

Personal Health Record (PHR) Focus Group Questions for Older Adults

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This is a focus group guide designed to be conducted with patients within a home setting. The tool includes questions to assess user's perceptions of personal health records.

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PHR Focus Group Questions for Caregivers of Older Adults

1. Distribute handout #1. Does anyone here keep a personal health record, either on paper or on the computer to track medication use and medical diagnoses for yourself or the person that you care for?
 - a. How do you keep a list of the medications that you share with all healthcare providers?
 - b. What is on the list?
 - i. Do you write down the reason for using the medication?
 - c. Do you share it with all physicians? Pharmacists? Nurses? Caregivers?
 - i. What barriers exist to sharing your medication list?
 - d. How are you able to keep the list of medications and medical diagnoses current/updated?
 - e. What about something like your glucose levels? allergies? test results?
2. Keeping in mind the medications and the things you do for the person that you care for....the next questions are focused on what we're trying to achieve by taking medications and how we keep up with that. Certainly better health and longer lives are the overall goals. We often have interim things we're trying to achieve like blood pressure control or going on a trip. So...
 - a. Do you and the physician or others set goals for the medications?
 - i. What kind of goals? Please share some examples.
 - ii. How do you know if you're meeting the goal/s?
 - b. Distribute handout #2. When I say "monitor how the medications are working for the person you care for"...what does that mean to you?
 - i. What types of things do you tell the physician if you are asked that question?
 - ii. Positive effects as well as side/bad effects?
 - c. When I say "monitor the effects of each of the medications"...what does that mean to you?
 - i. What types of things do you tell your physician if you are asked that question?
 - ii. What are some examples of desired effects ?
 1. How do you "monitor"?
 - iii. Side effects or unwanted effects?
 1. Do you report? Why would you NOT report it to your physician?
 - d. When I say "monitor the goals for each of the medications?"...what does that mean to you? For example, you might be trying to lower your blood pressure...do you know the exact number you want to reach?
 - i. What types of things do you tell the physician if you are asked that question?
 - e. (If needed because not clear from b-d, then ask) What are the differences between *monitor how your medications are working for you* versus *monitoring the effects of medications* versus *monitoring the goals of medications*?
 - f. Let's say that you know the blood pressure goal is 140/90...you take it and keep a record of it. If I say that I want you to be keep a record that you could share with the doctor of how treatment

goals are being met.....what is the best way to say that so that everyone will understand what I mean?

- i. Keep track of or keep a record of or write down
 - g. How do you [insert terminology from f] [insert whatever terminology we arrive at after questions b-d]?
 - h. [This could be 2 behaviors as monitor effects may be different than monitor goals....be prepared to separate and ask 2 separate questions about each for keeping track/recording.]
 - i. keeping track/recording.]
3. When I say symptom....is that clear? From Wikipedia...it is a physical condition which indicates a particular illness or disorder. Like a rash, cough, nausea...something you experience and notice that makes you think about whether you are OK or not.
 - a. What things influence how much you tell physicians about symptoms?
 - b. What if the person you care for had a new symptom that you thought was related to one of the medicines?
 - c. What would you do?
 - d. How would you monitor the symptom?
 - e. Would you write it down in some way?
 - f. Have you ever kept a symptom diary or log to monitor any condition?
 - i. How did you do that?
4. Doctors and pharmacists sometimes say “patients manage their medications” or you may be asked “how do you manage your medications?” What comes to mind when I say that...just tell me what you immediately think of.
 - a. Anything else?
5. How could a computer personal health record help you in managing the health of the person you care for?
 - a. What would help you to use a computerized personal health record and keep that information in one place...then you could give access to the health care providers to review it?
 - b. Prompts: Could you add information to a personal health record about...
 - i. Medications or medication list
 - ii. Medical conditions
 - iii. Allergies
 - iv. Treatment goals....progress toward goals
 - v. Adverse effects/side effects
 - vi. New bothersome symptoms
 - c. What barriers do you personally face in using a computerized personal health record?