



Focus Groups with People with HIV as a Component of RWHAP Part A Needs Assessment

Focus groups can be used for many purposes and with many types of participant groups. For many planning councils/planning bodies (PC/PBs), focus groups that target various subpopulations of people with HIV (PWH), in and out of care, are a common component of RWHAP Part A needs assessment, used along with other approaches like PWH surveys and town hall meetings. They involve relatively small groups of people but allow for more depth of discussion than more quantitative approaches. Participants for these types of focus groups are usually carefully chosen to share some characteristics but be diverse in others. For example, recruitment for a focus group of PWH diagnosed in the past three years might target individuals who differ in how soon after diagnosis they entered care, as well as in age, gender identity, race/ethnicity, and risk factor. Combined with other data sources, focus groups can provide valuable information about the service needs, barriers, and gaps of PWH within a Part A Eligible Metropolitan Area (EMA) or Transitional Grant Area (TGA). This overview describes PWH focus groups, including their goals, advantages, limitations, composition, and logistics¹. It also identifies key elements that need attention in planning and conducting focus groups - including tips for conducting remote or virtual focus groups.

What is a focus group?

A focus group is a structured discussion among a small group of people with certain similar characteristics. The focus group is used to collect qualitative (non-numerical) information about a topic. Participants interact in a group setting facilitated by a trained moderator, who uses a pre-determined “script” or set of questions to guide the discussion.

Use of Focus Groups in RWHAP Needs Assessment

Focus groups:

- Are widely used by RWHAP planning councils and planning bodies (PC/PBs) to learn from people with HIV (PWH) about their service needs, experiences, barriers, and gaps
- Provide “qualitative” (narrative rather than numerical) data and permit in-depth discussion of key topics, which helps PC/PBs and recipient personnel understand the service needs, barriers, gaps, and concerns of different PWH subpopulations
- Are most often used with PWH, but groups can also be made up of case managers, RWHAP program directors, service providers, or community activists – any group that may have valuable insights about service needs and barriers





As part of a comprehensive needs assessment, focus groups should help PC/PBs learn about met and unmet needs for HIV care, satisfaction with current services, and service barriers and access issues as viewed by particular PWH subpopulations. Focus groups can provide information about the extent to which specific subpopulations are aware of available services, are being reached and served, feel their needs are being met, and/or face barriers to entering or remaining in care and/or are adhering to medications. They can provide differing perspectives about the perceived quality and acceptability of service programs or the system of care and elicit possible ways for improving program access and services. Comparisons across focus groups can highlight similarities and differences across subpopulations – e.g., older PWH, young African American MSM, Latinx immigrants, or residents of outlying counties.

PC/PBs often conduct a series of focus groups every 1-3 years to update needs assessments and obtain in-depth input from several specific subpopulations. Focus groups may be conducted before a formal client or community survey, to help develop the questions and response alternatives. For example, if a PC/PB isn't sure what barriers to list as response options in a multiple-choice survey question, focus groups can identify barriers to include. A focus group can also be used after a survey to explore in more depth some of the issues identified or to clarify unexpected findings, as input to decisions about priorities and allocations, or as a basis for directives for program refinement. Focus groups are also used by PC/PBs to better understand statistics such as why client utilization data indicates that a particular subpopulation is less likely than others to use a specific service. Focus groups can be used with hard-to-reach populations, but only if they are coordinated and conducted with people and in places where the potential participants feel comfortable.

Relation to Legislative Requirements

Focus groups address the legislative requirements for a Planning Council to:

- “Determine the needs” of the population of individuals with HIV/AIDS
[Section 2602(b)(4)(B)]
- Obtain “input on community needs and priorities”
[Section 2602(b)(4)(C)(iii) and (G)]





BENEFITS & ADVANTAGES OF FOCUS GROUPS	LIMITATIONS & CHALLENGES OF FOCUS GROUPS
<ul style="list-style-type: none"> • Provide examples and insights related to HIV service needs and experiences from the perspectives of different subpopulations of PWH, which help to increase a PC/PB's understanding of service needs and barriers, and contribute to sound decision making about service allocations and improvements • Can focus on specific subpopulations, contributing to understanding of their special perspectives, needs, and service barriers • Complement and supplement surveys: can be used before a survey to guide development of questions and response options, or afterwards to add context and help explain quantitative survey findings • Allow for in-depth discussion of issues, strengthened by the interaction that occurs among participants • Involve relatively low cash costs: if done in person, often conducted in a provider or other community facility; main costs other than planning and recruitment are a gift card or other incentive, a simple meal or refreshments, and transportation • Can be led by PC/PB or consumer committee or caucus members, if they receive appropriate training • Can be adapted for remote implementation using an electronic platform 	<ul style="list-style-type: none"> • Involve small numbers of people, so results cannot be assumed to reflect the view of all PWH in that subpopulation – findings cannot be “generalized” to the entire subpopulation – so they are best used along with other types of data collection, such as surveys or review of secondary (existing) data • Require careful recruitment to reach PWH who are not already providing their input in other ways, through participation in the PC/PB or a consumer committee or caucus • Work best when carefully planned, with a full “script” or set of instructions to guide the process, and attention to logistics • Need a skilled moderator, who can manage available time, make participants feel comfortable sharing their experiences, and prevent 1-2 people from monopolizing discussion • Require some “over-recruitment” to allow for no-shows • If conducted remotely, may be challenging to involve high-priority but hard-to-reach subpopulations since they may have limited access to the Internet

Composition and Logistics of Focus Group

Size: A focus group should have enough participants to provide multiple perspectives and support active discussion, but not so many that you lose the opportunity for every participant to respond to each major question or topic. Appropriate size depends on factors such as the level of participant knowledge and engagement with the topic, targeted participant groups, and moderator skills and experience. Researchers often suggest 8-12 participants for a face-to-face focus group, and 6-8 for an online group. Duration also matters. A one-hour focus group might be limited to 6-8 people, while a two-hour focus group might allow time to fully involve 10-12 participants.²



Duration: Typically 1½ to 2 hours, including pre-discussion time for people to arrive, a mid-session break, and post-discussion time for participants to receive their gift cars or other incentives (perhaps half an hour less if conducted online).³

Participants: Focus group participants should have certain predetermined common characteristics related to the purpose of the focus group. These can be relatively limited or involve multiple factors. For example:

- If your PC/PB wants to explore service needs and barriers to care for subpopulations with high rates of HIV, then recruitment may be relatively straightforward. You will want at least one focus group made up of people from each of your identified subpopulations – for example, African American men under age 35, Hispanic/Latinx men under age 35, transgender people, or residents of a specific zip code or neighborhood. Membership in that subpopulation – based on race/ethnicity, age, and gender identity – may be the only criterion for participation. You often want diversity in other characteristics, such as place of residence, time since diagnosis, and linkage to and retention in care.
- If your PC/PB wants to better understand why people with HIV from certain subpopulations are less likely to adhere to medications, keep appointments, and be virally suppressed, you may need to consider multiple factors. For example, existing data may indicate that these issues are particularly common among young African American MSM, recently incarcerated people, immigrants with limited English proficiency, PWH who have mental health or substance use issues, and people with unstable housing. You might decide to arrange 5 focus groups, one for each of these subpopulations. In recruitment and screening, you will be concerned both with ensuring that they belong to one of these subpopulations – based on age, race/ethnicity, sexual orientation, nationality, English language proficiency, and mental health and substance use diagnosis – and that they fit the treatment status criteria. For example, you might look for people with the following characteristics: they are still connected to care but not virally suppressed, appear in danger of falling out of care (e.g., still getting at least one RWHAP service but have missed a medical visit or have not filled a prescription for medications in the past six months, or the case manager considers them loosely connected to care), or have returned to care within the last six months after being out of care for a specified period.

Location/Remote Platform: Focus groups need to be held in a location where participants feel safe and comfortable. This might mean different locations for different subpopulations. Some groups may be very comfortable in a community center or nonprofit service provider's facility. Others may not want to meet in an identified HIV service facility due to stigma. Some participants may prefer a comfortable public space like a meeting room in a library. Some may not want to come downtown. Even if you pay for transportation, convenience may be important – a location that is convenient to a bus or mass transit stop or in a space with parking. During a pandemic, focus groups can be held online, using a platform like Zoom, where participants can see each other. However, some population groups are less likely to have access to the Internet or may have a very limited data plan for their smartphone, computer, or tablet. Focus groups can be conducted via telephone, without video, but such an arrangement works best with a smaller group (5-8) and an experienced facilitator.



Keys to a Successful Focus Group

Here are some important elements to pay attention to in planning and conducting an effective focus group. While focus groups are generally conducted in person, tips for planning and conducting remote or virtual focus groups are also provided.

- 1. Effective recruitment.** Recruitment of focus group participants can be challenging. First you need to clearly define the required characteristics for each focus group, then consider recruitment methods and sources. The process usually works best when your PC/PB receives help from service providers and community organizations in identifying potential participants. For example, if you want to find people who are loosely connected to care, medical or case management providers, or peer navigators may be able to identify clients who fit your criteria. It is usually very difficult to recruit PWH who are not in care. They usually aren't easy to find, and may not be eager to come together because of stigma and concern about their status becoming known – often some of the same factors that led them to be out of care. Formal or informal support groups, community organizations, your consumer committee or caucus, and non-HIV service providers may be helpful. To encourage participation, also carefully consider location, time of day, and an incentive.



REMOTE FOCUS GROUP TIPS:

- When recruiting for a virtual focus group, decide up front how to address connectivity issues. You can limit yourself to people who have good connectivity and are not worried about the impact of participation in a 60-90 minute focus group on their smartphone minutes or their Internet data plan. You may be able to work with providers to identify potential participants who are already receiving Lifeline Program or other assistance that gives them connectivity for telehealth services, and perhaps add time to their data plan.
- If your target population includes people with limited or no connectivity, consider splitting each focus group into two smaller sessions and doing them as conference calls without video; since you won't be providing refreshments or paying for transportation, consider reallocating those funds to pay for a prepaid smartphone with needed minutes and some left over as part of the incentive.
- Be sure to build in time to go over use of the platform. For example, you might ask people with limited online experience to join a few minutes early so you can show them how to turn their video on and off, change how they see other participants, adjust volume, and use the chat room.



- 2. A safe and comfortable environment.** Choose a location that is accessible, private, welcoming, quiet, and allows for good-quality audio-recording. You may need to hold focus groups in several locations, each chosen to provide a safe space for a particular target group. In addition to physical space, the environment needs to encourage active engagement. Be sure to let potential participants know during the screening process that you plan to record the session, so anyone uncomfortable with that can decide not to participate. All participants are generally asked to sign a consent form⁴ that describes the purpose of the focus group, indicates that participants should not share their full name and may use a nickname, and need not respond to a question if they don't wish to, and asks them to agree to having the session recorded and to keeping the identities and expressed views of other participants confidential. Focus groups usually begin with one or two questions that are not sensitive and help to establish a safe environment. While participants are likely to become more comfortable with each other as the focus group progresses, some may remain hesitant about discussing sensitive topics in a group setting. Participants should be reminded that they always have the right to "pass" and should never be pressured to respond to a question. They can be encouraged to introduce themselves to the group with only their first names or a nickname, and should not be expected to share identifiable personal information. When addressing difficult issues, the facilitator needs to carefully watch how the group interacts, enforce respectful interaction, and minimize peer pressure.



REMOTE FOCUS GROUP TIPS:

- Being able to see the other participants helps create a friendly environment during a focus group, and many Zoom platforms enable participants to see each other. However, if people are very concerned about anonymity, it helps to give them the option of keeping their video off, whether they connect via computer, tablet, or smartphone.
- In a face-to-face setting, it is easy to have each participant sign a Consent Form. For a remote focus group, you can project the form on screen at the beginning of the focus group, read it aloud, and ask each person to indicate in the chat room, in a note to the facilitators only, that they agree to the taping and confidentiality requirements. Anyone unwilling to "sign" should be asked to leave the session.



- 3. Use of a carefully developed and realistic “script” or discussion guide** that describes the process, order, and flow of the focus group and states the questions and issues to be covered. The script includes “prompts” or “probes” and examples that can be used to clarify a topic or get discussion going if participants are slow in responding. It reminds the moderator to have participants sign in, get consent forms signed, allow for breaks, and provide incentives at the end of the session. The script should include a manageable number of questions for a focus group lasting 60-90 minutes, with time to explore questions and issues in some depth. If certain questions are considered especially important, they are clearly identified for the moderator. Once developed, the script is used flexibly, but all the key points are covered. Experienced moderators may not need a detailed script that goes beyond the questions, but it is very important for less experienced moderators and teams – and always helpful in ensuring consistency across focus groups.

WHAT IS A FOCUS GROUP “SCRIPT”?

A detailed plan or outline that guides a focus group, including the introductions and discussion of confidentiality, the key questions and extra “probes” to guide discussion and obtain desired information, planned breaks, and closing.



REMOTE FOCUS GROUP TIPS:

- Adjust your script to immediately welcome participants as they join the session and make sure you know who has joined. You can ask them to “sign in” by providing their name in the chat room in a message only to the moderator.
- Allow some time at the start of the focus group to make sure everyone is comfortable with the platform – including how to adjust the volume and the “view” so they can see other participants and how to use the “chat room” to communicate only with the moderator team.
- If the focus group lasts more than an hour, either let participants know that they can take a quick break when necessary and ask them to mute themselves before leaving, or stop for a few minutes mid-session to allow everyone a quick break.



- 4. An experienced, friendly, and neutral moderator, and at least one additional team member to serve as note taker/assistant moderator and deal with logistics.** If feasible, it helps to have a three-member team, so one can lead the group, another can take notes and assist the moderator, and a third can handle logistics (greeting people, helping them sign in, making sure refreshments are available, dealing with audio-visual equipment, and giving people their transportation reimbursements and gift card or other incentive). Someone should take notes even if the session is recorded, in case there is a problem with the recording. You may or may not want the note taker to help with facilitation; make sure that decision is made and understood ahead of time. Avoid having many observers, since this can make participants uncomfortable. It is best if your team members are not affiliated with a service provider. Though you won't be asking participants to evaluate individual providers by name, you will be asking people about their experience in obtaining services. They are likely to be less comfortable or honest if they feel something they say may be reported back to their case manager or other provider staff. Moderators should be knowledgeable but should not bias the discussion by sharing their own views.

While a "match" between moderator and group is not essential, team members with some characteristics in common with participants, particularly race/ethnicity, approximate age, and gender, can help participants feel comfortable sharing their views and experiences – for example, a woman for a focus group for women, a bilingual Latino for a group of Latinos, or a young male moderator for a group with young men. If the focus group will be conducted in a language other than English, look for a bilingual/bicultural moderator rather than an interpreter. Be sure the moderator has appropriate fluency and knowledge of terms related to the topics covered in the focus group – including HIV and RWHAP terminology.



REMOTE FOCUS GROUP TIPS:

- Be sure the moderator and team are familiar with the remote platform and how to use basic components like the chat room. At least one member of the team should have the skills to handle any technical issues.



Steps in Planning and Conducting a Focus Group

Here is a ten-step process for planning and implementing a focus group.⁵

- 1. Do initial planning.** Agree on purpose and number of focus groups planned, and the issues to be explored. If the focus group will be remote, consider the implications for size, duration, and process. Be sure there is agreement on how confidentiality will be protected.
- 2. Determine the desired participant “mix” and composition of each focus group** (e.g., race/ethnicity, gender, income, age, geographic area of residence, and other factors based on the purpose of the focus group, such as care status, co-morbidities, or whether the individual has children). Focus groups typically work best when participants have certain common characteristics. For example, it is often harder to get frank responses and full participation in a mixed-gender group.
- 3. Develop a strategy for recruiting and screening potential participants.**⁶ Think about how you will let people know about the focus group opportunity, and how you can partner with health care providers, community-based organizations and other groups to reach potential participants. Decide what incentives to provide (e.g., gift cards, transportation stipend). Typical incentives might be a \$20 grocery or big box store gift card, and a cash payment to cover transportation. If you don't have enough money to provide incentives, you can still use focus groups. Sometimes stores will donate gift cards to nonprofit organizations. Communities have been successful in recruiting people for focus groups when providing lunch or refreshments, transportation reimbursement, and a referral to care or other useful information, rather than a gift card.

10 STEPS IN FOCUS GROUP PLANNING AND IMPLEMENTATION:

1. Do initial planning
2. Determine desired participant mix and composition
3. Develop a strategy for recruiting and screening participants
4. Select the moderator/facilitator and team
5. Develop a “script” or guide
6. Recruit and screen participants
7. Arrange logistics
8. Conduct the focus group
9. Debrief
10. Prepare the report



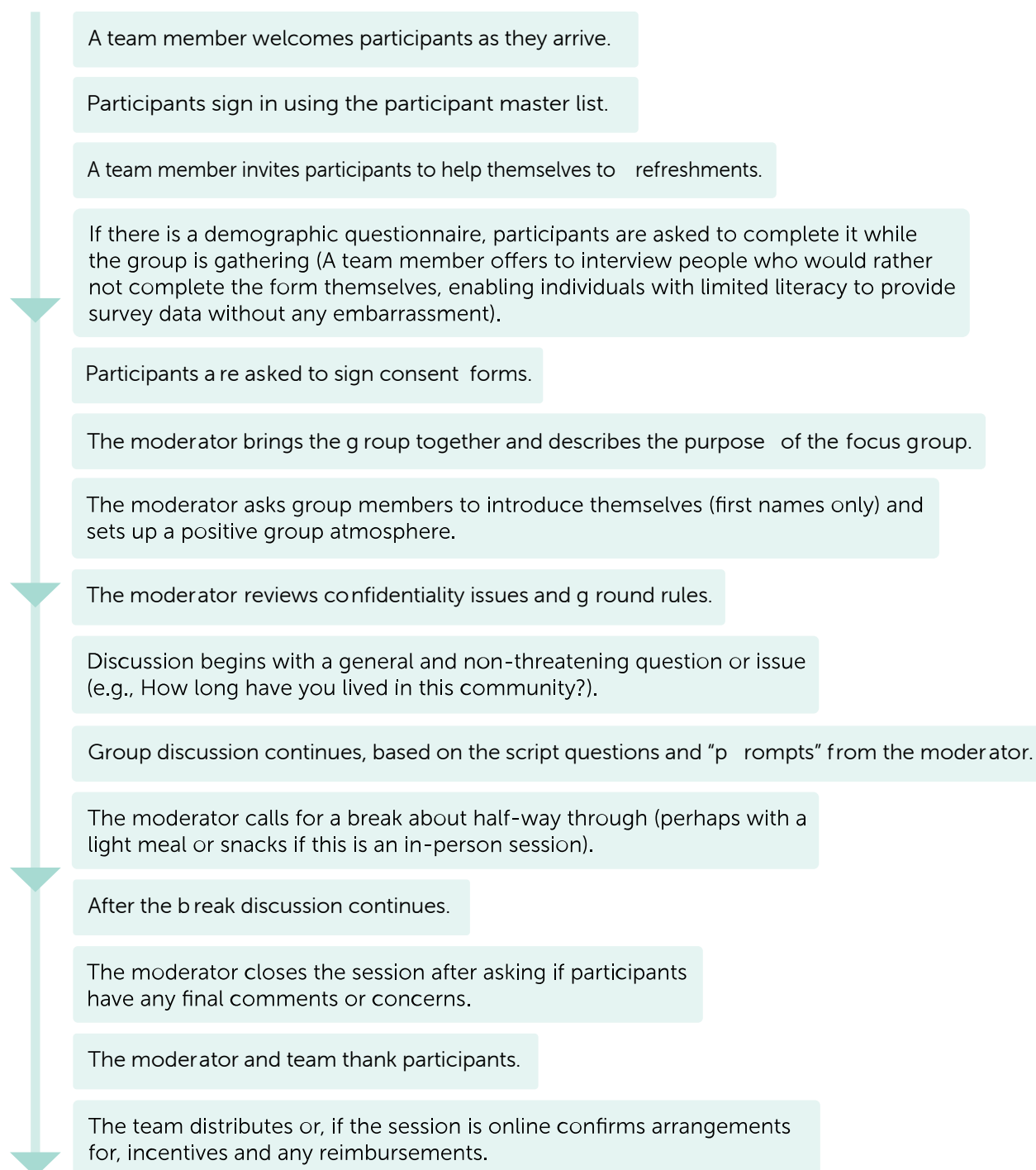
- 4. Select a trained moderator/facilitator and supporting team.** The moderator should be an effective facilitator with prior focus group experience, knowledgeable about the topic area, and appropriate for specific focus group participants. Also, arrange for at least one additional person who will take notes on the discussion, observe reactions during the session and help with logistics. You may want a trained consumer to be the primary moderator, but have a trained researcher or planner assist, take notes, and prepare the report. Be sure the team has time to plan together, agree on who does what, and review arrangements and the script once it is developed.
- 5. Develop a “script” or guide for the focus group.**⁷ If you are planning to conduct multiple focus groups for different populations, include a common set of questions for all groups so you can compare the responses, but add questions appropriate to each specific focus group population. For example, if you do a focus group in a language other than English, ask participants whether language differences are a barrier to care. If one focus group targets people with HIV who are parents, ask whether lack of child care is a barrier for them. If your focus group targets LGBTQ people with HIV or community of color focus group participants, ask about service provider cultural competence or unequal treatment. In addition to the discussion, you can develop a brief questionnaire to get some basic demographic information about focus group members.⁸ If you conduct the focus group remotely, you can use polling to obtain similar information, but may want to do it late in the session, after some trust has been developed. Be sure to emphasize that you will not record individual responses, just the total of all responses from participants.
- 6. Recruit and screen focus group participants while other planning is ongoing.** Talk to potential participants to ensure that they meet your established criteria. Tell them about the incentives (e.g., gift card) being offered. Be sure to ask about language preferences and identify special needs. If the focus group will be online, explore this issue to be sure potential participants have needed access to the Internet – and be prepared to cover the costs of extra data use if necessary. Work in partnership with service providers, community-based organizations or other established groups (e.g., support groups, people with HIV caucuses) to help you recruit participants. Do not simply send out a flyer and hope people come; get names and contact information and screen individuals to be sure they meet your participation criteria. If recruitment is difficult, consider asking people who agree to participate if they can recommend someone else, then screen that person. If you want 12 participants, recruit 15-18 to allow for late cancellations or no-shows.



- 7. Arrange logistics.** Set a time and arrange for a location (or online platform) for each focus group that is safe, accessible and convenient for its specific participants. Arrange for transportation assistance if needed, and order refreshments. Remember that the ideal location or time for one population group may be completely inappropriate for another. The most comfortable physical setting is a room that provides privacy and includes a single table big enough for the participants and the moderator and note-taker to sit around. Be sure there is a place within the room to set up refreshments.
- 8. Conduct the focus group.** Implement planned logistics and follow the script. Follow all planned procedures, from registering participants to getting consent forms signed, managing the discussion, and providing any reimbursements and incentives. If the focus group is online, record the session and arrange to send reimbursements and incentives.
- 9. Debrief after the focus group.** As soon as possible after the focus group, have the focus group team debrief in person or online, and include the individual(s) from the PC/PB committee overseeing the focus group process. This is especially important after the first focus group. Review how the focus group went, decide whether the script was too long or any questions were missing or need clarification, and determine any other needed changes before the next focus group.
- 10. Prepare the focus group report.** If you are conducting multiple focus groups, agree on a format for analysis and reporting to be used for all focus groups, to facilitate comparisons and ensure consistent levels and types of information. Be sure that your report does not use participant names – not even first names or nicknames used by participants – and maintain confidentiality. Prepare the report as soon as possible after focus groups are completed, and have it reviewed by all members of the team.⁹



TYPICAL FLOW OF A FOCUS GROUP





References

- 1 Based on materials prepared by Emily Gantz McKay for Mosaica under Project Consumer LINC: Linking Individuals to Needed Care, a cooperative agreement with the HIV/AIDS Bureau; significantly revised in 2020 for JSI Planning CHATT.
- 2 For other views on focus group size and related factors, see Caroline J. Oates & Panayiota J. Alevizou, "Participants in a Focus Group," Chapter 4 in *Conducting Focus Groups for Business and Management Students*, Sage Publications, 2018, at https://www.sagepub.com/sites/default/files/upm-binaries/24056_Chapter4.pdf;
 "Helpful Hints for Conducting a Focus Group," Office of Institutional Research and Assessment, Central Connecticut State University, at <https://www.ccsu.edu/oira/assessment/files/FocusGroupsHints.pdf>; and K.L. Becker, "Community Health Decision-Making: the Power of Focus Groups in Rural Communities," July 2017, at <https://www.omicsonline.org/open-access/community-health-decisionmaking-the-power-of-focus-groups-in-ruralcommunities-2161-0711-1000542.php?aid=91728>.
- 3 It is helpful to schedule with participants based on the total time commitment you want from them – 2 hours will allow almost 1½ hours for actual discussion, which is often suggested as the appropriate maximum. Some experts recommend shorter focus groups for adolescents versus adults; for example, the UCLA Center for Health Policy Research suggests one hour for adolescents and two hours for adults, assuming a group of 6-12 participants. See Section 2. Focus Groups, at https://healthpolicy.ucla.edu/programs/health-data/trainings/Documents/tw_cba21.pdf.
- 4 See Attachment 1: Sample Consent Form.
- 5 See Attachment 2: Focus Group Planning Template.
- 6 See Attachment 3: Sample Recruitment and Screening Plan and Criteria for ideas.
- 7 See Attachment 4: Sample Focus Group Script.
- 8 See Attachment 5: Sample Demographics Questionnaire.
- 9 See Attachment 6: Sample Format for a Focus Group Report.
- 10 See Attachment 6: Sample Format for a Focus Group Report.

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