

Johnny Blair, Survey Research Center, University of Maryland

Diane Binson, Center for AIDS Prevention Studies, University of California at San Francisco

Patricia Murphy, Hines VA Hospital, Hines, IL

Johnny Blair, 1103 Art/Sociology Building, College Park, MD 20742

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## 1 Background

Small population domains are often of particular importance in a survey either because they require separate analysis or because they have higher prevalence of a key attribute than the total population. When such domain members are not easy to include in pretest samples and also have potentially different response effects than the total population, the development of effective instruments and procedures can be hampered. In this paper, we report on a project in which laboratory methods and paid volunteer respondents were used to assess the suitability of a questionnaire and survey procedures for use with intravenous drug users (IVDUs). We outline the National Household Seroprevalence Survey [NHSS] survey design, describe the laboratory study and choice of methods. We then present key findings, assess the effectiveness of the laboratory procedures, and suggest implications for future laboratory studies of this type.

The NHSS was a planned face-to-face survey designed to measure prevalence of HIV in the U.S. population. The NHSS design called for a fairly elaborate process to gain cooperation, after which respondents were to complete a self-administered questionnaire and provide a small blood sample for testing. The draft questionnaire asked about sexually transmitted diseases (STDs), blood transfusions, HIV testing, drug use since 1978 and in the past year, sexual history and practices since 1978 and in the past year, standard demographics and reasons for participation in the study. Respondents were to be paid \$50 for participation in the NHSS.

Because of IVDU's very high rates of infection, their participation and response validity was of particular concern. There are several reasons why one might expect different participation and response behavior among IVDUs than the general population.

- a. Drug use is stigmatized and illegal. The admission of drug use may easily be seen by respondents as putting them at legal risk, should that admission become known.
- b. Many IV drug users know that they are at high risk for AIDS, which may add to the sensitivity of answering questions about HIV tests and results.
- c. The experience of IV drug users with law

enforcement and other government agencies may make them reluctant participants in a government survey.

- e. Questions about sexual behavior, sensitive to anyone, may be of particular sensitivity for people who may feel that they are seen as major transmitters of a fatal sexually-transmitted virus.

The laboratory study had two major objectives. The first was to examine which aspects of the NHSS design might affect respondents' willingness to cooperate. The second was to examine potential questionnaire response effects among IVDU respondents.

A group of IV drug user subjects was recruited through an outreach program (the Chicago AIDS Outreach Intervention Project at the School of Public Health, University of Illinois at Chicago, Dr. Wayne Wiebel, Principal Investigator). Our study was carried out at the Northside community office. The laboratory methods used included think aloud interviews, special probing, dimensional card sorts and hypothetical scenarios (Forsyth and Lessler 1991; Ericsson and Simon 1984).

## 2 Components of the NHSS

The NHSS data collection plan included a number of components, any of which could affect cooperation; these were:

1. Advance letter mailed to the household  
Household contact by an interviewer
2. Household enumeration and selection of a sample person
3. Sample Person letter [including mention of the incentive]
4. A video about the study shown to the respondent
5. Consent form
6. Drawing blood [two possible methods]
7. Self-administered questionnaire
8. Payment of a \$50 incentive

### 3 Choice of Methods

For reasons of access to subjects and the limited budget of the laboratory study, it was clear that the possible sample size would be small. Yet the number of potential issues and the large number of NHSS procedures and documents would require a relatively large amount of information from each subject. Also, we sought not only to determine sources of survey problems particular to IV drug users, but to gain some insights into possible reasons for the identified problems. So obtaining some information about response formation and perceptions of survey questions and procedures would be useful. Lastly, we did not want to structure the laboratory protocol so tightly that unanticipated issues relevant to IVDU cooperation and response effects could not emerge.

For these reasons, and the experiences of other researchers using laboratory methods (Royston, 1989; Royston et al. 1986) we thought that a qualitative approach in a "laboratory" setting would maximize our ability:

- a. to probe responses thoroughly;
- b. to use verbal protocols to examine response formation;
- c. to create an atmosphere in which subjects would be willing to discuss reservations or suspicions about the NHSS survey plans; and
- d. to allow the research to proceed in an iterative fashion—that is, as interviews were completed and no points came up or old issues were not yielding additional information, the focus of subsequent interviews could be shifted.

The methods selected for use were: concurrent and retrospective think aloud; follow-up probing on each question; dimensional card sorts; hypothetical reactions to NHSS procedures and materials. (See Figure 1)

### 4 Laboratory Protocol

It is important to keep in mind that in the laboratory research, although interviewers were guided by a written laboratory protocol, its content changed over time. An iterative process was used in which the experience from laboratory interviews brought out additional issues, and we revised the laboratory protocol to include investigation of those issues. Laboratory interviews also sometimes suggested better questions or probes which were incorporated as well. Finally, when there seemed to be no variance in responses to an issue or question, the item was dropped from the laboratory protocol, or the time allotted to it was reduced.

Our initial plan was to take subjects through the entire

process of the NHSS (advance letter, household screening, consent form, video, and questionnaire), [the blood draw could, of course, only be described and discussed] and to get reactions to the hypothetical experience of being contacted and selected for the NHSS, and exposed to each of its stages and documents. Although this approach was followed in the first 11 interviews, questions about the household screening and consent form components of the NHSS were dropped because these seemed difficult for respondents to discuss hypothetically. Showing of the video and questions about the method of drawing blood samples were discontinued when interviews were no longer yielding new information. Although simulation of the household listing was discontinued, subjects were questioned in general about issues related to the listing and to obtaining sample coverage of IV drug users.

We should also note that the content of the laboratory interviews varied somewhat even when the same protocol was used because the protocol served as a general guide, not a series of questions administered verbatim. We often pursued topics raised by subjects that were not in the laboratory protocol. Although we tried in each interview to cover all of the topics specified in the protocol, the extent to which each was explored depended on how responsive the subject was.

Below is an outline of the major components of the initial laboratory protocol, and the objective of each one.

#### Outline of Laboratory Protocol

<u>NHSS Component</u>	<u>Laboratory Method</u>	<u>Objective</u>
. An advance letter	Probing to determine hypothetical and personal reactions	Assess legitimacy & suspicion Letter clarity
. Household contact by an interviewer	Probing to determine hypothetical and personal reactions	Willingness to allow access
. Household enumeration and selection of a sample person	Probing to determine hypothetical and personal reactions	Inclusion of IVDU in HH listing

## Outline of Protocol (con't.)

<u>NHSS Component</u>	<u>Laboratory Method</u>	<u>Objective</u>
. Sample Person letter [including mention of [incentive]	Probing to determine hypothetical and personal reactions	Letter clarity Incentive effect
. Video	Probing to determine hypothetical and personal reactions	Clarity of survey importance & goals
. Consent form	Probing to determine hypothetical and personal reactions	Belief in anonymity clarity
. Drawing blood HIV testing	Probing to determine hypothetical and personal reactions	Willingness to provide blood sample using different methods
. Self-administered questionnaire	Probing to determine hypothetical and personal reactions. Think aloud. Vocabulary card sort. Focused probing.	Understanding Clarity Willingness to provide information
. Method of payment of incentive	Probing to determine hypothetical and personal reactions	Acceptance of method

### 5 Sampling and interviewing

A group of known intravenous drug users was recruited by the Chicago Outreach Project. Subjects were not part of the Outreach Project itself, but were neighborhood residents known to the outreach workers. A total of 36 people were interviewed. Of these, 26 were male and 10 were female. Almost two-thirds (23) of the subjects were Black, while the remainder (13) were White. The mean age of subjects was 38.9 years. Nineteen subjects were 30-39 years old at the time of the interview; 4 were 24-30 years old, and the remaining 13 were 40-60 years of age.

Of the 36 subjects, 15 had less than a high school education, and 5 had less than 9 years of education. Eight subjects had either completed high school or had a GED. Some college was reported by 13 people.

Most individual laboratory interviews were conducted one-on-one, in private interviewing rooms equipped with desks and chairs. Interviews were tape-recorded and ranged in length from 30 minutes to 2 hours. Most interviews lasted about 45 minutes. All interviews were audio-tape-recorded. Subjects were paid \$20.

A portable video cassette player was used to show the NHSS video produced by NCHS to 13 subjects. To simplify logistics, the NHSS video often was shown to two subjects together, but with the subsequent laboratory interviews conducted separately.

### 6 Data Analysis

Three procedures were used to prepare the interviews for analysis: (a) abstracting the interviews, using a standardized form; (b) tallying results of the card sorting task used to identify words that subjects found difficult to read or understand; and (c) discussing the interviews as a research team following each interviewing session, to record information and refine the protocol or procedures.

### 7 Results

#### a. NHSS findings

Regarding participation in the NHSS, the main concerns of the IV drug users in this project were suspicions about why they might have been chosen for such a study, and whether anonymity would truly be maintained. Since IV drug users know that they are often identified on various lists as known drug users, it is easy for them to think that they were chosen from some such list. Some subjects also suggested that IVDU respondents might think that they were selected for the NHSS survey because they had AIDS.

An unanticipated issue raised was the role of the NHSS as a source of education about AIDS. A number of the subjects felt that if education about risk behaviors could be provided as part of the NHSS, it would be a major incentive to participate.

The last key issue related to the decision to participate is the method of drawing blood. The condition of the veins of many IV drug users make standard techniques for drawing blood difficult, painful, or impossible. The emphasis in the NHSS on using venipuncture (versus finger stick) for the blood draw was seen as a strongly negative factor and a disincentive for participation in the NHSS.

Regarding response bias, a number of problems arose from the self-administered nature of the questionnaire which were not directly related to the respondent's IVDU status. These issues concerned mainly reading ability. The card sort turned up expected problems with words like "seroprevalence" and "hemophilia", but also with the words "anal," "marital" and "assurances." Further, it was found that subjects might understand one grammatical form of a word but not another. For example, "vagina" was known by most subjects, but "vaginal" was not.

There were also problems with the questions on drug use, sex practices, and HIV test results which seem to differ for IV drug users compared to the general population. The terminology for drug use practices was sometimes inappropriate. For example, "street drugs" was not uniformly interpreted. For some subjects it meant drugs of low quality, while for others it meant drugs excluding illegally obtained pharmaceutical drugs.

The questions about sharing needles were problematic. IVUDs who cleaned their "works" before sharing them did not want to be grouped, as the draft questionnaire did, with IVUDs who shared needles without first cleaning them.

Lastly, the lack of skip instructions, thought to simplify the instrument, confused and irritated some subjects who had to answer inappropriate items-- even though Not Applicable N.A. (which was itself not always understood) was available to them. For example, many heterosexual men resented being asked about sex with other men.

#### b. Methodological findings

Two aspects of subjects' reactions should be mentioned: to the general laboratory interview procedures and to the attempts to simulate the NHSS survey. For the most part, the laboratory interviews worked well, but for several subjects it was not absolutely clear, at the outset, what was being asked of them. The notion of discussing, rather than just providing, their responses took some getting used to. This was especially the case for those who had previously participated in traditional surveys. We learned quickly that more time was needed at the start of each session to explain what we were trying to do before launching into the laboratory interview itself.

As noted above, initially we had planned to go through all NHSS materials in sequence, explaining as we went along how the NHSS would be conducted, and getting respondent reactions. This was abandoned after two interviews. These hypothetical scenarios proved very difficult for the subjects, as well as adding to the session length, which was already quite long.

The hypothetical aspect of the protocol took two forms. First, respondents were asked how they thought they might personally react to a particular component of the NHSS if they were actually confronted with it. Second, they were

asked how they thought other people might react to the same component on NHSS. Respondents had trouble with both situations, but mainly with other people's possible reactions.

A minor point, but worth mentioning for this population, is that even with careful recruitment, a few respondents arrived "high" for the session or were obviously in need of drugs and eager to be done with the session, obtain the monetary incentive and leave. It would be difficult for interviewers not used to dealing with this population to judge respondent competence before actually attempting the interview. Having someone available who is used to working with this population was very important.

Those problems having been given, it should be noted that most respondents were quite helpful and capable. There was little if anything in their reactions to the methods themselves that we would attribute to their being drug users. We feel that the outcome was highly successful.

One method that was both simple and effective was the card sort. It was easy to explain to respondents, did not take long to conduct, and provided a simple measure of perceived vocabulary complexity. As far as we could tell, respondents did not see the task itself as sensitive. This might well have been because we allowed them to note both words they did not understand and words that they thought many people might not understand. While a clearer measurement would result from limiting the "sort" to words that the respondent himself/herself did not understand, we think that the approach we chose was more helpful in this interview context.

In the think-aloud procedure, respondents were asked to think aloud concurrently and also were asked after each answer, "How did you come up with your answer?" or "What were you thinking about?" This was useful especially in regard to the NHSS reference periods. A respondent's failure to mention how the time period was used in formulating a response suggests that the reference period was not being considered, at least this seemed to happen frequently for the period since 1978.

There may be some tendency in retrospective thinking aloud to fabricate--after the fact of response formation--a more detailed and elaborate response process than probably occurred in the amount of time taken to answer a question. As with other populations where, in our experience, this seems to occur, the line between reporting--vs. explaining or justifying--response formation may be a hard one to detect.

One has to be especially careful not to use leading probes in such an open-formatted, conversational setting. For these respondents, the \$20 they were paid is not a trivial amount. Under these circumstances some respondents may look for clues for how to "please" the

interviewer. One must take care that the probes do not inadvertently provide such clues, since many drugs users are very practiced at "reading" and manipulating personal interactions.

Respondents were willing to discuss their reservations or suspicions about the NHSS, though this openness might be owed to the neighborhood rapport and reputation of the Chicago Outreach Project, rather than to our particular methods. Still, this approach certainly allowed respondents the opportunity to express their reservations and/or suspicions about NHSS, which other, more structured, methods might not do as well.

Here again, the caution about the respondents' desire to please applies. Although purely a subjective judgment, we did not sense a reluctance of respondents to express their concerns in this area.

Adjusting the focus of subsequent laboratory interviews based on new issues arising or old issues not yielding new information did work well, and was not just valuable, but essential, to the study. It also allowed us to take maximum advantage of the small sample size. We should point out, however, that these ongoing laboratory protocol adjustments do not come without some costs and cautions.

Much care has to be given to communicating the modifications of the laboratory protocol to all interviewers. Otherwise, not only are the discussions after the interview sessions based on different experiences, but the direction that further modifications should take becomes problematic.

More important, changing the protocol can potentially affect how the quantitative data should be interpreted. Not only does the sample base vary as items are dropped or added, but the context differs as well. To the extent that the protocol, as a type of survey instrument, has its own context effects, the quantitative data may be affected—even for items that, in themselves, remain the same. For example, at the very start of laboratory data collection, discussion of the advance letter, sample person letter and consent form occupied a major part of the interview. All of these items focus, in various ways, on the idea of anonymity. That is, as part of the focus interview they convey information about anonymity. And, as part of going through the NHSS survey questionnaire, we raise issues about anonymity.

Later in the data collection period, the advance letter, the sample person letter, and the consent form were dropped or given less time. As a consequence, the information they conveyed about anonymity was reduced as well. In this changed context, respondent reaction to issues of anonymity that come up as part of going through the questionnaire may be different later in the data collection period than earlier. Hence, analysis of an item, after some protocol modification, may not be comparable to prior analysis.

## 8 Suggestions for similar research

In planning future studies of this type, several points are worth consideration:

- ◆ Some of the things found are no different for IVDUs than for the general population. In the hypothetical and probing parts of the laboratory protocols, IVDUs need to be reminded that the interest is in how IVDUs might respond to aspects of the survey.
- ◆ Some pretesting is advisable, even when the study is small. For this laboratory study, pretesting would have likely shown the need to spend more time explaining the respondent task in focus interviews. The difficulty subjects have dealing with hypothetical situations may also have been determined. Pretesting would also reduce the need for later changes in the laboratory protocol.
- ◆ Great care must be taken to set tasks clearly. Maybe a video of such a laboratory interview being conducted could be developed and shown to respondents while they are waiting to begin. It would be necessary to use a generic presentation to avoid respondents parroting back what they see in the video. But a video might be a way to clarify a novel task that can easily be misunderstood.
- ◆ The sample size should allow for some "dud" sessions due to the respondent being either "high" or otherwise unable to perform the required tasks. Respondents should be screened immediately prior to the session—by someone used to working with drug users.
- ◆ The uniformity and non-directionality of probes need careful attention.
- ◆ Some thought should be given to possible context effects in the protocol itself, especially if changes in the laboratory protocol are anticipated during the data collection period. If resources permit, a control group, in which the protocol either does not change or changes one chronological step behind the experimental group, might be effective. Each time a change was made in the laboratory protocol, some cases can be done without the change for the sole purpose of looking for response variation due to the altered context. This might, however, require larger samples than usual for this type of research.
- ◆ When a large number of survey materials need to be tested, some consideration might be given to

randomizing various non-core materials across respondents. However, again, some attention to possible context effects is necessary.

In sum, then, we found that the use of laboratory methods and volunteer respondents can be a useful tool for investigation of both response effects— as many other researchers have shown (Royston et al. 1986; Royston 1989)— and also effective for investigating issues of participation decisions and other planned survey procedures. While this study focused on a single population domain, the methods would seem generally applicable to other groups.

It may be useful to note here that survey researchers have generally used methods borrowed from cognitive psychology in two ways. First, there has been research in which theories from cognitive psychology have been used in experimental designs to investigate the survey response process. Second, as in this project, the methods of cognitive psychology — especially the think aloud procedures — have been used in traditional survey settings as simply additional tools for improving a particular instrument or survey design. While the former approach is most likely to have a lasting impact on advancing survey research as a science, we think that the second use is also a valuable tool for practitioners to understand the thoughts and perceptions of potential respondents. However, it is important to note that in the latter case, the generalizability of the results may be severely limited.

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### **Figure 1: Laboratory Methods**

***Concurrent and retrospective think aloud***  
respondents are asked to describe out loud what they are thinking as they respond to each question

***Follow-up probing on each question***  
after each response, the interviewer discusses each question's meaning and clarity with the respondent

***Dimensional card sorts***  
respondents are given a set of index cards on which are written words from the questionnaire. they are asked to sort the cards into two groups

***Hypothetical reactions: respondent vs others***  
a survey procedure— such as an interviewer arriving at the respondent's household requesting survey participation— is described. the subject is asked how he [or others like himself] would react.