

Community Engagement Studio Agenda

Sample: Between 5 and 10 community members (goal 6-8) who are postmenopausal and have had, or frequently have, UTIs will participate in community engagement studios at a community location. Community members will provide their expertise on what they think would be a potentially acceptable study design for a trial aimed at preventing UTIs. Two studios will be conducted in English and two will be conducted in Spanish. Studios will be conducted in-person, with a facilitator and co-facilitator. Robust notes will be taken. No audio or video recording will be permitted.

Design: Community members will be welcomed to the session. There will be 6 sections for the session. The first section will be an introduction to the studio goals, ground-rules, outline, and personnel. The following 4 sections will review various study design aspects (1: general thoughts/reactions to hearing about the study; 2: trial design; 3: outcome measures; 4: urobiome aspect). The final section will consist of an opportunity for summarization, thanks, follow-up preferences, and further comments.

Process: This agenda is a guide for facilitators. The intent statements explain the scope and goals of each section and precede the major queries. Facilitators will use this agenda to ensure that the same broad topics are covered in the various studios, but still allows a natural conversation to flow. Topics that arise in line with the intent statements will be further explored in the studio they emerge in, and in future studios.

Overall Intent: The overall intent of the studios is to gain community feedback regarding study design and acceptability. We are seeking community input to see how the proposed trial can be adapted to meet the needs of those whom it is being designed to help, and ensure that the study, and its eventual findings, are acceptable and relevant to patients with recurrent UTIs. Community members will provide their initial reaction to hearing about the trial, points that need further clarification, areas of potential concern, their opinions on the relevancy and ease of use of various outcome measures, thoughts on how study procedures could be optimized for ease and acceptability, and opinions regarding the urobiome component. Facilitators will solicit this feedback, and also potential solutions to concerns raised. This data will help inform the design of a trial that would be more realistically able to be implemented in our community. Facilitators will rely heavily on probes asking, “What else?” “Anything else?” “What do you mean by...?” and “Tell me more..”

Section 1 - Preliminaries and Introduction

Intent: The goal of this section is to welcome the community members and orient them to the session. Prior to starting the session, community members will have been provided with relevant study materials and the studio process and confidentiality measures explained. The facilitators will introduce their roles (i.e., as facilitators who are seeking the expertise of community members) and answer any questions about the studio format of interaction.

1. Thank the community members for coming.
2. Introduce facilitator roles (to guide the conversation; have certain questions we do want to get to, but otherwise hope it will be a relatively casual conversation, community members are the experts, we want to learn what makes sense to them, there is no “right” answer, etc.)
 - Include statements including that the goal is to learn how people in the community think about things, what the facilitator thinks/believes/feels is not relevant, as the goal is to understand what the participant thinks

- There is no medical care being provided at the studio, and we cannot answer specific personal medical questions during the session
- We will treat all information shared with the utmost confidentiality, no recording is planned or permitted. However, we cannot control what other participants do after they leave, and we want everyone to be mindful about sharing things they may later feel uncomfortable about.
- We are allies trying to learn what works and does not work for the community
- Some questions may seem obvious -- we want to hear things in your words
- Some questions may be thought provoking -- be as honest and open as you're comfortable with
- Some questions may be hard to understand -- we want to know when this happens
- If uncomfortable -- okay to "pass" or "skip" questions/items/topics
- Hope to have a natural conversation

3. Explain the process: we want to hear your opinions and thoughts about this study and what it is asking: we want to have you discuss what is important to you, including what you would want to know about this study and what you would want to learn from this study.

4. The goal is to finish this conversation in about 1-2 hours. In order to cover all topics, we might choose to shorten a discussion on one subject in order to move along to the next topic.

5. We are taking rigorous notes -- we aren't keeping a formal record of who says what, rather we want to ensure we are writing down all the important points that people will bring forth -- not who says what. Every point is equally as important.

6. Feedback learned here will be used to change the way the study is done, so that it can help more people by being realistic

7. Facilitator: Answer questions

8. Overview of the Study -- PowerPoint with a high-level description of the study, including objectives and scope.