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Methods for assessing HIV and HIV risk among IDUs and for evaluating interventions

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Abstract

A wide range of methods is now available for assessing the nature and characteristics of drug injecting populations, and for evaluating the effectiveness of interventions developed to reduce injecting related harms. The public health surveillance tasks in relation to injecting drug use populations and associated health problems are the same, in principle, as for the surveillance of other health problems. These are: to describe the patterns of the condition, the nature of the problem and the environment (context) in which it occurs; to determine the scale of interventions needed and estimated coverage required, to forecast future health care needs; to mobilise resources and target prevention; and to evaluate interventions. Countries vary in their existing levels of information as well as resources for surveillance systems, research and evaluation. We propose three levels of assessment: basic assessment, which is suitable in situations of low awareness and information, routine surveillance, and enhanced surveillance, which requires more complex research and/or analyses of data collected from routine surveillance.

Keywords: Assessment; Injecting drug use; HIV; Research; Public health surveillance; Evaluation

Key issues for assessment and evaluation

In their own national, regional and local settings, policy-makers and planners need to assess the extent and nature of the public health problem of HIV related to injecting drug use (IDU), to decide what interventions are appropriate (as described elsewhere in this supplement), to implement and evaluate them, as well as to modify policy and interventions in the light of evaluation and ongoing assessment. This paper provides an overview of research methods that provide policy-makers and planners with information for HIV prevention. It describes methods that have been developed for assessing the characteristics of injecting drug users (IDUs), IDU-related risk behaviours and the health consequences as well as for evaluation of HIV prevention interventions.

Countries are not all starting from the same place. Some have virtually no information about IDU and HIV, while others have considerable sources of information from routine surveillance systems and research. We suggest three levels of data collection, analysis and interpretation. First, *basic assessment* should include rapid assessment of the problem and surveys of IDUs to establish HIV prevalence. Second, attention should be given to developing *routine surveillance* by enhancing existing, and developing new, data sources of IDU in contact with prevention, care, treatment, social, and criminal justice services. These data will also provide the necessary information for estimating coverage. Thirdly, once baseline data have been collected further *enhanced surveillance* work can be undertaken to improve the evidence base, estimate incidence and evaluate specific programmes.

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Table 1
Five issues for public health surveillance and for effective HIV/AIDS policy making and planning

Public health surveillance	Key questions for effective HIV/AIDS policy making and planning	Objective (cross refer to Table 2)
Describe patterns of disease	What is the HIV prevalence among IDUs? How is prevalence changing over time?	1. Assess prevalence of HIV
Describe nature of the problem and the environment (context) in which it occurs	What are the main characteristics of IDUs? What drugs are used? What are the risk behaviours? What influences risk behaviours?	2. Describe the behaviour of IDU population
Determine scale of interventions needed and estimate coverage. Forecast future health care needs	How many IDUs are there? What are the current HIV prevention interventions?	3. Estimate numbers of IDUs and coverage of current interventions
Mobilise resources and target prevention	What potential is there for intervention against the spread of IDU and against the harms associated with IDU (e.g. risk of HIV infection). Where will investment achieve best results?	4. Predict epidemic trends and scenarios
Evaluate prevention programmes	What evidence is there that interventions are working?	5. Evaluate interventions as well as region or country-wide programmes

Public health surveillance in general is concerned with the ongoing measurement and description of a health problem as well as with influencing policy, i.e. collecting information in order to take action (Centers for Disease Control, 1992; Thacker & Berkelman, 1988). Assessment allows informed decisions about required interventions while evaluation helps decide whether interventions are having the desired results. Methods used in assessment are also appropriate for evaluation, and data generated from assessment can be used in evaluation. The assessment of IDU populations and associated health problems is set out in the left hand column in Table 1. Five questions relevant to HIV prevention for IDUs are listed in the middle column of Table 1. The right hand column translates these into specific objectives, and this framework guides the discussion in this paper.

Basic, routine and enhanced assessment and evaluation

The three levels of assessment and evaluation that are proposed are shown in Table 2 and are mapped against the public health surveillance objectives outlined in Table 1.*Basic assessment* is suitable in situations of low awareness and information, i.e. where there is little or no information on IDUs available or little information available on a particular aspect of IDU. It utilises quick methods to appraise the situation and should be linked to intervention development, advocacy, policy development and the establishment of better information including routine surveillance. Many methods of basic assessment are low cost and rapid.*Routine surveillance* involves collecting ongoing data from populations in contact with interventions. It can track changes in drug use behaviour and HIV epidemics, and be used to monitor and evaluate intervention development and effectiveness. It is ongoing as data are collected over time; routine because the information is collected as part of the work of an agency; and systematic because standardised data collection and reporting forms are used.

Enhanced surveillance requires either more complex analyses of data collected from routine surveillance and research, for example, the statistical modelling of the possible impact of interventions on HIV epidemics, or more rigorous evaluation of interventions, for example, randomised controlled trials of specific treatments. It requires routine surveillance information systems to be in place, supplemented by research data. While it is unlikely to be undertaken in many countries, by extrapolating the results, it can provide added value to national and global knowledge of how to respond to HIV and IDUs.

Gaining access to injecting drug users – a 'partially' hidden population

IDUs are often considered to be a hidden and difficult to reach population. A better description is a 'partially hidden population' (Des Jarlais, Dehne, & Casabona, 2001) and thus one which can be accessed with some effort. IDUs can be recruited from agencies such as treatment programmes, residential rehabilitation and prisons; and in the community through outreach, at drug use or other venues (shooting galleries, homes, parks and drop-in-centres) and drug dealing areas; from purposely established store-fronts, and from community based agencies, including needle syringe programmes (NSPs). The advantages of populations accessed through agencies are: institutions may help in gaining access to research subjects, availability of sampling lists enabling clear sampling procedures; and clear criteria for inclusion and the characteristics of the population may be known.

Table 2
Three levels of assessment and evaluation

Objective (cross refer to Table 1)	Basic assessment	Routine surveillance	Enhanced surveillance (add these items to routine surveillance)
	Lower levels of awareness and information Lower cost and complexity	Medium levels of awareness and information Medium cost and complexity	Higher levels of awareness and information Higher cost and complexity
1. Assess level of HIV associated with IDU			
Measure HIV prevalence	Selected agency and community samples Rapid Assessment and Response (RAR) studies	Sentinel surveillance using multi-agency samples Sentinel surveillance using community recruited samples with repeated samples for time trends	
Monitor reports of HIV associated with IDU	HIV test reports from agencies	Laboratory surveillance of HIV-positive and negative tests results Clinical surveillance of AIDS cases and related deaths	
Measure HIV incidence			Cohort studies of HIV sero-converters Modelling incidence from serial prevalence and from serological markers and CD4 Back-calculation models of HIV incidence and future AIDS cases
2. Describe the IDU population			
Describe characteristics of IDU populations	Selected agency and community samples RAR studies	Sentinel surveillance using multi-agency samples Sentinel surveillance using community recruited samples Repeated samples for time trends	Geo-spatial mapping
Describe HIV risk behaviours	Surveys in agencies and the community Observations, focus groups and interviews in the community RAR studies	Sentinel surveillance – questionnaires and reporting systems in agencies and community recruited samples In-depth qualitative studies in the community Behavioural sentinel surveillance (BBS) in agencies and communities	
3. Estimate numbers of IDUs			
Estimate prevalence of IDUs	Simple enumeration (e.g. counts of IDUs in street or agency settings) and estimates from key informants RAR studies	Case-counting from agency reporting systems Multipliers Capture–recapture	Extended multiplier methods Capture–recapture with covariates Back-calculation System dynamic modelling
Estimate coverage	Collate key indicator data (e.g. number of syringes distributed, number of visits to NSPs, number in contact with treatment agencies, number of arrests) RAR studies	Use data in capture–recapture exercises and estimates of coverage.	Establish ongoing surveillance system across multiple data sources
4. Predict epidemic trends and scenarios			
Predict epidemic and impact of interventions	Simple estimates based on RAR and comparative international data, and knowledge of evidence for action	More rigorous estimates based on surveillance and comparative international data, and knowledge of evidence for action	Statistical modelling using data from routine surveillance
5. Evaluate interventions and region or country-wide programmes			
Evaluate specific interventions, or region or country-wide programmes	Secondary data, inferences from international data, and site inspections	Implementation evaluation	Impact and cost effectiveness studies
	Simple estimates of programme coverage and delivery	Evaluation using routine surveillance and process indicators Community samples to estimate coverage and infer impact	Policy impact studies

Disadvantages are: they may be biased subsets of IDUs (by intensity of drug use, range of problems, length of drug use, geographical location, criminality, gender, sexuality and/or socio-economic status), and responses may be biased and cooperation may be perceived as coerced.

Recruitment methods for community sampling include cold-approaches such as street-based contact making, using 'indigenous' or 'privileged access' interviewers (e.g. current IDUs, people with access to IDUs), and social network recruitment (Broadhead et al., 1998; Heckathorn, 1997; Heckathorn, Semaan, Broadhead, & Hughes, 2001). Site mapping can identify recruitment locations. Community recruitment has been shown to be feasible in developing, developed and transitional countries (Eicher, Crofts, Benjamin, Deutschmann, & Rodger, 2000; Panda et al., 1998). Advantages of community recruitment are: access to IDUs whose risk behaviour, characteristics and HIV status may be different to those in agencies; possibly less bias because subjects are interviewed in their own settings and not subject to fear or favour of an agency; possibility of 'added value' by collecting information on drug use venues and observations of behaviour; and collection of multipliers for prevalence estimation and reported coverage. The disadvantages of community-based recruiting are: accessibility; absence of sampling lists; sampling methods may be unclear; the characteristics of the population are not known; sampling sites may be biased (e.g. may recruit the more 'visible' IDUs in the community); and the possibility that respondents, who have similar characteristics, i.e. homophiles, will be recruited.

One problem is that IDU social networks from which IDUs are recruited may also be HIV transmission networks, and this can bias overall results and associations. Some control over potential bias may be attempted by using multiple contact points and quotas to control for location and social network effects. Some randomness may be introduced into sampling when there is a choice of subjects. *Homophilic* effects are minimised by increasing the length of recruitment chains (Heckathorn et al., 2001). Repeat studies using the same recruitment methods tend to produce similar samples, indicating some reproducibility using the method (Rodés & Pérez, 2000; Stimson et al., 1996). The WHO study of Drug Injecting and HIV infection (Stimson, Des Jarlais, & Ball, 1998) sampled from both community and treatment agency settings in order to reduce the bias that might result from recruiting in one setting only.

Objective 1: Assess level of HIV infection associated with IDU

A fundamental question is 'How much HIV infection is related to IDU?' (Table 1). Therefore, a basic assessment priority is to assess the level of HIV infection associated with IDU (Table 2).HIV testing should be done in the community as well as in agency settings because risk behaviours and prevalence of HIV infection may differ in different IDU populations (e.g. younger IDUs, people not in contact with services or people in prison). HIV testing of community recruited IDUs has been successfully carried out in, inter alia, central and eastern Europe, Africa (Adelekan, 2000), South America (Mesquita, 2000), North America (Des Jarlais et al., 1994), China (Wu, 1998), South and South East Asia (Hien, 2000; Samson & Francis, 2000), Russia (Rhodes, Fitch, & Stimson, 2002; Rhodes, Lowndes, et al., 2002) and Western Europe. Many community studies use oral fluid samples for HIV testing which is less invasive than a blood sample.

Surveying IDU populations directly is essential for properly measuring the prevalence of HIV and should be the cornerstone of IDU-HIV surveillance. IDUs may be specifically recruited for sentinel surveillance. The Australian Needle and Syringe Program Survey is a simple low cost routine surveillance monitoring programme that collects information on IDUs from Australian NSPs. This survey has been carried out annually, over one week, since 1995 using a brief self-administered questionnaire and finger prick blood sample to be tested for HIV, HCV and HBV (MacDonald and Robotin 2001).

Fig. 1. Ongoing surveillance of IDUs: the Australian Needle and Syringe Program Survey.

Single measures of HIV prevalence are insufficient because policy-makers need to know about trends (is the problem getting worse – or likely to get worse? has it improved since interventions were introduced?). Repeat surveys using similar recruitment methods enable description of time trends in risk behaviour and HIV prevalence (Fig. 1). In Barcelona, Spain, the WHO Multi City survey has been conducted with community recruited IDUs in 1993, 1996 and 1999 allowing cross-sectional time trend data on drugs consumed, risk behaviour and HIV infection (Rodés & Pérez, 2000). Other time trend examples include New York (Des Jarlais et al., 2000), Amsterdam (Van Ameijden & Coutinho, 1998) and London (Stimson et al., 1996). The interpretation of serial prevalence studies is discussed in detail by Ades (1995).

HIV surveillance systems assist in targeting prevention activities, planning responses and monitoring the national response (Walker et al., 2001). In 1988, WHO proposed the introduction of sentinel surveillance to monitor the extent of and trends in HIV epidemics. Most surveillance programmes measure the incidence of HIV/AIDS through the collation of clinical and laboratory reports of people who have AIDS or have undergone an HIV test, and AIDS-related deaths. Surveillance of IDU populations should be part of national surveillance systems and include exposure category.

HIV prevalence data should be interpreted cautiously taking into account changes in the IDU population. It is reasonably safe to infer HIV trends from prevalence data using repeat cross-sectional sampling in relatively stable IDU populations and when prevalence is rapidly rising. Ideally, HIV/AIDS policy-makers need data about HIV incidence – the number of new cases that are occurring over time.

Normally, HIV incidence studies only form part of enhanced surveillance. For example, the information can be

obtained from cohort studies (time-consuming and expensive but which give high quality information) where a sample of IDUs, who are not HIV-positive, is followed overtime to measure how many people become HIV infected (Des Jarlais et al., 2003; Van Ameijden, Van den Hoek, Mientjes, & Coutinho, 1993).

Alternatively, statistical models can be used to estimate incidence. Epidemiologists have developed a technique of fitting incidence to cross-sectional data (by age and ideally over time), which are used to estimate incidence from information on antibody status for HIV from antenatal seroprevalence data. In theory incidence estimates could be fitted to IDU data on prevalence by years of injecting, but there are few examples to date. Incidence could also be estimated by using "detuned" assays (which test samples with a sensitive assay that can identify infection within days or weeks and a less sensitive assay that can only identify infection months later) to estimate the number of sero-converters and thereby estimate incidence. This method has been used in many different populations, including drug users (Turchi et al., 2002).

Prevalence of other health problems in addition to HIV

IDUs are at risk of other health problems, including hepatitis B and C, overdose, endocarditis, septicaemia, abscesses and bacterial infections, drug dependence, neonatal withdrawal and violence. Drug related morbidity and mortality vary because of differences in drug taking, risk behaviour, the risk environment, including the legal and policy environment and the availability of treatment. It is important to monitor these in their own right, as well HBV, HCV and overdose as these are also surrogate markers for IDU. Sexual behaviour is also important. In Eastern Europe, for example, there have been major increases in STI transmission notably syphilis, which increased 60-fold in many parts of the former Soviet Union (Tichonova et al., 1997). At the same time, there are major epidemics among IDUs of HIV and evidence of high levels of STIs. Modelling is being used to estimate the contribution of IDU to HIV epidemics in the non-IDU population (Grassly et al., 2003; Saidel et al., 2003).

Objective 2: Describe the IDU population

In order to develop and target interventions policy-makers and planners need to know about the characteristics of IDUs, their risk behaviours and where they may be found (Table 1). Describing the IDU population is a priority for basic assessment and routine surveillance (Table 2).

Characteristics of IDU populations

Characteristics of IDUs vary between and within countries with implications for the associated risks, how IDUs can be contacted, the types of interventions that are needed, IDUs potential access to interventions and amenability to interventions. Factors to be considered include ethnicity (e.g. Estrada, 1998), gender, sexual orientation, age, drugs injected (e.g. heroin or cocaine) (Dunn & Laranjeira, 2000), other drugs used, socio-economic status, literacy, history of imprisonment, contact with services, and relative deprivation or advantage. IDU populations change over time, so one off cross-sectional studies need to be supplemented by historical and epidemiological trend analyses (see below). For example, Asian countries adjacent to the Golden Triangle have witnessed an evolution in drug use from traditional opium smoking to heroin eating, smoking, and finally heroin injecting (McCoy et al., 2001). Information about IDUs can be collected from the agencies and the community by means of quantitative surveys and qualitative investigation.

HIV risk behaviours

Risk behaviours such as sharing of injecting equipment and drugs as well as sexual behaviour, which place a person at risk of HIV infection, are influenced by individual predispositions, community norms, and social, economic and political contexts (Rhodes, Fitch, et al., 2002; Rhodes, Lowndes, et al., 2002; Stimson, 1990). Basic assessment usually utilises surveys in agencies and the community and qualitative methods and rapid assessments in the community (Fig. 2). Routine surveillance allows for collection of behavioural data from questionnaires and reporting systems in agencies, and more in-depth ethnographic studies (Table 2).

HIV risk behaviours can be measured using short questionnaires in routine surveillance (e.g. Jenkins et al., 2001; MacDonald, Robotin, & Topp, 2001; Valenciano, Emmanuelli, & Lert, 2001) and more detailed questioning in agency (e.g. Li, 2000) and community settings (e.g. Wu et al., 1997). The World Health Organization Multi-City Study of drug injecting and HIV infection (Stimson, Jones, Chalmers, & Sullivan, 1998) provides questions on sexual and drug using risk behaviours and has been translated into Chinese, Farsi, Malay, Portuguese, Russian, Spanish, Thai, and Vietnamese. Quantitative surveys are an efficient means for collecting standardised information on a large number of people. Repeat surveys of risk behaviour (often including HIV testing) have shown reductions in risk over time, e.g. cross sectional studies in New York (e.g. Des Jarlais et al., 2000) and Glasgow (Taylor, Goldberg, Hutchinson, Cameron, & Fox, 2001) and follow-up of cohorts in Amsterdam (e.g. Van Ameijden, Langendam, Notenboom, & Coutinho, 1999).

Some policy-makers believe that IDUs do not tell the truth in surveys. However, the evidence is that drug users are sufficiently reliable and able to provide descriptions of drug use, drug-related problems, their history of drug use, criminality and HIV-risk behaviours (Darke, 1998). There is a high correlation between self-reports of syringe sharing and DNA analysis of the contents of used syringes, and between self-report of HIV status and antibody tests carried out on used syringes (Menoyo et al., 1998). An Australian study found that IDUs were motivated to participate in studies because of

Rapid Assessment and Response (RAR) projects are typically undertaken where information has to be generated quickly and to initiate or guide action. Commentators have described RARs as attempts to "blur the conventional separation between research and intervention", where the "process of assessment [is] the beginning of the response itself" (Greig and Kershnar 2000). In the field of substance use, RAR was systematised in a number of guides appearing from 1998 onwards (Stimson et al 1998b; Rhodes et al 2002; United Nations International Drug Control Programme 1999) It is an assessment tool suited to situations where little is known, where there are inadequate resources, political will or capacity for full-scale research or public health investigations. The approach is characterised by the use of multiple methods including the analysis of existing data, interviews with key-informants, focus groups, observations, mapping of target populations and estimation of the population size, and the use of multiple data sources. RAR typically involves profiling the study area and the context, and then assessing the populations who are at risk of IDU, their drug use and health risk behaviour, assessing health, social and other structural issues such as legal and policy environments, and what current interventions are available.

Critical to the diffusion of RAR was the development of informal networks of supportive practitioners, trainers, agencies and organisations. For example, in 1998, with the support of the Russian Ministry of Health, Médecins Sans Frontières-Holland (MSF-H) established a programme of training, assessment and intervention development which aimed to prevent the rapid spread of HIV among IDUs. RAR was a central component of this programme (Burrows et al 1999). From 1988 to 2000 MSF-H trained over 200 health professionals and NGO workers in Russia. As part of this 65 RARs were conducted using the WHO Rapid Assessment and Response Guide on Injecting Drug Use (Stimson et al 1988), leading to the formation of more than 30 harm reduction programmes (Frost 2000, Burrows et al 2000).

A retrospective evaluation of RAR (Fitch and Stimson 2003) found that at least 83 rapid assessment studies had been conducted between 1983 and 2001. Nearly 7 out of 10 of these rapid assessments were conducted between 1998 and 2001. RAR has been undertaken in at least 322 different sites in at least 70 countries; the majority of these were conducted in less economically developed countries or in countries - such as the Russian Federation - experiencing immense political transition and social change (e.g. Fazey 2000; Sarkar 2000; Burrows et al 2000; Donoghoe 2001; Stimson et al 1998a; Howard et al 1998; Rhodes et al 2002).

A RAR results in an action plan with recommendations for new or modified interventions (Fitch and Stimson 2003; Fitch et al 2004). It has also been shown to lead to interventions. In a prospective evaluation of RAR in 10 cities substantial gains in knowledge and response capacity were reported in all sites (Stimson et al forthcoming). Before the assessment commenced, prevention and intervention programmes were absent or inadequate in most sites. The RARs resulted in many new or modified interventions: seven sites reported 24 health-related interventions that were subsequently developed and which were influenced by the RAR. With relatively little external funding, RAR appears to be effective in linking assessment and the development of appropriate interventions. RAR is itself part of the intervention process.

Fig. 2. Basic assessment: rapid assessment and response (RAR) development.

economic gain, an expression of citizenship, altruism, personal satisfaction, drug user activism or as part of seeking information or assistance (Fry & Dwyer, 2001).

Behavioural sentinel surveillance

'First generation' surveillance systems focus on HIV prevalence trends, especially in the general population. 'Second generation' surveillance systems (WHO and UNAIDS, 2000) include data on behaviour and focus on population sectors where most new infections are likely to be concentrated. Family Health International's Behavioural Surveillance Surveys (BSS) are designed to track trends in HIV knowledge, attitudes and risk behaviours to inform HIV/AIDS prevention programmes (Family Health International, in press). BSS uses a set of quantitative indicators, which focus on behaviours that are determinants of HIV transmission (i.e. condom use, multiple partners and needle sharing). In IDU populations BSS should become part of routine surveillance (Table 2), as a by-product of surveys to establish HIV prevalence. BSS among IDUs can monitor changes in behaviours over time, which can provide some basis for making inferences about the effects of public health interventions, when used with other serological and qualitative data. For an example, see Fig. 3.

Since the first recorded HIV infection in 1987, Bangladesh has been considered a low prevalence country. Debates about the future course of the epidemic required data for decision making. In 1998, the Government, supported by UNAIDS and with technical advice from FHI, undertook expanded surveillance. This included screening for HIV and syphilis, and assessing risk behaviours among selected groups with high risk behaviour. The BSS data was used by the National AIDS Program and donors to advocate for increased investment in prevention as well as to measure the effect of interventions. In 2000, the BSS of IDUs in North-western Bangladesh showed that those who received some clean needles from an NGO programme were less likely to share needles than other IDUs.

Govt. of the People's Republic of Bangladesh, undated; Govt. of the People?s Republic Of Bangladesh, 2000

Fig. 3. Behavioural sentinel surveillance (BSS) and government decision-making in Bangladesh.

Qualitative research on risk

Quantitative surveys can miss some of the specific details of IDU risk behaviours, the meanings that IDUs give to their behaviour and how the social, legal and policy contexts influence risk behaviour. Qualitative research by contrast involves the description and interpretation of risk behaviours, social meanings and their context. Methods include observation, focus groups, in-depth interviews and, less commonly, biographies, diaries or analysis of written and visual media.

Qualitative research has shown that the meanings and practices of needle and syringe sharing depend on, for example: the influence of perceived social or network norms and expectations (Rhodes and Quirk, 1996; Wiebel, 1996) interpersonal and social relationships, the physical and social settings in which drug use occurs (Ouellet, Jimenez, & Johnson, 1991; Turnbull, Power, & Stimson, 1996; Wiebel, 1996); and wider structural, economic and policy factors (Bourgois, Lettiere, & Quesada, 1997; Grund, Stern, Kaplan, Adriaans, & Drucker, 1992). For example, the sharing of drug

Qualitative studies have highlighted the diversity and complexity of injecting equipment sharing practices i.e. in Rotterdam, Denver and El Paso (Grund et al, 1992; Koester 1994). In many cases, IDUs were found to be unwittingly engaging in HIV-related risk behaviours through "syringe-mediated drug sharing". Based on observations of how IDUs go about mixing, dividing, distributing, and injecting drug solutions; Koester and Hoffer identified nine distinct types of injecting equipment sharing, which included the shared use of rinse water, cookers, mixers, and cotton filters, as well as ?front-loading? and ?back-loading?, in addition to direct sharing of a previously used needle or syringe. They termed these practices "indirect sharing" to distinguish them from the "direct use of a single syringe by two or more IDUs and to suggest their more masked character". These insights informed quantitative research and raised awareness among policy-makers of how viral transmission might occur.

Fig. 4. Links between qualitative and quantitative research on risk behaviour.

solutions and injecting equipment is not only pragmatic or economic but also influenced by shared rules and norms in drug user relationships. Principal among these can be the communication or display of reciprocity and trust within social relationships.

The sharing of drug solutions and injecting equipment have social meanings for IDUs, highlighting that there are multiple meanings of 'sharing' that complement epidemiological measures of 'sharing' (Fig. 4). Semi-structured interviews have found multiple interpretations of sharing, with some IDUs understanding sharing only to mean the use of another's syringe during the same injecting episode. Qualitative work on injecting in prison has also noted that re-using equipment from a different injecting occasion was viewed as "just using old works" – rather than 'sharing' (Turnbull et al., 1996).

Qualitative research helps to target interventions in cognisance of local drug use norms and practices, and show how different social, economic and other structural factors influence drug users' capacity for initiating and sustaining behaviour change. Furthermore, an understanding of the social processes shaping everyday drug use is a prerequisite for developing interventions which are meaningful and useful. Research highlights the pragmatic contribution of qualitative research to intervention and policy development, particularly with regard to the design and evaluation of community-based initiatives. Qualitative research is a means of 'action-oriented' research and intervention development (Stimson et al., 1999) and has a role in basic assessment. Routine surveillance involves more in-depth qualitative research, undertaken on a periodic basis among the clients of agencies but especially in the community as a necessary complement to quantitative agency data.

Mapping the location of IDUs

Where IDUs are to be found is important for intervention planning. At a local level, micro mapping is used in ethnographic and rapid assessment studies to examine the interaction between risk behaviour and the local context to help identify intervention sites (Stimson, Fitch, & Rhodes, 1998) and is an important component of basic assessment and routine surveillance.

Geo-spatial mapping of IDU is in its infancy and only suitable for enhanced surveillance (Frischer & Heatlie, 2001; Table 2). In Brazil, Barcellos and Bastos (1996) showed that HIV transmission among IDUs was roughly coincident with the major cocaine trafficking routes. The western region of Sao Paulo (the richest and most industrialised Brazilian state, free of malaria for decades) functioned as a cross-road for IDUs moving between two regions subjected to malaria, generating a syringe-borne outbreak of malaria in a network of IDUs, many of whom were HIV-positive (Bastos, Barcellos, Lowndes, & Friedman, 1999).

A simpler analysis in South East Asia combined knowledge of drug trafficking and migration routes with key epidemic dates to reconstruct the spread of HIV in the region (Stimson, 1994). This was later confirmed by the geographical distribution of molecular epidemiology of HIV sub-types (Beyrer et al., 2000). Mapping can be used to predict areas vulnerable to IDU and HIV within countries and across borders.

Objective 3: Estimate the numbers of IDUs

Estimating the number of IDUs (prevalence) can assist in calculating the level of resources required and in measuring the coverage and impact of interventions. As populations cannot be counted directly, various "indirect" methods have been developed for estimating the size of IDU populations (Hickman et al., 2003).

Simple enumeration (e.g. counts of IDUs in agencies) and estimates from key informants can provide some rough information for basic assessment, and the implementation of routine surveillance (Table 2) can improve case-counting from agency reporting systems.

Routine data, though partial as they miss people in the target population who are not in contact with agencies, are essential for two purposes. First, they are the data sources or raw material for indirect methods of estimating prevalence. Second, these data sources are needed to estimate coverage, i.e. for establishing the number of IDUs in contact with specific services, and then dividing this by the estimate of IDU prevalence to estimate the proportion of IDUs in contact with services. There are a number of guidelines and discussion papers on prevalence estimation (see EMCDDA, 1997, 2000a, 2000b; Hser, Anglin, Wickens, Brecht, & Homer, 1992; Taylor & Hickman, 2002).

Indirect estimation methods start from information about drug users from partial and limited sets of data and – under different assumptions depending on the method – estimate the proportion of the total population observed in the data sets to arrive at an estimate of the total population. Estimation methods require good basic data, and cannot be done routinely unless ongoing reporting systems are in place (Table 3). An assessment of the availability of data sources and potential

Table 3
Data sets from routine surveillance that can be utilised in enhanced assessment for population estimates and modelling

Data source	Example – IDUs . . .
Specialist drug treatment	. . . in methadone treatment, attending treatment agencies, or in residential care
Low threshold drug agencies	. . . attending drop-in sites or contacted by outreach workers
Needle exchange	. . . at needle syringe programmes (NSPs)
Accident and emergency	. . . attending because of an overdose
Laboratory	. . . tested for HIV, HCV or HBV
Police/prison	. . . arrested or imprisoned for drug offences or number of IDU arrested for any/other crimes
Probation/court assessments	. . . number of IDU in court or on probation
Social services – assessments	. . . assessed by local social services
Hostels for drug users	. . . living in hostels
Addict registers	. . . reported to a central register
Surveys of drug users	. . . in community surveys
Death statistics	. . . opioid overdose deaths

for prevalence estimation should be part of a RAR if carried out. Two basic types of indirect methods are multiplier and capture–recapture.

Multiplier methods require the total number of IDU recorded by the data source and an estimate of the proportion of IDU in contact with the data source. Capture–recapture methods require preferably three or more data sources to identify the number of IDU on one, two or all three data sources.

Multiplier methods can be used with a variety of data sources, and need (a) benchmark data on IDUs that have experienced an event – such as the number of IDUs in treatment, who have been arrested or have died from an overdose; and (b) an estimate of the proportion of IDUs that have experienced that event – such as the proportion in treatment or arrested or the overdose mortality rate (see Table 3). The inverse of this amount is the multiplier. The two are multiplied to get the prevalence estimate. It is simple enough to be used in basic assessment (if the data are already available) and routine assessment, which involves a community-recruited survey. Fig. 5 shows an example using information on the number of HIV tests by IDUs and an estimate of the proportion of IDUs that have been tested in the same year.

In addition to sources of information such as overdose mortality, treatment, and arrest; if a survey of IDUs is conducted in the community, questions can be added to obtain a range of multiplier estimates. However, multiplier methods assume that benchmark data are accurately recorded and, crucially, that the multiplier is representative of the population of IDUs under investigation. The first can be difficult to achieve, while the second is both difficult to achieve and impossible to test. Therefore, it is best to use several multipliers and other methods such as capture–recapture.

Capture–recapture methods have been used extensively in epidemiology (Hook & Regal, 1995; International Working Group for Disease Monitoring and Forecasting, 1995).

Multiplier estimate of IDUs from HIV tests in Toronto (Archibald et al 2001)

Benchmark (B): the number of HIV tests where IDU was the exposure category. Source: laboratory reports for 1996. Total = 4050

Multiplier (M): this was derived from the proportion of IDUs tested for HIV in the same year - from a community survey of IDUs asking how many had been tested for HIV = 23% The multiplier (M) is the inverse of this proportion (M = 1/0.23 = 4.35).

Prevalence estimate: B * 100/M = 17,609

Capture-recapture to estimate IDUs in Bangkok

In Bangkok, in 1991, Mastro and colleagues (1994) collected two samples: 4064 heroin users in methadone treatment and 1540 people, who had been arrested and tested positive for opioid after urine testing. There were 171 people on both lists giving an estimate of 36,600 opioid users (0.5% of total population) in Bangkok, in 1991.

Fig. 5. Multiplier and capture–recapture – two examples.

They require information collected on IDUs from two or more sources. The number of matches – i.e. the number of people that occur in more than one data source – is identified. The proportion of matches is the indirect estimate of the "sampling intensity" or the proportion of the total population observed by the study. For instance, with two data sources n1 and n2, there will be m matches of people on both and a total population to be estimated (N). The method assumes that n1/N (the proportion of the total population observed in a data source 1 is equivalent to m/n2 (the proportion of people in data source 2 that are also on data source 1. Thus, N will equal n2 × n1/m. Fig. 2 gives an example of a two sample study.

Two sample studies assume that samples are independent of each other, which is un-testable and probably not justifiable in many instances. For example, if people on methadone maintenance treatment (MMT) were more likely to be arrested then the calculation would underestimate the true prevalence, and if people on MMT were less likely to be arrested then the calculation would over-estimate the true prevalence. Studies with three or more data sources use log–linear models to estimate prevalence and the "unobserved" number of IDUs. The advantage of log–linear models is that they can model "dependencies" and adjust the estimates accordingly. As more data sources need to be collected, the statistical complexity increases but these techniques can be easily taught and should become part of routine surveillance. The critical issue is to identify three or more data sources that collect information on IDUs. Once a prevalence estimate has been made, consideration can be given to how the data sources can be organised in order to allow regular prevalence estimates in future. Examples of studies can be found in the general texts in the references and increasingly multiple data source capture–recapture studies are being carried out in developing and transitional countries.

There are other techniques or advances that could be utilised as part of an enhanced surveillance programme given the statistical expertise and/or available data sets. For

example, a range of indicators of drug use and a number of local prevalence estimates can be combined to generate synthetically a national estimate (Frischer, Hickman, Kraus, Mariani, & Wiessing, 2001). Such a method is only possible once the prevalence of drug use has been estimated in a number of sites, but could become part of a rolling programme of prevalence estimation within an enhanced surveillance system that collects a wide range of indicators. Capture–recapture with covariates enhances the efficiency of traditional capture–recapture methodology by including age, sex, and other factors within the model rather than demanding separate model estimates (Tilling, & Sterne, 1999), and has recently been employed in England and Togliatti, Russian Federation. Finally, back-calculation models have recently been used to estimate long-term trends in the incidence and prevalence of opiate use based on trends of opioid overdose deaths in Australia and England (Law, Lynskey, Ross, & Hall, 2001).

Objective 4: Predict epidemic trends and scenarios

Intervention need, appropriateness and feasibility can be demonstrated using the assessment techniques described above. This is not enough for many HIV/AIDS policy-makers and planners: they want to judge the likely impact and cost effectiveness of interventions when deciding on the allocation of resources (Table 1). Such judgements may be made using assessments from basic or routine surveillance data, together with (a) knowledge of the course of epidemics elsewhere, and (b) knowledge about the effectives of different interventions.

Decision-making could be improved by using statistically derived models of the current and future course of an epidemic so as to understand what is driving the epidemic and to estimate epidemic trends under different scenarios.

Methods include: (a) direct models, which simply extrapolate from existing data series into the future; (b) back calculations, which use current cases (e.g. AIDS or opioid overdose deaths) and known time lags (e.g. from HIV infection to AIDS, probability of an overdose) to calculate the likely underlying trend (e.g. HIV infection or IDU prevalence) (Brookmeyer & Gail, 1994; Law et al., 2001); (c) transmission dynamic models, which use a series of parameters such as the size of IDU populations, recruitment to and exit from injecting, rate of needle and syringe sharing, number of sexual partners and HIV transmission probabilities to model the epidemic and likely change following an intervention.

Models require data from routine surveillance, in particular information on current HIV prevalence, injecting risk behaviour and the size of the population. However, such data may not always be collected in a way that can be used by modellers so better liaison is needed to improve data collection for input to models. For example, modelling the spread of HIV from IDU into the general population requires data on the sexual behaviour of IDUs and the general population as well as data on the size of the IDU sex worker population.

Various models have been developed that estimate the impact of NSPs on IDU behaviour and epidemic course (Kaplan, 1989; Vickerman & Watts, 2002). It has been estimated that the NSP in Svetlogorsk, Belarus, averted 414 HIV infections between 1998 and 2000, and caused a 6.5% decrease in IDU HIV prevalence compared to if there had been no intervention. The model also estimated the detrimental impact of a funding gap in 1998–1999 (Vickerman & Watts, 2002).

Modelling is still in its infancy and is not feasible except with enhanced surveillance. Modellers are beginning to make their tools more accessible: for example, *HIV tools* is a set of models and costing guidelines developed for UNAIDS that can be used to estimate the cost-effectiveness of HIV prevention packages (www.unaids.org). Using models does not require high-level statistical competence but the data inputs can be complex. Costing guidelines for HIV/AIDS prevention strategies for IDUs have been developed (Kumaranayake et al., 2000).

Models help assess the likely impact of interventions, for example, 'if we doubled drug treatment, what would be the impact on the HIV epidemic in IDUs?' Models are not reality. Given the assumptions about data parameters and interactions, such models are best viewed as aids for decision-makers rather than real predictions. Given the epidemiological complexity of HIV epidemics, models are simply a set of assumptions about what is driving the epidemic as well as tools for exploring their consequences (Garnett, 1998; Kaplan, 1989; Kaplan & Heimer, 1992; Vickerman & Watts, 2002).

Objective 5: Evaluate specific interventions and region or country wide programmes

Policy-makers and planners want to know the impact on the HIV epidemic of the interventions that they have funded (Table 1). Evaluations answer common questions about interventions such as: their coverage, whether they have worked as intended, effectiveness, cost, and unintended or negative effects (Rossi & Freeman, 1993). Evaluations and subsequent adjustment to programmes can help maximise the effectiveness of interventions; assist in advocacy; justify them to communities, governments and the public; improve accountability; and identify both their positive and negative effects. Evaluation uses the same methods of assessment outlined in this paper, to answer questions about outputs, outcomes and impact.

Outputs are the deliverables of an intervention (for examples, number of media slots where HIV and IDU are mentioned, the number of people treated with drug substitution maintenance therapy or the number of needles and syringes distributed). *Outcomes* are changes that occur in the target population (e.g. in risk behaviour as a result of receiving

needles and syringes, in drug injecting as a result of drug substitution maintenance treatment or reduction in HIV incidence).

A key question is 'Did the intervention cause the outcome?' Many evaluations report relationships between interventions and outcomes. It is harder to prove causality, i.e. whether the change(s) observed in the target population is/are a result of the intervention. *Impact* is the extent to which a programme causes the desired change in the target population over and above what would have occurred without the intervention. It can be difficult to assess due to varying degrees of plausibility and it is necessary to rule out confounding factors.

All interventions are in principle capable of being evaluated, e.g. a project that delivers services to clients (substitution treatment, NSPs); a mass media campaign aimed at a specific target population (HIV media campaign); a law (e.g. whether it is appropriately enforced, or has the intended impact); a government policy (e.g. is it understood by the target population, how it is implemented and what is its impact). The main requirements for effective assessment are clear aims and objectives, as well as indicators and appropriate methodologies. Unfortunately many interventions lack these.

There are different types of evaluation: (a) implementation evaluation (process evaluation or programme monitoring) assesses how the intervention is being implemented; (b) impact evaluation assesses the negative and positive impact of an intervention on the target population and other people; and (c) economic evaluation assesses whether an intervention is good value for money.

Evaluation as part of basic assessment uses existing data (such as how many people are in treatment facilities) and reports (e.g. project activities), project site inspections and inferences from knowledge of how such projects operate elsewhere as a benchmark comparison to make a judgment about the adequacy of the intervention. Evaluation using routine surveillance data indicates project activity and trends using key indicators (e.g. HIV prevalence among IDU, self-reported risk behaviours, the number of HIV tests and results, number of clients seen, number of methadone prescriptions written). Evaluation of enhanced surveillance involves specially designed outcome studies of various levels of sophistication and cost.

Evaluating how an intervention has been implemented requires data on the target group, how it is delivered and its immediate outputs. Many studies of IDU/HIV interventions have been observational studies that focus on implementation rather than impact. Basic assessment and routine surveillance usually do not go beyond evaluation of implementation.

HIV/IDU interventions are complex – delivering a wide range of activities (e.g. needle and syringes, condoms, counselling, referral to treatment, etc.) in unusual settings (e.g. outreach in the community) and using unconventional staff (e.g. indigenous and peer delivered interventions). It may be unclear to staff and evaluators what item of service or combination of item being delivered actually are having an effect (Booth & Koester, 1996). Describing the activities that are delivered is also important for assessing whether the programme is being delivered as intended.

Coverage is the extent to which the intervention reaches its target population. Common problems are poor and incorrect coverage. Key questions are: Who is reached? What proportion are they of the larger target population? Is there bias in the coverage of the project? Who is not reached (e.g. female IDUs)? Data are required on the number and characteristics of those reached (e.g. from project records or surveys) and estimates of the size and characteristics of the target population. (See for examples, Wiessing (2000) for estimates of coverage of harm reduction interventions in Europe, and Parsons et al. (2002) for an estimate of coverage of NSP distribution in United Kingdom.) An alternative is to survey suitable community recruited samples to assess how many IDUs have been reached.

There should be a clear description of activities which are undertaken and actually delivered. Common problems are interventions which were funded but were never established, interventions that were not fully implemented, interventions that deliver the wrong services and interventions with inconsistent service delivery. Key questions are: What are the actual methods used for contacting the target population (e.g. outreach, referral)? What are the organisational arrangements, project procedures and activities? What is provided (e.g. needles, syringe, condom, medication, counselling and health leaflets)? Is the product appropriate and acceptable to the target population? Data are required on staffing and training; intervention organisation, procedures and activities; measures of activity (e.g. hours worked, people contacted, frequency of contacts, materials); 'customers' views (and non-customers); quality of the intervention and the context in which the project operates.

Finally what resources (paid and unpaid) were used? Data required, include project budgets, staff numbers (administrators, project workers, volunteers, peer educators and outreach workers) and their costs including training, accommodation and other facilities (e.g. vehicles), materials purchased and used (such as leaflets, medications, needles, syringes and condoms), communications (telephone, postage) and transport/travel.

Impact assessments are made by comparing information on participants and non-participants or by comparing the same participants over time. Rigorous impact evaluation, i.e. ruling out confounding factors is complex and expensive and normally conducted as part of enhanced surveillance.

Economic evaluation assesses 'value for money', e.g. the cost, how economically efficient, how it compares with other interventions and benefits compared with costs. This can assist decision-makers in choosing between competing interventions. Cost effectiveness is the efficacy of an intervention in achieving its desired outcomes in relation to its cost (see Fig. 6). Cost benefit assesses all the benefits and costs of a project usually translated into monetary terms. Cost benefit analysis can be at different levels: to the individual – what

Kumaranayake estimated that for Svetlogorsk, Belarus the average costs per IDU HIV infection prevented was about $68. The costs of delivering needle exchange, outreach, and counselling for IDUs and a city wide media campaign were compared against HIV infections prevented (as estimated using a transmission dynamic model). (Kumaranayake et al 2000b)

A similar approach (using proxy cost data and modelling of infections averted) was used to assess the US National AIDS Demonstration Research Programme (Pinkerton et al 2000). This programme used community outreach provided by mostly ex-drug users to assist participants reduce their sexual and drug injecting-related risk behaviours in 28 sites in high drug use neighbourhoods (Coyle et al 1998; Stephens et al 1993). Results were expressed as cost savings (savings in medical care costs) and cost effectiveness (net costs per quality adjusted life years saved). Costs savings occurred if the project costs were less than $2107 per person, and the project would be cost effective if the costs were less than $10,264 per person. In fact, the estimated cost was $273 per person suggesting both high cost and effectiveness savings.

Fig. 6. Examples of cost-effectiveness studies.

benefit the individual obtains from the project and what they lose (e.g. direct payments, time off from work); to the sponsor – a government agency might invest in a work training programme for migrant youth, and the benefits to the government might be more people in employment, increases in tax revenue; or the whole community – this considers all costs and benefits to different groups.

International comparative evaluation

A more ambitious evaluation approach is to assess what factors make whole cities or countries differ in their HIV epidemic history. Underlying this question is why epidemics have developed differently and to understand the links between policy and interventions, risk behaviours and the course of an HIV epidemic. This has taken the form of single country case studies (e.g. Stimson, 1995); city case studies (e.g. Harvey et al., 1998; Schechter et al., 1999); and comparisons between countries with different levels of interventions (Des Jarlais et al., 1995).

The methodology of comparative studies is difficult and underdeveloped – for example, countries cannot be randomised to different interventions. Some progress has been made with developing internationally comparative 'core' indicators of drug use, e.g. the UN Global Assessment Programme on Drug Abuse (McKetin, 2000; UNDCP, 2001) and the European Monitoring Centre for Drugs and Drug Addiction (EMCDDA), which has developed key indicators for drug use and HIV for reporting national level drug use prevalence in the general population, young people and high risk populations as well as the extent of HIV and HCV infections. Another project by EMCDDA attempts to measure coverage of harm-reduction measures for IDUs in Europe (Wiessing, 2000).

However, in many developing and transitional countries, basic surveillance data are not available to provide comparative indicators. More difficult still is measuring the macro risk environment (i.e. the broader legal, social, cultural, economic and welfare environment) that makes populations vulnerable (Barnett, Whiteside, Khodakevich, Kruglov, & Steshenko, 2000) or in which IDU and HIV occur and responses are undertaken. There is an urgent need to do more comparative international research on different intervention approaches.

Conclusion

As a consequence of stereotypes concerning IDUs' behaviours and motivations, some policy-makers may be apprehensive about research into IDUs. Drug use is relatively hidden, drug users may be hard to find and there are no definitive lists from which to draw random samples. Such problems may lead policy-makers to consider abandoning the task of collecting good information. This pessimism is contradicted by the experience of researchers. As this paper shows, there is considerable evidence garnered over the past 20 years supporting a range of research methodologies for assessing drug use and evaluating interventions.

There is no single, simple, assessment and evaluation method applicable in all settings. Firstly, no single discipline, research method or data source exists that can provide a complete picture of IDU behaviours, HIV epidemics and intervention effectiveness. Second, countries are at different stages in awareness of and knowledge about IDUs and HIV/AIDS. This paper has described different methodologies in the context of a threefold schema of basic, routine and enhanced surveillance.

All three assessment levels require a mix of methods. For example: epidemiological and survey studies measure associations between exposure and outcome, whilst qualitative research can help identify the key exposures and sampling sites as well as assist in interpreting findings. Some methods depend on data collected from other data systems; for example, enhanced surveillance cannot be done without routine surveillance data. As a consequence, public health surveillance for any setting needs to consider the relevance of a variety of methods for a comprehensive assessment of drug use and risk behaviours, and the risk and intervention environments. Furthermore, because of the need for a mix of methods, and the interdependence of different methods and data sources, assessment and evaluation should not proceed in an ad hoc fashion but should be part of a strategic plan for an information system that supports national and local policy development and planning for HIV prevention, care and treatment.

There is still a gap between what researchers want to research and what is needed for policy and intervention development. Researchers need to be more aware of advocacy, policy and interventions; while policy-makers and planners need to learn more about research, assessment and evaluation. What is most needed is for researchers, policy-makers and planners to develop an assessment and evaluation mentality oriented towards intervention development.

International networks have played a key role in facilitating assessment capacity, the exchange of experience, the diffusion of assessment methods and competence, and in encouraging an assessment and evaluation mentality. An example of the role of rapid assessment and response (RAR) in building capacity and in leading to the development of interventions is given in Fig. 2. There are other examples of such international efforts. The WHO Multi-City Study of Drug Injecting led to a large number of publications in many countries, which have fed into policy and interventions (Stimson, Des Jarlais,et al., 1998). The Global Research Network on HIV Prevention in Drug-Using Populations (GRN) provided an infrastructure for HIV prevention researchers and others to exchange information on HIV/AIDS epidemiology and HIV prevention (GRN, 2000). The EMCDDA in the European Union has promoted assessment capacity through its work on pan-European indicators. The harm reduction networks established with the support of the International Harm Reduction Association have also facilitated intervention capacity and advocacy. Harm reduction networks now operate in Central and Eastern Europe (Honti, 2000), Africa, Asia, Latin America, North America and Oceania (Deaney, 2000). An example of how networks can facilitate rapid collection of data and its dissemination is the Hidden Epidemic report (Asian Harm Reduction Network, 1988) which gave an overview of IDU and HIV infection in South and South-East Asia. The exchange of experience internationally provides information, knowledge and builds capacity in assessment and evaluation in the ever widening circle of people responding to IDU HIV-related epidemics.

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