

Listening to Learn:
**Using Focus Groups
to Strengthen AD
Initiatives**

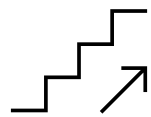


A photograph of three white darts with white flights, positioned on a white target board. The darts are arranged in a slightly curved line, with the central dart pointing directly at the bullseye. The target board has concentric circles and a central bullseye. The background is a soft, light gray.

Goals for This Session



Understand how focus groups can **strengthen AD project design**



Explore **practical strategies for planning, facilitating, and analyzing** focus groups



Review **examples of how focus group findings** can inform detailing content

The Case for the Patient Voice

- **Statistics only convey so much**
- People are **more than just numbers**
- The patient voice can **counteract misconceptions about groups of people**
- Patients are **experts on their own experiences**
- Incorporating the patient voice into your detailing campaign **honors their humanity**
- **Ensures that we don't "miss the mark"** in educating clinicians about what patients actually need

Pause & Reflect

In 2022, 54.6 million people needed substance use treatment.

Only 1 in every 4 of them got it.
(13.1 million)

Centers for Disease Control and Prevention

In your mind, rate how compelling you think this statistic is to motivate behavior change.

1 = Not very compelling

5 = Somewhat compelling

10 = Very compelling

Pause & Reflect

“Hospitals treat us horribly. [I’ve] seen my friends risk their lives with bad infections because they don’t want to go to the hospital. They’ll just find something wrong with you so they can boot you.”

“I went to 5 rehabs last year and now there is a note at [hospital name] that I don’t have psych problems, it’s drugs, so I can’t get help or [be] admitted. The best I ever felt was after being admitted to psych, I got stabilized and I can’t get back there.”

In your mind, rate how compelling you think these statistics are to motivate behavior change.

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The Power of Qualitative Data



- Qualitative data is **just as rigorous as quantitative data** (when collected and analyzed systematically) and often more actionable for tailoring interventions to specific populations of patients
- Qualitative data **reveal context, emotions, and lived experience** that quantitative data can't capture, especially around stigma and barriers to care
- Storytelling through qualitative data helps shift clinician behavior by **humanizing data and deepening empathy**

What is a Focus Group?

- A **qualitative data** collection method where a facilitator:
 - Interviews **6-12 people** who share **similar characteristics** that a researcher wants to study
 - Guides a **60-90-minute group interview**
 - Creates an **environment** that encourages **engagement** and **sharing** from participants



Hosting Focus Groups: Participant Recruitment

- **WHO?** Think about the AD intervention you're building. Which **patient population** does it benefit?
 - Determine the characteristics of your desired participants. Screen participants to ensure they meet your desired criteria.
- **HOW MANY?** Identify the **number of participants** you want in your focus group.
- **HOW TO FIND?** **Recruit participants** through your own organization, community organizations, social media, professional networks, or existing advisory structures.



Hosting Focus Groups: Discussion Guides

- Acts as a “**road map**” for the facilitator
- An **outline of topics** and **open-ended questions** that are clear and aligned with your objectives
- **Examples of focus group questions:**
 - *“What do you think people get wrong about X?”*
 - *“What do you think is most important for people to know about how Y impacts how people are treated by clinicians?”*
 - *“What might be different if clinicians got direct feedback from patients who Z?”*



Hosting Focus Groups:

Budget Considerations

- **Virtual vs. in person focus groups**
- **Compensate participants** for their **time** and **expertise** (*treat people with lived experience as experts!*)
 - Market value for other experts in this area
- **Data processing & analysis**
 - Transcription
 - Coding/themes

Hosting Focus Groups:

Human Subject Considerations

- Ask leadership about **guidelines** for working with **human subjects**
- **Recording permission**
- Develop a **consent form.**
Example →

Focus Group Consent Form

Suggested Format

This document provides a suggested format for a focus group consent form and may not be applicable to all studies. Please contact the Clemson University Institutional Review Board for specific questions regarding consent forms.

Purpose

You have been invited to participate in a focus group sponsored by [name of unit, department, or program] under the direction of [name of responsible party or individual]. The purpose of this focus group is [explain research questions to be addressed]. The information learned in this focus group will be used to [explain how the information will be utilized in the future].

Procedure

As part of this study, you will be placed in a group of 6 – 12 individuals. A moderator will ask you several questions while facilitating the discussion. As approved through Clemson University's Institutional Review Board, this focus group will be audio-recorded and a note-taker will be present. However, your responses will remain confidential, and no names will be included in the final report.

You can choose whether or not to participate in the focus group, and you may stop at any time during the course of the study.

Please note that there are no right or wrong answers to focus group questions. [Name of unit, department, or program] want(s) to hear the many varying viewpoints and would like for everyone to contribute their thoughts. Out of respect, please refrain from interrupting others. However, feel free to be honest even when your responses counter those of other group members.

Benefits and Risks

Your participation may benefit you and other [name relevant groups] by [list potential improvements]. However, no risks are anticipated beyond those experienced during an average conversation.

Confidentiality

Should you choose to participate, you will be asked to respect the privacy of other focus group members by not disclosing any content discussed during the study. Researchers within [name of unit or department] will analyze the data, but—as stated above—your responses will remain confidential, and no names will be included in any reports.

Contact

If you have any questions or concerns regarding this study, please contact:

[Name of Responsible Party]
[Email address]
[Phone number]

Clemson University Institutional Review Board
223 Brackett Hall, Clemson, SC
(864) 656-1525

I understand this information and agree to participate fully under the conditions stated above.

Sign name: _____ Date: _____

Print name: _____

Hosting Focus Groups: **Limitations**

- **Generalizability**
 - Findings from focus groups are often not representative of the larger population
- **Group Opinions**
 - Participants may agree with dominant opinions or hesitate to share differing views
- **Facilitator Influence**
 - The facilitator's tone or phrasing can unintentionally influence participants' responses
- **Social Desirability Bias**
 - People may give answers they think are socially acceptable rather than what they truly believe, especially on stigmatized topics
- **Data Complexity**
 - Qualitative data from focus groups can be difficult and time-consuming to analyze
- **Limited Depth**
 - Focus groups may not allow for deep exploration of individual perspectives

Hosting Focus Groups: Using the Data

| Broad Issue | Issue Identified by Focus Group Participants | Key Message |
|---|--|--|
| <p>People who use drugs feel unheard and are treated unfairly</p> | <p><i>"I'd be more comfortable if I had somebody who walked in my shoes. A doctor who knows what it's like to go through withdrawals and the cravings, and be able to help us get the exact treatment that we need. [...] Just doctors treating me like a real person."</i></p> | <p>Identify opportunities to reduce potential harms using a patient-centered, trauma-informed approach</p> |

"The Power of WE: Elevating the Voices of People with Lived Experience"

Mary Hightower

Regional Health Specialist

*Iowa Department of Health &
Human Services*

Darla Peterson

Regional Health Specialist

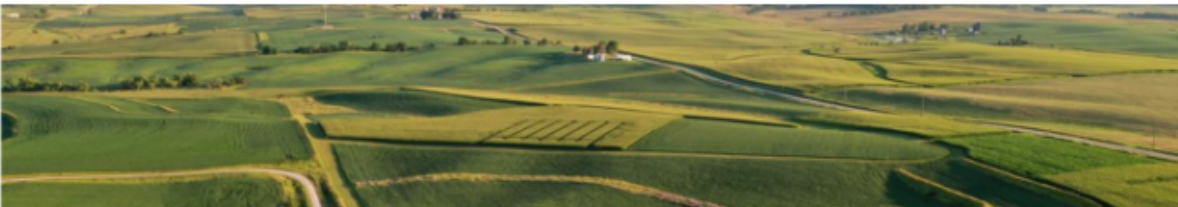
*Iowa Department of Health &
Human Services*

"Professional people like doctors, and lawyers and disability see my background my history of drug abuse and my history of living in the streets they would see that and automatically wouldn't want to help me."



HIV-Related Stigma in Iowa

- **66%** of respondents work hard to keep their HIV a secret.
- **78%** worry about people discriminating against them because of their HIV status.
- **33%** of respondents experienced someone physically back away from them when they learned they have HIV.
- **27%** said they waited to get tested because of the stigma associated with HIV.



Ways to Involve People with Lived Experiences

- ▶ People with lived experience asked Iowa HHS to hire AD for rural communities to discuss HIV, STI, and Hep
- ▶ Invite them to co-present during training or outreach
- ▶ Use quotes or short videos detailing visits
- ▶ Include them on advisory boards, planning teams, community meetings, or group counseling sessions
- ▶ Ask for feedback on provider messaging and materials
- ▶ Support paid roles for lived experience advisers

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Explore our website for examples of patient inclusion in detailing campaigns.



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[COMMUNITY](#)

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A photograph of two women sitting at a white table in a clinical or office setting. The woman on the left has short, light-colored hair and is wearing glasses and a striped shirt. The woman on the right has dark, curly hair and is wearing a white lab coat with a stethoscope around her neck. They are both smiling and looking at each other. On the table in front of them is a tablet computer, a glass of water, and a blood pressure cuff. A desk lamp is visible in the background.

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narcad.org/ad-summit-series



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THANK YOU.

Feedback or questions?



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