

Introduction

My name is xxx, and I will be interviewing you today.

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Thank you for taking the time today to participate in this interview for A Disease Inclusive Pathway for Transitions in Care (ADAPT). ADAPT is an implementation initiative for the Home to Hospital to Home Transitions Guideline (H2H2H) focused on three of the six guideline elements: admit notification, transition planning, and follow-up to primary care. Our team is working on the development of a new survey called a patient reported experience measure, or PREM, to look at transitional care experiences with a focus on the follow up care provided in primary care visit and coordination with acute care. We have a draft of this survey, and as part of validating it in the pilot phase, we are looking for patient advisor feedback as a first step.

The goal of this interview is for you to reflect on a series of questions that ask about patient experience with care transitions in relation to your most recent admission/discharge within the past 2 years. Care transitions include the process of preparing for discharge while still in the hospital, returning home and managing your care in the community, and the transition of your care and/or follow-up with your primary care provider.

I received your consent form, thank-you for sending this to us. Do you have any questions about the information provided in the consent form?

We will be recording our conversation today and everything you say will be stored, transcribed, and analyzed without revealing your identity to anyone outside the research team. Do I have your permission to record this interview?

[Begin recording]

There are no right or wrong answers. If at any point today, you become tired or are uncomfortable you can end the interview at any time. You can skip any questions that you may not be comfortable answering. This interview should take approximately 1 hour to complete.

Your responses will be themed and brought back to you in a group session that you will be invited to once the results have been aggregated.

Do you have any questions before we begin?

I will start by asking a few questions about you so we have a better understanding about our volunteers who tested the survey:

1. What is your gender?
2. What is your age?
3. What is your ethnicity, or race?
4. What is your highest level of education?
5. Do you live in a metro/urban (over 25,000 people) or rural (less than 10,000 people) area?
6. Do you have personal lived experience with any chronic health conditions (e.g., heart failure or mental health)? (YES or NO)
7. Are you a key caregiver for someone with chronic health conditions? (YES or NO)
8. Do you have lived experience with a transition from hospital back to your home in the past 2 years? (YES or NO)
9. Did you feel like you were supported during your most recent transition in care? (YES or NO)
10. Do you have a regular primary care provider? (YES or NO)

We will be going through each question one at a time to give you time to think of how you would respond, then I will ask you a set of questions about your thoughts on the question before we move onto the next one.

The first set of questions are related to the discharge preparations that occur prior to leaving the hospital and returning home. Please take as much time as you need to answer each question, there is no time limit so please do not feel rushed. Please also keep in mind that I may ask you some repetitive questions, and I may ask some questions that seem like they have very obvious answers. I am not asking you because I think you don't know but rather to get as much information as possible so that we can make any necessary changes to the survey formats. If you have any comments about the survey please do not hesitate to share them with me, no matter how minor you may think they are. Are you ready to start?

Question 1 states: Before leaving the hospital, the discharge instructions I received from the hospital were clear and concise.

- Please read this question and let me know when you are ready to respond.
- What is your response to Question 1?
 - What does this response mean to you?
- Using your own words, what is this question asking about?
- What does the phrase "discharge instructions" in this question mean to you?
- What does "clear and concise" in this question mean to you?
- Was it easy or difficult to answer this question? If difficult, how was it difficult?
- Do you have any recommendations how to phrase this question?

Question 2 states: Before leaving the hospital, I was given information on who to contact for any symptoms that may require a need for urgent attention (e.g., specialist, family physician, homecare).

- Please read this question and let me know when you are ready to respond.
- What is your response to Question 2?
 - What does this response mean to you?
- Using your own words, what is this question asking about?
- What does the phrase “information” in this question mean to you?
- What does the phrase “urgent attention” in this question mean to you?
- Was it easy or difficult to answer this question? If difficult, how was it difficult?
- Do you have any recommendations how to phrase this question?

Question 3 states: Before leaving the hospital, I was given information on my medications including purpose and directions for use.

- Please read this question and let me know when you are ready to respond.
- What is your response to Question 3?
 - What does this response mean to you?
- Using your own words, what is this question asking about?
- What does the phrase “information on my medications” in this question mean to you?
- Was it easy or difficult to answer this question? If difficult, how was it difficult?
- Do you have any recommendations how to phrase this question?

Question 4 states: Before leaving the hospital, I was clear on when to follow up with my primary care provider.

- Please read this question and let me know when you are ready to respond.
- What is your response to Question 4?
 - What does this response mean to you?
- Using your own words, what is this question asking about?
- What does the phrase “clear on when to follow up” in this question mean to you?
- What does the phrase “primary care provider” in this question mean to you?
- Was it easy or difficult to answer this question? If difficult, how was it difficult?
- Do you have any recommendations how to phrase this question?

Question 5 states: Before leaving hospital, I had the support I needed arranged for when I returned home (e.g., my family or informal caregivers, homecare).

- Please read this question and let me know when you are ready to respond.
- What is your response to Question 5?
 - What does this response mean to you?
- Using your own words, what is this question asking about?

- What does the phrase “support I needed arranged for” in this question mean to you?
- Was it easy or difficult to answer this question? If difficult, how was it difficult?
- Do you have any recommendations how to phrase this question?

Question 6 states: Before leaving hospital, I felt confident to manage my care at home.

- Please read this question and let me know when you are ready to respond.
- What is your response to Question 6?
 - What does this response mean to you?
- Using your own words, what is this question asking about?
- What does the word “confident” in this question mean to you?
- What does the phrase “manage my care” in this question mean to you?
- Was it easy or difficult to answer this question? If difficult, how was it difficult?
- Do you have any recommendations how to phrase this question?

The second set of questions are related to the time after you return home after leaving the hospital but prior to any follow-up appointments in your community. Once again, please take as much time as you need to answer each questions. And just a reminder that if you have any comments about the survey please do not hesitate to share them with me, no matter how minor you may think they are. Are you ready to proceed?

Question 8 states: After I returned home, I was able to follow the discharge instructions given to me by hospital staff.

- Please read this question and let me know when you are ready to respond.
- What is your response to Question 8?
 - What does this response mean to you?
- Using your own words, what is this question asking about?
- What does the phrase “I was able to follow” in this question mean to you?
- Was it easy or difficult to answer this question? If difficult, how was it difficult?
- Do you have any recommendations how to phrase this question?

Question 9 states: After I returned home, I had the right support services I needed in place to effectively manage my recovery at home (e.g., homecare, family, caregiver/support person).

- Please read this question and let me know when you are ready to respond.
- What is your response to Question 9?
 - What does this response mean to you?
- Using your own words, what is this question asking about?
- What does the phrase “right support services” in this question mean to you?
- What does the phrase “effectively manage” in this question mean to you?
- What does the phrase “my recovery at home” in this question mean to you?

- Was it easy or difficult to answer this question? If difficult, how was it difficult?
- Do you have any recommendations how to phrase this question?

Question 10 states: After I returned home, the following health care providers followed up with me about my recent hospital stay: (Choose all that apply)

- Please read this question and let me know when you are ready to respond.
- What is your response to Question 10?
 - What does this response mean to you?
- Using your own words, what is this question asking about?
- Are there any key health care providers you think are missing from the list provided?
- Was it easy or difficult to answer this question? If difficult, how was it difficult?
- Do you have any recommendations how to phrase this question?

Question 11 & 11a state: After I returned home, I was able to schedule a follow up visit with my primary care provider. If yes, how was your follow-up visit with your primary care provider scheduled.

- Please read this question and let me know when you are ready to respond.
- What is your response to Question 11?
- What is your response to Question 11a?
 - What does this response mean to you?
- Using your own words, what is this question asking about?
- Is there anything unclear or missing from the dropdown options provided?
- Was it easy or difficult to answer this question? If difficult, how was it difficult?
- Do you have any recommendations how to phrase this question?

The third, and last, set of questions are related to follow-up care with your primary care provider and team. Once again, please take as much time as you need to answer these questions. And a last reminder that if you have any comments about the survey please do not hesitate to share them with me, no matter how minor you may think they are. Are you ready to start the last section?

Question 13 states: I was able to attend a follow up appointment (in person or virtually) with my primary care provider or member of their team.

- Please read this question and let me know when you are ready to respond.
- What is your response to Question 13?
 - What does this response mean to you?
- Using your own words, what is this question asking about?
- What does the phrase “able to attend” in this question mean to you?
- Is there anything unclear or missing from the dropdown options provided?

- Was it easy or difficult to answer this question? If difficult, how was it difficult?
- Do you have any recommendations how to phrase this question?

Question 14 states: My medication list was thoroughly discussed with me by a member of my primary health care team before or during my primary care visit.

- Please read this question and let me know when you are ready to respond.
- What is your response to Question 14?
 - What does this response mean to you?
- Using your own words, what is this question asking about?
- What does the phrase “thoroughly discussed” in this question mean to you?
- What does the phrase “member of my primary health care team” in this question mean to you?
- Was it easy or difficult to answer this question? If difficult, how was it difficult?
- Do you have any recommendations how to phrase this question?

Question 15 states: Issues related to my recent hospital stay that were important to me were discussed.

- Please read this question and let me know when you are ready to respond.
- What is your response to Question 15?
 - What does this response mean to you?
- Using your own words, what is this question asking about?
- What does the phrase “issues related to my recent hospital stay” in this question mean to you?
- What does the phrase “important to me” in this question mean to you?
- Was it easy or difficult to answer this question? If difficult, how was it difficult?
- Do you have any recommendations how to phrase this question?

Question 16 states: My care plan was aligned with my needs.

- Please read this question and let me know when you are ready to respond.
- What is your response to Question 16?
 - What does this response mean to you?
- Using your own words, what is this question asking about?
- What does the phrase “my care plan” in this question mean to you?
- What does the phrase “aligned with my needs” in this question mean to you?
- Was it easy or difficult to answer this question? If difficult, how was it difficult?
- Do you have any recommendations how to phrase this question?

Question 17 states: My family or informal caregivers (e.g., friend) were involved in follow-up care the way I wanted them to be.

- Please read this question and let me know when you are ready to respond.
- What is your response to Question 17?

- What does this response mean to you?
- Using your own words, what is this question asking about?
- What does the phrase “informal caregiver” in this question mean to you?
- What does the phrase “involved … the way I wanted them to be” in this question mean to you?
- Was it easy or difficult to answer this question? If difficult, how was it difficult?
- Do you have any recommendations how to phrase this question?

Question 18 states: After my follow-up visit with my primary care provider, I felt confident to manage my care at home.

- Please read this question and let me know when you are ready to respond.
- What is your response to Question 18?
 - What does this response mean to you?
- Using your own words, what is this question asking about?
- What does the phrase “confident to manage my care at home” in this question mean to you?
- Was it easy or difficult to answer this question? If difficult, how was it difficult?
- Do you have any recommendations how to phrase this question?

Question 19 states: I was satisfied with my primary care follow-up appointment.

- Please read this question and let me know when you are ready to respond.
- What is your response to Question 19?
 - What does this response mean to you?
- Using your own words, what is this question asking about?
- What does the word “satisfied” in this question mean to you?
- Was it easy or difficult to answer this question? If difficult, how was it difficult?
- Do you have any recommendations how to phrase this question?

Question 21 states: Overall, my care was well coordinated by my healthcare team(s).

- Please read this question and let me know when you are ready to respond.
- What is your response to Question 20?
 - What does this response mean to you?
- Using your own words, what is this question asking about?
- What does the phrase “well coordinated” in this question mean to you?
- What does the phrase “healthcare teams” in this question mean to you?
- Was it easy or difficult to answer this question? If difficult, how was it difficult?
- Do you have any recommendations how to phrase this question?

Now I would like to think about the survey as a whole:

- Overall, did you find the instructions clear and easy to follow?

- Overall, what did you think of these questions?
 - Was there anything in the survey that was confusing?
 - Are there any important things about a transition from hospital to home that were not asked about in this questionnaire? (e.g., was anything important missing?)
- How long after your hospitalization do you think you could respond to these questions without having difficulty remembering your experience?

Now let's look at the response options for this survey: "Strongly disagree" "Disagree," "Neutral", "Agree," "Strongly Agree," "Not applicable/Unsure"

- Was it easy or difficult to answer the questions using this response scale? If difficult, how was it difficult?
- What does the response "Strongly disagree" mean to you?
- What does the response "Disagree" mean to you?
- What does the response "Neutral" mean to you?
- What does the response "Agree" mean to you?
- What does the response "Strongly Agree" mean to you?
- What does the response "Not applicable" mean to you?
- Was the number of response options adequate?

After all questions evaluated in "Next Steps" Slide:

Thank you for testing our draft survey and for your input on these questions.

After all interviews are complete, we will take some time to summarize and theme everyone's feedback, and the survey will be revised based on these results. You will then be invited to a group session where you will have a chance to review the revised survey and provide any final feedback.

We will contact you as soon as possible to work with you and all participants to book a date and time for this group session. We hope to be able to do this by mid to late June.