Fibromyalgia Last updated 10/22/10

DRAFT Moderator's Guide

I. Introduction of Moderator

- A. Independent consultant hired to moderate these discussions
- B. No vested interest in receiving any particular point of view

II. Ground Rules

- A. You have been asked here to offer your views and opinions; everyone's participation is important
- B. Audio/observers
- C. Speak one at a time
- D. No side conversations
- E. No right or wrong answers
- F. It's OK to be critical. If you dislike something or disagree with something that's said, I want to hear about it.
- G. All answers will be kept private to the extent provided by law, so feel free to speak your mind.

III. Brief Explanation of the Focus Group Purpose/Introduction of Topic

We have brought you here today because you all share the experience of having experienced either fibromyalgia or otherwise longstanding, chronic pain. We are interested in your stories, as they relate to your medical condition, your experiences with the health care system, and your experiences with treatment options. There are no right or wrong answers so please feel free to speak your mind. It is okay if there is disagreement—that will provide us with important information too.

IV. Participant Introductions

To begin, I'd like to have you go around the table and introduce yourselves. Please give me:

- a. your first name only
- b. how long you have had chronic pain
- c. hobbies

V. Preliminary Questions

1. Please describe briefly your experience with the disease. Please keep in mind that we have nine people to hear from, so please keep it brief and please do not be offended if I

stop you early.

- a. How long did it take to get diagnosed?
- b. How old were you when symptoms started?
- 2. What have you learned in your time dealing with this disease?
 - a. What do you wish you had known in the beginning?
 - b. What would you tell another person who is newly dealing with this disease?

VI. Treatment

- 1. Who do you get medical care from? Please tell us all members of your "medical team," for instance, general doctor, specialists, nurses, acupuncturists, etc.
- 2. How do you feel about your medical team?
- 3. Are you satisfied with your doctor or doctors?
 - a. How many doctors have you had during your time with fibromyalgia?
 - b. Have you ever switched doctors?
 - -Why or why not?
 - c. Have you felt as if you had to be a squeaky wheel, really standing up for yourself?
 - -In what way or ways?
- 4. Can you remember an interaction with your healthcare provider where you suggested a specific treatment?
 - a. If so, please describe.
- 5. What treatments have you tried for fibromyalgia?
- 6. Have you ever switched treatments?
 - a. What made you switch treatments (e.g., lack of efficacy, side effects)?
 - b. What was the result?
- 6. Have you ever seen treatments for fibromyalgia or chronic pain advertised?
 - a. What treatments?

- b. Where have you seen them advertised?
- c. Do you ever receive emails or materials through the mail from pharmaceutical companies? If so, please describe.
 - d. What do you think of the prescription drug treatments for fibromyalgia?
 - e. What do you think of the advertising for these treatments?
 - f. Have you ever taken an action after seeing an advertisement for a fibromyalgia drug? If so, please describe.

VII. Ad Exercise

Show participants (real or mock) DTC advertisement(s) for fibromyalgia.

- 1. What is the main message in this ad?
- 2. What do you think the drug advertised in this ad will do for you? (Prompt to expand)
 - What in the ad makes you think that?
- 3. What actions would you take, if any, after seeing this ad?
- *4.* Is this ad similar to other ads you've seen for fibromyalgia treatments? How or why not?

VIII. False Close

Moderator checks with observers to see if they have additional questions or clarifications.

IX. Close

Thank you for spending your time with us tonight. Your comments are very helpful.