

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

Paperwork Reduction Act Submission

Supporting Statement B

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Section B

This section provides information on the five points outlined in Part B of the supporting statement for the collection of information for the evaluation of the Testing Experience and Functional Tools (TEFT) Demonstration.

B1. Respondent Universe and Sampling Methods

Sampling Plan.

The approach is to survey the universe of community-based long-term services and supports (CB-LTSS) Medicaid Waiver beneficiaries in each state identified as Personal Health Record (PHR) users for up to 250 users. For all states except Kentucky, the user population has been identified as 250 CB-LTSS beneficiaries or less. Kentucky is planning a state-wide launch of its PHR solution; however, this may be delayed resulting in a pilot sample of less than 250 CB-LTSS Medicaid Waiver beneficiaries in that state.¹ A response rate of 80% is expected for this data collection.

We will field this survey in a web-based format and provide beneficiaries with a web-link to the survey via the PHR interface (e.g., a link will be posted to the main page of the state-offered PHR). If a state prefers, the state can mail communications to registered PHR users. The PHR User Survey will only capture state identified PHR users, who are offered the PHR in the three months prior to the survey period. Respondents can work with their care or case managers or family or other caregivers on completing the survey. Our sampling strategy is designed to capture the early experiences and changes in beneficiary perceptions of care by sampling the universe of PHR users in each state. This convenience sample is based on the TEFT Demonstration's model for a targeted testing of the PHR component. While state target populations vary in size, the specification of targeting all PHR users and/or their surrogates per state will capture the aggregate of PHR experience in the demonstration.

The TEFT evaluation team will not collect any identifiers for the survey population outside of a selection of demographic and disability type questions in the survey. Participating states will be asked to disseminate information to registered PHR users about the survey via mail and where supported via the state's TEFT PHR interface.

The estimated universe of CB-LTSS participants and PHR users to be surveyed in each state is summarized in **Table 1**. It should be noted that each state will be offering the PHR platform to user groups of varying sizes, which will create variation in the sampling size of the survey in each state. Where a state is implementing the TEFT PHR among a large population ($n > 250$), like Kentucky may be planning to, a random sample of 250 individuals will be selected for surveying.

¹ As Kentucky is planning to offer the PHR option to the universe of Medicaid beneficiaries, CMS will work with the state to identify a random sample of 250 PHR users who are CB-LTSS beneficiaries for the survey.

Table 1. Data Collection Target Survey Participants by State, as of September 2016

State	Targeted PHR User Population Size ²	Estimated PHR User Respondents (assumes 80% response rate)
Colorado	200	160
Connecticut	200	160
Georgia	30	24
Kentucky	250	200
Maryland	20 ³	16
Minnesota	20 ⁴	16
Total	720	576

A month following initial survey launch, states will distribute a second set of communications with support from the TEFT evaluation team to all PHR users, encouraging their response to the survey or thanking them for prior completion. A TEFT evaluation team phone number and email address will also be provided in the survey description to ensure beneficiaries that they can ask questions anonymously if they wish. When beneficiaries seek survey support, they will not be expected to provide any identifying information to TEFT evaluation team staff.

B2. Information Collection Procedures

The six states participating in the PHR component of the TEFT Demonstration are in different stages of PHR implementation. Consequently, while the same survey will be utilized across the grantees, separate survey data collection timelines will be used for each state.

To increase the response rate for this data collection, the TEFT evaluation team and CMS have developed a recruitment strategy. The TEFT evaluation team will work with grantees to establish recruitment efforts in advance of survey launch that engage provider agencies and other key stakeholders that can support

² CMS plans to survey the universe of PHR users in states up to 250 individuals. Where a state is implementing the TEFT PHR among a population of larger than 250 individuals, states will take a random sample of 250 PHR users to survey.

³ Maryland’s overall target for the PHR is the total of 10,000 people in the population. However, the target for the Pilot to test the tool is approximately 20 people. CMS is assuming the highest amount in this range.

⁴ Minnesota plans on up to 20 users to pilot test their PHR during the TEFT Demonstration. CMS is assuming the highest amount in this range.

recruitment of respondents. This may also include introductory communications from grantees to beneficiaries emphasizing the purpose of the survey.

The survey will use a purposeful approach to sample the universe of TEFT PHR users in each state. The TEFT evaluation team will provide to states all documents and protocols necessary for the recruitment process. This will include the introductory communications for potential respondents, links to the survey website, explanation of the survey's purpose, uses of response data and other items, as needed. With support from the TEFT evaluation team, states will disseminate the survey link through the PHR platform and/or mail upon request.

B3. Methods to Maximize Response Rates

The TEFT evaluation team and CMS will work with each state to maximize response rates for the PHR User Survey, including the following methods:

- Use of a short and uncomplicated survey instrument with clear instructions for completion;
- Limited number of open-ended questions in the survey instrument;
- Flexibility about the time of response (eight weeks); and
- Follow-up communications to all targeted PHR users to encourage their response to the survey.

Specifically, the TEFT evaluation team will:

In Advance of Surveying:

- Encourage states to communicate and collaborate with stakeholders, such as state agencies, waiver agents, Area Agencies on Aging, provider associations, financial management services vendors, and consumer groups to message the purpose of the surveys. Stakeholders such as these can play an important role in encouraging survey recipients to respond.
- The TEFT evaluation team will provide language for and request communications from state TEFT teams explaining the importance of the survey and assurance of confidentiality to encourage PHR User Survey recipients to respond.
- The TEFT evaluation team will offer training to state case managers about the survey so that they are well-positioned to answer any questions respondents may have about the survey, as well as encourage survey completion.

Surveying:

- The state TEFT teams will be responsible for disseminating the survey to the target populations. Although the PHR User Survey recipients will be asked to respond within four weeks of receiving the survey, the survey will be in the field for eight weeks to allow for completion and follow-up to non-responders.
- To minimize the burden of completing the survey, the survey instrument was edited to include only key questions and written at a 6th grade reading level. Most questions have multiple-choice response options.

Following Surveying:

- States will send all sampled PHR users a follow-up reminder of the survey four weeks after the initial survey distribution. This communication will encourage recipients to complete and submit the survey by the due date (eight weeks following survey launch).

Non-response bias will not be evaluated as this is a purposeful sample of an already random selection of beneficiaries. Since states are selecting different PHR platforms, the TEFT evaluation team will not be comparing states to each other as part of the data analysis.

In the event that we receive paper survey responses, the data entry system will provide special administrative features for each question for data enterers to designate non-responses and confusing/contradictory responses. Missing data will be assigned a “missing” code, and the number of respondents will be noted for each statistic reported.

B4. Test of Procedures

Feedback from States & TEFT Partners

In December 2015 and January 2016, the state-based agencies participating in the TEFT Demonstration were asked to review drafts of the survey and provide feedback. The TEFT evaluation team received feedback from grantees about the survey in written form. Feedback from states was used to identify priority questions in the survey refinement process. The states also provided ideas for individual question improvement and clarity.

Helpful feedback was received from CMS regarding an initial list of potential questions. This feedback highlighted the importance of:

- Clear explanation of the survey purpose and how respondent feedback will be used;
- Person-centered concepts of care and assessment of beneficiary experience through PHR use across survey structure; and
- Use of positive, clear language and skip patterns to support respondents.

State feedback on an initial list of potential questions helped to prioritize questions for inclusion in the survey and refine language of complex questions to support respondent understanding. This feedback is outlined in Supporting Statement A.

Reading level testing

We used Microsoft Word’s reading level tool to test the reading level of the survey questions. The tool uses the Flesch-Kincaid Grade Level Test, a validated and published test that rates text on a U.S. school grade level. We modified the question and instruction wording until they were at a 6th grade reading level or lower, based on previous research indicating that this is the reading level needed to ensure that the surveys are understandable by the target population.

The Flesch-Kincaid Grade Level for the final survey submitted for OMB review is 6th grade.

Pre-testing

Pre-testing has been completed with four beneficiaries of CB-LTSS and one caregiver. We did not receive edits to the survey based on pre-testing.

B5. Individuals Consulted on Statistical Aspects of Design

The TEFT evaluation team will administer the PHR User Survey and complete data collection and analysis. CMS has contracted with the Lewin Group to conduct the TEFT evaluation. The Lewin Group led the development of the survey and methodology, in partnership with CMS and the TEFT grantees. The Lewin Group will be responsible for survey oversight, data collection and analysis.

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