



The Shared Care Plan: Designing a Truly Patient-Centered HIT Tool and Evaluating its Impact

Speakers:

Dawn Gauthier, Web Usability Engineer, PeaceHealth

Lori Nichols, Director, Whatcom Health Information Network, LLC (HInet) and Shared Care Plan Personal Health Record

Background:

The May Webinar featured the experiences of a not-for-profit health care system as they developed, implemented – and continue to refine – a patient-centered Personal Health Record (PHR). PeaceHealth efforts have involved extensive user-centered design principles; in fact, they set out to create a chronic disease management tool, but quickly learned that patients preferred to have a PHR tool instead.

IxInsights from PeaceHealth

Insight #1: User-centered design is a philosophy and a process in which the tasks, needs, wants, and limitations of the end user of a system are given extensive attention at each stage of the design process.

- PeaceHealth used a variety of research methods, including one-on-one contextual interviews, to figure out what tasks patients were actually trying to accomplish.
- Contextual interviews involve:
 - The person, the computer, and the environment
 - Observing how patients go about completing tasks in real life
 - Listening to patient stories
 - Asking patients questions about why they go about competing tasks in particular ways.

Insight #2: Extensively involving users in the design process demonstrates new uses for existing technologies, such as medication management.

- While patients were testing a prototype of a medication name search tool, researchers discovered that patients were using the medication lists for an unintended purpose.

- Instead of “just” selecting a particular medication and dosing regimen to find the generic equivalent, they were taking note of where their dosage fell compared to the range of available options.
- This is information patients found interesting and helpful, but to which they would otherwise generally not have access.

Insight #3: Not every step to building a PHR requires the latest technology; many steps are iterative and involve paper-based “hand drawn” web mockups.

- Rather than create web pages and seek consumer feedback after they were developed, PeaceHealth started an iterative process of getting feedback by asking patients to point to where they would click with their mouse, but with their finger.
- Instead of creating, tweaking, and redoing user interfaces, they were able to develop user-friendly forms before any high-tech work was done.

Insight #4: Rather than focus on cool features, developers should focus on tasks patients actually perform.

- It’s fun to sit around and talk about bells and whistles, but the best way to find out what consumers will use is to ask them and observe consumer actions.
- Task analysis involves creating an actual list of tasks observed. After all, patients are the best experts.
- This has the added benefit of helping to focus resources and energy on how your product will be used in the real world by real people.

Insight #5: When it comes to PHRs, little design details make a big difference in terms of usability. For example, in the section on allergies, does a blank mean the patient does not have any allergies, or does it mean they have not filled this section out yet?

- The solution devised was to create a checkbox next to the statement, “I have no known allergies.”
- That way, instead of the allergy section being blank for a patient without allergies, the clinician will see the statement “I have no known allergies.”

Insight #6: The user/patient can play an active role in addressing Privacy and security challenges in their PHR.

- Patients select each member of their “Care Team,” via the PHR, to be allowed access to their PHR.
- The patient is empowered to not only select who views their PHR, but also determine the level of access allowed for each person (e.g., Edit, View Only).
- Patients are also allowed to assign access for each diagnosis in their PHR.
 - For example, a patient may choose for her primary care physician, but not her gynecologist, to have access to her sleep apnea diagnosis.
- Patients are able to allow additional access in emergency situations.
- Patients have access to an audit record so they can see who accessed their record and when.

Insight #7: Patients use the audit trail...to make sure their medical professionals are reviewing their PHRs.

- One of the findings of PeaceHealth research was that patients were using the audit capability to make sure their record was being accessed by their doctor.
- Patients were upset when their PHRs were NOT being accessed by their care team.

Insight #8: Health literacy challenges can be addressed by providing focused outreach to patients who need it.

- PeaceHealth provided a drop-in lab for anyone to come and practice with an expert.
- They also did presentations at community centers, churches, and other locations in the community.

Insight #9: Patients will understand the value of PHRs when they start actually seeing them significantly improving their experiences with the health care system.

- When patients realize they no longer have to repeat their medication lists over and over or fill out repetitive forms on each visit, the perceived value of the PHR increases.
- PHRs were seen as more valuable the more participating clinicians seemed to be using it.

Insight #10: PHRs are continually evolving systems and can be integrated with other data sources, such as HealthVault.

- The newest version with the latest technology was just launched, enabling more integration with data sources, such as HealthVault.

IxInsights from Whatcom Health Information Network

Insight #11: Some assumptions about consumers and the health care system are debilitating to efforts to promote HIT and patient engagement. These debilitating assumptions include:

- Ø Chronic care and prevention is like acute care
- Ø Patients and old people are incompetent
- Ø Doctors and hospitals are the center of health caring
- Ø People cannot get access to the web
- Ø Business medical records must be adopted before personal health records/support systems
- Ø Everyone must adopt PHRs before they are useful
- Ø It's OK for every business to "provide" a different health record.

These assumptions derail progress towards promoting HIT and patient engagement.

Insight #12: Patients are more invested in the accuracy of the PHR than anyone else in the system.

- A big concern of medical team members was whether or not patients would enter their own health information correctly.
- PeaceHealth found this concern to be unfounded.

Insight #13: The Medical Home approach to health care is a helpful framework for developing and implementing PHRs.

- The PHR can focus on the individual and their network of supporters (patients can allow family or friends to have access to their PHR/Shared Care Plan).
- PHRs can be a quick path to very useful health information integration focused on the patient by importing all:
 - Labs
 - Prescriptions
 - Pointers to electronic images
 - Payer diagnosis codes
 - Patient-entered information.

Insight #14: Technology is only a tool; patients and providers also find great practical value in paper corollaries to the PHR.

- In addition to wallet-sized information cards, the PHR is designed to print one page summaries of health information.
- In different medical situations, including an emergency situation, medical personnel can read medical information on a piece of paper easier than they can off something like a flash drive.

Insight #15: The Patient Activation Measure (PAM) is a way to measure patient engagement over time.

- Questions on this measure indicate the extent to which patients:
 - Believe taking an active role (in their health care) is important
 - Have the confidence and knowledge to take action
 - Take action
 - “Stay the course” under stress.

Insight #16: PHRs can support coordination and communication to facilitate patient participation in their health care. The majority of PHR participants found that the PHR:

- “Helps me use my local healthcare system more effectively”
- “Helps me communicate with health care professionals”
- “Makes me feel more confident when interacting with the health care system”
- “Helps me feel more confident that I can figure out solutions when new situations or problems arise with my health.”

Insight #17: The PHR is a tool that should facilitate conversations and understanding, coordination of care, improved processes and access to information, making care more patient-centered, and creating community.

Additional Resources

Full source code and complete documentation of the original Shared Care Plan PHR are available at www.peacehealth.org/scp.

A video of a patient talking about their experience with the Shared Care Plan PHR is available at <http://www.wvpp.org/users/0000002/2005/07/19.html#a487>.