RAPID POLICY ASSESSMENT & RESPONSE

Module I: Project Planning & Community Action Boards

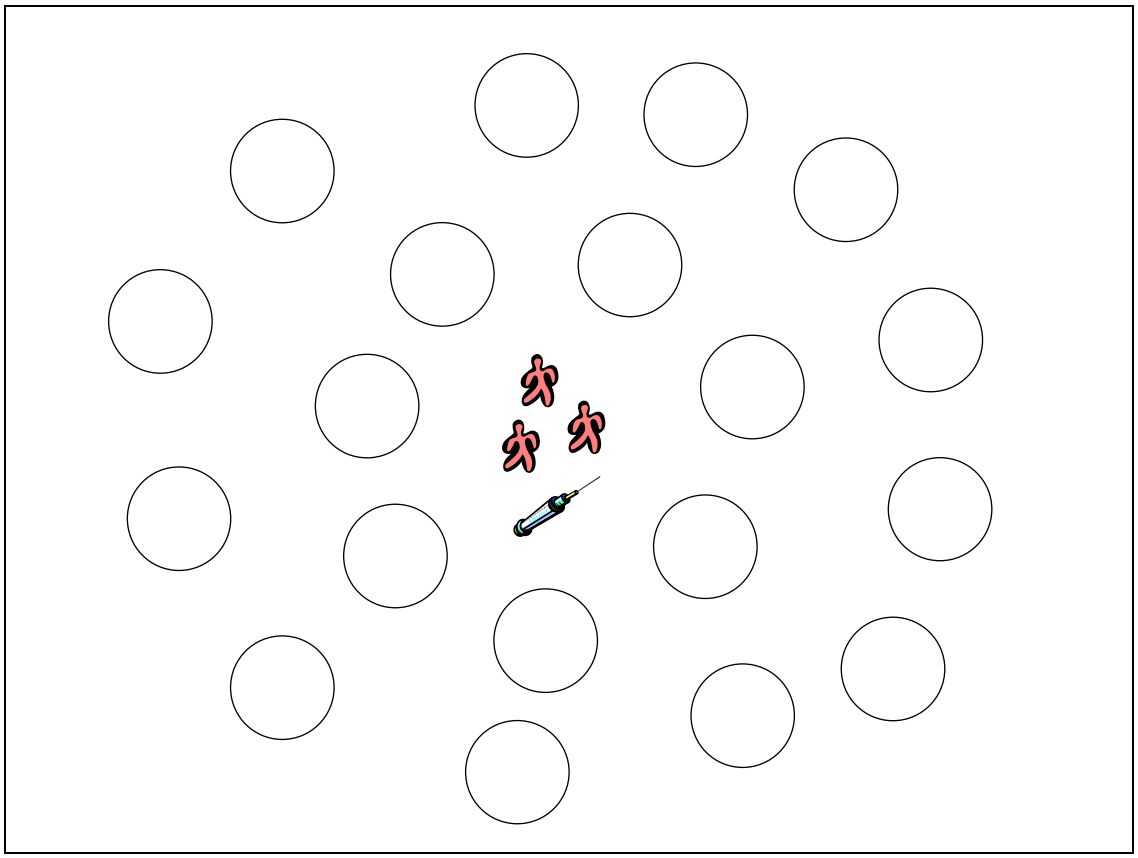
Tools

The Power Map

A power map is a picture showing the *formal and informal organizations* that wield influence over (or "govern") the conditions of the drug and sex markets and the behavior of drug users and sex workers.

Equipment Needed

PowerPoint or similar software and/or flip charts, pens and tape



A Blank Power Map

Step 1: Identify the organizations that matter

A. Identify organizations

Try to identify organizations. If important individuals come up, list their organizations for now.

B. Refine the list

a. Which of these organizations are really made up of some number of smaller units?

Sometimes a large organization, like the police, is actually made of many units that operate more or less on their own, like a homicide bureau or a particular police station.

b. Are there organizations that, after discussion/reflection, should be added or removed?

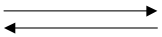
Participants can decide what criteria to use to decide whether an organization is not important enough to include at this point.

Step 2: Chart the "influence connections" among the organizations

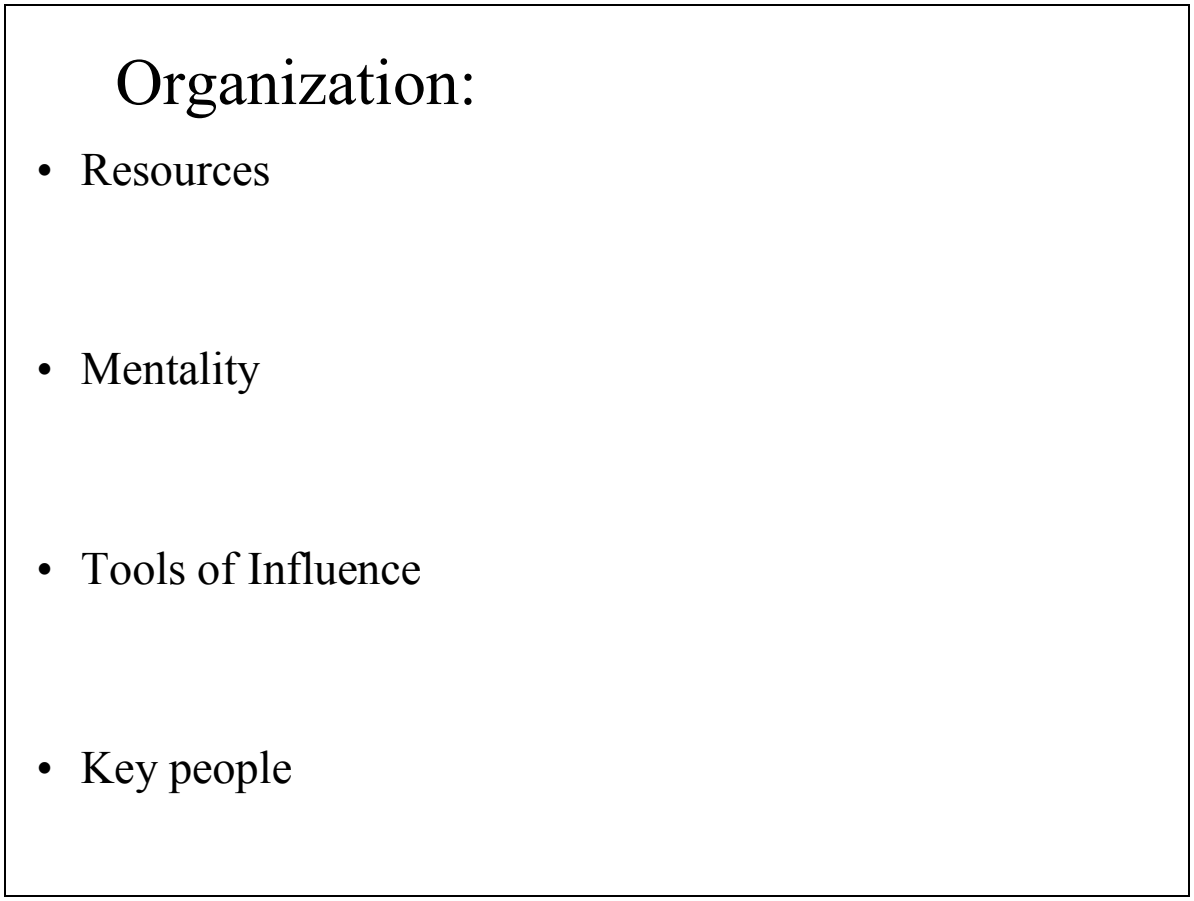
Which organizations influence which other ones?

Use arrow direction to indicate one way or two way influence
Use thickness of arrows to roughly indicate how powerful the influence is – large or slight

Strength and Direction of Influence

	More Influence	Less Influence
One way		
Two way		

Step 3: Write down what is known about the internal characteristics of each organization on a separate page/slide



Internal Characteristics Form

Step 4: On the main slide/map, identify important groups (e.g., IDUs) who do not have an organization they can exert influence through

> *People in the community sometimes try to get things changed. But people who don't have an ongoing organization to work through will tend to have less effectiveness than people who are working together in an organized group over time.*

Problems and Solutions Exercise

Along the with Power Map, the Problems and Solutions Exercise is a means for the CAB members to exchange ideas about what policy and practice changes are needed to address HIV and how to achieve them.

Equipment Needed

Problems and Solutions Form in Word software or a flip chart with pens and tape.

Process

Ask every member of the CAB to quickly identify one problem that may be increasing the risks of drug use, sex work and other behaviors addressed in the RPAR, and a possible solution related to policy or policy implementation. Write the ideas in Word or on a flip chart. Emphasize that

- this is a creative exercise, designed to get many ideas out on the table without judging how correct or important they are
- even speculation about possible problems is useful and welcome
- everyone must offer one idea that is different from the ones already offered
- there is no discussion of or comment on the problems and solutions offered
- you will not be recording who made what contribution

The exercise should take only a few minutes. The goal is to get everyone to offer an idea, to build a team environment in which everyone feels entitled to participate. This is NOT the time to discuss or comment on the ideas.

Problems and Solutions Exercise

Problems and Solutions Form

Meeting # _____

Problem	Solution

Community Action Board
Purpose and Process

A Community Action Board (CAB) is a group of people who have knowledge and interest in drug policy, health, local government and any other area the team thinks is important to the success of the RPAR project.

Purpose

The purpose of the (CAB) is to:

- Organize and mobilize allies the important stakeholders in the community
- Provide the research team with informational, social, moral and political support for the collection and analysis of policy data
- Collaborate with the research team to turn the data and analysis into an action plan
- Implement the action plan

Process

The CAB and the research team are collaborators on the RPAR project. The research team will meet with the CAB at least seven times. Each meeting is chaired by a member of the research team and has a specific agenda. In general, the research team uses each meeting to present data or information about the project to the CAB, and to learn more about the site and the priorities of the CAB. ***After each Meeting,*** the research team should organize the data collected from the CAB in the appropriate data organization form.

Community Action Board Meeting
#1

When: **As soon as possible after the beginning of the assessment**

The goal for the first meeting is to:

- Get CAB input on sources of existing epidemiological and legal data
- Revise the research team's first version of the power map
- Generate one suggestion per CAB member for policy or practice change in the Problems and Solutions Exercise

Agenda is included.

After the Meeting:

- Organize the data you collected in the attached Sources of Existing Data form
- Prepare a new version of the Power Map

Community Action Board Meeting
#1
Agenda

1 – Introduction of members of Community Action Board and Research Team

2 – Brief summary of the RPAR methodology including the plan, timeline, activities and role of the CAB

3 – Brief summary of epidemic and policy situation, as necessary

4 – Power Map Exercise

5 – Problems and Solutions Exercise

6 – Identify sources of existing legal, criminal justice and epidemiological data

7 – Review agenda and date for next meeting

8 – Conclude meeting

Existing Data Sources
CAB Meeting #1

Sources of Existing Data

Data Type	Source	Contact Person
Epidemiological Data		
HIV		
Drug Use		
Other Diseases		
Law on the Books		
Law Enforcement Data		

Add more rows or topics as needed.

Community Action Board Meeting
#2

When: **About the 12th week of existing data collection, when there are data to present but also in time to begin identifying key informants and focus group members**

The second meeting of the Community Action Board is intended to:

- Identify candidates for focus group and key informant interviews
- Review and discuss implications of existing data collection
- Revise the power map
- Generate one suggestion per CAB member for policy or practice change in the Problems and Solutions Exercise

See Agenda attached.

After the Meeting:

- Organize the data you collected in the Power Map, Focus Group Participants Candidate List and the System and Interactor Participants Candidate List
- Organize meeting notes

Community Action Board Meeting
#2

Agenda

1 – Presentation of existing data from Module II on law, epidemiology and law enforcement

2 – Revise power map

3 – Conduct Problems and Solutions Exercise

4 – Resolve any outstanding problems with existing data collection

5 – Identify potential focus group participants and key informants

We will need at least 6 people for a focus group of

1. *law enforcement personnel;*
2. *"risk interventionists"*
3. *drug treatment providers and clinical health care providers.*

6 – Review agenda and date for next meeting.

7 – Conclude meeting.

Suggested Focus Group Members
CAB Meeting #2

Focus Group Participants Candidate List			
Rationale	**Name**	**Organization**	**Contact Information**

Community Action Board Meeting #2

System and Interactor Participants Candidate List

Rationale	Name	Organization	Contact Information
Prison Officials (1)			
Prison Guards (2)			
Judges (1)			
Legal Academics (1)			
Political Authorities (1)			
Police Officers (2)			

Rationale	Name	Organization	Contact Information
Prosecutors (2)			
Public Health Authorities (2)			
Narcological Program Directors (2)			
Narcological Program Staff/Volunteers (2)			

Rationale	Name	Organization	Contact Information
Health Care Providers/AIDS Doctors (2)			
Emergency Room Clinicians (2)			
Harm Reduction Workers (2)			
NGO staff working with IDUs (2)			
NGO staff working with HIV (2)			

Community Action Board Meeting
#3

When: **About the 4th week of qualitative data collection, after the completion of focus groups and near the beginning of key informant interviews**

The third meeting of the Community Action Board is intended to:

- Gather community level input on preliminary results of the focus groups
- Update or modify potential list of key informants based on community level feedback
- Revise the power map
- Generate one suggestion per CAB member for policy or practice change in the Problems and Solutions Exercise

See attached agenda.

After the Meeting:

- Organize the data you collected in the System and Interactor Participants Candidate List and the Power Map
- Evaluate the CAB suggestion for RPAR and organize meeting notes

Community Action Board Meeting
#3
Agenda

1 – Report and discussion of results of focus groups

2 – Revise Power Map

3 – Conduct Problems and Solutions Exercise

4 – Update list of systems and interactor key informants and suggestions for alternates

5 – Presentation of overall progress and timelines according to plan

6 – Review agenda and date for next meeting

7 – Conclude meeting

Community Action Board Meeting
#4

When: **Near the end of qualitative data collection**

The fourth meeting of the Community Action Board is intended to:

- Gather input on data yielded from finished key informant interviews
- Inform remaining system and interactor key informant interviews based on advice and suggestions from community members
- Revise the Power Map
- Introduce Root Causes Exercise (Module IV) to analyze problems identified in Problems and Solutions Exercises in meetings 1-3

See attached agenda.

After the Meeting:

- Organize the data you collected in the System and Interactor Participants Candidate List, the Power Map and the appropriate forms of the Root Causes Exercise
- Evaluate the CAB suggestions and organize meeting notes

Community Action Board Meeting
#4
Agenda

1 - Summary and discussion of key informant data

2 – Revise Power Map

3 – Conduct Root Causes Exercise based on problems selected from earlier Problems and Solutions exercises

4 – Identify more system and interactor key informants as necessary

5 – Review agenda and date for next meeting

6 – Conclude meeting

Community Action Board Meeting
#5: Workshop

When: **About the 4th week of action planning and analysis, after the research team has made substantial progress organizing the data**

The fifth meeting of the Community Action Board is a half-day to full day workshop intended to:

- Conduct the Root Causes Exercise to analyze problems developed in RPAR data collection
- Identify solutions for risk reduction
- Conduct Priority-Setting Exercise

See attached agenda.

After the Meeting:

- Record results using the forms for the Root Causes and Priority-Setting Exercises
- Evaluate the CAB suggestion for RPAR and add new notes as needed for the RPAR.

Community Action Board Meeting
#5: Workshop
Agenda

This meeting, and meeting 6, are workshops, expected to require a half day to a full day of work.

1 – Present findings in rough draft

2 – Conduct Root Causes Exercise

3 – Identification of potential solutions (policy, practice interventions or reforms)

4 – Conduct Priority-Setting Exercise

5 – Review agenda and date for next meeting

6 – Conclude meeting

Community Action Board Meeting
#6: Workshop
Purpose and Intended Product

When: **About 2 weeks after CAB meeting 5**

The sixth meeting of the Community Action Board is a half-day to full day workshop intended to

- Conduct the Priority-Setting Exercise Again
- Compare the two sets of results and agree on priorities for action
- Conduct Power Map Action Exercise to develop strategies for action

After the Meeting:

- Organize the data you collected in the appropriate forms from Module IV.
- Integrate CAB ideas into the Final Report draft

Community Action Board Meeting
#6: Workshop
Agenda

1 – Repeat Priority-Setting Exercise

2 – Compare results with previous exercise

3 – Review and revise prioritized list of potential solutions

4 – Conduct Power Map Action Exercise

5 – Plan implementation using Analysis and Action Plan Form 3

6 – Review agenda and date for next meeting

7 – Conclude meeting

Community Action Board Meeting
#7

When: About 3 weeks after CAB meeting 6, near the conclusion of the RPAR

The seventh meeting of the Community Action board is intended to:

- Gather feedback on final report
- Allocate responsibility for disseminating and implementing the Action Plan and Final Report
- Plan future meetings of implementation group
- Conclude RPAR and describe evaluation activities

After the Meeting:

- Integrate CAB suggestions in final draft of Report and Action Plan

Community Action Board Meeting
#7
Agenda

Topic:

1 – Present and discuss final report

2 – Repeat and revise implementation roles and responsibilities plan (Form 3)

3 – Set date and time for next meeting of CAB or successor group with responsibility for implementation

4 – End of RPAR, explanation of evaluation

RAPID POLICY ASSESSMENT & RESPONSE

Module I: Project Planning

Training Materials

The Goals of Rapid Policy Assessment and Response (RPAR)

RPAR mobilizes local knowledge and capacity to fight HIV/AIDS among injection drug users (IDUs) in the site area. Some IDUs may be sex workers or gay men or members of other socially marginalized populations, and so sometimes policies relating to these groups will be included. The goal of RPAR is to identify ways in which policies and policy implementation increases or can reduce the risk of disease among IDUs, and to catalyze community action to bring about healthful change.

Acknowledgements

The Rapid Policy Assessment and Response model was originally designed with support from the International Harm Reduction Development Program of the Open Society Institute, and revised under grant number R01 DA17002-02 from the National Institutes of Health, U.S.A. The designers of the RPAR model were Scott Burris, Patricia Case, Zita Lazzarini and Joseph Welsh. The RPAR was strongly influenced by the Rapid Assessment and Response model designed by Gerry Stimson, Chris Fitch and Tim Rhodes at the Imperial College School of Medicine, London, for the World Health Organization. Portions of the training materials for the RPAR have been adapted from the RAR Technical Guide and the IDU-RAR technical guide.

Project Flowchart

When	What	Module
Before RPAR project begins	Initial Consultation	I
Week 0 (first day of training)	PI Meeting	I-V
	Local Team Training	
Week 1	Begin existing data collection modules	II
	Recruit CAB	I
Weeks 1 - 12	First CAB meeting	I
	Collect existing data	II
	Prepare team for qualitative data collection	III
	Second CAB meeting	I
Week 13	End existing data collection	II
Week 14	Begin qualitative data collection	III
Week 15-21	Conduct focus groups	III
	Third CAB meeting	I
	Conduct key informant interviews	III
Weeks 23-26	Begin Analysis and Action Plan	IV
	Fourth CAB meeting	I,IV
Week 25	Complete qualitative data collection	III
Week 27	CAB meeting 5 (Workshop)	I, IV
	Continue drafting report	
Week 29	CAB meeting 6 (Workshop)	I, IV
Week 32	CAB meeting 7	IV
Week 36	End RPAR	

Project Planning

The success of local rapid assessments can be defined by the extent to which they provide information of *practical relevance* for local interventions. It is necessary to conduct an Initial Consultation to make some initial judgments about the focus and parameters of the assessment.

The Initial Consultation is a brief consultation which takes place prior to the rapid assessment. It provides an immediate overview of the local situation based on existing experts' knowledge and experience in order to make initial judgments about how to plan the rapid assessment. The Initial Consultation will also assist sites in developing proposals for local rapid assessments using the methodology described in this guide.

Purpose

The purpose of preliminary planning is to determine whether the site city is suitable for a Rapid Policy Assessment and Response (RPAR) project, to acquaint the project leaders with the general situation in the site city, and to prepare for the development of funding proposals and research protocol for a local rapid assessment.

Guiding Principles of the Consultation

There are five principles which guide the Initial Consultation. These help to ensure that the Initial Consultation leads to rapid assessments that maintain their 'investigative' nature as well as their practical relevancy. The guiding principles of the Initial Consultation, which build on the principles of the WHO Rapid Assessment and Response (RAR) as a whole, are summarized below.

Principles of the Initial Consultation:

- existing knowledge of the situation varies by city, country and community
- there is a need to balance existing knowledge with new investigation
- the practical needs of rapid assessments vary by city, country and community
- community involvement is essential to the success of the project
- the Initial Consultation provides only initial judgements

The first principle is that the focus and outcomes of the Initial Consultation are dependent on the local situation, particularly with regards to the extent and nature of existing knowledge and expertise on health problems associated with injection drug use.

Existing knowledge about the local situation:

In a country with little existing knowledge about the local situation, initial judgments about the focus of a rapid assessment are likely to emphasize a broad approach which can provide a broad overview. In a country where there exists some knowledge about the local situation, initial judgments may emphasize the importance of including certain sub-populations of substance users given their known increased risk of adverse health consequences, such as HIV infection or STDs.

The second principle is that there is a need to balance existing knowledge with new investigation. Existing knowledge can provide *initial indicators* of what should be included in the assessment, but it is extremely important that *this does not exclude* other avenues of investigation. Participants in the Initial Consultation, including local research, intervention and policy experts, must be encouraged to use their existing knowledge creatively. The knowledge and experience of one expert may contradict or negate the knowledge and experience of another. The role of the rapid assessment is to follow up initial ideas in an investigative and inductive manner. It is as important to follow up areas of consensus as it is to follow up areas of disagreement between participants at the Initial Consultation.

The third principle is that the practical needs of rapid assessments will also vary by country, city or community context. Where there is existing knowledge about the prevalence and distribution of adverse health consequences associated with drug injection the assessment may give greater emphasis to populations of substance users known to be at greatest risk of HIV infection and other STDs. The success of local rapid assessments is dependent on the production of practical findings for populations at greatest risk of HIV and STDs and in greatest need of interventions and services.

Case study: focusing the rapid assessment on practical needs

The Initial Consultation identified existing key informant data which highlighted that cocaine injectors may be engaging in 'high risk' sexual behavior. Health workers from one of the city's health clinics indicated that there are increasing numbers of cocaine injectors who report themselves to be HIV-positive. It was decided that emphasis, at least initially, would be given to assessing the sexual behavior of cocaine injectors.

The fourth principle is that community involvement is essential to the success of any intervention. Inviting key persons and organizations in the community to participate in the initial consultation increases the sense of community ownership for any future intervention. Individuals knowledgeable about injection drug use, HIV, and marginalized populations in the community should actively be involved in decisions regarding the parameters of the rapid assessment and the applicability of rapid assessment findings in their community. Good community participation can also be sought at this stage through consultation with community groups. These groups should represent a good cross section of the community where the rapid assessment and intervention will occur.

The fifth principle is that the Initial Consultation only provides *initial* judgments. Its purpose is to provide a forum for immediate and preparatory discussion. The initial judgments made about the type of rapid assessment required should not constrain the actual course of investigation once the assessment has begun. It merely provides *pointers* to how to plan the assessment.

Key areas of assessment

There are a number of questions which can be used to direct the Initial Consultation towards identifying the focus and parameters of the assessment. These are summarized below.

Key questions to help plan the Initial Consultation:

1. What is the local situation with regards to adverse health consequences associated with injection drug use?
2. What are the potential sub-populations and samples which may be included in the rapid assessment?
3. What are the methodological and practical parameters of the rapid situation assessment?
4. What level of community participation is desirable and feasible?
5. What individuals and organizations participate in managing drug use and sex work in the city?
6. What individuals and organizations are wielding power in drug policy, criminal justice, and public health?
7. What policies have an important influence on HIV among IDUs and sex workers, and on the ability of government and NGOs to respond?

These questions, which are only a *guide*, should provide the discussion and data necessary for making initial judgments about the type of rapid assessment required and, where necessary, for developing funding proposals for local rapid assessments. In the Initial Consultation, these key questions may not actually be asked as direct questions to the participants. Instead, they may be used to guide the agenda and expected outcomes of a meeting.

The Initial Consultation also provides an occasion for the research team to identify key people. Key people include:

- *gate-keepers* (people who control activities; or who have access to information, people and sites; of whose permission is needed or whose support is beneficial);
- *funders* (people who have resources that can be used to fund projects, or who can act as intermediaries to those with resources);
- *sponsors* (people who can promote the project and act as advocates for it, and can act as intermediaries to people with resources, and as intermediaries to people who are the target of the intervention).

Key people and organizations in the community are those with some sense of ownership who will be likely to benefit from the results of the rapid assessment and intervention or those who exercise power over IDUs in the community or whose permission may be needed for the rapid assessment to proceed. This will include people in government and other positions of power at a *national, regional or city level*, people in the *community* where projects may be introduced, and people who may benefit from the intervention. Identifying key persons and organizations will enable the rapid assessment team to make informed decisions about who to involve in the Initial Consultation as well as who to involve in an advisory role throughout the period of the assessment and intervention development.

Potential Key Persons and Organizations

International organizations • UN Organizations • UN Theme Groups on HIV/AIDS and other UN interagency groups • International NGOs	**Government organizations** • Politicians and their advisors (national, regional and local) • Policy makers and implementers
Health care workers and organizations • health educators • drug treatment services • psychologists	**Welfare workers and organizations** • street outreach workers • social workers • crisis relief services
Community members and groups • community service organizations, e.g. Rotary Clubs • community advocacy groups • religious organizations • charitable organizations • business community, including industry and local companies • community leaders	**Law enforcement and human rights services** • police or military representatives • judges, prosecutors, and defense attorneys • local executive (mayor), legislators at the city, regional or national level • jail or prison personnel • legal aid services • drug users' organizations • harm reduction organizations
Media • newspapers • TV and radio representatives • associations of journalists	**Accommodation services** • crisis accommodation services • government housing services • boarding houses and hostels

Methods and data sources

The Initial Consultation is undertaken *before* the rapid situation assessment begins. The information generated should provide the rapid assessment team with enough data for preliminary judgments to be made about how to plan and conduct the

assessment. These data should be recorded so that they can be feed into the rapid assessment at a later point.

The Initial Consultation may be undertaken through an invited meeting or 'focus group' between the rapid assessment team, local experts and key informants in the fields of substance use, social research, law enforcement, public health and HIV/AIDS. Possible participants include representatives from: national or local Health Departments; health and community organizations; hospital and community health clinics; non-governmental organizations; social science and health research; youth affairs; law and criminal justice; media; education; political and policy organizations; and international agencies resident in the country or city.

As necessary or convenient, the Initial Consultation may be undertaken in the form of meetings with individual informants.

Example: format and agenda of an Initial Consultation

- introduction by the rapid assessment team on: rationale and background to the rapid assessment; and the objectives and expected outcome of the meeting
- pre-prepared short presentations (5-10 minutes) by selected invited participants on issues relevant to each of the key questions
- group 'brain-storm' and discussion following invited presentations
- facilitated group work (either single or multiple groups) focusing on: key issues emerging; key questions to be addressed; and plans for the rapid assessment
- feedback to the group from the rapid assessment team on the methodological and practical implications of the group discussion for the proposed assessment

Community Action Board
Purpose and Process

A Community Action Board (CAB) is a group of people who have knowledge and interest in drug policy, health, local government and any other area the team thinks is important to the success of the RPAR project.

Purpose

The purpose of the (CAB) is to:

- Organize and mobilize allies in the community
- Provide the research team with informational, social, moral and political support for the collection and analysis of policy data
- Collaborate with the research team to turn the data and analysis into an action plan
- Implement the action plan

Process

The CAB and the research team are collaborators on the RPAR project. The research team will meet with the CAB at least seven times. Teams and CABs may wish to add additional meetings. A member of the research team chairs the meeting, and each meeting has a specific agenda. In general, the research team uses each meeting to present data or information about the project to the CAB, and to learn more about the site and the priorities of the CAB. ***After each Meeting,*** the research team should organize the data collected from the CAB in the attached data organization form, and add new notes as needed for the RPAR process.

Community Action Boards: Basic Questions for Training

1: What is community participation?

2: Why do we need community participation? What will it add to the RPAR project?

3: Who should be on the CAB? How are the members selected?

4: What will the CAB do at each of its meetings?

5: What does the research team take away from each meeting?

6: How will the CAB analyze policy and practice questions to develop an action plan?

Community Action Boards: Basic Questions for Training

1. What is community participation?

Community participation means 1) that the work of the research team will be guided and enriched by the knowledge and talent of people who live and work in the site every day, and 2) that people who live and work in the community will have the opportunity to act on the findings of the RPAR project as they think best.

What is a 'community'?

There are many definitions and concepts of community.

Definitions

There are three broad ways of defining a community:

1. *Locality or neighborhood* - a group of people living together within a fixed geographic location;
2. *Social relationships* - a set of social relationship mostly taking place within a fixed geographic location;
3. *Identity/common interest* - a shared sense of identify such as a group of IDUs

It is important to realize that people will hold and use different definitions of community. Whilst doing a rapid assessment to develop targeted interventions, it is usually advisable for the research team to use the broadest definition of community available, but at the same time remain aware that certain interventions will need to target specific communities. As the multi-sectoral nature of rapid assessments will involve the wide-ranging participation and definitions of numerous individuals, groups and organizations, the RPAR team will need to balance this participation with the consideration that the plan of action for interventions may need to focus on a specific community.

While the general principles of community participation outlined here can be used in conducting rapid assessment at macro-level (regional, national), in this section community participation is discussed within the framework of local, small-scale rapid assessment and intervention development.

Rapid Policy Assessment and Response is about power: who has it, who doesn't, how it is exercised, how it is evaded or contested – and how all that influences the risk for HIV. RPAR is based on a specific theory of how this happens, a theory called "nodal governance." "Governance" is simply a word for how people in a particular place organize themselves to manage the course of events. The "nodal" part refers to the idea that governance is, for the most part, carried out by formal and informal groups that are organized as points (or nodes) on a network. When we think of community in an RPAR, we want always to be looking at the network of governing nodes managing that

community, and the set of links between nodes within and outside the geographic of social communities that make up the site city.

Levels of community participation:

Although community participation is integral to any research or intervention development, community participation can be problematic. People can attend many meetings but participate only in a limited sense. In any activity involving a range of people, attention should be given as to how 'participatory' everyone's involvement actually is.

Consider the levels of participation given below.

Type of participation	*Key elements of each type*
Manipulative participation	Participation is a pretence - people's representatives on official boards but having no power.
Passive participation	People participate being told what is going to happen or what has already happened. A unilateral announcement by an outside agency; people's responses are not taken into account.
Participation by consultation	People participate by being consulted. External agencies define both problems and information gathering processes. Such a process does not concede any share in decision-making and professionals are under no obligation to consider people's views in designing interventions.
Participation by material incentives	People participate by providing resources e.g. Time, labor, in return for food, cash or other material incentive.
Functional participation	People participate by forming groups to meet predetermined objectives related to the project. Such involvement tends to occur after major decisions have been made.
Interactive participation	People participate in joint analysis, which leads to action plans and the formation of new local groups or the strengthening of existing ones. It tends to involve interdisciplinary methodologies that seek multiple perspectives and make use of systematic and structured learning processes. These groups take control over local decisions, and so people have a stake in being involved.
Self-mobilization	People participate by taking initiatives independent of external institutions to change system/situation.

What kind of community participation is best for rapid policy assessment?

The RPAR is designed to mobilize community knowledge and capacity for action to change policies and practices that increase the health and risks and social costs of injection drug use. It is essential to engage CAB members who will begin with interactive participation and move through the course of the project to self-mobilization.

The principles of rapid assessment encompass both an assessment of the situation/problem and an assessment of the resources available that might be needed to address the problem. To that end, rapid assessments aim to provide practical information necessary for developing intervention responses.

Translating these principles into practice, rapid assessments are designed to explore the experiences/concepts of a community around specific issues of injection drug use and/or substance use related to sexual risk behavior. Concretely, the experience of an IDU will be explored from the viewpoint of the IDU him/herself and also from the viewpoint of service providers, law enforcement, and community leaders, among others, as part of the generalized view of injection drug use and IDUs in the larger community.

Rapid assessments do not assess the community at random - instead, an inductive process is employed whereby different methods of data collection and investigation are used to construct a 'picture' of the situation from numerous points of views. Thus, the levels and types of community participation will vary over the period of the rapid assessment and will probably change as the plan of action for intervention is developed. The extent to which participation can be effectively developed depends upon the levels of trust which can be built up between the rapid assessment team and the community. The team will need to try to understand, and be receptive to, the concerns of the community. This is particularly important given that substance use is both an illegal and stigmatized activity in many communities.

Community Action Boards: Basic Questions for Training

2. Why do we need community participation? What will it add to the RPAR project?

Community participation and ownership in programs has long been recognized as critical to the success and effectiveness of most prevention programs (HIV prevention being the most obvious example). Without broad support and involvement from the community from the early stages of a rapid assessment, even the best designed plan of action for intervention is unlikely to be implemented effectively.

A Community Action Board is a tool to develop and implement community participation. The philosophy behind a CAB is that every participant or community member shares ownership of a project. The tasks of the CAB include:

- to support the rapid assessment socially and politically
- to share knowledge, responsibilities and resources on the issue of substance use in the community
- to link the RPAR project to the broader community
- to support those who are working directly with drug users
- to provide on-going feedback on the findings of the situation assessment
- to help establish a climate for intervention development based on the findings of the rapid situation assessment
- to participate in developing the action plan for interventions
- to influence the way in which the community acknowledges and responds to drug users
- to carry out the action plan when the assessment is complete

It is important to communicate the level and type of support the research team needs from the Community Action Board. The CAB's role will continue to change throughout the research. The board's first role is to serve as a source of information for data collection. As data is collected throughout the research, the CAB will serve as a sounding board to guide the research team towards important community issues regarding drug users and HIV. Finally, the CAB will serve as a mobilizing force to gain community support for change.

Community Action Boards: Basic Questions for Training

3. Who should be on the CAB? How are the members selected?

The effectiveness of a CAB or any other community participation organization will depend partly on its members. Deciding whom to invite is therefore an important decision. It is likely that an initial list of potential members for the CAB will consist of those key people and institutions that will already be involved in the Initial Consultation. The CAB should have at least ten and no more than twenty members. At that size, the team cannot hope to create a *representative* board -- one that has members drawn from all interested organizations. Thus it will not, for example, include one representative from every drug treatment program or every AIDS service organization or government department. Selecting the CAB poses the task of inclusion with the necessity of diversity, influence and enthusiasm.

The research team can also use the Power Map technique, described further below, to identify useful members of the CAB.

Other issues to consider when selecting members

After the RAR team has made a list of potential members, the next step is to shorten the list by considering the following issues.

- *Members must be able to empathize with drug users*. Participants need to be able to understand the situation of drug users and recognize their need for supportive interventions, which emphasize prevention and treatment. Individuals who favor a punitive approach to substance users may have difficulty supporting all of the project activities.

- *Individuals with regular contact with drug users, either independently or through an organization, are very important to have on the committee*. It is especially necessary to include direct service providers who have had intensive contact with drug users.

- *The services and people represented on the committee should be diverse*. They should include services that drug users want, but currently cannot gain access to. The committee should also include members with different backgrounds, experiences, and opinions.

- *Government representation should be relevant*. If feasible, any government should be represented through local officials responsible for programs and policies, which affect drug users.

- *Committee members should have influence*. The committee needs members who have social, political, and financial power that could be used for the benefit of drug users. At the very minimum, some of the participants should be well-respected by the local community and influential within their own organizations.

- *Members can be allowed to act as representatives of certain organizations*. However, representatives should ideally have the freedom to express their own opinions, independent of the position of their organizations. Personal experiences, rather than organizational policies, often form a better basis for creative thinking and decision-making.

- *Try to involve drug users wherever possible.* Try inviting a few responsible, older drug users to work on the committee. The presence of drug users at meetings greatly helps to keep the work focused on the most important, current problems facing drug users. It also demonstrates to the participants and to the other members of the committee that drug users have the power to improve their own lives.

Barriers to community participation

The overview of community participation previously outlined illustrates the range of possibilities for community participation on a spectrum from passive participation to interactive participation. It is important to recognize that the mechanism determining the level of community participation is not only dependent on the willingness of the research team to *involve key persons and organizations* in the rapid assessment and intervention development, but also very much depends on local and national *structural frameworks* (political, economic, social, religious etc.).

Consequently, an important principle of community participation is the need to understand how things work in a particular community - there are many differences between countries, societies and regions and it is essential that the RPAR team be flexible about how to get the process of community participation started. For example, in many countries, community-based organizations may be rare and the idea unusual, so the concept of community participation needs to be adapted to these situations. It is also crucial that involving existing organizations and networks be considered as part of the process of community participation. The underlying principle is to be flexible and involve all the key persons, institutions, and organizations.

Case study:
In Vietnam, each province has its AIDS committee with the same structure as the National AIDS Committee. The Committee comprises 16 inter-sectoral members representing ministries and departments and mass organizations. The chair of the Provincial AIDS Committee is the Vice Chair of the People's Committee. The Committee Secretariat acts as Program Coordinator. The Committee is responsible for all HIV/AIDS control and prevention activities. Political and technical authorities in Vietnam are highly conscious of drug use and HIV infection. Therefore, the AIDS Committee is the main partner in rapid situation assessment for interventions.

To conduct a rapid situation assessment, and ensure that its findings are implemented, it is therefore important to:
- contact the Committee secretariat to discuss the need of conducting rapid situation assessment for intervention

- ask the AIDS Committee for commitment and approval
- establish the research team which includes at least representatives from the AIDS Committee, the University, NGOs and outreach workers
- discuss the plan of rapid situation assessment
- conduct rapid situation assessment
- inform the AIDS Committee about the progress of rapid situation assessment
- distribute and discuss the results of rapid situation assessment through workshop/meetings
- implement and evaluate interventions

Another potential barrier to community involvement is the perception of drug use within communities. Many community members see drug use as someone else's problem and something not desirable to have in a community. This attitude can make it extremely difficult to respond to the drug use situation and its associated harms. It often means that there are conflicts within the community as to how to 'deal' with the 'problem' of drug use. The importance of being flexible and involving key persons and institutions or organizations can mean that the RPAR team will have to balance the differing opinions of the police alongside that of a drug treatment worker. Part of the process of community participation will be to identify and bring these differing opinions together to help activate interventions at the community level.

Community Action Boards: Basic Questions for Training

4. What will the Community Action Board do at each of its meetings?

The CAB will serve as your connection to the community by providing you with key information about existing data, participants for the qualitative research and new and emerging issues that affect injection drug users. The CAB is also the key agent of change when the project moves from assessment to action planning. In order to keep the CAB engaged in the research process you should prepare a clear set of expectations for the members and keep the members involved in the research throughout the entire project. The RPAR tools material contains a schedule and sample agendas for CAB meetings. In order to encourage the CAB to become an active change agent, the meetings will also be used to engage the CAB members in thinking creatively about how to change the community for health. During the planned nine month schedule, the CAB will meet at least seven times to share information, feedback and action planning. The suggested purposes for the seven meetings are:

Community Action Board Meeting #1

When: As soon as possible after the beginning of the assessment

The goal for the first meeting is to:

- Get CAB input on sources of existing epidemiological and legal data
- Revise the research team's first version of the power map
- Generate one suggestion per CAB member for policy or practice change in the Problems and Solutions Exercise

Community Action Board Meeting #2

When: About the 12th week of existing data collection, when there are data to present but also in time to begin identifying key informants and focus group members

The second meeting of the Community Action Board is intended to:

- Identify candidates for focus group and key informant interviews
- Review and discuss implications of existing data collection
- Revise the power map
- Generate one suggestion per CAB member for policy or practice change in the Problems and Solutions Exercise

Community Action Board Meeting #3

When: About the 4th week of qualitative data collection, after the completion of focus groups and near the beginning of key informant interviews

The third meeting of the Community Action Board is intended to:

- Gather community level input on preliminary results of the focus groups
- Update or modify potential list of key informants based on community level feedback
- Revise the power map
- Generate one suggestion per CAB member for policy or practice change in the Problems and Solutions Exercise

Community Action Board Meeting #4

When: Near the end of qualitative data collection

The fourth meeting of the Community Action Board is intended to:

- Gather input on data yielded from finished key informant interviews
- Inform remaining system and interactor key informant interviews based on advice and suggestions from community members
- Revise the Power Map
- Introduce Root Causes Exercise (Module IV) to analyze problems identified in Problems and Solutions Exercises in meetings 1-3

Community Action Board Meeting #5

When: About the 4th week of action planning and analysis, after the research team has made substantial progress organizing the data

The fifth meeting of the Community Action Board is a half-day to full day workshop intended to:

- Conduct the Root Causes Exercise to analyze problems developed in RPAR data collection
- Identify solutions for risk reduction
- Conduct Priority-Setting Exercise

Community Action Board Meeting #6

When: About 2 weeks after CAB meeting 5

The sixth meeting of the Community Action Board is a half-day to full day workshop intended to

- Conduct the Priority-Setting Exercise Again
- Compare the two sets of results and agree on priorities for action
- Conduct Power Map Action Exercise to develop strategies for action

Community Action Board Meeting #7

When: About 3 weeks after CAB meeting 6, near the conclusion of the RPAR

The seventh meeting of the Community Action board is intended to:

- Gather feedback on final report
- Allocate responsibility for disseminating and implementing the Action Plan and Final Report
- Plan future meetings of implementation group
- Conclude RPAR and describe evaluation activities

Community Action Boards: Basic Questions for Training

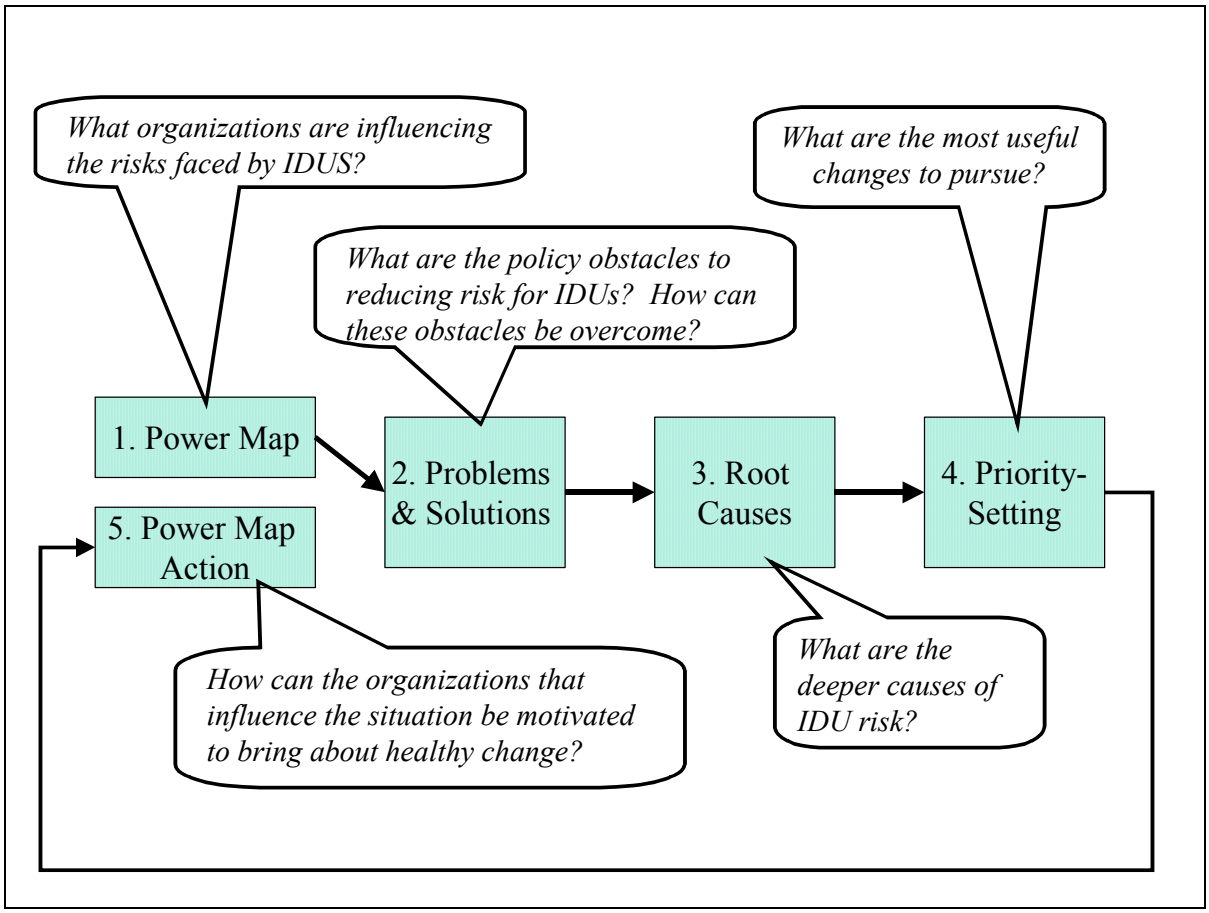
5. What does the research team take away from the meeting?

The CAB provides essential guidance throughout the process. At all meetings, there are specific topics on which the CAB will provide input, and the RPAR includes forms for investigators to use in recording the information the CAB provides. It is essential to document the CAB's input on the appropriate forms at the completion of each meeting. This process will insure that you can recall the important information and perspectives of your board for future research, meetings and policy analysis.

Community Action Boards: Basic Questions for Training

6. How will the CAB analyze policy and practice questions to develop an action plan?

The RPAR is designed to give communities information and analytic techniques that will help them take action to change policies and practices that interfere with HIV/AIDS prevention. Over the course of the intervention, the research team will go through five analytic steps with the CAB, using tools presented here and in Module IV. The steps and their purposes are shown below.



The Power Map

Laws and formal and informal policies that government entities use to implement laws are basic tools for the exercise of power. But government is complicated, even at the city level: different parts of government have different kinds and levels of power, and are often in competition. Moreover, much power in the community is outside government, wielded by non-governmental organizations ranging from legitimate charitable foundations to drug gangs. The RPAR is aimed at understanding how power in the site city is used to manage drug use, sex work and public health. The RPAR will consistently study *all sources of power,* both in the government and outside it. One of the basic tools for this research is the "power map."

A power map is a picture showing the *formal and informal organizations* that wield influence over (or "govern") the conditions of the drug and sex markets and the behavior of drug users and sex workers. The map documents four important kinds of information:

1) The formal and informal organizations that wield influence
2) The connections between these organizations – i.e., what organizations can influence other organizations in the governance system and the relative strength of each connection
3) The internal characteristics of each organization – its culture, its resources, the tools it uses to get things done
4) The people in the system who *are not* part of an organization that can speak for them and wield power on their behalf – i.e., who is excluded from the governance of the community

The power map will be used throughout the RPAR process to capture and share the accumulating knowledge of the city. It will grow through the contributions and revisions of the team leaders, the team members, the CAB and the research participants.

The Power Map is created in four steps.

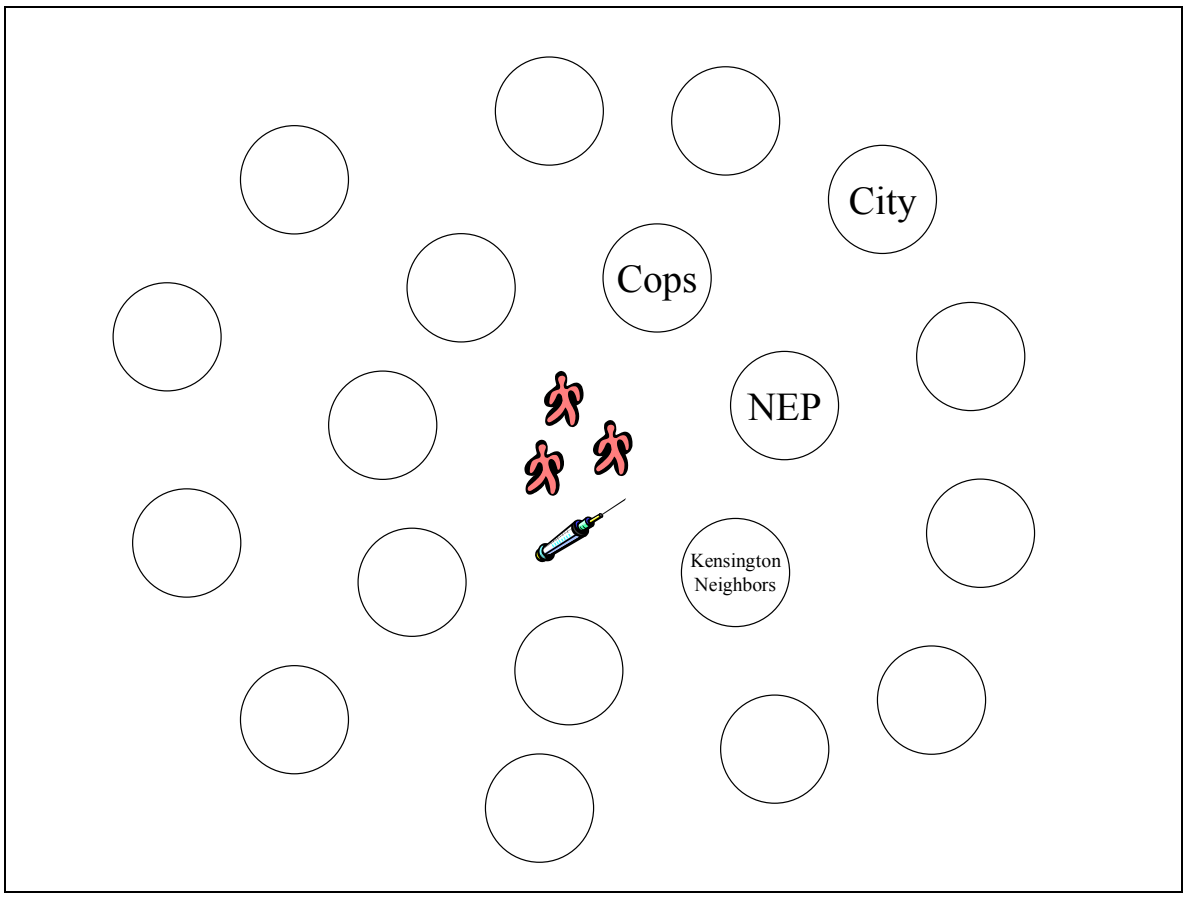
<u>Step 1: Identify the formal and informal organizations that wield influence</u>

In this step, participants first think about and discuss what organizations "govern" the issues of interest to the project: the drug scenes, the sex trade, HIV prevention and treatment, etc. Key concepts in this step include:

- Formal and informal organizations: for our purposes, an organization is any group of people who see themselves as part of a stable group working together to achieve specific ends. The organization can be formally constituted – like a police department or a legally established NGO – or it can be informally established – like a drug gang or a group of sex workers who together regulate prostitution in a certain street or park.
- Governance: governance is defined as organized activity aimed at managing the course of events in a social setting. A governing organization is able to wield

influence over what individuals and other organizations do in that social setting. Some groups have less influence – less power – than others, but the map should start with as complete a picture as possible.

In the sample power map below, participants have begun to identify groups that govern drug use in Philadelphia.

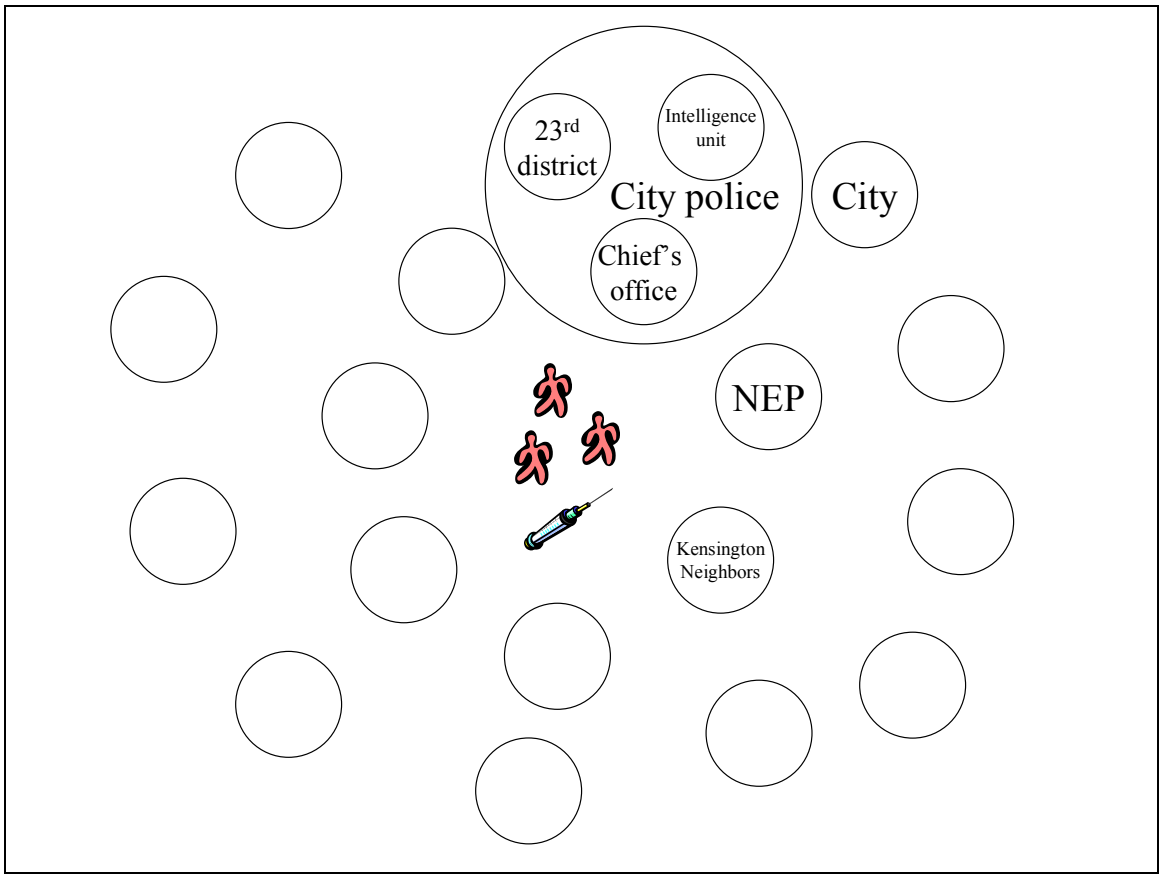


Participants in a mapping session would continue to identify organizations until no new ideas are offered. At that point, participants are asked to look at the map again and refine the roster of organizations in two ways:

1) Are there organizations that, after discussion/reflection, should be added or removed?
2) Which of these organizations are really made up of some number of smaller units tied in a mini-network?

Some large organizations, like the police department, can be better understood as networks of smaller entities, such as specific bureaus (narcotics, homicide), police stations or even work teams. As knowledge is added to the map throughout the RPAR process, many large organizations may come to be seen in this way. An example of how

to map this is below, where the police are now seen as a network made up of at least three separate units:



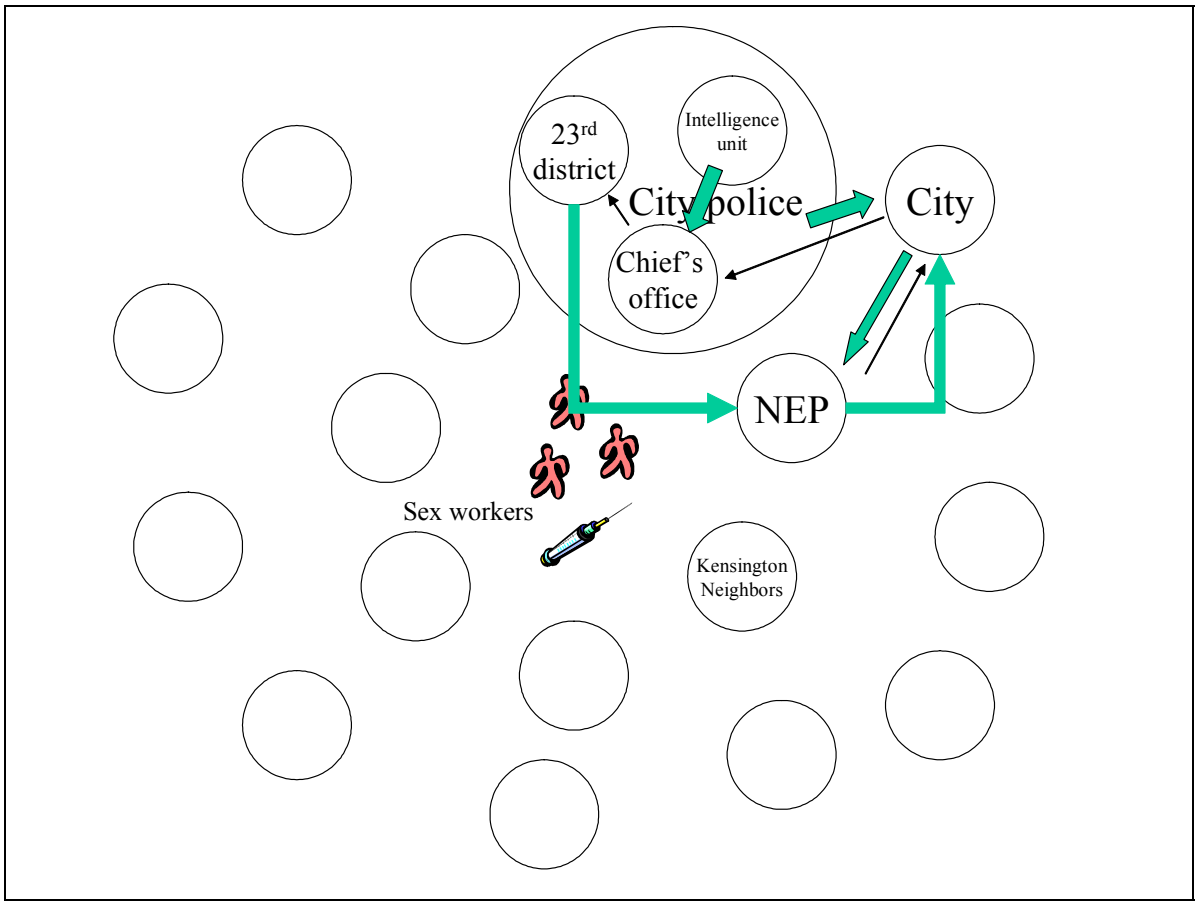
Step 2: Chart the "influence connections" among the organizations

The next step in mapping is to identify how these various organizations relate to each other in terms of power/influence. We ask participants to say which organizations each organization influences, and what organizations it is in turn influenced by; and we ask whether this influence – this ability to get other organizations to do what they are told – is relatively stronger or weaker. This is indicated on the map by the arrows defined here:

Strength and Direction of Influence

	More Influence	Less Influence
One way		
Two way		

Applied to Philadelphia, it looks like this:



This map now describes several points about governance in Philadelphia's harm reduction system. It shows that

- One police district has considerable power over the needle exchange program
- The NEP has no influence on the police directly, but must go through the city
- The city is also influenced by a neighborhood association that has no connection at all with the needle exchange
- The city has a little influence over the chief of police, but not as much as the police's internal intelligence unit
- The chief has relatively slight authority over the 23rd district

Step 3: Write down what is known about the internal characteristics of each organization on a separate page/slide

The next step is to gather information about the key characteristics of each organization that determine its capacity to wield influence in the setting. These are:

- Material resources: money, facilities, and equipment are important factors in an organization's ability to wield influence. Poor organizations are not always weaker than rich ones, but resources are clearly helpful.
- Mentality: every organization has a way of thinking about the issues it deals with that is more or less shared by its members and which helps the members to interpret what is happening in the environment and to collaborate in efforts to govern. Every organization has a way of thinking about how decisions are made within the group.
- Tools of influence: every organization has techniques or tools it uses to get others to obey them: legal organizations file lawsuits; police organizations arrest people; NGOs use personal connections or persuasion or expertise. Some tools are obvious, such as police use of force. Others are more subtle: any government agency can seek to get people to obey by using a social tool called "legitimacy," which is the belief people have that they should obey the government just because it is the government.

In some organizations, many or all members of the organization can represent it in its dealings with other organizations. In others, there is one or a few people who actually make contact with other organizations, and so have an extra importance within the organization or the community. The form you will use also includes space to identify these key network operators.

Organization: Needle Exchange

- Resources
  - City budget of $280,000; $100,000+ in foundation grants and contributions; a mobile van; drop-in center and office; staff of 18 full time and 30 volunteers
- Culture
  - Harm reduction ethos, but getting bureaucratic with success
- Tools of Influence
  - Expertise on IDU health (staff and collaborating academics); media advocacy; participation through supporters in political campaigns; NGO networking; membership on regional HIV planning council
- Key people
  - Casey Cook, exec director

Step 4: On the main slide/map, identify important groups (e.g., IDUs) if any who do not have an organization they can exert influence through

The map is designed to show what organizations are governing the areas of interest to the assessment, but it also can be used to show important persons in the community who do not have access to any sort of governing organization. This is important information: it indicates important voices that are not being heard and needs that are not being articulated. As we discuss further in the analysis and action planning discussion, one potentially useful strategy for change is to create access for such individuals to new or existing organizations.

In the map above, sex workers are identified as an important group of individuals in Philadelphia who do not have access to a governing node.

"Step 5": Revise, revise, revise

The power map is a fluid document. The power map will be used again and again throughout the RPAR process to refine or add information. As more information comes in from more perspectives, it will change. The research team should prepare a new edition of the map after each use.

Problems and Solutions Exercise

The Community Action Board will ideally reach the stage of self-mobilized participation in the course of the RPAR project, but it may not begin there. Along the with Power Map, the Problems and Solutions Exercise is a means for the research team to get the CAB members used to having and freely exchanging their own ideas about what policy and practice changes are needed and how to achieve them.

Equipment Needed

PowerPoint and/or flip charts, pens and tape, Research Team Data Form

Process

In this exercise, each member of the CAB is asked to quickly identify one problem that increases the risks of drug use, sex work and other behaviors addressed in the RPAR, and a possible solution related to policy or policy implementation. The researcher conducting the exercise emphasizes that this is a creative exercise, designed to get many ideas out on the table without judging how correct or important they are. Even speculation about possible problems is useful and welcome. The exercise should take only a few minutes, and there is no discussion of or comment on the problems and solutions offered.

Participants may be uncomfortable with such brainstorming, so the exercise should be conducted quickly, with humor and energy. The researcher can make clear that everyone is obliged to offer something, and that all ideas will be written down without attribution to a particular person. The researcher conducting the exercise writes down the problems and solutions on flip charts or PowerPoint, while another member of the team notes the problem and the solution on the Research Team Data Form. The problems and solutions collected will be fed back to the CAB in later meetings and used as one of the inputs into the analysis and action plan.

RAPID POLICY ASSESSMENT & RESPONSE

Module II: Existing Data

Topic Areas:
(2) Epidemiology
(3) Law Enforcement Tools

Epidemiology of HIV, Other Communicable Diseases, Injection Drug Use, and Law Enforcement Data

Topic Areas (2) and (3)

In this part of Module II of the RPAR, researchers gather and analyze

- Existing data on the spread of disease in the country and the community
- Existing data on the numbers of drug users and types of drugs used, and
- Existing data about crime and the operation of the criminal justice system.

Purpose

The information collected will provide a foundation upon which to build the remaining research of the RPAR. Data on HIV and other significant diseases is essential to assessing the severity of the health policy problem in the country. Criminal justice statistics are an important measure of crime, the extent of the country's reliance on incarceration, and the extent of drug use.

Process:

This tool includes the following three steps:

Step 1: Obtain data

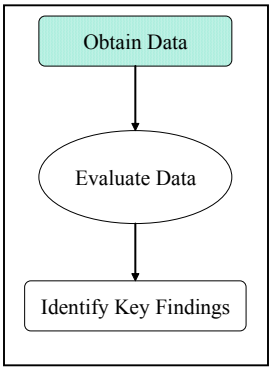
> *Be sure that each table or other data item you find is clearly labeled as to source and time period covered.*
>
> *As you collect data, compare what you find with the domains below to check how well you are doing. Do NOT stop just because you find one source of data covering a topic on the list, because different sources may have different statistics on the same disease or behavior.*
>
> *We expect that most of the data sources you find will be in tables or contain tables. There is no need to re-enter the data or create new tables in most cases.*
>
> *Reports and published epidemiological studies or reviews will often include analysis and discussion of the most important data and trends in the epidemic. Part of the work of this Module is to identify and summarize these expert assessments.*

Step 2: Assign a number or other identifier to each data source or set of data and fill out the Data Evaluation Form for each one. Sometimes one source, such as a national AIDS center, will provide more than one set of data. Evaluate each set independently.

Step 3: Review the data and identify and list key findings on the Key Findings Form.

Step 1: Obtaining Data
Topic Area (2)

Epidemiology of Relevant Diseases
Characteristics of HIV Epidemic and Other Communicable Diseases



Domains*:* For each disease listed, try to obtain data covering the past ten years for

- the country
- the site city
- the region surrounding the site city

For each disease listed, collect:

1) Statistics:
    a) Prevalence rates and numbers (actual and / or estimated)
        i) Overall, and
        ii) By risk group or population, age, gender, sexual orientation, ethnicity
    b) Incidence rates and numbers where available or feasible (actual or estimated)
        i) Overall, and
        ii) By risk group or population, age, gender, sexual orientation, ethnicity

2) Analysis and discussion
    a) Identifying the most important data
    b) Summarizing any trends or important points identified in epidemiological reports or studies.

1.1 HIV/AIDS

1.2 TB

1.3 Hepatitis B

1.4 Hepatitis C

1.5 Syphilis

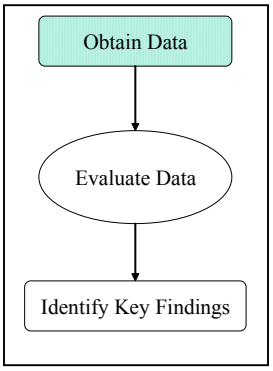
1.6 Other locally important STDs for which data are available

1.7 Statistics for any of these conditions in prisons or jails

1.8 Data on HIV drug resistance at the national, regional and site city level?

1.9 Data on TB drug resistance at the national, regional and site city level?

Epidemiology of Injection Drug Use
Characteristics of drug use



Domains: For each disease listed, try to obtain data covering the past ten years for

- the country
- the site city
- the region surrounding the site city

For each disease listed, collect:

1) Statistics:
   a) Prevalence rates and numbers (actual and / or estimated), by:
      i) Risk group or population
      ii) Age, gender, sexual orientation, ethnicity
   b) Incidence rates and numbers where available or feasible (actual or estimated)
      i) By risk group or population
      ii) Age, gender, sexual orientation, ethnicity
2) Analysis and discussion
   a) Identifying the most important data
   b) Summarizing any trends or important points identified in epidemiological reports or studies.

2.1 Heroin

2.2 Home-made opiates (e.g., kompott)

2.3 Methamphetamine

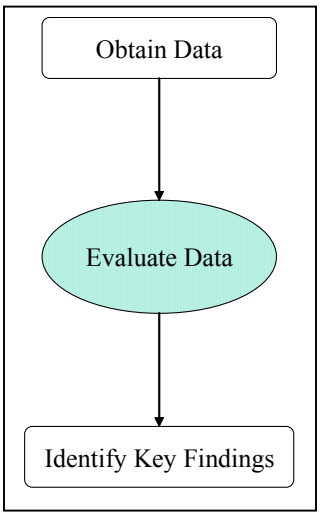
2.4 Home-made methamphetamine (“e.g.. chemistry)

2.5 Cocaine and crack cocaine

2.6 Other locally important drugs such as (ecstasy, ketamine)

Step 2: Evaluate Data

Topic Area (2)



Assign a number or other identifier to the data source and fill out the Data Evaluation Form for each source.

For each source from which you have obtained data, and for distinct sets of data from a single source, use the Data Evaluation Form to record source, citation, and any important information about the reliability or availability of the information.

Complete citation - For all data, make sure you have a complete citation for the source. Then assign a number or other unique identifier to the source. This number will allow you to identify the source easily, and to refer to the source in other tables and forms. Record both citation and source on the data evaluation form.

A single source, may provide more than one relevant data set. For example, a national AIDS center may have data taken from a telephone survey on sexual behavior and also data taken from a registry of AIDS cases. In such cases, assign a different identifier to each data set and evaluate them separately.

In the box on disease or topic give a short description of the basic subject matter of the source. For example "Cumulative AIDS cases since 1995".

In the box on limitations on validity, record any limitations on the validity or accuracy of the data of which you are aware. For example, if official sources estimate drug users using only those identified and registered with the state narcological institute, this would be important to note along with a comment that the actual number of (non-registered) drug users is likely to be much higher. "Non-registered users are not included in state estimate. Local treatment officials estimate 5-10 non-registered/each registered drug user in Kaliningrad."

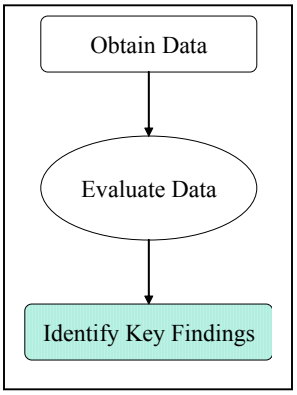
In the box on notes on access record any barriers to access you encountered. For example, "Arrest data were only available in paper files stored in basement of police station" or "It took 4 written requests to get permission to inspect data". Or, conversely, note where data is publicly available in useable format. For example "On-line data available, search possible by year, type of crime, etc."

Data Evaluation Form

Source and Citation	Disease or topic	Limitations on validity	Notes on access

Step 3: Identify Key Findings
Topic Area (2)

Review the Data and Identify and List Key Findings on the Key Findings Form



At the end of each part of this module, we ask researchers to review the data they have collected to identify key findings. Researchers will have available the published statistics as well as the discussion and analysis in any published papers. The goal of this step is to identify the important information that can be used in the RPAR.

To identify key findings you should do several things. One is to note the important, relevant conclusions of the studies and reports you reviewed, these will usually appear in "Discussion" "Findings" "Conclusions" sections of the report. Not all findings or conclusions of all reports will be relevant to this project, but some may be. Additionally, you must look at the actual data for important findings. Some examples follow.

Important information to look for:

- Trends (changes over time) of the same disease or behavior in the same group. For example, are the numbers of cases of HIV (or AIDS, or TB, or hepatitis) among IDUs increasing or decreasing? Are the numbers of IDUs in treatment up, down, or remaining steady? Are arrests up or down for possession of heroin?
- Changes geographically. Are different parts of the city, region or country reporting disease (drug resistant TB) or behavior (methamphetamine use) that was previously rare?
- Changes among demographic groups. Has the distribution of new HIV cases appeared to shift from IDUs to sexual partners of IDUs? Are many new cases in the 15-24 year old age group?
- Absolute numbers can also be noteworthy, even if the numbers do not represent a trend or change. For example, are there focal points, age, ethnic, or risk groups where the epidemic is particularly severe?

The Key Findings form will be used to prepare your presentation for the CAB and as part of your action planning process.

Key Findings Form

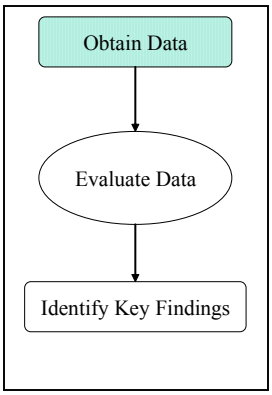
Topic Area:_____

Source	Key Findings:

Step 1: Obtaining Data
Topic Area (3)

Domains: For each disease listed, try to obtain data covering the past ten years for

- the country
- the site city
- the region surrounding the site city



For each crime listed, collect:

1) Statistics:
   a) Arrests
   b) Prosecutions
   c) Convictions
   d) Sentences

   Where possible, collect data that breaks down statistics by gender, ethnicity, age or other demographic criteria.

2) Analysis and discussion
   a) Identifying the most important data
   b) Summarizing any trends or important points identified in criminological reports or studies.

1.0 Criminal law domains:

1.1 Violation of drug laws (possession, sale, manufacture, trafficking)

- By type of drug (e.g. arrest and conviction data for all crimes involving heroin)
- By type of crime (e.g. for criminal possession charges for all drugs*)
- Where possible include data on the drugs listed below
  - Heroin
  - Kompott
  - Other opiates
  - Methamphetamine
  - Other amphetamines
  - Cocaine and crack
  - Ecstasy and other club drugs
  - Other locally significant drugs
  - Drug trafficking patterns

1.2. Possession of syringes

- Alone
- In connection with other charges

1.3 Harm reduction activities
- Overall
- NEP operation
- Providing information
- Other

1.4 Sex work
- By gender?
- By other specifics (selling, buying, running a brothel, etc)

1.5 Homosexual identity or behavior
- By gender
- By particular behavior

2.0 Data on drug seizures:
- For each locally relevant drug: Are there data on purity or quantity of drugs seized?

3.0 Data on civil law suits:
- Are there data on numbers and outcomes of anti-discrimination claims brought by HIV+ persons?
- Are there data on numbers and outcomes of privacy claims brought by HIV+ persons?

4.0 Are there data on the structure, personnel and resources of the legal system?
- Numbers of police, prosecutors, judges, and salaries of each group
- Budgets, distribution of court houses and jails
- Backlog, if any of cases in the court system

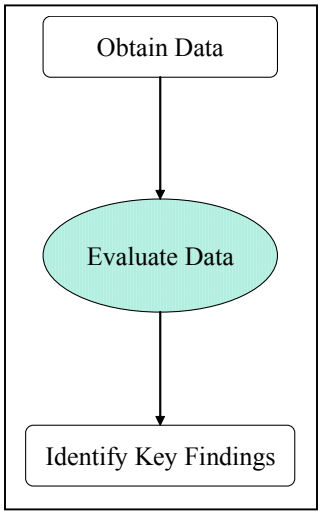
5.0 Are there data on incarceration/
- The number of people held in pretrial detention?
- The average time in pretrial detention?
- The number of people held in jails and prisons
- The estimated capacity of jails and prisons
- Number of people on post-sentence supervision (parole)
- Number of people receiving alternatives to incarceration (probation, community service, mandatory drug treatment)

6.0 Are there data on the availability of private or publicly funded lawyers for people charged with crimes?

Step 2: Evaluate Data

Topic Area (3)

Assign a number or other identifier to the data and fill out the Data Evaluation Form



For each source from which you have obtained data, and for distinct sets of data from a single source, use the Data Evaluation Form to record source, citation, and any important information about the reliability or availability of the information.

Complete citation - For all data, make sure you have a complete citation for the source. Then assign a number or other unique identifier to the source. This number will allow you to identify the source easily, and to refer to the source in other tables and forms. Record both citation and source on the data evaluation form.

A single source, may provide more than one relevant data set. In such cases, assign a different identifier to each data set and evaluate them separately.

In the box on disease or topic give a short description of the basic subject matter of the source.

In the box on limitations on validity, record any limitations on the validity or accuracy of the data of which you are aware.

In the box on notes on access record any barriers to access you encountered.

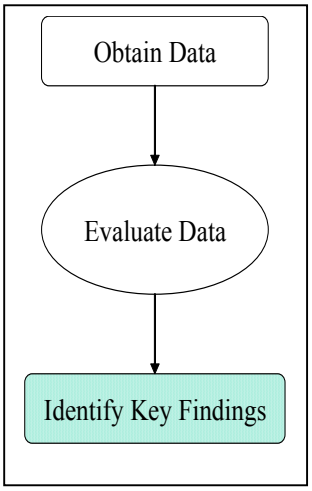
See form in previous section.

Step 3: Identify Key Findings
Topic Area (3)

Review the data and identify and list key findings on the Key Findings Form

At the end of each part of this module, we ask researchers to review the data they have collected to identify key findings. Researchers will have available the published statistics as well as the discussion and analysis in any published papers. The goal of this step is to identify the important information that can be used in the RPAR.

To identify key findings you should do several things. One is to note the important, relevant conclusions of the studies and reports you reviewed, these will usually appear in "Discussion" "Findings" "Conclusions" sections of the report. Not all findings or conclusions of all reports will be relevant to this project, but some may be. Additionally, you must look at the actual data for important findings. Some examples follow.



Important information to look for:

- Trends (changes over time) of the same disease or behavior in the same group. For example, are the numbers of cases of HIV (or AIDS, or TB, or hepatitis) among IDUs increasing or decreasing? Are the numbers of IDUs in treatment up, down, or remaining steady? Are arrests up or down for possession of heroin?
- Changes geographically. Are different parts of the city, region or country reporting disease (drug resistant TB) or behavior (methamphetamine use) that was previously rare?
- Changes among demographic groups. Has the distribution of new HIV cases appeared to shift from IDUs to sexual partners of IDUs? Are many new cases in the 15-24 year old age group?
- Absolute numbers can also be noteworthy, even if the numbers do not represent a trend or change. For example, are there focal points, age, ethnic, or risk groups where the epidemic is particularly severe?

The Key Findings form will be used to prepare your presentation for the CAB and as part of your action planning process.

See form in previous section.

RAPID POLICY ASSESSMENT & RESPONSE

Module II: Existing Data

Law on the Books
Tools

RAPID POLICY ASSESSMENT AND RESPONSE

Module II

Topic Area (1)

Laws

In this part of Module II of the RPAR, researchers gather and analyze the law relevant to HIV/AIDS among injection drug users.

For purposes of the RPAR, "law" consists of:

- Constitutions and any treaties that have the force of law
- Statutes passed by the national or regional legislature
- Ordinance (statutes) passed by local legislative bodies
- Administrative regulations with the force of law, issued by administrative agencies at the national, regional or local level
- Court decisions interpreting laws or regulations
- Executive orders or decrees with some binding effect issued by executive officers at the national, regional or local level
- Internal documents created by agencies to guide their enforcement or interpretation of laws and regulations
- Guidance on the interpretation of laws issued for the public by an agency or executive body
- Standard operating procedures, manuals or other documents defining enforcement practices, agency interpretation of laws or guidelines for public behavior

Purpose:

The information collected will provide a foundation upon which to build the remaining research of the RPAR. The laws you collect are define the policy issues to be addressed in qualitative research and the work of the CAB. Change in law may be a major goal of the Action Plan.

Process:

This tool requires standard legal research using the normal methods and resources in the site country. Recording and analyzing the law data for the RPAR requires the following three steps:

Step 1: Identify laws and obtain the complete citation in correct local format.

As you collect data, compare what you find with the domains below to ensure you are finding all that is required. If you find laws not mentioned below, but which you think may be relevant, include those in domains 13.0 or 14.0.

Because you are collecting a broad range of documents that fall within the RPAR definition of "law," there may be more than one provision applicable to a domain or topics within a domain. For example, there may be both national criminal laws and administrative regulations that deal with possession of heroin or other drugs. Be sure to get the full range of relevant laws.

Indicate the type of the provision --a statute/law, an administrative regulation with the force of law, an executive directive from an agency or official (e.g., a presidential decree), a written policy of an agency without the force of law, a written standard operating procedure or other management directive of a law enforcement agency, or a form of legal guidance issued by a law enforcement agency.

Step 2: Copy the law.

We expect that virtually all laws will be available for copying. If not, please hand-copy the most important provisions and provide a more detailed summary in Step 3.

If you find an English translation of the statute, please copy that also.

Step 3: Provide a narrative summary and analysis of the law.

You may wish to create more than one summary box for a domain or topic within a domain.

Make sure your narrative addresses all the key topics in each domain. Note any particularly important elements (e.g., methadone is listed as a controlled substance, or possession of up to a gram of heroin is not a crime)

The purpose of the narrative is to succinctly summarize key points for your later work with the CAB and final report. Because you will have copies of the law, there is no need for lengthy discussion or detailed paraphrasing of the law.

Important note: CAB meetings and research in Module III may lead to more areas of relevant law being identified, and require additional legal research.

The Domains of Law in the RPAR

1.0 Drug use

- Drug control laws
- Syringe laws
- Needle exchange programs
- Drug treatment

2.0 Commercial sex work

3.0 Homosexuality and homosexual behavior

4.0 HIV-specific criminal exposure or transmission

5.0 Criminal justice/procedure

6.0 Right to health care/ right to HIV treatment

7.0 Reportability of HIV, AIDS, HCV, HBV, TB, Syphilis, and STDs

8.0 HIV testing laws

9.0 Privacy of medical information

10.0 Anti-discrimination provisions

11.0 National provisions related to international human rights norms

12.0 International drug control agreements

13.0 Other laws identified by CAB or Module III research that influence risk or stigma among drug users in a significant way

14.0 Other laws identified by CAB or Module IV that influence the work of HIV prevention organizations in a significant way

RAPID POLICY ASSESSMENT AND RESPONSE

Module II
Topic Area (1)
Law on the Books

COLLECTION INSTRUMENT

1.0 Drug use

1.1 Drug use, possession and sale

1.1.1 Identify regulated drugs, quantities, and penalties.

1.1.2 Most countries publish a list or "schedule" of prohibited drugs. Find the most recent version of this schedule and identify which drugs are regulated. Determine the status of those drugs that are relevant to the transmission of HIV and other blood-borne diseases among IDUs. Include at least heroin, cocaine, methamphetamine, opium, marijuana, other psychotropic drugs, and any other locally relevant drugs that are mentioned (such as "kompot" or "chemistry"). Note also the status of drugs that may have begun to be widely used recently, such as ketamine or "ecstasy."

1.1.3 For each relevant drug, determine the minimum quantity (usually by weight) that may legally be possessed. For some drugs there will be no minimum, any detectable trace of the drug presents possible criminal penalties. For others, the schedule may set a threshold below which possession is decriminalized.

1.1.4 Determine where there are non-criminal penalties, such as where possession is punishable by a fine or administrative penalty.

1.1.5 For each relevant drug, determine whether each of the following is criminalized or otherwise penalized and if the law proscribes different penalties for: possession (of what quantity); sale; or manufacture.

1.1.6 For each relevant drug, does the law proscribe other behavior or provide other penalties, such as special penalties for "trafficking", or being a "drug king-pin"?

1.1.7 For each relevant drug determine whether repeat offenders face different penalties.

1.1.8 If you have not done so already, identify and summarize any available executive decrees, agency policies or other laws relating to drug possession or the enforcement of drug possession laws.

1.1	**Drug use, possession and sale**
Citation	
Type of provision	
Narrative summary	

1.2 Status crimes related to drug use

1.2.1 Does the law formally make it a crime to be a drug user?

1.2.2 Being in the company of drug users?

1.2.3 Other activities related to status as drug user?

1.2.4 If you have not done so already, identify and summarize any available executive decrees, agency policies or other laws relating to the status of being a drug user.

1.2	**Status crimes related to drug use**
Citation	
Type of provision	
Narrative summary	

1.3 Registration of drug users or "addicts"

1.3.1 Identify the circumstances, if any, under which a person must be registered with government as a drug user or "addict."

1.3.2 Identify the officials who are authorized or required to identify people to be placed in such a registry (e.e., police, physicians).

1.3.3 Identify the officials who are authorized or required to maintain the registry.

1.3.4 Identify those who have access to the registry.

1.3	**Registration of drug users or "addicts"**

Citation	
Type of provision	
Narrative summary	

1.4 Mandatory drug testing of suspected drug users.

1.4.1 Identify the circumstances, if any, under which a person may be tested for drug use without the person's consent.

1.4.2 Identify the process for legally ordering a drug test and what officials are authorized to conduct such testing.

1.4	**Mandatory testing of suspected drug users**
Citation	
Type of provision	
Narrative summary	

1.5 Drug paraphernalia

1.5.1 Identify any laws that prohibit possession of drug paraphernalia -- syringes, bleach, cookers or other items that can be used with illegal drugs.

1.5.2 What are the penalties for possession of drug paraphernalia by drug users?

1.5.3 What are the penalties for sale of drug paraphernalia to drug users?

1.5	**Drug Paraphernalia**
Citation	
Type of provision	
Narrative summary	

1.6 Regulation of sale or possession of syringes and needles.

1.6.1 Identify any provision other than drug paraphernalia provisions governing the sale or possession of a hypodermic needle and syringe.

1.6	**Regulation of sale or possession of syringes and needles**

Citation	
Type of provision	
Narrative summary	

1.7 "Propaganda" about, promotion or facilitation of drug use

1.7.1 Identify any law that addresses activities deemed to promote or facilitate drug use.

1.7.2 Identify any law that explicitly addresses harm reduction activities in terms of promotion or facilitation of drug use.

1.7	**"Propaganda" about, promotion or facilitation of drug use**
Citation	
Type of provision	
Narrative summary	

1.8 Naloxone or other treatment for drug overdose

1.8.1 Determine whether naloxone is a "scheduled drug" or "controlled substance."

1.8.2 Identify any law governing its use in the treatment of drug overdose.

1.8.3 Determine whether it may legally be provided to drug users as part of an overdose prevention program.

1.8.4 Repeat items 1-3 for any other medication used in the area to treat drug overdose.

1.8	**Naloxone or other treatment for drug overdose**
Citation	
Type of provision	
Narrative summary	

1.9 Needle exchange programs (NEPs):

1.9.1 Are NEPs authorized by law, forbidden by law, or neither?

1.9.2 If needle exchanges are allowed, identify all provisions governing their approval, operation or other oversight.

1.9	**Needle Exchange Programs (NEPs)**
Citation	
Type of provision	
Narrative summary	

1.10 Operation of drug treatment programs generally

1.10.1 Identify any law regulating the establishment and operation of drug treatment programs, including what individuals or organizations may operate programs, what licenses or other approvals are required for such programs, and whether and how these rules differ for different types of programs (detoxification, in-patient treatment, out-patient treatment, buprenorphine, methadone, other opiate replacement therapies, behavioral modification, twelve step, or other modalities).

1.10	**Operation of drug treatment programs generally**
Citation	
Type of provision	
Narrative summary	

1.11 Opiate replacement:

1.11.1 Determine whether methadone, buprenorphine, and any other drug currently used in opiate replacement therapy are "scheduled drugs" or "controlled substances."

1.11.2 Identify any other provisions regulating the use of opium replacement therapies, including what drugs may be used, purposes of which they may be used (e.g., detoxification, long-term maintenance), dosages, time limits, and periodic drug testing of patients.

1.11	Opiate replacement
Citation	
Type of provision	
Narrative summary	

1.12 Access to drug treatment

1.12.1 Is there a legal right to drug treatment?

1.12.2 Identify any law governing the payment of the costs of drug treatment, including any provisions on government-paid treatment, eligibility for aid and time limitations on state-paid treatment.

1.12.3 Identify any law governing the acceptance of voluntary drug treatment as an alternative to arrest, prosecution or incarceration.

1.12.4 Identify the circumstances, if any, under which a person may be required to undergo mandatory drug treatment.

1.12.5 Identify the procedures under which individuals can be required to undergo mandatory drug treatment, and the officials who are authorized to order such treatment,

1.12	Access to drug treatment
Citation	
Type of provision	
Narrative summary	

2.0 Commercial sex work

2.0.1 Identify any law prohibiting participating in or profiting from commercial sex work (e.g., offering sex for money, being a sex worker, owning or operating a brothel, pimping, soliciting sex for money).

2.0.2 Identify any law prohibiting the possession or sale of condoms.

2.0.3 Identify the penalties for violating these laws.

2.0.4 Does the law related to sex work apply differently to male and female sex workers, and if so, how?

2.0	Commercial sex work
Citation	
Type of provision	
Narrative summary	

3.0 Criminal or other penalties for homosexual identity or behavior

3.0.1 Does the law prohibit homosexual conduct (acts) or status (identity)?

3.0.2 Identify the penalties for violating these laws.

3.0.3 Do these provisions apply differently to men, women, or transgendered persons?

3.0	Criminal or other penalties for homosexual identity or behavior
Citation	
Type of provision	
Narrative summary	

4.0 Criminal provisions specific to people with HIV

4.1.1 Does the law prohibit any of the following by a person with HIV?
- Any act that could expose another to HIV
- Exposure with intent to infect with HIV
- Actual transmission of HIV
- Sexual intercourse
- Other sexual contact
- Sharing injection equipment

4.1.2 What is the penalty for each?

4.1.3 Are there any affirmative defenses?
- If the person with HIV uses a condom
- If the person with HIV infection discloses his/her status and obtains consent for contact

4.1	Criminal penalties for knowing exposure to HIV
Citation	
Type of provision	

Narrative summary	

4.2 Additional penalties for crimes committed by persons with HIV

4.1.1 Identify any law imposing additional penalties for engaging in sex work while infected, purchasing sex while infected, assault while infected, or other criminal activities?

4.2	**Additional penalties for crimes committed by persons with HIV**
Citation	
Type of provision	
Narrative summary	

4.3 Other HIV-specific criminal laws

4.3.1 Identify any other HIV-specific criminal laws.

4.3	**Other HIV-specific criminal laws**
Citation	
Type of provision	
Narrative summary	

5.0 Criminal justice/procedure

5.1 Criminal procedure

5.1.1 Identify any law that regulates criminal justice, including police searches and arrests, pre-trial detention, bail, and conditions of confinement.

5.1.2 Identify any law that regulates criminal procedure, including time to trial, right to an attorney (court-appointed or otherwise), and appeal.

5.1.3 Are there any other important protections or guarantees not included above?

5.1	**Criminal procedure**
Citation	
Type of	

provision	
Narrative summary	

5.2 Structure of the courts and legal system

5.2.1 Describe the structure of your country's court system.

5.2.2 Describe the structure of your city's court system.

5.2	**Structure of the courts and legal system**
Citation	
Type of provision	
Narrative summary	

5.3 Enforcement of defendant rights

5.3.1 Where and how can a defendant enforce the criminal justice/procedural rights described above.

5.3	**Enforcement of defendant rights**
Citation	
Type of provision	
Narrative summary	

6.0 Right to health care/HIV treatment

6.1 Does the law establish a "right to health care"?

6.1	**Right to health care**
Citation	
Type of provision	
Narrative summary	

6.2 Right to treatment for HIV/AIDS

6.2.1 Does the law establish a right to HIV/AIDS medicines, specifically anti-retrovirals?

6.2.2 Does the law indicate how to allocate scarce HIV/AIDS medicines, such as by setting up criteria for anti-retroviral treatment or setting priorities for types of patients (for example, pregnant women)?

6.2	**Right to treatment for HIV/AIDS**
Citation	
Type of provision	
Narrative summary	

7.0 Reportability of HIV/AIDS and other communicable diseases

7.1 Reporting and registries

7.1.1 Determine whether the law requires reporting of AIDS, HIV, Hepatitis (B or C), TB, and/or syphilis to health authorities.

7.1.2 Who must report cases of infection or disease?

7.1.3 What agency or agencies maintain the registries?

7.1	**Reportability of HIV/AIDS and other communicable diseases**
Citation	
Type of provision	
Narrative summary	Or use table below

[Reportability Table]

Disease/condition	**Local health author**	**National health author**	**Hospitals**	**Other gov. entity (list)**	**Other non-gov. entity (list)**
AIDS					
HIV infection					
HBV					
HCV					
TB					
Syphilis					

Other STDs					

7.2 Permitted uses of HIV-status information in registries

7.2.1 Who has access to the data (with individually identifiable information)?

7.2.2 For what purpose can health officials or others use the data?

7.2.3 Is registry information also covered by general privacy laws collected in domain 9, below?

7.2.4 Are there penalties for improper use or disclosure?

7.2	**Permitted uses of HIV-status information in registries**
Citation	
Type of provision	
Narrative summary	

8.0 HIV testing laws

8.1 Determine whether the law requires informed consent for HIV testing.

8.2 Determine whether the law allows HIV testing without consent for any of the following:

- Narcological patients
- Drug users
- Commercial sex workers
- Prisoners
- Military recruits
- Law enforcement officers (police)
- Other governments employees
- Health care workers
- Patients with STDs
- Patients with TB
- Pregnant women
- Newborns
- Other groups

8.0	**HIV testing laws**
Citation	
Type of provision	

Narrative summary	

9.0 Privacy of medical information

9.1 Medical information generally

9.1.1 Does the law protect personally identifiable medical information?

9.1.2 Does the law define personally identifiable medical information?

9.1.3 When may a physician/health care worker disclose personally identifiable health care information to others (such as)

- Health department
- Other health care workers involved in care
- Law enforcement officers who may have been exposed
- Institutional workers who may have been exposed
- Patient's family
- Patient's regular sex partners
- Patient's casual sex partners
- Law enforcement / courts for use as evidence
- Other individuals at risk of infection/exposure
- Researchers
- Others (list)

9.1	**Medical information generally**
Citation	
Type of provision	
Narrative summary	

9.2. HIV/AIDS information

9.2.1. Identify any law specifically protecting HIV/AIDS information.

9.2.2 Is there a penalty for unauthorized disclosure?

9.2.3 Determine whether and under what circumstances HIV/AIDS information may be disclosed to the health department, health workers involved in care, or law enforcement officers or institutional workers who may have been exposed to infected blood or body fluids.

9.2.4 Determine whether and under what circumstances HIV/AIDS information may be disclosed to the patient's families, the patients regular or casual sex partners, or other individuals at risk of infection or exposure.

9.2.5 Determine whether and under what circumstances HIV/AIDS information may be disclosed to law enforcement agents or courts for use as evidence.

9.2.6 Determine whether and under what circumstances HIV/AIDS information may be disclosed to researchers.

9.2.7 Identify any other person or agency entitled to receive HIV/AIDS information and the circumstances under which such information may be disclosed to them.

9.2	**Protection of HIV/AIDS information**
Citation	
Type of provision	
Narrative summary	

10.0 Anti-discrimination provisions

10.1 Specific anti-discrimination protection for people with HIV/AIDS

10.1.1 Does the law specifically prohibit discrimination against persons with HIV/AIDS?

10.1.2 Describe the forms of discrimination prohibited (e.g., employment, public programs, professional services)

10.1.3 What are the enforcement mechanisms and remedies (money damages, fines, etc)?

10.1	**Specific anti-discrimination protection for people with HIV/AIDS**
Citation	
Type of provision	
Narrative summary	

10.2 Discrimination based on disability

10.2.1 Identify any law prohibiting discrimination based on disability.

10.2.2 Describe the forms of discrimination prohibited (e.g., employment, public programs, professional services)

10.2.3 What are the enforcement mechanisms and remedies (money damages, fines, etc)?

10.2.4 Does the definition of disability encompass HIV/AIDS or drug addiction?

10.2	**Discrimination based on disability**
Citation	
Type of provision	
Narrative summary	

10.3 Other anti-discrimination laws

10.3.1 Identify any other anti-discrimination laws that are or could in the future be construed to provide protection to people with HIV or drug users

10.3.2 Describe the forms of discrimination prohibited (e.g., employment, public programs, professional services)

10.3.3 What are the enforcement mechanisms and remedies (money damages, fines, etc)?

10.3	**Other anti-discrimination laws**
Citation	
Type of provision	
Narrative summary	

10.4 Government agencies enforcing anti-discrimination provisions

10.4.1 Determine whether there is a government agency or body to oversee or enforce anti-discrimination provisions.

10.4.2 Does this agency or body also interpret the law related to anti-discrimination?

10.4	**Government agencies enforcing anti-discrimination provisions**

Citation	
Type of provision	
Narrative summary	

11.0 International human rights treaties and national law

11.1 Identify the provision of law that govern the status of international human rights treaties and conventions in relation to national laws

11.2 Determine to what extent, under these provisions, international human rights conventions take priority over national or local laws, and whether the conventions are enforceable or binding.

11.0	**International human rights treaties and national law**
Citation	
Type of provision	
Narrative summary	

12.0 Bilateral agreements on drug control

12.1 Determine whether the country has participated in any bilateral agreements on drug control and describe any agreements.

12.0	**Bilateral agreements on drug control**
Citation	
Type of provision	
Narrative summary	

13.0 Other laws that influence risk or stigma among drug ay

13.1 Document any other laws identified by the CAB or Module III research that are applied to target groups in way that influences their risk of HIV or the stigma of HIV or drug use in a significant way.

13.0	**Other laws that influence risk or stigma among drug users**

Citation	
Type of provision	
Narrative summary	

14.0 Other laws that influence the work of HIV prevention organizations

14.1 Document any other laws identified by the CAB or Module III research that significantly influence ability of HIV prevention organizations to do their work (for example, limits on NGO fund-raising).

14.0	**Other laws that influence the work of HIV prevention organizations**
Citation	
Type of provision	
Narrative summary	

RAPID POLICY ASSESSMENT & RESPONSE

Module II: Existing Data
Topic Areas (1), (2), (3)

Training Materials

Sources of Existing Data

Purpose and Intended Products

In this module of the RPAR, researchers gather

- Laws on drug use, drug treatment, syringe access, the rights of people accused of crimes, and public health activities
- Existing data on the spread of disease in the country and the community, and
- Existing data about crime and the operation of the criminal justice system.

Purpose

The information collected will provide a foundation upon which to build the remaining research of the RPAR. Law on the books is the starting point for any discussion of policy effects on health. Data on HIV and other significant diseases is essential to assessing the severity of the health policy problem in the country. Criminal justice statistics are an important measure of crime, the extent of the country's reliance on incarceration, and the extent of drug use.

Intended Product

At the conclusion of this module, the researcher will have

- Compiled and categorized the relevant law
- Compiled and analyzed existing epidemiological data
- Compiled and analyzed existing criminal justice system data

Module Two: Existing Data

Roadmap for Training

Why we are collecting existing and new health data?

Basic concepts and terminology in health and social epidemiology

Basic principles and characteristics of harm reduction

Basic definitions related to legal research in the RPAR

Basic domains of criminal justice data

How to use the tools

Justification for Collecting Existing Health and Drug Use Data

We are collecting existing and new health data in order to understand

- The extent and nature of health and risk behaviors among IDUs.
- Why IDUs engage in risky behavior.
- The factors that inhibit or enable risk reduction among IDUs.
- How community norms and practices influence health and risk behavior.
- How community settings and contexts influence health and risk behavior.
- How different social groups and networks influence health and risk behavior.
- How local and national policies and attitudes influence health and risk behavior.
- How the social, legal and economic environments influence health and risk behavior.

Epidemiological Data on HIV, communicable diseases and drug use

Collecting detailed and highly accurate epidemiological data is not the focus of the project, but effective policy analysis and development depends on using the best data available (even if it is to argue that better data must be collected in the future). Teams should devote minimal independent research to this portion of data collection, ***because this is not the primary focus of this assessment***. During the key informant interviews with public health and other experts, teams should identify additional sources of data that expert informants can supply.

Where new sources of data are collected, it is important for teams to ensure that they keep accurate citations to the source of the data. Collection sheets should facilitate this and where on-line sources are used, keeping a hard copy in addition to the URL is very important because web resources may change over time.

The following sections on use of existing information and model queries to guide data collection are drawn directly from the WHO-IDU-RAR.[1]

Existing information allows the researcher to:

- use information that they would not otherwise have the resources to collect
- compile profiles of factors which can obstruct or facilitate activities and behaviors
- use local information to obtain a 'snap-shot' of what is currently happening in the area

It can include such things as:

[1] WHO. The Rapid Assessment and Response Guide on Injecting Drug Use (draft for field-testing). Geneva: WHO, 1998. (English)

- *routinely collected data* from government bodies, treatment centers and university researchers
- *documentary sources* such as television news programmes and NGO annual reports, and local information from community organizations, religious groups and outreach workers

Skills in using existing information are important, as:

- in the *early stages* of a rapid assessment it involves the collection of background data on the local area, surrounding region, and national situation. This is useful in understanding the context in which the study is being conducted
- in the *early and middle stages* it can identify gaps in current knowledge and practice which could be investigated further
- in the *later stages* it can monitor and cross-check findings from other methods

It can be tempting to only collect information that is readily available and not to make any specific efforts to search out information. However, information should be:

- *actively located* - this will avoid important information being omitted from the study ***[Note, this advice while valid for primary objectives, is not necessary for the purposes of the RPAR]***
- *systematically managed* - to allow materials to be easily located and distributed at a later date

The key strengths of using existing information are:

- it is usually cheap and easily obtainable
- it can provide *representative* descriptions of the distribution of behaviors or characteristics in a population
- it can be used to *triangulate* findings

Existing information rarely provides an unproblematic description of the situation:

- documentary sources vary widely in terms of their accuracy
- statistics must always be interpreted carefully by the researcher as they can be biased or inaccurate
- the information is often produced with a particular audience in mind.

Basic Concepts and Terminology in Health

Diseases We Are Tracking:

HIV/AIDS

HIV/AIDS is caused by infection with the Human Immunodeficiency Virus. Infection usually results in flu-like symptoms 4-6 weeks after exposure. It may not cause other noticeable symptoms for many years. HIV undermines the immune system, eventually resulting in most cases with the breakdown of immunity and illness and death caused by various other infections. A person with these serious symptoms has AIDS, which is defined according to a uniform AIDS case definition.

HIV is difficult to transmit. It is normally spread by the transfer of infected blood during injection drug use, and through sexual contact involving exposure to semen, blood and vaginal fluids.

Tuberculosis

Tuberculosis is a respiratory disease caused by a bacterium. People who have been infected may not have any symptoms or be able to transmit the disease; these people are said to have "latent" TB. In "active" TB, the person is ill and can spread the disease through the air. Prolonged exposure is usually required to transmit the disease. Treatment can take months or years.

Syphilis

Syphilis is a sexually transmitted disease. It normally can be treated. Syphilis incidence is often used to estimate the rate of HIV spread through sex, because syphilis is more quickly detected and more often reported.

Hepatitis

Hepatitis is a disease of the liver. There are actually many hepatitis viruses, the most important for our purposes being B and C. Both are readily spread through drug use. They are easier to transmit than HIV, and less dramatic in their effects. Both can lead to severe liver disease and death.

Other STDs

You may be able to get statistics on gonorrhea, chancroid or chlamydia. These sexually transmitted diseases, like syphilis, are useful indicators of trends in unprotected sexual activity.

Drug Resistance

All the diseases above can be treated, including HIV. When treatment is interrupted or improperly administered, however, the bacteria or viruses being targeted can mutate and develop resistance to the medicine. Such "drug resistant" strains become more difficult to treat, and can be spread from person to person.

Tracking Cases:

Incidence vs. Prevalence

Incidence is the number of new cases occurring in a certain time period. Prevalence is the total number of people with the condition in a certain time period.

Reported Cases vs. Actual Cases

Reported cases are the cases of which the authorities have been informed. Because reporting and tracking systems rarely get complete information, the number of reported cases is usually lower than the number of actual cases, which are estimated using statistical methods or surveys. The worse the reporting rate, the greater the difference between reported and actual cases.

Typical data tables:

Data on Russia from The European Centre for the Epidemiological Monitoring of AIDS

Year	Reported AIDS cases		Reported New HIV infections		Homo/bi Contact #		Injection Drug Use #		Heterosexual Contact #		Perinatal Transmission #	
	#	Rate/ Million	#	Rate/ Million	HIV	AIDS	HIV	AIDS	HIV	AIDS	HIV	AIDS
1993	14	0.1	108	0.7	-	-	-	-	-	-	-	-
1994	34	0.2	158	1.1	-	-	-	-	-	-	-	-
1995	39	0.3	196	1.3	-	-	-	-	-	-	-	-
1996	50	0.3	1546	10.5	91	17	1021	0	84	12	5	0
1997	71	0.5	4399	29.8	49	19	2474	5	199	14	38	1
1998	66	0.4	3947	26.8	66	23	1667	4	249	12	67	2
1999	40	0.3	20163	137	68	4	10678	19	630	6	178	2
2000	22	0.1	55123	374.5	48	0	23482	6	792	3	136	0
Cumul Totals	451	-	86249	-	650	119	39329	29	2251	72	438	7

Reported HIV Infections, Russia

	1995	1996	1997	1998	1999	2000	2001	2002
New Infections	196	1526	4375	4055	19846	59340	82852	
Total Infections	1074	2000	6975	11030	30876	90216	173068	
Prevalence/100,000	0.7	1.8	4.7	7.5	21.1	62.1	199.5	
Incidence/Year/100,000	0.1	0.1	3	2.8	13.6	40.9	57.2	

Source: Ministry of Health and Federal AIDS Center of the Russian Federation

Individual and Social Causes of Illness

People usually speak about HIV/AIDS as a disease that is caused by individual behavior.

Risk behavior

"Health behavior" is a general term that describes actions people take that influence their health (such as diet, exercise, and other aspects of lifestyle such as employment and living conditions). "Risk behaviors" are actions that increase the likelihood of harmful health outcomes. "Risk reduction behaviors" are actions that reduce the chances of harm occurring. Injection drug use and unprotected sex are said to be risk behaviors for HIV, but it is important to be specific. A drug user who prepares and injects his drug by himself, using equipment that has not been used by anyone else, will not get HIV or hepatitis from the injection. A monogamous, uninfected couple will not spread HIV in unprotected sex. There may be an interaction between different health and risk behaviors. People who use drugs also have sex, for example. It is important to see people in their full complexity

Risk Behavior in Social Context

It is important to understand how individuals get HIV/AIDS, but the individual focus is incomplete. Individual behavior is influenced by:

- Others (such as sex partners, family, others in the community, and community-wide 'norms').
- By the setting in which behavior occurs (such as a drug scene).
- Structural factors on behavior (such as public attitudes, policies and laws).

These may increase or decrease the ability of people to lead healthy lives and may increase or decrease the risk of harm among populations at risk. In fact, these may be the most important factors.

Case Study: 19th Century Sociologist Emile Durkheim Studies Suicide in Paris

Durkheim demonstrated the importance of the social environment by studying one of the most individual and intimate behaviors imaginable -- suicide. In his work, Durkheim noted that suicide rates in countries and groups exhibit a patterned regularity over time, even though individuals in these groups come and go. If suicide is a product of anguishing intimate and deeply personal problems, it is puzzling to see that rates of suicide in these groups remain higher or lower even though individuals move in and out of groups. These social factors in the environment would not, of course, determine which individuals in the group would commit suicide but they would help to explain group differences in the rate over time.

The perspective of Durkheim was to see that the health and well-being of a community were affected by the social milieu within which people lived. [Yet] most research in epidemiology today nevertheless continues to focus on the individual. We tend to study risk factors in individuals and we tend to focus interventions on individual behavior. The problem with this approach is that even if these interventions were completely successful, new people would continue to enter the at-risk population at an unaffected rate since we have done nothing to influence those forces in the community that caused the problem in the first place.

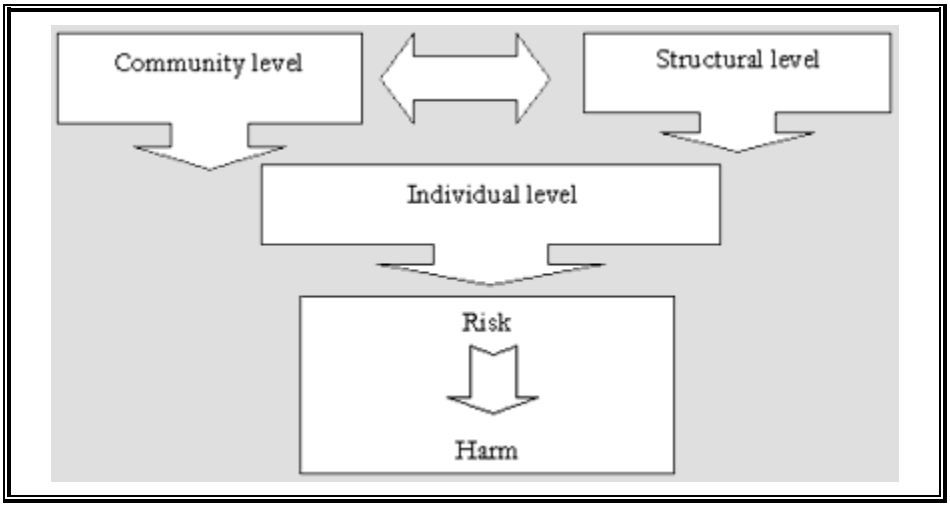
From S. L. Syme, "Foreword," in L. Berkman and I. Kawachi, eds, Social Epidemiology (New York: Oxford) University Press, 2000): ix-xii, at x.

At least three key ideas emerge from this passage:

- that community characteristics are important determinants of health of the people who live within it;
- that health itself may be seen as a characteristic of populations as much as individuals: the differences in suicide rates are telling us indeed more about the population and its social and physical environment than about their individual members; and
- that addressing the immediate causes of illness and death (like suicide) does not necessarily address the deeper causes operating through the proximate ones, and so may not substantially alter the distribution of well-being in the population.

Risk reduction and health promotion require changes in behavior, knowledge and beliefs (individual change), changes in peer group norms and attitudes (community change) as well as changes in public attitudes and policy (structural change).

Health and Risk Behavior at Three Related Levels

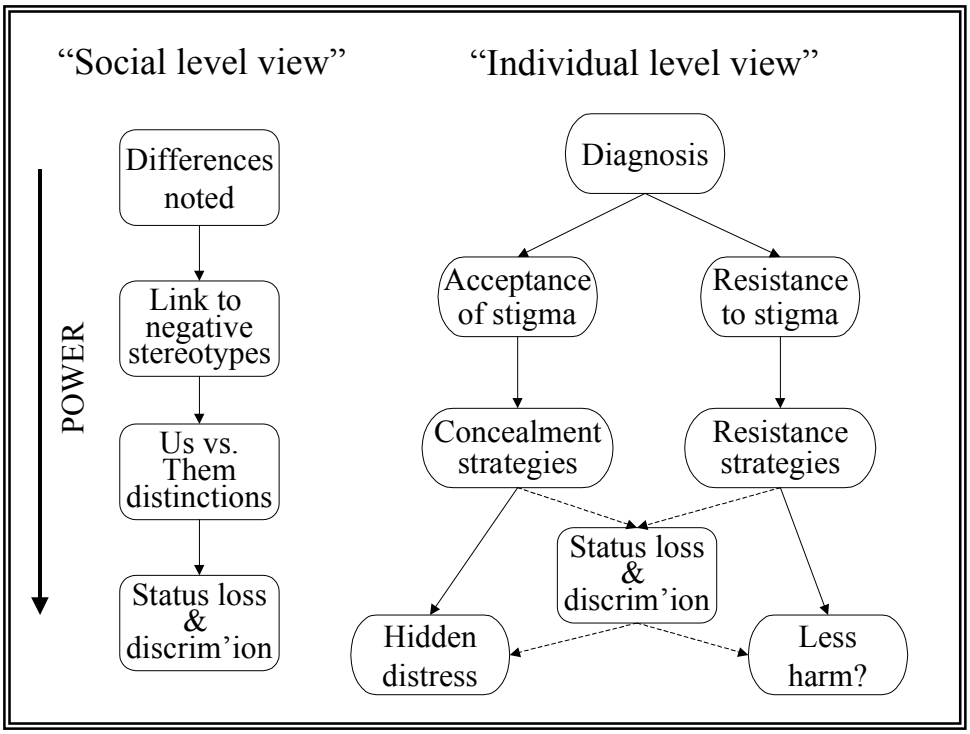


Stigma

In the case of HIV, stigma is a potentially important factor in behavior and social attitudes. Stigma is a mode of social control consisting of negative cultural beliefs about a trait that are operationalized in social attitudes and practices (including the operation of the legal system) and in the affective responses and coping strategies of stigmatized individuals. The power of stigma derives from its decentralized and internalized operation. Although law may support and enforce it, ultimately stigma operates through the attitudes and behaviors of individuals. As Erving Goffman described it, "We construct a stigma theory ... to explain [the stigmatized person's] inferiority and account for the danger he represents, sometimes rationalizing an animosity based on other differences, such as social class." The selection of the trait, its association with negative attributes, and its embedding in group distinctions is performed and maintained collectively through the countless ways in which meaning is made and those of lower status are diverted, marginalized, and excluded by those of higher status. "We use specific stigma terms," Goffman writes for example, "such as cripple, bastard, moron in our daily discourse without giving thought to the original meaning." We make self-serving assumptions about the preferences or needs of the stigmatized. Stigma is also enforced – and sometimes most significantly enforced – by the stigmatized people themselves, who simply conform their attitudes and behavior to the asserted norm of spoiled identity.

At its strongest, stigma is hegemonic – accepted as natural and sensible, without reflection. It is enforced in everyday life simply by the way individuals react to such a "reality." At the same time, the culturally contingent nature of stigma is also its weak point: stigma can be thought of as a rebuttable social presumption. Dispositive if conceded, once challenged it may prove quite weak. Simply reducing self-enforcement can have a considerable effect on its severity, and the conversion of an unchallenged hegemony to a battle of competing ideologies can significantly alter the expression and potentially the extent of stigma.

This table portrays two current models to understanding how stigma operates.



It is important to recognize that stigma is only one facet of social risk. Not all discrimination or prejudice directed at people with a disease can be regarded as flowing from stigma. In some instances a condition creates risks that justify "legitimate" discrimination – for example, driving restrictions for people whose epileptic seizures were not clearly controlled. What is legitimate, or merely a reflection of stigma (e.g., exclusion of people with HIV from military service) is certainly not always easy to discern, but there will be some instances with most disease in which discrimination can be reasonably justified. Likewise, some arguably illegitimate discrimination could be based on factors other than stigma: for example, an insurance company might seek to deny certain coverage to people with HIV on economic grounds, without its staff in any way sharing a stigmatized view of applicants with HIV.

Stigma tends to be seen as a force that drives people with HIV underground, away from services and care. The tendency of someone facing stigma is to hide the stigmatized trait if possible. HIV can be concealed for a long time. Some research and the experience of HIV advocates in many countries, however, suggest that in many instances it may be better for people to fight the stigma openly. From a policy perspective, it is important to ask whether and how law can play a role in facilitating this important process.

Although stigma cannot be measured directly by any single type of existing data or legal provision, documentation of incidence and prevalence of multiple diseases and law enforcement activity, as well as the existence or non-existence of legal provisions can help identify both the possible markers of and contributing factors to stigma and potential means to reduce stigma.

What happens through law at the social level to reduce the actual incidence of stigma and to support collective resistance to stigma's effect on culture would certainly be important. Enforcement of rules against discrimination, and voluntary compliance, can be expected to reduce the objective risks of exposing a stigmatized trait just as laws that impose penalties upon people with the trait can encourage concealment. In protecting people from discrimination or other forms of mistreatment, rights can be "powerful silent partners, shaping experiences and opportunities" even when they are not invoked or even noticed by those they protect. It is nonetheless important to recognize the often weak link between objective risks of enacted stigma and the risks perceived by the person acquiring the stigma. Law's effect on the initial process of coping with stigma is likely to be far less than (and mediated through) the behavior and attitudes of health care and social service providers who convey the diagnosis and take some deliberate or inadvertent role in helping the individual understand their new world. Given any chance of serious social harm arising from publication of the individual's disease, many, if not most, people will at least initially see concealment as the most psychologically comforting strategy.

Case Study: HIV Among African-American IDUs

The striking racial disparity in HIV, particularly injection-related HIV, in the U.S. has been attributed by some commentators as a product of racial disparities in policing. The suggested mechanisms are plausible:

First, intense police surveillance, combined with laws against possession of drug paraphernalia, has made the possession of clean syringes in minority neighborhoods extremely risky. Fear of arrest compels injection drug users to rely on syringes borrowed at the moment of injection. Second, persistent police harassment has promoted the spread of underground shooting galleries. These are the most risky sites of HIV transmission, because of both sharing of infected syringes and sex for drugs exchanges. Third, differential arrest rates have exposed black and Latino males to unsafe drugs and sex in prison. Fourth, the frequency of shared syringes, shooting galleries, and unsafe sex and drugs in prison has increased the rate of HIV infection among black and Latino males and made it more likely that an adult "who borrows a needle from a friend is much more likely to borrow an infected needle than is the young white adult who borrows a needle from another white." Fifth, the high rate of HIV among black and Latino males has exposed women and their offspring who live in those neighborhoods to a much higher risk of infection from unprotected sex.

From C.L. Schneider, "Racism, Drug Policy, and AIDS," Political Science Quarterly, 113 (1998): 427-447

Basic principles and characteristics of harm reduction

Harm Reduction

"Harm reduction is a set of practical strategies that reduce negative consequences of drug use, incorporating a spectrum of strategies from safer use, to managed use to abstinence. Harm reduction strategies meet drug users "where they're at," addressing conditions of use along with the use itself."[2]

Criminal justice measures to combat drug use are easily identified in most countries. The RPAR Module II asks the research team to collect and analyze those provisions along with other criminal laws often relevant to the lives of IDUs including access to drug treatment and other familiar public health measures. However, understanding the full range of options (legal, practical, and political) available to communities to combat drug use requires considering approaches beyond traditional criminal and public health law. The theory and practice of harm reduction offers a range of ways to reach drug users and to help reduce the health risks they encounter daily.

[2] The Harm Reduction Coalition. Definition and principles. Available at: http://www.harmreduction.org/prince.html .

Harm reduction practices should reflect the specific needs of drug users and the local community. Therefore there is no single set of principles to describe harm reduction. The Harm Reduction Coalition presents the following principles as central to harm reduction practice.

- Accepts, for better and for worse, that licit and illicit drug use is part of our world and chooses to work to minimize its harmful effects rather than simply ignore or condemn them.
- Understands drug use as a complex, multi-faceted phenomenon that encompasses a continuum of behaviors from severe abuse to total abstinence, and acknowledges that some ways of using drugs are clearly safer than others.
- Establishes quality of individual and community life and well-being--not necessarily cessation of all drug use--as the criteria for successful interventions and policies.
- Calls for the non-judgmental, non-coercive provision of services and resources to people who use drugs and the communities in which they live in order to assist them in reducing attendant harm.
- Ensures that drug users and those with a history of drug use routinely have a real voice in the creation of programs and policies designed to serve them.
- Affirms drugs users themselves as the primary agents of reducing the harms of their drug use, and seeks to empower users to share information and support each other in strategies which meet their actual conditions of use.
- Recognizes that the realities of poverty, class, racism, social isolation, past trauma, sex-based discrimination and other social inequalities affect both people's vulnerability to and capacity for effectively dealing with drug-related harm.
- Does not attempt to minimize or ignore the real and tragic harm and danger associated with licit and illicit drug use.[3]

Educating the key members of the local community about the purposes of harm reduction can be a crucial step in gaining community support for the RPAR. Harm reduction has a well-established place in public health and clinical programs as varied as smoking cessation and fighting obesity. However, harm reduction has also become associated with campaigns to legalize drugs. Understanding that harm reduction strategies have been widely endorsed by public health and legal organizations could assist local efforts to increase support for harm reduction among city officials or drug treatment personnel.

Because harm reduction must be tailored to the specific community, no single list of best practices could be imposed for all harm reduction programs. However, a number of organizations interested in the reducing the harm from drug use have endorsed some or all of the practices described below in the “Best Practices Grid”.

[3] The Harm Reduction Coalition. Definition and principles. Available at: http://www.harmreduction.org/prince.html .

Best Practices Grid

IDU Best Practice	World Bank	UNAIDS	UNGASS	SOROS	US CDC	USAID	GHC	ABA
Counseling	X	X	X	X	X	G		
a. Voluntary Counseling	G	X	X	X				
Drug Abuse Treatment	X	X	X	X	X			
Outreach Program	G	X	G	X	X	G		
Testing		X	G	X	G	G	G	
Needle Exchange Program		X	X	X	G	N	G	G
a. in prisons		X		X	X	N		
b. Machines		X		X		N		
c. Pharmacies		X		X		N		
d. Clean Injecting Equipment	X	X	X	X		N		X
e. Free Needles	X			X		N		
Laws and Gov Policy Change	G	X	X	G		G	G	G
Education	X	X	X	X		G		
a. Peer Education	G	X	G	X				
Reduce Poverty	X	X						
Condoms	X		X	X				
Overdose Prevention				X		N		
Methadone				X		N		
Reduce Stigma	G	G	X	X				
Reduce Demand for Drugs		X						

Legend X = Lists as a Best Practice, G = Supports as Best Practice, N= Does not support

Legal Research in RPAR

What is "law"?

Law is both what is written in the books AND the behaviors and attitudes and expectations of people about how the community is governed.

The RPAR is built on a sociological view of law (including human rights) as both 1) state-linked rules and the system of practices and institutions that support them ("state law"), and 2) the social meaning that both produces and is produced by the rules ("legality").

State law is comprised of the explicit, formalized rules governing social life and understood to be law or enforceable through law -- from the decisions of courts to the public international law of treaties. The realm of state law also embraces the institutions and technologies for creating, interpreting, enforcing or otherwise implementing, and studying/teaching law.

State law includes all law that is enforceable through a variety of mechanisms such as administrative or criminal penalties, legal judgments, or official powers to coerce behavior, seize or dispose of property or decide disputes. State law includes laws, statutes, or ordinances enacted by elected or appointed legislative bodies. Regulations, rules and official opinions issued by government agencies and decrees, directives or orders from agencies or executives that are enforceable as well as court opinions and judgments that interpret or establish the law.

Law on the books consists of

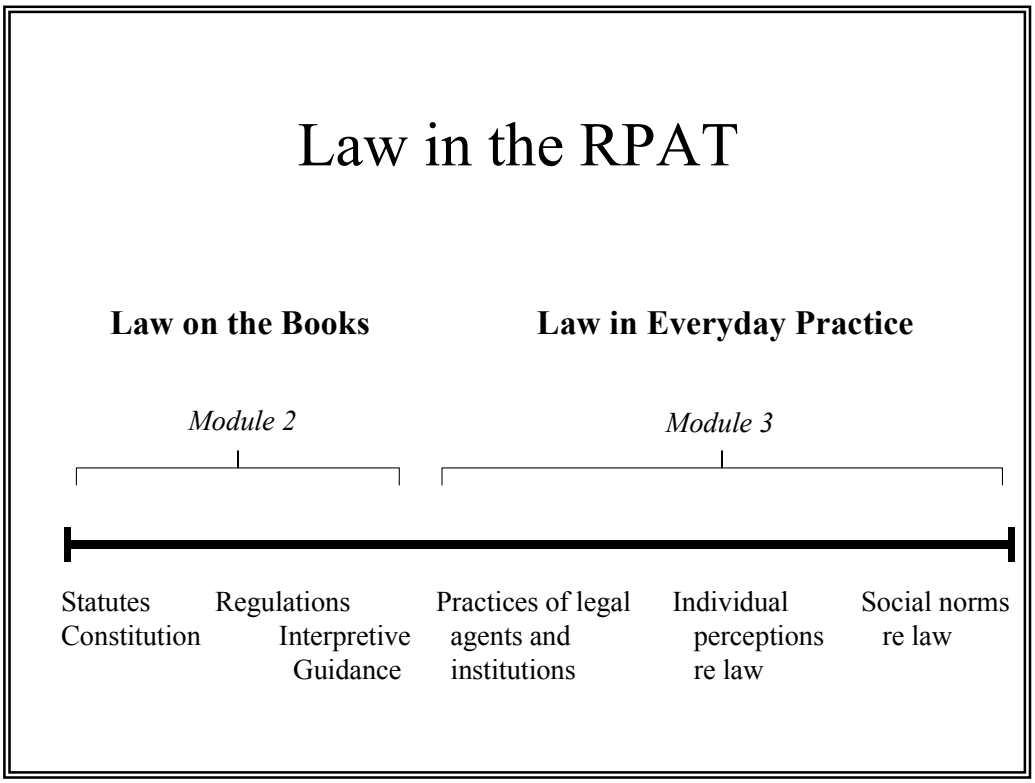
- Constitutions and any treaties that have the force of law
- Statutes passed by the national or regional legislature
- Ordinance (statutes) passed by local legislative bodies
- Administrative regulations with the force of law, issued by administrative agencies at the national, regional or local level
- Court decisions interpreting laws or regulations
- Executive orders or decrees with some binding effect issued by executive officers at the national, regional or local level
- Internal documents created by agencies to guide their enforcement or interpretation of laws and regulations
- Guidance on the interpretation of laws issued for the public by an agency or executive body

What happens within the system of state law is heavily influenced by the characteristics of the society in which the state law system operates. Conversely, the system of state law penetrates society, both in the sense that much if not most legal activity takes place outside the official system of courts, bureaucracies and legislatures, and in the broader sense that law and legal ideas contribute to the forms of thought and behavior in the society outside the formal legal system. On this view, law is not viewed as separate from the society within which it operates; we do not have law *and* a society,

but law *in* society. Law can be seen as of the same ilk as religion or education, as at once a product and a producer of meaning and behavior in a population.

Sociolegal scholars use the terms "legal consciousness" or "legality" to refer to a population's set of ideas about the law. Ewick and Silbey define legality as:

> the meanings, sources of authority and cultural practices that are commonly recognized as legal, regardless of who employs them or for what ends... Legality ... operates through social life as persons and groups deliberately interpret and invoke law's language, authority and procedures to organize their lives and manage their relationships. In short, the commonplace operation of law in daily life makes us all legal agents insofar as we actively make law, even where no formal legal agent is involved.[2]



Human rights

Human rights are a concept that has links to both law and advocacy in public health. Human rights are a set of positive entitlements and negative immunities, rooted to some extent in international law but more fundamentally in a vision of the basic, essential rights due to any human being. John Mann and colleagues wrote:

> Several fundamental characteristics of modern human rights include: they are rights of individuals; these rights inhere in individuals because they are human; they apply to all people around the world; and they principally involve the relationship between the state and the individual. The specific rights which form the corpus of human rights law are listed in several key documents: foremost is the Universal Declaration of Human Rights (UDHR), which, along with the United Nations Charter (UN Charter), the International Covenant on Civil and Political Rights (ICCPR) – and its Optional Protocols – and the International Covenant on Economic, Social and Cultural Rights (ICESCR), constitute what is often called the "international Bill of Human Rights."
>
> ....
>
> Building upon this central core of documents, a large number of additional declarations and conventions have been adopted at the international and regional levels, focusing upon either specific populations (such as the International Convention on the Elimination of All Forms of Racial Discrimination...) or issues (such as the Convention against Torture and Other Cruel, Inhuman or Degrading Treatment or Punishment...).

As this description suggests, the scope of human activity in some sense regulated or informed by human rights and international human rights law is extremely broad. Also to be inferred from the quoted description is an important but subtle distinction between *human rights* and *human rights law*, the former term referring to the universal entitlements of human beings to certain opportunities and immunities, and the latter to the evolving body of international and state law more or less effectively embodying and implementing these rights. On this view, "law" is a somewhat narrower concept than human rights, at best an instrument of their fulfillment, at worst a violation of human rights, and in many instances simply irrelevant. The fact that a state may not have embodied a particular human right in its constitution, statutes or judicial decisions does not reduce the entitlement of that state's citizens to the observance of that right.

Human rights includes a range of positive social and economic rights, and has come to be understood to creating obligations on states to take affirmative action to ensure their enjoyment, including the regulation of the behavior of citizens towards one another. These government duties may be conceived quite broadly to include: (a) *respect* – the state's obligation not to infringe human rights, (b) *protection* – the state's obligation to prevent private violations (e.g., anti-discrimination laws), and (c) *fulfillment* – the state's obligation to promote human rights (e.g., education and services).

As commentators like Stephen Marks and Lawrence Gostin have observed, the term "human rights" is commonly used in the literature in at least three distinct senses: 1) A set of legal obligations of states set out in international and state law; 2) A mode of moral reasoning rooted in or articulating a vision of the good in social relations; and 3) A strategy for attaining specific policy goals in state and international political struggle.

Criminal Justice Data

Why we are collecting criminal justice data?

Existing information about the workings of the criminal justice system can be important to understanding the scope of the law's influence on health, as well as a guide to advocacy solutions. Key data to watch out for include:

- A high volume of arrest, particularly in drug related crimes
- A high rate of incarceration
- Prison overcrowding
- Many people in pre-trial detention for long periods of time
- High rates of disease in prisons

The budget of courts and police is also of considerable interest. In some instances, support for more funding (for speedier trials or better conditions of confinement, for example) may be indicated. In other instances, the advocate could make the case that money wasted on arresting IDUs could better be spent on harm reduction programs.

What we are collecting?

Data related to arrest and prosecution, conviction and sentencing for specific crimes:

- Arrest, prosecution, conviction and sentencing data, where available for drug, sex work and sexual orientation related crimes;
- Breakdown of types of drugs
- If possession of syringes or other paraphernalia is a crime, any separate data on arrests for possession of paraphernalia alone;
- Any data on arrests or prosecutions for interference with harm reduction activities (aiding drug use, illegal distribution of syringes, etc)
- Data on purity of drugs seized, if available;
- Data on structure and functioning of the legal system:
    - Number of people held in pretrial detention;
    - Average time of pretrial detention;
    - Number of defendants represented by lawyers paid for by the state
    - General data on court system backlogs
    - Number of people imprisoned, proportion imprisoned for drug offenses
    - Number of police officers, prosecutors and judges working in the system
    - Budgets for local, regional and national court systems

Any data on civil suits for

- Discrimination;

- Breach of confidentiality;
- Enforcement of non-criminal HIV protection provisions.

How do we collect these data?

Where available, these data, can provide valuable objective evidence of enforcement or non-enforcement of specific criminal provisions as well as highlight settings in which drug users might be placed at increased risk. For example, if arrest data are generally available, but there are no recorded arrests for a specific crime, it could suggest that the law is generally not enforced through arrest and prosecution. Or, data showing increasingly long periods of pre-trials detention may suggest that the court system is becoming unable to handle new cases and that drug users (and others) held in pretrial detention may be at risk for disease transmission.

These data may be available online, through published statistics at the local, regional or national level, or held by the local prosecutors. Efforts should be made to identify quickly whether these data are generally available or whether special requests must be made to local authorities. Where data are publicly available they can be obtained and summarized for statistics relevant to this project.

Expect possible delays where requests have to be approved by officials or data is held in non-public databases. Wherever possible consider using a sympathetic local official to request the data directly from law enforcement agencies. A formal letter from the mayor's office may well produce a more timely response from local police than a letter from an independent researcher.

Finally, while these data can provide useful objective evidence, they are NOT the primary focus of this project. It is anticipated that some, if not most, of the categories of data listed in the tools and training materials may be unavailable for your locality, region, or nationally. The RPAR anticipates this and asks you to use these data as only part of your analysis of the local and national situation. Do NOT let difficulties in finding specific law enforcement data delay other parts of the research.

How to Use the Tools

When to use these tools?

Data collection from existing sources formally begins as soon as the team has completed the RPAR training. In fact, however, some of these data may have been identified or collected during the Initial Consultation. Often local officials, health department, or drug treatment personnel may have and refer to their own sources of existing data during these initial interviews. The team may well have received basic documents on local HIV status or new legal provisions. These tools are intended to organize the collection of all existing data.

Collection of existing data may also continue into the phase of qualitative interviews based on identification of new sources of data or new legal provisions of interest.

Topic Area 1: Law

Completing this tool may require using on-line databases of current laws and/or use of court and academic libraries. If working in teams, it may make sense to divide the research according to which areas are covered together in the local laws. Frequent communication between team members should prevent duplication of effort.

How to proceed?

For each specific area of law covered:

The following four steps should be used to guide the collection and recording of legal provisions throughout the RPAR. The tools section provides specific questions related to each of the 14 substantive areas identified as well as a forms to record the citation and narrative summary of the legal provision.

Step 1: Identify laws and obtain the complete citation in correct local format

- Identify national, regional and local laws and ordinances related to each substantive area and its related questions;
- Using correct citations allows others to find, cite, use, or verify the provision later.

Step 2: Copy the law

- Copy the whole statute or legal provision, determine whether an English translation exists and copy the translated law also.
- Many times the meaning and application of legal provisions depends on the exact language of the original provision, therefore the actual text is always important.

Step 3: Provide a narrative summary and analysis of the law

- In doing so, address each of the domains listed in relation to each question.

- Type of provision: Distinguish whether the rule is a statute/law, an administrative regulation with the force of law, an executive directive from an agency or official (e.g., a presidential decree), a written policy of an agency without the force of law, a written standard operating procedure or other management directive of a law enforcement agency, or a form of legal guidance issued by a law enforcement agency.
- CAB meetings and research in Module III may lead to more areas of relevant law being identified, and require additional legal research.

The Domains of Law in the RPAR

1.0 Drug use
Drug control laws
Syringe laws
Needle exchange programs
Drug treatment
2.0 Commercial sex work
3.0 Homosexuality and homosexual behavior
4.0 HIV-specific criminal exposure or transmission
5.0 Criminal justice/procedure
6.0 Right to health care/ right to HIV treatment
7.0 Reportability of HIV, AIDS, HCV, HBV, TB, Syphilis, and STDs
8.0 HIV testing laws
9.0 Privacy of medical information
10.0 Anti-discrimination provisions
11.0 National provisions related to international human rights norms
12.0 International drug control agreements
13.0 Other laws identified by CAB or Module III research that influence risk or stigma among drug users in a significant way
14.0 Other laws identified by CAB or Module IV that influence the work of HIV prevention organizations in a significant way

Research team members may identify other relevant areas of "law on the books" during the course of the key informant interviews, focus groups and Community Action Board Meetings (areas 13 and 14). When these are identified, team members with legal research capacity should immediately document the area to be searched and its relevance to reducing HIV among drug users and other HIV prevention efforts. The law should be summarized in the same way the other areas of law have been (for each, make a copy of the actual text, provide a complete citation, indicate the type of provision, and provide a narrative summary).

Topic Areas:

2: Epidemiology of HIV, Other Communicable Diseases and Drug Use
3: Law Enforcement Data

These Topic Areas provide important context for the RPAR by documenting health and disease risks in the country and the local community, by providing a sense (where the data is available) about the extent and changing patters of drug use, and by providing a sense of the behavior of law enforcement personnel and how the legal system works. However, ***these data are not the primary focus of the RPAR***, so the training materials and tools will continue to emphasize the collection of ***existing data***. The RPAR does not include its own epidemiological survey of disease, drug use, or arrests. We only expect the research team to collect the ***best available data***, to be persistent in identifying new sources of data, and to collect, and use the data as fully as possible.

The goal should be to get as complete, recent and reliable information as possible about prevalence and incidence of HIV, TB and other conditions the local, regional and nationals level and as complete data as possible about the prevalence of drug use and information about drugs used at eh local and national level for Topic Area 2. For Topic area 3, the data sought include statistics on arrests, prosecutions, convictions and sentencing for drug and drug related crimes (same substantive areas as Topic Area 1: Law on the Books) as well as data on the structure, resources and functioning of the criminal justice system.

Multiple sources are useful because each may give an incomplete picture of the epidemic and even data sources of similar scope can provide triangulation of data estimates.

Where possible, data should be collected in the most useable format possible. We expect the data will normally be available in table form, which can be attached to or clipped into your research data records. On occasion, you may need to create tables or graphs. Sometimes, data may be found in reports or published epidemiological studies. These sources may also have useful discussion and analysis. It is likely that different sources will categorize the data differently (e.g., some will lump together all opiates, others will separate home-made opiates and heroin).

What to do about incomplete or missing data?

We anticipate that no RPAR team will be able to collect data in tables or other format that answers *every question* included in the tools. We expect the RPAR research team to use the tools, use all available sources, and collect data *as completely as possible*. Sometimes the absence of data in particular areas may be a research result worth noting and presenting to the CAB, local officials and others.

As you collect data, compare what you find with the domains below to check how well you are doing; don't stop just because you find something on the list because different sources will have different numbers.

For each source of data:

How complete are the data?
What years do they cover?
Do they cover the entire country?
Specific regions only?
Specific cities only?
The site city?

These questions will help guide your additional searching to fill in the gaps of the data you have already found.

Steps of data collection and documentation

Step 1: ***Obtain data***

For each domain below, find and copy available data for up to *ten years* if possible.

It is absolutely crucial to identify, label and record the source of the data if that is not immediately obvious. For example, a table showing numbers and distribution of new HIV cases should be identified by source (Department of Health, Division of Epidemiology, 2004) as well as by scope (new reported cases for the region, city, oblast, or country) or the table will be useless.

For epidemiological data and drug use data:

The prompts in the tools indicate some of the subcategories that are important or that represent the standard epidemiological way of recording and displaying data (for example, among all communicable diseases obtaining *prevalence and incidence data, where possible, both by numbers and by rates per 100,000 population).* Demographic subdivisions are also important, see prompts, many disease data will be broken down by *age, gender, sexual orientation, and race or ethnicity*. Additionally, for HIV and AIDS, data is often broken down by *mode of transmission* (e.g., IDU, MSM, heterosexual contact, other).

Since disease levels and behaviors differ across geographically it is important to obtain both data that are locally relevant (city or region level) and that illustrate the "big picture" such as national data. Sometimes it will also be important to have data from other countries. For example, for border cities, knowing that there is a sharp increase in recent months or year of new cases of hepatitis B or TB reported immediately across the border clearly identifies a risk of spread to drug users, homeless or prisoners in the local city.

While ideally HIV and other communicable disease data will be available in all these categories across multiple years, it is likely that not all these data will be available for all categories. We do not expect the research team to be able to find data on every disease for every year or for every demographic group. Do not stop collecting if one source of data is missing some categories. And, do not stop if you find a single source that seems to answer all the questions. Multiple sources of data are important because they allow triangulation – a method of verifying the probable accuracy of the data through comparison of multiple sources.

Domains:

HIV and other communicable diseases

- HIV/AIDS
- TB
- Hepatitis B and C
- Syphilis
- Other, locally important communicable diseases
- HIV drug resistance
- TB drug resistance
- Statistics for these conditions in prisons or jails

Drug use

- Heroin
- Kompott
- Other opiates
- Methamphetamine
- Other amphetamines
- Cocaine and crack
- Ecstasy and other club drugs
- Other locally significant drugs
- Injection and injectors
- Drug trafficking patterns

For law enforcement and legal system data

We expect you will find most information in tables, reports, published papers, official or unofficial compilations of data.

Collect the data in the most useable form possible (usually tables or published reports). You do not need to re-record the data in most cases.

- For each substantive area of data collection (see 1.2 below), locate the types of data indicated in 1.1, if possible
- Collect data for up to the last 10 years
- Look for the important variables listed within each substantive area
- Determine who holds the data and how easy or difficult it may be to review, copy or collect the data.
- Determine how complete the data source is (to guide additional search):
  - What years do they cover?
  - Do they cover the entire country?
    - Specific regions only?
    - Specific cities only?
    - The site city?

1.0 Arrest and Prosecution Data:

1.1 Types of Data:

1.1.1 Arrest data
1.1.2 Prosecution data
1.1.3 Conviction/sentencing

1.2 Substantive law domains:

1.2.1 Violation of drug laws (possession, sale, manufacture, trafficking)

- By type of drug (e.g. arrest and conviction data for all crimes involving heroin)
- By type of crime (e.g. for criminal possession charges for all drugs*)
- Where possible include data on the drugs listed below:

  - Heroin
  - Kompott
  - Other opiates
  - Methamphetamine
  - Other amphetamines
  - Cocaine and crack
  - Ecstasy and other club drugs
  - Other locally significant drugs
  - Drug trafficking patterns

1.2.2 Possession of syringes:

- Alone
- In connection with other charges

1.2.3 Harm reduction activities:

- Overall
- NEP operation
- Providing information
- Other

1.2.4 Sex work:

- By gender?
- By other specifics (selling, buying, running a brothel, etc)

1.2.5 Homosexual identity or behavior:

- By gender
- By particular behavior

2.0 Data on drugs:

- For each locally relevant drug: Are there data on purity or quantity of drugs seized?

3.0 Data on civil law suits:

- Are there data on numbers and outcomes of anti-discrimination claims brought for discrimination against HIV+ persons?

4.0 Data on the structure, personnel and resources of the legal system:

- Numbers of police, prosecutors, judges, and salaries of each group
- Budgets, distribution of court houses and jails
- Backlog, if any of cases in the court system

5.0 Data on incarceration:

- The number of people held in pretrial detention
- The average time in pretrial detention
- The number of people held in jails and prisons
- The estimated capacity of jails and prisons
- Number of people on post-sentence supervision (parole)
- Number of people receiving alternatives to incarceration (probation, community service, mandatory drug treatment)

6.0 Are there data on the number of defendants represented by lawyers paid for by the state?

Step 2: ***Evaluate Data***

Assign a number or other identifier to the data source and fill out the Data Evaluation Form for each source. For all data, make sure you have a complete citation for the source. Then assign a number or other unique identifier to the source. This number will allow you to identify the source easily, and to refer to the source in other tables and forms.

This form includes columns listing: source (unique identifier), disease or topic of form, limitations of validity, and notes on access.

In the box "limitations on validity," record any limitations on the validity or accuracy of the data of which you are aware. For example, if official sources estimate drug users using only those identified and registered with the state narcological institute, this would be important to note along with a comment that the actual number of (non-registered) drug users is likely to be much higher. "Non-registered users are not included in state estimate. Local treatment officials estimate 5-10 non-registered/each registered drug user in Kaliningrad."

In the box "notes on access", record any barriers to access to encountered (e.g., "Arrest data were only available in paper files stored in basement of police station." or, "It took 4 written requests to get permission to inspect data"). Or, conversely, note where data is publicly available in useable format. For example, "on-line data available, search possible by year, type of crime, etc."

Step 3: Identify Key Findings

Review the data and identify and list key findings on the Key Findings Form.

At the end of each part of this module, we ask researchers to review the data they have collected to identify key findings. Researchers will have available the published statistics as well as the discussion and analysis in any published papers. The goal of this step is to identify the important information that can be used in the RPAR.

To identify key findings you should do several things. One is to note the important, relevant conclusions of the studies and reports you reviewed, these will usually appear in "Discussion" "Findings" "Conclusions" sections of the report. Not all findings or conclusions of all reports will be relevant to this project, but some may be. Additionally, you must look at the actual data for important findings. Some examples follow.

Important information to look for:

- Trends (changes over time) of the same disease or behavior in the same group. For example, are the numbers of cases of HIV (or AIDS, or TB, or hepatitis) among IDUs increasing or decreasing? Are the numbers of IDUs in treatment up, down, or remaining steady? Are arrests up or down for possession of heroin?
- Changes geographically. Are different parts of the city, region or country reporting disease (drug resistant TB) or behavior (methamphetamine use) that was previously rare?
- Changes among demographic groups. Has the distribution of new HIV cases appeared to shift from IDUs to sexual partners of IDUs? Are many new cases in the 15-24 year old age group?
- Absolute numbers can also be noteworthy, even if the numbers do not represent a trend or change. For example, are there focal points, age, ethnic, or risk groups where the epidemic is particularly severe?

The Key Findings form will be used to prepare your presentation for the CAB and as part of your action planning process in Module IV.

RAPID POLICY ASSESSMENT & RESPONSE

Module III: Qualitative Data

Tools

Qualitative Data: Key Informants
Tools

Purposes

- To learn qualitative data about key domains:
    - Police behavior towards IDUs, people with HIV, CSWs and MSMs
    - Perceptions
    - Access to harm reduction services
    - Social stigma
    - Social risk
    - Social attitudes

Intended Products

1. Qualitative data regarding knowledge, attitudes, and perceptions about police behavior toward IDUs, people with HIV, commercial sex workers CSWs, and MSMs.
2. Qualitative data on access to harm reduction services, including what structural barriers, if any that prevent IDUs who may be people with HIV, commercial sex workers CSWs, and MSMs from accessing those services.
3. Qualitative data on stigma, social risk, and social attitudes as it applies to IDUs, people with HIV, commercial sex workers CSWs, and MSMs.

After the Meeting:

- Organize the data you collected in the attached data organization form.
- Add new notes as needed for the RPAR.

Module III
Qualitative Data: Key Informants
Tools

Introduction to the module:

Module III interviews cover the following topic areas:

1. Enforcement of drug laws
2. Enforcement of prostitution laws
3. Enforcement of laws on homosexuality
4. Enforcement of laws on criminal HIV exposure or transmission
5. Operation of courts and prisons
6. Drug policy politics
7. Harm reduction and public health interventions
8. Advocacy resources
9. Epidemiologic data on HIV and drug use
10. Criminal justice data

Key Informant Interviews

1. There will be a total of 26 system and interactor interviews (see Table A below) and 14 IDU interviews (see Table B)

2. There are two different interview guides; one for system and interactor interviews and one for IDU informants. Be sure you use the correct one.

3. Every day you should plan your interviews. Pack all the required materials in a bag; things such as extra tapes and batteries, interview guides, incentives, pens, paper, and anything else you might need to conduct interviews

4. After every interview, label and date the tape, write pertinent notes, and begin to organize your data by entering findings into table that corresponds to our numbered topic areas. You may have to listen to relevant parts of the tape in order to remember how people responded. Be sure to find a confidential space to do this.

Number and Type of Interviews

You have learned about system, interactor and IDU key informant interviews. We are asking you to recruit and interview particular types of people as well. For system and interactor interviews, if you are unable to recruit a type of person you may interview another types of person.

For example if you are unable to recruit two police officers and can only get one, you might recruit a member of the local military as the second interview. However, before making any substitutions, ask yourself if you have exhausted every means of recruiting a police officer. It will be a much better assessment if you adhere as closely as possible to the numbers in Tables A and B.

A. System and Interactor Interviews

System/Interactor	Number
Legal systems	
Prison officials	1
Judges	1
Legal academics	1
Policy-makers or local authorities	1
Legal interactors	
Police	2
Prosecutors	2
Prison guards	2
Public health systems	
Public health authorities	2
Narcological facilities: officials	2
Public health interactors	
Public health clinicians	2
Emergency/casualty department physicians	2
Harm reduction workers	2
Narcological facilities: staff	2
Advocacy interactors	2
NGO staff working with IDUs	2
NGO staff working in HIV	
Total	**26**

B. Street Informant IDU Interviews

IDUs	Number
Men	2
Women	2
Commercial Sex Workers – Male	2
Commercial Sex Workers – Women	2
New injectors	2
MSM-IDUs	2
Locally significant minorities	2
Total	**14**

General Directions

Collect data on each of the questions asked below, unless the subject does not want to answer, or does not have information relevant to the specific question. Informants might answer several questions at once. In that case the questions are there to remind you to collect information on each one. Also, for some questions, prompts are included to help you get more complete information if the informant gives very brief answers.

System and Interactor Key Informant Interview Guide
Enforcement of Drug Laws
Topic Area 1

To the interviewer: This question is designed to get specific information from the informant about what actually takes place between police and IDUs. We want to get data on how and when police choose to arrest drug users, harassment, and corruption, extortion, violence.

Now we want to ask you questions about enforcement of drug laws. Do you have knowledge about this area and would you be willing to talk about it?

Circle one: YES NO

IDUs and law enforcement

1.1-SI Tell me about how the police treat drug users.

Prompts

- *Do police harass people they suspect of being IDUs?*
- *How do police and prosecutors treat IDUs?*
    - *Does it depend on certain characteristics of the defendant?*
    - *Which characteristics (i.e. age, gender, ethnicity, race, location)?*
    - *Do police treat men and women differently??*
- *Do police appear to target IDUs for arrest?*

1.2-SI Tell me what happens when police arrest an IDU in possession of syringes.

1.3-SI Are police afraid of being stuck by syringes or other health consequences from being in contact with IDUs?

1.4-SI Do police use known sites of syringe exchanges or other harm reduction programs to identify IDU-clients for stops, questioning, or arrest?

1.5-SI Do police take money, drugs, sex, or other bribes from IDUs in exchange for release or to avoid arrest?

1.6-SI Do police ever detain IDUs and turn them over to narcological facilities?

1.7-SI Do police use physical violence or force against IDUs?

Prompt

- *Do they use physical violence or force against IDUs instead of arresting them?*

Attitudes towards drug control, IDUs, and persons with HIV

1.8-SI Tell me about your feelings about drug use being a crime.

Prompts

- *Should drug use be a crime?*
- *Do you think that criminal penalties are working? Why or why not?*

1.9-SI What would make criminal system more effective in reducing drug use?

1.10-SI In general, how do people treat IDUs?

Prompts

- *Are they afraid of IDUs?*
- *If it is known that you are an IDU, will you lose your job house/friends/medical care/state benefits/ chance to go to school?*

1.11-SI In general, how do people treat people with HIV?

Prompts

- *Are they afraid of people with HIV/AIDS?*
- *If it is known that you have HIV/AIDS, will you lose your job house/friends/medical care/state benefits/ chance to go to school?*

1.12-SI [Insert here any important questions identified in the CAB process]

1.13-SI Who should I talk to next for more information on the enforcement of drug laws?

System and Interactor Key Informant Interview Guide
Enforcement of Sex Work/Prostitution Laws
Topic Area 2

To the interviewer: This question is designed to get specific information from the informant about what actually takes place between law enforcement personnel (police, the military, or other law enforcement entities) and sex workers. We want to get data on how and when police choose to arrest CSW, whether or not there is harassment, corruption, extortion, or violence.

Now we want to ask you questions about enforcement of laws against commercial sex work and commercial sex workers CSW. Do you have knowledge about this area and would you be willing to talk about it?

Circle one: YES NO

Prostitution and soliciting and law enforcement

2.1-SI Tell me about how police treat prostitutes and clients of prostitutes.

Prompts

- *If there are laws against prostitution, soliciting, offering services of a sex worker to another, how do police enforce these laws?*
- *Do police harass people they suspect of being sex workers?*
- *Do police use STD clinics, HIV health settings, or syringe exchanges to identify clients that may be sex workers for stops, questioning, or arrest?*
- *How do police decide whom to arrest for prostitution or solicitation?*

2.2-SI Do police treat women and men who are suspected of CSW differently?

2.3-SI Tell me what happens when a CSW is arrested.

Prompts

- *If someone is arrested for CSW, will she or he stay in jail a long time or be released before trial?*
- *Is someone arrested for CSW likely to be convicted?*

- *In general, how long are sentences?*

2.4-SI In bringing these cases, do prosecutors usually use the most serious charge possible, or a lesser charge, or does it depend on certain characteristics of the defendant?

Prompt

If the answer is "it depends":

- *What kinds of characteristics of a defendant would make prosecutors likely to charge a sex worker more using a more serious charge/serious crime (i.e. such as race/ethnicity, appearance, gender, geographic location [tourist neighborhood v. native])*

2.5-SI Do police take money, drugs, sex, or other bribes from CSWs in exchange for release or to avoid arrest?

2.6-SI Do police use force or violence against CSW?

Attitudes towards sex workers

2.7-SI In general, tell me about how people treat commercial sex workers.

Prompts

- *Are they afraid of sex workers?*

- *If it is known that you are a sex worker, will you lose your job house/friends/medical care/state benefits/ chance to go to school?*

2.8-SI [Insert here any important questions identified in the CAB process]

2.9-SI Who should I talk to next for more information about enforcement of sex work and prostitution laws?

System and Interactor Key Informant Interview Guide
Enforcement of Laws on Homosexuality
Topic Area 3

***To the interviewer**:* This question is designed to get specific information from the informant about what actually takes place between law enforcement personnel (police, the military, or other law enforcement entities) and men who have sex with men (MSMs). We want to get data on how and when police choose to arrest MSMs, and whether or not there is harassment, corruption, extortion, or violence.

Now we want to ask you questions about enforcement of laws related to homosexuality or men who have sex with men (MSMs). Do you have knowledge about this area and would you be willing to talk about it?

Circle one: YES NO

MSMs, homosexuality and law enforcement

3.1-SI Tell me about how police treat MSMs.

Prompts

- *If there are laws against being a homosexual gay/lesbian/"bi"/queer, how do police enforce them?*
- *Do police harass people they suspect of being MSMs?*
- *Do police use STD clinics, HIV health settings, or syringe exchanges, bars or clubs to identify MSMs for stops, questioning, or arrest*

3.2-SI Tell me what happens when an MSM is arrested.

Prompts

- *If someone is arrested for homosexuality, will he stay in jail a long time or be released before trial?*
- *Is someone arrested for homosexuality likely to be convicted?*
- *In general, how long are sentences?*
- *Do men sometimes pay to avoid arrest?*

3.3-SI How do police decide whom to arrest for MSM prostitution or solicitation?

Prompt

- *Do male CSWs sometimes pay to avoid arrest? How much?*

3.4-SI In bringing these cases, do prosecutors usually use the most serious charge possible, or a lesser charge, or does it depend on certain characteristics of the defendant?

Prompt

If the answer is "it depends":

- *What kinds of characteristics of a defendant would make prosecutors likely to charge a MSM using a more serious charge/serious crime (i.e. such as race/ethnicity, appearance, gender, geographic location [tourist neighborhood v. native])*

3.5-SI Do police take money, drugs, sex, or other bribes from MSMs in exchange for release or to avoid arrest?

3.6-SI Do police use force or violence against MSMs?

3.7-SI Are laws or practices against homosexuals applied differently to men and women?

Prompt

- Tell me about female homosexuals.

Attitudes toward MSMs

3.8-SI In general, how do people treat MSMs?

Prompts

- *Are they afraid of MSMs?*

- *If it is known that someone is an MSM will he lose his job house/friends/medical care/state benefits/ chance to go to school?*

3.9-SI [Insert here any important questions identified in the CAB process]

3.10-SI Who should I talk to next for more information about enforcement of laws about homosexuality?

System and Interactor Key Informant Interview Guide
Enforcement of Laws on Criminal Exposure or Transmission of HIV
Topic Area 4

To the interviewer: This question is designed to get specific information from the informant about what actually takes place between law enforcement personnel (police, the military, or other law enforcement entities) and persons with HIV who may have exposed others. We want to get data on how and when police choose to arrest persons suspected of HIV exposure or transmission, and whether or not there is harassment, corruption, extortion, or violence.

Now we want to ask you questions about enforcement of laws related to exposure or transmission of HIV. Do you have knowledge about this area and would you be willing to talk about it?

Circle one: YES NO

Law enforcement and people with HIV

4.1-SI Tell me about how police treat people with HIV they believe may have exposed others to HIV or transmitted HIV.

Prompts

- *If there are laws against being knowingly exposing or transmitting HIV, how do police enforce them?*
- *Do police harass people they suspect of exposing others to or transmitting HIV?*

4.2-SI Do police use STD clinics, HIV health settings, or syringe exchanges, bars or clubs to identify persons who might have exposed others for stops, questioning, or arrest?

4.3-SI Tell me what happens when the police arrest someone they believe may have exposed others to HIV or transmitted HIV…

Prompts

- *If someone is arrested for this, will she or he stay in jail a long time or be released before that?*
- *If someone is arrested for this likely to be convicted?*

- *In general, how long are sentences for this?*

4.4-SI In bringing these cases, do prosecutors usually use the most serious charge possible, or a lesser charge, or does it depend on certain characteristics of the defendant?

Prompt

If the answer is "it depends":

- *What kinds of characteristics of a defendant would make prosecutors likely to charge someone using a more serious charge/serious crime (i.e. such as race/ethnicity, appearance, gender, geographic location [tourist neighborhood v. native])*

4.5-SI Are laws or practices against exposure or transmission applied differently to men and women?

4.6-SI Do police take money, drugs, sex, or other bribes from HIV + people in exchange for release or to avoid arrest?

4.7-SI Do police use force or violence against those they suspect of exposing others to HIV or transmitting HIV?

4.8-SI In general, do police treat women or men suspected of having HIV differently?

Attitudes towards persons who might transmit HIV

4.9-SI In general, tell me how people treat those suspected of exposing others to HIV or transmitting HIV.

Prompts

- *Are they afraid of persons with HIV who are suspected of exposing others to HIV or transmitting HIV?*

- *If it is known that someone is suspected of exposing others to HIV or transmitting HIV will he lose his job house/friends/medical care/state benefits/ chance to go to school?*

4.10-SI [Insert here any important questions identified in the CAB process]

4.11-SI Who should I talk to next for more information about law enforcement and exposure and transmission of HIV?

System and Interactor Key Informant Interview Guide

Operation of Courts and Prisons

Topic Area 5

To the interviewer: This question is designed to get specific information from the informant about the function of the legal system, practice related to the rights of defendants, and conditions in prisons and jails.

Now we want to ask you some questions about the operation of courts and prisons. Do you have knowledge about this area and would you be willing to talk about it?

Circle one: YES NO

Protection of rights of defendants

5.1-SI Tell me about how IDU, CSW, HIV + and MSM defendants receive legal representation

5.2-SI In practice do IDU, CSW, HIV + and MSM defendants receive legal representation from a defense lawyer?

Prompts

- *Who pays for lawyer or provides representation?*
- *Is legal representation of defendants adequate?*
- *Are defense lawyers as experienced as prosecutors?*
- *Do they have resources of similar quality as prosecution?*

Pre-trial detention

5.3-SI In practice, are defendants able to post bond/bail, be released before trial, see an attorney, and have a speedy trial?

Trials

5.4-SI Tell me about how trials are conducted**.**

Prompts

- *Are trials open to the public?*
- *Can defendants appeal a guilty verdict?*
- *How often do defendants appeal?*

Function of legal system

5.5-SI What is the impact of drug control efforts on the function of legal system?

Prompts

- *Have arrests increased significantly?*
- *Has this affected defendants' time in pretrial detention?*

5.6-SI What is the impact of enforcement efforts to limit sex work or homosexual activity?

Prompts

- *Have arrests for CSW or homosexuality increased or decreased?*
- *Have these changes affected pretrial detention?*

Evidence

5.7-SI Do prosecutors collect, handle and test evidence in drug cases in what you would consider to be reliable ways?

Sentencing

5.8-SI Are there sentencing guidelines for drug offenses and if so, how do they affect actual sentences?

Prompts

- *Do judges feel bound by them? Do judges impose these sentences?*
- *Do guidelines prescribe impose particularly long sentences for drug related crimes? Which ones in particular?*

Corruption

5.9-SI Tell me about corruption in the legal system outside of police practices.

5.10-SI (If corruption exits, …) Who takes money, drugs, sex or other bribes in the legal system?

Prompts

- *Do prosecutors or judges take money, drugs, sex, or other bribes in exchange for release or to avoid arrest?*
- *Do defense attorneys take money, drugs, sex or other bribes in order to present a strong defense?*
- *Do defendants have to pay bribes to be released pretrial?*

5.11-SI Tell me about the ways that the legal system is failing and ways that you would recommend for fixing it.

Prison/jail conditions

5.12-SI Tell me about the conditions in prison.

Prompt

- *Tell me about prison conditions with respect to these factors (ask about only topics not already mentioned)*
  - *Food,*
  - *Crowding*
  - *Medical care*
  - *Violence*
  - *Sexual assault*
  - *Anything else?*

5.13-SI Are prison/jail conditions different for men and women, and if so, how are they different?

5.14-SI Are pregnant women incarcerated? What happens to their children?

Tuberculosis and Health in Prison

5.15-SI Tell me about TB in jail and prison.

5.16-SI What is being done to identify and treat cases of TB?

Prompt

- *Do prisons have resources to diagnose and treat MDR-TB?*

5.17-SI How successful are current TB treatment regimens in prisons?

Prompt

- *Do prisons collect data on completion of therapy, persistence of TB symptoms, and "cure" rates?*

Other programs in prison

5.18-SI Are there drug treatment programs in prisons?

5.19-SI (If yes, …) Tell me more about drug treatment in prison…describe the treatment, how long the programs are, and what kind of treatment it is.

5.20-SI Are there HIV/AIDS education programs in prisons? Tell me about them…

5.21-SI Are there programs <u>in prison</u> to "rehabilitate" prisoners or prevent recidivism teach trades, continue education, and teach anger management or parenting skills? Tell me about them.

5.22-SI Are there programs for people getting <u>out of prison</u>, to help them find jobs, housing, medical care, drug treatment, or other necessities? Tell me about them…

5.23-SI [Insert here any important questions identified in the CAB process]

5.24-SI Who should I talk to next for more information about operation of the legal and court system?

System and Interactor Key Informant Interview Guide
Drug Policy Politics
Topic Area 6

To the interviewer: This question is designed to get specific information from the informant about the drug and HIV policy and politics.

Now we want to ask you some questions about drug and HIV policy in your country. Do you have knowledge about this area and would you be willing to talk about it?

Circle one: YES NO

Drug policy

6.1-SI Which of these are elements of the drug policy in your country?

Ask all the elements first and then ask respondent to rate each element's national priority using the following scale:

High priority = 1; low priority = 2; disfavored = 3, don't know=4

Policy	**Priority**
Interdiction at national borders	
Arresting drug users	
Local policing to reduce street sales	
Enacting/enforcing more stringent drug laws for use Laws about drug sales	
Laws about drug possession	
Focus control efforts on traffickers	
Public education about risks of drug use	
Detoxification programs for drug users	
Drug treatment: Substitution therapy (i.e. methadone)	
Rehabilitation programs for former IDUs	
Drug treatment: Replacement therapy (i.e. heroin prescription	
Harm reduction needle exchanges	
Harm reduction: Unrestricted pharmacy sales of needles	
Legalization of use	
Legalization of possession	
Legalization of sales	

6.2-SI How is drug policy implemented here, in this city or region?

6.3-SI Tell me your opinion about why your country has these policy priorities? Who is for or against it? Who has an interest in maintaining these policies?

HIV policy

6.4-SI Which of these are elements of the HIV prevention and control policy for IDUs in your country?

Note: Ask all the elements first and then ask respondent to rate each element 's national priority using the following scale:

High priority = 1; low priority = 2; disfavored = 3, don't know=4

Policy	**Priority**
Public education campaigns	
Education efforts targeted to IDUs	
Street outreach education programs targeted to IDUs	
Confidential public counseling and testing programs	
Anonymous public counseling and testing programs	
Counseling and testing programs targeted especially to high risk groups	
Supportive social services for those infected	
Medical treatment for IDUs	
Harm reduction programs	
Other programs (list)	
a.	
b.	
c.	

6.5-SI Tell me about how HIV policy is actually implemented here.

6.6-SI [Insert here any important questions identified in the CAB process]

6.7-SI Who should I talk to next for more information about drug policy?

6.8-SI Who should I talk to next for more information about HIV policy?

System and Interactor Key Informant Interview Guide

Harm Reduction and Public Health Interventions

Topic Area 7

***To the interviewer**:* This question is designed to get specific information from the informant about the harm reduction and public health interventions.

Now we want to ask you some questions about harm reduction and public health interventions. Do you have knowledge about this area and would you be willing to talk about it?

Circle one: YES NO

Drug treatment programs

7.1-SI What kinds of treatment are available? (ask all questions related to table)

Type of treatment	**Available? Y/N**	**If not available, why not?**
Counseling only		
Detoxification		
In-patient treatment		
Methadone		
Other opiate replacements		
Opiate replacements for **detoxification**		
Opiate replacements for **maintenance**		
Time limits on opiate replacements		
Behavioral modification		
Other modalities		

Capacity of drug treatment programs

7.2-SI Is outpatient drug treatment available?

Prompts

- *In general, how long is the treatment course?*
- *How many spaces are there in this kind of drug treatment?*
- *Is there a waiting list?*

- *How is the treatment paid for? About how much does it cost?*

7.3-SI Is in-patient drug treatment available?

Prompts

- *In general, how long is the treatment course?*
- *How many spaces are there in this kind of drug treatment?*
- *Is there a waiting list?*
- *How is the treatment paid for? About how much does it cost?*

7.4-SI Under what circumstances is drug treatment mandatory?

7.5-SI What are professional and care-taking staff like at narcological facilities?

Prompts

- *Are there adequate professional staff?*
- *Are they well trained, and experienced?*
- *Are there adequate care-taking staff?*
- *Are they well trained?*

7.6-SI Do narcological facilities work with/cooperate with…

- HIV prevention, testing or treatment programs?
- Other public health programs [TB, STD, and other disease control]?
- Basic medical care community clinics?

7.7-SI What are the biggest barriers to drug treatment programs? What would you like to see work differently?

HIV Testing

7.8-SI Tell me about HIV testing and counseling policies and availability.

Prompts

- *Is testing mandatory or voluntary? For whom is testing mandatory?*
- *Are test results kept confidential? Does the government have access to them?*
- *Are IDUs afraid of being tested for HIV?*

7.9-SI Is HIV testing common among…… [answer Y/N]

- IDUs?
- Sex workers?
- General population?
- Pregnant women?

7.10-SI Why or why not?

Basic medical care for IDU and HIV+

7.11-SI Can IDUs or HIV+ people get basic medical care easily?

Prompt

- *Is there basic care that is sponsored by the government, by NGOs, by private sources?*

Syringe exchange and distribution programs

7.12-SI Do harm reduction, public health workers, advocates, or clinicians distribute sterile syringes to IDUs?

7.13-SI Are there needle/syringe exchange programs here? Are they "legal"?

7.14-SI Tell me about how the police deal with NEPs.

Other harm reduction programs

7.15-SI Tell me about the availability of condoms here.

Prompts

- *Are they widely available for free? low cost? at market prices?*
- *What is the market price of a condom?*
- *Where are condoms available?*

7.16-SI Tell me about programs that distribute condoms? Do local health clinics distribute condoms?

7.17-SI What other kinds of harm reduction programs are available in your city/country? What kinds are needed?

7.18-SI What are barriers to effective harm reduction? What could be done to remove those barriers?

Attitudes towards harm reduction

7.19-SI Tell me what you think about harm reduction programs such as needle exchange programs and opiate replacement programs?

7.20-SI Do you think the government should sponsor harm reduction programs?

7.21-SI Who else should be involved in harm reduction?

7.22-SI In general, do people here know much about "harm reduction" principles?

7.23-SI How acceptable is a harm reduction approach among community members, physicians, other health care providers, church leaders, local political leaders, and national political leaders?

Barriers to interventions for IDUs and HIV

7.24-SI Tell me about the primary barriers to reducing use of illegal drugs in your city/province/country?

7.25-SI What are the primary barriers to reducing HIV/AIDS in your city/province/country?

7.26-SI [Insert here any important questions identified in the CAB process]

7.27-SI Who should I talk to next for more information on harm reduction and public health interventions?

System and Interactor Key Informant Interview Guide

Advocacy Resources

Topic Area 8

To the interviewer: This question is designed to get specific information from the informant about resources for advocacy.

Now we want to ask you some questions about advocacy resources. Do you have knowledge about this area and would you be willing to talk about it?
Circle one: YES NO

Government agencies, NGOs Community/civic agencies

8.1-SI What kinds of local, civic, or religious organizations exist?

8.2-SI In general, what do the do [negative or positive] for the community?

8.3-SI Are there illegal local organizations [gangs, crime bosses]?

8.4-SI In general, what do they do [negative or positive] for the community?

8.5-SI What do you have to do to avoid them?

8.6-SI What kinds of local/ civic organizations would you like to see exist?

8.7-SI Are there other community or civic agencies that could be key actors in shaping/changing public health interventions?

8.8-SI What other community or civic agencies could be key actors in shaping/changing drug and health policy?

Matching resources to opportunities

8.9-SI What strengths do local resources create for intervention/policy change efforts?

8.10-SI What weaknesses do local resources create for intervention/policy change efforts?

8.11-SI [Insert here any important questions identified in the CAB process]

8.12-SI Who should I talk to next for more information about advocacy resources?

System and Interactor Key Informant Interview Guide

Epidemiological Data on HIV and Drug Use

Topic Area 9

To the interviewer: This question is designed to get specific information from the informant about potential new sources of epidemiological data on HIV and IDU that the project has not already collected not contained in preliminary report or identified through the research in Module I.

Now we want to ask you some questions about epidemiological information on HIV, and drug use. Do you have knowledge about this area and would you be willing to talk about it?

Circle one: YES NO

Epidemiology of HIV

9.1-SI Do you know about <u>any</u> sources of epidemiological information on the HIV epidemic nationally and locally that is not easily available? And, can you make it available to us?

9.2-SI In your opinion, about how many people with HIV live here [in this city, this region]?

9.3-SI What groups are most at risk of IDU-related HIV, in your opinion?

9.4-SI Is there anything new about the HIV epidemic locally or nationally that you think are particularly important to harm reduction and other HIV prevention efforts.

Epidemiology of IDU

9.5-SI Do you know about any sources of data related to injection drug use that are not easily available? And, can you make them available to us?

9.6-SI How would you characterize the current use of illegal drugs? Tell me more about that.

9.7-SI How has the use of illegal drugs changed over the last 5 years or so? Tell me more about that.

9.8-SI Currently, what are the drugs of choice for IDUs first, second, third, etc?

9.9-SI Do you think injection practices and drug use has changed recently? Tell me more about that.

9.10-SI About how many IDUs do you think live here [in this city, this region]?

9.11-SI Has that number changed over the last 5 years (increased, decreased, or stayed the same)?

9.12-SI In your opinion, about what percent of IDUs in this city are:

9.12-SI Demographics of IDUSs	**Estimated percent of IDUs**
Female?	
Female CSWs?	
Male CSWs?	
MSMs?	
New injectors(started injecting in last year)?	
Under 30 years old?	
Migrants from somewhere else?	
Ethnic minorities (such as Rom)?	
HIV positive?	
Hepatitis C positive?	
Primarily heroin users?	
Primarily methamphetamine users?	
Primarily cocaine users?	

9.13-SI Have the percentages you listed changed over the last 5 years or so – increased or decreased or stayed about the same?

9.14-SI Among which groups do you think drug use is growing most rapidly?

9.15-SI What is your sense of how many overdoses, fatal or not, there were in the last year?

9.16-SI Has that number changed over the last 5 years or so – increased or decreased or stayed about the same?

9.17-SI [Insert here any important questions identified in the CAB process]

9.18-SI Who should I talk to next for more information on the epidemiology of HIV and IDU?

System and Interactor Key Informant Interview Guide
Criminal Justice Data
Topic Area 10

To the interviewer: This question is designed to get specific information from the informant about criminal justice data on criminal justice data.

Now we want to ask you some questions about potential new sources of criminal justice data.. Do you have knowledge about this area and would you be willing to talk about it?

Circle one: YES NO

Sources of data

10.1-SI Do you know of any potential sources of criminal justice data arrests, prosecutions, sentences, operation of the jail, court, pre-trial system that are not easily available? And, can you make them available to us?

10.2-SI Do you know of any data on the street price of drugs such as heroin and methamphetamine? Is there any data on the purity of illegal drugs?

Prompt:

- *Where are the data on price or purity from [sources of data]?*

10.3-SI Is there any police, criminal justice, or other source of data available on drug overdoses?

10.4-SI [Insert here any important questions identified in the CAB process]

10.5-SI Who should I talk to next for more information on this topic?

IDU Interview Guide

IDU Key Informant
Interview Guide
Enforcement of Drug Laws
Topic Area 1

To the interviewer: This question is designed to get specific information from the informant about what actually takes place between police and IDUs. We want to get data on how and when police choose to arrest drug users, harassment, and corruption, extortion, violence.

Now we want to ask you questions about enforcement of drug laws. Do you have knowledge about this area and would you be willing to talk about it?

Circle one: YES NO

IDUs and law enforcement

Note*: Ask all IDUs the following questions*

1.1-IDU Tell me about an experience that you have had with the police in relationship to your drug use in the past five years.

1.2-IDU Tell me about a time that you had an experience with the police that was different than that one.

1.3-IDU Do you feel you were treated differently from other IDUs because of some characteristic of yours such as your gender, ethnicity or something else?

1.4-IDU In general, how the police usually treat drug users?

Prompts

- *Do police harass people they suspect of being IDUs?*
- *How do police and prosecutors treat IDUs?*
- *Does it depend on certain characteristics of the defendant?*
- *Which characteristics (i.e. age, gender, ethnicity, race, location)?*
- *Do police treat men and women differently?*
- *Do police appear to target IDUs for arrest?*

1.5-IDU Tell me what happens when police arrest an IDU in possession of syringes.

1.6-IDU Are police afraid of being stuck by syringes or other health consequences from being in contact with IDUs?

1.7-IDU Do police use known sites of syringe exchanges or other harm reduction programs to identify IDU-clients for stops, questioning, or arrest?

1.8-IDU Do police take money, drugs, sex, or other bribes from IDUs in exchange for release or to avoid arrest?

1.9-IDU Do police ever detain IDUs and turn them over to narcological facilities?

1.10-IDU Do police use physical violence or force against IDUs?

Prompt

- *Do they use physical violence or force against IDUs <u>instead</u> of arresting them?*

Attitudes towards drug control and IDUs

1.11-IDU Tell me about your feelings about drug use being a crime.

Prompts

- *Should drug use be a crime?*
- *Do you think that criminal penalties are working? Why or why not?*

1.12-IDU What would make criminal system more effective in reducing drug use?

1.13-IDU In general, how do people treat IDUs?

Prompts

- *Are they afraid of IDUs?*
- *If it is known that you are an IDU, will you lose your job house/friends/medical care/state benefits/ chance to go to school?*

1.14-IDU In general, how do people treat people with HIV?

Prompts

- *Are they afraid of people with HIV/AIDS?*
- *If it is known that you have HIV/AIDS, will you lose your job house/friends/medical care/state benefits/ chance to go to school?*

1.15-IDU [Insert here any important questions identified in the CAB process]

1.16-IDU Who should I talk to next for more information on the enforcement of drug laws?

IDU Key Informant
Interview Guide
Enforcement of Sex Work/Prostitution Laws
Topic Area 2

To the interviewer: This question is designed to get specific information from the informant about what actually takes place between law enforcement personnel (police, the military, or other law enforcement entities) and sex workers. We want to get data on how and when police choose to arrest CSW, whether or not there is harassment, corruption, extortion, or violence.

Now we want to ask you questions about enforcement of laws against commercial sex work and commercial sex workers (CSW). Do you have knowledge about this area and would you be willing to talk about it?

Circle one: YES NO

Prostitution and soliciting and law enforcement

2.1-IDU Have you ever exchanged sex for money? How about in the last five years?

***Note**: Ask above question to all IDUs, including **males**. If no, then skip to general questions. If yes, ask the following five questions and then the general questions.*

2.2-IDU Tell me about sex work in this city. How is it organized? (i.e. in terms of street locations, prices, getting clients and relationships with the police)

2.3-IDU Tell me about an experience that you have had with the police in relationship to your work as a CSW use in the past five years.

2.4-IDU Tell me about a time that you had an experience with the police that was different than that one.

2.5-IDU Do you feel you were treated differently from other IDUs because of some characteristic of yours such as your gender, ethnicity or something else?

2.6-IDU Have you ever paid money or sex to avoid being arrested?

ASK EVERYONE THE FOLLOWING QUESTIONS

2.7-IDU Tell me about how police treat prostitutes and clients of prostitutes.

Prompts

- *If there are laws against prostitution, soliciting, offering services of a sex worker to another, how do police enforce these laws?*

- *Do police harass people they suspect of being sex workers?*

- *Do police use STD clinics, HIV health settings, or syringe exchanges to identify clients that may be sex workers for stops, questioning, or arrest?*

- *How do police decide whom to arrest for prostitution or solicitation?*

2.8-IDU Do police treat women and men who are suspected of CSW differently?

2.9-IDU Tell me what happens when a CSW is arrested.

Prompts

- *If someone is arrested for CSW, will she or he stay in jail a long time or be released before trial?*

- *Is someone arrested for CSW likely to be convicted?*

- *In general, how long are jail or prison sentences?*

2.10-IDU In bringing these cases, do prosecutors usually use the most serious charge possible, or a lesser charge, or does it depend on certain characteristics of the defendant?

Prompt

<u>If the answer is "it depends":</u>

- *What kinds of characteristics of a defendant would make prosecutors likely to charge a sex worker using a more serious charge/serious crime (i.e. such as race/ethnicity, appearance, gender, geographic location [tourist neighborhood v. native])*

2.11-IDU Do police take money, drugs, sex, or other bribes from CSWs in exchange for release or to avoid arrest?

2.12-IDU Do police use force or violence against CSW?

Attitudes towards sex workers

2.13-IDU In general, tell me about how people treat commercial sex workers?

Prompts

- *Are they afraid of sex workers?*

- *If it is known that you are a sex worker, will you lose your job house/friends/medical care/state benefits/ chance to go to school?*

2.14-IDU [Insert here any important questions identified in the CAB process]

2.15-IDU Who should I talk to next for more information about enforcement of sex work and prostitution laws?

IDU Key Informant
Interview Guide

Enforcement of Laws on Homosexuality
Topic Area 3

To the interviewer: This question is designed to get specific information from the informant about what actually takes place between law enforcement personnel (police, the military, or other law enforcement entities) and MSMs. We want to get data on how and when police choose to arrest MSMs, and whether or not there is harassment, corruption, extortion, or violence.

Now we want to ask you questions about enforcement of laws related to homosexuality or MSMs. Do you have knowledge about this area and would you be willing to talk about it?

Circle one: YES NO

Personal experience and law enforcement

***Note**: Ask the following question of **all male** IDUs*

3.1-IDU Have you ever had sex with a man? How about in the last five years?

Note: In this section, ask MSM participants the next four questions and then ask everyone the general set.

3.2-IDU Tell me about an experience that you have had with the police in relationship to homosexuality.

3.3-IDU Tell me about a time that you had an experience with the police that was different than that one.

3.4-IDU Have you ever paid money or sex to a police officer to avoid arrest?

3.5-IDU Do you feel you were treated differently from other MSM because of some characteristic of yours such as your gender, ethnicity or something else?

ASK EVERYONE THE FOLLOWING QUESTIONS

3.6-IDU Tell me how many, in your opinion, how many MSMs are there in this city? What percentage use drugs?

3.7-IDU Tell me more about homosexuality in this city. Where do people meet each other and what kinds of partners do they have?

MSMs, homosexuality and law enforcement

3.8-IDU Tell me about how police treat MSMs in general…

Prompts

- *If there are laws against being a homosexual gay/lesbian/"bi"/queer, how do police enforce them?*
- *Do police harass people they suspect of being MSMs?*
- *Do police use STD clinics, HIV health settings, or syringe exchanges, bars or clubs to identify MSMs for stops, questioning, or arrest*

3.9-IDU Tell me what happens when an MSM is arrested.

Prompts

- *If someone is arrested for homosexuality, will he stay in jail a long time or be released before trial?*
- *Is someone arrested for homosexuality likely to be convicted?*
- *In general, how long are sentences?*
- *Do men sometimes pay to avoid arrest?*

3.10-IDU How do police decide whom to arrest for MSM prostitution or solicitation?

Prompt

- *Do male CSWs sometimes pay to avoid arrest? How much?*

3.11-IDU In bringing these cases, do prosecutors usually use the most serious charge possible, or a lesser charge, or does it depend on certain characteristics of the defendant?

Prompt

<u>If the answer is "it depends":</u>

- *What kinds of characteristics of a defendant would make prosecutors likely to charge a MSM using a more serious charge/serious crime (i.e. such as race/ethnicity, appearance, gender, geographic location [tourist neighborhood v. native])*

3.12-IDU Are laws or practices against homosexuals applied differently to men and women?

Prompt

- *Tell me about female homosexuals…*

3.13-IDU Do police take money, drugs, sex, or other bribes from MSMs in exchange for release or to avoid arrest?

3.14-IDU Do police use force or violence against MSMs?

Attitudes toward MSMs

3.15-IDU In general, how do people treat MSMs?

Prompts

- *Are they afraid of MSMs?*
- *If it is known that someone is an MSM will he lose his job house/friends/medical care/state benefits/ chance to go to school?*

3.16-IDU [Insert here any important questions identified in the CAB process]

3.17-IDU Who should I talk to next for more information about enforcement of laws about homosexuality?

IDU Key Informant
Interview Guide
Enforcement of Laws on
Criminal Exposure or Transmission of HIV
Topic Area 4

To the interviewer: This question is designed to get specific information from the informant about what actually takes place between law enforcement personnel (police, the military, or other law enforcement entities) and persons with HIV who may have exposed others. We want to get data on how and when police choose to arrest persons suspected of HIV exposure or transmission, and whether or not there is harassment, corruption, extortion, or violence.

Now we want to ask you questions about enforcement of laws related to exposure or transmission of HIV. Do you have knowledge about this area and would you be willing to talk about it?

Circle one: YES NO

Note*: These questions can be asked of all IDUs*

Law enforcement and people with HIV

4.1-IDU Tell me about how police treat people with HIV they believe may have exposed others to HIV or transmitted HIV.

Prompts

- *If there are laws against being knowingly exposing or transmitting HIV, how do police enforce them?*
- *Do police harass people they suspect of exposing others to or transmitting HIV?*
- *Do police use STD clinics, HIV health settings, or syringe exchanges, bars or clubs to identify persons who might have exposed others for stops, questioning, or arrest?*

4.2-IDU Tell me what happens when the police arrest someone they believe may have exposed others to HIV or transmitted HIV.

Prompts

- *If someone is arrested for this, will she or he stay in jail a long time or be released before that?*

- *If someone is arrested for this likely to be convicted?*

- *In general, how long are sentences for this?*

4.3-IDU In bringing these cases, do prosecutors usually use the most serious charge possible, or a lesser charge, or does it depend on certain characteristics of the defendant?

Prompt

If the answer is "it depends":

- *What kinds of characteristics of a defendant would make prosecutors likely to charge someone using a more serious charge/serious crime (i.e. such as race/ethnicity, appearance, gender, geographic location [tourist neighborhood v. native])*

4.4-IDU Are laws or practices against exposure or transmission applied differently to men and women?

4.5-IDU Do police take money, drugs, sex, or other bribes from HIV + people in exchange for release or to avoid arrest?

4.6-IDU Do police use force or violence against those they suspect of exposing others to HIV or transmitting HIV?

4.7-IDU In general, do police treat women or men suspected of having HIV differently?

Attitudes towards persons who might transmit HIV

4.8-IDU In general, tell me how people treat those suspected of exposing others to HIV or transmitting HIV?

Prompts

- *Are they afraid of persons with HIV who are suspected of exposing others to HIV or transmitting HIV?*

- *If it is known that someone is suspected of exposing others to HIV or transmitting HIV will he lose his job house/friends/medical care/state benefits/ chance to go to school?*

4.9-IDU [Insert here any important questions identified in the CAB process]

4.10-IDU Who should I talk to next for more information about law enforcement and exposure and transmission of HIV?

IDU Key Informant
Interview Guide
Operation of Courts and Prisons
Topic Area 5

To the interviewer: This question is designed to get specific information from the informant about the function of the legal system, practice related to the rights of defendants, and conditions in prisons and jails.

Now we want to ask you some questions about the operation of courts and prisons. Do you have knowledge about this area and would you be willing to talk about it?

Circle one: YES NO

Personal Experiences

5.1-IDU Have you ever been:

- Arrested?
- Tried?
- Convicted?
- Incarcerated?

Protection of rights of defendants

Note*: In this section, if the participant <u>does not have personal experience</u> with being a defendant, skip to the box in this section to ask about general knowledge.*

5.2-IDU Tell me about the last time you were arrested.

Note*: Probe about the date, what the arrest was for and details about the arrest.*

5.3-IDU Did you have legal representation?

5.4-IDU Was your lawyer a defense lawyer or some other kind of lawyer?

Prompts

- *Who paid for the lawyer or provided representation?*
- *Was your legal representation adequate?*
- *Are defense lawyers as experienced as prosecutors?*

5.5-IDU Did your lawyer have resources of similar quality as the prosecution?

5.6-IDU Was your experience with the lawyer typical of how IDU, CSW, HIV+ and MSM defendants receive legal representation?

5.7-IDU If not, what is different about your last experience and other people's experience with legal representation?

ONLY ASK PERSONS WITH NO EXPERIENCE OF BEING A DEFENDANT

5.8-IDU In general, tell me about how IDU, CSW, HIV + and MSM defendants receive legal representation.

5.9-IDU In practice do IDU, CSW, HIV + and MSM defendants receive legal representation from a defense lawyer?

Prompts

- *Who pays for lawyer or provided representation?*
- *Is legal representation of defendants adequate?*
- *Are defense lawyers as experienced as prosecutors?*

5.10-IDU Do defense lawyers have resources of similar quality as the prosecution?

Pre-trial detention

***Note**: If the participant <u>does not have personal experience</u> with arrest, skip to the box in this section to ask about general experiences.*

5.11-IDU Tell me about the last time you were in pre-trial detention either after your last arrest or some other time ---– what happened?

5.12-IDU During that time, were you able to

- Post bond or bail?
- Be released before trial?
- See an attorney?
- Have a "speedy" trial (a timely trial)?

5.13-IDU What do you think defines a "speedy trial" – i.e. how soon after arrest must a trial occur in order for it be timely, fair, or speedy?

ONLY ASK PEOPLE WHO HAVE NEVER BEEN IN PRE-TRIAL DETENTION

5.14-IDU In practice, are defendants able to

- Post bond/bail?
- Be released before trial?
- See an attorney?
- Have a speedy trial?

Trials

***Note**: In this section, if the participant <u>does not have personal experience</u> with being tried, skip to the box in this section to ask about general knowledge.*

5.15-IDU Thinking back to the last time you were part of a court proceeding and trial, tell me what happened.

Prompts

- *Was the trial open to the public?*
- *Were you convicted?*

5.16-IDU Were you allowed to appeal the verdict? Did you?

5.17-IDU How often do your friends who get tried appeal the verdict?

ONLY ASK PEOPLE WHO HAVE NEVER PARTICIPATED IN A TRIAL

5.18-IDU Tell me about how trials are conducted.

Prompts

- *Are trials open to the public?*
- *Can defendants appeal a guilty verdict?*
- *How often do defendants appeal?*

Function of legal system

***Note**: All IDUs should be asked these questions*

5.19-IDU Has the fact that there are laws against drug use, homosexuality, or commercial sex work decreased your activities in these areas? Did you decide not to engage in a behavior because it was illegal? Tell me about that.

5.20-IDU In general, what do you think is the impact of drug control efforts on the function of the legal system?

Prompts

- *Have arrests increased significantly?*
- *Has this affected defendants' time in pretrial detention?*

5.21-IDU In general, what is the impact of enforcement efforts to limit sex work or homosexual activity?

Prompts

- *Have arrests for CSW or homosexuality increased or decreased?*
- *Have these changes affected pretrial detention?*

Evidence

5.22-IDU Do prosecutors collect, handle and test evidence in drug cases in what you would consider to be reliable ways?

Sentencing

***Note**: In this section, if the participant <u>does not have personal experience</u> of being sentenced, skip to the box in this section to ask about general experiences.*

5.23-IDU Tell me about your sentence the last time you were convicted.

5.24-IDU Were you sentenced fairly?

5.25-IDU Are there sentencing guidelines for drug offenses and if so, how do they affect actual sentences?

Prompts

- *Do judges impose these sentences?*
- *Do judges feel bound by them?*
- *Do guidelines prescribe impose particularly long sentences for drug related crimes? Which ones in particular?*

ONLY ASK PEOPLE WHO HAVE NEVER BEEN SENTENCED

5.26-IDU Are there sentencing guidelines for drug offenses and if so, how do they affect actual sentences?

Prompts

- *Do judges impose these sentences?*
- *Do judges feel bound by them?*

Corruption

***Note**: Ask all IDUs these questions*

5.27-IDU Tell me about corruption in the legal system outside of police practices?

5.28-IDU Have you ever had to pay a bribe as a result of your IDU, MSM, CSW or HIV+ status? Tell me about it.

Prompt

- *Describe any time you have had to pay to anyone in the legal system other than a police officer. Say more about that..*

5.29-IDU (If corruption) Who takes money, drugs, sex or other bribes in the legal system?

Prompts

- *Do prosecutors or judges take money, drugs, sex, or other bribes in exchange for release or to avoid arrest?*
- *Do defense attorneys take money, drugs, sex or other bribes in order to present a strong defense?*
- *Do defendants have to pay bribes to be released pretrial?*

5.30-IDU To the best of your knowledge, what are the usual prices for bribes:

- to avoid arrest
- to get out of jail before trial
- to present a strong defense

- to have charges dropped
- to shorten or eliminate a prison sentence
- to get special treatment or privileges in prison.

5.31-IDU Are there any other bribes paid in the legal system that we should be aware of?

5.32-IDU Tell me about the ways that the legal system is failing and ways that you would recommend for fixing it.

Prison/jail conditions

***Note**: In this section, if the participant <u>does not have personal experience</u> with prison or jail, skip to the box in this section to ask about general experiences.*

5.33-IDU Tell me about the last time you were in prison – how long and why you were there, and what the conditions were like.

5.34-IDU Tell me about the conditions in prison when you were there.

Prompt

- *Tell me about prison conditions with respect to these factors (ask about only topics not already mentioned)*

  - *Food*
  - *Crowding*
  - *Medical care*
  - *Violence*
  - *Sexual assault*
  - *Anything else?*

5.35-IDU Are prison/jail conditions different for men and women, and if so, how are they different?

5.36-IDU Are some prisons worse than others in terms of conditions? Which ones?

5.37-IDU Are pregnant women incarcerated? What happens to their children?

Other programs in prison

(Read to participant)

I would like you to tell me about other programs in prison. If you participated in a program please tell me about your personal experience. If you didn't participate, please tell me about your knowledge of the program.

5.38-IDU Are there drug treatment programs in prisons?

5.39-IDU (If yes) Tell me more about drug treatment in prison…describe the treatment, how long the programs are, and what kind of treatment it is. Tell me about your own experience if you participated in one.

5.40-IDU Are there HIV/AIDS education programs in prisons? Tell me about them. Tell me about your own experience if you participated in one.

5.41-IDU Are there programs <u>in prison</u> to "rehabilitate" prisoners or prevent recidivism teach trades, continue education, and teach anger management or parenting skills? Tell me about them. Tell me about your own experience if you participated in one.

5.42-IDU Are there programs for people getting <u>out of prison</u>, to help them find jobs, housing, medical care, drug treatment, or other necessities? Tell me about them. Tell me about your own experience if you participated in one.

ONLY ASK PEOPLE WITH NO PRISON EXPERIENCE

Prison conditions

5.43-IDU Tell me about the conditions in prison…

Prompt

- *Tell me about prison conditions with respect to these factors (ask about only topics not already mentioned)*
  - *Food,*
  - *Crowding*
  - *Medical care*
  - *Violence*
  - *Sexual assault*
  - *Anything else?*

5.44-IDU Are prison/jail conditions different for men and women, and if so, how are they different?

5.45-IDU Are some prisons worse than others in terms of conditions?

Tuberculosis and Health in Prison

***Note**: In this section, if the participant <u>does not have personal experience</u> with prison, skip to the box in this section to ask about general experiences.*

5.46-IDU Tell me what you know about TB in jail and prison?

5.47-IDU Did you have TB in jail /prison?

5.48-IDU [If yes] Tell me about your experience with TB?

Prompts

- *How was your TB identified?*
- *Were you routinely tested for TB?*
- *Did you have MDR-TB?*
- *How was it treated?*
- *Did you finish TB treatment in jail / prison?*

5.49-IDU Have you had a recurrence of TB since you got out of prison, or do you still have TB?

5.50-IDU Did you know other prisoners who had TB in prison?

5.51-IDU In your opinion, how many prisoners in your facility had TB? How many prisoners were there overall in your facility?

ONLY ASK PEOPLE WITH NO PRISON EXPERIENCE

TB in Jail / Prison

5.52-IDU Tell me about TB in jail and prison?

5.53-IDU What is being done to identify and treat cases of TB?

Prompt

- *Do prisons have resources to diagnose and treat MDR-TB?*

5.54-IDU How successful are current TB treatment regimens in prisons?

Prompt

- *Do prisons collect data on completion of therapy, persistence of TB symptoms, and "cure" rates?*

Other programs in jails and prisons

5.55-IDU Are there drug treatment programs in prisons?

5.56-IDU (If yes) Tell me more about drug treatment in prison…describe the treatment, how long the programs are, and what kind of treatment it is.

5.57-IDU Are there HIV/AIDS education programs in prisons? Tell me about them…

5.58-IDU Are there programs in prison to "rehabilitate" prisoners or prevent recidivism teach trades, continue education, teach anger management or parenting skills? Tell me about them.

5.59-IDU Are there programs for people getting out of prison, to help them find jobs, housing, medical care, drug treatment, or other necessities? Tell me about them.

IDU Key Informant
Interview Guide
Drug Policy Politics
Topic Area 6

To the interviewer: This question is designed to get specific information from the informant about the drug and HIV policy and politics.

Now we want to ask you some questions about drug and health policy in your country. Do you have knowledge about this area and would you be willing to talk about it?

Circle one: YES NO

Drug policy

6.1-IDU Which of these are elements of the drug policy in your country?

Ask all the elements first and then ask respondent to rate each element's national priority using the following scale:

High priority = 1; low priority = 2; disfavored = 3, don't know=4

Policy	**Priority**
Interdiction at national borders	
Arresting drug users	
Local policing to reduce street sales	
Enacting/enforcing more stringent drug laws for use Laws about drug sales	
Laws about drug possession	
Focus control efforts on traffickers	
Public education about risks of drug use	
Detoxification programs for drug users	
Drug treatment: Substitution therapy (i.e. methadone)	
Rehabilitation programs for former IDUs	
Drug treatment: Replacement therapy (i.e. heroin prescription	
Harm reduction needle exchanges	
Harm reduction: Unrestricted pharmacy sales of needles	
Legalization of use	
Legalization of possession	
Legalization of sales	

6.2-IDU How is <u>drug policy</u> implemented here, in this city or region?

6.3-IDU Tell me your opinion about why your country has these policy priorities? Who is for or against it? Who has an interest in maintaining these policies?

6.4-IDU Is this country's drug policy working? How do you know?

6.5-IDU Have you personally ever encountered one of these elements of drug policy (e.g. bought a syringe in a pharmacy, enrolled in a methadone program)? Tell me about that.

HIV policy

6.6-IDU Which of these are elements of the HIV prevention and control policy for IDUs in your country?

***Note**: Ask all the elements first and then ask respondent to rate each element's national priority using the following scale:*

High priority = 1; low priority = 2; disfavored = 3, don't know=4

Policy	**Priority**
Public education campaigns	
Education efforts targeted to IDUs	
Street outreach education programs targeted to IDUs	
Confidential public counseling and testing programs	
Anonymous public counseling and testing programs	
Counseling and testing programs targeted especially to high risk groups	
Supportive social services for those infected	
Medical treatment for IDUs	
Harm reduction programs	
Other programs (list)	
a.	
b.	
c.	

6.7-IDU How is HIV prevention policy actually implemented here, in this city or region?

6.8-IDU Tell me your opinion about why your country has these policy priorities? Who is for or against it? Who has an interest in maintaining these policies?

6.9-IDU Is this country's HIV prevention policy working? How do you know?

6.10-IDU Have you personally ever encountered one of these elements of the HIV prevention policy (e.g. encountered an outreach worker on the street or received counseling about HIV risk)? Tell me about that.

6.11-IDU Which of these are elements of the HIV prevention and control policy for IDUs in your country?

6.12-IDU [Insert here any important questions identified in the CAB process]

6.13-IDU Who should I talk to next for more information about drug policy?

6.14-IDU Who should I talk to next for more information about HIV policy?

IDU Key Informant
Interview Guide
Harm Reduction and Public Health Interventions
Topic Area 7

***To the interviewer**:* This question is designed to get specific information from the informant about the harm reduction and public health interventions.

Now we want to ask you some questions about harm reduction and public health interventions. Do you have knowledge about this area and would you be willing to talk about it?

Circle one: YES NO

Drug treatment programs

7.1-IDU What kinds of treatment are available? (ask all questions related to table)

Type of treatment	**Available? Y/N**	**If not available, why not?**
Counseling only		
Detoxification		
In-patient treatment		
Methadone		
Other opiate replacements		
Opiate replacements for **detoxification**		
Opiate replacements for **maintenance**		
Time limits on opiate replacements		
Behavioral modification		
Other modalities		

7.2-IDU Have you ever been in drug treatment in this city? Tell me about the last time you were in drug treatment – what kind was it, where did you go, how long were you there etc.

Capacity of drug treatment programs

7.3-IDU Is out-patient drug treatment available?

Prompts

- *In general, how long is the treatment course?*
- *How many spaces are there in this kind of drug treatment?*
- *Is there a waiting list?*
- *How is the treatment paid for? About how much does it cost?*

7.4-IDU Is in-patient drug treatment available?

Prompts

- *In general, how long is the treatment course?*
- *How many spaces are there in this kind of drug treatment?*
- *Is there a waiting list?*
- *How is the treatment paid for? About how much does it cost?*

7.5-IDU Under what circumstances is drug treatment mandatory?

7.6-IDU What are professional and care-taking staff like at narcological facilities?

Prompts

- *Are there adequate professional staff?*
- *Are they well trained, and experienced?*
- *Are there adequate care-taking staff?*
- *Are they well trained?*

7.7-IDU Do narcological facilities work with/cooperate with…

- HIV prevention, testing or treatment programs?
- Other public health programs [TB, STD, and other disease control]?
- Basic medical care community clinics?

7.8-IDU Was there ever a time when you wanted drug treatment and couldn't get it? Tell me more about that.

7.9-IDU What are the biggest barriers to drug treatment programs? What would you like to see work differently?

HIV Testing

7.10-IDU Have you ever been tested for HIV? (if yes)Tell me about it – how did you get tested (If no) Why not?

Prompts

- *What year was your last test for HIV?*
- *What was your result?*
- *(If positive) Are you on antiretroviral medication? Tell me about finding out you were positive*

7.11-IDU Tell me about HIV testing and counseling policies and availability.

Prompts

- *Is testing mandatory or voluntary? For who is testing mandatory?*
- *Are test results kept confidential? Does the government have access to them?*
- *Are IDUs afraid of being tested for HIV?*

7.12-IDU Is HIV testing common among…… [answer Y/N]

- IDUs?
- Sex workers?
- General population?
- Pregnant women?

7.13-IDU Why or why not?

Basic medical care for IDU and HIV+

7.14-IDU Can IDUs or HIV+ people get basic medical care easily?

Prompt

- *Is there basic care that is sponsored by the government, by NGOs, by private sources?*

Syringe exchange and distribution programs

7.15-IDU Do harm reduction, public health workers, advocates, or clinicians distribute sterile syringes to IDUs?

7.16-IDU Are there needle/syringe exchange programs here? Are they "legal"?

7.17-IDU Tell me about how the police deal with NEPs….

7.18-IDU Have you ever gotten a sterile syringe from a program, clinic, outreach worker or needle exchange program?

7.19-IDU The last time you injected, where did you get the needle? How much did it cost?

7.20-IDU Is that your usual way of getting needles?

Other harm reduction programs

7.21-IDU Tell me about the availability of condoms here.

Prompts

- *Are they widely available for free? low cost? at market prices?*
- *What is the market price of a condom?*
- *Where are condoms available?*

7.22-IDU Tell me about programs that distribute condoms? Do local health clinics distribute condoms?

7.23-IDU Have you ever received a condom from a program or health clinic?

7.24-IDU What other kinds of harm reduction programs are available in your city/country? What kinds are needed?

7.25-IDU What are barriers to effective harm reduction? What could be done to remove those barriers?

Attitudes towards harm reduction

7.26-IDU Tell me what you think about harm reduction programs such as needle exchange programs and opiate replacement programs?

7.27-IDU Do you think the government should sponsor harm reduction programs?

7.28-IDU Who else should be involved in harm reduction?

7.29-IDU In general, do people here know much about "harm reduction" principles?

7.30-IDU How acceptable is a harm reduction approach among community members, physicians, other health care providers, church leaders, local political leaders, and national political leaders?

Barriers to interventions for IDUs and HIV

7.31-IDU Tell me about the primary barriers to reducing use of illegal drugs in your city/province/country?

7.32-IDU What are the primary barriers to reducing HIV/AIDS in your city/province/country?

7.33-IDU [Insert here any important questions identified in the CAB process]

7.34-IDU Who should I talk to next for more information on harm reduction and public health interventions?

IDU Key Informant
Interview Guide
Advocacy Resources
Topic Area 8

To the interviewer: This question is designed to get specific information from the informant about resources for advocacy.

Now we want to ask you some questions about advocacy resources. Do you have knowledge about this area and would you be willing to talk about it?

Circle one: YES NO

Note*: These questions can be asked of all IDUs*

Government agencies, NGOs Community/civic agencies

8.1-IDU Who do you ask for help when you need it? What kinds of agencies or programs? What have they helped you with?

Note*: Interviewer should make sure the participant lists everything by asking "Anything else" until the list is complete.*

8.2-IDU In general, what do these organizations, programs or agencies do [negative or positive] for the community or for IDUs?

8.3-IDU Tell me what happened the last time you asked for help from a program or agency? What happened?

8.4-IDU What agency or program would you ask for

- help getting into drug treatment?
- help obtaining clean syringes?
- help with a ride to the hospital?
- help finding a job?
- medical care?
- dental care?
- mental health care?
- help with housing?
- help with a small loan of money?
- other kinds of help?

8.5-IDU Do you ever ask local illegal organizations [gangs, crime bosses] for help with things like a loan or some other kind of help?

***Note**: Interviewer should make sure the participant lists everything by asking "Anything else" until the list is complete.*

8.6-IDU In general, what do illegal organizations do [negative or positive] for the community?

8.7-IDU Tell me about the last time you asked for help from a gang member, a crime boss, or another kind of person like that. What happened?

8.8-IDU Do you have to avoid illegal organizations? How do you do it?

8.9-IDU Are there other kinds of local or civic organizations would you like to see exist?

8.10-IDU Are there other community or civic agencies that could play an important role in key actors in shaping/changing public health interventions?

8.11-IDU Are there other communities or civic agencies could play an important role in shaping or changing drug and health policy?

8.12-IDU [Insert here any important questions identified in the CAB process]

8.13-IDU Who should I talk to next for more information about advocacy resources?

IDU Key Informant
Interview Guide
Epidemiological Data on HIV and Drug Use
Topic Area 9

To the interviewer: This question is designed to get specific information from the informant about potential new sources of epidemiological data on HIV and IDU that the project has not already collected not contained in preliminary report or identified through the research in Module I.

Now we want to ask you some questions about epidemiological information on HIV, and drug use. Do you have knowledge about this area and would you be willing to talk about it?

Circle one: YES NO

Note*: These questions can be asked of all IDUs*

Epidemiology of HIV

9.1-IDU In your opinion…

- About how many people with HIV live here [in this city, this region]?
- What groups are most at risk of IDU-related HIV?

9.2-IDU Is there anything new about the HIV epidemic locally or nationally that you think are particularly important to harm reduction and other HIV prevention efforts?

Epidemiology of IDU

9.3-IDU About how many IDUs do you think live here [in this city, this region] ?

9.4-IDU Has the number of IDUs changed over the last five years or so– increased or decreased or stayed about the same?

9.5-IDU About how many IDUs in this city: *[**Note**, answer may in percent (50%) or proportion (about half).]*

9.5-IDU IDU risk behavior	**Estimated percent or proportion**
Use a new syringe for every injection?	
Use a condom every time they have sex?	
Are enrolled in a drug treatment program?	
Use a needle exchange program to get needles?	
Clean their needles with bleach?	
Buy syringes in the pharmacy?	

9.6-IDU How would you characterize the current use of illegal drugs in this city? Tell me more about that.

9.7-IDU Currently, what are the drugs of choice for IDUs first, second, third, etc?

9.8-IDU Tell me the average street price of 1) heroin 2) cocaine 3) methamphetamine 4) opium or poppies 5) and any other popular drugs.

9.9-IDU If there are different types of each drug (i.e. home-made or dealer imported) please let me know what the price differences are?

9.10-IDU On average, how pure are each of the drugs you listed? ***Note****: Ask participant to express purity in terms of a percent, such as "It's about 75 % pure"*

9.11-IDU Do you think injection practices and drug use has changed recently? Tell me more about that.

9.12-IDU In your opinion, about what percent of IDUs in this city are:

9.12-IDU Demographics of IDUs	**Estimated percent of IDUs**
Female?	
Female CSWs?	
Male CSWs?	
MSMs?	
New injectors(started injecting in last year)?	
Under 30 years old?	
Migrants from somewhere else?	
Ethnic minorities (such as Rom)?	
HIV positive?	
Hepatitis C positive?	
Primarily heroin users?	
Primarily methamphetamine users?	
Primarily cocaine users?	

9.13-IDU Have the percentages you listed changed over the last 5 years or so – increased or decreased or stayed about the same?

9.14-IDU In your opinion, among which groups do you think drug use is growing most rapidly?

9.15-IDU In general, has the type of drug that IDUs used over the last five years or so changed?

9.16-IDU In general, have the ages of IDUs changed over the last five years or so – are IDUs older, younger or about the same?

9.17-IDU Have you ever overdosed on a drug? (If yes) Tell me about the last time it happened.

9.18-IDU What is your sense of how many overdoses, fatal or not, there were in the last year?

9.19-IDU Has that number changed over the last 5 years or so – increased or decreased or stayed about the same?

9.20-IDU [Insert here any important questions identified in the CAB process]

9.21-IDU Who should I talk to next for more information on the epidemiology of HIV and IDU?

IDU Key Informant
Interview Guide
Criminal Justice Data
Topic Area 10

To the interviewer: This question is designed to get specific information from the informant about criminal justice data on criminal justice data.

Now we want to ask you some questions about potential new sources of criminal justice data. Do you have knowledge about this area and would you be willing to talk about it?

Circle one: YES NO

Note*: These questions can be asked of all IDUs*

Criminal justice data

10.1-IDU In your opinion, has the number of arrests and prosecutions for drug related crimes changed over the last five years or so– increased or decreased or stayed about the same?

10.2-IDU Have sentences given to IDUs changed over the last five years or so – have they gotten longer or shorter or stayed about the same?

10.3-IDU Have prison or jail conditions changed over the last five years or so – have they gotten better or worse or stayed about the same?

10.4-IDU Has the number of people asking for money so that an IDU can avoid arrest, prosecution or jail time changed over the last five years --– increased or decreased or stayed about the same?

Sources of data

10.5-IDU Do you know of any potential sources of criminal justice data arrests, prosecutions, sentences, operation of the jail, court, pre-trial system that is not easily available? And, can you make them available to us?

10.6-IDU [Insert here any important questions identified in the CAB process]

10.7-IDU Who should I talk to next for more information on criminal justice data?

DATA ORGANIZATION FORMS

Instructions:
At the end of each day's data collection focus group or interviews, you should go over all the information you obtained, identify information relevant for the final report and planning process, and record summary information on the following data organization forms. Identifying and summarizing these data are the first step necessary for the Analysis and Action planning module of the RPAR module IV. These sheets will help you:

- Identify important issues and root causes of problems in HIV prevention among IDUs in your community;
- Facilitate reporting of information to the CAB;
- Facilitate completion of the final report;
- Assemble important information for the process of analysis and developing solutions;
- Assemble information necessary for the process of planning community response

Use these steps to fill out the following table summarizing your findings.

1. Identify the source of the summary information by the unique number assigned to each Interview. For example, Pol-S-1, for "Poland, systems interview 1".

2. Identify the Category and Type of informant. For example:
   Category code: S=System, I=Interactor, IDU=Street informants
   IDU or SI Type: What type of IDU interview i.e. MSM-IDU or MSM-CSW-IDU?-- or --
   What type of SI interview i.e. Emergency room physician or police officer.

3. Identify the Topic area(s) of the finding. For example, 2 (sex work), 5 (operations of courts and prisons).

4. Summarize key finding(s) from that interview and topic area. This should not be a full description of the interview, but it should provide enough detail to capture the key points made by each informant on each topic area. Do not be afraid to include more than one finding per topic area. For example, a single IDU informant may provide many key findings about arrest and incarceration or about specific drugs used and the demographics of local IDUs.

5. Include any comments relevant to the finding. For example, "Informant has been arrested more than 10 times in this city and has spent extended time in pre-trial confinement."

FORM: DATA ORGANIZATION
For Key Informant Interviews

Inter-view#:[1]	Category & Type[2]	ID# of Topic Area[3]	Information summary, key points	Comments:

[1] Each interview should be assigned a unique identifying number, for example, Pol-S-1, for "Poland, systems interview 1".
[2] Category code: S=System, I=Interactor, IDU=Street informants
Type of informant: What type of IDU interview i.e. MSM-IDU or MSM-CSW-IDU?-- or --What type of SI interview i.e. Emergency room physician or police officer.
[3] Topic area by number, for example, 2 (sex work).

RAPID POLICY ASSESSMENT & RESPONSE

Module III: Qualitative Data

Training Materials

Key Informants
Purpose and Intended Products

Purpose

To learn qualitative data about key domains:

- Police behavior towards IDUs (injection drug users), people with HIV, CSWs (commercial sex workers) and MSM-IDUs (men who have sex with men and inject drugs).
- Perceptions
- Access to drug treatment and harm reduction services
- Social stigma
- Social risk
- Social attitudes

Intended products:

1. Qualitative data regarding knowledge, attitudes, and perceptions about police behavior toward IDUs, people with HIV, CSWs, and MSM-IDUs.

2. Qualitative data on access to drug treatment and harm reduction services, including what structural barriers, if any that prevent IDUs, people with HIV, CSWs, and MSM-IDUs from accessing those services.

3. Qualitative data on stigma, social risk, and social attitudes as it applies to IDUs, people with HIV, CSWs, and MSM-IDUs.

After the interview:

- Organize the data you collected in the attached data organization form
- Label and date the tape and any notes
- Summarize key findings for the RPAR

Steps to Conducting Key Informant Interviews

Step 1: Understand Key Informant Interviews

Step 2: Identify Appropriate Key Informants

Step 3: Coordinate Logistics of Interviews

Step 4: Define and Tailor Interview Structure

Step 5: Develop Interview Guide

Step 6: Conduct the Interview

Step 7: Recording Data from Key Informant Interviews

AT A GLANCE
Key Informant Interviews

An interview involves systematically talking and listening to people because they *already have had* the experiences and knowledge that researchers want to study or they *already know* about local meanings and understandings of risk behaviors and health consequences but often wouldn't be consulted or listened to by policy makers and planners

Interviews can either try to

- *explore* this knowledge and understanding through unstructured questioning
  target specific topics and ask particular pre-defined questions through structured interviews

Interviews will be held with

- specific individuals – individual interviews are suited to collecting in-depth information about sensitive issues

Researchers will need

- good communication, facilitation and rapport building skills
- the ability to ask effective questions and use probes and prompts where necessary
- An interview guides. This is a list of the categories, areas, topics or questions that a researcher wishes to investigate.

Interviews may require

- discussion with other researchers and key informants to help select and recruit participants
- a location that is as neutral, comfortable, accessible and free of interruption as possible
- a tape recorder to record the discussion, and extra batteries and labels

Interviewing skills are needed for

- collecting background data on a topic that a researcher has little knowledge of
- taking advantage of informal or casual conversations that relate to the rapid assessment

Interviews can be affected by

- *interviewer bias* - the interests, experience and expectations of the researcher can affect an interview
- *informant bias* - informants may give answers that they think the researcher wants to hear rather than their own opinions. Respondents may exaggerate about behavior within a group. Alternatively, they may not give details of behaviors they are ashamed or embarrassed about.

Step 1: Understand Key Informant Interviews

What are interviews?

Often, the most effective way to collect data in a rapid assessment is to simply *ask* someone a question. The collection of data through systematically asking questions and carefully listening to the answers given is called *interviewing*. Interviews are useful as they:

- *Provide access to information* - interviews offer indirect access to a range of experiences, situations and knowledge that researchers would not be able to study otherwise. Informants may describe private or sensitive behaviors, events that happened before the rapid assessment began, or key locations inaccessible to outsiders.

- *Uncover meanings* - interviews allow the meanings and definitions that individuals give to events and activities to be explored and understood. This is particularly useful for understanding what individuals think 'risk' behaviors are.

- *Facilitate interventions* - local problems usually have local solutions. Talking and listening to local people is important for highlighting the constraining and facilitating factors that an intervention may face.

Interviews can take place in any location, at any time, and with different individuals or groups of people.

Step 2: Identify Appropriate Key Informants

Who should be interviewed during a rapid assessment?

You are going to interview Key Informants who are the *types* of key informants specified in Tables A and B but there are no fixed rules about which *people* who should and should not be interviewed during a rapid assessment.

Given the short time available for study, researchers should try to adopt a systematic and pragmatic approach to selecting informants. This can be useful in ensuring that interviews are conducted with a wide range of key people, rather than reflecting the attitudes of only a few individuals or groups. Researchers should always try to build diverse samples.

In the RPAR the primary source of potential key informants for the systems and interactor interviews will be:

- Community Action Board and Focus Groups
- Power Mapping Exercise

Other ways to identify potential key informants, particularly for IDU interviews include:

- NGO and government agencies,
- "snowballing,"
- being present in drug using neighborhoods,
- recognizing icons/signs (clothing, badges, insignia),
- through doctors and hospitals

Types of Sampling

The systematic selection of informants is called *sampling*. Sampling techniques useful for deciding who to interview include:

- Purposive sampling - individuals are interviewed on the assumption that they will provide the best information. This can quickly improve the existing understanding of complex topics, such as risk behavior; highlight new directions for research, and crosscheck findings from other methods.

- Quota sampling - certain types and numbers of informant are targeted for interview. This can ensure that key individuals and groups are included or consulted during the rapid assessment. In this assessment we are using quota sampling with the hope that researchers will also be purposive in selecting the individuals with the best information within each category of key informant.

- Network sampling - this is useful for undertaking interviews with members of 'difficult to reach' populations. Key informants (individuals with special access or knowledge) are used to contact members from these populations to interview. After the interview, these members are asked to introduce the researcher to other people in the group. This continues until no new data or insights are produced.

However, there will be times during a rapid assessment, when a researcher will not know or will be unsure which informants to interview. In such cases, it may be helpful to consider:

What information needs to be collected? The more *specific* a researcher can be about the data they want to collect, the easier it is to identify potential informants. One way of doing this is for the rapid assessment team to reduce larger topic areas (such as risk behavior) into smaller, more manageable items (*see Box below*). Discussion with colleagues and key informants can be used to suggest which informants could be contacted.

Can 'mapping exercises' help locate informants? Mapping is particularly useful in the early stages of a rapid assessment, as it allows a researcher to identify potential informants in the local area. You can ask your early IDU key informants to indicate on a map of the city key street locations to find IDUs.

Are key informants able to help? Key informants can often suggest and arrange access to other individuals and groups that a researcher may be able to interview.

Is the researcher ready to conduct interviews on the spot? Researchers should be aware that interviews could occur spontaneously. This often happens when a researcher is conducting an observation and has a chance or casual conversation with someone interesting or relevant to the rapid assessment. Similarly, the researcher may suddenly find that individuals who previously refused interviews change their mind when they see other people talking to researchers. In both

cases, the researcher will not need to deliberately target or select individuals for interview. Particularly when conducting interviews with IDUs, the researcher should always have their "field bag" with all the materials needed to conduct an interview on the spot, in case an appropriate individual is discovered spontaneously.

In our assessment, we are interviewing three types of key informants:

1) Systems
2) Interactors
3) Street Key Informants

(1) Systems Interviews: A systems key informant is someone who has an overview of a whole system such as a judge, a project director, a police chief. The central goal of the systems is to understand the system in its entirety. While individuals interviewed at a system level may not have had very direct contact with IDUs, they will have access to general indicator information about IDUs, the policy environment within each system, and the nature of how laws and policy are formally or informally put into practice. Moreover, prior experience with this procedure has demonstrated that early contact with persons in these positions can be instrumental in rapidly acquiring institutional information from highly bureaucratized systems.

(2) Interactor Interviews: An interactor key informant is someone who is on "the front lines" in systems that affect injection drug users. These are people who have daily direct contact with IDUs. They could be police officers that work on the street, narcological staff members, or prison guards. Prior experience with these kinds of interviews has demonstrated that these individuals can provide very practical on-the-ground information about the implementation of policy and conduct. The interview numbers and types of people for both Systems and Interactor interviews are summarized in Table A below.

(3) IDU Interviews: In addition to Systems and Interactor interviews, a sample of 14 IDUs will be recruited by the research team for participation in semi-structured, qualitative interviews. Efforts will be made to recruit a diverse sample of IDUs with respect to gender, gender of sexual partners, participation in commercial sex work, minority group status, and length of participation in injection as outlined in Table B below. The sample of IDUs must be diverse because laws, policies, and law enforcement practices may vary considerably as they are applied to IDUs with these different characteristics. The interviews will be focused on acquiring the respondent's knowledge of the social and local meaning of risk behaviors, law enforcement practices, formal and informal policies, and health consequences of those practices on the street. From the IDU data we anticipate gaining information about policing practices, attitudes towards police and the legal system, knowledge of drug use and drug risks, and attitudes towards public health interventions, specifically harm reduction and drug treatment efforts.

Numbers of Interviews

A. System and Interactor Interviews

System/Interactor	Number in each city
Legal systems	
Prison officials	1
Judges	1
Legal academics	1
Policy-makers or local authorities	1
Legal interactors	
Police	2
Prosecutors	2
Prison guards	2
Public health systems	
Public health authorities	2
Narcological facilities: officials	2
Public health interactors	
Public health clinicians	2
Emergency/casualty department physicians	2
Harm reduction workers	2
Narcological facilities: staff	2
Advocacy interactors	
NGO staff working with IDUs	2
NGO staff working in HIV	2
Total	**26**

We are also interviewing 14 "street" informants, that is, active IDUs who can provide information about issues that affect the health of IDUs. In order to do this, the terms used (such as IDU) must be defined carefully and individuals selected on the basis of those definitions. While these terms can be defined in many ways, in this rapid assessment we are using the following:

IDU: A person who has injected any non-prescribed drug at least twice in the last three months

CSW-IDU: A person who has injected at least twice AND exchanged sex for money at least twice in the last three months

MSM-IDU: A person who has injected at least twice AND had sex with a man at least twice in the last three months

New Injector: A person who has injected a non-prescribed drug at least twice in the last three months AND injected a non-prescribed for the first time in the last year.

B. Street Informant Interviews

IDUs	Number in each city
Men	2
Women	2
Commercial Sex Workers-Men	2
Commercial Sex Workers-Women	2
New injectors	2
MSM-IDUs	2
Locally significant minorities	2
Total	**14**

Step 3: Coordinate Logistics of Interviews

When will interviews be conducted during this rapid assessment?

In this rapid assessment, you will be conducting key informant interviews for eight weeks starting about week 14 and ending about week 22. This is a relatively short period of time to conduct interviews so to maximize efficiency interview activities should be well planned out. The following are some tips for coordinating logistics.

- *Systems and interactor key informants* - System and interactor key informants are very busy and researchers should start attempting to schedule interviews for these informants as soon as they are chosen or from day 1 of the qualitative research period. It is useful to assign responsibility for obtaining interviews from particular people to one researcher so that there is no duplication of efforts.

- *IDU key informants* - As we have specified particular types of IDUs to interview, these may also be difficult to schedule. Start trying to interview IDUs from day 1. *Guides*, such as local drug users, can take the researcher to key locations and answer questions about what is going on in particular venues.

- *Don't wait* – Don't try to "save" certain kinds of key informants for the end of the data collection period. There may be unknown difficulties in scheduling and if you wait, you may not complete the interviews on time.

- *Timing* -- Interviews may take longer to schedule, prepare for, conduct and complete than the researcher may think. As a general rule, plan on each researcher being able to conduct two interviews a day and plan accordingly.

- *Field bag* -- Researchers should always be prepared to conduct an interview on the spot. It is really useful to have a small backpack or field bag packed with everything needed to conduct an interview. Contents should include a tape recorder, tapes, pens, extra batteries and tapes, paper, interview guides, consent forms and anything else needed for interviews.

- *Confidentiality* -- After an interview is completed, tapes and paperwork should be taken to the office. Used tapes and other materials should not be left where other people might see them.

How to organize an interview

Researchers will have to interview specific people (such as regional and national AIDS coordinators, known drug dealers or police officers) and contact should be made with them *as soon as possible*. These individuals will often be busy or difficult to contact. Once an informant is contacted, the researcher should:

- *Explain* why the researcher wants to talk to the informant. Try to stimulate the informant's interest in the study by mentioning its importance or the personal benefits to the individual. If the individual is interested in participating, engage in the Informed Consent Process.

- *Correct* any misconceptions that the informant may have. Informants may distrust strangers who want to ask them questions.

- *Assure* informants that all the information they provide will be confidential

- Mention any *incentives* offered to participants to take part. These may include gifts, money, or refreshments. Check with key informants concerning locally appropriate incentives.

- *Negotiate* at what time, and if necessary, on what date the interview will take place. The researcher should clearly state how long the interview will take

- *Collect contact details* from the participant. The researcher could also give the informant a telephone number or address where they can be contacted. This allows interviews to be rearranged if unexpected circumstances arise.

Interviews should be conducted in a location that facilitates discussion. This should be neutral, free from interruptions (such as people who could distract or influence the informants responses), and as comfortable as possible. If a number of interviews are being conducted over the course of a few days, the researcher could consider hiring a local school classroom or using a room in a health center. The location should be accessible. Researchers could visit informants in their own home, relocate from busy town squares into quieter side-streets, or simply ask anyone not involved in an interview to move away or be quiet.

Step 4: Develop Interview Guide

How to prepare for an interview

Before undertaking an interview the researcher should use the interview guides attached. In this assessment there are separate interview guides for system/interactor interviews and IDU interviews. We will be using these already developed interview guides. In general, *structured* interviews require a more detailed or instructive guide than *unstructured* interviews. The interviews for this assessment are designed as structured interviews.

Definition

An *interview guide* is a list of all the questions, topics and issues that a researcher wants to address during the interview. It can also include instructions on how to respond to certain answers, the order that and wording that questions should be asked in, and any useful *probes* and *prompts*. These are methods of encouraging the respondent to produce more information or talk about certain topics.

Although we have supplied interview guides to be used in the assessment, it is useful to know how they are designed for future use. There are five main steps to devising an interview guide:

1. *Identify appropriate topics and questions* – Sample guides are attached but researchers should also discuss other areas to include with colleagues and key informants. Researchers should select topics and questions that will help triangulate or fill any 'gaps' in existing knowledge.

2. *Decide on the level of detail* - The guide can range from broad topics which act as reminders, to specific questions which the researcher must ask in a precise order. As mentioned above, this partly depends on the interviewing technique used.

3. *Draft the questions* - Researchers will need to think carefully about the questions they are going to include in the interview guide. Badly phrased questions will usually produce poor quality data. If there is time, it is often useful to discuss the draft with a key informant to identify any problems with language.

4. *Order the questions* - interviews normally produce better data when questions are grouped into a logical order. For example, researchers may find it useful to ask a series of questions or concentrate discussion on a single topic, rather than jumping from subject to subject. Additionally, *culturally sensitive* questions may need to be addressed towards the end of an interview to allow sufficient *rapport* to be built up.

5. *List any probes or prompts* - if inexperienced interviewers are used then it may be useful to offer instructions on how to encourage respondents to give answers.

Questions

Interview guides should avoid questions that are:

C*omplex or technical* - use clear and simple language which will be easy to understand and unlikely to be misinterpreted

L*ong or multiple* - these can confuse informants and result in participants only responding to the parts of the question that they can remember. e.g. 'what do you feel about the risks involved in sharing syringes now as opposed to five years ago?'

Leading - these questions that result in participants coming to conclusions that they would not have otherwise considered. e.g. 'why is there so *much* prostitution in this area?' is perhaps better rephrased as 'is there any prostitution in this area?' or 'tell me about prostitution around here'

During a rapid assessment, interview guides should be modified to take into account new developments and data. Researchers will need to be familiar with the interview guide. Although this does not mean memorizing its contents, participants can lose interest in a discussion where a researcher is unconfident, poorly prepared, or disorganized. Conducting several practice interviews with friends will help the interview become more proficient at using the interview guide.

TIP: Practice makes perfect!

Step 5: Define and Tailor Interview Structure

What interview techniques can be used in a rapid assessment?

In this assessment we are using a "structured" interview approach. Interview guides have been developed and appended to the materials. While we expect that all the areas on the interview guide will be covered in each interview, the interviewer is free to pursue in more depth new topics that may come up or add questions submitted by the CAB.

While you will use this approach and cover areas specified in the attached interview guide, for future reference, the following information is included about interview structure.

There are three main interview techniques that can be used: *unstructured, structured* and *group*. These are not mutually exclusive: it is often useful to use a *combination* of these interviewing techniques. For example, although a researcher may wish to spend time in an interview focusing on specific issues and in a certain order, it may be useful to conclude the interview by exploring topics not on the interview guide that have emerged.

Unstructured interviews

Unstructured interviews are where the range of topics covered and the responses given by a respondent are not constrained by a detailed interview guide. Although researchers may still cover key topics, they will also encourage a respondent to discuss (often in depth) any *relevant* areas or subjects not on the interview guide. This flexible approach means that the exact order and wording of questions in each interview will vary from respondent to respondent.

The aim of unstructured interviews is to get informants to freely offer their opinions, knowledge and experience. The researcher should encourage the respondent to provide as much detail and be as frank as possible. The key to this is thinking carefully about which questions to ask, how they are phrased and when to use probes and prompts.

Unstructured interviews require good communication and facilitation skills. A researcher must listen carefully to respondents and be aware of any new or interesting information. However, they should not let informants discuss irrelevant issues in too much detail. Politely, but firmly change the subject.

- No restrictions on what can be discussed. Useful for collecting background data in the early stages of a rapid assessment, when a researcher has little knowledge of a topic
- Flexible enough to allow the interviewer to modify their line of inquiry, follow up interesting responses and investigate underlying motives.
- Inexperienced researchers may introduce *bias* by using poorly worded questions.

- Can encourage the respondent to talk about irrelevant and unimportant issues. This can make the interview quite lengthy if the researcher is not assertive enough.

- As there is no set format, each interview tends to be unique. This can make it difficult to code and analyze the data.

Structured interviews

Structured interviews are used when a researcher wants more control over the topics discussed and the format of an interview. These often use a detailed interview guide that outlines areas and questions to cover and sometimes the order in which they should be asked. It may also suggest a precise wording for questions that the researcher has to adhere to.

Structured interviews are often undertaken after some *exploratory* research has already been conducted. This allows findings from other methods or existing information sources to identify topics that the researcher wishes to investigate further.

- The common format across each interview makes it easier to code, analyze and compare data.
- The interview guide allows the researcher to decide how long should be spent discussing each question or topic. This can ensure that interviews do not over-run, or be used to prioritize questions when only a short amount of time is available.
- Detailed interview guides allow inexperienced researchers to undertake interviews
- Strict adherence to the guide may prevent the collection of unexpected but relevant information.
- Although a standard format is used, informants may hear and understand the questions in different ways. This can affect comparison between respondents.

Group interviews

Group interviews involve a researcher asking several informants a question at the same time, with participants providing answers individually. Unlike a focus group, the researcher will usually not encourage the informants to discuss the question amongst themselves. Group interviews can use unstructured and structured interviewing techniques. Information from group interviews cannot be treated like data from individual interviews. The researcher should be aware that answers could be influenced by *group dynamics*. Prominent individuals or subgroups can dominate an interview, sensitive issues may be suppressed, or group pressure to express a 'common' view can stop other views being expressed.

Step 6: Conduct the Interview
Eleven Tips on Conducting Interviews

1. *Arrive early* at the location where the interview is to take place. Try and ensure that the location is as quiet and as free of interruptions as possible.

2. *Translators* should be briefed on what is going to happen. If a tape recorder is used it should have an external microphone, and you should have extra batteries and tapes.

3. *Introduce anyone present* to the participant. Introduce people in a non-threatening way. This means referring to a researcher present as Anand, rather than Dr Singh. Assure participants that everything discussed will be confidential. Engage in the Informed Consent Process.

4. *Assure* informants that, if specifically requested, the identity of the respondent will be kept confidential. *Inform* the respondent that unless they request anonymity, the respondent's identity will be noted and information or opinions may be attributed to the respondent by name.

5. *Use clear and simple language* when introducing topics or questions. Allow participants time to think and speak.

6. *Sensitive subjects* can be introduced by asking what 'other' people are said to do, and then inviting critical comment.

7. *Reflecting participants' answers* back in their own words is a good way of checking that you understand what they are trying to say.

8. *Be a good listener and ask why and how.*

9. *Check with the respondent* that it is acceptable to continue an interview if it looks as though it may last longer than expected.

10. *Always collect demographic information* such as age, ethnicity, type of drug use, source of income, and status. This will be useful in speculating about the link between certain types of people and specific behaviors.

11. *Summarize the key issues and opinions* when the interview is finished. Ask if participants have anything to add or any questions. It is important that the researcher *does not* give advice or answers that they are not in a position to offer. It is often useful to carry health promotion leaflets or the address of local treatment clinics.

In the training and on the interview guides we have specified different ways to ask questions and different interviewing approaches. The box below summarizes interviewing question types.

Types of Interview Questions

- *Factual* - specify, confirm or refute a fact. These are normally closed questions.

  Ex: 'Do you use condoms when you have sex with clients?'

- *Opinion* - open ended questions which encourage the informant to elicit ideas and beliefs

  Ex: 'Tell me about using syringes your friends use first?'

- *Clarification* - used to check that the researcher understands or to gain additional information

  Ex: 'And you were the only person there at the time?' or

  'Are there any other reasons why you think a syringe exchange program wouldn't work here'?

- *Representativeness* - to check whether an event is typical of the persons experience or common to other people in the community

  Ex: 'Do you see the same doctor every time you visit the clinic?' or

  'Do other people that you know also rinse their syringes with urine?'

- *Hypothetical questions* - allows the researcher to explore situations that the individual has not yet experience or are perhaps too 'sensitive' or 'shameful' to directly explore

  Ex: 'Let us say that you were able to obtain free condoms, would this change your behavior?' or

  'Imagine that a man needs to buy heroin, where would he go first?'

- *Ordering questions* -allows the researcher to check the importance or significance of certain factors

  Ex: 'In order of importance, which risk behaviors are most common among amphetamine users?'

  Probes - To encourage a person to provide more information or continue speaking. May be silent, as simple as "Tell me more…" or a specific additional question.

  Prompts - Encourages informants to raise issues that have not spontaneously arising. One example used when talking about buying syringes – "Tell me how much the syringe cost"

Maximizing the Interview Process

The RPAR uses structured interviews. Other rapid assessments can include related exercises to gather similar information from subjects. Two of these methods are described below: *mapping and free listing*. Although mapping may be useful for interviews involving questions about the spatial distribution of certain activities, such as: drug treatment centers, drug use, sex work, or drug markets, the RPAR will not specifically require mapping or free listing.

These activities, as well as some strengths and weaknesses, are described for your information.

- *Mapping* - individuals are asked to help draw maps of the local area or indicate on a map the central locations where IDUs or IDUs of a particular type may be found.

- *Free listing* - individuals are asked to write down or mention everything they can think of that is related to a particular topic. When informants cannot think of any more examples, the researcher starts another list by asking about a related topic. In the early stages of research, such lists can be useful for collecting local terminology, drug types and locations where sex work is conducted.

Case Study

During a rapid assessment, a researcher used free listing to identify the types of drug available in the local area, their slang names, and if home-produced, the different types of production methods. By asking the question "Tell me all the different names for heroin" and then asking about the differences between the names, the researcher discovered two sets of slang names for heroin. One set of five names referred to heroin produced by the user from opium poppies and the other set of three names referred to heroin made somewhere and purchased from local dealers. After talking about the names of the drug, the researcher was able to ask more informed questions about the home production of heroin.

Such exercises can be useful for:

- Making participants feel involved in the research process
- Building rapport and trust
- Retaining the attention of younger informants such as street children
- They can however take time to explain, arrange and analyze the findings
- They also require good facilitation skills

Step 7: Recording Data from Key Informant Interviews

Many interviewers feel that it may be challenging to elicit long, open, reflection on the interview topics from participants. To the contrary, it is often difficult to terminate the interviews especially when the participant is at the "street level" like police officers that are in the community or injection drug users are very eager to tell their story. They have rarely, if ever, been asked to participate in research and are enthusiastic about being asked to reflect on their lives. In the training, we have covered many ways of eliciting conversation such as using prompts and asking open-ended questions. The following box contains a brief summary of things to remember about interviewing, recording and data organization.

During the interview

- *Be aware of sources of bias while asking questions*: For example, the interests and expectations of the researcher can affect an interview (also known as *interviewer bias*). For example, if an interviewer is very interested in proving that harm reduction works to reduce risk, they may ask numerous and detailed questions about harm reduction and downplay or completely skip questions about drug treatment programs. Be aware of your biases and work to remain open and unbiased during an interview. If you tell participants your bias, they may try to answer desirably, conceal their actual experience or lie about their experience (sometimes known as *informant bias*).
- *Be aware of who <u>you</u> are in the interview*. If the researcher discloses his or her own history or tries to identify with the respondent by presenting themselves as "knowledgeable" the respondent may assume the researcher doesn't want to hear basic information. For example, if the researcher self-discloses their own drug use history to an IDU informant, the informant may skip important information about buying drugs, assuming the researcher knows all about it. The researcher may or may not know all about it, but we are interested only in what the informant knows. Limit self-disclosure or attempts to identify with the informant. If the informant believes the researcher to be naïve and says so, there is no need for the researcher to correct that impression. In fact, the best stance that a researcher can take is one of "student" to the informants "teacher". Start each interview fresh with an open mind, even if you have heard the same information from other informants.
- *Translation:* Address informants as if you were talking directly to them. Have the translator stand to the side or behind you but never in front. The translator will get tired and this can affect communication.

While recording data

- *Recording:* In this assessment we are stressing the use of tape recorders. If an informant insists on not using a tape recorder (which rarely happens, even among IDUs) the researcher will have to take notes. Unless a colleague is available to do this, the interview will take longer to conduct. Try to note the most important points and do not be afraid to ask informants to talk more slowly or repeat things. It is very important to use the tape recorder wherever you can as interviews conducted without taping lose some of their value.
- *Spares:* <u>Always</u> carry spare batteries and extra tapes. Some interviewers carry an extra tape recorder. Without fail, test the recorder before conducting the interview. It is very frustrating to conduct a great interview and then find that the recorder had malfunctioned.

Immediately after the interview

- *Label and date* any materials: This includes any notes, maps or other items. This will make it easier to identify and locate them at a later date.
- *Reflection and Notes:* immediately after the interview reflect on what happened. Review notes and ask yourself: Are there any weaknesses in the way the interview was conducted? Were any topics of discussion missed? What useful issues arose that hadn't been previously considered? Make brief notes on the interview itself. This must happen immediately after the interview. Make notes about where the interview was conducted, how the participant responding, his or her mood, and anything else that is relevant. In addition, start organizing the day using the included form. These tasks may require repeated listening to the tape.

RAPID POLICY ASSESSMENT & RESPONSE

Module III: Qualitative Data

Focus Group — Tools

Focus Groups: Tools
Purpose and Process

Purpose

- To learn qualitative data about key domains:
  - police behavior towards IDUs, commercial sex workers and MSM-IDUs
  - perceptions about these groups
  - access to harm reduction services
  - access to health care and drug treatment services
  - social stigma towards these groups
  - social risk behaviors involving these groups
  - social attitudes towards these groups.

- To identify potential systems and interactor key informants

Process

In this module, you will

- Identify focus group candidates
- Conduct focus group meetings
- Label and date tapes of the focus group
- Organize the data you collected in the attached data organization form.

The following forms will guide you through the process:

- Form to track potential candidates for focus groups
- Focus group note taker's data collection sheet
- Model moderator's guide for focus groups
- Form to track suggested people for system and interactor individual interviews
- Master data collection form

FORM: Suggested Focus Group Participants

Suggested Focus Group Members: The attached form can be used to track potential focus group participants.

Use codes to describe the rationale for recruitment	
LE	Law enforcement
RI	Risk interventionists
DTHC	Drug treatment and health care

Focus Group Participants Candidate List			
Rationale	**Name**	**Organization**	**Contact Information**

FOCUS GROUP NOTE SHEET

Topic Area	Focus Group Description:
HIV/AIDS	
Other Infectious Diseases	
Injection Drug Use	
Public Health Interventions	
Economic and Social Indicators	
Law Enforcement	
Other Topics	

FORM: Topic Guide
Model Moderator Topic Guide

The Model Topic Guide illustrates primary questions that could be addressed to each focus group as well as probes to encourage discussion of the topic.

Key Domains	Probes
How does law enforcement treat IDUs? How about people the police think are HIV+, MSM-IDUs, or CSW?	*Do police harass people they suspect of being IDUs, HIV+, or CSW?*
	Does treatment depend on certain characteristics (age, gender, ethnicity, race, location)?
	Do police treat men and women differently?
	Do police appear to target IDUs for arrest?
What happens once people are arrested?	*What is the process?* *Do police ask for bribes?* *What happens legally?*
How accessible are harm reduction methods (syringes, condoms, STD treatment, drug treatment)?	*What are the locations of harm reduction programs?* *Can people get syringes or condoms in other places like health clinics?*
What barriers prevent IDUs, CSWs, HIV+ from using them?	*Location barriers?* *Attitudes of the workers?* *Fear of the police?*
Stigma	*Is there any way that stigma influences HIV risks?*
Social risk	*How do attitudes and stigma affect IDUs, CSWs, and MSM-IDUs social risk?*
Social attitudes	*How are IDUs, CSWs, MSM-IDUs treated in general? By the police? By institutions?*
What questions didn't we ask that we should have?	
Who should be interviewed as key informants? [After brief introduction defining types of system and interactor key informants]	

FORM: Suggested System and Interactor Interview List

Suggested system and interactor interview list: The attached form can be used to record people suggested by the focus groups as candidates for system or interactor interview candidates.

Use codes to describe the rationale for recruitment	
LE	Law enforcement
RI	Risk interventionists
DTHC	Drug treatment and health care
	AND
SY	System
IN	Interactor

System and Interactor Interview Candidate List Suggested by Focus Group # _____			
Rationale	**Name**	**Organization**	**Contact Information**

DATA ORGANIZATION FORM
Master Report Section

Instructions:

At the end of each day's data collection (focus group or interviews), you should go over all the information you obtained, identify information relevant for the final report and planning process, and record summary information on the following data organization forms. Identifying and summarizing these data are the first step necessary for the Analysis and Action planning module of the RPAR (Module IV). These sheets will help you:

- Identify important issues and problems in HIV prevention among IDUs in your community;
- Facilitate reporting of information to the CAB;
- Facilitate completion of the final report;
- Assemble important information for the process of analysis and developing solutions;
- Assemble information necessary for the process of planning community response.

Example
Filling Out the Form

Topic area/ domain	Category informant/ focus group	Information summary, key points	Comments:
HIV status and arrests	LE/ FG #1	Key Point #1 FG #1 was made up primarily of police officers. The group felt that all IDUs were HIV infected and thus were reluctant to arrest them for fear of becoming infected themselves. This health risk was considered to be the primary reason police accepted bribes instead of arresting IDUs. One person also reported that the "jails were full" as another reason police accepted bribes.	Added comment on (date): Individual interviews with police officers have confirmed the general finding of this focus group about HIV status and arrests. Officers interviewed individually suggested several other reasons why police are more likely to take a bribe than to arrest an IDU. See individual interviews with police officers for more detail.

FORM: Data Organization Form

Master Report Section

Topic area	Category informant/ focus group	Information summary, key points	Comments:

RAPID POLICY ASSESSMENT & RESPONSE

Module III: Qualitative Data

Focus Groups — Training Materials

Focus Groups
Purpose and Intended Products

Purpose

- To learn qualitative data about key domains:
  - police behavior towards IDUs, people with HIV, CSWs, and MSM-IDUs
  - perceptions
  - access to harm reduction services
  - social stigma
  - social risk
  - social attitudes
- To identify potential key informants

Intended Product

1. Qualitative data regarding knowledge, attitudes, and perceptions about police behavior on toward IDUs

2. A list of key informants to be interviewed

After the Meeting:

- Organize the data you collected in the attached data organization form.
- Add new notes as needed for the RPAR.

AT A GLANCE
Focus Groups

A focus group is a number of individuals who are interviewed together because they:

- Have common experience
- Come from a similar background
- Have a particular skill

These characteristics provide both:

- A focus for discussion
- And help people express individual and shared experiences and beliefs

A focus group may require:

- A location that is as neutral, comfortable, accessible and free of interruption as possible
- A guide of discussion issues or topic areas
- A tape recorder and extra batteries, tapes and labels
- A blackboard, whiteboard or paper and pens
- A key informant to help recruit participants

Rapid assessment team members may be required to act as:

- A *moderator* - a member of the rapid assessment team who takes part in the focus group and encourages participants to talk about interesting and relevant issues
- A *note-taker* - a member of the rapid assessment team who will observe and record significant verbal and non-verbal details

Focus groups are good for:

- Producing a lot of information quickly
- Identifying and exploring beliefs, attitudes and behaviours

The key disadvantages are:

- The researcher has less control than in an interview
- The data cannot tell you about the frequency of beliefs and behaviours
- The group may be dominated by one or two participants who can influence the views of others

Steps to Conducting Focus Groups

This section provides a step-by-step approach to conducting a policy focus group. There will be three focus groups, each consisting of six to ten participants. Three groups will be convened, the first consisting of law enforcement personnel; the second, of risk interventionists such as outreach workers, public health providers and the like; and the third, of drug treatment providers and clinicians treating drug users.
For all groups, follow the following approach:

Step 1: Understand Focus Group Discussions

Step 2: Identify Appropriate Focus Group Participants

Step 3: Recruit Focus Group Participants

Step 4: Coordinate Focus Group Logistics

Step 5: Review Your Topic Guide

Step 6: Define Role of Focus Group Moderator

Step 7: Moderate the Focus Group

Step 8: Collect Data from Focus Group Discussions

Step 1: Understand focus group discussions

What is a focus group?

A focus group is a number of individuals who are interviewed together because they have had a common experience, come from a similar background, or hold a particular expertise relevant to the rapid assessment. This does not mean that individuals in a focus group will know one another, although they may. A focus group is not the same as a group interview. A group interview also has a researcher asking a group a series of questions but participants provide answers to these individually. Focus groups encourage individuals to discuss and explore questions. Focus groups are small and usually consist of no more than 6 - 10 people.

What is a focus group useful for?

Focus groups are good for collecting information quickly. A focus group will often arrive at an agreement or consensus about an issue through group discussion. At an *early* stage of the rapid assessment a focus group can be used for:

- Discovering opinions, information, and behaviours that the rapid assessment team may not know much about, that existing data do not address, issues that had not been considered by the researcher
  Generating hypotheses and ideas, and new directions for research
  Providing detail about issues that might not get uncovered in any other way

During the *middle* period of the rapid assessment a focus group may be used for:

- Validating, triangulating, and crosschecking findings from other data and hypotheses. Participants can be asked about a particular issue and their responses compared with other data sources
- Exploring further what the group feels about a topic. Changes in opinion and attitude could be recorded and possibly related to wider external factors

Definition

Validation is a way of checking whether two sources of data are in agreement and assessing differences. For example, a focus group of police officers might conclude that few heroin users are arrested, and arrest data might show that many heroin users were arrested. This contradiction can be explored in a focus group in order to understand why the two sources differ.

At the *concluding* stage of the rapid assessment focus groups may be used for:

- Validating and cross-checking findings from other methods
- Assessing the representativeness of emerging findings. A focus group could be held in an area outside of the original study with groups of a similar composition and the results compared
- Judgement of the reaction of selected groups to suggested interventions arising from the rapid assessment. Participants may be able to identify cultural obstacles, problems and issues.

What are the advantages and disadvantages of focus groups?

Strengths of focus groups

Focus groups:

- Can produce a lot of information more quickly and at less cost than individual interviews
- Are useful for identifying and exploring beliefs, attitudes and behaviours
- Are useful for identifying questions for individual interviews
- Can indicate the range of beliefs, ideas or opinions in a community

Weaknesses of focus groups

- Group dynamics can influence who speaks and what they say. Participants who are uncomfortable with speaking in groups are at a disadvantage.
- The number of questions that can be addressed is smaller than in individual interviews
- It is hard to facilitate a focus group. It is important to know how to manage the group so that all participants are able to share their views.
- Taking good notes during focus group discussions is difficult, and transcribing from tape recordings is time consuming and costly
- Researcher has less control over discussion's flow (compared to the individual interview)

- Focus groups can only represent the opinions of the people in the group and cannot give information about the opinions of the whole community.

Step 2: Identify appropriate focus group participants

Which participants should be included in a focus group?

There will be three focus groups, each consisting of six to ten participants. The first group will consist of law enforcement personnel; the second, of risk interventionists such as outreach workers, public health providers, harm reductionists and the like; and the third, of drug treatment providers and clinicians treating drug users.

Focus groups cannot be used to generalise about the reaction or behaviour of an entire population. Therefore, the simplest method for selecting participants is choosing individuals you think will provide the most useful information. This is known as *purposive sampling.* The general rule for selecting such participants is that they should be reasonably *homogeneous.*

Definition

Homogeneous - a common characteristic, experience, or expertise. Examples of homogeneous focus groups include: a group of young drug injectors; a collection of law enforcement personnel; or staff from an STD clinic.

This can be difficult. Individuals who are similar in some respects have very different backgrounds. This could restrict the range of the discussion.

Example

Law enforcement officers who work on the street may be very different from higher-level police. One difference is that street officers may differentially enforce the law or have other informal practices. Front-line police may be very reluctant to admit to these practices in front of their supervisors. Researchers will want to consider occupational roles as part of preparing for the focus group.

The researcher has to consider how homogenous focus groups need to be. An awareness of an individuals' background will allow appropriate groups to be assembled. For example, groups may be assembled on the basis of what type of work a participant does, with attention to diversity within each group, making sure that women or important minorities are represented. However, such organisation may not always be possible.

During a rapid assessment, you may come across a number of individuals who were not previously available for questioning, or resource constraints may mean that a

researcher does not have the time to interview participants individually. In such cases, spontaneous focus groups can be held with groups of people. If this happens it may be useful to bear the following in mind:

- You may wish to exclude individuals from the focus group who are likely to obstruct the flow of the discussion or even disrupt discussion
- You may wish to conduct the focus group with a non-homogenous set of individuals. Here, good moderator skills are required. If acceptable, you should tape record the discussion. This will allow you to concentrate on the issues being discussed.
- If necessary, identify the most important participants and choose to conduct individual interviews instead. Attempt to arrange to talk with other individuals at a later time.

You can fill in the attached form to track potential focus group participants.

Step 3: Recruit Focus Group Participants

How to organize a focus group

Think creatively about how to recruit members. For this assessment there will be three focus groups, each consisting of six to ten participants. The first group will consist of law enforcement personnel; the second, of risk interventionists such as outreach workers, public health providers, harm reductionists and the like; and the third, of drug treatment providers and clinicians treating drug users.

Recommendations for focus group members should be solicited from the CAB. In addition, researchers may wish to do their own recruiting of focus group members who may be part of organizations not known to the CAB members. Every effort should be made to recruit people who will have a diversity of opinion.

Example

The CAB may only recommend police officers that are considered "good" representatives of the department. The researcher could ask a recommended police officer to recommend someone in the Department "who is different from you". He may select someone with a different approach to policing, enforcement, a woman, or someone who differs in another way. Using this method, sometimes called "snowball sampling", can produce focus groups that are relatively homogenous, but where members may represent different points of view.

Once you have decided who should attend the focus group those participants need to be informed about it. Recruitment should begin as early as possible to allow potential candidates who decline to participate to be replaced. Potential focus group candidates should be told:

- Why they have been recruited, the topic that you wish to discuss and how many people are likely to be in the group. You may also mention the importance of that person's contribution to the success of the rapid assessment
- Where, and on what date, the focus group will take place, the time participants should arrive and how long it will take
- Of any incentives offered to encourage people to take part. These may include gifts, money, or refreshments. Check local knowledge to find out what incentives are acceptable, desirable and appropriate. This may vary according to local customs and the time of the year.

Step 4: Coordinate focus group logistics

Secure a location

You should record a contact address and phone number for participants as this allows notice to be given if arrangements change. Regular contact should be maintained with participants if a focus group is organised for the near future. Remind individuals at regular intervals that the focus group is 'a week away', 'in 3 days time', 'tomorrow', or 'today at 3:00pm'.

Although focus groups may be conducted in any location that facilitates discussion and encourages participants to attend (such as a health center, a classroom or just under a tree), careful attention should be given to the following:

- The location should be as *neutral*, *free of interruptions* (such as telephone calls, other members of staff) and *comfortable* for participants as possible. This could include hiring a local school classroom or relocating from a busy town square to a quieter side street. It is probably a good idea not to hold the focus group in the offices of a participant unless you can conduct the group after working hours when the staff has gone home.
- The location should be *accessible* – participants should be able to find and get to the site easily.
- The location needs to be *private.* In pursuing topics, which may be culturally "delicate", it may be preferable to hold the group in a discrete location.

Step 5: Review Your Topic Guide

The *topic guide* in the training materials section contains a list of questions that will be addressed within the focus group. It is best to prepare this guide in advance to keep the conversation on track. This is important, as participants can lose interest in a discussion where a researcher is poorly prepared, disorganised or unconfident. The research team should all become familiar with this topic guide. Practicing moderating and using the topic guide in advance with a group of friends can be very useful.

Step 6: Define role of focus group moderator

Running a focus group is a skilled task.

The *moderator* must be able to control and mediate discussion between a number of individuals, focusing and maintaining their attention on issues relevant to the rapid assessment. Discussion not directly related to the rapid assessment should be kept to a minimum. However, relevant discussion should be encouraged and moderators need to make sure that one or two individuals do not dominate the focus group. This task may be best accomplished by someone with experience of qualitative research, facilitating public debates and meetings, or from a background in journalism.

It is useful to have an additional *note-taker* or observer. The note-taker does not moderate or participate in the focus group. The note-taker takes notes on how the participants were acting, emotional cues they may give, and any other observations that may help later, when the tape is examined. They are able to observe and record information that the moderator could overlook.

Step 7: Moderate the Focus Group

Asking questions

A moderator must have control of the group. **High control** is good when you have a strong agenda or need confirmation of previous findings. **Low control** is good for exploration of new questions. In these focus groups, we have specific topics to focus on, so the moderator should exercise high control over the group, always referring the topic guide to direct conversations.

Avoid asking leading or opinionated questions. You can ask spontaneous questions, but if a participant gets off topic, you can focus the group by going on to the next question from the topic guide.

Examples

Leading or judgmental questions

"Everyone here would agree that drugs are bad, correct?"

- Better way: How do people feel about drugs?

"Do people think that sex workers are dirty?"

- Better way: Tell me about sex workers.

Probing

Probing is the practice of eliciting good follow-up comments.

A good probe:

- Is specific
- Is connected to the discussion underway
- Can sometimes just be silence or waiting for more comments
- Can be a "listening response" – repeating what the speaker is saying so that the speaker knows you are listening
- Is not a judgmental statement or a statement of opinion.

Dealing with certain problem participants

You might experience the following personality types in your focus group, and you should know how to deal with them.

- **Experts:** people who *must* tell everyone everything they know
- **Non-participants:** people who remain quiet
- **Limelight hogs:** people who need attention and will talk louder than the other participants

The three important periods in an initial focus group process are the:

- Greeting, acquaintance-making period
- Either an "ice-breaker" or informal chatting period
- Focus group start-up and introduction period

Example

Ice-breaker Exercise

The point of this exercise is to have everyone introduce someone else. After forming into pairs, the first person interviews the other person to find out their name and institution and other non-professional things such as hobbies, pets, or favorite vacation spot. At three minutes, the leader calls time and the second person interviews the first. At three minutes everyone returns to the circle and then each member of the group introduces their partner.

Ten steps to conducting a focus group:

1. Arrive early at the location where the focus group is to take place.

2. Arrange the location so that the group will sit in a loose circle. This allows everyone to see and hear what is going on. The moderator should sit with the participants, but note takers and any observers can sit anywhere outside the circle where they can hear and that has a good view.

3. Ensure that the location is as quiet and as free of interruptions as possible. The tape recorder should ideally have an external microphone to pick up individual voices. You will also need extra batteries, tapes and labels. Test the recorder before the session begins.

4. Welcome participants warmly and when assembled introduce yourself and any assistants present. Explain why the focus group is taking place. Participants may never have been to a focus group before, and you may need to outline what is expected. Reassure members why people are taking notes, watching them and asking for their consent to tape record the discussion. Stress the fact that anything said is confidential.

5. Either use the introductions ice-breaker exercise or allow participants to briefly introduce themselves to the group. This may be a good opportunity to test if the tape recorder is working. Introduce the first topic slowly and coax participants into talking. Participants should have informal nametags so that the moderator and others will address them by name. This is useful to have on tape so that speakers can be identified later.

6. Be a good listener and cultivate the habit of asking ‘why’ and ‘how’.

7. Summarise the discussion at appropriate points. You may wish to do this on a large piece of paper taped to the wall so everyone can remember the points already covered.

8. Refreshments and breaks may be required in longer focus groups. Find out what is culturally appropriate beforehand. In some cultures people do not eat during specific times of the year or day, or may not accept food from strangers.

9. When the focus group is finished, summarise the key issues and opinions and ask if anyone has anything that they want to add.

10. At the end, thank participants and if you have not already done so, take down any contact details. You may wish to contact them in the near future.

One of the last questions of the focus groups is to inquire about people who should be interviewed in individual, in-depth interviews. These people can be divided into two kinds of people: 1) people with knowledge about *systems* that affect IDUs and 2) people with first-hand knowledge of IDUs, also known as *interactors.* Both kinds of interviews are important in order to develop a complete picture of how IDUs are treated.

Examples of people with overall knowledge about systems affecting IDUs include: police chiefs, directors of health clinics, the mayor, elected representatives, the director of the needle exchange program, or prison officials. People who have a systems perspective may have never encountered an IDU personally but may have in-depth knowledge of how their system is organized and what the implications might be for the health of IDUs.

Examples of people with first-hand or interactor knowledge of IDUs include prison guards, the receptionist at the drug treatment clinic, an outreach worker with many contacts among IDUs, street-level police officers, or even people such as bartenders or particular pharmacists who sell needles to IDUs. An interactor has daily contact with IDUs and first hand knowledge of IDUs daily lives.

Both systems and interactors people should be nominated by focus groups as candidates for individual interviews. Record these suggestions on the System and Interactor Interview Candidate List.

Step 8: Collect Data from Focus Group Discussions

How to manage data from a focus group

Immediately after the focus group, the research team should discuss how the focus group went and any immediate reactions that they had. The notes should be added to the note-takers records for use during the analysis. The focus group will still be fresh in your mind and you may have observations that you wish to discuss with colleagues.

Immediately after the group, when participants have left, you should:

- **Label and date the tape** This makes it easier to identify and locate tapes at a later date. The label and date should be both on the tape and the case. In addition, the moderator should say the date into the tape at the start. Materials should be kept in a safe place to ensure confidentiality.
- **Play back the recording or parts of the recording** If other researchers are involved compare notes and discuss their significance.
- **Write a summary of the key points of the group** This should be done by all the researchers present. Are there any weaknesses in the way the focus group was carried out? Were any topics missed? What useful issues arose that hadn't been previously considered?

NOTE: This process cannot be left to a later time, as it is difficult to remember all the things that happen in a focus group. It is best to debrief right after the meeting.

RAPID POLICY ASSESSMENT & RESPONSE

Module IV: Analysis, Action Plan, & Report

Tools

Analysis, Action Plan, & Report
Tools

Purpose:

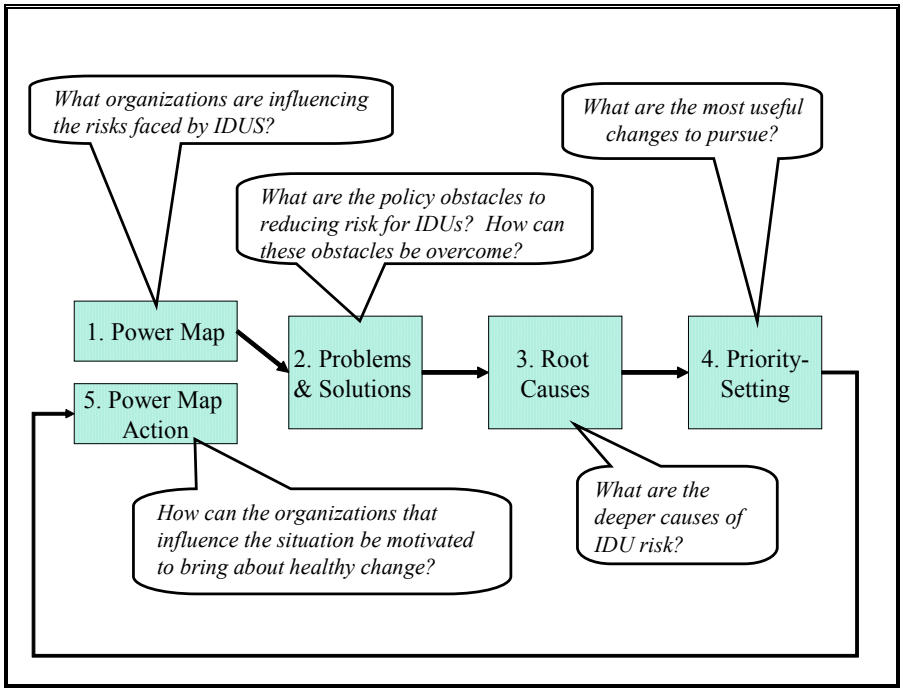
The purpose of this module is

1. To organize the data obtained from the other modules, and
2. To work with the CAB to produce the Action Plan and Final Report.

Process:

During the process you will:

- Organize main findings for presentation to the CAB
- Work with the CAB to
  - identify problems in law and policy that interfere with HIV prevention and harm reduction;
  - Identify the root causes of policy problems in the Root Causes Exercise;
  - Identify possible solutions to policy problems and root causes;
  - Prioritize and evaluate possible solutions in the Priority Setting Exercise;
  - Develop strategies to successfully bring about policy and practice changes in the Power Map Action Exercise
- Plan implementation of these strategies and recommendations
- Produce a final report summarizing findings, making recommendations for solutions or interventions, and describing an action plan for implementation.



The Five Steps of Policy Analysis in RPAR

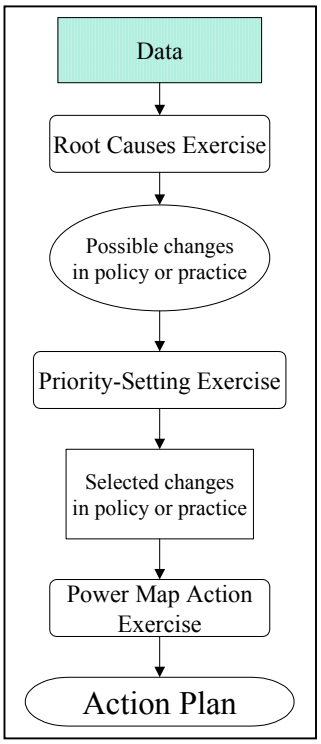
Organizing Data for the CAB

When: Before CAB meeting # 5

Purpose: To convey the chief findings of the RPAR research to the CAB.

Process:

Record (1) key findings from the Data Organization Forms and (2) relevant results of earlier Problems and Solutions and Root Causes Exercises into the Key Findings column on the Analysis and Action Form 1.



RAPID POLICY ASSESSMENT AND RESPONSE

Analysis and Action Plan Form 1[1]

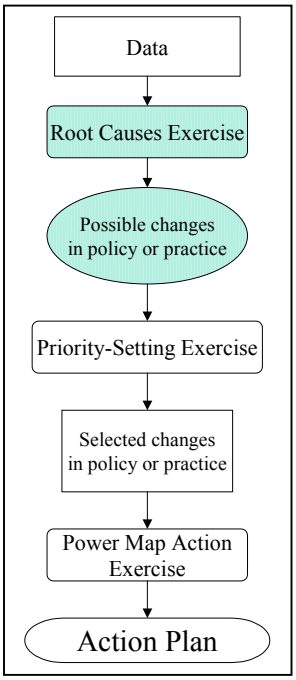
Key Findings	Law or Policy Problems	Root Causes	Possible Responses

[1] Adapted from RAR materials developed by the Centre for Research on Drugs and Health Behaviour Department of Social Science and Medicine, Imperial College, London, as part of its projects on rapid assessment and response.

Root Causes Exercise

When: CAB meeting # 5

Purpose: To describe a web of factors contributing to HIV risks in the target population, and to identify "pressure points" where significant gains could be made from policy or practice change.



Process:

1) The CAB reviews the chief findings set out in Analysis and Action Plan Form 1.

2) The most serious problems (e.g., HIV and Hepatitis among IDUs) are entered into the bottom row of the Root Causes Form.

3) Causes of the risks are entered higher on the form, and then causes of causes and so on, until participants feel they have mapped the issues.

Prompts and Probable Responses:

Prompt: *Why are IDUs at risk of HIV?*
Response: *Because they share needles. [Add "needle sharing" to Root Causes Form]*
Prompt: *Why do they share needles?*
Response: *Because they are afraid to carry new ones. [Add "fear of carrying needles" to Root Causes Form]*
Prompt: *Why are IDUs afraid to carry needles?*
Response: *They fear arrest or police interference. [Add "fear of police action" to Root Causes Form]*

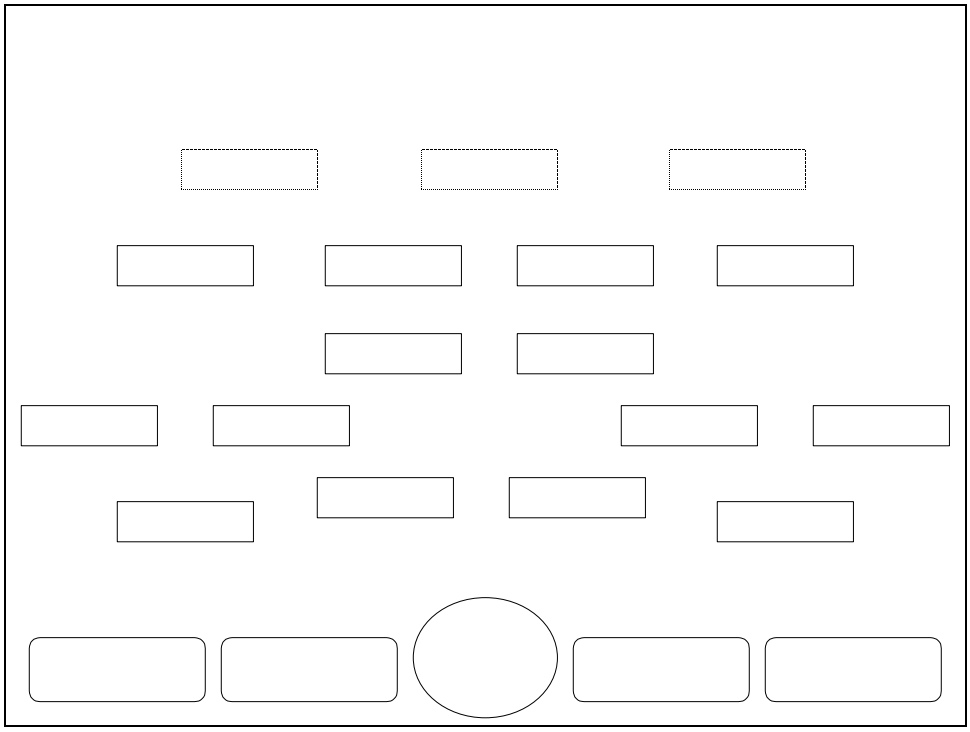
4) Identify policies and implementation practices that are acting as important "root causes" of the problems in column 1 of Form 1. Enter results in columns 2 and 3 of Form 1.

Prompt: *What policies and practices on this root-causes picture seem to be causing the most harm?*

5) Identify changes in laws, policies or practices that are needed to alter root causes of problems. Record possible responses in column 4 of Form 1.

RAPID POLICY ASSESSMENT AND RESPONSE

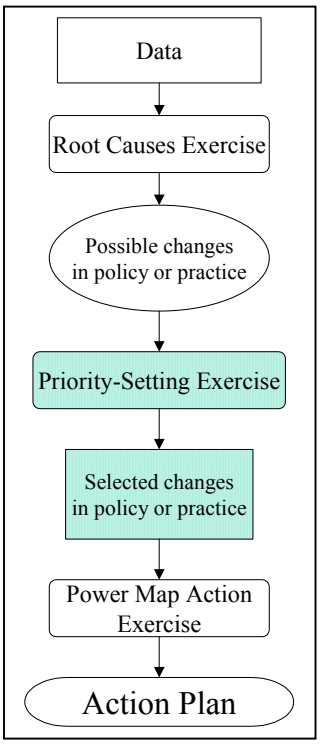
Root Causes Form



Priority-Setting Exercise

When: CAB meeting # 5 & 6

Purpose: To identify the most useful and attainable policy and practice changes available to the CAB



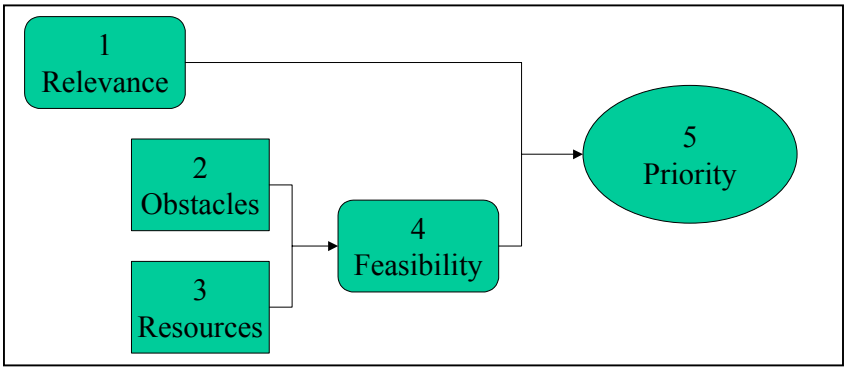
Process:

The process of setting priorities among possible targets and methods of change can be more or less formalized. The exercise described in the body of the text below uses a more formal set of steps in which the CAB as a group performs the prioritization using Analysis and Action Plan Form 2. A less formal approach is set out in the text box. The research team should decide what approach or combination of approaches makes the most sense for a particular CAB.

Using Analysis and Action Plan Form 2, list possible responses drawn from Form 1. Through group discussion:

1) Evaluate each potential response for relevance. Relevance is expressed in a score, with "1" being very relevant and "3" being the least relevant.
2) Describe obstacles (political, economic, and social) to successfully implementing the response.
3) List resources needed to implement the response.
4) Evaluate feasibility by considering both obstacles and resources. Feasibility is expressed as a score with "1" being the most feasible and "3" the least.
5) Prioritize each response by combining Relevance and Feasibility.

Priority Setting Criteria



The highest-scoring items represent the group's preferred action options for change in policy or practice.

Dot-Voting: An Alternative Approach To Setting Priorities

1) Using Analysis and Action Plan Form 2, list possible responses drawn from Form 1. The responses should also be entered onto one or more flip chart pages and displayed on the wall.
2) Discuss the Priority Setting Criteria as a group.
3) Ask each individual CAB member to determine their own ratings, using Analysis and Action Plan Form 2 if they wish.
4) After ten or fifteen minutes, give each member of the research team and the CAB five small adhesive dots. Instruct the participants to place dots next to the solutions they think have the highest priority. They may select five different solutions or weight their preference by putting two or more dots at the same point. The "score" for each solution represents the group's aggregate assessment of its priority. The product is a set of preferred action options.

RAPID POLICY ASSESSMENT AND RESPONSE

Analysis and Action Plan Form 2[2]

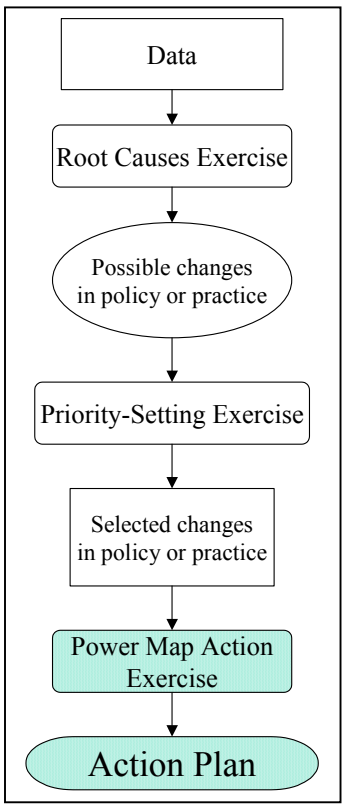
	Relevance (1)	Obstacles (2)	Resources (3)	Feasibility (4)	Priority (5)
Response 1					
Response 2					
Response 3					
Response 4					
Response 5					
Response 6					
Response 7					
Response 8					

[2] Adapted from RAR materials developed by the Centre for Research on Drugs and Health Behaviour Department of Social Science and Medicine, Imperial College, London, as part of its projects on rapid assessment and response.

Power Map Action Exercise and Action Plan

When: CAB meeting # 6 & 7

Purpose: To develop strategies to successfully bring about policy and practice changes, and to incorporate them into a draft Action Plan



Process:

1) Distribute or display the latest version of the Power Map

2) Review the priority responses identified using Form 2 and the Priority-Setting Exercise. Enter the priority responses in column 1 of the Power Map Action Exercise Form.

3) For each priority response, use the Power Map and the Power Map Action Exercise Form to list organizations that must cooperate in order to bring about the change in policy or policy implementation.

Prompts:
What are the organizations whose practices we want to change?
What organizations do we need to support us?
What organizations can influence the organizations we want to change?
Are there any important groups that don't have an organization to work through – "missing organizations"?

4) For each organization, identify:

- Any key individuals
- Existing organizations that could influence the target organization to change or support change
- Organizations that don't exist ("missing organizations") but could potentially be created to give voice to important people who are now unrepresented in governance, such as sex workers
- "Resource strategies": Ways to influence the target organization by changing the flow or its resources (e.g., finding money for poor organizations, or rewarding prisons for effective TB treatment)
- "Tool strategies": Ways to influence the target organization by changing the tools it uses to get things done (e.g., creating a program to divert drug suspects from jail to treatment)

- "Mentality strategies": Ways to influence the target organization by changing its culture (e.g., educating police about drug use and HIV, officially adopting harm reduction as prison policy)

5) Using Analysis and Action Plan Form 3, take the solutions and strategies developed in previous steps and begin to form an Action Plan. For each of the responses and strategies listed in the Power Map Action Exercise, decide:

- The specific steps that must be taken to implement the response
- The resources needed to implement the response
- What individuals and organizations agree to take action to implement the response
- The time frame for action
- And indicators that will show whether there has been success or not

The Action Plan combines the ideas for change with specific assessments of the resources and commitments needed to carry out effective advocacy. The Action Plan can take a variety of forms, but regardless of the form, it represents a commitment by the community to begin implementing identified responses.

RAPID POLICY ASSESSMENT AND RESPONSE

Power Map Action Exercise Form

Response number	Target organization and key people	*Organizations and key people that could influence the target*		*Resource strategies*	*Tool strategies*	*Mentality strategies*
		Existing	*Missing*			
1						
2						
3						
4						
5						
6						
7						
8						
9						
10						

RAPID POLICY ASSESSMENT AND RESPONSE

Analysis and Action Plan Form 3[3]

Response number	What needs to be done (specific steps)	Resources Needed	Time Frame	Responsible person or agency	Indicators of Success
1					
2					
3					
4					
5					
6					
7					
8					
9					
10					

[3] Adapted from RAR materials developed by the Centre for Research on Drugs and Health Behaviour Department of Social Science and Medicine, Imperial College, London, as part of its projects on rapid assessment and response.

The Final Report

When: Weeks 1-36

Purpose:

- To assist research team assemble and review key information and issues during the RPAR
- To present data to and highlight policy issues for the CAB meetings 2-7
- To produce a final report summarizing findings, making recommendations for solutions or interventions, and describing an action plan for implementation.
- To provide a document that can be used for local, regional or national advocacy

Process:

Step 1: Identify key findings from existing and qualitative data collection modules (Modules II and III) and present to CAB as described in Module I

- Existing data : law on the books, epidemiology, and criminal justice
  - Present at CAB meetings #2 & 3 (weeks 1-18)
- Qualitative data: focus groups, key informant interviews
  - Present at CAB meeting #4 (weeks 14-26)

Step 2: Identify policy problems related to HIV prevention among IDUs in the community

- Use the power map and problems and solutions exercises and root cause analysis developed with the CAB at regular meetings #1-6 (weeks 1-29)

Step 3: Organize the findings, issues, policy problems into a preliminary draft report

- Discuss draft report at CAB meeting # 5 (weeks 23-27)

Step 4: Integrate prioritized solutions and plans for implementation into the draft report

- Use the Priority-Setting Exercise (CAB meetings #5 and 6)
- Distribute revised draft report at CAB meeting #6 (weeks 27-29)

Step 5: Draft and distribute final report (weeks 32-36).

- Collect feedback on draft report from CAB at meeting #7
- Include details of final action plan
- Distribute report through the HIV and drug policy network and through local, regional national networks as appropriate

These steps are intended to help the research team organize the collection of data for and drafting of the report. They are not meant to limit the team to a single form for the final report, or a single method for collecting information and drafting the report.

First, the time frame for each step is estimated, but some steps will overlap throughout the RPAR. For example, the team should be able to identify most of the key

findings from the existing data (**Step 1**) during or soon after completion of existing data collection at week 13, but new sources of problematic law or policy may be identified later during the qualitative data collection.

Second, other steps may include using information that is developed in an iterative process by the CAB at more than one meeting. For example, the power map and problems and solutions exercise will be conducted at almost every CAB meeting and the draft and final reports should reflect the changing results.

The Form of the Final Report

There is no single best model for a final report in every country. The research team should outline the final report in a form that best meets their local needs for communicating data and supporting advocacy. The research team should review relevant models of reports and advocacy documents for ideas and guidance. The following are a few guidelines to creating an effective report:

- Organize the report to emphasize the most important policy issues
    - The report is not an epidemiological summary or a descriptive piece about the law
    - The report should illustrate the relationship between HIV risks in the community and law, policy and practice problems
    - Findings and recommendations should be clearly related and succinctly set out
    - Usually, an effective report focuses on a few key problems and recommendations, but when little has been done in the past a comprehensive and detailed report with a long list of recommendations may be useful

- Offer detailed plans for action and implementation
    - The report provides an opportunity to explain the recommendations, plan for action and implementation developed by the CAB
    - It is intended to guide the decisions and actions of people who may not have been involved in the CAB or even had a prior knowledge of the HIV problem
    - Detailed recommendations may look, and be, more feasible
    - Document community involvement in the process and action plan

- Link the goals of this project to other projects for HIV prevention among IDUs and other populations
    - Indicate how data from this project might be used by other projects
    - Describe other gaps in law, policy, practice and / or locally important data that are relevant to HIV, drug policy, and IDUs and identify those that need additional resources, advocacy or research

RAPID POLICY ASSESSMENT & RESPONSE

Module IV: Analysis, Action Plan and Report

Training Materials

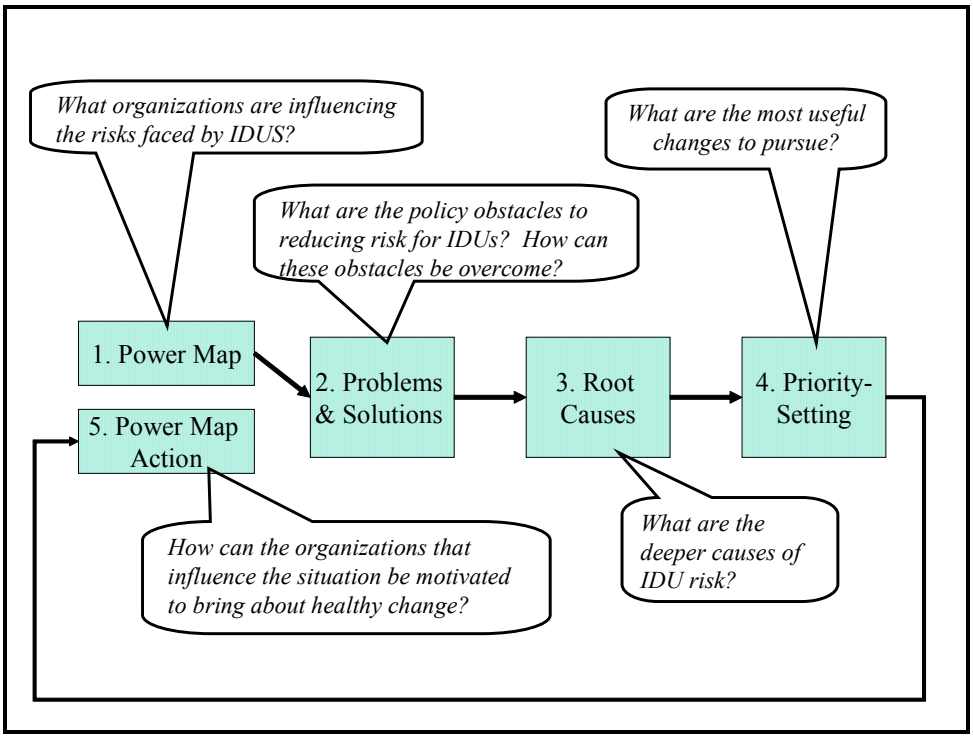
Analysis, Action Plan, & Report
Purposes and Intended Product

Purpose:

The purpose of this module is to organize the data obtained from the other modules, and to work with the CAB to produce the Action Plan and Final Report.

During the process you will:

- Organize main findings for presentation to the CAB;
- Work with the CAB to
    - Identify problems in law and policy that interfere with HIV prevention and harm reduction
    - Identify the root causes of policy problems in the Root Causes Exercise
    - Identify possible solutions to policy problems and root causes
    - Prioritize and evaluate possible solutions in the Priority Setting Exercise
    - Develop strategies to successfully bring about policy and practice changes in the Power Map Action Exercise
- Plan implementation of these strategies and recommendations;
- Produce a final report summarizing findings, making recommendations for solutions or interventions, and describing an action plan for implementation.



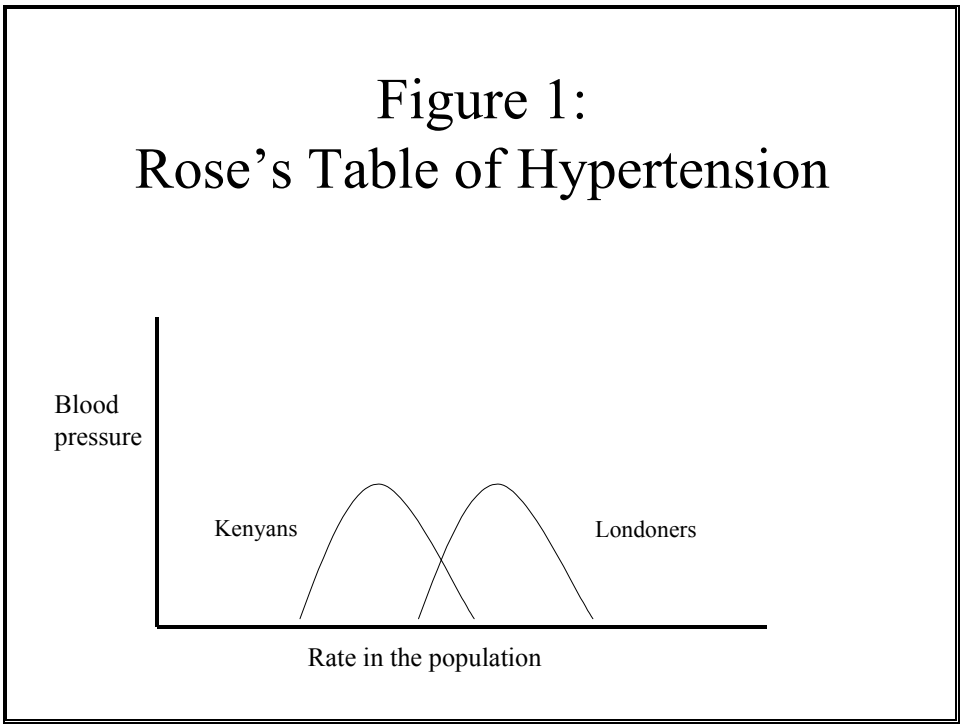
The Five Steps of Policy Analysis in RPAR

Social Causes of Disease, and Structural Interventions

Social Epidemiology

Recall Leonard Syme's account of Durkheim's work on suicide, from Module II. The idea that health in a population is predominantly influenced by factors in the social and physical environment is the basis for the emerging field of "social epidemiology." Thirty years ago, the British epidemiologist, Geoffrey Rose, did much to invent social epidemiology in his celebrated essay *Sick Individuals and Sick Populations*. Rose drew a distinction between two kinds of epidemiological inquiries: into the causes of cases -- "Why do some individuals have hypertension?" – and the causes of incidence – "Why do some populations have much hypertension whilst in others it is rare?" He illustrated the point by comparing the distribution of systolic blood pressure in two populations, Kenyan nomads and London civil servants. Both form a bell curve, but the curve for the London civil servants is shifted to the right, so that far more civil servants are in the morbid range. (See Figure 1.)

> The familiar question, "Why do some individuals have higher blood pressure than others?" could be equally well asked in either of these settings, since in each the individual blood pressures vary (proportionately) to about the same extent; and the answers might well be much the same in each instance (that is, mainly genetic variation, with a lesser component from environmental and behavioural differences). We might achieve a complete understanding of why individuals vary, and yet quite miss the most important public health question, namely 'Why is hypertension absent in the Kenyans and common in London?' The answer to that question has to do with the determinants of the population mean; for what distinguishes the two groups is nothing to do with the characteristics of individuals, it is rather a shift of the whole distribution—a mass influence acting on the population as a whole. To find the determinants of prevalence and incidence rates, we need to study characteristics of populations, not characteristics of individuals.



Individual genetic and behavioral characteristics may account for why a particular person gets cancer, but the overall burden of cancer in a society can only be explained by identifying the factors that members of the population are all more or less uniformly exposed to:

> There is hardly a disease whose incidence rate does not vary widely, either over time or between populations at the same time. This means that these causes of incidence rate, unknown though they are, are not inevitable. It is possible to live without them, and if we knew what they were it might be possible to control them. But to identify the causal agent by the traditional case-control and cohort methods will be unsuccessful if there are not sufficient differences in exposure within the study population at the time of the study. In those circumstances all that these traditional methods do is to find markers of individual susceptibility. The clues must be sought from differences between populations or from changes within populations over time.

Social epidemiology conceives of illness not primarily as the result of a discrete pathogen or toxin, nor as a function of personal choices, but rather as a product of the interaction of people with their social and physical environment. This understanding of public health does not see diseases that are listed on death certificates as "causes" of death at all, but merely as "pathways" along which more fundamental causes have exerted their effect. Research in social epidemiology suggests looking for these fundamental causes of health in what we may loosely call a society's distribution of social status. In a 1995 article, Link and Phelan offered a nomenclature informed by social psychology that highlighted some important aspects of the workings of social factors in health: Link and Phelan suggested that "factors that involve a person's relationships to other people," should be seen as "fundamental social causes" of disease. These causes, defined "broadly to include money, knowledge, power, prestige and the kinds of

interpersonal resources embodied in the concepts of social support and social network," work through intermediate factors such as drug use, and immediate ones such as communicable disease, to influence multiple risk factors and disease outcomes. This transitivity of mechanism and effect likewise explains, in Link and Phelan's view, the durability of social factors in health outcomes: "In the context of a dynamic system with changes in diseases, risks, knowledge of risks, and treatments ... [socioeconomic] resources ... are transportable from one situation to another, and as health related situations change, those who command the most resources are best able to avoid risks, diseases, and the consequences of disease." Similarly, if one immediate cause of death or disease is removed, but the more fundamental social causes are not addressed, overall morbidity and mortality in the population will not be reduced for the same reason that Syme alluded to in his discussion of Durkheim's findings on suicide.

By definition, fundamental social causes of disease do not leave a distinct fingerprint in the manner of a specific disease, but rather operate through the accumulation of less dramatic events: societies "structure the life experiences of their members so that the advantages and disadvantages tend to cluster cross-sectionally and accumulate longitudinally." It is therefore necessary to apply what is called by some a "life-course" perspective to the analyses of causation, an analysis that tries to understand how small, daily life factors can accumulate over time to produce socially-determined differences in health outcome. Krieger proposes an "ecosocial theory" to this end:

> Taking literally the notion of "embodiment," this theory asks how we incorporate biologically – from conception to death – our social experiences and express this embodiment in population patterns of health, disease, and well-being... [T]his theory draws attention to why and how societal conditions daily produce population distributions of health. ... Ecosocial theory thus posits that how we develop, grow, age, ail, and die necessarily reflects a constant interplay, within our bodies, of our intertwined and inseparable social and biological history.

From the point of view of social epidemiology, a society's pattern of ill health is a mirror: disease reflects how a society produces and distributes wealth, creates conditions for human health (or its antithesis), constructs social norms, and organizes its peoples and communities.

Structural Interventions

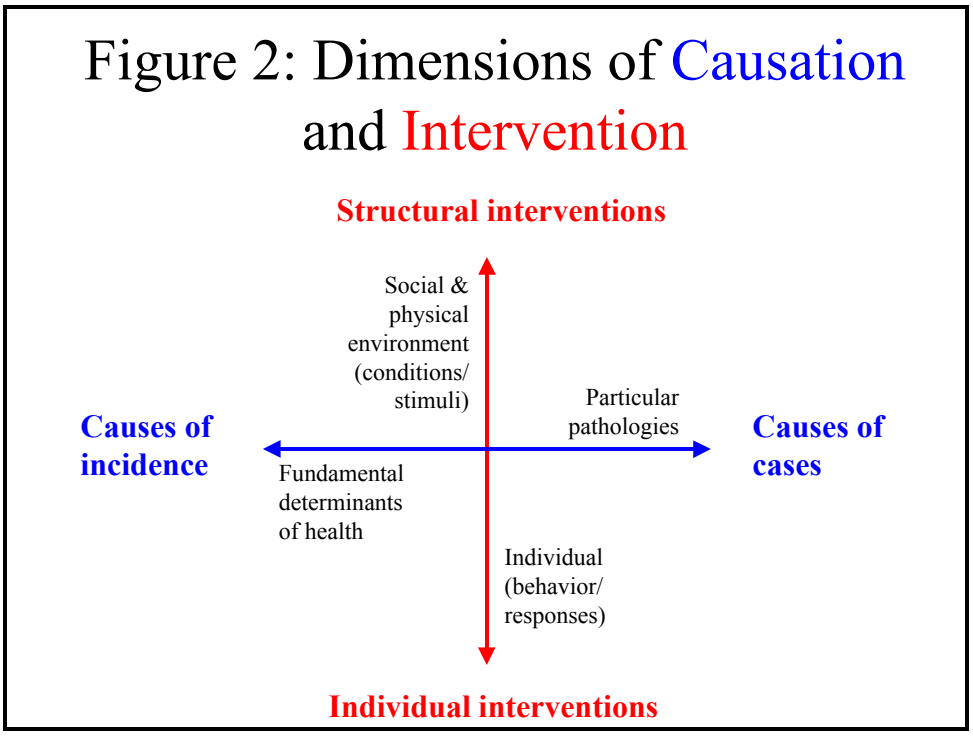
The adoption of a social theory of the determinants of health implies, if it does not compel, public health interventions aimed at the social conditions that produce unhealthy behavior or environmental hazards. Blankenship, Bray and Merson defined "structural interventions in health" as "interventions that work by altering the context within which health is produced and reproduced." Structural interventions can take a variety of forms, including policy implementation (broadly defined to include legislation, litigation, regulation, law enforcement, and the setting of administrative, organizational, and product standards) and community advocacy or organizing.

Structural interventions

- promote public health by altering context in which health is produced and reproduced.
- are built on the view that health is a product of social context/location in the social structure.
- may be promoted through a variety of strategies—Law is one important strategy.

Structural interventions rest on the premise that even fully informed individuals may not make healthy choices because contextual factors may prevent them from doing so: individuals may know they should use condoms but be unable to find them or afford them, or fear that their partner will harm them for suggesting it. A structural response to HIV would address the social construction of sexual behavior and sexuality. Such a response suggests the need to support strong gay relationships and recognizes the negative impact of stigma and discrimination on gay men's willingness and ability to engage in behavior that protects self and others. Smoking provides another example. Smokers may wish to quit, but find it difficult to do so in an environment of intense marketing of inexpensive tobacco products, or a peer group that constitutes itself in part by smoking. Structural interventions include restrictions on advertising, taxes on cigarettes, and withdrawal of direct and indirect tobacco subsidies.

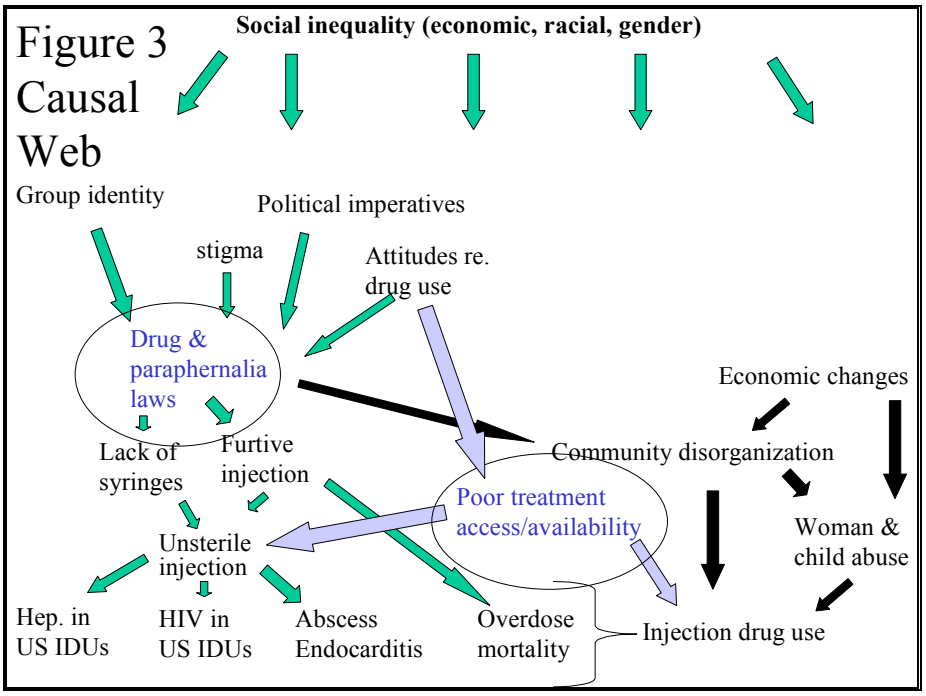
Figure 2 illustrates the place of social epidemiology and structural interventions within epidemiology and public health generally. Public health work guided by risk-factor epidemiology and bounded by political limitations tends to operate within the lower right quadrant, providing interventions that help at-risk individuals cope with a given set of more or less pathological conditions. The value of this is, as Rose suggested, certainly not to be underestimated. Long-term change in social conditions provides little immediate protection; for most individuals at any given moment in time, coping effectively with adverse social conditions is the best hope of maintaining health. Yet the aggregation of individual coping will rarely achieve a major change in population outcomes, which requires the replacement of unhealthy with healthy conditions. This sort of work takes place in the upper left quadrant. It was in this quadrant, which corresponds with the core of social epidemiology, that we primarily situated ourselves for this project.



The RPAR uses the concept of structural interventions as the basis of a method for identifying *root causes*. Root causes – the deeper social determinants of health – may be connected to many problems, not just one. Using the root causes approach allows researchers and communities to see past the immediate crisis to the deeper causes of the community's vulnerability to disease – and to take more effective action.

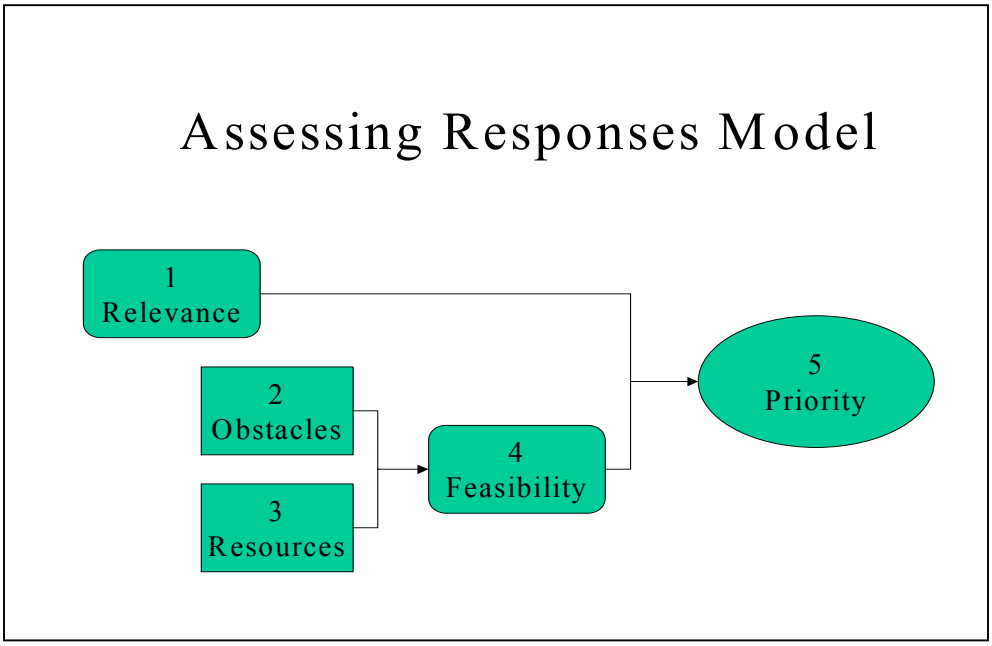
Finding Root Causes

The Root Causes Exercise is based on a simple idea: beneath every problem, there is usually another, deeper problem. If a drug user is at risk of HIV because of needle-sharing, the method asks "Why does the drug user share needles?" If the answer is that he is unwilling to carry his own needle, the method asks "Why won't he carry his own needle?" and, because our focus is policy, "How have law or policy contributed to this problem?" The answer may be that law specifically authorizes actions that place drug users at risk (e.g., detention without arrest in narcological facilities, or mandatory testing for drugs or HIV) or that law fails to protect IDUs from abuses (e.g., corrupt practices of police, or prolonged pretrial detention in dangerous prison conditions). As the questions are asked and answered, a *web of causes* emerges. We see that many of the more immediate risks are attributable to the same deeper causes; we see that other problems besides HIV go back to those deeper causes, too. Deeper causes in policy and practice that influence many problems, or that we think we can change, are epidemiological "pressure points" that can be targeted for change. This is illustrated in the web of causes in Figure 3 below. Using the root causes approach helps the researcher and the CAB identify the most important targets for action: those where change will have the most effects.



Identifying and Assessing the Priority of Responses

The root causes process should allow the researcher to make a list of possible interventions or responses that would break the web of causes at important pressure points. Usually, however, there will be many possible responses, and it is helpful to go through a process of assessing and prioritizing them for action. The result may range from one major priority for change to many smaller goals.



The rating process can be done systematically as a group exercise, or participants can be briefed on the criteria and asked to use them in a discussion and dot-voting process. These approaches are set out in the tools.

The following are useful criteria for assessing which possible responses to focus energy on in the action plan.

The first criterion is *relevance.*

Relevance is the relationship between the response and the root causes or problems you have identified. Assessing relevance requires the researcher or CAB to make a judgment about the degree to which successfully implementing the response will reduce the problem or eliminate the root cause. In making this judgement, assume that the response can be successfully implemented. *Relevance can be rated on a scale of 1 to 3:*

1 = Most relevant
2 = Relevant
3 = Least relevant

The second criterion is *obstacles*.

Obstacles are barriers to successfully implementing the response. Barriers will be of many kinds. Political barriers are those arising in the policy-making process, beginning with getting community support and ending in the creation of new policies by government. Social barriers can be found in public attitudes about drug users or HIV, in the inability of community members to work together or trust each other, or in religious or ethnic differences. Economic barriers range from the costs of supporting action within the community (for example, who pays for printing posters) to the problem of funding proposed responses (such as drug treatment or better police pay). The more obstacles a response faces, and the more severe they are, the harder it will be to successfully implement. *Obstacles can be listed.*

The third criterion is *resources*.

Resources are the things you need to make this intervention happen. They will be of many kinds. Money, of course, is key, from the question of how to fund advocacy efforts to how to pay for the intervention itself. But resources also include people and their talents, materials, information, and support networks within and beyond the community. The fewer resources a response requires to implement, or the more you have, the more promising the intervention. *Resources can be listed along with an estimate of the chances of obtaining them.*

The fourth criterion is *feasibility*.

Feasibility is a judgment, based on the obstacles and resources; about how likely you are to be able to implement the response effectively. Review the list of obstacles and resources. F*easibility may be rated on a scale from 1 to 3:*

1 = Most feasible
2 = Feasible
3 = Least feasible

The final criterion is *priority.*

Priority combines the first four criteria into an overall rating for action. Any action plan entails choices about where to put energy and other resources. The most promising interventions are those that have the fewest problems of feasibility, and the greatest relevance to the problem. Priority is based on feasibility and relevance; you may determine priority by adding the feasibility and relevance scores, or just by reviewing them and making a non-numerical judgment. P*riority can be rated on a scale from 1 to 3:*

1 = Highest priority
2 = Medium priority
3 = Lowest priority

Taking Action

The RPAR method supports two modes of producing action as a result of the research. First, the CAB and other key persons, institutions and organizations are supported in preparing their own community action plan. Action, and success, depends largely on the commitment and resources of the community and the barriers they must overcome. The researcher may or may not participate in this form of action, but is ultimately not responsible for its success or failure. Second, the researcher produces a Report that is distributed through the HIV and drug policy network to influence policy at the national and international levels. Research does not by any means usually determine policy, but research in public health can often play an important role:

- it can influence the decisions of policy makers
- it can help advocates sharpen and support their agendas
- it can create public support for change.

Around the world, advocacy for rational and humane public health policies happens at a variety of levels and takes a variety of forms. These are portrayed in Figure 4 and discussed in the case study below.

Case study: Improving Access to HIV Medications. The movement for better drug access emerged about the year 2000. From the start, research on the extent of the need and the role of law in creating it was crucial to the movement. Early on, public opinion was influenced by demonstrations, including some acts of civil disobedience. Advocates used the press to make the case for better access, a case that was built not only on medical research but also on policy research showing how intellectual property law was making it more difficult to produce low-priced drugs for poor people. Advocates fashioned and began to propose policy changes to address the problem, such as interpreting international intellectual property law to allow the production and distribution of generic versions of patented drugs in developing countries. As the movement grew, advocates lobbied governments, and some governments lobbied each other and international bodies, making the case for change based on data about HIV, the effects of law, and the need for medications.

Action planning involves taking the prioritized responses and setting out the concrete steps and commitments that must be made to actually implement them. Commitment is primarily signaled by participation: if people are working, they are committed and vice versa. Commitment can be signaled by signing form 3, or by making a joint statement or declaration, or simply by moving forward.

The Power Map and the Power Map Action Exercise focus on the importance of local organizations and their place on extended power networks. The "nodal governance" approach suggests four basic strategies for changing organizational practices or getting support for policy change initiatives.

1) Influence from other organizations: Most organizations both influence others and are themselves influenced. A power map shows which organizations influence others. Thus, if the CAB wants to influence the police, but cannot themselves do so, they can use their power maps to identify organizations they can influence who can influence the police. Sometimes there are people with an important stake and potential influence who do not have an organization to work through; these are "missing" organizations. Advocates may promote change by working to create new organizations that can wield helpful influence.

2) Resource strategies: sometimes an organization exists and could help implement an action plan – if only it had more resources (to pay for an additional staff member, a larger office, a computer or internet link). Advocates can make change by helping the organization get these resources and become a more influential point on the network.

3) Tool strategies: sometimes an organization lacks influence or increases health risks because of the problem-solving tools it has at its disposal. For example, a police department faced with neighborhood complaints about drug use has the tool of arrest

or threat of arrest to push drug users away. Providing a new tool – community mediation skills – can make it possible for the police to find different solutions.

4) Culture strategies: organizations frequently behave they way they do because of the attitudes, knowledge and beliefs of the people in the organization – rather than because it is the best-informed, most useful course of action. The culture of an organization often reflects the job it is trying to do, its mission, its norms of decision-making and interpersonal relations. Changing the way an organization thinks is often the best way to change how it behaves. Sometimes a change in mission can change culture, sometimes a change in tools, sometimes a change in resources. Education and training are direct ways to inculcate a new way of thinking. So training police about HIV, drug use and harm reduction is a culture strategy because it aims to change how police think about their work and its health consequences.

The Final Report

The second product of the RPAR is the final report. The report is in many ways a summary of all the activities that have occurred during the RPAR organized to highlight the most important research findings and key issues of law, policy, and practice effecting HIV among IDUs in the community. Preparation of the report is ongoing throughout the RPAR weeks 1-36.

The purpose of the final report is to:

- assist research team assemble and review key information and issues during the RPAR
- present data to and highlight policy issues for the CAB meetings 2-7
- produce a final report summarizing findings, making recommendations for solutions or interventions, and describing an action plan for implementation.
- provide a document that can be used for local, regional or national advocacy.

Process:

The research team should begin preparation of the final report as soon as collection of existing data begins and should continue to refine the findings, issues, potential solutions, recommendations and plans throughout the RPAR. The following steps illustrate one way to organize the information and drafting of the report.

Step 1: Identify key findings from existing and qualitative data collection modules (Modules II and III) and present to CAB as described in Module I

- Existing data : law on the books, epidemiology, and criminal justice
    - Present at CAB meetings #2 & 3 (weeks 1-18)
- Qualitative data: focus groups, key informant interviews
    - Present at CAB meeting #4 (weeks 14-26)

Step 2: Identify policy problems related to HIV prevention among IDUs in the community

- Use the power map and problems and solutions exercises and root cause analysis developed with the CAB at regular meetings #1-6 (weeks 1-29)

Step 3: Organize the findings, issues, policy problems into a preliminary draft report

- Discuss draft report at CAB meeting # 5 (weeks 23-27)

Step 4: Integrate prioritized solutions and plans for implementation into the draft report

- Use the Priority-Setting Exercise (CAB meetings #5 and 6)
- Distribute revised draft report at CAB meeting #6 (weeks 27-29)

Step 5: Draft and distribute final report (weeks 32-36).

- Collect feedback on draft report from CAB at meeting #7
- Include details of final action plan
- Distribute report through the HIV and drug policy network and through local, regional national networks as appropriate

These steps are intended to help the research team organize the collection of data for and drafting of the report. They are not meant to limit the team to a single form for the final report, or a single method for collecting information and drafting the report.

First, the time frame for each step is estimated, but some steps will overlap throughout the RPAR. For example, the team should be able to identify most of the key findings from the existing data (**Step 1**) during or soon after completion of existing data collection at week 13, but new sources of problematic law or policy may be identified later during the qualitative data collection.

Second, other steps may include using information that is developed in an iterative process by the CAB at more than one meeting. For example, the power map and problems and solutions exercise will be conducted at almost every CAB meeting and the draft and final reports should reflect the changing results.

The Form of the Final Report

There is no single best model for a final report in every country. The research team should outline the final report in a form that best meets their local needs for communicating data and supporting advocacy. The research team should review relevant models of reports and advocacy documents for ideas and guidance. The following are a few guidelines to creating an effective report:

- Organize the report to emphasize the most important policy issues
    - The report is not an epidemiological summary or a descriptive piece about the law
    - The report should illustrate the relationship between HIV risks in the community and law, policy and practice problems
    - Findings and recommendations should be clearly related and succinctly set out
    - Usually, an effective report focuses on a few key problems and recommendations, but when little has been done in the past a comprehensive and detailed report with a long list of recommendations may be useful

- Offer detailed plans for action and implementation

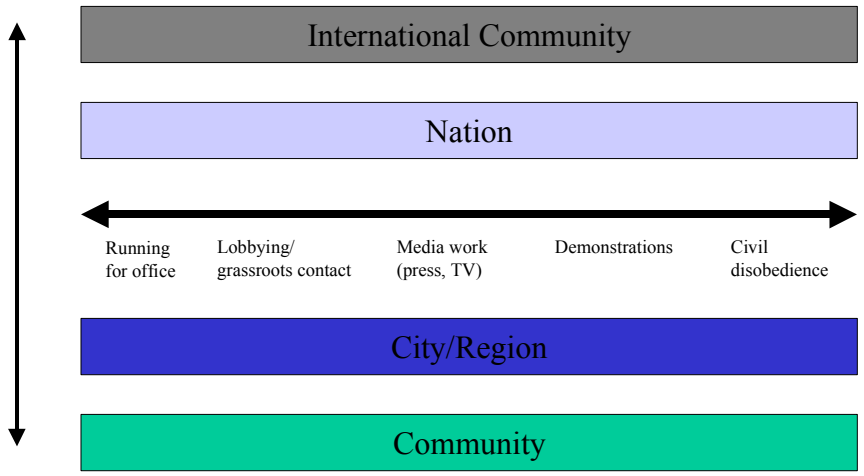
- The report provides an opportunity to explain the recommendations, plan for action and implementation developed by the CAB
- It is intended to guide the decisions and actions of people who may not have been involved in the CAB or even had a prior knowledge of the HIV problem
- Detailed recommendations may look, and be, more feasible
- Document community involvement in the process and action plan

- Link the goals of this project to other projects for HIV prevention among IDUs and other populations
  - Indicate how data from this project might be used by other projects
  - Describe other gaps in law, policy, practice and / or locally important data that are relevant to HIV, drug policy, and IDUs and identify those that need additional resources, advocacy or research

Levels of influence

Once the plan is made and the final report prepared, the members of the CAB and the research team can use a variety of strategies to make change at several important levels. As shown in Figure 4, the work of the RPAR team and CAB may influence national policies or even international awareness and action in relation to the site city or country. Locally, the action plan and follow-up may use many strategies simultaneously.

Figure 4: Policy Influence



RAPID POLICY ASSESSMENT & RESPONSE

Module V: Research Ethics

Tools

RESEARCH ETHICS
Tools

Forms Included:

Human subject and information protection protocol
Draft informed consent form (only for persons with knowledge of drug use)

Human Subject and Information Protection Protocol

Purposes:

- To summarize procedures to protect the safety and identity of human subjects in this research;
- To ensure that information is collected accurately, attributed correctly (when applicable), and protected from unintended disclosure;
- To ensure that national and international standards for research ethics are met and appropriate documentation maintained to establish compliance.

Human Subject Protection Protocol and Protecting Information and Identities:

Key principles:

- consent of subjects to participate;
- protection of confidentiality;
- limited disclosure with attribution when specifically permitted;
- anonymity of subjects and records where highly sensitive information is collected.

Process:

Observe the following requirements while collecting data from research subjects in the RPAR.

1. All subjects must give voluntary informed consent to participate.

2. Recruited subjects will be told that participation is fully voluntary and interviews or groups participation can be ended at any time without any penalty or adverse consequences to the subject's medical care, psychological services, or participation in other programs.

3. Informed consent must be documented for every participant, but participants who are not system or interactor interviewees will use initials or pseudonyms only on their consent forms and on all other documentation.

4. System and interactor informants will be informed that unless they object their names will be recorded and they may be quoted by name unless they specifically object. Interviewers will clearly note that informant has or has not given permission to use his or her name.

5. Any informant possibly engaged in illegal or otherwise sensitive activities will remain anonymous in the recorded data from the interview.

6. Any form (such as a list of potential key informants) that contains names should not designate people by status (such as "injection drug user") but instead indicate areas of expertise (e.g., "has information about drug use").

7. Research data and informed consent forms will be kept in a locked office, file cabinet, or on password protected computers.

8. Research team personnel will refrain from talking about interviews or focus group results in public in any way that could reveal the identities of participants who have not given such permission (researchers should be particularly careful of discussions in restaurants, institutional settings, elevators or on the street).

9. Research team personnel will protect participants from being identified as part of the project unless the participant has given permission for such identification.

10. Research team personnel who know subjects from other settings will not identify them as subjects without their permission.

Monitoring of the project

The investigators are responsible for ensuring that research subjects are protected from harm and that the subject and information protection protocol is followed. The following steps should be undertaken to monitor compliance with subject protection.

1. All researchers, staff and field workers should be trained about the details of this plan and the means to protect subjects.

2. The primary investigator should review the data collection, recording and storage techniques of staff and fieldworkers throughout the RPAR.

3. The U.S. investigators will inspect data collection and storage methods on at least annual visits to each site.

Informed Consent Forms

Attached is a sample form to be used in interviewing people who have knowledge of injection drug use. (This form has been approved by UCHC and modified slightly for ethical review in Poland.) A complete set of forms will be provided after final approval and translation.

Consent Form
Client interviews

Study Title: **Rapid Assessment of Drug Law & Policy in the CEE & FSU**

PI: Zita Lazzarini phone: 860-679-5494
email:Lazzarini@nso.uchc.edu
Co-PI's: Scott Burris (Temple University) & Patricia Case (Harvard Medical Schools)

Purpose of the Study:

You are being asked to participate in this study in order to share your experience and knowledge about the epidemics of drug use and HIV in Poland, Ukraine, and Russia. The study will use a new investigative process, the Rapid Policy Assessment and Response (RPAR), to help the local community document and respond to barriers to HIV prevention among injection drug users (IDUs) in Central and Eastern Europe and the Former Soviet Union. Approximately 14 client interviews will take place in each country.

Procedures:

The only procedures in this study will be collecting information from you on your knowledge of, and experience with, the criminal justice and public health systems as they are responding to the epidemics of drug use and HIV. After you agree to participate and sign an informed consent form, the investigators will collect information from you during an interview. The interview will last one to two hours. All sessions will be audio-taped and transcribed.

If you agree to participate in this study you will be interviewed individually and asked a series of semi-structured questions in four domains: 1) legal; 2) criminal justice; 3) injection drug use and public health response; and 4) HIV/AIDS and other communicable diseases. Specific questions address:

- enforcement of drug, syringe, and prostitution laws;

- any provisions criminalizing homosexuality and HIV exposure or transmission;
- operation of courts and prisons;
- drug policy politics;
- risk reduction and public health interventions;
- advocacy resources;
- epidemiologic data on HIV and drug use;
- criminal justice data

Emphasis within the interviews will vary based on your specific knowledge and experience. The RPAR research tools include screening questions for each topic area that allow you to skip any area in which you have no background or experience.

Potential Risks:

Risks to you are expected to be minimal, even if you have engaged in drug use or other illegal activities. You may become embarrassed, feel discomfort, or become afraid in the interview when asked to describe your drug use, other activities, or your engagement with law enforcement and other institutions of authority. The most serious risk, though still small, is loss of confidentiality. If your status as drug user became known, it could result in a number of harms, among them stigma, loss of employment or housing, arrest, or forced treatment for drug abuse. In addition, the process of reflecting on your drug use, may increase your desire to find referrals for drug treatment. Every effort will be made to protect your confidentiality and to provide you with referrals for drug treatment or medical care, if it is available.

Required disclosures:

The following persons may review the records of this project for compliance with informed consent and other federal requirements and may therefore have access to information you provide, although no personally identifiable information about you will be collected:

- Institutional Review Boards of University of Connecticut, Temple University, and Harvard Medical School in the United States (U.S.);
- National Institute for Drug Abuse, U.S.;
- Research Ethics Boards in Ukraine, Poland, and Russia.

Measures to reduce potential risks and assure confidentiality

Reducing Potential Risks:

Local investigators and field workers will be trained to respond to any participant who becomes uncomfortable during the interview by offering to take a break, skipping that set of questions, moving on to a different domain of the questions, or simply stopping the interview. You have the right to decline to answer any part of the interview or stop at any time.

The primary risks (although small) to subjects will be potential breaches of confidentiality, addressed below.

Confidentiality:

All investigators and staff will also be trained about the importance of confidentiality and the steps the project will take to protect confidentiality.

For interviews with injection drug users, or other informants who might have engaged in illegal acts, all interview tapes will be retained, but no personally identifying information will appear on transcripts, or summaries. All tapes, transcripts and summaries will be coded using unique codes, and signed consent forms will be unlinked to other materials. Interviews with IDUs will be completely anonymous and no identifying information will be kept on the tape, transcript or any other field materials. In addition, exact locations of venues and street scenes where IDUs congregate will not be published, only general neighborhood designations. Databases will be password protected in all sites, and data transmittal will occur by courier to the US.

To help us protect your privacy, we have obtained a Certificate of Confidentiality from the National Institutes of Health. With this Certificate, the researchers cannot be forced to disclose information that may identify you, even by a court subpoena, in any federal, state,

or local civil, criminal, administrative, legislative, or other proceedings in the United States. The researchers will use the Certificate to resist any demands for information that would identify you, except as explained below.

The Certificate cannot be used to resist a demand for information from personnel of the United States Government that is used for auditing or evaluation of Federally funded projects or for information that must be disclosed in order to meet the requirements of the federal Food and Drug Administration (FDA).

You should understand that a Certificate of Confidentiality does not prevent you or a member of your family from voluntarily releasing information about yourself or your involvement in this research. If an insurer, employer, or other person obtains your written consent to receive research information, then the researchers may not use the Certificate to withhold that information. The local lead investigator and the US PI will monitor adherence by field workers and staff to project confidentiality policies and procedures. The US PI or co-PI's will review and inspect the confidentiality practices of the foreign sites during periodic visits.

Potential Benefits from this Study:

This project will provide no direct benefit to individual participants, but the process may provide other benefits to participants and the community. The collective work of the CAB, focus group, system, interactor and IDU participants may benefit the community by identifying ways to improve HIV prevention locally, and participants may benefit from the increased sense of community involvement that their participation generates.

Participants will receive US$10.00 for their time and transportation expense for each meeting or interview in which they participate. IDUs will also benefit from receiving safe sex and injection supplies (no syringes), information and referrals to any locally available care and services. These benefits, though modest, balance the slight risks to individual subjects.

Costs to Participants

There will be no costs to participants for participation in this study.

Additional Information or Questions about this Study:

The interviewer and the investigators in this study are willing to answer any questions you may have about the study or about participation in research in general.

If you have further questions you can contact your local Principal Investigator:

Justyna Sobeyko
Polish AIDS Society
ul. Arkonska4
71-455 Szczecin, Poland
korkiniec@fol-plast.pl
+48 91 431 62 42

Or the overall Principal Investigator for the study:

Zita Lazzarini, JD, MPH
Director, Division of Medical Humanities,
Health Law, and Ethics
University of Connecticut Health Center
263 Farmington Ave. MC-6325
Farmington, CT 06030-6325
phone: 860-679-5494
fax: 860-679-5464
e-mail: lazzarini@nso.uchc.edu

For additional information on your rights as a research subject, you can also contact the office of the IRB at University of Connecticut Health Center at 860-679-3054 or email: chasse@adp.uchc.edu.

Voluntary Participation:

Your participation in this study is voluntary and you may choose NOT to participate or to end your participation at any time without any penalty.

By signing below you agree to participate in this study and confirm that you have read or had explained to you the details of this

study contained in this form, had the opportunity to ask questions and have them answered to your satisfaction, and received a copy of this consent form.

_____

participant (initials or pseudonym please) date

_____

investigator date

RAPID POLICY ASSESSMENT & RESPONSE

Module V:

Training Materials

Research Ethics
Purpose and Process

Purpose

- To describe need for ethical oversight of research studies involving humans
- To explain ethical principles that guide research
- To describe important documents relevant to policy research
- To present basic requirements for ethical review
- To facilitate identification and discussion of ethical issues arising in this research
- To train all staff and research team in human subject and information protection procedures for this project and each site.

Process

Discussion of

- potential local ethical issues
- human subject protection procedures as described in project protocol
- informed consent forms and process

Why is Ethical Oversight of Research Studies Involving Humans Important?

Research can be defined as a "systematic investigation, including research development, testing and evaluation, designed to develop or contribute to generalizable knowledge."[1] A human subject is "a living individual about whom an investigator (whether professional or student) conducting research obtains (1) data through intervention or interaction with the individual, or (2) identifiable private information."[2] Research involving human subjects includes a wide variety of scientific endeavors including: basic (non-clinical) science using biological samples, randomized clinical trials of new drugs or devices, epidemiological research of population health and behavior, and policy behavioral research involving surveys, observation, and interviews.

Human subject research has produced important new basic scientific knowledge, established the effectiveness of life saving treatments and vaccines, and advanced our understanding of behavioral and structural factors' role in health. Not all research, of course, leads to important discoveries. Sometimes research exposes subjects to real or potential risks. Regulation of human subjects' research aims to reduce these risks and prevent exploitation of research subjects while promoting ethical and well-designed research studies.

Historically, some research has exposed human subjects to real or potential harm, often without their full consent and sometimes without their knowledge. Examples include the Nazi doctors' experiments that involved exposing concentration camp prisoners to wounds, unnecessary surgery, infectious agents, and extremes of heat, cold, altitude, or other dangerous situations to document the impact on the human body even to the point of causing death. Other examples include the Tuskegee syphilis study in which African-American men with syphilis were deceived about their diagnosis, denied effective treatment when it became available, and observed for up to 30 years untreated. Additionally, throughout the 1940s, 50s, and early 60s, many well-respected researchers conducted studies involving patients without their fully informed consent and some exposed patients to much greater risks from experimental interventions than they would have faced with standard treatment. [3]

Instances of abuse and harm led to calls for oversight. Regulation, as it has developed in the U.S., has included oversight from courts and regulatory bodies within the government, and from the development of ethical codes and voluntary standards. Ultimately, federal regulation combined with international standards, currently define the requirements for U.S.-based researchers working in other countries. This section introduces the basic principles, documents, and requirements for ethical review of human

[1] 45 (US) Code of Federal Regulations (CFR) 46.102(d).
[2] 45 (US) Code of Federal Regulations (CFR) 46.102(f).
[3] H. K. Beecher, "Ethics and Clinical Research," *New England Journal of Medicine,* 274 (1966): 1354-1360.

subject research and identifies some of the potential ethical issues of policy research in particular.

The Basic Ethical Principles that Guide Research

In the past thirty years a consensus has emerged on basic ethical principles that should guide biomedical research, these are ***respect for persons, beneficence and justice***. They appear explicitly stated in the Belmont Report, the Council for International Organizations of Medical Sciences (CIOMS) Guidelines, and are reflected less explicitly in each of the important documents described in the next section. What follows is an excerpt from the most recent CIOMS guidelines describing the basic principles.

"Respect for persons incorporates at least two fundamental ethical considerations, namely:

a) respect for autonomy, which requires that those who are capable of deliberation about their personal choices should be treated with respect for their capacity for self-determination; and
b) protection of persons with impaired or diminished autonomy, which requires that those who are dependent or vulnerable be afforded security against harm or abuse.

Beneficence refers to the ethical obligation to maximize benefits and to minimize harms. This principle gives rise to norms requiring that the risks of research be reasonable in the light of the expected benefits, that the research design be sound, and that the investigators be competent both to conduct the research and to safeguard the welfare of the research subjects. Beneficence further proscribes the deliberate infliction of harm on persons; this aspect of beneficence is sometimes expressed as a separate principle, ***nonmaleficence*** (do no harm).

Justice refers to the ethical obligation to treat each person in accordance with what is morally right and proper, to give each person what is due to him or her. In the ethics of research involving human subjects the principle refers primarily to ***distributive justice*****,** which requires the equitable distribution of both the burdens and the benefits of participation in research. Differences in distribution of burdens and benefits are justifiable only if they are based on morally relevant distinctions between persons; one such distinction is vulnerability. "Vulnerability" refers to a substantial incapacity to protect one's own interests owing to such impediments as lack of capability to give informed consent, lack of alternative means of obtaining medical care or other expensive necessities, or being a junior or subordinate member of a hierarchical group. Accordingly, special provision must be made for the protection of the rights and welfare of vulnerable persons.

Sponsors of research or investigators cannot, in general, be held accountable for unjust conditions where the research is conducted, but they must refrain from practices that are likely to worsen unjust conditions or contribute to new inequities. Neither should they take advantage of the relative inability of low-resource countries or vulnerable

populations to protect their own interests, by conducting research inexpensively and avoiding complex regulatory systems of industrialized countries in order to develop products for the lucrative markets of those countries.

In general, the research project should leave low-resource countries or communities better off than previously or, at least, no worse off. It should be responsive to their health needs and priorities in that any product developed is made reasonably available to them, and as far as possible leave the population in a better position to obtain effective health care and protect its own health.

Justice requires also that the research be responsive to the health conditions or needs of vulnerable subjects. The subjects selected should be the least vulnerable necessary to accomplish the purposes of the research. Risk to vulnerable subjects is most easily justified when it arises from interventions or procedures that hold out for them the prospect of direct health-related benefit. Risk that does not hold out such prospect must be justified by the anticipated benefit to the population of which the individual research subject is representative."[4]

Important Documents

The current CIOMS guidelines describe many of the key international documents related to human subjects' research.

"The first international instrument on the ethics of medical research, the Nuremberg Code, was promulgated in 1947 as a consequence of the trial of physicians (the Doctors' Trial) who had conducted atrocious experiments on unconsenting prisoners and detainees during the second world war. The Code, designed to protect the integrity of the research subject, set out conditions for the ethical conduct of research involving human subjects, emphasizing their voluntary consent to research.

The Universal Declaration of Human Rights was adopted by the General Assembly of the United Nations in 1948. To give the Declaration legal as well as moral force, the General Assembly adopted in 1966 the International Covenant on Civil and Political Rights. Article 7 of the Covenant states "*No one shall be subjected to torture or to cruel, inhuman or degrading treatment or punishment. In particular, no one shall be subjected without his free consent to medical or scientific experimentation".* It is through this statement that society expresses the fundamental human value that is held to govern all research involving human subjects – the protection of the rights and welfare of all human subjects of scientific experimentation.

The Declaration of Helsinki, issued by the World Medical Association in 1964, is the fundamental document in the field of ethics in biomedical research and has influenced the formulation of international, regional and national legislation and codes of conduct.

[4] Council for International Organizations of Medical Sciences (CIOMS) International Ethical Guidelines for Biomedical Research Involving Human Subjects. CIOMS, World Health Organization, 2002, available at: http://www.cioms.ch/frame_guidelines_nov_2002.htm.

The Declaration, amended several times, most recently in 2000 (Appendix 2), is a comprehensive international statement of the ethics of research involving human subjects. It sets out ethical guidelines for physicians engaged in both clinical and nonclinical biomedical research.

Since the publication of the CIOMS 1993 Guidelines, several international organizations have issued ethical guidance on clinical trials. This has included, from the World Health Organization, in 1995, *Guidelines for Good Clinical Practice for Trials on Pharmaceutical Products*; and from the International Conference on Harmonisation of Technical Requirements for Registration of Pharmaceuticals for Human Use (ICH), in 1996, *Guideline on Good Clinical Practice*, designed to ensure that data generated from clinical trials are mutually acceptable to regulatory authorities in the European Union, Japan and the United States of America. The Joint United Nations Programme on HIV/AIDS published in 2000 the UNAIDS Guidance Document *Ethical Considerations in HIV Preventive Vaccine Research*.

In 2001 the Council of Ministers of the European Union adopted a Directive on clinical trials, which will be binding in law in the countries of the Union from 2004. The Council of Europe, with more than 40 member States, is developing a Protocol on Biomedical Research, which will be an additional protocol to the Council's 1997 Convention on Human Rights and Biomedicine.

Not specifically concerned with biomedical research involving human subjects but clearly pertinent, as noted above, are international human rights instruments. These are mainly the Universal Declaration of Human Rights, which, particularly in its science provisions, was highly influenced by the Nuremberg Code; the International Covenant on Civil and Political Rights; and the International Covenant on Economic, Social and Cultural Rights. Since the Nuremberg experience, human rights law has expanded to include the protection of women (Convention on the Elimination of All Forms of Discrimination Against Women) and children (Convention on the Rights of the Child). These and other such international instruments endorse in terms of human rights the general ethical principles that underlie the CIOMS International Ethical Guidelines."[5]

In addition to these international instruments, the United States has produced key documents of international import. The first, The Belmont Report, was published April 18, 1979, by the National Commission for the Protection of Human Subjects of Biomedical and Behavioral Research, reporting to the Secretary of Health, Education and Welfare. The Belmont Report is a statement of "basic ethical principles and guidelines that should assist in resolving the ethical problems that surround the conduct of research with human subjects."[6] Although not itself binding, and originally only a statement of departmental policy, the Belmont Report also provided the guiding principles for the

[5] Council for International Organizations of Medical Sciences (CIOMS) International Ethical Guidelines for Biomedical Research Involving Human Subjects. CIOMS, World Health Organization, 2002, available at: http://www.cioms.ch/frame_guidelines_nov_2002.htm.

[6] The National Commission for the Protection of Human Subjects of Biomedical and Behavioral Research. The Belmont Report. April 18, 1979. Available at: http://ohsr.od.nih.gov/guidelines/belmont.html.

development of the federal regulations that govern research in the US, referred to as the Common Rule."[7]

The Common Rule and institutional policies designed to comply with US federal regulations have direct impact only on U.S. researchers and institutions. However, they also have an enormous impact on research conducted around the world by U.S. researchers or funded by U.S. institutions since they require such research to adhere to U.S. standards for review and approval, *in addition to*, local and international requirements.

See documents and web sources at the end of these training materials.

The Basic Requirements of Ethical Review

General Requirements

As a general rule all research involving human subjects should conform to the international standards for research described in CIOMS and Helsinki, as well as respecting human rights, and complying with relevant local (national) law regarding the rights of research subjects and the responsibilities of investigators.

The primary responsibility for ensuring research is ethical and conforms to local, national and international standards rests with the investigators. It is the responsibility of the investigator to ensure that all persons involved in the project have a sufficient understanding of ethical issues in research to protect the rights of subjects during the project. First, investigators and staff must familiarizing themselves with the basic documents governing research and understand the steps necessary to protect subjects in their particular protocol. Additionally, a local board or committee whose mandate is to provide ethical review of new and ongoing protocols involving human subjects can assist investigators to identify ethical issues and solutions through the process of local review of their research plan. Local review may result in dialog between investigators and the committee to identify potential ethical issues, reduce research risks, protect subjects' confidentiality and physical well-being, and provide adequate procedures to meet requirements. In the U.S., such committees are usually called an Institutional Review Board(s) (IRB).

Research involving U.S. institutions

For research funded by the United States government or involving U.S. institutions the specific requirements that must be met through ethical review include:

- obtaining prior ethical review and approval by an IRB within the US;
- minimizing research risks in relation to possible benefits;

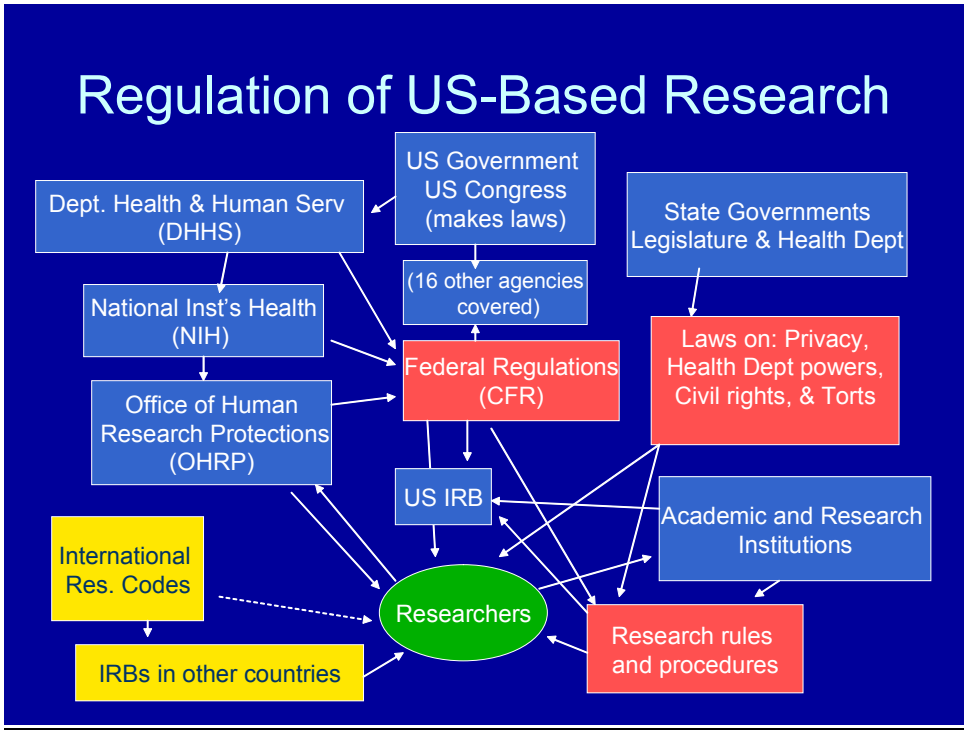
[7] 45 CFR 46, and 21 CFR (governing the Food and Drug Administration's activities).

- ensuring that the informed consent process and documentation is sufficient for fully informed and voluntary consent by research subjects or their legally authorized representatives;
- informing subjects of their rights as research subjects to withdraw from the study at any time;
- selecting subjects fairly;
- protecting confidential or identifying information about subjects;
- establishing safety monitoring, where appropriate;
- protecting vulnerable populations;
- re-reviewing the study at least once a year to monitor compliance with ethical rules and identify unanticipated risks.

Additionally, for research occurring outside the U.S., the study must also be reviewed by a local ethics committee or board (IRB) or the U.S. IRB must be advised by someone who is aware of ethical issues in the site where the research will occur.

The complex structure of institutions and documents that govern human subject research involving U.S. and foreign institutions is displayed in the following diagram. For the purposes of the RPAR it is important to know that:

- U.S. regulations cover even policy research relying mainly on interview data;
- The project must be reviewed both in the U.S. and by a committee or board that has knowledge of the local research environment (usually an in-country research ethics committee registered with the NIH);
- That the research must comply with both the international documents discussed above and the U.S. federal regulations; and
- For policy research, meeting these requirements should be easily achievable.



Informed Consent

Researchers and staff should be aware of the basic requirements of informed consent wherever they are responsible for recruiting subjects and / or obtaining informed consent from subjects, documenting informed consent, designing research protocols, or storing research data and informed consent documentation.

Informed consent is a process, not a form. Although, federal regulations and most projects require that research subjects sign and complete very specific informed consent forms and that investigators maintain records of such forms, subjects actually give fully informed and voluntary consent, only as part of a process. The *informed consent process* includes 1) disclosure of information about the project by someone involved in the project, or by documents prepared for this purpose; 2) discussion of the purpose, procedures, and other aspects of the project by the potential subject and the project representative including enough time for the subject to ask any questions she has; and 3) deliberation of the risks and benefits of the project by the potential subject. If, after weighing all these, the subject chooses to enroll, then she or he signs the consent form, a copy is given to the subject and another stored in the research records.

In order for informed consent to be possible, the subject must meet at least two pre-conditions – that the subject have the capacity to make an informed decision and that the decision be made free of coercion. Additionally, the researcher must provide sufficient information to the subject to make an informed choice. First, in order to have the capacity to make a decision, the potential subject must be capable of *understanding* the risks and benefits of the study, *deliberating* the balance of risks and benefits in the context of his or her own life, and *communicating* a choice clearly to the investigator or

staff. Thus, adults are assumed to be able to give consent unless there is evidence that they are unable to understand, deliberate or communicate. Children, however, are assumed not capable of consent, and permission to enter research is usually necessary from their parent or legal guardian. Adults with mental disabilities, dementia, mental illness, or those unconscious or heavily medicated, may or may not be able to give consent and must be evaluated on a case-by-case basis. The second precondition is that the subject must make the decision whether or not to participate freely, voluntarily and without coercion.

If both these pre-conditions are present, then the subject must be fully informed. This means that they have been presented the following information and have had an opportunity to ask questions and receive answers to those questions. Informed consent should include:

- the purpose of the study;
- reasonably foreseeable risk and discomforts to the subject;
- potential benefits to subjects;
- how risks will be minimized including protection of confidential information;
- possible alternative (non-research) procedures or treatments;
- participation is voluntary;
- subject may withdraw at any time;
- if the study poses greater than minimal risk, the subject should receive any information about potential compensation for harm or medical treatment;
- who to contact with questions about the research and their rights as subjects.

Documentation of informed consent is usually required, by a form that lists all the above information at a level of language understandable to the potential subjects, and is signed by the subject. Some institutions require a witness's signature or the signature of the person obtaining the consent.

See the informed consent forms in the Tools section of this Module (V) for examples of forms that meet these requirements.

Protecting subject's confidentiality

In many research projects, including those involving mainly interviews or surveys, the only risk to subjects is that confidential or sensitive information about them will be improperly disclosed. In all studies researchers have an obligation to protect subject identities and information. Common measures to protect information include:

- conducting interviews in private or in settings where the information disclosed cannot be overheard by other persons;
- keeping the identities of all research subjects confidential, even the fact that an individual *is* a research subject should be protected;

- identifying research data by code rather than name;
- not using names or other identifiable information in any published or circulated summary of the data or discussion of the results;
- storing research data, including informed consent forms in locked rooms or file cabinets, or on pass-word protected computers, to limit outsider's access to information;
- educating staff not to share interesting anecdotes from the research outside of the research setting.

Confidentiality in research:

Interviewers may know their research subjects from other settings such as street outreach, health clinics, on-going therapy groups, or other settings. They may have even recruited subjects in those settings. However, in all cases interviewers should not acknowledge the identity of a subject as a participant in a study in any setting, unless the subject identifies himself as such. Interviewers may even encounter research subjects socially at a later time. Once again, interviewers should not acknowledge their previous contact with the subject unless the subject does so.

Ethical Issues in Policy Research and this Project

Avoiding harm to subjects and others

Although policy research focusing on behavior is relatively low risk in comparison to some types of clinical trials or behavioral research, any research related to drug use or other illegal behavior poses some risks to subjects. For those not engaging in illegal activity themselves, the main risk is that sensitive or critical information revealed in an interview or focus group might be disclosed to their colleagues, friends, or associates. Or, there might be some possible stigma associated with working with the researchers identified with an "AIDS project" or a "drug user project."

For subjects engaged in or knowledgeable about illegal behaviors such as drug use, potential risks include both disclosure of stigmatizing information and potential legal risks if law enforcement authorities use information obtained in research for criminal justice purposes. These subjects, who may be reluctant to talk to researchers, deserve protection from possible mis-use of their information. For example, collecting data without personally identifiable information on subjects may be one way to insulate them from harm. Subjects could give their initials or use pseudonyms. Other precautionary measures include not recording precise locations where subjects were interviewed or illegal activity occurred so as to prevent police use of the information to conduct surveillance or make arrests.

Finally, in some cases the potential for harm comes from the implications of the results of the research. In these cases, researchers must balance the probable benefits of

the research against the possible harms that might occur from documentation of the results.

Case Study: do no harm – an ethical dilemma in prison

During planning for an investigation of HIV in a prison researchers were concerned that a backlash would result from prison staff and administration if the researchers revealed that there was injection drug use and sex in the prison. On balance the team decided that research was vital to convince policy makers and politicians to implement penal reform.

Neutrality

Researchers will need to have a non-judgmental stance. This means respecting the life choices that informants have made and any opinions they hold. During a rapid assessment, researchers should never attempt to change the behavior, beliefs or attitudes of an informant. Where conflict exists in a locality, either between individuals or political groups, researchers should avoid being associated with either side.

Case study: neutrality - an ethical dilemma

During street interviews with young heroin injectors, a researcher was often asked whether she thought they should be tested for HIV. Rather than express her own opinion about HIV testing, at the end of the interview she would give the interviewee a card with contact details for a free, confidential HIV testing and counseling service.

Consent

Informants should normally give their consent to being involved in the study. Where researchers record the identity of the respondent, consent is required. However, where researchers are only observing behavior, or where they have been advised not to explain what they are doing by a key informant, *and* the identity of the subject of the information is not recorded, the researcher must assess the most ethical course of action.

Case study: informed consent - an ethical dilemma

During research in a Baltic country, members of the team became involved in a conversation at a party. The young person they spoke to revealed, during the conversation, that she was involved in sex work and used drugs. She spoke quite openly about her experience and provided useful information about sex work and drug use in the city. However, the members of the research team did not reveal to the young person that they were researchers or the nature of their work. Since there was no informed consent, the researchers were faced with the ethical dilemma of whether or not to use the useful information.

Feedback

Those people who were involved in the rapid assessment should be given a chance to comment on the findings. As well as being ethical, this is often a useful final check on the validity of any results and the feasibility of any recommendations.

Consequences

Researchers should always be aware of the consequences of their actions. What seems ethical in strict research terms may have unethical consequences for others.

Example: Alcohol and ethics, Ireland

Research team members were interested in how 'poitin' is made. 'Poitin' is a home-made spirit that a lot of young people drink in our community. The only person who could show them how to make the drink was currently undergoing alcohol treatment. The team was aware that by asking this person prepare the drink, they could be placing the individual in a situation where she might be tempted to drink the solution. This ethical dilemma was solved when the opportunity arose to witness the 'poitin' production by individuals not in alcohol treatment.

Protecting Human Subjects in Policy Research and this Project

Investigators should develop a plan specific to their research project that foresees potential risks to research subjects (and staff), adopts means to reduce risks and establishes procedures to ensure that risks are minimized and subjects are protected throughout the course of the research project.

See Protection of Human Subjects in the tools section of this Module (V).

Documents and Sources:

The Belmont Report. National Commission for the Protection of Human Subjects of Biomedical and Behavioral Research. April 18, 1979, available at: http://ohsr.od.nih.gov/guidelines/belmont.html

Code of Federal Regulations (US) 45 CFR Part 46, available at: http://www.nihtraining.com/ohsrsite/guidelines/45cfr46.html

Council for International Organizations of Medical Sciences (CIOMS) International Ethical Guidelines for Biomedical Research Involving Human Subjects. CIOMS, World Health Organization, 2002, available at: http://www.cioms.ch/frame_guidelines_nov_2002.htm

Nuremberg Code, 1947. available at: http://ohsr.od.nih.gov/guidelines/nuremberg.html

Universal Declaration of Human Rights, 1948. available at: http://www.un.org/Overview/rights.html

World Medical Association, Declaration of Helsinki, available at: http://www.wma.net/e/policy/pdf/17c.pdf