

FDA Online Study

Phase IV – Focus Group Guide

Overview. The focus group will comprise the following steps:

1. **Consent Form:** Ask participants to read and sign the consent form.
2. **Survey:** As participants are seated, they will fill out a brief background survey.
3. **Welcome:**
 - a. **Welcome**—the moderator will welcome the participants and explain the purpose of the focus group session.
 - b. **Ground rules**—the moderator will provide guidance to ensure that participants are allowed to speak without interruption by other participants.
4. **Warm-up:** Participants will introduce themselves and provide a little information about themselves.
5. **Discussion:** In the focus group, participants will discuss the following topics:
 - a. Membership in online health communities and on social media sites
 - b. Activities within online communities
 - c. Use of online community information to make health decisions
6. **Closing**

Welcome (5 min)

Thank you for coming today. I'm _____, and I'm from RTI International. The purpose of this focus group is to learn more about how people use online health communities and other online resources to make health decisions.

Your experience and perspectives are very important to us, and we genuinely appreciate your time today. This session will last about two hours.

First, I want to cover two housekeeping items:

- **Audio Taping.** You have probably noticed the microphones in the room. They are here because we are audio taping today's session. At the end of all our focus groups, we want to summarize our findings. I want to give you my full attention and not take a lot of notes, so I will refer to the tape when writing the summary.

- **Client Observation.** Behind me is a one-way mirror. Some of the people working on this project are observing this discussion so that they can hear your opinions directly from you. However, your identity and anything you personally say here will remain confidential. Your names, addresses, and phone numbers will not be given to anyone, and no one will contact you after this group is over. When we write the summary, we will not refer to anyone by name.

Before we begin, I want to review a few ground rules for today's group discussion:

1. **Honest Opinions.** Most importantly, **there are no right or wrong answers.** We want to know your honest opinions, and those opinions might differ. This is fine. We want to know what each of you thinks about the issues we discuss.
2. **Speaking.** Please try to **speak one at a time.** I may occasionally interrupt you when two or more people are talking in order to be sure everyone gets a chance to talk and that responses are accurately recorded.
3. **Cell Phones.** As a courtesy to everyone, **please turn off your beepers, cell phones, and pagers** or place them on vibrate.
4. **Restrooms.** If you need to go to the **restroom during the discussion, please feel free to leave;** however, I'd appreciate it if you would go one at a time.
5. **Questions.** Do you have any **questions** before we begin?

Warm up (5 min)

I would like to begin our discussion by asking you to introduce yourself. Please tell us:

- Your first name
- Your favorite online source for health information

I'll start. I'm _____, and my favorite source is _____. Let's continue to my left. (Allow the group members to individually share information about themselves, keeping time so that no more than 5 minutes is used for this process).

Questions

Membership / Reasons for Joining

1. How often do you search for health information online?

2. What online health communities have you heard of? By online health community, I mean a site where patients and others gather to learn about and discuss health issues or illnesses.

3. What online health communities have you joined in the past five years?

Probes or Follow-Ups

- What types of information do you search for (e.g., illness information, treatment options, etc.)

- Who is the information for—yourself or someone else?

- How did you learn about these communities?

- How active are you in these communities? What does it mean to be “active”?

- How many people are members of these communities?

- What types of people belong to these communities (e.g., patients, caregivers, healthcare providers)?

- If you had to pick your favorite online community, which one would you choose? Why?

- [*Alternative: If you could be a member of only one online community, which one would you pick?*]

4. What first motivated you to join an online community?

- What were your other reasons for joining?
- [IF NEEDED] How important was your health status in the decision to join a community? A family or friend's health status?
- For those who've been affected by an illness—personally or through loved ones—at what points during the illness did you join an online community (e.g., suspicion, initial diagnosis, treatment decisions, etc.)?

5. Are there any of these communities you haven't visited in the past six months?

- Which communities have you stopped visiting?
- What prompted you to stop visiting those communities?

Community Selection

6. How did you learn about the online communities that you joined (e.g., provider, family member, friend, advertisement, other Web site, etc.)?

- What characteristics or features did you look for when choosing a community?
- What features were most important to you?
- What characteristics or features did you want to avoid?
- Did you compare similar communities before selecting one?

7. When selecting an online community, how concerned were you about its reputation?

- What does it mean for a community to be “reputable” or “trustworthy”?
- [IF NEEDED] How can you tell if a community is reputable?
- How easy or difficult was it to find reputable communities?

Activities and Participation

8. How often do you visit your favorite online community?

- Do you visit on a regular schedule?
- [IF YES] What schedule do you follow?
- [IF NO] What prompts you to visit?

9. What types of activities do you participate in within your communities (e.g., share links / news, ask questions, post personal health updates, chat with others, etc.)?

- What activities are most helpful to you?
- Do your communities have any special tools available (e.g., symptom tracker, physician locator, diary, etc.)?
- [IF YES] How often do you use these tools?

10. How easy is it to share information within your online communities?

- How well can you control who views the information you share (e.g., only a sub-group of members)?
- How well can you control the types of information you receive and view?

11. How concerned are you about privacy within your communities?

- What do you do to keep your personal information private?
- How does the community keep your information private? Who has access to it?
- How would you know if the community sponsor wasn't protecting your privacy?
- How have privacy concerns affected your participation?

12. How often are you an active participant (e.g., someone who posts information or moderates discussions) versus a passive participant (e.g., someone who reads or searches for information)?

- How do you decide whether to actively share information, lead discussions, etc.?
- What would make you more likely to actively participate in your communities?

Discussion Topics

13. What are the most common or popular topics discussed in your communities?

- How are the topics chosen?
- What types of topics are most useful to you? Least useful?
- How well do your communities meet your information needs?

14. How easy or difficult is it to understand the information that others share?

- How often do they use unfamiliar terms? Clinical language?
- When have you needed outside resources to help you understand information that others shared?

15. How often do you learn new information from online communities?

- How often do you learn about new resources (online or offline)?
- What would you say is the most important thing you've learned so far?

Treatment Options and Information Sources

16. How often do people discuss treatment options?

- What types of treatment do people discuss (e.g., medication, surgery, behavioral therapy)?
- What types of information do people share (e.g., personal experiences, news articles, medical reports)?
- When a treatment option is discussed, how often is there a balance between the advantages and disadvantages of the treatment?

17. How often do people discuss prescription drugs in your online communities?

- What types of information do they discuss (e.g., drug comparisons, side effects, etc.)?
- Who provides information on prescription drugs (e.g., patients / members, providers, pharma reps)?
- How often does someone share their personal experience taking a drug?
- When prescription drugs are discussed, how often is there a balance between the advantages and disadvantages?

18. How often do people cite sources when discussing treatment options?

- What sources do they cite?
- How often do they include links to these sources?

19. When you learn about a treatment option from your communities, what next steps do you typically take?

- How often do you seek out more information on the treatment?
- Where do you look for more information on the treatment?
- How do you decide if those sources are credible or trustworthy?

20. How have you used information from your communities to make treatment decisions?

- How often do you share this information with your healthcare provider? How has he or she reacted to it?
- Walk me through your decision process.

Outside Participants

21. How often do non-members participate in your discussions (e.g., healthcare providers, pharmaceutical reps)?

- What types of individuals participate?
- How do they identify themselves as a non-member?
- How comfortable are you having these individuals participate in discussions?

Branded Drug Communities

22. Have you ever joined or visited online communities sponsored by pharmaceutical companies?

- [IF YES] Which communities did you join / visit?
- [IF YES] Why did you choose to join or visit those communities?
- [IF NO] Why not?

23. How are these communities different from others that you've joined?

- Are you more or less active in them than in other online communities?

24. What types of information do these pharma-sponsored communities share?

- How easy or difficult is it to understand the information?
- How trustworthy are these communities? How confident are you that your information remains private? Why do you say that?
- When these sites mention a treatment option, how often is there a balance between the advantages and disadvantages of the treatment?

Closing Questions

25. How would you explain the advantages and disadvantages of online health communities to a friend?

26. If you could create your ideal online health community, what would it look like?

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Closing (2 min)

Thank you again for participating in today's group. Your experiences and input were extremely valuable in helping us to understand how individuals participate in online health communities.

Let's get you checked out at the front desk.