



Identifying Personal Health Record Requirements through Town Hall Meetings

Introduction

In May 2014, the State of Connecticut's Department of Social Services (DSS) received the Demonstration Grant for Testing Experience and Functional Assessment Tools (TEFT) from the Centers for Medicare and Medicaid Services (CMS). The Department subcontracted the University of Connecticut (UConn) to demonstrate the value of Personal Health Records (PHRs) for consumers receiving Community-Based Long Term Services and Supports (CB-LTSS).

According to the American Health Information Management Association (AHIMA), a PHR is "an electronic, universally available, lifelong resource of health information needed by individuals to make health decisions. Individuals own and manage the information in the PHR, which comes from healthcare providers and the individual. The PHR is maintained in a secure and private environment, with the consumer determining who has the right to access their record." PHRs are capable of storing a consumer's medication history, allergy list, previous surgeries and any information the user feels is pertinent to their health.

Connecticut's TEFT team held 12 Town Hall meetings to educate stakeholders about PHRs and collect participant responses to questions pertaining to Health Information Technology (Health IT) across the state. The information gathered from the Town Hall meetings was used to draft a Request for Proposal (RFP) to inform PHR vendors of the functional requirements developed through the Town Hall meetings.

Outreach Methodology

Starting in August 2014, UConn conducted statewide outreach to introduce the concept of PHRs to CT's CB-LTSS population. Outreach included:

1. Development of a TEFT specific webpage containing documentation from the Office of the National Coordinator, CMS, and UConn
2. Creation of flyers for distribution
3. Management of stakeholders and contact information
4. Outreach to state agencies, service providers, advocacy groups, senior centers and other resources
5. Town Hall style meetings to discuss and collect input on PHRs and the TEFT grant

Town Hall Meetings

Town Hall meetings were a key component of stakeholder outreach. UConn planned 16 meetings to discuss PHRs with CB-LTSS participants. Of those meetings scheduled, 12 meetings were held with consumer, advocate and provider groups as reported in Table 1; four meetings were canceled due to inclement weather or lack of interest. Consumers and advocates represented 28% of total meeting participants ($N = 219$).

Table 1. List of CT TEFT Town Hall Meetings

| Date | Organization (Consumer or Provider) |
|------------|--|
| 11/17/2014 | Leading Age (Provider) |
| 11/21/2014 | CT Association for Healthcare at Home (Provider) |
| 12/15/2014 | North Central Area Agency on Aging (Provider) |
| 12/19/2014 | DSS New Haven Office (Provider) |
| 2/11/2015 | Trumbull Senior Center (Consumer) |
| 3/11/2015 | Senior Resources (Provider) |
| 3/20/2015 | CT MFP Statewide Retreat (Provider) |
| 3/23/2015 | Meriden Senior Center (Consumer) |
| 4/1/2015 | Enfield Senior Center (Consumer) |
| 5/14/2015 | WCAAA Advisory Council (Consumer) |
| 5/19/2015 | Senior Resources Advisory Council (Consumer) |
| 6/1/2015 | CT Coalition on Aging (Consumer) |

Through telephone outreach, it was discovered that a majority of CT's CB-LTSS participants had limited or no knowledge of PHRs or the TEFT grant. The TEFT team determined that an educational presentation was needed to facilitate thoughtful discussion during Town Hall meetings. Topics in the educational presentations include:

1. The American Recovery and Reinvestment Act and the TEFT demonstration
2. PHR uses, features, and use outcomes
3. Blue Button plus
4. HIPAA and Direct secure messaging
5. Demonstration of publicly available PHRs

The educational portion of the presentation helped participants understand PHRs, enabling them to express their thoughts and concerns on PHRs and Health IT. During the discussion portion of the meetings, the TEFT team collected responses to the following questions:

1. What comes to mind when you think of Health IT? (First Impression)
2. What are the potential benefits of PHR use?
3. What are the potential challenges of PHR use?
4. What would you like to see in a PHR?
5. Who should have access to the information in a PHR?
6. For the purposes of this demonstration, how many different PHR systems should we use?

All Town Hall discussions began with participants answering the first impression question, “What comes to mind when you think if Health IT”. After the first impression responses were collected, participants guided the discussion. Responses were captured in sequential order using markers and flipcharts.

The TEFT team used a simple study design to obtain participant responses. While surveying the population was not openly discussed, the TEFT team conducted Town Hall meetings to ensure stakeholders were informed about PHRs, and to clarify any misconceptions they may have had. Participants remained anonymous. Using this design, CT collected 803 responses from participants at 12 unique meetings.

Results

Participant responses were organized in sequential order and mapped to the National Core Indicator (NCI) domains¹. Table 2 displays responses associated to the “Satisfaction” domain for the First Impression question. A Free List Analysis using Microsoft Excel (FLAME) was conducted using these filtered domains. This analysis

determines the value of each domain as a Smith’s *S* score²

Table 2: Satisfaction Domain: First Impression

| Satisfaction Responses: “What comes to mind when you think of Health IT?” | |
|--|------------------|
| Streamlined | Convenience |
| Innovative | Helpful |
| Person Centered | Consistent |
| Time-saving | Great |
| Fast | Not Wasting Time |
| Consumers can download it | Possibly helpful |

(Table 3) (Pennec et al, 2013). The Smith’s *S* Scores were

¹ The National Core Indicator program established indicators that measure the performance of LTSS within a state. The NCI domains were identified and drafted through a collaborative effort between NASDDDS and HRSI.

then used to create “Wordle” graphics and inform CT PHR requirements. One Wordle was created for each

Table 3: Smith S scores: First Impressions

| Original Response | Frequency | Average Rank | Smith Index |
|--------------------------|-----------|--------------|-------------|
| Safety | 90.91% | 2.500 | 0.722 |
| Information and Planning | 81.82% | 3.000 | 0.685 |
| Satisfaction | 81.82% | 3.000 | 0.673 |
| Respect/Rights | 45.45% | 4.800 | 0.367 |
| Access | 72.73% | 9.250 | 0.297 |

question.

As displayed in Fig. 1, participants’ first impressions of Health IT indicate that this technology needs to be safe to use and may help consumers in planning their care. Vendors must ensure that the security and privacy of the

Figure 1: First Impression Wordle



individuals health information is respected before potential consumers are willing to use PHRs.

A common theme in Town Hall discussions was an inherent distrust of Health IT security. Many meeting participants cited hacking incidents such as the Anthem data breach (Riley, 2015) as the root cause of their distrust. Several participants reported safety issues and potential violation of their rights as the greatest barriers toward PHR use. As shown in Fig. 2, the Safety, Respect & Rights, and Information & Planning were the highest rated domains, reflecting the distrust for technology found amongst participants. Without assurances that their information is safe, consumers may be wary of adopting a PHR.



² Smith’s *S* score is a numerical value that ranks the sequential order and frequency of words and compares them against other groups. Each domain is scored, with scores ranging between 0 and 1. A score of 1.00 indicates that the term appears in 100% of the lists and was the first term in all the lists.

Despite concern over security challenges, many meeting participants were optimistic about PHRs. Participants expressed how PHRs have the potential to:

1. Improve service coordination
2. Improve the ability to plan for care
3. Improve access to health information and education

Furthermore, participants indicated that PHRs can empower consumers to become equal partners in their care. As shown in Fig. 3 and 4, when asked about the potential benefits and features that should be included in a PHR, the domains of Information & Planning, Service Coordination and Safety were rated highly among participants. A desire for tools and features which would allow consumers to remain autonomous while residing in the community was noted. The need for robust security regarding this technology was also discussed. If vendors cannot secure their PHR users' information, then the adoption of PHRs may remain low.

Figure 3: Benefits of PHR use



Figure 4: Features to include in PHRs



Participants expressed the need to trust those who may have access to their PHRs and to have confidence in PHR security features. As displayed in Fig. 5, when asked who should have access to their records, participants indicated that doctors, trusted individuals and caregivers should have access to their records. Participants had greater opinions on who should not have access to their PHR, citing reasons such as untrustworthiness, apathy and personality differences as disqualifying characteristics for PHR access. Trust and security are not mutually

exclusive, as sentiments toward PHR security often reflected narratives of the potential for exploitation.

Figure 5: Access to PHRs



For the purposes of the TEFT grant, PHRs need to be tested by consumers. When asked, participants indicated that the best number of PHRs to test was three. Multiple PHR choices allows for consumers to choose which system best suits their needs. To stay true to the principle of person-centeredness, up to three PHRs will be offered during the Connecticut's PHR demonstration.

Discussion

This report describes how Town Hall meeting participants presently view Health IT and PHRs in Connecticut. While meeting participants expressed major concerns around internet security and privacy, they also indicated that PHRs can be useful, especially in regards to accessing information and planning for their care. After reviewing the collected data and related literature, PHR requirements were drafted. To address concerns around access, security, and service coordination the following functionality, features, and standards were written into the RFP:

- Direct Secure Messaging protocol³
- Single Factor Authentication
- HL7 Transport Standard
- USA Hosted PHRs
- ADE Alerts
- Web Content Accessibility Guidelines⁴
- Proxy Access with data rights set by the consumer
- Calendar/Service Appointment Reminders
- Section 508 compliance⁵

These requirements address the challenges associated with PHRs as identified by meeting participants. While there are several PHRs available for use today, many existing PHRs were created for a certain population (i.e. mental health) or only to address a few of the concerns reported by participants. As a result, CT will procure up to three PHRs for consumers to choose from for the purposes of this demonstration. This will allow consumers to choose which PHR best suits their needs,

the highest level of security and access. The Access guidelines promote technologies which are user-friendly and ergonomic.

⁵ Section 508 of the Amendment to the Rehabilitation Act of 1973 was enacted to eliminate barriers to information technology for individuals living with physical disabilities (such as blindness). The amendment encourages development of technologies that will help achieve these goals such as teletypewriters and non-visual desktop access support.

³ Direct messaging is a data transmission protocol and standard allowing for the transport of personal health information. Direct is HIPAA compliant and uses encryption as its primary method of data security.

⁴ The Web Content Accessibility Guidelines (WCAG) are a list of security and access standards created by the World Wide Web Consortium. These guidelines include 3 stages of security with ratings ranging from A-AAA with AAA being

and enable them to participate in their care with the goal of improving their health.

The TEFT team strived to conduct meetings throughout the state to provide all residents the opportunity to provide input on PHRs. This approach created a diverse pool of participants, ensuring participation from individuals with unique clinical conditions, demographics and socioeconomic standing.

Figure 6: Map of CT Outreach



Conclusion

The TEFT grant was created in an effort to improve public health through the use of Health IT. The organizing principle behind PHRs is consumer empowerment. Through the use of PHRs, consumers will become better informed, enabling them to become equal partners in their care. Consumer empowerment has been associated with improved health outcomes for individuals living with mental health issues (Nelson, Lord & Ochocka, 2001), adolescents, (Wallerstein, 2006) and the socioeconomically disadvantaged (University of Chicago, 2012). The researchers reported improved study participation when a “champion” (i.e. community leaders) for empowerment was identified within study populations. PHRs have the potential to become an avenue to which individuals become empowered in their health decisions.

PHRs have the potential to improve health outcomes for CT’s CB-LTSS participants. Future researchers interested in studying older adults should engage their state’s network of:

1. American Association of Retired Persons (AARP)
2. State Area Agencies on Aging
3. Advocacy groups

Engagement with these organizations can facilitate new partnerships, networking opportunities, and foster interest in scheduling outreach meetings.

When conducting Town Hall style meetings, the ability to speak several languages may improve participant understanding and response rates. Any presentations used during outreach meetings should be written in accordance

to the Federal Plain Language Guidelines⁶. Any videos used during these presentations should include subtitles and a hyperlink if available. Educating this population prior to outreach meetings may also improve participant response rates during discussions.

PHRs have the potential to empower consumers, allowing them to become equal partners in their care decisions. PHRs should be secure enough to ensure consumer privacy is respected, and enable users to plan their care accordingly and in a timely manner. Failing to meet these specification may negatively impact PHR adoption and use in CT.

A RFP for a PHR system addressing the needs and requirements identified by Connecticut’s CB-LTSS population has been drafted using the information gathered during the Town Hall meetings. In the spirit of person-centeredness, a multivendor PHR marketplace will be created, enabling consumers to select the PHR of their choice. The TEFT team believes PHRs have the potential to positively affect health outcomes for CB-LTSS consumers.

Suggested Citation

Tikoo M, Macri G, Rusnak R. *Identifying PHR Requirements through Town Hall Meetings*. Storrs, CT: University of Connecticut; 2015.

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⁶ The Federal Plain Language Guidelines can be found at www.plainlanguage.gov