

# TEFT Demonstration: Promising Practices

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# Grantee Experience with PHR Stakeholder Engagement

Truven Health TEFT Technical Assistance Team

# Grantee Experience with PHR Stakeholder Engagement

## INTRODUCTION

States that are participating in the Demonstration Grant for Testing Experience and Functional Assessment Tools (TEFT) in Community-Based Long Term Services and Supports (CB-LTSS) who have chosen the Personal Health Record (PHR) component of the grant<sup>1</sup> are charged with creating or procuring a PHR system and testing its use with recipients of long term services and supports (LTSS) to meet the goals of the demonstration.

Recipients of LTSS are persons with disabilities, many of whom are elderly, as well as those with intellectual and developmental disabilities, traumatic brain injury, and severe mental illnesses.

In order to perform this task successfully, grantees<sup>2</sup> need to design or procure a PHR solution that meets the specific needs of these populations, described in more detail below. TEFT



grantees determined that stakeholder involvement was critical to determining the requirements of the PHR system. After establishing the need for stakeholder engagement, the grantees devised four strategies to obtain and maintain stakeholder involvement in the TEFT initiative, each of which can be considered promising practices:

- Building a robust stakeholder body, including identification of relevant stakeholders and development of stakeholder feedback sessions;
- Simple and open session design for engaging stakeholders, including the use of various participation and engagement tools such as open discussion, interviews, online surveys, focus groups, and more to obtain information;
- Assessing stakeholder engagement, including evaluating success of the initiative through stakeholder feedback and participation; and
- Maintaining communication with stakeholders to ensure continued input throughout the entire development process.

## THE NEED FOR STAKE - HOLDER ENGAGEMENT

As the grantees embark upon developing the requirements of a PHR solution for the LTSS population, they are required to address the specific needs of that population. Field experience indicates that the elderly and persons with disabilities see the usefulness and value of PHRs. However, the desire to use a PHR is not currently met with accessible user-friendly technology. Many older adults and individuals with disabilities have medically complex histories including long, frequently-changing medication lists and multiple diagnoses by different providers. Outside of the physical, mental, and social needs of the individual using a PHR are the accessibility limitations of the software or web applications

<sup>1</sup> The grant program, known as TEFT, is designed to field test an experience survey and a set of functional assessment items, demonstrate personal health records, and create a standard electronic LTSS record. Additional information can be found on the [Medicaid.gov TEFT Tools website](http://Medicaid.gov/TEFTToolswebsite).

<sup>2</sup> Grantees of the TEFT project include the states of Arizona, Connecticut, Colorado, Georgia, Kentucky, Maryland, and Minnesota.

for this particular population<sup>3,4</sup>. The physical appearance of the screen, number of inputs, amount of data available, font size, and navigation are critical elements to allow individuals to easily move around a PHR. Other necessary accessibility elements include assistive technologies such as Braille display, screen readers, enhanced keyboards, switches, speech synthesizers, etc. Research findings reveal a disconnect between these needs and what is available in PHR systems today<sup>5</sup>.



To address all of the needs of LTSS recipients in the PHR solution development process, input from recipients, their caregivers

and a wide group of stakeholders who are part of the individuals' continuum of care is required. These key players are able to provide valuable insight into the various needs of the LTSS population which impact the development of requirements for an effective solution. Stakeholders include caregivers, clinical providers, service providers, health plans,

<sup>3</sup> I. Baedekers, V. Seakales, C. Stephanotis. Towards an Accessible Personal Health Record, Institute of Computer Science, Foundation for Research and Technology – Hellas Department of Computer Science, University of Crete, K.S. Nikita et al. (Eds.): *MobiHealth 2011*, LNICST 83, pp. 61–68, 2012.

<sup>4</sup> I. Basdekis, V. Sakkalis, C. Stephanidis. Towards an Accessible Personal Health Record, Institute of Computer Science, Foundation for Research and Technology – Hellas Department of Computer Science, University of Crete, K.S. Nikita et al. (Eds.): *MobiHealth 2011*, LNICST 83, pp. 61–68, 2012.

<sup>5</sup> D. Karavite, L. Goldberg, M. Rothberg, G. Freed, L. Frontino. “Accessible Designs for Personal Health Records: Project Report and Initial Findings”, Retrieved from <http://healthitaccess.wgbh.org/report.html>.

hospitals, facilities, home health providers, and others.

Advocacy groups and providers can prove to be incredible champions of PHRs and help encourage and spread the use of such technology. These groups highlight the importance of patient access to up-to-date, accurate information when navigating the health system and insist that PHRs can contribute to caregivers making informed and timely decisions. Most importantly, advocacy groups support the idea that PHRs can contribute to patient engagement in their personal health and care decisions<sup>6</sup>.

In the clinical settings, there is evidence that patients who were more satisfied with their providers were more likely to accept the PHR tool<sup>7</sup>. Providers serving the LTSS population have a key role in beneficiary use of PHR systems and advocacy groups have tremendous power to support these initiatives. All of these stakeholders are critical contributors to define the requirements of the solution.

Based on their stakeholder engagement activities, grantees have determined they need to address the following issues to build a successful PHR solution:

- What is the value of a PHR system to beneficiaries, caregivers, and providers?
- What are the strengths and weaknesses of a typical system?

<sup>6</sup> Blue Cross/Blue Shield. Quotes from Partner Organizations in Support of New Personal Health Record (PHR) Brochures [Internet]. Available from: <http://www.bcbs.com/healthcare-partners/personal-health-records/PHR-Quotes.pdf>.

<sup>7</sup> R. Agarwal, C. Anderson, J. Zarate, C. Ward. If We Offer it, Will They Accept? Factors Affecting Patient Use Intentions of Personal Health Records and Secure Messaging, *Journal of Medical Internet Research* 2013;15(2):e43. Retrieved from <http://www.jmir.org/2013/2/e43/>.



- What data elements need to be captured in the system that would be meaningful to users?
- What data elements are available?
- What are the technical requirements of the system?
- What are the privacy and security needs?

Beneficiaries and caregivers will be able to provide feedback to grantees regarding the value of the proposed PHR solution and their intended use. This feedback can include identifying what data elements (or information components) should be available in the system. Beneficiaries and caregivers can also provide feedback on the strengths and weaknesses of existing systems if provided an opportunity to review the PHRs. In addition, beneficiaries and caregivers can supply input regarding technical limitations, which affect their system use (such as connectivity and access issues). Advocacy groups can also provide valuable feedback on all of these issues, as well as on privacy and security needs.

Providers across the spectrum of care and service delivery for LTSS beneficiaries can assist grantee states in determining which data elements are available and could be used to populate the PHR, including which fields should be entered/edited by beneficiaries versus providers. Providers can also address issues such as sharing information internally and externally with other providers, protecting beneficiary privacy, technical requirements affecting their ability to help populate a PHR, and the effect a PHR can have on patient-provider communication.

The strategies employed for identifying stakeholders and soliciting input are described next.

## Strategy #1: Build a Robust Stakeholder

### Body



The first step in engaging stakeholders is identifying the types of stakeholders that should be included in the requirements development process. A number of TEFT grantees began the process of engaging stakeholders by creating teams of people within state government agencies serving the LTSS population to decide the composition of the stakeholder group(s). The list of stakeholders quickly grew to include LTSS beneficiaries, caregivers, independent providers, agency providers, LTSS advocacy groups, state information technology staff, and state health information exchange staff.

For example, Maryland began their stakeholder search with teams from their LTSS waiver programs and used their recommendations to contact key stakeholders. Consequently, the following stakeholders were invited to the series of discussions around the proposed PHR solution:

- Leadership from state agencies serving LTSS populations;
- Representatives of individual providers/caregivers;
- Representatives of home care agencies; and
- Representatives from Maryland's Health Insurance Exchange.

County health department officials in Colorado began their stakeholder process with outreach to organization directors, caregivers, and service providers to find out what the potential barriers would be for a client-controlled PHR

system and what stakeholders thought would be useful. Subsequently, Colorado engaged a much larger group that included state partners and state leadership not only within the Department of Health Care Policy and Financing (the Department) and Colorado Regional Health Information Organization (CORHIO), but also externally including the Office of Information Technology (OIT) at the Governor’s Office, both state Health Information Exchanges (HIEs) and provider organizations including the Colorado Hospital Association, Colorado Health Care Association, and the Colorado Department of Human Services Administration on Aging. Colorado found that building the internal stakeholder team fostered stronger interagency relationships which created a stronger connection among members and a willingness to cooperate and coordinate.

In their stakeholder outreach, Connecticut included beneficiaries, caregivers, service providers, advocacy groups, and IT specialists. Minnesota (MN) included staff from the MN Department of Health’s Office of Health Information Technology (OHIT) on the Oversight and Management Group for the MN TEFT Grant and coordinated with health information technology (health IT) efforts such as MN e-Health Initiative, MN State Innovation Model (SIM)<sup>8</sup> Grants, and others. They have not yet



included beneficiaries or caregivers because they want clear concepts of what an effective PHR solution can do for the community. Like others, Arizona included representation from impacted state agencies, state health IT staff, and relevant external organizations such as the state Health Information Exchange, advocacy groups, and agencies serving the developmentally disabled population.

### Strategy #2: Simple and Open Design for Engaging Stakeholders

Grantees encountered similar challenges and observed similar stakeholder needs as they began designing their approaches for engaging stakeholders. In response to the need to provide stakeholders with background information regarding the TEFT demonstration, grantees utilized a simple and open stakeholder session design. Grantees opened the session by providing basic information on the federal TEFT demonstration funding and the development of the PHR solution for the LTSS population. Grantees were challenged to provide a relatively disparate group of stakeholders with a basic understanding of PHRs and a common vocabulary in order to facilitate the discussions that would follow, without getting unduly technical. Therefore, early in the sessions, grantees explained the nature of a PHR, including the difference between a tethered PHR (sponsored by an organization, usually a healthcare provider, and automatically updated) and an untethered PHR (under control of a beneficiary with options to

<sup>8</sup> State Innovation Models Initiative (SIM): This initiative, sponsored by Centers for Medicare & Medicaid Services (CMS), provides financial and technical assistances to participating states for the development of health care payment and service delivery models that will improve system performance, increase quality of care, and decrease costs for Medicare, Medicaid, and Children’s Health Insurance Program (CHIP) beneficiaries, and for residents of participating states. See

[innovation.cms.gov/initiatives/state-innovations/](http://innovation.cms.gov/initiatives/state-innovations/) for more information.

grant access to individuals or organizations)<sup>9</sup>, and described how PHRs become integrated with HIEs and other similar systems. Grantees began stakeholder sessions with a simple introduction to TEFT and PHRs, and then proceeded to more interactive discussions, eliciting feedback from stakeholders on various topics.

- Typical session topics included:
  - Technical components, such as connectivity and PHR system core functionality.
- Open discussion topics included:
  - First impressions of PHRs;
  - Benefits of PHRs;
  - Challenges of PHRs;
  - What beneficiaries would like to see in a PHR;
  - Desirable functions of a PHR;
  - Privacy and security of PHR information; and
  - Survey of individuals currently using PHRs.

Grantees found that a combination of methods for reaching stakeholders and obtaining their input was most effective.



Grantees used visioning sessions, focus groups, interviews (in-person and telephonic), online surveys, and various

combinations of all these methods to engage stakeholders. In all cases, simplifying the message and maintaining dialogue were effective.

For example, Arizona designed five questions to inspire thought and prepare participants for their visioning sessions related to a PHR solution for the intellectually/developmentally disabled population (IDD). The five questions were as follows:

1. What is the capacity of the state agencies to effectively implement and adopt a PHR solution as a standard part of the program serving the IDD population?
2. What strengths do the two state agencies serving the IDD population bring to a PHR implementation for this population?
3. What are the weaknesses for both agencies with regard to implementing and adopting a PHR for this population?
4. Are there opportunities within the state or the community that these agencies can take advantage of?
5. What are the barriers, threats, or challenges that may impede or prevent the effective implementation and adoption of the PHR for this population?

These five questions were sent to participants prior to the meeting so they had time to think about them and respond thoughtfully. Distributing the questions prior to the meeting made for a more efficient and productive meeting.

While all stakeholder input modalities yielded important information and feedback, several grantees found in-person meetings to be the most effective in eliciting responses from participants.

<sup>9</sup> Health Technology Center/The Children’s Partnership. Technology Profile: Personal Health Records [Internet]. 2009. Available from: [http://www.childrenspartnership.org/storage/documents/OurWork/Technology\\_Enabled\\_Innovations/TechnologyProfilePHRs.pdf](http://www.childrenspartnership.org/storage/documents/OurWork/Technology_Enabled_Innovations/TechnologyProfilePHRs.pdf).



### Strategy #3: Assess Stakeholder Engagement

In keeping with person-centered principles for the TEFT project, stakeholders are central to the design of any tool that will improve their lives. Therefore, assessing the level of stakeholder engagement quickly becomes one of most critical pieces of the project. Do you have the right people involved? Are stakeholders properly represented? Are stakeholders comprehending the message and engaging in dialogue about the topic? Is there demonstrated interest in the project/PHR use? These questions can be answered by determining methods that will help gauge the effectiveness of the outreach. Grantees of the TEFT project used the following strategies to assess their engagement with stakeholders:

- Level of active participation;
- Diversity of populations represented;
- Quantity/quality of questions;
- Amount of participant interaction;
- Participant comprehension;
- Participant interest in PHR topic or use of PHR; and
- Participant interest in subsequent efforts (focus groups, testing, piloting).

Arizona gauged success by the level of participation and engagement, as well as feedback provided. Likewise, Colorado assessed success by the level of active participation of the stakeholders, the variety of the populations served that were represented by the attendees, the questions and interest displayed at the meeting, and whether people understood the content. They also viewed stakeholder willingness to participate in future focus groups as an indicator of successful stakeholder engagement. Minnesota gauged success by the level of participation of attendees. Maryland assessed the variety of

stakeholder feedback in order to gain unique perspectives on LTSS beneficiaries and systems. Connecticut observed the tone of the discussion and noted stakeholder receptivity to the topic, as well as stakeholder interest in more information on the project.

Gathering this information helped grantees determine if more stakeholder sessions were needed, if certain stakeholder populations were absent, if the message was appropriate to engaging stakeholders, and if the session design was effective. Having these types of indicators allowed grantees to refine the session framework, materials, and messaging and also drew attention to any missing stakeholder groups so that more outreach could occur.



### Strategy #4: Maintain Communication with Stakeholders

For the TEFT PHR solution development component, stakeholder communication is needed to ensure continued input is received during the development and acquisition process, that stakeholders are involved in designing PHR outreach and rollout strategies, and that coordination across multiple parallel projects occurs to leverage all opportunities that affect the PHR development, outreach, and implementation processes. Grantees have a variety of ways they have maintained and will continue to engage in communication with stakeholders. Some examples include:

- Ongoing email updates and public presentations;



- Regular stakeholder meetings;
- Focus groups;
- Community collaborative work;
- PHR system demonstrations;
- Usability testing; and
- Training.

For example, Colorado will continue outreach efforts through quarterly state partnership meetings, monthly focus groups in five geographic areas, and monthly formalized communication sent to all stakeholders. Maryland plans ongoing contact with stakeholders through emails and phone calls. Minnesota will have monthly email updates, ongoing public presentations to interested groups, and collaborative work with beneficiaries and caregivers.

Continued interaction and communication will ensure stakeholders are engaged and will continue to guide the development or procurement of the PHR solution, along with

the testing and implementation of the PHR system. Continued education and engagement of beneficiaries will improve buy-in to the value of the PHR and encourage its utilization.

## CONCLUSION

The LTSS population presents unique challenges for PHR system adoption and utilization. To address these challenges, TEFT grantees identified and built a body of stakeholders that represents beneficiaries, caregivers, providers, and other relevant parties to address the specific needs of the LTSS population during the PHR solution requirements development process. Engagement of these stakeholders and their organizations will serve as a resource to TEFT grantees throughout the PHR requirements development process - during adoption, implementation and rollout of the PHR solutions. This also will support sustainability of the solutions selected by grantees beyond the grant period.

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## About the TEFT Demonstration & This Promising Practice Series

In March 2014, CMS awarded TEFT planning grants to nine states to test quality measurement tools and demonstrate e-health in Medicaid community-based long term services and supports (CB-LTSS). The grant program is designed to field test an experience of care survey and a set of functional assessment items, demonstrate personal health records, and create a standard electronic LTSS record. Grantees are participating in one or more of the four TEFT components:

- **Experience of Care (EoC) Survey** – The EoC survey elicits feedback on beneficiaries’ experience with the services they receive in Medicaid CB-LTSS programs. It was designed as a cross-disability survey, i.e., it is population agnostic. As contractor to CMS, Truven Health Analytics conducted a field test of the survey in all nine grantee states with a range of CB-LTSS beneficiaries, including frail elderly, physically disabled, intellectually disabled and developmentally disabled, those with acquired brain injury and person with severe mental illness. In the out years of the demonstration, grantees will administer the finalized survey to their CB-LTSS beneficiaries and use the results to assess and improve quality in their programs.
- **Continuity Assessment Record and Evaluation (CARE)** – Under prior initiatives, CMS invested in the development of the CARE for use in post-acute care settings. Under TEFT, Research Triangle Institute modified some CARE items for assessing CB-LTSS beneficiaries. TEFT grantees will provide a sample of beneficiaries across disabilities upon which the adapted CARE items will be field tested in 2015. Following the field test, the CB-LTSS items will be finalized and grantees will then demonstrate their use in their CB-LTSS programs.
- **Personal Health Record (PHR)** – Grantees will demonstrate use of PHR systems with beneficiaries of CB-LTSS. The PHR is intended to provide CB-LTSS grantees with a range of personal LTSS and health information to facilitate decision making about care. The PHR can encourage a more active role for beneficiaries/caregivers in managing care and result in better outcomes through more efficient management of services.



- **Electronic Long Term Services and Supports Standard (e-LTSS)** – Grantees will pilot test an e-LTSS standard in conjunction with the Office of National Coordinator’s (ONC) Standards and Interoperability (S&I) Framework.

This document is the second in a series of several Promising Practice offerings that the TEFT TA Contractor will issue over the course of the TEFT Demonstration. These Promising Practices draw upon the experiences of TEFT grantees as they address the various components of TEFT. They are intended to inform the ongoing work of the Demonstration grantees as well as other stakeholders interested in incorporating aspects of TEFT into related endeavors.

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