



Evaluation Tools for Personal Health Record Initiatives in Medicaid Home & Community-Based Services Programs

Final Report

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I. Personal Health Records Demonstration Background

Since 2014, six states have managed personal health record (PHR) pilots with funding from the Centers for Medicare & Medicaid Services (CMS) Testing Experience and Functional Tools (TEFT) Demonstration Program. The pilots specifically focused on implementing a PHR for beneficiaries of Medicaid home and community-based services (HCBS) programs. HCBS beneficiaries commonly include older adults with disabilities, individuals with intellectual and developmental disabilities, individuals with acquired brain injuries, and individuals diagnosed with severe mental illnesses. Through the PHRs, CMS and states aimed to demonstrate the use of PHRs containing medical and social service information. The Lewin Group (Lewin) conducted an evaluation of the TEFT states' PHR pilots using three main evaluation and monitoring tools: an Office of Management and Budget (OMB)-approved user feedback survey, a survey messaging tool, and a PHR initiative planning guide. These PHR evaluation tools are included in **Appendices 1-3**. The following sections provide additional information about the TEFT Demonstration's PHR pilots, when the tools were introduced, and how they were used to understand the HCBS beneficiary experience with the PHRs. Lewin compiled these tools to help other states and local communities that are considering launching and evaluating a PHR. For an overview of the TEFT state experience in developing and implementing these PHRs, please refer to the [Medicaid TEFT website](#).

Individuals typically use paper-based or electronic PHRs to store personal health information, such as relevant medical history and demographic information. The PHR can make this information available to individuals, family caregivers, and other healthcare providers, as needed.¹ The PHRs

The TEFT states' PHRs have expanded health IT systems to include information about an individual's social services.

developed in the TEFT Demonstration were unique in that they did not focus solely on medical information, but also incorporated non-medical, HCBS information into a person-centered health information technology (IT) system. There is a need for care coordination

between HCBS (e.g., home health, personal care assistance), medical, and behavioral health services to enhance the quality of care individuals receive, since individuals receiving long-term services and supports (LTSS) tend to have complex needs across different provider types.² Six TEFT states participated in the PHR pilots: Colorado, Connecticut, Georgia, Kentucky, Maryland, and Minnesota.

Some past PHR pilots and surveys focused on the ability of older adults and persons with chronic illnesses and disabilities to use a PHR. Although these past pilots did not focus specifically on Medicaid HCBS beneficiaries, many of the lessons learned are applicable to these populations due to potential common experiences for people with multiple chronic conditions. Lessons learned from past studies include: preparing for issues with computer literacy;³ understanding the potential

¹ Lober, W.B., Zierler, B., Herbaugh, A., Shinstrom, S.E., Stolyar, A., Kim, E.H., & Kim, Y. (2006). Barriers to the use of a personal health record by an elderly population. AMIA Annual Symposium Proceedings, 514-518.

² Agency for Healthcare Research and Quality. (2014). What is Care Coordination? Care Coordination Measures Atlas Update. <http://www.ahrq.gov/professionals/prevention-chronic-care/improve/coordination/atlas2014/chapter2.html>

³ Sharit, J., Lisigurski, M., Andrade, A.D., Karanam, C., Nazi, K.M., Lewis, J.R., & Ruiz, J.G. (2014). The roles of health literacy, numeracy, and graph literacy on the usability of the VA's personal health record by veterans. *Journal of Usability Studies*, 9(4), 173-193.

PHR users' goals, motivations, and interests in the system;⁴ and understanding the most commonly used features by similar populations, such as medication management.^{5, 6} Past studies demonstrated that a targeted PHR for HCBS populations could be useful. However, the PHR systems in past studies did not focus on the integration of social service information into the PHR or the development of an interface to display various pieces of HCBS provider information.

PHR platforms are available in an off-the-shelf model or are custom-built. Off-the-shelf models are completely built PHR platforms that can be implemented quickly, but offer few options for customization. Custom-built PHRs typically require

Most TEFT states required PHR system customization to connect to the state case management system, other state system, or health information exchange.

more time in the design phase, as the state and its partners determine which features and functions to prioritize. The state must also identify what information, and from which sources, will populate the PHRs. Mapping state and HCBS provider information systems, such as a case management system, is common in the planning phase. This helps determine which organizations use each information source and how complex the information is in each IT system (e.g., billing). As demonstrated in **Table 1** below, TEFT states were split between off-the-shelf and custom-built PHRs, contracted with different vendors, and used information from various types of systems. However, even the states with off-the-shelf PHRs required a degree of system customization and testing to connect the systems that populated the information on HCBS beneficiaries.

Table 1: TEFT State PHR Platforms, Developers, and Main Information Sources

State	Type of PHR Platform	PHR System Developer	Information Source
Colorado	Off-the-Shelf	Colorado Regional Health Information Organization, with FEi Systems and Quality Health Network	Health information exchanges
Connecticut	Off-the-Shelf	InterSystems	State information systems and state data aggregator
Georgia	Custom	Georgia Tech Research Institute	State information systems
Kentucky	Custom	Deloitte	State case management system
Maryland	Custom	FEi Systems (web-based), Xerox (phone-based)	State case management system
Minnesota	Off-the-Shelf	RelayHealth	Medicaid management information system and state data aggregator

⁴ Tom, J., Magione-Smith, R., Solomon, C., 7 Grossman, D. (2012). Integrated personal health record use: association with parent-reported care experiences. *American Academy of Pediatrics*.
<http://pediatrics.aappublications.org/content/130/1/e183.long>

⁵ Kahn, J.S., Hilton, J.F., Van Nunnery, T., Leasure, S., Bryant, K.M., Hare, C.B., & Thom, D.H. (2009). Personal health records in a public hospital: experience at the HIV/AIDS clinic at San Francisco General Hospital. *Journal of the American Medical Informatics Association*, 17, 224-228.

⁶ Kim, E.H., Stolyar, A., Lober, W., Herbaugh, A., Shinstrom, S., Zierler, B., Soh, C. & Kim, Y. (2007). Usage patterns of a personal health record by elderly and disabled users. *AMIA Annual Symposium Proceedings*.
<http://www.ncbi.nlm.nih.gov/pmc/articles/PMC2655817/>

II. PHR Planning and Evaluation Tools

State teams that are planning and implementing a PHR must consider such details as the status of current information systems; where information about HCBS populations exists; what pieces of information and system functions should go into the PHR; opportunities for stakeholder outreach and education; and other decisions related to privacy, security, and access. The first TEFT evaluation tool in this document, the ***PHR Planning and Implementation Tool***, can help states and other entities with the complex process of selecting a PHR.

Appendix 1: PHR Planning and Implementation Tool can be used as a self-assessment guide or checklist for PHR planning, as it contains important system design considerations. States and communities may use this document for facilitating early discussions with internal stakeholders and vendors about PHR features and functions for an HCBS population.

Lewin developed the PHR Planning and Implementation Tool in 2015 while TEFT states were in the PHR planning phase. The tool helped Lewin monitor the state planning processes, including desired features and functions. Lewin cross-walked the topics in the tool with the Health Level Seven International (HL7) PHR-System Functional Model⁷ to incorporate industry standards. The PHR Planning and Implementation Tool is comprised of two sections. The first section, pages 1-17 of Appendix 1, includes a PHR Review Template for identifying both the medical and social service information that states may plan to include in a PHR to meet the needs of HCBS beneficiaries. The second section, the Health IT Environmental Scan, pages 18-22 of Appendix 1, focuses on the assessment of existing state health IT and health information exchange (HIE) system infrastructure and planned state system improvements that may be important to consider in relation to the PHR initiative.

As states and communities test and implement PHRs with their HCBS beneficiary populations, it is important to assess the usefulness and impact of the PHR

The PHR users volunteered to test the systems and then provide feedback through the Lewin PHR User Survey, following a user period of at least four weeks.

for users. The second TEFT evaluation tool is the OMB-approved ***PHR User Survey***, which is accompanied by a set of ***PHR User Survey Frequently Asked Questions***. In the TEFT Evaluation, PHR users received a voluntary, anonymous survey generally four to six weeks after the TEFT state launched its PHR. **Table 2** summarizes the strategy and timeline associated with each state's PHR roll-out and Lewin's survey efforts. The TEFT states also set up other opportunities, such as focus groups and interviews, for PHR users to provide feedback about their systems.

⁷ Health Level Seven International. (2014). Personal Health Record System Functional Model. http://www.hl7.org/implement/standards/product_brief.cfm?product_id=88

Table 2: TEFT Demonstration PHR User Sample Approaches and Timelines

TEFT State	PHR Pilot Approach	PHR Launch Date	PHR User Survey Period
Colorado	Phased roll out with approximately 20 HCBS beneficiaries	March 2018	April – May 2018
Connecticut	Offered the PHR to all Money Follows the Person beneficiaries	August 2018	N/A
Georgia	Tested with two HCBS beneficiary groups; one is a control group	March 2018	April – May 2018
Kentucky	All Medicaid HCBS beneficiaries were eligible to set-up an account. Those who created accounts were counted as PHR users	September 2017	January – March 2018
Maryland	Piloted with 14 beneficiaries, then marketed the PHR to all Medicaid HCBS beneficiaries with a mailed brochure	September 2017	January – March 2018
Minnesota	Piloted with 19 beneficiaries in the 1 st Region and 28 beneficiaries in the 2 nd Region. The PHR was also available to legal guardians and case managers	October 2016 (1 st Region); June 2017 (2 nd Region)	May – November 2017 (1 st Region); April – May 2018 (2 nd Region)

Lewin developed the PHR User Survey to assess how individuals with different disabilities chose to use a PHR system. The survey asks about the user experience in order to measure any perceived impact or outcomes attributable to the PHR systems. Lewin was specifically interested in measuring impacts, such as improved communication with providers, improved service coordination, and improved functional or health status. Lewin finished the draft PHR User Survey and began to pursue OMB clearance in January 2016. OMB clearance was required because Lewin planned to survey more than nine individuals about their PHR experiences. OMB approved the survey in February 2017. OMB clearance allowed for some modification, including using the name of the state's PHR and removing questions unrelated to the state initiative. Additionally, the PHR User Survey differentiated two types of survey respondents: active users and those who reported choosing not to use the PHR. Survey respondents were considered active PHR users if they reported viewing or updating the PHR, taking an action like logging into the system to view certain information, or texting or forwarding information from the system to someone else.

Appendix 2: PHR User Survey includes questions for individuals who used the PHR and for those who were offered the PHR but did not use it, as well as demographics questions.

Appendix 3: PHR User Survey Frequently Asked Questions can be used to clarify the messaging about the PHR User Survey and proactively pose and answer questions that survey respondents may have. It explains the purpose of the survey and assures beneficiaries that their HCBS benefits will not be impacted by participating.

The PHR User Survey is designed to be both anonymous and confidential. In the future, some states may choose to remove anonymity for the purpose of developing a pre-pilot survey and linking responses to the post-survey, tracking PHR user responses for targeted follow-up, or linking survey respondents back to the type of HCBS that they receive. If removing anonymity, states and communities may also modify and scale back the demographics section, as some demographic information will be available from Medicaid or other sources.

III. TEFT State Next Steps

As of this report, Colorado, Connecticut, and Maryland have plans to sustain their PHRs or to start new PHR initiatives after the TEFT Demonstration ends in 2019. These states built the PHRs to enhance their existing state workflow, improving processes like beneficiary communications and HCBS visit verification. Colorado secured funding from the Colorado General Assembly to expand the PHR to the general Medicaid population. Similarly, Connecticut received an enhanced federal match through 2021 that the state will use to roll out the PHR to the broader Medicaid population. As Kentucky's PHR was designed as a module in its state case management system, the state will maintain and advertise it to HCBS populations when the Medicaid department is ready. Maryland also expects to offer the PHR to new agencies and programs and plans to implement additional features.

Following the four-year TEFT Program, most TEFT states are going to continue offering their PHRs to HCBS beneficiaries. They have direct beneficiary feedback about likes and dislikes available through the survey to influence ongoing plans.

Georgia and Minnesota do not have plans to sustain the PHRs in their current form, but they will continue to use lessons learned from the PHR pilots for future state health IT initiatives and may plan new PHR initiatives. Georgia conducted user experience testing with both beneficiaries and case managers prior to designing the PHR tool. The lessons learned from this research will inform future consumer-facing tools developed by the state health department. However, the state realized it was not feasible to sustain the PHR in its current form since it depends on manual data entry. Minnesota gathered lessons learned and best practices throughout the TEFT Demonstration and compiled them into a PowerPoint presentation that state staff shares with stakeholders. Through the PHR pilot, Minnesota also gained capabilities that helped establish automated data transfer between state systems.

Appendix 1. PHR Planning and Implementation Tool

Objectives:

1. Provide considerations for the staff that plan and implement personal health record (PHR) initiatives for home and community-based services (HCBS) populations.
2. Act as a guide for facilitating discussions with internal stakeholders and vendors regarding important considerations related to the features and functions of the PHR.
3. Help identify these critical considerations, including existing HIT systems, data sources for information on HCBS populations, system functionality considerations, opportunities for stakeholder outreach and education, and other decisions related to privacy, security, and access.

Development: The Lewin Group, 2015; the topics in this document were cross-walked with the Health Level Seven International (HL7) Personal Health Record Functional Model to support state efforts to accept and exchange information in a manner that is consistent with industry standards.

Audience: State aging and disability program leadership, CMS staff

Structure:

- The first section, the *PHR Review Template* (pg. 1-15), helps identify key programmatic initiatives to align with the PHR, the medical and social services data elements to include in the PHR to meet the needs of HCBS beneficiaries, and other system considerations for the planning phase, including methods for PHR user access, account management and outreach and education.
- The second section, the *Health IT Environmental Scan* (pg. 16-20), focuses on existing state health IT infrastructure and planned state health IT system improvements. It helps assess baseline health IT infrastructure at the state and provider levels, including HIE and Medicaid Management Information Systems at the state level, and Electronic Health Record adoption and long-term services and supports providers information exchange at the provider level.

PHR Planning and Coordination with Other State Efforts

I. PHR Planning

1. **What Medicaid HCBS program population(s) are/will be targeted for the PHR? Briefly describe the considerations related to each population’s specific needs that may influence the ultimate design and functionalities for the PHR (e.g., multiple PHRs offered, assistive technology, data elements).**

HCBS Program Name	HCBS Population	Description of Considerations Related to PHR Design
Click here to enter text.	Click here to enter text.	Click here to enter text.
Click here to enter text.	Click here to enter text.	Click here to enter text.
Click here to enter text.	Click here to enter text.	Click here to enter text.

2. Has the state chosen a PHR solution?

- Yes >>SKIP TO QUESTION 4>>

If yes, please specify the name and number of PHRs offered: [Click here to enter text.](#)

- No >>PROCEED TO QUESTION 3>>

3. If your state has not yet chosen a PHR solution, please describe current steps/progress in identifying a solution, including any systems that have been reviewed thus far.

[Click here to enter text.](#)

>>If the state has not selected a PHR solution, this is the final question in the PHR Review Template, skip to the HIT Environmental Scan.>>

4. What type of PHR system is/will be used? Select one:

- Stand-alone PHR
 Patient messaging portal
 Tethered or connected PHR
 Other

If other, please specify: [Click here to enter text.](#)

5. What entity is/will host the PHR? Select all that apply:

- State

If state, name the agency/department: [Click here to enter text.](#)

- Contractor/Independent third party

If Contractor/Independent third party, name the entity: [Click here to enter text.](#)

- Healthcare provider

If Healthcare provider, name the entity: [Click here to enter text.](#)

- Insurance Company

If Insurance Company, name the entity: [Click here to enter text.](#)

- Employer

If Employer, name the entity: [Click here to enter text.](#)

- Other

If other, please specify: [Click here to enter text.](#)

6. Is the PHR system operational at this time?

- Yes >>SKIP TO QUESTION 8>>

- No >>PROCEED TO QUESTION 7>>

7. If this system is not currently in place, what is the projected timeline for implementation and go-live?

Please describe: [Click here to enter text.](#)

II. PHR Standards Based Interoperability**8. Does/will the PHR adhere to HL7 PHR System Functional Model Standard or other PHR standards?**

- Yes

If yes, please specify the PHR standards: [Click here to enter text.](#)

- No

9. Does/will the PHR integrate or interface with any other health information system(s)?

Yes >>PROCEED TO QUESTION 10>>

If yes, please describe the system(s): [Click here to enter text.](#)

No >>SKIP TO QUESTION 17>>

10. If data is exchanged, what standard(s) are/will be used for sending and receiving data?

- HL7
- CCDA/CDA
- DIRECT
- SOAP
- REST
- OpenID
- Oauth
- Other

If other, please specify: [Click here to enter text.](#)

11. What systems does/will the PHR integrate or interface with? Please specify how data is/will be exchanged through the PHR. Select all that apply:

HIT System	PHR will interface (Check if yes)	Bi-Directional	Send Data Only	Receive Data Only
HIE Organization	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>
MMIS	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>
EHR	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>
Case Management IT	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>
Other	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>

If other, please specify: [Click here to enter text.](#)

12. What types of data are/will be exchanged through the PHR? Select all that apply:

Unstructured, viewable electronic data (e.g., scans of paper forms)

Please list the users/systems exchanging data: [Click here to enter text.](#)

Structured, viewable electronic data (e.g., electronically entered data that cannot be computed by other systems)

Please list the users/systems exchanging data: [Click here to enter text.](#)

Computable electronic data (e.g., electronically entered data that can be computed by other systems)

Please list the users/systems exchanging data: [Click here to enter text.](#)

13. How does/will the state or HIE organization(s) match patient records or identify the account holder?

- Store more than one unique identifier from multiple caregivers
- Link unique identifier from multiple caregivers
- Controlled method to capture, integrate or link information stored in external systems
- Other

If other, please specify: [Click here to enter text.](#)

14. If data is exchanged, what identifier(s) are/will be used to match PHR data?

- Social Security Number
- Master Patient Index
- Name and Date of Birth
- Other unique ID

If other unique ID, please specify: [Click here to enter text.](#)

15. Will the PHR link to the state or regional HIE organization(s) in the long term?

- Yes

If yes, please explain how the HIE organization will be connected and what key data will be exchanged: [Click here to enter text.](#)

- No

III. PHR Security and Information Management**16. What security measures are/will be in place to protect the privacy of users and ensure confidentiality of PHR information? Please select all that apply:**

- Users are required to set up a password-protected personal account
- Users must set password that meets minimum security standards
- Users must enter DOB, Zip Code, SSN or other identifying information
- Secure message standards
- Other

If other, please specify: [Click here to enter text.](#)

17. What storage method is/will be used for PHR data? Select one:

- Internet-accessible database
- Within a provider's EHR
- On the consumer's personal computer
- Using a portable device such as a thumb drive or smart card
- In a privately maintained database
- Cloud
- Other

If other, please specify: [Click here to enter text.](#)

18. Does/will a record or log of the information shared and information recorded (or entered) exist in the PHR, including a record of who entered, accessed, or modified the information?

- Yes >>PROCEED TO QUESTION 20>>
- No >>SKIP TO QUESTION 22>>

19. If a record or log of the information shared and information recorded in the PHR exists, what data is included in the log based on standards (e.g., ASTM 2147.024, RFC 3881)? Please check all that apply:

- Date and time of event
- Individual identification
- User identification
- Access device
- Type of action
- Event outcome indicator
- Identification of the data that was accessed
- Source of access
- Reason for access
- Other

If other please specify [Click here to enter text.](#)

20. If a record or log of the information shared and information recorded in the PHR exists, who has access to this information?

Please specify: [Click here to enter text.](#)

Personal Health Information

IV. Types of Data Accessible in the PHR

21. What method is/will be used to populate the PHR with data? Select one:

- Push model
- Pull model
- Push and Pull model

22. Please indicate the types of data that are/will be accessible in the PHR. Please check all that apply:

- Demographic information
- Current and historical clinical data
- Social services information
- Functional assessment data
- Cognitive assessment data
- Wellness preventive medicine and/or self-care data
- Data to support managing health education
- Decision-support tools
- Support to manage encounters with providers (e.g., discharge instructions)
- Other

If other, please specify: [Click here to enter text.](#)

23. Please indicate the types of demographic information that are/will be accessible in the PHR and the method for gathering data including auto-populated, and/or manually entered or updated by providers or users. Please check all that apply:

Data Type	Accessible in the PHR	Auto-Populated	Manually entered or updated by providers	Manually entered or updated by users
Personal identification (name, DOB, SSN, or state identifier)	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>
Emergency contact information	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>
Provider contact information	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>
Health insurance/benefit information	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>
Other	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>
<i>If other, please specify:</i>	Click here to enter text.			

24. Please indicate the types of data that are/will be accessible in the PHR and the method for gathering data including auto-populated, sent from other external systems, and/or manually entered or updated by providers or users. Please check all that apply:

Data Type	Accessible in the PHR	Auto-Populated	Manually entered or updated by providers	Manually entered or updated by users
Family history (Important events, dates, hereditary conditions)	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>
Medical history	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>
Surgical history	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>
Genetic information	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>
Social history	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>
Behavioral health history	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>
History present illness	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>
Eye records	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>
Dental records	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>
Physical exam	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>
Test results	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>
Lab results	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>
Health summary	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>
Problems	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>
Conditions/Chronic disease	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>
Symptoms	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>
Medication history/Current pharmacy data	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>
Patient instructions	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>
Review of systems	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>
Social services history	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>
Functional assessment data	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>
Cognitive assessment data	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>
Physical and occupational therapy services received	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>
Receipt of durable medical equipment, homemaker, and other services	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>
Vital Signs	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>
Consult(s), Assessment(s), and Plan(s)	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>
Recommendations	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>
Other	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>
<i>If other, please specify:</i>	Click here to enter text.			

25. Please indicate the types of wellness preventative medicine and/or self-care data that are/will be accessible in the PHR and the method for gathering data including auto-populated and/or manually entered or updated by providers or users. Please check all that apply:

Data Type	Accessible in the PHR	Auto-Populated	Manually entered or updated by providers	Manually Entered or updated by users
Medication list	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>
Immunizations	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>
Allergies	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>
Personal health data	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>
Personal health journals	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>
Other	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>
<i>If other, please specify:</i>	Click here to enter text.			

26. What types of data to support managing health education are/will be accessible in the PHR? Please check all that apply:

- Automatically connects users to specific health content for each test result or health issue
- Encyclopedia
- Glossary
- Virtual coaching
- Automated Health Programs (ex. diet, exercise, disease management)
- Other

If other, please specify: [Click here to enter text.](#)

27. What types of decision-support tools are/will be accessible in the PHR? Please check all that apply:

- Automatically triggers alert to call doctor for abnormal results
- Ability to query external clinical decision support services
- Ability to query case manager contact information
- Provide clinical decision support appropriate to use of PHR in self-care, home health and remote settings
- Population-specific decision-support tools for physical and developmental disabilities
- Other

If other, please specify: [Click here to enter text.](#)

28. What types of data to support managing encounters with providers are/will be auto-populated and/or manually entered or updated by providers or users in the PHR? Please check all that apply:

Data Type	Auto-Populated	Manually entered or updated by providers	Manually entered or updated by users
Case manager contact information	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>
Living Wills and Advance Directives	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>
Guardianship Forms	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>
Power of Attorney	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>
Formal and/or informal caregiver contact information	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>
Budget (Utilization of available services)	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>
Service Agreements	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>
Care Management Plans	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>
Personal Care Planning	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>
Organ Donor Authorization	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>
Permission forms for release of information	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>
Correspondence with provider(s)	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>
Other	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>
<i>If other, please specify:</i>	Click here to enter text.		

29. If fields are auto-populated, how do/will account holders (e.g., PHR users, HCBS beneficiaries, family members, guardians, LTSS providers) correct an error? Please check all that apply:

- Account holders can review the data and select which information is stored
- Account holders can edit the information
- Account holders can annotate records or leave a comment on each page but are not permitted to change or destroy data populated by other systems
- Account holders can email the provider to change the information
- Account holders do not have an option to edit or correct information

V. Types of PHR Features and Functions Available to Users

30. What scheduling and appointment features and functions are/will be available to users through the PHR? Please select all that apply:

- Request appointment
Please specify types of appointments available, including the types of providers and LTSS services that might be accessed, through this functionality: [Click here to enter text.](#)
- Schedule appointment in real-time
- Manage or cancel appointment
- Appointment reminders
- Calendar with appointments
- Reminder to complete forms for appointment
- Review personal health benefit information
- Identify available services
- Estimate/Compare health care costs
- Other
If other, please specify: [Click here to enter text.](#)

31. What secure messaging features and functions are/will be available to users through the PHR? Please select all that apply:

- Send secure messages to health care providers and clinicians
- Receive secure messages from health care providers and clinicians
- Send secure messages to LTSS providers and/or care managers
- Receive secure messages from LTSS providers and/or care managers
- Other consumer/provider communication tools (aside from secure messaging)

If other, please specify: [Click here to enter text.](#)

32. What disease and self-management features and functions are/will be available to users through the PHR? Please select all that apply:

- Order new or renew prescriptions
- Prescription refill reminders
- Electronic notifications when new or changed information appears
- Medication management tools
- Decision support tools
- Personal goal setting tools
- Chronic disease self-management tools
- Consumer education
- Graphing vital signs and health status
- Hyperlinks that define technical terms
- Aids to assess significance of laboratory and other diagnostic tests
- Document storage
- Other

If other, please specify: [Click here to enter text.](#)

33. Does/will your state integrate an individual's eligibility determination information into the PHR system?

- Yes
- No

34. What clinical or LTSS features and functions are/will be available to users through the PHR? Please select all that apply:

- View personal clinical data
- Edit existing personal health or clinical data
- Enter or create new personal health data (i.e., user generated data)
- Personal health journal
- View EHR data
- Transfer data to or from a provider's EHR
- View social service and other LTSS data
- Edit existing social service or other LTSS data
- Guideline based reminders
- Drug-drug interactions
- Formulary management
- Clinical trial eligibility
- Other

If other, please specify: [Click here to enter text.](#)

PHR Users

VI. PHR Account Holder Profile

35. How will users establish a PHR account?

Please describe: [Click here to enter text.](#)

36. Do/will PHR users complete a consent form before first use of the PHR?

- Yes
 No

37. Can/will users assign secondary PHR access account holders?

- Yes >>PROCEED TO QUESTION 38>>

If yes, please describe what individuals, including caregivers and/or family members that could be granted this access:

[Click here to enter text.](#)

- No >>SKIP TO QUESTION 41>>

38. If users are/will be able to designate secondary PHR access, what types of data will these additional account holders be able to access?

Please describe: [Click here to enter text.](#)

39. Can/will PHR users select or authorize who has access to clinical and other LTSS information available through the PHR?

- Yes >>PROCEED TO QUESTION 40>>

If yes, please explain: [Click here to enter text.](#)

- No >>SKIP TO QUESTION 41>>

40. Can/will users select some information to share and restrict access to other personal health information or results?

- Yes

If yes, which sections can be restricted:

[Click here to enter text.](#)

- No

41. Do/will PHR users have the ability to access the PHR in languages other than English?

- Yes >>PROCEED TO QUESTION 42>>

- No >>SKIP TO QUESTION 43>>

42. If the system will operate in languages other than English, please list those other languages.

- Spanish
 Other language

If other, please specify: [Click here to enter text.](#)

VII. PHR Outreach and Education

43. Who is/will be responsible for conducting outreach and education about the PHR? Please select all that apply:

- State
- Independent third party
- Healthcare provider
- LTSS provider
- Insurance company
- Employer
- Other

If other, please specify: [Click here to enter text.](#)

44. What methods are/will be used to inform PHR users of their privacy and security rights?

- Privacy notice on vendor website
- Privacy notice within PHR
- Email
- Other

If other, please specify: [Click here to enter text.](#)

45. Does/will the state or responsible entity inform PHR users if privacy practices and notices change?

- Yes
- No

46. What type(s) of marketing strategy(ies) does/will the state or responsible party use to market the PHR to users? Please select all that apply:

- Community outreach
- Print campaign (flyers, newspaper)
- TV
- Radio
- Email
- Internet
- Social media (Facebook, Twitter)
- Other

If other, please specify: [Click here to enter text.](#)

47. Does/will the state or responsible party use population-specific materials in PHR outreach and education or marketing strategies?

- Yes
- No

If yes, please list the populations: [Click here to enter text.](#)

48. Does the agency/organization responsible for overseeing PHR outreach and education have a dedicated website?

- Yes >>SKIP TO QUESTION 50>>

If yes, please provide the link to the website: [Click here to enter text.](#)

- No >>PROCEED TO QUESTION 49>>

49. If the agency/organization does not have a dedicated website, does the agency/organization plan to develop a website for this project?

- Yes
- No

50. If the agency/organization has a dedicated website, do they plan to disseminate information and resources about the PHR on the website?

- Yes

If yes, please describe what information will be shared:

[Click here to enter text.](#)

- No

51. Who is/will be responsible for educating users on how to register and use the system once users learn about the PHR? Please select all that apply:

- State
- Independent third party
- Healthcare provider
- LTSS provider
- Insurance company
- Employer
- Caregiver or family member
- Other

If other, please specify:

[Click here to enter text.](#)

52. How does/will the state or responsible party educate users on how to register and use the PHR system? Select all that apply:

- User guide available within PHR
- User guide on vendor website
- User guide mailed to providers or users when requested
- Training available online (webinar, video demonstration)
- Training available in-person or one-on-one in home
- Training is not available
- Customer support call-center
- No formal direction provided
- Other

If other, please specify:

[Click here to enter text.](#)

53. How does/will the agency/organization responsible for PHR outreach and education support users that are not comfortable with computers and technology?

Please describe the strategy:

[Click here to enter text.](#)

54. How does/will the state or responsible party communicate the value of a PHR to users?

- Develop materials (pamphlet or user guide) for providers to distribute
- Develop ads for TV, newspaper, radio, billboards
- Conduct literature review and share with providers to increase awareness
- Share Success stories (website, newspaper, interview on TV, etc.) of families/individuals who have benefited
- Develop short video series that shows users accessing information
- Perform demonstration in hospital or other facility in the community
- In-home one-on-one discussions with individuals/caregivers
- Other

If other, please specify: [Click here to enter text.](#)

55. Does/will LTSS provider staff receive training in use of PHR to assist consumers?

- Yes
- No

56. How does/will the state or responsible party monitor the progress and implementation of the PHR system (e.g., PHR usability testing, user feedback for modifying PHR)?

Please describe: [Click here to enter text.](#)

57. Does/will the state or responsible party conduct an evaluation of the progress and implementation?

- Yes
- No

If yes, please describe the evaluation plan/measures: [Click here to enter text.](#)

VIII. PHR Access and Support**58. What tools does/will the state employ to support broad access by intended users including blind, physically disabled, individuals with low literacy, and individuals with barriers to use of technology? Please check all that apply:**

- Design meets or exceeds 508 compliance
- Font size adaptation for on screen viewing
- Tags for images and pictures
- Instructions tailored for users with cognitive disabilities
- Definitions for fields and terms used
- Help features
- Appropriate literacy levels
- Other

If other, please specify: [Click here to enter text.](#)

59. What platforms are/will be available for account holders to access the PHR? Please check all that apply:

- Paper
- Personal computer
- Internet
- Smartphone mobile application
- PHR smart card
- Other

If other, please specify: [Click here to enter text.](#)

60. Describe the types of devices or assistive technology that are/will be supported for the HCBS beneficiary to access their PHR.

[Click here to enter text.](#)

61. Does/will the PHR generate reports or dashboards for users to view information in a concise/user-friendly way?

- Yes

If yes, please describe the reports generated: [Click here to enter text.](#)

- No

62. Can/will PHR users print reports or forms from the PHR?

- Yes
- No

63. Is there any cost to the user for accessing the PHR?

- Yes

If yes, please describe the cost to the user: [Click here to enter text.](#)

- No

64. Can/will users download or transfer information from the PHR to another PHR?

- Yes

If yes, please describe the information that can be transferred: [Click here to enter text.](#)

- No

65. What kind of consent model is being used?

- Opt-out
- Opt-out with exceptions
- Opt-in
- Opt-in with restriction
- No consent
- Other

If other, please specify: [Click here to enter text.](#)

66. What kinds of technical support will the state provide for PHR users? Please select all that apply:

- Self-Help Support (e.g., state-developed user manual, FAQ)
 - Existing call center (800 number)
 - If existing call center, please list vendor name:* [Click here to enter text.](#)
 - New call center (800 number)
 - If new call center, please list vendor name:* [Click here to enter text.](#)
 - 3-1-1
 - Dedicated email
 - In-home staff to assist individual/caregiver with PHR data entry and data review
 - Website
 - Other
- If other, please specify:* [Click here to enter text.](#)

67. What support does the vendor offer for users of the PHR? Please select all that apply:

- Self-Help Support (e.g., Website, Downloadable guides, FAQ)
 - In-home staff to assist individual/caregiver with PHR data entry and data review
 - Create user names
 - Password reset
 - Troubleshoot data entry
 - None
 - Other
- If other, please specify:* [Click here to enter text.](#)

68. How do users contact vendor customer service? Please select all that apply:

- Customer service (24/7)
 - Customer service (Business Hours)
 - Chat feature within PHR
 - Dedicated email
 - No customer service available
 - Other
- If other, please specify:* [Click here to enter text.](#)

IX. PHR Administrative Management**69. What does/will the state budget through state initiatives as far as costs associated with updating and maintaining the software and hardware for the PHR system? Please describe the high-level financial cost. This total cost may include hiring new staff, purchasing new software/hardware, or supporting additional features (mobile phone, appointments).**

[Click here to enter text.](#)

70. Do third parties have access to health information data for research purposes?

- Yes >>PROCEED TO QUESTION 71>>
- No >>If third parties do not have access to data, this is the last question in the PHR Review Template, skip to HIT Environmental Scan.>>

71. How is PHR information shared for secondary use?

- Personally identifiable
 - Statistical/de-identifiable
 - Other
- If other, please specify:* [Click here to enter text.](#)

72. Are PHR users informed when information is shared for secondary use or accessed by a third party?

- Yes
 No

73. How does/will the state or responsible entity inform account holders about the potential secondary uses and disclosures of personally identifiable health information? Please select all that apply:

- Account holders mailed notice
 PHR website displays PHR Model Privacy Notice
 Account holders emailed notice
 Account holders are not informed
 Other

If other, please specify: [Click here to enter text.](#)

HIT Environmental Scan**I. State HIT Infrastructure****A. Health Information Exchange****1. Does your state have an operational HIE organization(s), including HIOs or HISPs?**

- Yes >> SKIP TO QUESTION 3>>
 No >>PROCEED TO QUESTION 2>>

2. If your state does not currently have an operational HIE organization, does your state plan to facilitate HIE in the future?

- Yes >>SKIP TO QUESTION 5>>

If yes, please specify the planned timeline: [Click here to enter text.](#)

- No >>SKIP TO QUESTION 9>>

3. What type of HIE is currently operated in the state?

- One centralized HIE for the state

If centralized, please specify the name: [Click here to enter text.](#)

- Regional HIE(s)

If regional, please specify region(s): [Click here to enter text.](#)

- Private HIE(s)

If private, please specify the organizational name: [Click here to enter text.](#)

- Hybrid HIE (Centralized and decentralized model)

If hybrid, please specify the name: [Click here to enter text.](#)

4. What types of providers and organizations currently participate in the HIE? Select all that apply. Please indicate the total number of participants by type of provider or organization.

	Participate in HIE	Total Number of Participating Organizations
Hospital	<input type="checkbox"/>	Click here to enter text.
Hospital Affiliated Clinic	<input type="checkbox"/>	Click here to enter text.
Federally Qualified Health Center	<input type="checkbox"/>	Click here to enter text.
Mental or Behavioral Health Center	<input type="checkbox"/>	Click here to enter text.
Psychiatric Treatment Facility	<input type="checkbox"/>	Click here to enter text.
Accountable Care Organization	<input type="checkbox"/>	Click here to enter text.
Managed Care Organization	<input type="checkbox"/>	Click here to enter text.
Mid to Large Medical Group	<input type="checkbox"/>	Click here to enter text.
Physician Office	<input type="checkbox"/>	Click here to enter text.
Dialysis Center	<input type="checkbox"/>	Click here to enter text.
Imaging Center	<input type="checkbox"/>	Click here to enter text.
School Health Clinic	<input type="checkbox"/>	Click here to enter text.
Home Health agencies	<input type="checkbox"/>	Click here to enter text.
Hospice agencies	<input type="checkbox"/>	Click here to enter text.
Pharmacies	<input type="checkbox"/>	Click here to enter text.
Medicaid providers	<input type="checkbox"/>	Click here to enter text.
Medicare providers	<input type="checkbox"/>	Click here to enter text.
Long Term Care providers	<input type="checkbox"/>	Click here to enter text.
Skilled Nursing Facility/Rehabilitation providers	<input type="checkbox"/>	Click here to enter text.
Respite providers	<input type="checkbox"/>	Click here to enter text.
Other Health Care providers	<input type="checkbox"/>	Click here to enter text.
Other Ancillary Service providers (e.g.; lab or radiology providers)	<input type="checkbox"/>	Click here to enter text.
Health Plan or Insurance Company	<input type="checkbox"/>	Click here to enter text.
Other payers	<input type="checkbox"/>	Click here to enter text.
State Health Agency	<input type="checkbox"/>	Click here to enter text.
Local Health Department	<input type="checkbox"/>	Click here to enter text.
Community/Non-Profit Organization	<input type="checkbox"/>	Click here to enter text.
College or University	<input type="checkbox"/>	Click here to enter text.
Other	<input type="checkbox"/>	Click here to enter text.
<i>If other, please specify:</i>	Click here to enter text.	

Refer to **questions 5 to 8** if the state HIE organization(s) is operational or planned. If more than one HIE organization is operational or planned in the state, provide the **names for each HIE organization in question 5** and **complete questions 6 to 8 for each HIE organization.**

5. Please identify the name(s) of the HIE organizations?

[Click here to enter text.](#)

6. What types of services are/will be available through the HIE organization(s)?

- Patient portals
- Clinical messaging
- Clinical data interoperability services
- Testing and results reporting
- Other clinical documentation sharing
- Electronic health record
- Personal health record
- Record locating services
- Administrative services (claims, authorization, payment systems)
- Disease management services
- Community and public health reporting
- Other

If other, please specify: [Click here to enter text.](#)

7. What types of data are/will be exchanged through the HIE organization(s)? Select all that apply:

- Unstructured, viewable electronic data (e.g., scans of paper forms)
Please list the organizations exchanging data: [Click here to enter text.](#)
- Structured, viewable electronic data (e.g., electronically entered data that cannot be computed by other systems)
Please list the organizations exchanging data: [Click here to enter text.](#)
- Computable electronic data (e.g., electronically entered data that can be computed by other systems)

Please list the organizations exchanging data: [Click here to enter text.](#)

8. What types of data (e.g., unstructured, viewable electronic data; structured, viewable electronic data; computable electronic data) are/will be available through the HIE organization(s)?

Data	Unstructured, viewable electronic data (e.g., scans of paper forms)	Structured, viewable electronic data (e.g., electronically entered data that cannot be computed by other systems)	Computable electronic data (e.g., electronically entered data that can be computed by other systems)
Inpatient and outpatient	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>
Emergency department	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>
Pathology	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>
Radiology	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>
Disease management	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>
Pharmacy	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>
Laboratory	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>
Quality measures/data analytics	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>
Medicaid Enrollment/Eligibility	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>
Medicaid Claims/MMIS	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>
HCBS functional assessment	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>
Person-centered plan	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>
LTSS service provision history	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>
Other	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>
If other, please specify:	Click here to enter text.	Click here to enter text.	Click here to enter text.

B. Medicaid Management Information System

9. Describe the current Medicaid Management Information System.

[Click here to enter text.](#)

10. Who has access to MMIS? Describe the features or functions users can access.

Users	Yes	No	<i>If yes, describe features or functions users can access:</i>
Beneficiaries	<input type="checkbox"/>	<input type="checkbox"/>	Click here to enter text.
HCBS Providers	<input type="checkbox"/>	<input type="checkbox"/>	Click here to enter text.
Care or Case Managers	<input type="checkbox"/>	<input type="checkbox"/>	Click here to enter text.
Acute Care Providers	<input type="checkbox"/>	<input type="checkbox"/>	Click here to enter text.
Other healthcare provider	<input type="checkbox"/>	<input type="checkbox"/>	Click here to enter text.
<i>If other, please specify:</i>	Click here to enter text.		

11. What systems are/will be integrated with the MMIS system?

System	Yes	No	<i>If yes, describe the features or functions that are/will be integrated:</i>
HIE	<input type="checkbox"/>	<input type="checkbox"/>	Click here to enter text.
EHR	<input type="checkbox"/>	<input type="checkbox"/>	Click here to enter text.
PHR	<input type="checkbox"/>	<input type="checkbox"/>	Click here to enter text.
Other IT system	<input type="checkbox"/>	<input type="checkbox"/>	Click here to enter text.
<i>If other, please specify:</i>	Click here to enter text.		

II. Provider HIT Infrastructure

A. Electronic Health Record

12. What percentage of acute care providers in your state have certified EHRs?

[Click here to enter text.](#)

13. What percentage of hospitals in your state have certified EHRs?

[Click here to enter text.](#)

14. What percentage of long-term care providers in your state have certified EHRs?

[Click here to enter text.](#)

15. What percentage of home health agencies in your state have certified EHRs?

[Click here to enter text.](#)

16. What percentage of hospice agencies in your state have certified EHRs?

[Click here to enter text.](#)

17. What percentage of behavioral health providers in your state have certified EHRs?

[Click here to enter text.](#)

B. Long-Term Services and Supports Providers

18. What methods are currently used to exchange health information between LTSS providers? Select all that apply:

- Information is not shared regularly
- Fax/Mail/Phone
- Secure e-mail or Direct Secure Messaging
- Access to IT system
- Other

If other, please specify:

[Click here to enter text.](#)

Appendix 2. Personal Health Record User Survey Instrument

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. **Your answers are anonymous and will be kept confidential.** 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 the introduction to these questions. 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

1. Introduction

1. I am completing the survey (Check only one):
 - By myself, as a person receiving services (like meals brought to my home, self-care help with bathing and dressing, or help at home 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 provides you with services like home delivered meals, personal care assistance, and/or homemaker services)
 - Doctor
 - Focus group or other community support 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)

2. Personal Health Record User Questionnaire

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].	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>
I have physical problems (like problems with my vision) that make viewing the [Insert state-specific PHR name] hard.	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>
I think the information on [Insert state-specific PHR name] is safe and secure.	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>
I would recommend the [Insert state-specific PHR name] to a friend or family member.	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>
I would like to continue using the [Insert state-specific PHR name].	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>

4b. Social Services and Needs

My [Insert state-specific PHR name]....	Agree	Disagree	Not Applicable
Helps me to communicate my needs to those caring for me	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>
Helps me to know about the care I receive	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>
Helps me understand my eligibility for services at home	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>
Gives me contact information for my care team members	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>
Keeps me informed about scheduled visits for services I will receive	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>
Gives me access to helpful information resources	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>
Provides a place for my caregivers to receive information about me and my needs	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>

4c. Health Services and Needs

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

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)
 - Help desk (like a 1-800 number or online chat)
 - Computer lab training
 - Family member or friend
 - Other: Click here to enter text.

6. Where do you use [Insert state-specific PHR name]? (Please check all that apply)
 - At home (on my private computer or mobile phone)
 - When I am out of the house (using a mobile phone)
 - At a computer in a public place (like at the library)
 - 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 information
 - 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
 - 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 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 provides services like meals brought to my home, self-care help, and/or help with my home)
 - Doctor
 - 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 questionnaire.]

3. Non-User Questionnaire

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 caring for me	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>
Know about the care I receive	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>
Understand my eligibility for services at home	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>
Give me contact information for my care team members	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>
Keep me informed about scheduled visits for services I will receive	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>
Give me access to helpful information resources	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>
Provide a place for my caregivers to receive information about me and my needs	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>

17b. Health Services and Needs

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

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

4. Demographic Information Questions

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 introduce people to new technologies
 - I have to be one of the first people to buy a new technology
 - I am afraid to use new technology
 - I am the last of my peers to begin using a new technology

5. 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.

Appendix 3. PHR User Survey Frequently Asked Questions and Consent to Participate

We are asking you to complete a Personal Health Record (PHR) user survey.

You do not have to answer the PHR user survey.

If you say yes, you can quit at any time.

Your services and supports will not change in any way.

Why are you doing this survey?

This survey will ask you questions about an electronic tool that you were recently offered for your computer or phone called [Insert state-specific Personal Health Record 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.

What happens if I say yes, I want to answer the questions?

If you say yes, you will:

- Fill out an online survey that asks you questions about your experiences with [Insert state-specific Personal Health Record name].

There are no right or wrong answers to these questions. It is okay if you ask for help with your answers from someone you trust.

How long will the survey take?

The survey will take about 20 minutes of your time.

What happens if I say no, I do not want to answer the survey?

No one will treat you differently. You will not be penalized. The services and supports you get will not change.

What happens if I say yes, but change my mind later?

You can stop answering the questions at any time. You will not be penalized. The services and supports you get will not change.

Who will see my answers?

Only the people who field this survey will see your answers. They will not know the answers are yours. This survey is anonymous, which means that your name is not connected to your answers.

Will it cost me anything to answer the questions?

No.

Will answering these questions help me in any way?

Answering the questions will not help you right now, but may help older adults and people with disabilities in the future.

Is there any way answering the questions could be bad for me?

No.

What if I have questions?

Please call the researchers at [INSERT NUMBER] if you have any questions about the study.

Do I have to give consent?

No. You only give your consent if you want to answer the questions.

What should I do if I want to be in the study?

You already have the online version of the survey. If you agree to complete it, select “agree” below. If you complete the survey, you are saying:

- You agree to be in the study.