and are likely to underestimate prevalence in IDUs.
*Data in part or totally before 2003 (Spain 2002-03; France 2002-03; Latvia 2002-03; Netherlands 2002) and from 2005 in case of Estonia (for more detail and sources see www.emcdda.europa.eu)

Figures 2a and b Prevalence of HIV and hepatitis C antibodies among injecting drug users in the European Union Turkey and Norway (EMCDDA, 2006, Wiessing et al. 2006)

(a) HIV



Country	% infected
Belgium	[37.35-75.96]
Czech Republic	29.7 - 52
Denmark	67.0
Germany	[75.0]
Estonia	[90.5]
Greece	44.19-61.18 / [23.58-75.76]
Spain	[59.1-73.3]
France	n.a.
Ireland	[72.3]
Italy	65.1 / [42.1-97.2]
Cyprus	9,1
Latvia	[83.0]
Lithuania	79.0
Luxembourg	n.a.
Hungary	13.98 / [30.0]
Malta	34.4
Netherlands	[76.7]
Austria	41.0 / [23.0-56.0]
Poland	[55.97-68.33]
Portugal	44.5-85.3
Slovenia	22.5
Slovakia	[45.87]
Finland	[15.3-56.6]
Sweden	n.a.
United Kingdom	[27.0-74.0]
Bulgaria	[55.8]
Romania	[47.6-80.4]
Turkey	[47.4]
Norway	[68.0]

Notes:
Figures represent the (range in) percentage infected among national and [subnational] samples of IDUs. Colour indicates the midpoint of national data, or if unavailable, of subnational data.
Data for Italy and Portugal include non-injectors and are likely to underestimate prevalence in injectors
* Data in part or totally before 2003 (Czech Republic 2002-03; Estonia 2002; Latvia 2001; Lithuania 2000) (for more detail and sources see www.emcdda.europa.eu)

(b) Hepatitis C

trated in sub-populations with high-risk behavior such data can provide important additional information for designing focused interventions. It is likely that in the case of IDUs data on hepatitis C, and in the case of MSM data on STI, can be used as additional indicators of risk behavior. A combination of several routine data sources, likely including basic behavioral items, and special studies, may strongly improve the overall quality of information.

Nevertheless, behavior data need to be calibrated by their potential limitations. Information collected on attitudes and

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behavior are generally regarded as "soft" data as the willingness and ability to give correct answers is often influenced by known as well as unknown factors (e. g. socially accepted answers or shame). Specificity and sensitivity of questionnaires need to be tested and costs and complexity of qualitative studies should be taken into account. Adding data on STI or viral hepatitis could improve both specificity and sensitivity of surveillance by using "objective" laboratory tests. For 2nd generation HIV/AIDS surveillance the potential advantages of "triangulation" of different data sources (HIV, STI & behavioral data, coverage of prevention measures such as needle exchange) should be realized. One of the major advantages of this approach to surveillance is that it is likely to be more sensitive to detect changes, and that it is potentially timelier, which is essential for prevention. In contrast to the classical AIDS case reporting and HIV serosurveillance, where information is only collected and used after individuals are infected, SGS may generate early warning signals already when attitudes and behaviors start changing, or when the hepatitis C prevalence in new injectors starts rising, potentially even prior to an increase in the incidence of HIV that could be detected through HIV case reporting systems. This form of surveillance builds on the lessons learnt in the first decade of HIV surveillance and attempts to capture the diversity of the HIV epidemics in different regions and over time, while it takes into account the state of the epidemic. It integrates biological surveillance with "risk" surveillance or intervention coverage, and it looks at new methodologies and improved ways for using epidemiological data 'for action'.

Hepatitis C prevalence can be an especially important indicator of injecting drug use and deserves specific attention as an additional component of 2nd generation HIV/AIDS surveillance. The hepatitis C epidemic in Western Europe shows the pattern of a concentrated epidemic. Transmission is currently mainly concentrated among injecting drug users and prevalence reaches very high levels within these populations across various countries (see Fig. 2b) but are mostly low outside them. Prevalence levels in the general population in Western Europe are thought to be around 0.1–1 % (Desenclos 2003). Although higher levels have been found in smaller regions in some countries, these infections have probably occurred before systematic blood-screening was introduced and IDUs currently account for up to 60–90 % of newly reported infections in several countries of the EU (EMCDDA 2004).

Hepatitis C monitoring has two specific aspects. Firstly, it can be a very sensitive indicator for injecting risk behavior (this is due to very high prevalence and incidence in this risk group as compared to limited transmission by other routes). Secondly, it is a serious health problem with high prevalence of HIV/HCV co-morbidity and related complications amongst IDUs. STI monitoring among MSM and sex workers can serve similar purposes, both as indicators of HIV sexual risk and to prevent the STI themselves. For routine monitoring a range of different settings can be used (drug treatment, needle exchange, prisons etc.; see EMCDDA guidelines EMCDDA 2000). A specific option for the surveillance amongst IDUs is to monitor prevalence in young and especially in new IDUs (e. g. less than 2 years of injection history) as this is a more sensitive measure for changes in the overall prevalence (incidence) amongst this risk group. As a measure of HCV incidence in the general population, and thus a potential proxy of injecting drug use, statutory notification data are often used, but these data may in the case of hepatitis B and C be of very poor quality due to large proportions of asymptomatic cases, in combination with various amounts of biased and under-reporting and potential misclassification of transmission routes (Hagan et al. 2002; Strauss et al. 2003; Nalpas et al. 1998). Therefore serological surveillance normally should provide more reliable information. Here the obstacles related to added costs, organizational and individual implications need to be taken into account. However there is a clear need for comparative validation studies to assess the validity, reliability and cost-effectiveness of currently existing traditional and enhanced HIV/AIDS surveillance systems.

In conclusion, to get an as complete as possible overall picture of the HIV epidemic and associated infections, data from all available sources should be used and interpreted in conjunction. The European experience of developing specialized hepatitis and HIV surveillance in IDUs may be useful in the further development of 2nd generation HIV surveillance.

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