

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

## **Paperwork Reduction Act Submission**

### **Supporting Statement A**

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## Introduction

The Centers for Medicare & Medicaid Services (CMS) in the U.S. Department of Health and Human Services (HHS) funds the Testing Experience and Functional Tools (TEFT) in community-based long term services and supports (CB-LTSS) Demonstration program (herein referred to as the TEFT Demonstration). A key component of the TEFT Demonstration is the testing of a personal health record (PHR) with Medicaid beneficiaries of CB-LTSS. CMS seeks approval for a beneficiary survey to assess their experience with and perceptions of the TEFT PHRs. This section provides supporting statements for each of the eighteen items outlined in Part A of the OMB supporting statement.

### Background on the Need for the TEFT Demonstration

The 2010 Patient Protection and Affordable Care Act (ACA) included many incentives for states to build capacity in their CB-LTSS systems and standardize quality measures. Section 2701 of the ACA focuses on adult health care quality measurement. It directs the HHS Secretary to identify and publish an initial voluntary core set of health care quality measures for adults eligible for Medicaid. Further activities associated with the provision called for the Secretary to establish a Medicaid Quality Measurement Program for Adults and publish annual updates to the initial core set of adult health quality measures.

The TEFT Demonstration seeks to advance Section 2701 of the ACA by making available national adult health care quality measurement tools for the populations of individuals using CB-LTSS. More specifically, the TEFT Demonstration seeks to determine the reliability and effectiveness of a set of tools designed to help states measure participant experiences across service settings, share data across service settings, and measure and improve quality in home and community-based services programs (HCBS). Ultimately, CMS wants to understand the feasibility, usability, and implementation of the proposed functional assessment tools (process) and the potential benefits of using the tools (outcomes).

In March 2014, CMS awarded TEFT planning grants to nine states (Arizona, Colorado, Connecticut, Georgia, Kentucky, Louisiana, Maryland, Minnesota, and New Hampshire).<sup>1</sup> As of March 2016, six of the state grantees are implementing the PHR component of the TEFT Demonstration. Participating states include Colorado, Connecticut, Georgia, Kentucky, Maryland, and Minnesota.<sup>2</sup> The TEFT Demonstration provides states the opportunity to study, develop, implement, and assess the most beneficial web-based PHR systems for select Medicaid CB-LTSS beneficiaries in their states.

### PHR Component Goals

States participating in the PHR component of the grant are creating or procuring a PHR system and testing the use of the PHR with recipients of CB-LTSS. Common recipients of CB-LTSS include Medicaid beneficiaries with disabilities including older adults, individuals with intellectual and developmental disabilities, individuals with acquired brain injury and populations diagnosed with severe mental illness. State grantees must develop a PHR solution that meets the specific needs of these

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<sup>1</sup> The State of Louisiana participated in early stages of one component of the TEFT Demonstration, but is not continuing its participation.

<sup>2</sup> The State of Arizona originally planned to participate in the PHR component, but elected to stop plans for PHR implementation and focus on other components of the TEFT Demonstration in December 2015.

populations for the TEFT Demonstration. While research has shown that PHR use can be beneficial in care management, the TEFT Demonstration represents the first time PHRs have been targeted for recipients of CB-LTSS.<sup>3</sup> The target populations for the TEFT Demonstration have medically complex histories that often involve multiple diagnoses and a variety of providers. In addition to physical health, mental health and social services considerations, PHR design and technical functionalities in the TEFT Demonstration seek to address the needs and care coordination requirements for this population. This survey will help inform the future development and use of PHRs among Medicaid beneficiary populations receiving both clinical and non-clinical services.

## **A1. Circumstances Making the Collection of Information Necessary**

Section 2701 of the ACA calls for a TEFT Demonstration program in CB-LTSS. Research on user experience with a PHR is limited and this Demonstration tests the PHR user experiences of a specific targeted population of Medicaid CB-LTSS beneficiaries.

### **Evaluation of the PHR Component**

We are seeking clearance for a PHR user survey designed to assess this PHR component as part of the beneficiary impact and outcomes evaluation of the TEFT Demonstration. The evaluation will contribute to accomplishing TEFT Demonstration goals by assessing the following:

- 1) Impact, benefits, and barriers of PHR use
- 2) Experiences of the beneficiaries

For states participating in the PHR component, CMS is interested in understanding how states, providers, and individual beneficiaries can realize improved care and decreased costs through a more integrated approach. The PHR component includes the collection of CB-LTSS information and “treatment” experiences within the PHR system and dissemination of this information to beneficiaries, their families and/or guardians, case or care managers, and providers.

### **Legal or Administrative Requirements that Necessitate the Collection**

There are no legal or administrative requirements that necessitate the collection of this data. CMS is undertaking the collection at the discretion of the agency.

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<sup>3</sup> Kaelber, D., Pan, E. (2008). The Value of Personal Health Record (PHR) Systems. AMIA Annual Symposium Proceedings Archive; 2008: 343-347. Accessed February 5, 2016 from: <http://www.ncbi.nlm.nih.gov/pmc/articles/PMC2655982/>.

## **A2. Purpose and Use of the Information Collection**

The PHR user survey is important to the TEFT Program Evaluation and understanding the impact of the TEFT PHR on Medicaid CB-LTSS beneficiaries. The TEFT evaluation team's approach includes monitoring state PHR implementation efforts and fielding a survey to CB-LTSS program participants that asks about their experiences using the PHR. This will be distributed as a web-based survey to the universe of PHR users in each state with less than 250 targeted PHR Users. For states with more than 250 targeted PHR users<sup>4</sup>, the state will take a random sample for survey dissemination.

The PHR user survey is designed to answer the following research questions:

- 1) What outcomes are associated with having access to integrated data through the PHR for people with different kinds of disabilities receiving CB-LTSS and their families?
- 2) How and to what extent will people with different kinds of disabilities who are receiving HCBS services, their families, and their health care providers use a PHR?
- 3) What features of the PHR do people receiving CB-LTSS find most useful?
- 4) What features of the PHR (e.g., information available in the PHR) are most associated with self-reported improved experience?

By addressing the research questions listed above, the evaluation of this component of the TEFT Demonstration seeks to measure the degree to which the PHR is implemented in an accessible manner for Medicaid beneficiaries of CB-LTSS. The survey also is designed to assess the user experience of the PHR, including access and usability, as well as some measures of user satisfaction and perceived impacts of PHR use.

## **A3. Use of Improved Information Technology and Burden Reduction**

To reduce respondent burden the PHR User Survey is offered online, unless requested in paper form.

## **A4. Efforts to Identify Duplication and Use of Similar Information**

There are no other similar evaluations being conducted of the TEFT Demonstration. The evaluation and analysis plan outlined in **Part B** reflects careful attention to the potential sources of information for this evaluation as of March 2016. The information collection requirements for the evaluation of the TEFT

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<sup>4</sup> This currently only represents Kentucky, which is still determining whether the PHR will be offered to all Medicaid beneficiaries in the state vs. a smaller sample.

Demonstration will build on sources already available and avoid unnecessary collection of information from multiple sources. This plan is dependent on a stable state environment.<sup>5</sup>

States are engaging with TEFT PHR stakeholders (e.g., case managers, Medicaid agency leadership) through workgroups and focus groups to discuss PHR planning and usefulness. The grantees are in varying stages of PHR selection and implementation. To date, four states have selected PHR platforms and are proceeding with their implementation timelines. Meanwhile, one state is in the final stages of vendor selection and one state is still in the planning and platform selection phases of their PHR rollout. The PHR User Survey will be implemented in a way that accounts for varying grantee timelines for implementation of this component.

## **A5. Impact on Small Businesses or Other Small Entities**

Not applicable. The collection of the TEFT PHR User Survey data does not impact any small businesses or other small entities.

## **A6. Consequences of Collecting Information Less Frequently**

This is a one-time data collection activity for each TEFT state. CMS would like to administer the PHR User Survey once during the TEFT Demonstration. The date of survey implementation in each state will vary based on timing of TEFT PHR rollout. We want to ensure that a similar level of user experience is assessed.

If this survey is not fielded, CMS will not be able to fully evaluate the TEFT Demonstration's impact on beneficiary PHR experience and preliminary, self-reported outcomes. PHR use has yet to be piloted among the CB-LTSS beneficiary population. The TEFT Demonstration represents the first time PHR platforms have been designed for this population and the PHR User Survey represents an opportunity to measure how approaches to the PHR platform are accessible to and used by beneficiaries.

## **A7. Special Circumstances Relating to the Guidelines of 5 CFR 1320.5**

There are no special circumstances that would require an information collection to be conducted in a manner that requires respondents to:

- Report information to the agency more often than quarterly;
- Prepare a written response to a collection of information in fewer than 30 days after receipt of it;

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<sup>5</sup> Changes to state implementation plans will be accounted for as part of this data collection as necessary.

- Submit more than an original and two copies of any document;
- Retain records, other than health, medical, government contract, grant-in-aid, or tax records for more than three years;
- Collect data in connection with a statistical survey that is not designed to produce valid and reliable results that can be generalized to the universe of study;
- Use a statistical data classification that has not been reviewed and approved by OMB;
- Include a pledge of confidentiality that is not supported by authority established in statute or regulation that is not supported by disclosure and data security policies that are consistent with the pledge, or which unnecessarily impedes sharing of data with other agencies for compatible confidential use; or
- Submit proprietary trade secret, or other confidential information unless the agency can demonstrate that it has instituted procedures to protect the information's confidentiality to the extent permitted by law.

## **A8. Comments in Response to the Federal Register Notice and Efforts to Consult Outside the Agency**

### **A.8.1 60-day Federal Register Notice**

The 60-day notice published in the Federal Register on June 13, 2016 (81 FR 38187). Comments were submitted during the comment period from two TEFT states (Georgia and Maryland) via direct e-mail. None were submitted via Regulations.gov. A detailed listing of the comments can be found in **Appendix D**.

Changes have been made to the survey as a result of the states' feedback. The changes include modifying the definition of PHR "use" to viewing and updating the PHR, combining questions that get to the same purpose of PHR use/satisfaction, and adding questions related to other PHR functions like receiving or giving access to information, if applicable to a state's PHR.

Burden estimates have been modified as a result of the changes. The original 15 minute per survey estimate is now 20 minutes, which is reflected in Supporting Statement section A.12. During the comment period, more information was received about the number of individuals each state is targeting for the PHR Demonstration, which reduces the overall burden. Specifically, we estimated 824 individual respondents in the 60-day PRA package and now estimate 576.

### **A.8.2 Efforts to Consult Outside Agency**

CMS authorized receipt of TEFT state feedback on the PHR User Survey. The following feedback was received based on an older version of the PHR User Survey from January 2016. As noted above, states had the opportunity to comment on the updated survey during the 60-day comment period and those comments are reflected in **Appendix D**. For the information below, the referenced question numbers in

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the feedback may no longer be in line with the survey instrument as the current survey reflects the state feedback and may have been reorganized as a result. We received feedback from TEFT PHR component representatives from Colorado, Connecticut, Georgia, Maryland, and Minnesota. **Tables 1 and 2** include state responses to prompts about the survey.

**Table 1: State responses to the prompt: Do you have any suggested edits to the survey questions? Please provide an explanation of your suggested changes for each relevant question.**

State Comment	CMS/Lewin Response
Consider removing/changing language describing a personal health record. It is possible (and likely) that users will not consider things like Meals on Wheels as part of their “health information”. Instead, you may want to be more generic and talk about a web-based tool that allows them to stay informed of or manage the services described.	The language of the introduction has been simplified in an effort to clearly explain what a personal health record is and refers to services more generally as “help”. For now, the survey will continue to use “personal health record” instead of referring to the state’s platform specifically.
Consider bolding the important words in long responses such as these (e.g. Person receiving services)	This will be considered when the web-based survey is designed.
Add this sentence following “your responses are confidential” – “It is your choice to answer these questions. None of your services will change if you decide to answer them.”	Language has been added.
Question 1 - 4 <sup>th</sup> response option – add “/Case” after “Care” – and throughout the survey	Clarification added throughout survey.
Question 2 - Is the survey being sent out electronically? If yes, the answer will always be yes?	Internet use questions deleted per this recommendation.
Question 3 - Rephrase smartphone options to: (iPhone, Android, or other handheld device). Droid is a brand name and some (very few) users may have Windows phones.	Question has been deleted.
Consider adding a question related to using public computers. A lot of low income older Adults interviewed may have a smartphone but access the internet via a public computer in their building. This could be a barrier to them using a health-related application since health-related information is considered to be a private thing.	The survey currently asks where an individual is accessing their PHR and includes an option for public computers.
Question 7 - Sometimes “Case Manager” is used instead of “Care Manager”. Consider using “Doctor or someone in his/her office” as they could learn from a nurse. Consider adding non-personal channels of learning about the application such as mail or change the question to “Who told you about your PHR?” The state Medicaid office may be another option.	Language is updated throughout the survey to read “case or care manager” in response to this noted difference.  Categories for how an individual learned about the PHR may be added if the question is kept.
Question 7 and several others that follow assume that there is only one personal health record. While that would be the ideal case for this population, if they have visited an acute care provider within the past year or two and if that acute care provider has an electronic health record system with a patient portal feature, it's plausible	Communications to beneficiaries clearly identify the state-offered PHR through TEFT as the target of the data collection.

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<b>State Comment</b>	<b>CMS/Lewin Response</b>
that they may have multiple personal health records. Without further clarification, this question could be applied to multiple different kinds of personal health records.	
Question 8 - “Currently” is a loaded word. What if I used it once before for something important and intend to use it again but I am not “currently” using it? Consider, “Have you ever used the application?” followed by “For what purpose” and “Do you plan to use it again?”	“Currently” deleted.
Question 8 - Question – change “a” to “your” – I assume you’re talking about the PHR we’re testing here. What if the person already has another PHR – are you asking about that here?	“Your” added. It is also our assumption that communications to beneficiaries regarding the survey will clearly identify what PHR the data collection is targeting.
Consider changing “Please check only one” questions to having radio buttons instead of check boxes.	This will be noted for web-based survey development.
PHR Questions: You may want to ask what information they currently CAN view as every state’s tool may be slightly different in terms of the information it provides.	The categories of information have tried to be inclusive of all of the information state platforms might provide. From there, this question can assess patient perceptions of what is available to them.
Question 12 - How often do you update your Personal Health Record? (Please check only one) --- Some individuals will have their PHR auto populated and changed via automation that might be an answer option as well. Also you might want to expand the ONLY check one answer option because there may be more than one answer (example: when I have appointments and also once every two weeks for journaling purposes).	Question has been deleted
Question 12 assumes that the beneficiary will be able to update their PHR	Question has been deleted
For Question 13, are they viewing or updating these items? There is a very big difference between these capabilities because a beneficiary may not be allowed to update certain items in their PHR but could view them (i.e. certain medical information, their services and supports information, their care plan, enrollment and eligibility information, test results, prescription drug information, etc.)	We are merging the capabilities because they will differ across the state. Our goal is to assess which components are most used (whether viewed or updated) of those available.
Question 14: Seems a little redundant with 17. Either clarify the difference or remove.	Question deleted.
Not sure how much we want the questions to be related to preference and aspirations, but it would be good to know things like, “Who would you like to have access to some of your information?” and “For each of those checked above, what information would you like them to be able to access?”	Given the length of the survey, it’s not likely that we can add this question. We hope that the question regarding who individuals have shared their information with can address this for now.
Question 17 assumes the beneficiary knows what ‘secure email’ is and how to send it	This is being used as an example in two places in the survey. Not adding clarification for now, but the issue is noted.

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<b>State Comment</b>	<b>CMS/Lewin Response</b>
Question 19 - This question lines up nicely with the User Experience Honeycomb which is a way of measuring the User Experience of the tool. Consider moving the question into the Participant Experience section.	Agreed. The final survey will not include separate sections, but this will be aligned with experience related questions.
Question 19 - Wording on some of the choices available for consumers to select may be leading. More detailed and specific comments for rewording can be found directly associated with each component of this multi-level question in the attached document.	Edits incorporated into new iteration.
Question 19 - 4 <sup>th</sup> response option – add “within the application” after the word “solution” and before the parenthetical	Question has been reworded.
Question 21 - Option 4 – change “by blood sugar” to “your blood sugar”	Correction made.
Question 22 - Great question for measuring patient empowerment and patient engagement. May consider adding a question to the effect of asking if they feeling like they have less uncertainty or more control over their services.	See questions for modified approach that assess whether consumers feel more confident and empowered in their choices.
Question 22 - After Option 1 add “I have choices when I need social services.”	Options have been modified for this question.
Question 22 - Reworking of options may make more sense for consumers and be less repetitive. Suggestion is to combine options and reword some other. More detailed and specific comments for rewording can be found directly associated with each component of this multi-level question in the attached document.	Edits incorporated into new iteration.
Question 21 - This seems redundant to 13 and 18 other than collecting frequency information. Frequency information is not necessarily valuable as I might want to access a key piece of information at a critical time (once) and never access it again. Consider removing this question.	Question deleted.
Question 23 - Consider adding a choice related to, “I don’t see the value in using it” Consider having responses that are a reflection of question 19 (the User Experience Honeycomb questions)	Option added.
Question 24 - Consider changing “would” to “could” as “would” could make the question difficult to answer.	Language change made.
Question 24 assumes that the PHR will have a function for the beneficiary to communicate with their caregiver, doctor, case manager, and service provider	Question has been modified to be more general
Question 24 - After Option 1 add “Help me have choices when I need social services.”	Options have been modified for this question.
Question 25 - Remove the mention of the tool itself and focus on how interested they are to get to, store, update or communicate information about their health and services electronically.	Keeping question, but modified for clarity
Question 25 assumes the beneficiary will be able to	This question language has been significantly

State Comment	CMS/Lewin Response
update certain health information in the PHR	updated.
Question 34 – First response reads oddly	Quality of life questions have been deleted from the survey.
Consider structuring the survey such that even if the participant dropped out of the survey after 5 (or even 2) questions, you could have some useful data. This may include putting some demographics questions towards the front of the survey.	Key value questions have been moved to the front of the survey per recommendation. Demographic questions have been left at the end for now.

**Table 2: State responses to the prompt: Do you have any suggested questions that could be removed from the survey? Please include an explanation for your recommendations.**

State Comment	CMS/Lewin Response
Question 2 - If this survey is intended to be performed online, this question appears to be unnecessary.	Question deleted
Question 6- Not relevant	Question deleted
Question 9 - We're already going to know this on a programmatic level – why ask in the survey?	Question kept in current version, but considered for deletion in future iterations.
Questions 26-39 - Not relevant and make the survey much too long	Quality of life questions have been deleted entirely, while some questions from demographics have been kept for analysis purposes.

We did not receive state responses to the prompt: Are there PHR questions or topics the survey instrument currently does not assess, that you would like to include? Please specify.

## A9. Explanation of Any Payment or Gift to Respondents

There will be no payments or gifts offered to survey respondents for this data collection.

## A10. Assurance of Confidentiality Provided to Respondents

The methodology for the PHR User Survey is intended to ensure the anonymity of survey respondents. The TEFT evaluation team, CMS, and states will collaborate to ensure this data collection effort is implemented effectively and in alignment with federal and state policies and industry Internet security practices. The TEFT evaluation team will employ the following safeguards to carry out confidentiality assurances:

- Access to identities of potential respondents will be limited to the state staff
- Contact information and PHI will not be collected in survey responses
- Data analyses and reports will reflect aggregate findings, never on the individual respondent level

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- Data when in transit from Research.net to the TEFT evaluator will be secure
- Access to survey data will be strictly limited to those who are responsible for entering and analyzing data
- A consent statement will be included, if requested by a state
- Sampled respondents are not required to participate and can opt to not respond to any question

Specifically, all data collection activities will safeguard respondent confidentiality and anonymity as per the guidelines of the Privacy Act. CMS also provides assurance that the data collected are exclusively for statistical purposes and individuals will not be identified in any analyses or reports. CMS is able to provide this assurance under the Confidential Information Protection and Statistical Efficiency Act of 2002 (CIPSEA) (Pub. L. No. 107-347, title V). Specifically, the TEFT evaluation team will not solicit respondents' names, and will ask respondents to provide minimal demographic information (e.g., sex, education), allowing web-based survey responses to be submitted anonymously. The TEFT evaluation team will not attach any codes or addresses to responses. Further, respondents who request a paper-based survey will be asked to submit their completed documents in a return envelope that will not require participant identifiers, such as name and address. Finally, upon analysis of the survey responses, reports will not identify any individual respondents. No state agency will take any action to the benefit or detriment of responders or non-responders' program participation.

The TEFT evaluation team will not have access to any individual's contact information or protected health information. The TEFT states will oversee communications to individuals in the survey samples and the TEFT states will not be able to link survey responses to these individuals. The TEFT evaluation team intends to use Research.net for online surveys and create a unique web address for each state's survey. The TEFT evaluation team will track the denominator and numerator of responses in each state, but will not track individual-level non-response or duplicate submissions. Reports presenting the survey findings will not identify any individual respondents. All personally identifiable information will be destroyed at the study's conclusion.

## **Security**

The respondents' data when in transit from the survey website to the TEFT evaluation team will be safe, secure, and available only to TEFT evaluation staff assigned to the tasks of data collection and analysis. Communications with the Research.net website will be appropriately protected with Secure Sockets Layer (SSL) and Transport Layer Security (TLS) technology and using both server authentication and data encryption. Research.net maintains industry security protections related user security, physical security, availability, network security, storage security and organizational and administrative security.

The TEFT evaluation team's security protections once the survey data are transmitted from Research.net will include storage in a password-protected folder and secured on a private network. The TEFT evaluation team provides privacy and security training to the TEFT team staff annually. Additionally, access to the survey data files will be set on a need-to-know/least privilege necessary basis. The TEFT evaluation team also maintains information security policies, including incident response plans, and regularly reviews and updates them. For paper-based surveys, documents will be stored in locked files and cabinets and completed materials will be shredded.

Because the survey does not solicit protected health information, the TEFT evaluation team and respondents will not require HIPAA-enabled accounts.

### **Consent**

Prior to data collection, the TEFT evaluation team will discuss with state staff and strictly follow any state-level policies related to consent in state quality improvement/assurance initiatives. The TEFT evaluation team will address consent as specified by the needs of each state. If requested by the state, the TEFT evaluation team will add a consent acknowledgement in the online and paper-based surveys (if paper is requested). Research.net provides the capability to ask respondents to agree to a consent statement outlining data transfer practices, privacy practices or other policies. Research.net also includes “no response” or “prefer not to respond” as an option for questions. The TEFT evaluation team will include “prefer not to respond” to questions at the request of any TEFT states, as per state policies. Additionally, in the survey introduction, respondents will be informed that participation is voluntary and information provided will be confidential.

The data and security plan is further outlined in **Appendix B**. A consent form is in **Appendix C**.

## **A11. Justification for Sensitive Questions**

The PHR User Survey contains limited sensitive questions. It will seek information regarding respondents’ disability status, such as the primary condition for which they receive LTSS. This question supports the analysis of responses across subpopulations of PHR users and identify differences in utilization, experience, and outcomes across those groups. Without data collection related to individual health and disability status, CMS will not be able to determine any differences across the CB-LTSS population related to the value and favored features of the PHRs. This differentiation is directly tied to the nature of information included in the PHRs, including health, provider, and LTSS services information.

It is important to note that responses to this sensitive question will not be required. In the survey (**Appendix A**), this is question #23.

## **A12. Estimates of Annualized Burden Hours and Costs**

The PHR User Survey (Appendix A) was designed to capture detailed and specific information about the experience of PHR users and whether PHR use is associated with positive self-reported experiences.

The Survey link will be distributed by the six TEFT states to the universe<sup>6</sup> of PHR users identified by each TEFT state by mail and/or the PHR platform. As states may elect to name their PHR platforms differently, the survey language will be updated to specifically identify the state’s PHR. This specification will require unique survey links to be developed for each state individually. Communications will be

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<sup>6</sup> In participating states excluding Kentucky, the universe of PHR users will be a cohort of CB-LTSS waiver eligible beneficiaries. In Kentucky, the PHR may be offered more widely to all Medicaid eligible individuals.

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distributed to PHR users introducing the survey and its purpose, as well as instructions for how to access and respond to it online. Our aim is to use the PHR platform and web-based survey format as extensively as possible in an effort to reduce burden. Users will have the option to complete the survey in a paper-based format upon request. Individuals completing the survey online will be asked to respond to PHR user and non-user survey questions based on responses using basic skip-pattern logic. Individuals requesting a paper-based survey will receive two versions of the survey concurrently: a user survey and a non-user survey. Included with the two surveys will be instructions for beneficiaries to identify whether or not they are PHR users or non-users, and based on this status complete only the survey relevant to their experience.

Key survey design considerations:

- While we anticipate the PHR systems used by each state to be different and to contain different features, we have developed a single standardized PHR User Survey for use across all states. The question text will only be tailored to specify the exact name of the state's PHR system (e.g., FEi Systems, GetRealHealth). Answer categories will also be removed if they do not apply to the state's PHR systems (e.g., if the state does not offer "updating" the PHR with new information, then those answer categories will be removed). CMS has developed a longer list of answer categories in anticipation of this.
- We have designed the survey to ensure that the questions, layout, and instructions are appropriate for a population with a 6<sup>th</sup> grade reading level, and to minimize participant burden hours (see **Exhibit A12.1**).
- We have reviewed existing surveys related to PHR use (for general populations, not for CB-LTSS beneficiaries) to refine our questions.
- Key indicators to be measured by this survey are:
  - Reasons for using the PHR;
  - Ease of use and accessing support (e.g., ease of accessing PHR, ease of logging in, definitions, help screens);
  - Sense of security;
  - Value of main features and functions of the PHR;
  - Perceived value of PHR for improving service coordination; and
  - Perceived value of PHR for communicating and coordinating with providers, and formal and informal caregivers.

*Burden*

Table 3 provides a summary of the total number of respondents by type, estimated response time per survey, and the total response time and cost for the different respondents. Based on pre-testing conducted with five individuals who are recipients of CB-LTSS, the PHR User Survey is expected to take **20 minutes** per respondent, including the time required to review instructions, and complete and review

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responses. Please note that the pretesting phase has been completed. OMB approval was not required since the number of respondents was nine or fewer. This information collection request seeks approval to implement the survey.

Prior to data collection, the TEFT evaluation team will discuss with state staff and strictly follow any state-level policies related to consent in state quality improvement/assurance initiatives. The TEFT evaluation team will address consent as specified by the needs of each state. If requested by the state, the TEFT evaluation team will add a consent acknowledgement in the online and paper-based surveys (if paper is requested). Research.net provides the capability to ask respondents to agree to a consent statement outlining data transfer practices, privacy practices or other policies. Research.net also includes “no response” or “prefer not to respond” as an option for questions. The TEFT evaluation team will include “prefer not to respond” to questions at the request of any TEFT states, as per state policies. Additionally, in the survey introduction, respondents will be informed that participation is voluntary and information provided will be confidential.

**Table 3: Estimated Annualized Burden Hours and Cost to Respondents**

<b>Estimated Number of Respondents<sup>7</sup></b>	<b>Number of Surveys per Respondent</b>	<b>Average Burden Hours per Respondent</b>	<b>Total Burden Hours</b>	<b>Estimated Hourly Rate<sup>8</sup></b>	<b>Total Cost</b>
~ 576 individuals across 6 states	1	0.33 hours	190.08 hours	\$25.39	\$4,826.12

As shown in the table above, the estimated seasonally adjusted hourly earnings for all employees on private nonfarm payrolls in February 2016 were \$25.39/hr (U.S. Bureau of Labor Statistics, 2016). The total estimated burden cost for respondent’s time will be \$4,826.12 assuming **576 responses** across the six TEFT PHR states. The majority of respondents will likely not be employed as a result of their age and/or disability and, if employed, respondents may be employed in low-wage situations.

Since consent forms are generally excluded from the definition of “information” (see 5 CFR 1320.3(h) (1)) we are not setting out such burden but are adding the form to this information collection request as a courtesy and to demonstrate that the form entails no burden other than that necessary to identify the respondent and the nature of the instrument.

Since state reporting is limited to 6 states, it is excluded from the definition of “collection of information” (see 5 CFR 1320.3(c)). Consequently, we are not setting such burden.

*Collection of Information Instruments/Instructions*

- Personal Health Record (PHR) User Survey (see Appendix A)
- Personal Health Record Survey Consent Form (see Appendix C)

<sup>7</sup> Estimate is based on an 80% response rate for a sample of 720 PHR users surveyed.

<sup>8</sup> Bureau of Labor Statistics, Economic News Release. Accessed May 19, 2016 from: <http://www.bls.gov/news.release/empsit.t19.htm>.

## **A13. Estimates of Other Total Annual Cost Burden to Respondents and Record Keepers**

Not applicable. There are no capital, start-up, or annualized maintenance costs associated with this data collection for respondents.

## **A14. Annualized Cost to the Federal Government**

The total contract cost to the federal government of the PHR User Survey component of the TEFT Evaluation effort is \$174,323. The cost covers staff time conducting inventories of existing surveys, designing the survey, developing survey communication and implementation materials for TEFT states, processing and analyzing the data, and preparing reports. This cost is based on the TEFT evaluation team's previous experience in managing data collection efforts of this type and analyzing the results.

In addition to the contract cost specified above, it is estimated that CMS Project Officer efforts to oversee survey implementation will cost less than \$4,914.45 based on 5% of a GS-13 Level 3 salary in 2016.<sup>9</sup>

In total, it is estimated that this data collection will cost the federal government **\$179,237.45**.

## **A15. Explanation for Program Changes or Adjustments**

Not applicable. This is a new collection.

## **A16. Plans for Tabulation and Publication and Project Time Schedule**

This section contains plans for tabulating and analyzing results and the publication plans and time schedule for completing the project.

### **A16.1 Analysis Plan**

The PHR User Survey will allow CMS to survey the universe of individual beneficiaries targeted by the six states participating in this component of the TEFT Demonstration. This approach will maximize the capacity of CMS and TEFT grantee states to collect preliminary information on the experience of a

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<sup>9</sup> Office of Personnel Management, Salary Table 2016-DCB. Accessed January 20, 2016 from: <https://www.opm.gov/policy-data-oversight/pay-leave/salaries-wages/salary-tables/pdf/2016/DCB.pdf>.

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targeted population of CB-LTSS beneficiaries as they participate in the PHR pilot. The survey rollout will occur following receipt of OMB approval throughout 2017 in conjunction with grantee implementation of the PHR component of the TEFT Demonstration. Following data collection, the TEFT evaluation team will perform basic descriptive analysis of the survey at the state level and aggregate levels (across all 6 states). No inference statistics will be utilized as part of survey data analysis.

Calculations will include:

- o Average frequency of PHR utilization;
- o Most frequently viewed or updated PHR components;
- o Average occurrence of beneficiaries sharing PHR information with their care team;
- o Average perceived ease of use of the PHR tool; and
- o Most frequent reasons for using the PHR tool.

The TEFT evaluation team will also analyze the survey administration process to examine response rates overall, as well as response rates and error rates for particular questions. An example of this analysis approach is provided in **Table 4**.

**Table 4: Example Analysis of Survey Responses Across State Level**

<b>Average Frequency of PHR Use</b>	<b>CO</b>	<b>CT</b>	<b>GA</b>	<b>KY</b>	<b>MD</b>	<b>MN</b>	<b>Aggregate</b>
Every day	N (%)	N (%)	N (%)	N (%)	N (%)	N (%)	N (%)
Several times a week	N (%)	N (%)	N (%)	N (%)	N (%)	N (%)	N (%)
Once a week	N (%)	N (%)	N (%)	N (%)	N (%)	N (%)	N (%)
Once every few weeks	N (%)	N (%)	N (%)	N (%)	N (%)	N (%)	N (%)
Once a month	N (%)	N (%)	N (%)	N (%)	N (%)	N (%)	N (%)
Not using PHR	N (%)	N (%)	N (%)	N (%)	N (%)	N (%)	N (%)

The TEFT evaluation team will calculate descriptive statistics based on response rate. We will provide suggestions to states on additional data analyses they might wish to conduct. Non-response bias will not be measured as part of this survey analysis. The aim of this survey is not to draw specific conclusions for each state, but to assess the implementation and experience of PHRs among the target population across participating states.

Response rates overall in each state will be calculated using the number of responses and total number of beneficiaries contacted during the data collection process. Survey item non-response analysis will be conducted for responses received.

## A16.2 Time Schedule and Publications

As illustrated in **Table 5**, this is a one-time data collection activity. CMS would like to administer the PHR User Survey once per state in 2017. States are on different timelines for rolling out their PHRs, and CMS will coordinate survey implementation based on these individual timelines. The OMB time period will be sufficient for administering and analyzing the surveys.

**Table 5: Timetable for Data Collection, Analysis, and Publication**

Activity/Deliverable	Expected Date of Completion (month after OMB approval)
OMB Review and Approval	May - December 2016
PHR User Survey	January – October, 2017 (3 months) *Note: Timing of implementation in each state may vary based on their PHR rollout and will likely extend through 2017
Data Processing and Analysis	February - December, 2017 (10 months)
Data Reporting	December, 2017 (14 months)
Final Contract Reporting	March 2018

## A17. Reason(s) Display of OMB Expiration Date is Inappropriate

CMS does not seek this exemption. All materials for the PHR User Survey will display the expiration date.

## A18. Exceptions to Certification for Paperwork Reduction Act Submissions

Exception to the certification statement is not requested.