

**Summaries of Focus Groups and Key Informant Interviews
for the HIV Patient Satisfaction Questionnaire Development Project
(New York EMA Phase)**

Psych Research, Inc.
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In order to gather information directly from consumers and providers about developing an HIV patient satisfaction survey, Psych Research conducted 5 focus groups and 10 key informant interviews for the New York EMA Phase of the project. Two additional focus groups were conducted with consumers and providers in upstate New York (summaries of these groups will be included in a separate document).

Focus groups for the New York EMA Phase of the project were conducted with the following:

- Attendees at the HIVQUAL meeting (providers)
- HIV Clinical Scholars Program (providers)
- Narco Freedom (providers)
- Narco Freedom (consumers)
- PWA Advisory Group members (consumers)

Through these focus groups, we were able to gather information from a range of providers, including NPs, MDs, DMDs, RNs, PAs, case managers, substance use counselors, program administrators, and receptionists. Providers represented Designated AIDS Centers (DACs), Non-DAC hospital-based infectious disease clinics, free-standing community health centers, and free-standing drug treatment centers that offer HIV primary care.

Key informant interviews were conducted by telephone with 10 individuals who have expertise in various areas related to the development of the survey. Interviewees included the following (each interviewee agreed to allow his or her name to be used in this report):

- Susan Dooha, GMHC (consumer advocacy)
- Jeffrey Rothman, AIDS Institute (HIV primary care)
- Diane Rudnick, AIDS Institute (substance use treatment)
- Joseph Rukeyser, independent consultant (consumer education)
- Dan Tietz, AIDS Institute (consumer advocacy)
- Jay Freedman & Lisa Tackley, AIDS Institute (case management)
- Dr. Arthur Levin (consumer education)
- Jennifer Parr, AIDS Institute (consumer materials, reading level)
- Sallie Perryman, AIDS Institute (peer education)
- Dr. Cyndi Miller, Albany Medical College (HIV primary care)

Methodology

Focus groups were tape-recorded, and the tapes were used as the basis for creating the following summaries. Notes were taken during key informant interviews, and these notes served as the basis for creating the interview summaries.

Provider focus groups were organized with the assistance of the AIDS Institute or directly with the service agency. Key informant interviews were contacted directly by telephone. Focus group participants provided written consent prior to their participation, and consumer participants received a \$25 cash incentive. Key informant interviewees provided verbal consent prior to the interview.

Focus group and interview guides, consent forms, and other materials are attached to this summary report.

Summaries

Focus groups participants and key informants were asked to comment on content of the patient satisfaction questionnaire, questionnaire design and language, and questionnaire administration. The following summaries are organized in accordance with these categories. Much of the following summaries is made up of participants' suggestions for actual survey questions.

During analysis, information from key informant interviews and focus groups were organized by theme. While responses varied widely, they converged on several themes, which were used as part of the basis for designing the first draft of the survey. These themes were:

- Access to services and providers
- Waiting time
- Cleanliness and comfort of the facility
- Respect for the patient/patient's perception of discrimination
- Helpfulness of the staff and providers
- Quality of relationship and communication between provider and patient
- Quality of medical care (including thoroughness of assessment)
- Patient involvement/self-advocacy (including patient education)
- Coordination of care

With regard to design, two issues predominated. These were survey length (responses ranged from a half-page to 2 pages front and back) and the need for simple language.

Most respondents agreed that the survey should be administered while a patient is waiting to see the provider. Respondents differed on how to return the survey (by mail, placing in a box, directly to a staff person who would provide an incentive).

The focus groups and key informant interviews indicated that having specialty modules in the following areas would be useful:

- Substance use treatment
- Case management
- Mental health services
- OB/GYN services
- Medicaid managed care

Patient Satisfaction Questionnaire Development Project: Focus Group

Group: Clinical providers attending the HIVQUAL meeting at the
AIDS Institute – 5 Penn Plaza, New York, NY

Number of Participants: 5 (two P.A.'s and three M.D's)

Content

1. Are you currently using a patient satisfaction survey in your facility? What do you like about it? What would you change?

- One site uses two surveys – the AIDS Institute survey and one that is specific to drug treatment. The survey had to be re-designed because it was too long, and patients complained. Providers also complained that questions were redundant. The survey was reduced from 6 to 3 pages.
- One site used an electronic input system; patients entered data directly into a key-pad; but this occurred only once and has not been done on an ongoing basis.
- One site surveys patients regularly; patients have also complained about the length; they are provided with telephone cards as an incentive. The survey provides good information on trends, but questions tend to overlap and could be consolidated.
- Survey data is not always used effectively to improve services; having a CQI committee helps to ensure that data are used well.

2. What aspects of service provision should be covered in the questionnaire?

- Are patients' questions about medication and adherence being addressed?
- Does the patient feel comfortable asking the provider questions?
- Does the patient feel the provider has enough time for him or her?
- My provider takes the time to listen to my questions. My provider takes the time to discuss test results with me. My provider allows me to make suggestions about my own treatment. I feel comfortable discussing [intimate issues, my personal problems, sexual issues, reproductive options . . .] with my provider.
- Comfort level with all levels of staff should be asked about: reception staff, clinical staff, etc.
- Does the HIV-positive patient feel that he or she is being treated the same as other patients?
- Does the patient feel that his or her confidentiality is being protected?
- Does the patient feel comfortable with the non-HIV specific areas of the clinic or facility and how he or she gets treated in those areas?
- For methadone maintenance: is the speed of the dispensing line adequate?
- Is the patient aware of the range of services available to him or her?
- Facilities, waiting time, comfort level with staff, relationship with their provider, adequacy of health and treatment education for patient, cultural sensitivity.
- General questions about quality of health services and medical outcomes: How do you feel your health is after being treated here? Do you think your medical condition has improved as a result of being treated here? Have preventive and health maintenance

issues been addressed adequately? Have HIV prevention issues been discussed (negotiation with partners, prevention education)?

- Rather than asking, have your dental needs been addressed, ask: did your provider talk to you about going to the dentist.
- Provider availability.
- Courtesy of staff.
- Can you get people on the phone? Do staff call you back?
- Is it easy to make appointments?
- If you have a problem, can you get your needs met in a timely way?
- Perception of wait time is subjective: patients may tend to exaggerate; ask people to be specific about how long they had to wait, as well as how they felt about the wait time. Ask – time of arrival, time appointment started, time leave.
- Does your provider have your information available during your visit (charts, lab results, etc.)
- Cultural sensitivity.
- Immigrant sensitivity.
- Transgender sensitivity.
- Language competence.

3. Which services are most important to ask about?

- Support groups. Are patients aware of them?
- Nutritional services. The nutritionist understands the way I like to eat.
- Need to ask about non-medical services, such as treatment education by treatment educators. Patients may be satisfied with services in general, but this may be due to interactions with non-medical staff.
- Mental health. Have your mental health needs been addressed? Do you feel comfortable discussing your feelings/sadness with your provider (rather than saying “mental health,” which is too abstract.)
- Substance use services; drug treatment
- GYN
- Case management. For some sites, case management is provided through a totally separate unit, or even by other agencies.
- Many services are not offered by all sites. Ask: if your clinic offers this service, . . . then answer this question. If this service is not offered, would you like it to be offered?
- But it’s difficult, because patients are not always aware of the range of services offered at the site.

4. Should the survey include questions about whether medical standards of care are met?

- Maybe in a general way; for example, “do you receive good preventive care, i.e., pap smear, PPD?”
- Patients could get confused about whether certain procedures or treatments had been provided, or when they had been provided. “Patients tend to forget sometimes.”
- Patients may not know what procedures and treatments are appropriate and necessary.
- Patients may not know why certain procedures or treatments were not provided.

- “It would be very hard to assess providers’ compliance with medical standards by asking patients.”
- Patients at one facility are provided with a great deal of education about what procedures and treatments are supposed to be provided, and when; this information is provided in a booklet, which the patient is given, to log what takes place at his or her visits. “I rarely see this [booklet] again when they come for their visits.”

5. What types of issues that are specific to HIV should be asked about?

6. What special areas of service require a separate section of the survey?

7. How can patient’s suggestions for improvement be elicited?

- Hold focus groups.
- Open-ended questions. Comments section at the end of the survey.
- Suggestion boxes (more ongoing).
- If there was one thing you could change, what would it be?
- What services would you like that are not being offered? (Participants raised a concern that patients will express dissatisfaction about not getting popular treatments that providers may not think they should get – such as human growth hormone).

Design and Language

8. How long should the survey be?

- “Past half a page, you really have to have someone out there advocating for clients to be interested. Sometimes people may not have good reading skills.”
- No more than one page.
- No more than two pages.
- It depends on which group of patients and how comfortable they are with completing surveys.

9. How should the survey look?

- The survey should indicate that the AIDS Institute developed it, especially if the survey is required by the AIDS Institute. But saying “New York State Department of Health” may scare them because of the association with contact tracing.

10. How can the survey be worded to capture more subtle degrees of dissatisfaction or satisfaction?

- Patients often rate service as “good” or “very good” when response categories are provided, but are more likely to describe specific areas of dissatisfaction if given the opportunity to write-in their comments. Responses to open-ended questions can be categorized to show whether certain complaints recur. Having too many open-ended questions, however, may make it difficult to interpret results. These questions may also raise issues that the facility is not able to address.

Administering the Questionnaire

11. How should the survey be administered?

- It would help to have an interviewer to administer the survey. “The AIDS Institute should send somebody.”
- If there is no interviewer, patients should know that there is someone they can contact if they have questions about completing the survey. This person should not be a staff person.
- Have a bin at the front desk holding blank surveys with a sign asking people to complete it.
- This [the above suggestion] doesn’t work at our site. The most irate patients would pick up the form and complete it.
- Put the survey form on the front of the chart at the time of registration so the provider is sure to see it and give it to the patient. However, the provider should not administer the form.
- One site randomly selects patients to target with the survey. This helps minimize bias from certain types of patients self-selecting. This may work better at drug treatment sites, where patients may come more frequently.

12. When should the survey be administered?

- Mailing is not a good method. Many patients do not have a stable address.
- It may be more accurate to give the patient the survey before the visit, because it is a more accurate reflection of their experiences until this point. There may be a “Heisenberg” effect where staff behave differently if they know that the patient is evaluating them.

13. Will clients be resistant to completing the survey? If so, how can this be addressed?

- Incentives will help; but this may compromise anonymity. Patients will have to turn in their survey to a staff person to get the incentive from the staff person.
- Even small incentives help a lot. Incentives can include coffee and doughnuts.
- Some sites select a random sample of patients and follow up with them.
- Patient peer advocates are often good at getting other patients to complete surveys.

14. Will staff be resistant to promoting the survey? If so, how can this be addressed?

- Staff are busy so they are not likely to put a lot of effort into getting patients to complete the survey.

15. How should surveys be analyzed? Who should see the results?

- Results should be shared at staff meetings or committee meetings, which are multi-disciplinary, with those present who are able to remedy problems.
- Waiting times can be longer if the provider spends a lot of time with each patient. So, long waiting times can be balanced by a lot of provider attention. Some patients did not like this. Wait times are not necessarily directly comparable across sites.

Final Thoughts

- “Satisfaction is not necessarily driven by quality or performance. . . It’s really often driven by their relationships with their providers.”
- Go through current AIDS Institute survey to see what to keep and what to discard.

Patient Satisfaction Questionnaire Development Project: Focus Group

Group: HIV Clinical Scholars Program, AIDS Institute
Number of Participants: 10 in the room (2 entered after the content questions); 1 participated via teleconference

Content

1. Are you currently using a patient satisfaction survey in your facility? What do like about it? What would you change?

Most participants reported that no satisfaction survey is currently in use in their facilities. One participant's facility has one, but it has not been consistently used and she did not recall much about the tool. One participant recalled a survey used to assess women's health services that used all open-ended questions; the patients found this difficult to respond to.

2. What aspects of service provision should be covered in the questionnaire?

Responses fell into four categories:

Basic Clinic Operations

- Is the clinic easy to use? is it easy to make appointments and are the times for appointments convenient? is your chart there? Is your provider there? Do you feel comfortable with the care that you are getting?
- Do you know the name of your provider? do you get to see the same provider consistently? have you seen a single provider more than once?
- Have you ever been seen without a chart and has this affected the care that you have received?
- How much of a burden has it been to you to bring your medical data to the dentist at dental visits? Do you understand why the dentist needs the information?
- After clinic hours do you know how to get in touch with clinic staff? What is the availability of clinic staff other than when you come in for an appointment?
- Do you have to wait a long time what improvements can you suggest in these areas? are you happy with your care?

Provider Relations

- How do you connect with your provider? Is the provider empathetic and non-judgmental?
- How do the other staff members treat you, including front desk staff?
- Do you experience a language barrier? how much does this affect the services you receive?
- Are your questions answered? do you understand the information you receive?

Specialty Referrals

- Participants agreed that across the board there are problems with specialty referrals. "When patients have to go to other parts of the facility there is a lot of negativity. It would be important to find out how to eliminate this dissatisfaction."
- One participant suggested patients be asked about the communication between specialty services and the HIV clinic

Other Patient Needs

- What are the patients' non-clinical priorities or other needs, such as social services, housing?
- Do they have adequate food and shelter? Do they know how to stretch the benefits they have access to? Do they have childcare?

3. Which services are most important to ask about?

- Participants listed all the major clinical areas, including GYN and dental, and underscored the need to find out about mental health and social services

4. Should the survey include questions about whether medical standards of care are met?

- Absolutely. All participants agreed that it was important to ask these types of questions. “Responses would tell us how well patients are getting educated about what type of care they should be receiving.”

5. What types of issues that are specific to HIV should be asked about?

- Partner notification
- Treatment adherence which is more important in HIV than in other areas
- Sexual health; whether people have resources to explore their sexuality and how that part of their lives can be sustained with an illness intimately involved in sexuality
- Understanding of the importance of the treatment regimen and their understanding of the adverse effects of the medication regimen
- Asses whether and how patients are actually getting educated about the entire process of HIV from what it is, how it is transmitted, to the treatment plan
- Do patients know about their reproductive options?
- Do patients know about co-infections?

6. What special areas of service require a separate section of the survey?

- Mental health
- Ophthalmology
- Ask about their participation in studies or clinical trials and whether they felt that they were offered the option. Another participant offered cautions about this area: “this has to be worded well because not all patients qualify for trails so not everyone can be given the option.”
- Ask about the experience of those who have been in Corrections how they have experienced re-integration into society

7. How can patient’s suggestions for improvement be elicited?

- Ask what new services they think might be beneficial
- Offer a list of 10-12 items (either service enhancements or new services) and ask them to rate the 3 most important items
- Ask patients to respond to very concrete ideas but also offer the option to write in their own ideas

- Ask questions about what services the patients actually used; did they use what the provider referred them to? did they think they needed those services?
- Ask patients about missed appointments; try to find out how much they think it is their or the clinic's responsibility; do you keep all of your appointments? If you have missed an appointment, have you been able to re-schedule easily? Does the clinic contact you? Should they or should you contact them? Why have you missed appointments? Child care issues, transportation issues?
- One participant suggested that we ask patients how cutbacks have concretely affected their lives and whether they believe that their diagnosis of HIV stigmatizes them, and if they were entitled to more or different benefits than people with other diseases. The purpose of these questions would be to try and assess where the patient is coming from regarding their sense of needs and what is available to meet those needs.

Design and Language

8. How long should the survey be?

Participants agreed that the survey should be short: “no more than 5 minutes” and “one page on two sides; if there are numerous pages patients get overwhelmed very quickly; if you can't say it on one page you are not saying it.”

9. How should the survey look?

- Check off instead of write in; this may be biased because designer will determine what the boxes say
- Use agree, disagree, not sure
- Bold face some questions and use different fonts to get people to focus in on the most critical issues
- For sicker populations, use large print

10. How can the survey be worded to ensure that patients understand the questions?

- The language should be straightforward without lots of complicated reasoning

11. Will patients reveal their dissatisfaction?

The participants agreed that the patients would be happy to express their dissatisfaction as long as they were not required to be specific about it. One participant offer the following suggested language to depersonalize the request for suggestions:

“We know that we need to improve. Even though you might be satisfied, what would you suggest or what have you heard from other people that might be worth trying? If you could change one thing about this place, what would help other people most.”

12. How can the survey be worded to capture more subtle degrees of dissatisfaction or satisfaction?

- Use a scale with 4 choices
- Offer the opportunity for those who are literate to write in their comments
- Focus on four or five areas to try and get subtle distinctions otherwise it will be too long

Administering the Questionnaire

13. How should the survey be administered?

Overall the participants felt that the questionnaire should be administered with an interviewer, despite the risk of bias. “Lots of or patients can’t read or they have short attention spans. This necessitates that someone is there doing it with them or at least available to clarify.” One participant suggested that the person administering it should not be affiliated with the clinic.

14. When should the survey be administered?

- There was a mix of opinions about whether to ask patients to fill out the survey on the way in or after their appointment. One participant said: “survey some people while waiting for an appointment and some after and see if anything differs.”
- There was also debate about whether to ask them to fill out the questionnaire on the day of the visit or on a day when they have not been at the clinic to get their sense of satisfaction over a period of time. There was discussion about the difficulty of reaching people by phone or mail. One participant suggested inviting patients to a pizza luncheon to do the questionnaire as a group; this would not work in upstate or suburban areas given transportation issues however.

15. Will clients be resistant to completing the survey? If so, how can this be addressed?

Participants felt that patients would not be resistant to filling out the survey if they are all asked to do it. They agreed that patients would not do it if it were left up to them without being asked.

16. Will some clients be more likely to complete it than others will?

- Yes. “This is a well-surveyed population. Some people will not want to do another survey, others will say sure.”

17. Will staff be resistant to promoting the survey? If so, how can this be addressed?

Participants overwhelming felt that staff would be resistant to promoting the survey. They offered the following suggestions:

- If staff could be convinced that the results of the survey would be used to allocate resources to improve things, you might be able to get staff on board. Otherwise staff will think that it will be used to find things that are wrong and it will be used to be punitive and not to improve things.
- If staff were given time to administer it rather than having to do it on top of everything else it would help.
- Offer staff basic education on CQI so that they understand why it is being done. Staff need to be shown how it may result in a benefit to them, whether they are a provider, front desk staff or a phlebotomist.

18. How should survey be collected?

- Definitely not handing it to the provider
- A box, especially one where patients can see that there are many surveys in the box
- The case managers would be a good person to give it to

19. How should surveys be analyzed? Who should see the results?

- Program Directors who would then share it with the rest of the staff and the patients
- The analysis should be done with statistical rigor but what is provided to the patients should be meaningful and understandable
- It should be available to the patients only if they are interested in seeing the results; this data is likely to result in ideas for making program improvements which is most interesting to clinic staff, not patients
- One participant shared a past experience when the Director of her clinic read the individual patient's surveys to the staff; the survey had not been administered regularly and primarily reflected patient complaints; it was very demoralizing because it was not presented in terms of gross numbers and instead focused on individual patient complaints; she emphasized that it is critical to be sensitive to how survey information is shared with staff
- Staff need to understand the rationale that is used to respond to issues raised in the survey

Final Thoughts

- Do you want to evaluate satisfaction on the day of the visit or satisfaction overall?
- Ask people to say both what they were most satisfied with and what they were most dissatisfied with.

Patient Satisfaction Questionnaire Development Project: Focus Group

Group: Narco Freedom (Providers)
Number of Participants: 7

Content

- 1. Are you currently using a patient satisfaction survey in your facility? What do like about it? What would you change?**
 - Yes, the AIDS Institute questionnaire.
 - It's very lengthy. It's about 5 pages. It takes about 10 to 15 minutes. That is too long. Too long according to the patients.
- 2. What aspects of service provision should be covered in the questionnaire?**
 - How do they feel about the clinic? Do they like it? Do they enjoy coming here?
 - Do they prefer a male or female provider?
 - Would they like additional services to be provided on site as opposed to being referred elsewhere? I've been asked many times if we have dental services.
 - How do you feel about the facility: cleanliness; security; accessibility to restrooms; changing tables for babies; conditions of the bathrooms?
 - What do you hate about the facility?
 - Are your concerns appropriately answered?
- 3. Which services are most important to ask about?**
 - Patient education. Are they being educated about their medication?
 - Are their needs being met?
 - Do they feel that the staff gives them the time they need, and not being rushed out?
 - Is staff courteous to them?
 - Is their confidentiality being maintained?
- 4. Should the survey include questions about whether medical standards of care are met?**
 - "No. It would be great to know but I don't think the patients know what the medical standards are. [physician's comment]"
 - "I think that the patients would know if they are getting good care or not. They would know if they are getting short-changed or not."
 - "Some of them do know. Some are well educated and they understand their treatment modality, but then there is the non-compliant population...you could teach and teach and they don't absorb."
 - "The majority of patients are not aware..."Hey, whatever you want to write for me, Doc, go ahead."
- 5. What types of issues that are specific to HIV should be asked about?**
 - Adherence. "Ask them in what ways we can help to make the treatment regimen more simple, easier to follow to improve adherence."

- Follow-up appointments because the HIV population needs to be followed more closely. “Do they know that they are expected to do more frequent doctor’s visits?” Every three or two months.
- Ask questions on domestic violence. It’s not unique to HIV but it’s important. Right now we have a questionnaire on domestic violence. Ask if they are experiencing mental or physical violence as this can affect adherence.
- Depending on the stage of the disease we would ask about guardianship, if they have made arrangements for their kids.
- Do they have a health proxy form and living will completed?

6. What special areas of service require a separate section of the survey?

- It depends on the population. For our patients those areas [harm reduction, comprehensive case management, mental health services] would be useful because we are in an area where there is a lot of IV drug use. In Brooklyn it might be totally different. The right issues here would be harm reduction, screening for depression as well.
- Do they understand their patient’s rights?
- Do they feel depressed? Does the provider talk about and screen for depression?
- Questions around drug use. How often do they do it? Are they still sharing needles? Are they following risk reduction practices?
- When they are under the influence do they ever think about harming their children or themselves?

7. How can patient’s suggestions for improvement be elicited?

- That is clear enough, as long as they don't have to write anything down. The highest-grade level of our patients is 9th and that means that they are at a 5th grade level.
- A check off list. That means they have to read
- Someone needs to help them

Design and Language

8. How long should the survey be?

- Very short. As short as possible. Clients are already bogged down with lots of questions. It has to be very short.
- 5 minutes. 1 page.
- A tricky way of doing it. Maybe 10 questions but within each question you have other questions. So from one question you can cover more things.
- The eye effect has a lot to do with it. If they see a lot of pages. They won’t want to do it.

9. How should the survey look?

- Big letters

10. How can the survey be worded to ensure that patients understand the questions?

- Third grade level if they are going to do it and someone is not going to help them.

11. Will patients reveal their dissatisfaction?

- Yes. Our patients are very quick to say they are not satisfied.

12. How can the survey be worded to capture more subtle degrees of dissatisfaction or satisfaction?

- Right now the new AIDS Institute survey has a scale. It's too much, too many choices. I think satisfied, dissatisfied...maybe just 4 choices.
- There is a certain bias when you use scales...I tend to check the same grade for all items. I just want to finish. Or if I'm just pissed off its bad all the way down.
- If someone is helping the patient fill out the survey you can have blank lines and scales. Maybe inter-mix scale questions and questions with blanks so that people will really have to read each question.

Administering the Questionnaire

13. How should the survey be administered?

- "By interviewing. I just received a client survey and some questions were left blank that required the patient to elaborate. It was left blank and she told me 'well you write whatever you want. You write it for me'."
- "I came across the same thing. We give it to the patients and are there to help them. Sometimes when they leave it blank I ask them "are you sure?" Then they'll say this and this and that and I'll write it down."

14. When should the survey be administered?

- Not by mail, you'll never get it.
- Before the appointment. After they just want to get out of here.
- While they are waiting.

15. Will clients be resistant to completing the survey? If so, how can this be addressed?

- Some might. I think a small percentage. Some can't read or write and wont volunteer that to you.
- We write it for them... interview them.
- And tell them that they can be truthful and that it won't be held against them.
- The first thing we tell them is that we don't need to know their name, that no one is going to get in trouble, that its just to make services better.

16. Will some clients be more likely to complete it than others will?

- Yes. The ones who tend to be better, the ones who are working and going to school will be more likely to finish the survey. They are the ones doing better who we see once every 3 months and they are doing great and there are no complaints and no issues. That's only 10% of our patients. What about the bulk of the patients who have problems, who are not working, who have children problems, housing issues, homelessness?
- We have the patients who are just not happy period and they don't want to be bothered and it will be skewed because we won't have their opinion.

- Offer counseling. Hold groups with other patients. Then we have confidentiality issues.
- It would be best done by the case manager, nurse or the providers because we see all the patients and say that they have to do it. Rather than putting the survey out in the waiting room because not everyone is going to pick it up. As long as every patient has an equal chance of doing the survey.
- I wouldn't pose it as a requirement. I would try to convince them: "Your opinion is important to us and we really would appreciate it if you would do it"...try to convince them.
- I say look, this is for the people that fund us so that we can be able to take care of you, and they want to know how you feel about it.

17. Will staff be resistant to promoting the survey? If so, how can this be addressed?

- If we tell them we expect something to be done, if they know it will benefit the patients and the facility, it will be done.

18. How should the survey be collected?

- Put in a box.
- If we use an interviewer, give it back to the interviewer.
- Someone would have to be monitoring the box.

19. How should surveys be analyzed? Who should see the results?

- The provider sites should get the results specific to us.
- AIDS Institute should analyze it and share the results.
- To get a true sample you want to be sure that every site submits all results, not just the good ones.
- All sites should see what works at the other sites...analyzed individually by site and shared with all the sites.
- If there is something we have been doing that is negative we need to know that.
- I see it as a lock box (tamper proof) that the Institute only has access to, that way no one knows at the site what the results are.
- Right now I am entering the results in a computer system. After we interview the patient we enter it in the computer. Not good...too many chances of error.
- The patients should get the results. Post it. Mail it to the patients. No. Give it to them at the visit.
- At this site there are non-HIV patients, so you don't want to post it. It is better if the provider gives it to them at the visit.

Final Thoughts

- None.

Patient Satisfaction Questionnaire Development Project: Focus Group

Group: Narco Freedom – Consumers 324 E 149th Street
Number of Participants: 6

Content

- 1. Are you currently using a patient satisfaction survey in your facility? What do like about it? What would you change?**
 - Everyone remembers filling out surveys at other sites, but none being filled out at the current site.
 - Past surveys were remembered for being short, and generally enjoyable.
- 2. What aspects of service provision should be covered in the questionnaire?**
 - Confidentiality. Everyone has their limits.
 - Attitude. Clients look for a positive attitude from the staff. Negative attitudes from the staff can be very hurtful. Attitudes about the client, or about HIV disease in general. The staff can be homophobic as well, and this reduces clients' willingness to come back.
 - “Do you feel that the person who took care of you was ignorant or naive?”
 - Separate “staff” from “doctors and nurses and counselors”.
- 3. Which services are most important to ask about?**
 - Section for adding services to a site... services that you would like to have at the site.
 - Referrals are generally satisfactory, but clients talk to and depend on each other for recommendations about the best referrals. The staff often follows up with clients about their satisfaction with a referral.
 - Interest in social services, social activities, recreation, parties, dances, retreats, exercise class, gym, etc. There is a lot of free time since many clients do not work. Lots of these things are available “in the city” but not in the Bronx.
 - Transportation. Not all clients get access to transportation for referrals, and not all referrals get transportation. This makes it impossible to get to some referrals.
- 4. What types of issues that are specific to HIV should be asked about?**
 - “Were you treated differently because of your HIV/AIDS status?” Most participants have stories to tell about discrimination occurring to them during medical, dental, and nursing care.
 - Confidentiality should be asked about, although no one had problems with staff maintaining confidentiality.
 - “Do you feel that you have been discriminated against in any way?”
 - Doctors should know about medication before the clients, but clients too often tell doctors about a medication.
 - “Would you like to see more HIV+ staff working here?” Only one site in the City has HIV+ staff, and it makes the clients feel very empowered.

Design and Language

5. How long should the survey be?

- 2 pages is good, front back of two pages. If you keep it interesting, then it could be longer.
- Each time you change doctors or services that there should be a new survey.

6. How should the survey look?

- The print has to be big enough to read.

7. Will patients reveal their dissatisfaction?

- Might depend on who collects the survey.

Administering the Questionnaire

8. How should the survey be administered?

- For illiterate clients, a peer should be asked to help them fill out the survey. Going to a staff person for help in filling out the survey would be embarrassing. The staff might look at you differently. Although there are understanding staff members who would keep it secret (the illiteracy).
- Other clients will go directly to a trusty staff person.

9. When should the survey be administered?

- Can't do the survey after the appointment, must be before, while waiting.

10. Will some clients be more likely to complete it than others will?

- Illiterate clients probably won't ever fill out the survey.

11. Will staff be resistant to promoting the survey? If so, how can this be addressed?

- Staff will not forget to give out the survey. Just pick out a time during the year (first month) when everyone has to fill out the survey.
- The staff could keep a list of clients, and check them off as they turn in the survey.

12. How should survey be collected?

- Even if there is no name on the survey, the staff will know who filled out the survey.
- There should be a box that only the state can open.
- Put the box in a trusted staff person's office.
- Will not want to give the survey to a secretary or staff person.
- Could mail the survey to some people's houses, but not everyone has a house.
- Could put the survey in a stamped addressed envelope to Albany.

13. How should surveys be analyzed? Who should see the results?

- Put the results out in a magazine.
- POZ... "Results of the NY Patient Satisfaction Survey". (Spanish and English).

- Q&A magazine.
- Body Positive (Spanish and English).
- Blade.
- Clients want to see their site against other sites and boroughs.

Patient Satisfaction Questionnaire Development Project: Focus Group

Group: PWA Advisory Group Members
Number of Participants: 5

Content

1. Are you currently using a patient satisfaction survey in your facility? What do like about it? What would you change?

- I thought they were too long...some were 8,9, 10 questions. I think it's too long. If you are sitting there and have things on your mind about your health...I spent about 5 or 10 minutes. And that was too long.
- It has a lot to do with subject matter. If the subject is entertaining as well then I find it a lot easier to fill out. I have been involved in developing questionnaires. What we do is we make some of the questions very relevant, some are sort of campy as well and as a result it engages people. I find those questionnaires really interesting. I filled out a questionnaire about going to Hawaii because I was interested in that. In the process I shared a lot of information.
- Surveys are too lengthy. Sometimes they cover things that do not relate to what you are experiencing and that throws you off. If its not relevant to the surroundings...the questions should pertain to where you are...people are dealing with their surroundings.
- I was involved with a provider survey. They wanted feedback from consumers. They had to change it and make to very specific for consumers. It needs to be really specific.
- I would say the same thing. They almost never apply to me down the line. I always have to pick out things. I know you have to cover all bases, but I don't cover all bases.

2. What aspects of service provision should be covered in the questionnaire?

- Will this be confidential? Yes. There are ways of finding out who answers what. For instance, if they ask you how old I am, where I live, they can find out who I am.
- Doctor patient relationship. You have doctors who want to force you on medications because of their contract. What is your doctor-patient relationship? How comfortable are you with your doctor? What would you like to see more of? For me its communication.
- How much time do you spend with your doctor? If you only have 3 minutes, that's not satisfactory.
- Waiting time. How much do you spend actually waiting?
- Cleanliness of the place. Ask about the sanitary conditions.
- Infrastructure. Is the place comfortable, clean? Is there a water cooler available in the clinic waiting area?
- Are you seeing the same doctor at each visit? [This participant described an experience of seeing multiple providers at St. Luke's and not being able to ask follow-up questions from the first visit, because a new doctor was assigned.]
- The receptionist. The way people talk to you and the way they treat you. They sometimes lack compassion. They need to have more sensitivity, counseling, and

diversity training if you want quality care. The overall atmosphere and how people treat you.

- The relationship between the social work department and the medical department. Whether there is good communication between the social worker and the medical staff. Sometimes you have to say something to one and then you don't want to repeat it to someone else again. And is the social work staff qualified to provide the services to people who have the virus.
- Does the doctor say to the patient when he comes in." If you have any questions the next time you come in, make a note of them before hand."

3. Which services are most important to ask about?

- We were talking before we started about mental health. I really think that should be incorporated and made much more paramount in the care for PWAs. I think something on this should be incorporated. Something geared to assessing how patients are dealing with the disease. "How is your anger level?"
- I think mental health should be a part of his. Would you like to see a mental health person as part of this team? If there were a mental health person, would you avail yourself of this service? If so, why? So the consumer could explain what they are going through. [Another participant interjected that it is important to keep the survey simple and by asking consumers to describe what they are going through may put people off. A back and forth ensued about how to make the questionnaire accessible (check-off, scales, etc.) One perspective was that open-ended questions might make people anxious. The response was that you cannot assume what people with disabilities can or cannot do, hence the use of check-off.]
- Emergency services are extremely important. How attentive is the clinic in providing services to people during off-hours? If you don't have the right contact person you will end up in the ER.
- Dental care. Is oral hygiene something that is emphasized as part of your overall treatment here?
- Substance abuse services. Is there a referral to substance abuse services? Phrase it in such a way that it doesn't offend anybody. Would you like it to be provided here or somewhere else? Have you ever used any of the following substances? Do you need assistance in dealing with any of these problems?
- Clarity of prescriptions is extremely important. How to take the pills. Sometimes the doctors don't really tell you. If it's a Spanish speaking person and the prescription says once a day that means 11! [We had a good joke here.]
- Look at the quality of life. Sometimes we are giving all these services and patients are homeless and they really aren't able to receive them. Ask if they are homeless. Do you have access to a refrigerator? Do you have a watch, given all these time sensitive medications? This makes your survey more proactive. You can actually get profiles of how certain individuals with certain qualities of life may view the same question. [Excellent idea! Marta's editorial comment! I told you this group was savvy.]

4. Should the survey include questions about whether medical standards of care are met?

- I think so. You want to ask consumers those questions. Is the medical care here up to your standards? Are you having any problems? Are they referring you to the right places?
- Yes. Definitely ask a couple of questions about standards. Keep it to 3 or 4 questions.
- Ask about medications, are they prescribed correctly. We want to know if phenotype/genotype testing is available. We also want to see if our viral load and C-4 counts are taken. Keep it simple and specific.

5. What types of issues that are specific to HIV should be asked about?

- There won't be one issue that is overall important to everybody.
- Mental health
- Sex. I just did a workshop on STDs and re-infections and I noticed great depression among the men...they felt really depressed about sex and living with the virus. Ask about how they are dealing with it.
- You mentioned the possibility of partner notification...I think this should be in the questionnaire. A lot of people still don't know what this is all about. [Participant explained that as an outreach worker he loses lots of people who don't want to disclose their name to SDOH or share the names of their partners.] "If you come into a clinic and that is not being asked then it stops a lot of service from getting to those who really need it." [Another participant responded that this is difficult to do. If the survey will be used in clinics with HIV+ persons and you have not revealed your partners...you are "sitting there with your secrets" you are not going to tell the survey the truth. How do we ask this information in a way that helps people psychologically, emotionally? Someone else clarified that there are circumstances under which disclosure is still voluntary.
- Does the clinic offer support groups?

6. What time frame should the survey cover?

- Is this a one-time survey or will you do it several times?
- If you are new to the clinic, you shouldn't be asked to fill out the survey.
- Ask patients how long they have been at the clinic and if services have improved since they started.
- That's tricky. It may not apply to everyone. Need a different form for new patients.
- Ask patients to comment on the entire time that they have been coming to the clinic.

7. How can patient's suggestions for improvement be elicited?

- Too open-ended. (your probes)
- Based upon the above survey, is there an area that disturbs you about our services?
- Has anyone from the hospital staff ever asked for your input? Your input in decisions about your care or how the clinic is run?
- We feel that the providers don't listen to us.

Design and Language

8. How long should the survey be?

- 1 page..no more than one... just front.

- Five minutes.
- You are asking a lot of questions...how are you going to do that?
- Front and back.7 minutes
- It depends...2 pages, front and back, 10 minutes
- Front and back, and it all depends how the questions are designed. If it is multiple choice that is a lot easier to answer. People don't have to do a lot of writing. 10 minutes max.
- No more than 30 questions, multiple choice. They need to be really focused. Succinct. Are you going to get what you are looking for?

9. What happens if the survey is too long?

- Bored, start fudging, checking anything off. Someone said they don't even turn it in.
- Once people pick up the survey and they look at the back that might deter them from doing it.
- If I look at the survey and it has questions about things that I think are important; I will do it and take my time doing it. Because it is interesting because this is what I want to see at my clinic...this is the input that I want to give, these are the changes that I want to see here.
- Some people don't really mind doing a page because it goes along with the territory.
- It depends on who is facilitating the survey. If you do it with someone who talks to them with a pleasant voice, and gives them an incentive, I will fill it out.

10. How should the survey look?

- Graphics are great
- A picture, image, logo, some design element.
- I like color, little pictures, little symbols. Each question and each box with colors
- Have as many check-off boxes as possible and keep the writing to a minimum

11. How can the survey be worded to ensure that patients understand the questions?

- Simple, to the point, no big words where I have to break down the syllables

12. Will patients reveal their dissatisfaction?

- Yes.
- They'll be happy that somebody asked them.

13. How can the survey be worded to capture more subtle degrees of dissatisfaction or satisfaction?

- "Sometimes, always or never ...when I come in this is done sometimes, always or never"
- 1,2,3.or 1 to 5. No I wouldn't do it with ratings. Keep it really simple.
- "Good, bad, terrible."
- It depends on how deep you want to go. You're going to be surface here. If you want more you need to follow-up with an interview.
- Needs improvement, satisfactory.

Administering the Questionnaire

14. How should the survey be administered?

- It's too expensive to have someone interview you. My preference would be for someone to interview me and give me a T-shirt, and incentive.
- You can reach more of an audience if you ask people to fill it out themselves.
- Majority prefers to do it themselves.

15. When should the survey be administered?

- If you are given the survey when you come in and your chart has already been pulled and you are getting called for your blood work you will stop doing the survey. The clinics will need to allow for some time to allow the patients to fill it out.
- Do it after the visit
- If it's after, most people will run out.
- People do sit and wait for their appointment...they will have time then. At the end people really want to leave.
- Give it to people when they come in and ask them to drop it off with the person who gives them their Metro Card.
- Majority prefers before the visit.

16. Will clients be resistant to completing the survey? If so, how can this be addressed?

- Yes. If it takes too much of my time. I also need to see that I will get some benefit from this.

17. Will some clients be more likely to complete it than others will?

- People who are sick will not fill it out
- The ones who will fill it out are the ones who are most satisfied; they are the most cooperative. The ones who are not giving you the survey back are the ones with the biggest issues. You are skewing the results to a positive group.... I think the way you deal with that is you interview. If someone is there to listen to my complaints and I feel they are interested enough I will participate.
- It also depends on the importance attached to the survey. If the individuals come in and part of their intake is the survey...in the waiting room you say there is a statewide survey that is very important...they will do it.
- Need to have a person who tells them what the survey is all about and how it is important.
- This discussion ended up in a suggestion to have peers present the survey to patients and offer them assistance in filling it out. Pay peers stipends. Someone the patients can identify with. They will give more feedback this way.

18. How should survey be collected?

- Give it to the person who is giving out the Metro Cards...very good idea.
- If you really want it from me you'll have a person take it. I won't necessarily leave it in a box.

19. How should surveys be analyzed? Who should see the results?

- The consumers should see the results. Providers always get the result, we don't. I never see any outcomes after I fill things out.
- How public will this be? We want to get it but they don't always want us to get it.
- In a report...lots of charts...simple, readable book in Spanish and English
- What is the purpose of the survey? Is it to put some pressure to affect changes? Or is it to get an overall picture of things? If it is designed to affect change then you need to develop a report card of the different clinics.
- It also has to be available quickly. Faster than 2 years! Within a month I would like, but that is not doable.

Final Thoughts

- Simple, colorful, easy to read
- Have the results come back to the consumers and a report showing the changes that have been made as a result of the survey
- What do you feel is the most important issue facing you?
- User friendly, professional presentation
- Simple and specific

Patient Satisfaction Questionnaire Development Project: Key Informant Interview

Name of Key Informant: Susan Dooha
Agency Affiliation: GMHC
Telephone: 212-367-1228

Content

1. What aspects of service provision should be covered in the questionnaire?

- Primary care, case management, mental health services, drug and alcohol services prescription drugs (how hard/easy is it to get ADAP?)
- Ask about the timelines and convenience of appointments; can you get appointments quickly?
- How hard/easy is it to get someone on the phone?
- Does the provider give you enough time to let you ask questions and get clear explanations?
- Is your practitioner aware of your values and preferences?
- Do practitioners come from a client-centered place; are they finding out why the patient is coming in? do they ask about side effects?
- What involvement does you provider give you in decisions about your treatment?

2. Should the survey include questions about whether medical standards of care are met?

- Yes. Compare the results of the survey to data and see how accurate their perceptions are.
- Is your provider knowledgeable?
- Have you been given effective information about treatment options and side effects?
- Do you have an understanding about ____ (to assess quality of treatment)
- Does the practitioner understand what I expect?

3. What types of issues that are specific to HIV should be asked about?

- I would go at it a different way. Instead, I would ask if the complex issues beyond medical treatment are being asked about and addressed.

4. What special areas of service require a separate section of the survey?

- Case Management, mental health and drug and alcohol services
- Are people able to access these services?
- Are they given time to deal with these issues?
- Do they feel involved in decision-making about these issues?
- Is there adequate follow-up? Is engagement with these services consistent or episodic?

5. How can patient's suggestions for improvement be elicited?

- Frame questions in terms of things they are interested in. People will pay attention when it is relevant to them. Link questions to something they care about or to information that they commonly seek.
- Say something very explicit like: Answering this question will make things easier for you

Design and Language

6. How long should the survey be?

- Brief

7. How should the survey look?

- Very graphic; give visual clues and brief instructions

8. How can the survey be worded to ensure that patients understand the questions?

- Very simple; 4th grade level; small number of questions in each section
- Need to make it accessible to people with limited attention spans

9. Will patients reveal their dissatisfaction?

- Depends on who does the interview and where; trust is the key
- The interviewer must have credibility with the community and have an understanding of the issues of the community; it should not be someone from the government
- It may be problematic to have it administered by staff from the program

10. How can the survey be worded to capture more subtle degrees of dissatisfaction or satisfaction?

- Ask sub-questions; ask a bunch of questions about one service; take apart the service bundle: can you get your doctor on the phone? Does the doctor know what you are coming in for? Does the doctor leave enough time in the visit for you to ask questions?

Administering the Questionnaire

11. How should the survey be administered?

- Focus group; interviews

12. When should the survey be administered?

- In the waiting room

13. Will clients be resistant to completing the survey? If so, how can this be addressed?

- If they think it does not matter to them or if it will take too much time or they do not know what to do with it

14. Will some clients be more likely to complete it than others will?

- People with multiple issues, with care giving responsibilities (women) and people who are homeless will be less likely to complete it.

15. How should survey be collected?

- Give it back to the interviewer immediately

16. How should surveys be analyzed? Who should see the results?

- It should be reported by facility
- Results should be linked to things that are familiar to clients and to information that consumers know how to use
- Providers and consumers should get the results
- The results should be visual and graphically pleasing, presented in simple sections, use overview sentences, explain what it is and how to use it in simple steps.

Patient Satisfaction Questionnaire Development Project: Key Informant Interview

Name of Key Informant: Jeffrey Rothman
Agency Affiliation: AI
Telephone: 518-486-6806

Content

- 1. What aspects of service provision should be covered in the questionnaire?**
 - All aspects of HIV primary care
 - Is care respectfully delivered?
 - Ask about waiting time; staff responsiveness; referrals
 - Are their physical ailments addressed professionally and effectively?
 - Are they educated about their own ailments and what they need?
 - Other ancillary services should be asked about: case management, counseling and testing and support services

- 2. Should the survey include questions about whether medical standards of care are met?**
 - Mostly consumers wont know about formal medical standards of care
 - Ask them to compare what they get at this site to other experiences they have had
 - Did this provider treat you capably compared to others?

- 3. What types of issues that are specific to HIV should be asked about?**
 - The medication piece is a problem that can be complicated and should be asked about
 - Partner notification: ask them if they are given enough support, education and reminders on working with their partners
 - Are they educated about their condition and about ways to stay as health as possible?
 - Do they understand symptoms associated with HIV?

- 4. What special areas of service require a separate section of the survey?**
 - Ask about the availability of harm reduction services. Are they offered education about where to get clean needles (this will only apply to some programs)
 - Is behavior modification counseling being offered?
 - Are they getting education and counseling about avoiding Hep C? Do they know their Hep C status? Has this been discussed with them? If they have Hep C have they been appraised of treatment options?

Design and Language

- 5. How long should the survey be?**
 - Not to exceed 12 minutes (their current survey is like this and is working well; 12 minutes is based on empirical data)

6. **How should the survey look?**
 - 12 font or larger
7. **How can the survey be worded to ensure that patients understand the questions?**
 - Simple; grade school
8. **Will patients reveal their dissatisfaction?**
 - General dissatisfaction, no.
9. **How can the survey be worded to capture more subtle degrees of dissatisfaction or satisfaction?**
 - If worded in terms of specific events: “The last time that you were here, how long did you wait?” Ask them to then respond to that experience. Encourage the client to focus.

Administering the Questionnaire

10. **How should the survey be administered?**
 - Self-administered. Where necessary use an interview
11. **When should the survey be administered?**
 - As they come in; ask them to complete it before they leave. This helps to get more immediate impressions
12. **Will clients be resistant to completing the survey? If so, how can this be addressed?**
 - We get good responses for the most part
13. **Will some clients be more likely to complete it than others will?**
 - Don't have direct experience to allow me to comment
14. **Will staff be resistant to promoting the survey? If so, how can this be addressed?**
 - No. They have experience with this.
15. **How should survey be collected?**
 - In a box or mailed in
16. **How should surveys be analyzed? Who should see the results?**
 - By AI; every question individually and by program; similar programs should be compared and trended over time.
 - The results should be given to the Office of Medical Director, the Bureaus responsible for the contracts and to providers in a responsive timeframe (within a couple of months of getting all the surveys back)
 - It is not a problem to share the results with consumers as long as you tell the programs that you plan to do so from the very beginning

Final Thoughts

- It is a lot of work to get the providers to implement the survey
- You need to carefully and repeatedly educate providers about why you are doing this, and what the implications will be for their funding. Need to tell them up-front how it will be released and who'll see it.

Patient Satisfaction Questionnaire Development Project: Key Informant Interview

Name of Key Informant: Diane Rudnick
Agency Affiliation: AI
Telephone: 518-268-6111

Content

- 1. What aspects of service provision should be covered in the questionnaire?**
 - Are the hours convenient? Is the program accessible? Are your childcare needs met? Are the days of appointments convenient?
 - Cultural competence
 - Gender sensitivity
- 2. Which services are most important to ask about?**
 - Patient education: do you feel your medical condition and medication regimens have been explained to you clearly?
- 3. Should the survey include questions about whether medical standards of care are met?**
 - Yes, patients can comment on whether treatments are working. It is patronizing to think that they can't.
 - How have you responded to your treatment? Any side effects? Have you experienced any changes in your overall health as a result of what you are taking?
 - Do you feel that the provider is clear in explaining how the medications are supposed to work? Are they available to listen to your questions?
- 4. What types of issues that are specific to HIV should be asked about?**
 - Disclosure to family members; impact on children
 - How the medications work; "lipo-distrohpy;" things that affect the quality of life: "If you take this medication it may have this effect on your physical appearance. Does this influence your decisions about taking the medications? How does it feel?"
- 5. What special areas of service require a separate section of the survey?**
 - Substance use: this is the common denominator to all people with HIV
 - Need to frame the questions so that you do not imply that they should stop using
 - If you are using, how is it affecting your HIV treatment and overall health?
 - Have you been educated on how to reduce the impact of substance use on HIV and Hep C?
 - What are you doing to address Hep C? Any changes in your lifestyle? Are you still drinking? If so, have you thought about changing your habits?
 - Did you feel it was necessary to stop taking drugs to be taken seriously by your provider? Questions should be along this line. We need to see whether providers still hold the view

that if the person does not stop using, they [the provider] are not responsible for the effectiveness of the prescribed treatment regimen.

- Did your provider discuss the interactions between illicit drugs and the medications?

6. How can patient's suggestions for improvement be elicited?

- Be straightforward. If you could change how you are getting your care, what would you do? How would you make it better?

Design and Language

7. How long should the survey be?

- 15-20 min; half hour max.; 5 pages max.

8. How should the survey look?

- How it looks is important. It should not have too much text; not visibly intimidating; softer

9. How can the survey be worded to ensure that patients understand the questions?

- Simple; 8th grade is the NY Times

10. Will patients reveal their dissatisfaction?

- It has to be safe to reveal dissatisfaction; confidentiality must be ensured

Administering the Questionnaire

11. How should the survey be administered?

- Not mail; will never come back
- Self administered gives you the most honest answers
- Must give the message that this will not get their provider in trouble

12. When should the survey be administered?

- Before; offer an incentive

13. Will some clients be more likely to complete it than others will?

- Those who are either very satisfied or very dissatisfied.
- Be sure to sample for gender

14. How should survey be collected?

- In a box

15. How should surveys be analyzed? Who should see the results?

- Don't know how it should be analyzed
- Both patients and providers should see the results

Final Thoughts

- The success of this will depend on patient's comfort level with disclosing what they are really feeling without repercussions

Patient Satisfaction Questionnaire Development Project: Key Informant Interview

Name of Key Informant: Joseph Rukeyser
Telephone: 212-299-8364

Content

- 1. What aspects of service provision should be covered in the questionnaire?**
 - Meeting patient needs
 - Are services relevant to patient needs?
 - Are services patient friendly? Is the language used clear and understandable?
 - Are providers accessible?
 - Are your question answered?
 - Does the provider provide you with the complete picture?
 - Ask about the tone: is the provider condescending? Is you provider there for you?

- 2. Which services are most important to ask about?**
 - Clinical
 - Clinical trials
 - Case management
 - Counseling
 - Treatment education

- 3. Should the survey include questions about whether medical standards of care are met?**
 - Yes. Patients can appreciate how the medial care they get compares to what they have heard about or read. Possible questions include: Do you feel that adequate lab tests are done? Are the results explained clearly?
 - IS the provider attentive to al aspects of care, including psychosocial issues?
 - How do you compare the provision of services from this provider with other providers? Or to services you know to be received by others?

- 4. What types of issues that are specific to HIV should be asked about?**
 - Is your provider knowledgeable about the current standards of care and about research in HIV?
 - Does the provider respect your confidentiality?
 - IS the provider non-judgmental? (You never see this in other disease categories.)
 - Does the provider judge your behavior or you based on the source of your HIV infection?

- 5. What special areas of service require a separate section of the survey?**
 - GYN, Substance abuse, Co-infection with Hep-C. For all these areas ask:
 - Are you satisfied with the care provided?
 - Is the provider sensitive to your unique needs?

- Is the provider judgmental?
- Is your provider thorough? Does the provider spend adequate time with you? (the amount of time spent is key to folks who feel marginalized)
- Is the provider interested in your concerns

6. How can patient's suggestions for improvement be elicited?

- Ask very direct questions (like the probes) general probes do not work.

7. Are there any specific questions you would like to see included?

- Does the patient feel they have learned from the provider?
- How would you rate your service provider as an educator?

Design and Language

8. How long should the survey be?

- 10 to 15 minutes

9. How should the survey look?

- Give lines to write responses to give people an idea of how much feedback you are looking for
- Use questions with a range from 1 to 5; have people circle their selection
- Give examples and explanations
- The more specific the better; ask for a general rating followed by specific examples
- Have ratings and explanations side by side

10. How can the survey be worded to ensure that patients understand the questions?

- Don't let the AIDS Institute write it.
- The writer should have to answer it as a test
- It should be simple and direct; no complex sentences.

11. Will patients reveal their dissatisfaction?

- Yes they will, but a lot depends on the conditions. If their names are not used and if they believe that the information they give will be used to improve care, they will reveal that they are dissatisfied.

12. How can the survey be worded to capture more subtle degrees of dissatisfaction or satisfaction?

- Ask them if they think that the provider is doing well by them, if they think that they are getting good care. Are the providers giving them the time they need? Are they personable, non-judgmental? Tease apart the interpersonal piece from other parts of the experience at the site.
- Is the waiting room full of people that you are not comfortable with?
- Is the provider keeping appointments?
- Is the clinic accessible? How long does it take you to get there?

Administering the Questionnaire

13. How should the survey be administered?

- Flexible; some people who cannot read will need help to fill it out

14. When should the survey be administered?

- The waiting room is a good place assuming that confidentiality can be maintained. Perhaps an area of the waiting room should be set aside.
- It is better to administer it after the visit

15. Will clients be resistant to completing the survey? If so, how can this be addressed?

- Some will, they will be suspicious. Whoever is giving out the survey should be very knowledgeable and be able to explain exactly how it will be used.
- It might be interesting to follow-up with those patients who decline to fill it out to find out why (Not enough time today? Not feeling well? Don't trust how the information will be used?)

16. How should survey be collected?

- Not mailed. It should be handed to the person who is taking them through it. It should be put in an envelope.

Final Thoughts

- Strategies for accessing consumers: contact case managers or staff who run support groups at every AIDS treatment center. Get yourself on the agenda of the weekly support group.
- Offer money for food and a small honorarium for the consumers. This filled the rooms for them
- Sandara Houston (973-675-1522) did all the logistics for their focus groups and could provide direct advice.

Patient Satisfaction Questionnaire Development Project: Key Informant Interview

Name of Key Informant: Dan Tietz
Agency Affiliation: AI
Telephone: 518-473-2903

Content

- 1. What aspects of service provision should be covered in the questionnaire?**
 - Waiting time at appointments
 - Did they receive a complete assessment as a new patient?
 - Was the assessment updated quarterly?
- 2. Which services are most important to ask about?**
 - Case management; support services; mental health; transportation; primary care; referrals to specialists; nutrition
- 3. Should the survey include questions about whether medical standards of care are met?**
 - Yes. Are you happy with your primary care provider?
 - When you are referred to specialists, are you given time to explain your needs?
 - When you see a specialist are you happy with the services provided?
 - Ask about the type of inpatient care experiences they have had. (recent staff reduction in hospitals have resulted in lots of bad experiences lately)
- 4. What types of issues that are specific to HIV should be asked about?**
 - Psychosocial and substance abuse
 - Have you, at much time during your illness, felt that you were dealing with anxiety and depression? If yes, have you received psychosocial services and are your feeling different because of those services/
 - Have you been an active user? Have you used substance abuse treatment services and because of these services.”
- 5. How can patient’s suggestions for improvement be elicited?**
 - Be as direct as possible.
 - Culturally competent
 - Use language that people identify with; “slang or street language”

Design and Language

- 6. How long should the survey be?**
 - Short; 1 page double sided; no more than 15-20 minutes

7. **How should the survey look?**
 - Large font
8. **How can the survey be worded to ensure that patients understand the questions?**
 - Simple language; 8th grade level
9. **Will patients reveal their dissatisfaction?**
 - They may not; depends on how it is distributed

Administering the Questionnaire

10. **How should the survey be administered?**
 - Sample both in person interview and by mail
 - You will need incentives if you do it by mail; include postage paid envelope and a cover letter that offers them a reward (coupon for dinner) once the finished survey is returned
 - If face-to-face, use someone not from the site; explain that the survey will be anonymous; the message must be clear that it is not going to affect them
11. **When should the survey be administered?**
 - Before going in to the appointment
12. **Will clients be resistant to completing the survey? If so, how can this be addressed?**
 - Depend on the client's medical and psycho-social needs
 - More affluent, educated consumers will have no problem
 - It might help if the provider asks their patients to fill out the survey before it is actually given to them
13. **How should survey be collected?**
 - At the end of the interview and sealed in an envelop in front of the consumer
14. **How should surveys be analyzed? Who should see the results?**
 - It should be analyzed by an external consultant and subject to statistical analysis
 - Results should be presented in a report with clear tales
 - Results should be given to providers, the administration of the site, the program Board of Directors and CEO
 - Consumers should see results broken down in a different format that is user friendly; in the mail

Final Thoughts

- Regarding accessing upstate consumer groups he recommended that we reach out to the Network Coordinators of each regional Ryan White Title II Care Network. They can hook us up with the PWA Advisory Committee for each regional network
- With regards to working with the LTI, he said that he would prefer to talk directly with Clemens

Patient Satisfaction Questionnaire Development Project: Key Informant Interview

Name of Key Informant: Jay Freedman & Lisa Tackley
Agency Affiliation: AI
Telephone: 212-674-7105

Content

- 1. What aspects of service provision should be covered in the questionnaire?**
 - Relationship with the doctor; do they get enough time with their doctor?
 - Is the physician respectful and treat them with dignity?
 - Do they have a thorough understanding of HIV and its treatments?
 - Is anyone discussing adherence issues with you?

- 2. Which services are most important to ask about?**
 - Case management. Avoid a separate section however. We are trying to integrate case management. Every site should have case management.
 - Do you see a case manager at this site?
 - Is the case manager someone other than your physician? A nurse? A social worker?
 - Do you meet with your case manager? How often?
 - Does your CM help you deal with housing, loss of benefits, food, and transportation?
 - Does your case manager talk to you about how you can prevent your partner from being infected? (Secondary prevention)
 - Does anyone (CM or physician) conduct a psychosocial assessment of your needs and prepare a service plan?
 - Does your CM help you acquire services by yourself?
 - Does your CM help you when you are having difficulty accessing services?
 - Has the CM accomplished anything for you?

- 3. Should the survey include questions about whether medical standards of care are met?**
 - Depends. Most patients are most concerned about trusting their physicians
 - Yes, ask. But standards of practice are up in the air. Ask about what is clear and non-controversial.
 - Do you see your doctor frequently enough?
 - Have you had a Pap smear this year?
 - Are you receiving viral load testing ___ times a year?

- 4. What types of issues that are specific to HIV should be asked about?**
 - Coordination of services: “ Is your doctor talking to your CM?”
 - Adherence issues
 - Ease of getting prescriptions
 - Side effects
 - Substance use, mental health and primary care coordination

- Confidentiality issue

Design and Language

5. How long should the survey be?

- A survey they did was 2 pages, back and front and densely packed, and got a very low return rate
- Ideal is 1 page back/front, 5 questions per page, double spaced, yes/no, and allow a few open ended questions
- Make it as specific as possible

Administering the Questionnaire

6. How should the survey be administered?

- Have peers interview people; oral
- Paid focus groups get you good turn out
- Computerize it; put a kiosk in the waiting rooms of all sites where patients can touch screens to fill out survey.

7. When should the survey be administered?

- Link the survey to their annual exam; ask patients to look back to services received over the last year.

8. Will staff be resistant to promoting the survey? If so, how can this be addressed?

- Most don't have the time
- Pay them for it; AI has not done this
- Jeff Rothman had the analysis done by his Bureau staff; this was helpful in reducing burden on the sites
- Designate a peer to do it or require that each program have a QI person and have them be responsible

Patient Satisfaction Questionnaire Development Project: Key Informant Interview

Name of Key Informant: Dr. Arthur Levin
Telephone: 212-674-7105

Content

- 1. What aspects of service provision should be covered in the questionnaire?**
 - What do we mean by the question? We first need to define satisfaction. For most people it is limited to service issues, but it should also include quality of care.
 - Most people refer to navigational issues: how to get into the service, how to move around, problems with hand-offs
- 2. Should the survey include questions about whether medical standards of care are met?**
 - Yes!
 - This is not something that lay people think about, unless they have had a bad experience. It is easy to ask about a negative experience, like if you've been stuck 8 times to have your blood drawn.
 - The kinds of things you should ask: For example: Phlebotomy. This can be very uncomfortable and it is a standard part of care. Ask someone very specific questions about how the phlebotomy is done and you can learn about clinical quality.
- 3. What types of issues that are specific to HIV should be asked about?**
 - Don't know HIV issues
- 4. How can patient's suggestions for improvement be elicited?**
 - If you elicit a negative experience then follow up with "how would you make that better?"

Design and Language

- 5. How long should the survey be?**
 - Short: 5 to 7 minutes no more than 3-4 pages
- 6. How should the survey look?**
 - Nothing to say about this
- 7. How can the survey be worded to ensure that patients understand the questions?**
 - "Dumb it down." 6th to 8th grade reading level; give examples to illustrate what you mean; this will make it more accessible

8. How can the survey be worded to capture more subtle degrees of dissatisfaction or satisfaction?

- This is more difficult to do in a survey; you have to extract it; best if done in a conversation

Administering the Questionnaire

9. How should the survey be administered?

- Person to person is most effective; voice to voice on the phone; not by mail

10. When should the survey be administered?

- After the patient has seen the doctor; base the survey on that day's experience

11. Will some clients be more likely to complete it than others will?

- The more "active" clients will do it and the more "complacent" (those who do what they are told.)

12. How should survey be collected?

- Make it anonymous; assign a number to the survey, so it can be handed to some one and kept confidential.

13. How should surveys be analyzed? Who should see the results?

- Provider community: present it so that it gets their attention and they feel compelled to do something about the results
- Patients: present the data to compare what you most often get now vs. what you should expect. "Here are how other people's experience is at this clinic."
- Not sure I know who should analyze it.

Final Thoughts

- Give lots of examples of what you mean; this addresses the comprehension issue
- Design the survey in the context of that day's visit

Patient Satisfaction Questionnaire Development Project: Key Informant Interview

Name of Key Informant: Jennifer Parr
Agency Affiliation: AI
Telephone: 518-473-8815

Content

1. What aspects of service provision should be covered in the questionnaire?

- Access: transportation; easily accessible location
- Relationship and connection to providers at the clinic; is there someone at the site that they are comfortable with?
- Communication pattern between provider and client; when the provider describes medicines and procedures, are they able to understand?
- What resources are available to them? Are there easy to read materials in the waiting room or on the way out the door? Are materials in places where people are comfortable picking them up? Like the exam rooms?
- Are they receiving helpful referrals? Have they been referred to a mental health program that has met their needs, for example?
- The quality of non-clinical care is just as important as it can affect adherence and whether people come back.
- Do they make it to all their appointments? Regularly or once in a while?

2. Should the survey include questions about whether medical standards of care are met?

- With some patients definitely, other may not have the motivation to learn about this
- Have they gotten their viral load tested?
- The frequency of T-cells
- When they have complained about meds, do they feel satisfied with the response they received from the provider?

3. What types of issues that are specific to HIV should be asked about?

- Adherence: are providers responding to the side effects of the meds? Do peers or counselors talk about adherence? Has their support been helpful?
- Partner notification: I would caution you about asking about this in the survey. You may lose engagement of some people

4. What special areas of service require a separate section of the survey?

- Cover all of the issues on the list. Ask if a site is providing or making referrals for all of these services
- Are you receiving these services here?
- Rate these services on a scale to assess the benefit that the patient is receiving

5. How can patient's suggestions for improvement be elicited?

- What has been your most positive experience? What happened? What has been the most helpful service you have received? How were staff helpful to you?

Design and Language

6. How long should the survey be?

- 2 pages front and back

7. How should the survey look?

- Large type; soothing color (blue); have a front cover that is attractive

8. How can the survey be worded to ensure that patients understand the questions?

- Offer directions
- 7th to 8th grade level
- Careful with the use of street slang; it turns some people off
- Incorporate short sentences
- Large font

9. How can the survey be worded to capture more subtle degrees of dissatisfaction or satisfaction?

- A positive spin on a question yields a positive response
- Mix up the questions: “how helpful is this?” followed by “what were you dissatisfied with”
- If it's a positive question and you get a negative response you know there is something going on

Administering the Questionnaire

10. How should the survey be administered?

- Someone should give it to them
- Interview for half an hour; will need incentive

11. When should the survey be administered?

- On the way in

12. Will some clients be more likely to complete it than others will?

- Some who have had a negative experience will want to fill it out right away
- Some are interested in helping out

13. How should survey be collected?

- Leave it in a box

14. How should surveys be analyzed? Who should see the results?

- You should use a team approach for the analysis including HIV positive people, non-clinical people like educators or counselors, a statisticians and a physician. You will need all of these perspectives to understand the qualitative aspects of the responses.
- Everyone should get the results. The clinic should get it first.
- It should be mailed to the site administrators and posted at the site for the patients.

Patient Satisfaction Questionnaire Development Project: Key Informant Interview

Name of Key Informant: Sallie Perryman
Agency Affiliation: AI
Telephone: 212-674-7105

Content

1. What aspects of service provision should be covered in the questionnaire?

- Entitlements, housing, nutrition, and family/custody planning issues: are they accessing these? who is the resource person at the site to help them with each of these?
- Cultural sensitivity
- Staff attitudes
- Accessibility: times the facility is open; is care client-centered? If the patient has childcare needs, can they get it at the site?
- Waiting time
- Resourcefulness and networking ability of the organization: does staff have the skills to figure out how to meet the client's needs even if they do not provide a specific service?
- Is there one-stop shopping at the site?
- Is case management comprehensive? How is it set up? Are referrals given with follow-up?

2. Should the survey include questions about whether medical standards of care are met?

- Yes. There are many savvy patients with HIV.
- Frame it as "Do you think your doctor provides good medical care? What do you think good medical treatment is?"

3. What types of issues that are specific to HIV should be asked about?

- Do you feel confident in the way your provider handles your medical information?
- Partner notification is important: "How do you feel when you have a discussion with your doctor about partner notification? Threatened or comfortable?"

4. What special areas of service require a separate section of the survey?

- GYN: menopause; fibroids (prominent in communities of women of color); family planning (not pregnancy)
- What is the impact of current drug therapies on these things? What does your doctor know about these things?

5. How can patient's suggestions for improvement be elicited?

- What can we do to make you feel better?
- What would work for you?

Design and Language

6. How should the survey look?

- 12-14 point; not too wordy; not intimidating

7. Will patients reveal their dissatisfaction?

- If its anonymous, patients will reveal their dissatisfaction

8. How can the survey be worded to capture more subtle degrees of dissatisfaction or satisfaction?

- Ask them about their feelings

Administering the Questionnaire

9. How should the survey be administered?

- Different for different groups.
- MICA: focus groups; maximum 2 hours
- Affluent gay men: self-administered; 5 pages
- Immigrants: interview in their language; max. 1 hour with incentives

10. Will some clients be more likely to complete it than others will?

- Yes, those who are detail oriented will complete it
- You should offer incentives; you get \$25 after you complete the survey

11. How should survey be collected?

- Self addressed envelop with stamp; offer option of mailing it back to get the incentive

12. How should surveys be analyzed? Who should see the results?

- Needs to go to people who run programs and have the power to do something about the results
- Share it with client advisory boards

Final Thoughts

- Answer the question of what this survey is for
- Word it in a way to make people feel that they are part of the solution
- People who are not always included, when you tell them that they can make a difference they get more engaged, it makes them feel valuable.

Patient Satisfaction Questionnaire Development Project: Key Informant Interview

Name of Key Informant: Dr. Cyndi Miller, Medical Director
Agency Affiliation: Albany Medical Center
Telephone: 518-262-4027

Content

1. What aspects of service provision should be covered in the questionnaire?

- Are patients receiving adequate medical care? Ask specifically about accessibility. Can you reach your doctor? Ask about the amount of time they spend with their doctor. Is your doctor spending enough time going over your individual problems and needs? Is your doctor spending enough time telling you about your condition? Do you understand what your doctor is telling you?
- Ask about substance abuse treatment, case management, nutrition and mental health. For all of these ask if these services should be provided. If they are provided, ask about accessibility. Can you get together with your case manager when you need to? Do you understand what they are saying? Do they provide a useful service? Be sure to include the following statement: "If you do not utilize these services, do not answer the following questions."
- Perhaps ask about GYN, the same issues. Please note that our patients do not maximize this service when it is available.

2. Should the survey include questions about whether medical standards of care are met?

- Only doctors know what these are. How would patients know what to ask for? Are they qualified to answer this question? No. This should be put in some other survey such as JACCHO that checks on the adequacy of medical services.

3. What types of issues that are specific to HIV should be asked about?

- Partner notification is not something that typically gets asked at AIDS designated centers. This is done by primary care providers at the point of initial diagnosis or when a patient moves from HIV to AIDS. Sometimes case managers do partner notification when completing the initial assessment at our sites. But in general if you ask patients at HIV clinics if they received partner notification guidance the answer will be no.
- Confidentiality is important to ask about. Do you feel that your confidentiality is being maintained? If not, why not? Present some choices. This type of question may be legally compromising to the AI; it may require that they follow-up in cases where patients answer yes.
- Do you have access to Hep C treatment?
- Do you have access to other medical sub-specialty services without difficulty?

4. How can patient's suggestions for improvement be elicited?

- Be careful not to ask for suggestions that you would not be able to respond to

- It might be better to ask about specific things rather than an open ended question
- It might also be useful to ask patients how they think they can best offer suggestions. Provide a specific list of options, like focus groups, consumer advisory meetings, etc. and ask them to chose.

5. Specific questions:

- Are educational materials available at the site? Are these appropriate to your needs?
- Have you been tested for cholesterol? This is a way of getting at the standards of care issue.

Design and Language

6. How long should the survey be?

- 2 pages front and back

7. How should the survey look?

- No suggestions on this

8. How can the survey be worded to ensure that patients understand the questions?

- The simpler the better; use specific questions

9. Will patients reveal their dissatisfaction?

- Yes

10. How can the survey be worded to capture more subtle degrees of dissatisfaction or satisfaction?

- Don't know. The problem with using a scale is that they do not tell you what specifically they were dissatisfied with.

Administering the Questionnaire

11. How should the survey be administered?

- You get better answers form an interview; needs to be a person not affiliated with the site

12. When should the survey be administered?

- On the way in if self-administered; possibly give it to people to fill out in the exam room while waiting for the doctor
- On the way out if with interviewer; will be better if you offer patients \$10 as it will likely take more time with an interviewer

13. Will clients be resistant to completing the survey? If so, how can this be addressed?

- No

14. Will some clients be more likely to complete it than others will?

- Those who will not fill it out are those who are really sick or have lots of kids
- Spanish speaking patients may be able to fill out a survey in very simple English

15. Will staff be resistant to promoting the survey? If so, how can this be addressed?

- No

16. How should survey be collected?

- Leave it in a box

17. How should surveys be analyzed? Who should see the results?

- Results need to be very specific. The idea is to generate findings that we can do something about. This means that we need to know specific issues that people are dissatisfied with. For example, if you find that 50% of the patients say that they do not understand their doctors, then this is something that needs to be addressed systemically.
- Results should be given to the sites. I would like to see results in comparison to other sites, not using specific site names.
- Perhaps you may need to administer the survey in stages. Given the page limits, you may want to start with medical care, or the area that the AI is most concerned about or presents the worst problems, such as mental health services.

1. Remember to take:
 - Note pad and pen
 - Tape recorder and tapes
 - Fresh batteries
 - Participant Forms:
 - o Consent form (2 per participant)
 - o Focus Group Protocol (version to distribute)
 - Facilitator focus group protocol
2. Record the date, start time, venue, your name, and number of participants at the top of the facilitator focus group protocol.
3. Go over **Consent form**; ask them to sign one and return to you; they keep the other for their own information. Participants should only sign their first name or initials.
4. Distribute the **Focus Group Protocol** (participant version) as a guide to what the discussion will cover.
5. Tell participants you are turning on the tape recorder, and that it will run until the end of the focus group. Let them know that the tape will only be used to assist in writing up a summary of the focus group.
6. Conduct focus group.
7. At the end of the focus group, let participants know you are turning off the tape recorder. Inform them that they're welcome to contact us with any input, feedback, or questions.
8. Record end time at top focus group protocol.
9. Distribute \$25 cash incentive to participants. Ask participants to sign a receipt (again, only first name or initials).
10. Keep the forms from the focus group together. Send them to John with focus group summary. (Send focus group summary by e-mail also).

Date _____

Start Time _____

End Time _____

Venue/Site _____

Facilitator _____

Number of Participants _____

Patient Satisfaction Questionnaire Development Project

A project led by Psych Research, Inc., as a consultant to the New York State Department of Health – AIDS Institute

Focus Group Protocol (Patients)

My name is _____, and I'm working as a consultant for Psych Research, which has been hired by the AIDS Institute to develop a patient satisfaction survey.

The patient satisfaction questionnaire being developed is for use specifically in HIV medical clinics. In this focus group discussion, I'd like to get your input on what the survey should cover, how it should be worded, and how it should be carried out. We can discuss all aspects of patient care, but I am most interested in issues that are specific to HIV, which might not be addressed in a more general patient satisfaction questionnaire. Please keep in mind your experience of being a patient in an HIV clinic as we talk about this. I'm interested in knowing about your experiences and how they can help us to create a patient satisfaction questionnaire that will allow you to communicate what you really feel about the quality of the services you get.

I will ask a series of general questions and follow-up with specific questions, depending on the direction of the discussion.

[This discussion will be tape-recorded to help us in remembering what was said as we do the focus group summaries and analyses. The tape will run through the end of the group. I'm turning on the tape recorder now.]

Questionnaire Content

[As an ice-breaker; can see where it takes you]

Have you ever filled out a patient satisfaction survey?

- What do you like about it?
- What would you change about it?

What areas or aspects of service provision should be covered in the questionnaire?

What types of questions would you ask?

[for probing]

- Atmosphere, space
- Waiting time
- Protection of Confidentiality
- Staff attitude
- Patient-provider communication
- Staff knowledge and skills

Which services are most important to ask about?

What types of questions would you ask?

[for probing . . .]

- Basic medical care
- Access to combination therapies.
- Conditions such as Hep C, which are highly prevalent among those with HIV.
- Partner notification
- Mental health services
- Case Management services

In asking about satisfaction with the provision of services, should the survey include questions on whether services met *medical* standards of care (whether tests were performed at regular intervals, etc.)?

Do you feel comfortable or capable of answering questions about the quality of your care from a medical perspective?

If so, what types of questions would you ask?

What types of issues are specific to HIV that should be asked about?

What types of questions would you ask?

[for probing . . .]

- Protection of Confidentiality
- Partner notification
- Treatment education and adherence

What special areas of service – which aren't offered at all sites – require special sub-surveys or modules to ask specifically about those areas. In other words, are these services special or important enough to require their own mini-survey?

If so, what types of questions would you ask in those areas?

[for probing; priorities should be elicited]

Drug Treatment
Harm Reduction Services
Comprehensive Case Management
Licensed Mental Health Services
Complementary/Alternative Medicine
Dental Services
Nutrition Services
HIV Counseling and Testing Services
Treatment Adherence Education or Support
OB/GYN HIV Medical Care
Pediatric HIV Medical Care
Other areas?

How would you like to be asked about your suggestions for improving your care? How should the question sound?

- Asked what other services they'd like to see available?
- Asked specifically what they would do to make the place better?

Are there specific questions you would like to see included in the survey?

Design and Language

How long should the survey be?

How should the survey look – graphics, logos, size of type, etc?

How can the survey be worded to ensure that you understand the questions?

Will you feel comfortable revealing that you are dissatisfied? If not, why, and how can this be addressed in the design or language of the survey so that you can share your true feelings?

How can the survey be worded or structured to capture more subtle degrees of dissatisfaction or satisfaction?

Are there specific questions you would like to see included in the survey?

Administering the Questionnaire

How should the survey be administered? (Self-administered, interview, etc.)

When should the survey be administered? (In the waiting room, after a visit, by mail, etc.)

Have you ever felt unwilling to complete a patient satisfaction survey? If so, why, and how can this be addressed?

Will some patients be more likely to complete the survey than others? (For example, will the more satisfied clients be more likely to complete the survey?) If so, how will this skew results, and how can this be addressed?

Will staff be resistant to promoting the survey? If so, why, and how can this be addressed?

How should surveys be collected? (inserted in a box, mailed in, handed to your service provider, etc.)

How should the surveys be analyzed? Who should see the results? How should the results be distributed?

[Thank you very much; this completes the recorded portion of the focus group. Thank you for your time.

Facilitator: please record the end time.]

Patient Satisfaction Questionnaire Development Project

A project led by Psych Research, Inc., as a consultant to the New York State Department of Health – AIDS Institute

Consent to act as a participant in a focus group (for consumers)

I hereby agree to participate in a focus group led by Psych Research, Inc. to provide input into developing a patient satisfaction questionnaire for use in HIV ambulatory care settings. I understand that I am being asked to participate because of my experiences as a consumer of services in this area.

I understand that I do not have to participate in this focus group, and that I have the right to withdraw from it at any time without suffering any adverse effects on the services that I receive. I also understand that I have the right to refuse to answer any question that I may not wish to answer.

I understand that participation in this focus group is unlikely to produce discomfort and that participation may, in fact, produce benefits to me in improving my understanding of provider-patient relations.

I understand that no information that identifies me will be released without my separate consent except as specifically required by law.

I understand that if I have further questions, comments, or concerns about the focus group or the informed consent process, I may speak to John Chin, Psych Research, at 718-499-1527 or to Clemens Steinbock, Director for Quality Initiatives, AIDS Institute, at 212-268-6078.

In signing this consent form, I acknowledge that I have received a copy of this form or have heard a translation of this form in my own language.

Subject's Signature (first name or initials only)

Date

1. Remember to take:
 - Note pad and pen
 - Tape recorder and tapes
 - Fresh batteries
 - Participant Forms:
 - o Consent form (2 per participant)
 - o Focus Group Participant Information form
 - o Focus Group Protocol (version to distribute)
 - o Pilot Testing Site Form
 - Facilitator focus group protocol
2. Record the date, start time, venue, your name, and number of participants at the top of the facilitator focus group protocol.
3. Go over **Consent form**; ask them to sign one and return to you; they keep the other for their own information.
4. Ask participants to complete the **Focus Group Participant Information form**; this is to help us to understand the make-up of the group to help us decide what interviews and focus groups to conduct next (to ensure diversity of input).
5. Distribute the **Focus Group Protocol** (participant version) as a guide to what the discussion will cover.
6. Ask participants to consider being a pilot testing site for the new survey. We will pilot test the survey at about 10 sites to survey and interview about 150 patients, and also some providers. Some patients will just complete the survey and others will be surveyed and interviewed (about 1 hour). For patients who just complete the survey, they'll receive a \$10 incentive; those who complete the survey and are interviewed will receive a \$25 incentive.

Pilot test sites will be asked to coordinate with us to allow our consultants to come to the site for one to 1.5 days to survey and interview patients (and some providers). If sites are interested, they can complete the **Pilot Testing Site Form** and hand-in to you at the end of the session; or they can fax it to the fax number at the bottom. The form does not bind you to work with us. The information requested is to help us select appropriate sites to ensure that we capture diverse types of facilities.
7. Tell participants you are turning on the tape recorder, and that it will run until the end of the focus group. Let them know that the tape will only be used to assist in writing up a summary of the focus group.
8. Conduct focus group.

9. At the end of the focus group, let participants know you are turning off the tape recorder. Inform them that they're welcome to contact us with any input, feedback, or questions.
10. Record end time at top focus group protocol.
10. Send Pilot Testing Site Forms to John ASAP. Note date of focus group on the top form.
11. Keep the rest of the forms from the focus group together. Send them to John with focus group summary.

PRO.

Date _____

Start Time _____

End Time _____

Venue/Site _____

Facilitator _____

Number of Participants _____

Patient Satisfaction Questionnaire Development Project

A project led by Psych Research, Inc., as a consultant to the New York State Department of Health – AIDS Institute

Focus Group Protocol (Providers)

My name is _____, and I'm working as a consultant for Psych Research, which has been hired by the AIDS Institute to develop a patient satisfaction survey.

The patient satisfaction questionnaire being developed is for use specifically in HIV Ambulatory Care settings. In this focus group discussion, I'd like to get your input on what the survey should cover, how it should be worded, and how it should be administered. We can discuss all aspects of patient care, but I am most interested in issues that are specific to HIV, which might not be addressed in a more general patient satisfaction questionnaire. Also, please keep in mind the settings and the mind-sets of the patients as we discuss this; for example, in some situations, patients may feel they shouldn't "complain" about services and thus not reveal dissatisfaction.

I will ask a series of general questions and follow-up with specific questions, depending on the direction of the discussion.

[This discussion will be tape-recorded to help us in remembering what was said as we do the focus group summaries and analyses. The tape will run through the end of the group. I'm turning on the tape recorder now.]

Questionnaire Content

[As an ice-breaker; can see where it takes you]

Have you used a patient satisfaction survey in your facility?

- What did you like about it?
- What would you change about it?

What areas or aspects of service provision should be covered in the questionnaire?

What types of questions would you ask?

[for probing]

- Atmosphere, space
- Waiting time
- Protection of Confidentiality
- Staff attitude
- Patient-provider communication
- Staff knowledge and skills

Which services are most important to ask about?

What types of questions would you ask?

[for probing . . .]

- Basic medical care
- Access to combination therapies.
- Conditions such as Hep C, which are highly prevalent among those with HIV.
- Partner notification
- Mental health services
- Case Management services

In asking about satisfaction with the provision of services, should the survey include questions on whether services met *medical* standards of care (whether tests were performed at regular intervals, etc.)?

Do you feel that patients are capable of commenting on the quality of their care from a medical standpoint?

If so, what types of questions would you ask?

What types of issues are specific to HIV that should be asked about?

What types of questions would you ask?

[for probing . . .]

- Protection of Confidentiality
- Partner notification
- Treatment education and adherence

What special areas of service – which aren't offered at all sites – require special sub-surveys or modules to ask specifically about those areas. In other words, are there areas of service that are important or special enough that they require special attention?

If so, what types of questions would you ask in those areas?

[for probing; priorities should be elicited]

Drug Treatment
Harm Reduction Services
Comprehensive Case Management
Licensed Mental Health Services
Complementary/Alternative Medicine
Dental Services
Nutrition Services
HIV Counseling and Testing Services
Treatment Adherence Education or Support
OB/GYN HIV Medical Care
Pediatric HIV Medical Care
Other areas?

How can patients' suggestions for improvement be best elicited?

What types of questions would you ask?

- Asked what other services they'd like to see available?
- Asked specifically what they would do to make the place better?

Are there specific questions you would like to see included in the survey?

Design and Language

How long should the survey be?

How should the survey look – graphics, logos, size of type, etc?

How can the survey be worded to ensure that patients understand the questions?

Will patients reveal their dissatisfaction? If not, why, and how can this be addressed in the design or language of the survey?

How can the survey be worded to capture more subtle degrees of dissatisfaction or satisfaction?

Are there specific questions you would like to see included in the survey?

Administering the Questionnaire

How should the survey be administered? (Self-administered, interview, etc.)

When should the survey be administered? (In the waiting room, after a visit, by mail, etc.)

Will clients be resistant to completing the survey? If so, why, and how can this be addressed?

Will some clients be more likely to complete the survey than others? (For example, will the more satisfied clients be more likely to complete the survey?) If so, how will this skew results, and how can this be addressed?

Will staff be resistant to promoting the survey? If so, why, and how can this be addressed?

How should surveys be collected? (inserted in a box, mailed in, handed to your service provider, etc.)

How should the surveys be analyzed? Who should see the results? How should results be distributed?

[Thank you very much; this completes the recorded portion of the focus group. Thank you for your time.]

Facilitator: please record the end time.]

Patient Satisfaction Questionnaire Development Project

PRO.

A project led by Psych Research, Inc., as a consultant to the New York State Department of Health – AIDS Institute

Focus Group Participant Information Form

1. What is your title or job role (medical director, staff nurse, counselor, etc.)?

2. What type of medical/nursing/health degree or training do you have (M.D., N.P., R.N., etc., or any other type of relevant training or education)?

3. What is the name of the facility you work at? _____

4. What city or county is your facility located in? _____

5. What is the type of facility?

- Designated AIDS Center
- Non-D.A.C. Hospital-Based I.D. Clinic
- Free-Standing Drug Treatment Center
- Free-Standing Community Health Center
- Other _____

6. Approximately how large is the HIV-positive patient load at your facility? _____

6a. Approximately what percent speak primarily Spanish? _____%

7. What types of major services does your facility provide (please check all that apply)?

- HIV Primary Care
- Drug Treatment
- Harm Reduction Services
- Comprehensive Case Management
- Licensed Mental Health Services
- Complementary/Alternative Medicine
- Dental Services
- Nutrition Services
- HIV Counseling and Testing Services
- Treatment Adherence Education
- OB/GYN HIV Medical Care
- Pediatric HIV Medical Care
- Other _____

8. Is your facility a Medicaid managed care provider or a participant in the Medicaid managed care system? Yes No

9. Would you be willing to be contacted for follow-up questions if necessary?

Yes No

If yes, please provide the following information:

Name _____ E-mail Address: _____

Telephone Number _____ Fax Number: _____

Patient Satisfaction Questionnaire Development Project

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Consent to act as a participant in a focus group (for providers)

I hereby agree to participate in a focus group led by Psych Research, Inc. to provide input into developing a patient satisfaction questionnaire for use in HIV ambulatory care settings. I understand that I am being asked to participate because of my expertise in this area.

I understand that I do not have to participate in this focus group, and that I have the right to withdraw from it at any time without suffering any adverse effects on my job status. I also understand that I have the right to refuse to answer any question that I may not wish to answer.

I understand that participation in this focus group is unlikely to produce discomfort and that participation may, in fact, produce benefits to me in improving my understanding of provider-patient relations.

I understand that no information that identifies me will be released without my separate consent except as specifically required by law.

I understand that if I have further questions, comments, or concerns about the focus group or the informed consent process, I may speak to John Chin, Psych Research, at 718-499-1527 or to Clemens Steinbock, Director for Quality Initiatives, AIDS Institute, at 212-268-6078.

In signing this consent form, I acknowledge that I have received a copy of this form or have heard a translation of this form in my own language.

Subject's Signature

Date