Testing Experience and Functional Tools Demonstration: Personal Health Record (PHR) User Survey

Paperwork Reduction Act Submission

Appendix A: Personal Health Record Survey Instrument

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Personal Health Record (PHR) User Survey

Introduction

This survey will ask you questions about an electronic tool for your computer or phone called [Insert state-specific PHR name]. Using the tool, you can see information about the help you get. You may also use it to talk with the people who help you. These questions will help collect information about your experiences with [Insert state-specific PHR name]. It is okay if you ask for help with your answers from someone you trust. It will take you about 20 minutes to finish. Filling out this survey is voluntary. **<u>Your answers are anonymous and will be kept confidential.</u>** It is your choice to answer these questions. None of your services will change if you answer them.

By clicking START SURVEY you are confirming that you read this introduction. You also confirm that you agree to participate. You also understand that your participation in this study is voluntary.

For More Information:

If you have questions about the survey or how to respond, please contact [INSERT NAME] at [INSERT NUMBER] or e-mail [INSERT EMAIL].

Survey Questions

I) About Me

1) I am completing the survey (Check only one):

☐ By myself, as a person receiving services (like meals brought to my home, someone that helps with bathing and dressing, or helps with cooking and cleaning)
☐ With help from someone (like a family member or my case or care manager)
☐ As a caregiver or care provider that uses the [Insert state-specific PHR name] to manage someone else's care

☐ Other: __Click here to enter text._____

2) How did you learn about [Insert state-specific PHR name]? (Check all that apply)

☐ Family member or friend
☐ Case or care manager
☐ Service provider (like the agency that brings meals to my home, helps with bathing and dressing, or helps with cooking and cleaning)
☐ Doctor or nurse
☐ Focus group or other community group
☐ I have not heard about [Insert state-specific PHR name] (Survey will skip to **Question 15**)

☐ Other: __Click here to enter text._____

3) Do you view or update your [Insert state-specific PHR name]? (for example, using the [Insert state-specific PHR name] could include using a paper form, texting information to someone, or logging into the Personal Health Record to view or update information)

- ☐ Yes (Survey will continue to **Question 4**)
- ☐ I did, but I do not anymore (Survey will skip to **Question 15**)
- ☐ No, but I plan to start using it (Survey will skip to **Question 15**)

- ☐ No (Survey will skip to **Question 15**)

II) My Use of the [Insert state-specific PHR name]

4) Do you agree or disagree with the following statements about [Insert state-specific PHR name]?

4a. General PHR Use

Do you agree or disagree with the following statements about [Insert state-specific PHR name]?	Agree	Disagree	Not Applicable
It is easy for me to find and use [Insert state-specific PHR name].	☐	☐	☐
I would like to continue using the [Insert state-specific PHR name].	☐	☐	☐
I would recommend the [Insert state-specific PHR name] to a friend or family member.	☐	☐	☐
I have physical problems (like problems with my vision) that make viewing the [Insert state-specific PHR name] hard.	☐	☐	☐
I think the information on [Insert state-specific PHR name] is safe and secure.	☐	☐	☐

4b. Social Services and Needs

My [Insert state-specific PHR name]....	Agree	Disagree	Not Applicable
Helps me to communicate my needs to those helping me	☐	☐	☐
Helps me to know about the care I receive	☐	☐	☐
Helps me understand my eligibility for services at my home	☐	☐	☐
Gives me contact information for my care team members	☐	☐	☐
Keeps me informed about scheduled visits for services I am receiving	☐	☐	☐
Gives me access to helpful information resources	☐	☐	☐
Provides a place for my caregivers to receive information about me and my needs	☐	☐	☐

4c. Health Services and Needs

My [Insert state-specific PHR name]....	Agree	Disagree	Not Applicable
Helps me to know more about my health	☐	☐	☐
Helps me do things to improve my health (like improve my diet or exercise)	☐	☐	☐
Helps me make my own healthcare decisions	☐	☐	☐
Gives me access to information for doctor visits or home health visits	☐	☐	☐
Helps my caregivers to be up to date on my health information	☐	☐	☐

5) How did you learn to use [Insert state-specific PHR name]? (Check all that apply)

☐ I learned on my own
☐ One-on-one training (like with my case or care manager or personal aide)
☐ Group training (like a group class in my community)
☐ Written guide(s) (like a paper training guide with instructions)
☐ A video training, like on YouTube
☐ Help desk (like a 1-800 number or online chat)
☐ Computer lab training
☐ Family member or friend

☐ Other: __Click here to enter text._____

6) How do you use [Insert state-specific PHR name]? (Please check all that apply)

☐ My private computer
☐ My mobile phone or tablet
☐ A public computer

☐ Other: __Click here to enter text._____

7) Do you get help from someone to use [Insert state-specific PHR name]?

☐ Yes, I always need help to use the [Insert state-specific PHR name]
☐ Sometimes, I need help to use the [Insert state-specific PHR name]
☐ No, I do not need help to use the [Insert state-specific PHR name]

☐ Other: __Click here to enter text._____

8) How often do you view or update your [Insert state-specific PHR name]? (Please check only one)

- ☐ Every day
- ☐ Several times a week
- ☐ Once a week
- ☐ Once every few weeks
- ☐ Once a month

- ☐ Other: Click here to enter text.

9) What kinds of service information do you view or update in [Insert state-specific PHR name]? (Check all that apply)

- ☐ Personal information (like my name, address, or birthday)
- ☐ Services and supports data (like home delivered meals, self-care help, and/or help in my home)
- ☐ Care plan
- ☐ Medicaid eligibility (for receiving services at home)
- ☐ Care team contact information
- ☐ Care team availability

- ☐ Other: Click here to enter text.

10) What kinds of health information do you view or update in [Insert state-specific PHR name]? (Check all that apply)

- ☐ Doctor appointment scheduling
- ☐ Medical records
- ☐ Lab test results (like blood sugar levels)
- ☐ Medication information
- ☐ Health insurance information (like Medicaid)
- ☐ Resources about my condition

- ☐ Other: Click here to enter text.

11) What kinds of information do you receive from your [Insert state-specific PHR name]? (Check all that apply)

- ☐ Reminders about upcoming doctors' appointments
- ☐ Reminders about upcoming home visits
- ☐ Reminders about Medicaid eligibility (for receiving services at home)
- ☐ Reminders about medication refills
- ☐ Secure messages with my provider (like your doctor, nurse, or care or case manager)

- ☐ Other: Click here to enter text.

12) What kinds of information do you give access to from your [Insert state-specific PHR name]? (Check all that apply)

☐ Allow my providers and/or caregivers to get updates about how my day is going
☐ Allow my providers and/or caregivers to get updates about my health status (like doctor visits)
☐ Allow my providers and/or caregivers to view information about who I am and what I care about
☐ Allow my providers and/or caregivers to view information about possible health concerns
☐ Allow me to easily communicate issues with my support team

☐ Other: __Click here to enter text._____

13) I have shared (or given someone access to) information from [Insert state-specific PHR name] with: (Check all that apply)

☐ Family member or friend
☐ Caregiver
☐ Case or care manager
☐ Service provider (like the agency that brings meals to my home, helps with bathing and dressing, or helps with cooking and cleaning)
☐ Doctor or nurse
☐ I have not shared (or given access to) this information

☐ Other: __Click here to enter text._____

14) What kinds of information have you shared (or given someone access to)? (Check all that apply)

☐ Personal information (like my name, address, or birthday)
☐ Services and supports data (like home delivered meals, self-care help, and/or help in my home)
☐ Care plan
☐ Medicaid information
☐ Care team contact information
☐ Care team availability
☐ Doctor appointment scheduling
☐ Past and current medical records
☐ Lab test results (like blood sugar levels)
☐ Medication information
☐ I do not know
☐ Other: __Click here to enter text._____

☐ I have not shared information from [Insert state-specific PHR name]

[Survey will skip to **Question 18** for PHR Users in order to complete the rest of the survey.]

III) My Interest Level in a Personal Health Record

It is okay that you do not use [Insert state-specific PHR name]. Please give more information about why you are not using [Insert state-specific PHR name].

15) I do not use [Insert state-specific PHR name] because: (check all that apply)

- ☐ I did not know the [Insert state-specific PHR name] was available to me
- ☐ I did not see value in using the [Insert state-specific PHR name]
- ☐ I found the [Insert state-specific PHR name] difficult to use
- ☐ I worry about the privacy and security of my information
- ☐ It would take too much time
- ☐ I do not like computers/internet
- ☐ I do not have internet access
- ☐ I do not have a computer or mobile phone

- ☐ Other: Click here to enter text.

16) How interested are you in using [Insert state-specific PHR name] to look at your health and service information?

- ☐ Very much
- ☐ Somewhat

- ☐ Not really

17) Please mark whether you think [Insert state-specific PHR name] could be helpful for the following reasons. [Insert state-specific PHR name] would:

17a. Social Services and Needs

The [Insert state-specific PHR name] could be helpful to:	Agree	Disagree	Not Applicable
Communicate my needs to those helping me	☐	☐	☐
Know about the care I receive	☐	☐	☐
Understand my eligibility for services at my home	☐	☐	☐
Give me contact information for my care team members	☐	☐	☐
Keep me informed about scheduled visits for services I am receiving	☐	☐	☐
Give me access to helpful information resources	☐	☐	☐
Provide a place for my caregivers to receive information about me and my needs	☐	☐	☐

17b. Health Services and Needs

The [Insert state-specific PHR name] could be helpful to:	**Agree**	**Disagree**	**Not Applicable**
Know more about my health	☐	☐	☐
Do things to improve my health (like my diet or exercise)	☐	☐	☐
Help me make my own healthcare decisions	☐	☐	☐
Give me access to information for doctor visits or home health visits	☐	☐	☐
Help my caregivers to be up to date on my health information	☐	☐	☐

[Survey will continue with **Question 18**; all respondents will be asked to complete the rest of the survey.]

IV) Demographic Information

Thank you for answering questions about your experience with [Insert state-specific PHR name]. The last few questions focus on you. These questions will be used to help understand how different people experience the [Insert state-specific PHR name].

18) Please mark your sex.
- ☐ Male
- ☐ Female

19) Please mark what age range you are in.
- ☐ 18-24 years old
- ☐ 25-34 years old
- ☐ 35-44 years old
- ☐ 45-54 years old
- ☐ 55-64 years old
- ☐ 65-74 years old
- ☐ 75- 84 years old
- ☐ 85 years or older

20) Please mark your race or ethnicity. (Check all that apply)
- ☐ American Indian or Alaska Native
- ☐ Asian
- ☐ Black or African American
- ☐ Hispanic or Latino
- ☐ Native Hawaiian or Other Pacific Islander

☐ White

☐ Other: __Click here to enter text._____

21) Please mark the highest level of education you have completed. (Check all that apply)

☐ Did not complete high school

☐ High school/GED

☐ Some college

☐ Completed college

☐ Advanced college degree (Masters, JD, PhD, or MD)

☐ Other: __Click here to enter text._____

22) Which of the following do you experience? (Check all that apply)

☐ A vision or hearing impairment

☐ A speech or language disability

☐ A mobility or physical impairment

☐ A learning or developmental disability

☐ A cognitive impairment or dementia

☐ A mental health disorder

☐ A brain injury

☐ Other: __Click here to enter text._____

☐ None of the above

23) What do you get help with at home and in the community? (please check all that apply)

☐ Daily activities (like bathing, dressing, feeding, transferring, and mobility)

☐ Activities in my home (like cleaning, housekeeping, preparing meals, shopping, and managing money)

☐ Activities at my work, my job, or my school

☐ Activities in my community

☐ Social, emotional, or behavioral needs

☐ Medication or health care

☐ Transportation

☐ Other: __Click here to enter text._____

☐ None of the above

24) We want to understand how fast you start using new technology. Please check all the statements that apply to you below.

☐ I have to be one of the first people to buy new technology

☐ I am the last of my peers to begin using new technology

☐ I am afraid or unwilling to use new technology

☐ Other: __Click here to enter text._____

V) Additional Comments

25) Please provide any additional comments or feedback about [Insert state-specific PHR name].

__Click here to enter text._____

26) If you are a caregiver filling out this survey, or helping someone fill out this survey, please provide any additional comments about the [Insert state-specific PHR name].

   Click here to enter text.

Thank you for completing this survey. Your responses will be kept anonymous and confidential. Your responses will be used to understand experiences with PHRs.