Module III: Qualitative Data

Key Informant Interviews

Tools
Qualitative Data: Key Informants

Tools

This version of the Rapid Policy Assessment and Response Module has been created by Scott Burris, Patricia Case and Corey Davis for use in an “ethics risk assessment” for research subjects in the HPTN 058 trial. The next step will be review and revision of this instrument in collaboration with local researchers in China and Thailand.

Purposes

- To learn qualitative data about key domains:
  - Police behavior towards IDUs and people with HIV
  - Perceptions
  - Access to health 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, and people involved in research.
2. Qualitative data on access to harm reduction services, including what structural barriers, if any, prevent IDUs from accessing those services.
3. Qualitative data on stigma, social risk, and social attitudes as it applies to IDUs and people with HIV.
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. [Reserved]
3. [Reserved]
4. Enforcement of laws on criminal HIV exposure or transmission
5. Operation of courts and prisons
6. [Reserved]
7. Harm reduction and public health interventions
8. [Reserved]
9. [Reserved]
10. [Reserved]
11. [Reserved]
12. Effects of participation in research

Key Informant Interviews

1. There will be a total of 28 system and interactor interviews (see Table A below) and 16 IDU interviews (see Table B)

2. Unless the prompts specifically state otherwise, all interviewees should be asked all questions.

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. Qualitative interviewing is meant to produce exploratory data. Interview guides are meant to be just guides, not rigid questionnaire forms. Asking additional follow-up questions related to the comments of the participant is encouraged after asking the main questions. Prompts are written to make sure that certain areas are covered, but do not need to be asked again if the respondent has already covered that topic completely.

5. If new questions occur to the interviewer or new areas not covered on the Guide open up that are related to the experiences of IDUs with law enforcement or the experience of participating in research projects, the interviewer may pursue those topics. Avoid “yes or no” questions and always aim to encourage the participant to say more and tell stories about their experiences.
6. After every interview, label and date the tape, write 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.

A. System and Interactor Interviews

For the system and interactor interviews, we are asking you to recruit and interview particular types of people. For these interviews, if you are unable to recruit the listed type of person you may interview a similar type of person instead.

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 interviewee. 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. Make sure you note any such substitutions on the interview forms.

Table A. System and Interactor sampling plan

<table>
<thead>
<tr>
<th>System/Interactor</th>
<th>Number</th>
</tr>
</thead>
<tbody>
<tr>
<td><strong>Legal systems</strong></td>
<td></td>
</tr>
<tr>
<td>Prison official (such as a warden)</td>
<td>1</td>
</tr>
<tr>
<td>Judge</td>
<td>1</td>
</tr>
<tr>
<td>Prosecutor</td>
<td>1</td>
</tr>
<tr>
<td>Policy-makers or local authorities</td>
<td>1</td>
</tr>
<tr>
<td><strong>Legal interactors</strong></td>
<td></td>
</tr>
<tr>
<td>Police: Supervisory</td>
<td>2</td>
</tr>
<tr>
<td>Police: Street-level</td>
<td>2</td>
</tr>
<tr>
<td>Prison guards</td>
<td>2</td>
</tr>
<tr>
<td><strong>Public health systems</strong></td>
<td></td>
</tr>
<tr>
<td>Public health authorities</td>
<td>1</td>
</tr>
<tr>
<td>Narcological or drug treatment facilities: officials</td>
<td>1</td>
</tr>
<tr>
<td>NGO director of organization working with HIV</td>
<td>1</td>
</tr>
<tr>
<td>Reeducation camp director</td>
<td>1</td>
</tr>
<tr>
<td><strong>Public health interactors</strong></td>
<td></td>
</tr>
<tr>
<td>Public health clinicians</td>
<td>2</td>
</tr>
<tr>
<td>Emergency/casualty department physicians</td>
<td>2</td>
</tr>
<tr>
<td>Reeducation camp workers</td>
<td>2</td>
</tr>
<tr>
<td>Narcological or drug treatment facilities: staff</td>
<td>2</td>
</tr>
<tr>
<td>NGO staff working in HIV</td>
<td>2</td>
</tr>
</tbody>
</table>
B. Key Informant IDU Interviews

You have learned about system, interactor and IDU key informant interviews. For the IDU key informant interviews we are asking you to recruit and interview particular types of injection drug users. Some IDUs may be challenging to recruit. Use the tools and methods for recruitment you learned in the training materials. All IDUs recruited for this interview must meet the inclusion criteria outlined below.

Inclusion

The inclusion criteria for IDU participants are as closely matched to the HTPN protocol as possible. IDUs selected for interview must be

1) At least 18 years old
2) Willing and able to provide informed consent for study participation
3) Must be opiate dependent by self-report
4) Injected opiates at least twelve times in the last 28 days, according to self-report
5) If female, medically unable to become pregnant or using an effective method of contraception.

Participants should be divided into two groups, 1) those who have participated in a study of drug users on the site and 2) those who have not participated.

A new injector is defined as someone who has injected for the first time ever within the last 12 months. Local minorities are those deemed in advance of the interviews by the investigators to be minority populations at risk. These are intended to be members of a specific cultural group, sub-population or caste. If local minorities who are IDUs cannot be identified, another group of interest to local investigators may be specified such as fishery workers or long-distance truck drivers.

Table B. Key informant sampling plan

<table>
<thead>
<tr>
<th>IDUs</th>
<th>Number</th>
</tr>
</thead>
<tbody>
<tr>
<td>Participants or former participants in a study of drug users on the site</td>
<td></td>
</tr>
<tr>
<td>New injectors</td>
<td>2</td>
</tr>
<tr>
<td>Female non-pregnant IDU</td>
<td>2</td>
</tr>
<tr>
<td>Locally significant minorities IDU</td>
<td>2</td>
</tr>
<tr>
<td></td>
<td></td>
</tr>
<tr>
<td>------------------------------------</td>
<td>-----</td>
</tr>
<tr>
<td>Other IDUs</td>
<td>2</td>
</tr>
<tr>
<td>Drug users who have not been study</td>
<td></td>
</tr>
<tr>
<td>participants</td>
<td></td>
</tr>
<tr>
<td>New injectors</td>
<td>2</td>
</tr>
<tr>
<td>Female non-pregnant IDU</td>
<td>2</td>
</tr>
<tr>
<td>Locally significant minorities IDU</td>
<td>2</td>
</tr>
<tr>
<td>Other IDUs</td>
<td>2</td>
</tr>
<tr>
<td><strong>Total</strong></td>
<td><strong>16</strong></td>
</tr>
</tbody>
</table>

**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. For some questions, prompts are included to help you get more complete information if the informant gives very brief answers.
Key Informant Interview Guide

Enforcement of Drug Laws

Topic Area 1

To the interviewer: These questions are 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, and whether there are special circumstances around the arrest of IDUs.

IDUs and law enforcement

1.1 In general, tell me about how the police treat injection drug users.

Prompts

- Do police especially target people they suspect of being IDUs?

- Does police treatment of IDUs depend on certain characteristics of the defendant? Which characteristics (i.e. age, gender, ethnicity, race, location)?

- Do police treat men and women differently??

1.2 Tell me what happens when police arrest an IDU in possession of drugs.

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

Prompts

- Are police afraid of being stuck by syringes or other health consequences from being in contact with IDUs? (If yes) How do you know they are afraid…

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

1.4.1 (if yes, if IDU) Tell me about a time that happened either to you or someone you know…

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

1.5.1 (If yes, if IDU) Tell me about a time that happened, either to you or someone you know…
1.6 Do police ever detain IDUs and turn them over to narcological facilities, re-education, or other kinds of forced treatment? Say more about that…

1.6.1 (If yes, If IDU) Has this ever happened to you or a friend? Say more about that..

1.7 Tell me about the police and their use of physical violence or force against IDUs?

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

1.7.2 (If yes, If IDU) Tell me about a time that happened, either to you or someone you know…

Attitudes towards IDUs, and persons with HIV

1.8 In general, tell me about how people treat IDUs?

Prompts

- Are they afraid of IDUs?

1.9 If it is known that someone is an IDU, will they lose their job/house/friends/medical care/state benefits/chance to go to school?

1.10 How do people know that someone is an IDU?

1.11 Who should I talk to next for more information on the enforcement of drug laws?
Key Informant
Interview Guide

Enforcement of Laws on
Criminal Exposure or Transmission of HIV

Topic Area 4

To the interviewer: This topic area 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 are special circumstances surrounding arrests of persons suspected of HIV exposure or transmission.

Law enforcement and people with HIV

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

4.2 Tell me about whether the police target people they suspect of exposing others to or transmitting HIV?

4.2.1 If there are laws against being knowingly exposing or transmitting HIV, how do police enforce them?

4.3 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?

4.4 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, are they likely to be convicted?

- In general, how long are sentences for this?

4.5 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])

4.6 Are laws or practices against exposure or transmission applied differently to men and women?

4.7 In general, do police treat women or men suspected of having HIV differently?

4.8 In general, do police treat people of different races or classes suspected of having HIV differently?

4.9 Do police take money, drugs, sex, or other items from HIV + people in exchange for release or to avoid arrest?

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

Attitudes towards persons who might transmit HIV

4.10 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?

4.11 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, jails or re-education.

**IF SYSTEM OR INTERACTOR SKIP TO QUESTION 5.22**

### Function of legal system

*Note:* All IDUs should be asked these questions

5.1 Have you ever had to pay anyone as a result of your IDU status? Tell me about the last time that happened.

**Prompt**

- Describe any time you have had to pay to anyone in the legal system other than a police officer. Say more about that.

5.2 (If yes) Who takes money, drugs, sex or other items in the legal system?

**Prompts**

- Do prosecutors or judges take money, drugs, sex, or other items in exchange for release or to avoid arrest?

- Do defense attorneys take money, drugs, sex or other items in order to present a strong defense?

- Do defendants have to pay to be released pretrial?

5.3 To the best of your knowledge, what are the usual prices, and who do you have to pay:

- 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.

Personal Experiences

5.4  (IDUs only) Have you ever been:

• Arrested or detained for being a drug user?
• Tried?
• Convicted?
• Incarcerated in jail or prison?
• Incarcerated in re-education?
• Incarcerated in non-voluntary detoxification?

*IF the IDU has never been arrested or detained, skip to question 5.22*

Protection of rights of defendants

5.5  Tell me about the last time you were detained by the police…what happened?

*Note:* Probe about the date, what the detention was for and details…what was the outcome of the detention

5.6  Tell me about the last time you were arrested. If the same as the above time, ask about a different time: Tell me about a different time in the last 12 months that you were arrested

*Note:* Probe about the date, what the detention was for and details…what was the outcome of the detention

5.7  Did you have legal representation? Tell me more about that…

Prison/jail conditions

*Note:* In this section, if the participant does not have personal experience with prison, jail, or re-education, skip to question 5.22

*Note:* In China, we expect many drug user informants will have spent some time in a detoxification or re-education facility. These should be included in all queries regarding “prison,” and the differences between reports of prison and these other forms of incarceration should be carefully recorded.

5.8  Tell me about the last time you were in prison, jail, or re-education – how long and why you were there, and what the conditions were like.

5.9  Tell me about the conditions in prison, jail, or re-education 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?

5.10 Are conditions in prison, jail or re-education different for men and women, and if so, how are they different?

5.11 Are some prisons worse than others in terms of conditions? Which ones?

5.12 Are pregnant women incarcerated? What happens to their children?

**Other programs in prison, jails and re-education**

(Read to participant)

I would like you to tell me about other programs in prison, jail, or re-education. 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.

5.13 Are there drug treatment programs in prisons? (Note: this is different from re-education or mandated detoxification)

5.13.1 (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. Are there HIV/AIDS education programs in prisons?

5.14 Are there HIV education programs in prison, jail, or re-education?

5.14.1 (If yes) Tell me more about HIV education programs in prison…describe the education and how long the programs are, what kinds of information are distributed, what topics are discussed. Tell me about your own experience if you participated in one.

5.15 Are there programs in prison to “rehabilitate” prisoners or prevent recidivism, teach trades, continue education, and teach anger management or parenting skills?

5.15.1 (If yes) Tell me more about rehab programs in prison…describe the program and how long the programs are, and what kind of skills are covered. Tell me about your own experience if you participated in one.
5.16 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. Tell me about your own experience if you participated in one.

5.17 Have you ever been in re-education?

5.17.1 (If Yes) Tell me about your experiences there the last time you were in reeducation?

5.18 What are the key differences in the treatment of drug users between prison, jail, re-education and mandated detoxification?

Tuberculosis and Health in Prison and Jail

5.19 Tell me what you know about TB in jail and prison?

5.20 Did you have TB in jail / prison?

5.20.1 [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?*

5.20.2 Have you had a recurrence of TB since you got out of prison, or do you still have TB?

5.21 Did you know other prisoners who had TB in prison?

5.21.1 In your opinion, how many prisoners in your facility had TB? How many prisoners were there overall in your facility?

THESE QUESTIONS ARE FOR SI OR PEOPLE WITH NO PRISON EXPERIENCE
Note: In China, we expect many drug user informants will have spent some time in a detoxification or re-education facility. These should be included in all queries regarding “prison,” and the differences between reports of prison and these other forms of incarceration should be carefully recorded.

Prison conditions

5.22 Tell me about the conditions in prison…

Prompts

- 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?

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

5.24 Are some prisons worse than others in terms of conditions?

5.25 Are pregnant women incarcerated? What happens to their children?

5.26 Tell me about the key differences between prison, jail, re-education and mandated detoxification for IDUs.

5.27 Tell me about TB in jail and prison?

5.28 What is being done to identify and treat cases of TB?

Prompt

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

5.29 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

5.30 Are there drug treatment programs in prisons?

5.30.1 (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.

5.31 Are there HIV/AIDS education programs in prisons? Tell me about them…

5.32 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.

5.33 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.
Drug treatment programs

7.1 Tell me about the kinds of treatment that are available for drug users? (after response, work with ask all questions related to table)

<table>
<thead>
<tr>
<th>Type of treatment</th>
<th>Available? Y/N/DK</th>
<th>If not available, why not?</th>
</tr>
</thead>
<tbody>
<tr>
<td>Counseling only</td>
<td></td>
<td></td>
</tr>
<tr>
<td>Detoxification</td>
<td></td>
<td></td>
</tr>
<tr>
<td>In-patient treatment</td>
<td></td>
<td></td>
</tr>
<tr>
<td>Methadone</td>
<td></td>
<td></td>
</tr>
<tr>
<td>Other opiate replacements</td>
<td></td>
<td></td>
</tr>
<tr>
<td>Opiate replacements for detoxification</td>
<td></td>
<td></td>
</tr>
<tr>
<td>Opiate replacements for maintenance</td>
<td></td>
<td></td>
</tr>
<tr>
<td>Are there time limits on opiate replacements</td>
<td></td>
<td></td>
</tr>
<tr>
<td>Behavioral modification</td>
<td></td>
<td></td>
</tr>
<tr>
<td>Re-education</td>
<td></td>
<td></td>
</tr>
<tr>
<td>Other modalities</td>
<td></td>
<td></td>
</tr>
</tbody>
</table>

Capacity of drug treatment programs

7.2 Is outpatient drug treatment available? Tell me about outpatient treatment…

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 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 Is opiate substitution treatment using methadone or bupenorphine available? Tell me about it…

**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?*

Mandatory Treatment

7.5 Under what circumstances is drug treatment mandatory?

7.6 Tell me about what professional and care-taking staff are 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 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 Under what circumstances do IDUs get sent to re-education?

7.9 Tell me about what professional and care-taking staff are like at re-education?

Prompts

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

7.10 Do re-education 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?

7.11 In your opinion, which forms of drug treatment are most effective in treating IDUs so that they stop using drugs? Out-patient, re-education, in-patient, methadone or opiate substitution???

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

HIV Testing

7.13 Tell me about HIV testing and counseling policies …

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?

7.14 Tell me about the availability of HIV testing.

7.15 Is HIV testing common among……… [answer Y/N]

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

7.16 Why or why not?

**Basic medical care for IDU**

7.17 Can IDUs 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**

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

7.19 Are there needle/syringe exchange programs here? Are they “legal”?

7.19.1 (IF YES to NEPS) Tell me about how the police deal with NEPs.

**Other harm reduction programs**

7.20 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? Are they good quality?*
- *Where are condoms available?*

7.21 Tell me about programs that distribute condoms? Do local health clinics distribute condoms?

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

7.23 What are barriers to effective harm reduction? What could be done to remove those barriers?

**Attitudes towards harm reduction**
7.24 Tell me what you think about harm reduction programs such as needle exchange programs and opiate replacement programs?

7.25 Do you think the government should sponsor harm reduction programs?

7.26 Who else should be involved in harm reduction?

7.27 In general, do people here know much about “harm reduction” principles?

7.28 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**

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

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

7.31 Who should I talk to next for more information on harm reduction and public health interventions?
Key Informant Interview Guide
Research Among IDUs
Topic Area 12

To the interviewer: This question is designed to get specific information from the informant about knowledge and attitudes towards research involving drug users

ASK ALL; SI AND IDU

12.1 Are you aware of drug users participating in health research studies? Tell me about how you are aware of drug user participation in research studies.

12.2 In general, are police or other officials know who (IDUs) is participating in research? How do they know?

12.2.1 (If Yes) Tell me about the ways, if any, that police treat research participants differently from other IDUs?

12.2.2 Tell me more about how the police treat research participants….

12.2.3 Are IDUs more likely to be arrested if police know they are participating in a research study?

12.2.4 Are there other police-related risks to IDUs who participate in research studies?

12.3 In general, are people such as drug treatment providers, NGO staff, or harm reduction workers aware of or know who (IDUs) is participating in research studies? How do they know?

12.3.1 (If yes) Tell me more about how they treat research participants, are there any negative consequences of participation?

12.4 In general, are people in the community such as neighbors or relatives aware of or know who (IDUS) is participating in research studies? How do they know?

12.4.1 (If yes) Tell me more about how they treat research participants, are there any negative consequences of participation?

12.5 Tell me about the effect of participating in research on an IDUs ability to get care for HIV or other diseases? Drug treatment?

12.6 Tell me about the effect of participating in research on an IDUs ability to get housing or jobs?
12.7 (Final question for SI only, for IDUs, skip this question and ask the rest) Is there anything else about the potential for stigma and discrimination against IDUs who participate in research projects?

**IDUS ONLY:** Ask all IDUs regardless of recruitment category

12.8 Have you ever participated in a study of drug users?

12.8.1 (IF YES) Tell me about your experience of participating in study in detail please. When was the study…….(get all details, investigator name, topic of study, activities)

*Prompts*

- *Investigator name, topic of study, where study was conducted and when?*
- *What kinds of activities did you participate in(e.g. surveys, blood tests)*
- *Were you paid or given something in exchange for participating in the study? Tell me about that…*
- *Were you concerned that someone would find out you were in the study? Why or why not?*
- *What made it easy to participate in the study, what made it hard?*

12.8.2 (IF NO – Ask this question and stop) Have you ever been asked to be in a study?

12.8.2.1 (If yes) Tell me about why you did not participate in the study….

12.9 (For study participants) Tell me about what happened afterwards?

12.10 Tell me about any negative consequences of participating in the study, if any?

*Prompts*

- *Did anyone that you didn’t want to find out that you participated? Please say more – who found out, then what happened?*

12.11 Tell me about any positive consequences of participating in the study, if any...

12.12 Is there anything else you would like to say bout your participation in the study?
**FORM: DATA ORGANIZATION**  
For Key Informant Interviews

<table>
<thead>
<tr>
<th>Interview#: ¹</th>
<th>Category &amp; Type²</th>
<th>ID# of Topic Area³</th>
<th>Information summary, key points</th>
<th>Comments:</th>
</tr>
</thead>
<tbody>
<tr>
<td></td>
<td></td>
<td></td>
<td></td>
<td></td>
</tr>
<tr>
<td></td>
<td></td>
<td></td>
<td></td>
<td></td>
</tr>
<tr>
<td></td>
<td></td>
<td></td>
<td></td>
<td></td>
</tr>
<tr>
<td></td>
<td></td>
<td></td>
<td></td>
<td></td>
</tr>
<tr>
<td></td>
<td></td>
<td></td>
<td></td>
<td></td>
</tr>
<tr>
<td></td>
<td></td>
<td></td>
<td></td>
<td></td>
</tr>
<tr>
<td></td>
<td></td>
<td></td>
<td></td>
<td></td>
</tr>
<tr>
<td></td>
<td></td>
<td></td>
<td></td>
<td></td>
</tr>
</tbody>
</table>

¹ Each interview should be assigned a unique identifying number, for example, Xin-S-1, for “Xinjiang, systems interview 1”. These numbers are used only for analysis and can not be linked to any specific interviewee.

² Category code: S=System, I=Interactor, IDU=drug injector informants

Type of informant: What type of IDU interview i.e. NDS-IDU-F-1 which would read as “Non-drug study IDU, female, interview #1.” or --What type of SI interview i.e. Emergency room physician or police officer.

³ Topic area by number, for example, 12 (research study participation).