

Appendix B - Pilot Test Evaluation Protocol for Patients and Family Members

AHRQ – Building Diagnostic Safety Capacity

Patient Focus Group Script – Pilot Test Evaluation

MedStar Health Research Institute (MHRI) will conduct up to twenty (n=20) focus groups (one per practice) with patients during Pilot Testing. We will aim to recruit patients in the following manner:

- 6-8 patients, family members, and/or caregivers per primary care practice.
- Patients/family members who have been exposed to the intervention
- A diverse group of patients in terms of age, sex, race/ethnicity, income, education, and current self-reported health status.

Recruitment Criteria

Patients and family members who have been exposed to the intervention (i.e. attended the primary care practice during the period of implementation) will be eligible to participate in the focus groups. MHRI team members will work with the practice coordinators to identify and recruit patients to participate in the focus groups.

Focus Group Goals

The goals of the focus groups will be to:

- Obtain feedback on the intervention **patient-focused** materials
- Obtain feedback on the barriers and facilitators encountered for each intervention
- Obtain feedback on satisfaction with interventions
- Obtain feedback on receptivity and enhancements to intervention to improve adoption

Focus Group Materials

- Copies of the patient-focused materials implemented by the practice during the period of implementation
- Informed consent documents
- Paperwork for processing the Participant stipends
- Digital recorder

Focus Group Location

Focus groups will be conducted at a location within the practice’s community. Locations may include libraries and/or community centers.

Participant Stipends

Upon arriving at the focus group location and after the completion of the informed consent process, all participants will complete the required paperwork (W9) to receive the stipend for participation. The stipend for participation will be \$25.

Informed Consent Procedures

Participants will complete the informed consent process at the time of arrival to the focus group.

Proposed Agenda – Patient Focus Group

Focus Groups are approximately 60 minutes each.

<u>Agenda</u>	
Introduction	5 minutes
Background	10 minutes
Review Materials	10 minutes
General Experience with Intervention (satisfaction/barriers/enablers)	20 minutes

Enhancements	10 minutes
Closing	5 minutes
Total	60 minutes

Patient Focus Group Script – Pilot Test Evaluation

[bracketed text will depend on interviewee and topic]

WELCOME AND INTRODUCTION

- Thank you for agreeing to participate in the focus group about the strategy to improve patient and family engagement to improve diagnosis.
- My name is [INSERT NAME OF INTERVIEWER] and I am the facilitator for today's conversation. I am here with [INSERT NAME OF PROJECT STAFF] and HE/SHE will be taking notes of our conversation.
- With your permission we will also be audio recording the session. This will help make sure that we don't miss anything that you say and can share with other people who are working on this project. The recording will be deleted after we have the notes transcribed and are sure we have captured all your comments accurately.
- TODAY/TONIGHT we will be asking you questions about your experiences with engaging with your care team on diagnosis.
- Nothing that you say or share today will impact your treatment or care from your doctor's/Nurse Practitioner's office. We will not share your name or anything that you say with them.
- Do you have any questions before we begin?

GROUND RULES

- We want to hear from everyone and want to hear your honest opinions. There are no wrong answers.
- If you have something to add to the conversation, please feel free to jump in. We do have a lot to cover so we will try not to spend too much time on any one topic.
- It is important that when you do jump in that we try to make sure that we only have one person talking at any time. This will help us hear everyone's thoughts and opinions.
- Any questions?

So, let's get started.

This survey is authorized under 42 U.S.C. 299a. The confidentiality of your responses to this survey is protected by Sections 944(c) and 308(d) of the Public Health Service Act [42 U.S.C. 299c-3(c) and 42 U.S.C. 242m(d)]. Information that could identify you will not be disclosed unless you have consented to that disclosure. Public reporting burden for this collection of information is estimated to average 60 minutes per response, the estimated time required to complete the survey. An agency may not conduct or sponsor, and a person is not required to respond to, a collection of information unless it displays a currently valid OMB control number. Send comments regarding this burden estimate or any other aspect of this collection of information, including suggestions for reducing this burden, to: AHRQ Reports Clearance Officer Attention: PRA, Paperwork Reduction Project (0925-XXXX) AHRO, 5600 Fishers Lane, Room #07M12, Rockville, MD 20857

BRIEF INTRODUCTIONS

I would like to start with some brief introductions. We will go around the table. As we go around, please tell us all your first name and something about yourself like your favorite hobby or television show.

BACKGROUND

That is great! I am really pleased to meet you all. I would like to jump right in and start asking for your impressions about improving the process of diagnosis.

DIAGNOSIS

1. How would you describe the process of discussing your healthcare symptoms with your doctor/nurse practitioner?
 - a. What goes well?
 - b. What could go better?
 - c. How would you change the encounter if you could to improve the process of getting a diagnosis?

- d. Can you describe what might help you to better engage with your clinicians to help share your symptoms?
2. How do you think that patients or their family members can engage with their healthcare team to improve the process of diagnosis?
- a. What about asking questions? Is there something that might help you ask questions easier during your encounter?
 - b. What do you do to prepare for your visit?
 - c. Do you ever forget to ask the doctor or nurse something during your visit?

Your doctor's office has been implementing a new strategy to improve diagnosis. We would like to ask you about your experiences with some of the materials you may have seen in your doctor's office.

3. What is the first thing that comes to mind when you see this [Agenda Setting Tool/Poster]?
- a. Have you seen these materials before?
 - i. Where exactly did you see them?
 - ii. Did you pick them up or ask anyone about them?
 - 1. Why? Why not?
 - b. Did you think they were helpful? Why/Why not?
 - c. What would make them more useful to you?
4. Can you describe for me how you used/would use the [Agenda Setting Tool/Poster]?
- a. Did you find it helpful?
 - b. What would have made it better?
 - c. Did you feel like you needed more information about why you should use it?
 - d. Were you able to get help if you needed it?
5. If you could change one thing about the materials, what would that be?
- a. If nothing to change:
 - i. Did you personally get a chance to use these tools?

- ii. Did your family member?
- iii. Can you describe their experience?

6. What about the format of the [Agenda Setting Tool/Poster]? Is there a better way for us to think about presenting the materials?

Is there anything else you would like to share about your experiences with the materials? If not, let's move on to learning more about your experiences with the Agenda Setting Tool/Poster.

7. We want to get some more information about your thoughts on [Agenda Setting Tool/Poster]. Where did you first hear about the [Agenda Setting Tool/Poster]?

- a. Who first brought it to your attention, your doctor, another organization?
- b. How long ago, or when did you first get introduced to the [Agenda Setting Tool/Poster]?

8. When you were first given the [Agenda Setting Tool/Poster] what did you think?

- a. How did you feel about using it?
- b. How did you end up using the [Agenda Setting Tool/Poster], or did you end up not using it after all?
- c. If no, what prevented you from using it? Time? Challenges with the materials?
- d. Do you plan on using the [Agenda Setting Tool/Poster] in the future? If yes, how. If no, why not? Is there something we could do to help you with making it more usable?

9. How easy or challenging did you find the [Agenda Setting Tool/Poster] to be?

10. Specifically thinking about the clinical encounter and getting a diagnosis, how did you think this the [Agenda Setting Tool] addressed safety for you?

11. And what about patient engagement, how did the [Agenda Setting Tool/Poster] help you to engage or increase your engagement in your care?

CLOSING

12. Those were all the questions I had today. Are there any questions that I should have asked that I did not?

Thank you for your time and participation in this interview. Your comments will be very helpful to this project!