

Grant Final Report

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**Patient-Centered Informatics System to Enhance
Health Care in Rural Communities**

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Structured Abstract

Purpose: We conducted a demonstration study of the “Unified Health Resource” (UHR), a novel personal health record and electronic medical record system to promote shared-decision making, patient activation, and health management.

Scope: The focus of this project was on the design, adoption, and use of the UHR.

Methods: Primary care clinics in five rural communities were recruited to participate in this study. Three clinics used the UHR and two used an alternative electronic health record. Efforts to promote use of the UHR were systematically implemented in two of the UHR clinics. Evaluation methods included usability testing, measurement of adoption, and analysis of patterns of use. A survey was administered to patients at two UHR and two non-UHR clinics to assess patient activation, decisional preferences, self-management behaviors, and care processes.

Results: User feedback led to significant improvements in the design of the UHR. Distribution of physician letters to patients was a potent method of recruiting UHR users. Other clinic interventions were less effective. Almost half of the individuals who used UHR once used it again, sometimes frequently. Communication functions and medication management tasks were associated with more intensive use of the UHR.

Key Words: patient-centered care; personal health records; shared decision-making; cognitive support; rural health

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Final Report

Purpose

The aims of this study were:

1. Recruit two rural primary care clinics that use the Unified Health Resource (UHR) and two primary care clinics that use an alternative, non-UHR electronic medical record system to participate in a three year research demonstration project.
2. Apply formative evaluation methods to assess and improve usability, usefulness, and adoption of the UHR personal health system by patients.
3. Enroll patients from the four participating rural clinics into a prospective cohort study to assess the impact of the UHR personal health system on patient-centered care.

Scope

This project was about the design, adoption, and use of health information technology to advance patient centered care. We developed and implemented a system which we called the Unified Health Resource (UHR) because of its emphasis on integration of information. It comprised a clinic-facing electronic medical record, a patient-facing personal health record (PHR), and a communication resource. The brand name for the PHR component of the system was DirectMD, the term by which it was known by patients and clinic staff.

Our research team contributed significantly to the development of UHR. Study personnel met regularly with the software engineers associated with the technology partner for this project, CaduRx, a local health information technology company. We informed the design of each component of the system, provided direction on clinical content, elicited feedback from users, and devised new types of patient decision-support.

Design principles

Three key principles motivated the construction of patient-centered components of the UHR.

1. Provide support for patient activation, self-management, and shared decisionmaking.
2. Hand the patient the controls (of the personal health record).
3. Make the interfaces flexible, intuitive, and smart.

We designed our technology to provide cognitive and behavioral support for patients to be informed health consumers, active participants in shared-decision making, and knowledgeable practitioners of health maintenance. Self-determination theory (SDT) provided a conceptual framework to connect the technology development with these goals of patient-centered care. SDT explains the motivation for human behavior by focusing on understanding basic human needs for autonomy, competence, and relatedness. The UHR was designed to promote patient confidence and competence to engage in appropriate self-management behaviors. A number of features were added to The UHR to encourage patients to share information with their physicians in order to foster shared decision-making.

The principle of “handing the patient the controls” is consistent with SDT because it enhances autonomy and trust. Privacy protection and security was fully incorporated into the system actions. Patients selected which clinicians had access to the personal health record. Clinicians with privileges to open the patients’ personal health record were able to view, but not edit, the patients’ self-reported information. Patients were able to correct any errors they noted in the record and to supplement the record with outside information – such as medications not prescribed by the clinic.

Our software development philosophy was user-centered. Features of the UHR were extensively revised based on user input. The goals were to maximize the patient experience of ease of use, usefulness, and satisfaction. We applied heuristic principles to meet patient expectations that the system would be intuitive ("match between the system and the real world"), have built in error prevention ("careful design"), be easy to remember (recognition rather than recall), and show users where they were in they system ("visibility of system status").

Specific components of the PHR and communication resource

Home page. The home page displayed a to-do list which displayed health-related reminders. The message center on the home indicated the presence of unread messages. Options and tasks were displayed as menu items and in a bar across the top of the page.

Health history. The health history section was organized using file folder-type tabs (Figure 1). Tab categories included medications, allergies, procedures, illnesses, measurements, lifestyle, and family. Data were input using a combination of check-boxes, drop-down menus, and text boxes.

The patient was able to use either lay- or medical terms to describe conditions, procedures, symptoms, and other types of health information.

Figure 1. Summary information in health history

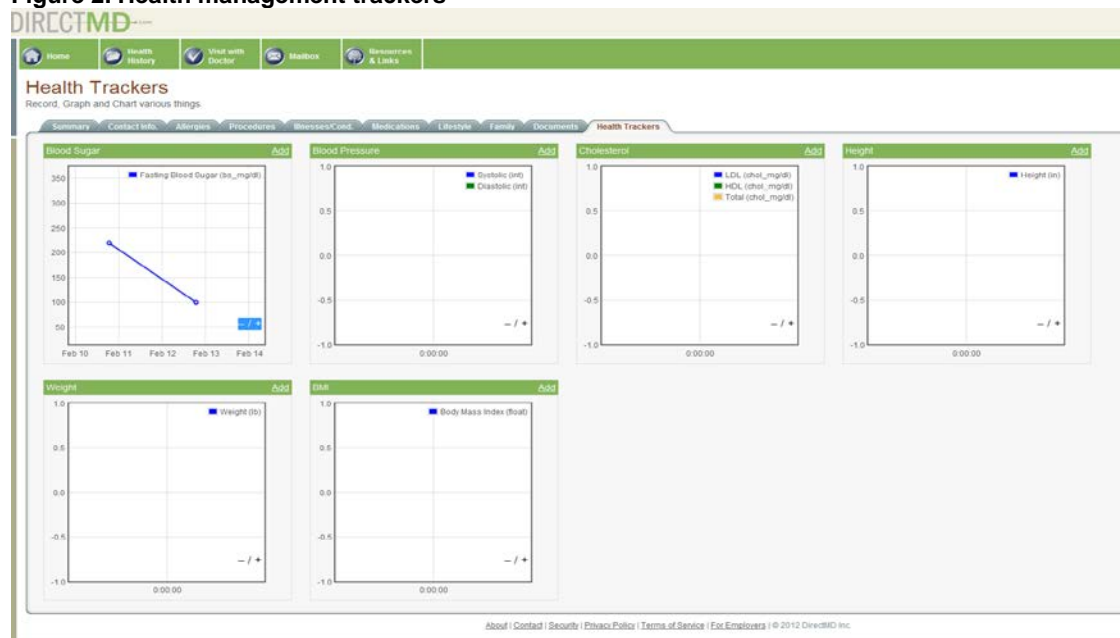


The UHR supported reconciliation of information between the PHR and the clinic electronic medical record. Both provider and patient were able to ‘accept’, ‘reject’ or ‘ignore’ medications added by the other party. The usability evaluation demonstrated that patients needed better cues to denote information which was available to update the patient-maintained record. A pop-up window was developed to draw attention to these items. Data suitable for reconciliation was highlighted in orange. A reconciliation button was created to display options when the user clicks on the highlighted item and to allow for multiple reconciliations. The patient was also given the option of disabling the pop-up box.

Health management trackers. The health history section included a tab for “health management trackers” for monitoring health metrics such as blood pressure, weight, blood glucose, and cholesterol. The interface employed calendar-based entry to allow accurate selection of dates and time. The potential for typographic errors was reduced by restricting permissible character types and setting boundaries to ensure that values were within realistic ranges.

Communication resource. Several communication functions were consolidated within a single interface. Medication requests and E-visits would be easier to navigate if consolidated. Disease-specific algorithms were developed to create a structured E-visit to enhance completeness and efficiency of transmitting information to clinicians pertinent to the problem. Emails were structured to provide decision support for the patient and to increase their utility to the clinician.

Figure 2. Health management trackers



Computer logic was written to generate a structured form to electronically send to patients who are started on selected drug classes. Patient starting anti-depressants received an automatic communication inquiring about suicidal feelings, medication side effects, and compliance. Embedded in the email was a structured response for the patient to complete and send back to the clinic. A message was sent to the patient's regular email indicating the presence of "a message from you doctor". For example, a new prescription or alteration in dosage for coumadin triggered an email reminder to return for the laboratory test of blood clotting.

Health maintenance. A customizable system for creating health maintenance reminders and alerts was developed. Clinicians had the ability to implement these reminders using rules to identify patient panels. It was also possible to generate to-do items and reminders at the individual patient level. Notifications were automatically delivered to patients, adding new tasks to their to-do lists.

Additional features. Tools were added to facilitate navigation across different components of the UHR. Patient "wizards" were developed to help guide first time users in the process of creating a personal history. Document upload functionality was extended. Links to internet-based references for health information were significantly expanded. A button to generate a Continuity of Care Record was added to support health information exchange. Capabilities for billing were significantly improved. The scheduler interface was altogether revised in response to feedback.

Figure 3. Structured E-visit

Sore throat [change]

When did this problem start or symptoms first appear?

- Only the last few days, or less.
- Several weeks ago
- Several months ago
- More than a year ago

Other:

What evaluation have you already received for this problem, if any? (Include lab tests, x-rays, etc.)

None

(500 character max)

List any treatment(s) you have received that have helped.

I've tried Cepacol lozenges. They help for a little while but wear off quickly.

(500 character max)

List any other treatments.

I've also taken acetaminophen but that doesn't seem to have helped much.

(500 character max)

Is there anything else you would like your doctor to be aware of pertaining to this online visit?

I also have really swollen glands in my neck.

(500 character max)

[<- Back](#) | [Cancel This E-Visit](#) | [Next ->](#)

Methods and Results for Aim 1

Overview of timeline

The first 2 years of the project were largely occupied with: 1) incorporation of novel patient decision support features into the UHR; 2) refinement of the UHR in response to user feedback; 2) meeting regulatory requirements; 3) recruitment of UHR and non-UHR clinics; 3) development of survey instruments. The need to submit a Federal Wide Assurance application to the Office for Human Research Protections (OHRP) was a cause for a delay in approval. The University of Utah IRB did not have prior experience with this process and was unfamiliar with the various steps. Each clinic had to submit its own application to OHRP. The three-way communication between OHRP, the IRB, and clinics was highly inefficient. IRB approval was obtained prior to initiation of study enrollment activities.

Usability testing was completed by the end of the second study year. Active recruitment of patients to use UHR began in October 2009 (the “hard launch” phase). The baseline phone survey of patients at UHR and non-UHR clinics was conducted during this period. Examination of adoption and analysis of patterns of use continued until December 2010.

Clinic recruitment

Clinics in rural communities with at least two primary care providers were considered eligible for participation in this study. A total of five clinics, in communities ranging in population size from 8,000 to 25,000, were recruited to participate, three in the UHR group and

two in the non-UHR group. Each clinic was visited 4-10 times during the second study year to complete enrollment, initiate training, interview providers, recruit patients for usability assessment, and collect survey data. One UHR clinic served as a non-intervention “control”, in that it did not participate in the interventions to promote UHR use. In addition, this clinic did not participate in the survey study. The three UHR clinics were staffed by twelve primary care providers. All twelve providers used the core features of the clinic electronic medical record part of the UHR, including electronic prescriptions. Use of the clinic electronic medical record to document problem lists, progress notes, and vital signs was more variable across providers.

Methods and Results for Aim 2

Usability Testing

The primary goal of usability testing was to elicit feedback to support enhancements to the design of the UHR. Usability testing also aided development of intervention strategies to promote adoption and guided selection of evaluation metrics.

Focus group sessions. Our first assessment of usability took place in February 2009. Students, university employees, and public health personnel were recruited to participate in group sessions to test the UHR. Each person was given scripted patient details which allowed them to interact with the UHR anonymously and make use of its features. We conducted a focus group immediately following each of the 2 sessions. Each session was attended by representatives from CaduRx to allow them to be on hand for errors reported and to hear the feedback from the volunteers on how the system performed and the interaction experience. Several system ‘bugs’ were discovered and corrected as a result of this initial testing. In addition, the interface was improved in several areas of the PHR, based on the feedback given during the focus group.

Usability tests with individual patients. The next stage of usability testing took place in between May and August 2009. Patients were recruited from the three rural UHR clinics. Eligibility criteria were age 18 or older, presence of a chronic illness, Internet access at home, experience using email, absence of a diagnosis of dementia, and English as primary language. Patients who agreed to be contacted received a phone call from a member of the research team to schedule a time to meet.

The usability test had three parts. First, a pre-testing interview and questionnaire to assess levels of previous Internet and computer usage, previous knowledge of PHR’s, methods for searching for health information, the patient’s perspective on communication with their provider about their health conditions and demographics. The REALM-R, a test of health literacy, was administered. Secondly, patients were given a series of tasks to complete with minimal assistance. The simple tasks included logging in and changing the password, populating the health history, visiting with doctor, viewing clinic notes. More complex tasks were developed around plausible patient scenarios. They involved medication reconciliation, requesting medication refills, recording health measurements and information searching and viewing. The usability test included time for free exploration. Finally, a post-testing interview and

questionnaire was administered to gauge the patient’s impressions of the PHR, the problems they had, and their suggestions for improvements to the system to make it more user-friendly. In addition, questions were asked about their intent to use the system in the future and the possible impact on their communication with their provider.

Each testing session was attended by two members of the research team, one acting as the test administrator and the other as an observer/recorder. The observer was assigned to capture the actions the participant took in the PHR test: paths taken to complete each task, reactions and comments. Each session was audio recorded, transcribed, and analyzed to supplement the information documented during each testing session. Participants were encouraged to use a “think aloud” approach to their interaction with the PHR during the usability test. This “think aloud” technique permits understanding the cognitive process of the user during the session.

The participant talked about what they were doing and why as they completed several additional tasks within the system. The participants were asked to complete the health history section, to look for medical information, to refill a prescription, and to find their account information. During the test we asked the patient to send an actual email message using the “Visit with my doctor” feature to demonstrate how this can become a communication tool with the physician.

The post-test interview and questionnaire was administered to elicit reactions to the patient experience with the PHR. Participants reported whether they recalled seeing particular items on the screen and provided opinions about things that could be improved. The post-test also included a scaled questionnaire designed to assess the patient’s perception of the utility and their projected use of the PHR. During the usability test and subsequent interview, the observer and test administrator took notes about the progress of the test, any difficulty or issues the participant experienced, the actions the participant took within the system, and any comments or non-verbal reactions from the participant.

All appointments were held in a private room in the rural clinic where the patient received care.

Usability Test Results

A total of 16 individuals from two UHR clinics were recruited. None of the participants had prior experience with an electronic PHR.

Table 1. Results of Usability Testing

Features listed in descending order of perceived usefulness	Comments
Request or refill medications	Regarded as highly convenient, especially during travel
Reconcile health information	Making this information visible at the time of log-in was commended
Receive clinic emails	Approved as novel but potentially useful form of communication with physician
View clinic visit notes	Endorsed particularly to help the patient remember what the physician said during the appointment
E-visits	Concerned expressed about payment
Search for information about medications	Unclear benefit over Internet search
Health maintenance trackers	Unclear benefit over paper/pencil tools

Common challenges were identified. Some participants needed assistance to navigate to the UHR website or to change their password. Icons and links were frequently misinterpreted. Some of the language within UHR, such as the term “tracker”, was unfamiliar or counter-intuitive. Usability testing also identified technical glitches, some of which were fixed immediately. A matrix report was provided to CaduRx which itemized the issues that were ascertained with each participant in the usability test; each issue was categorized with respect to criticality, temporality (how much time it would take to fix the problem), and projected cost.

All participants expressed an interest to use the UHR again at home. A follow up questionnaire was administered to 15 participants six months after the usability test. One of the 16 participants was unable to be reached to respond to questions. Nine of the fifteen individuals had used the UHR one or more times in follow-up and eleven had spoken with friends or family about their experience using UHR. Only two of the friends or family of those eleven had used UHR themselves.

Adoption of the UHR

Patients needed to activate an account before starting use of the UHR. Accounts were activated in one of three methods. One way was for a staff member to create a new UHR account from within the patient’s clinic electronic medical record. The account information was then either printed and handed to the patient in person or emailed to the patient. The second method was through the letters mailed to patients from their physicians. These letters contained a unique passcode that allowed the patient to activate an account by using their birthdate in combination with the passcode to link to their clinic records. A patient was also able to visit the UHR web site to create a new account on their own. When this method was chosen, the PHR was not linked to the clinic electronic medical record.

With the first login, the patient was required to change the password. The initial login also triggered a wizard that guided patients through entry of health history information.

Patient interactions with the UHR were captured in log files. Each action was associated with a user ID, session ID, page load ID, time stamp, and label. The label indicated the section of UHR and the nature of the action. Actions were grouped into categories described in more detail below in table 6.

Interventions to Promote Adoption

The UHR was implemented in three study communities, labeled “A”, “B”, and “C”. Clinic C did not participate in any marketing or educational activities to promote use of UHR. Thus, it served as a “control” intervention site to assess UHR adoption in the absence of active efforts to promote its use.

Use of UHR in the study communities progressed in three phases. The first phase was a soft launch; UHR was made available to patients but not promoted. In effect, Clinic C remained in this phase throughout the project.

The second phase was the hard launch; the main intervention during this phase was the distribution of letters from clinic physicians to patients. The letters invited patients to ‘take control of their health care’ with a new, free personal health resource, called DirectMD, that was being offered to patients at the clinic. The letter included instructions about how to login to the account that had been set up for them.

The letters were distributed twice, 20 days apart. The third phase was initiated three months after the hard launch. It consisted of a series of clinic interventions intended to further stimulate use of UHR. The dates of implementation of these approaches are listed in Table 2 below.

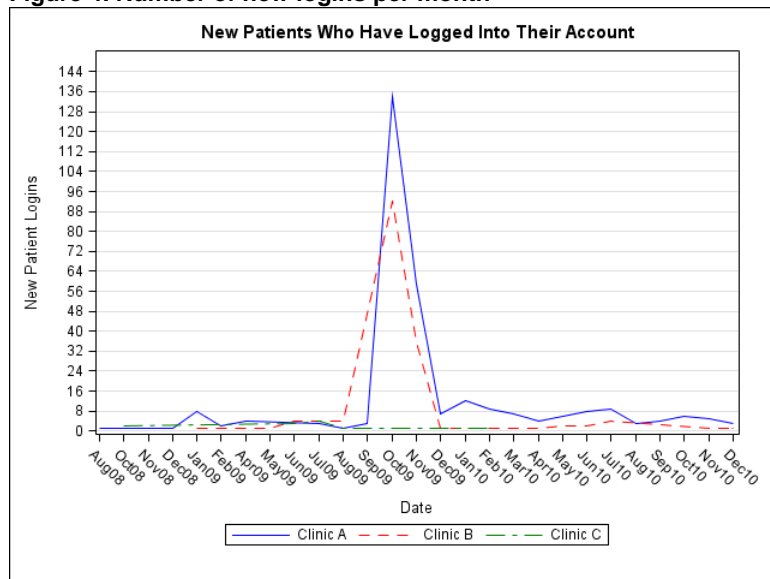
Table 2: Interventions during each launch phase

Year	Month	Phased Interventions in Clinics A & B	Number of New Logins Clinics A & B	Number of New Logins Clinic C
2009		Phase 1: Soft Launch Jan, '08-Sep, '09	32	8
2009	Jan	Clinic posters		
2009	Aug	Information fliers		
2009		Phase 2: Hard launch Oct, '09-Dec, '09	329	0
2009	Oct	Press releases in local newspapers		
2009	Oct	First wave of physician letters (beginning of month)		
2009	Oct	Second wave of physician letters (end of month)		
2009				
2010		Phase 3: Clinic interventions Jan, '10-Aug, '10	68	1
2010	Jan	New clinic posters and brochures Revised again in May		
2010	Feb- Mar	Patient health education classes		
2010	Mar- Apr	Clinic staff training		
2010	May- July	Clinic staff competition Clinic staff problem solving Emails to UHR users		

Analysis of Adoption

Few patients logged into UHR during the soft launch phase. In contrast, the clinic letters were a highly effective method of inducing initial logins, as demonstrated in figure 4. Other measures to promote adoption were much less effective.

Figure 4. Number of new logins per month

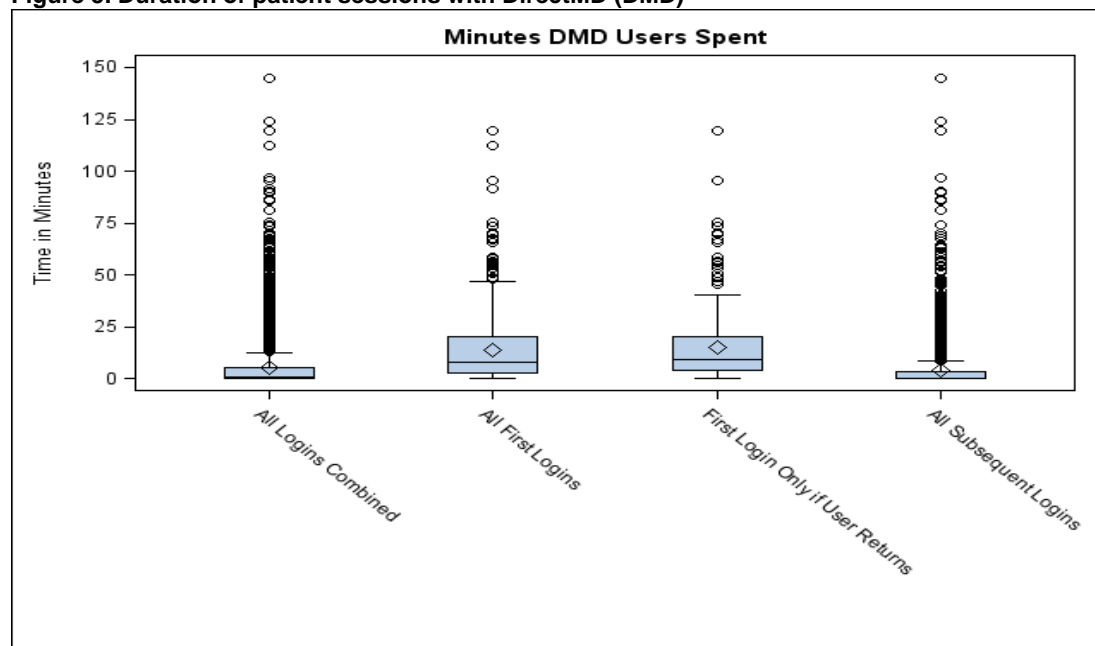


In clinic C, use of UHR remained extremely low throughout the course of the study. However, even in clinics A & B, despite multiple interventions, less than 10% of patients used the UHR.

The health history was at least partially completed at the initial login in 79% of instances. Overall, 49% of patients who initially logged into UHR used it again during follow-up. The statistical analysis of factors which predicted repeat use is described in detail below.

The duration of each session was calculated on the basis of the time stamps in the log files. As shown in Figure 5, the distribution was highly skewed. The overall median duration of a UHR (DirectMD) session was 0.77 minutes (mean = 5.3; standard deviation=11.02). The median duration of the first login was 8.1 minutes (mean = 14.1 minutes; standard deviation =16.45). The median duration of the first login excluding patients who did not have repeat logins was similar. The median duration of subsequent logins was 0.47 minutes (mean = 3.9 minutes; standard deviation=9.35). Thus, sessions associated with initial logins were significantly longer than sessions associated with repeat logins ($p<.001$).

Figure 5. Duration of patient sessions with DirectMD (DMD)



Predictors of Repeat Use

Factors that predicted repeat logins were examined in a multiple event, time-varying Cox regression model. The study cohort consisted of patients of clinics A or B whose initial login to UHR occurred between 2009 and 2010. Patients were entered into the cohort on the day of initial log-in. Follow-up continued until December 2010. Repeat log-in was the event of interest. To appropriately account for the occurrence of multiple events per individual, robust variance estimators were used. Thus, the hazard ratio (HR) represented the instantaneous rate ratio for repeat logins. A value greater than one indicated that the covariate was associated with an increased rate of login and value less than one indicated that the covariate was a decreased rate of login. Time windows around clinic visits and follow-up time after the first re-login were treated as time varying covariates.

A total of 448 patients representing 5,963 person-months of follow-up were included in this analysis. The single strongest predictor of repeat use was the time-varying covariate of time after the first re-login (Table 3). Provider and clinic was also highly associated with rate of logging in. One particular clinic A provider was associated with high rates of logging in (HR: 2.51) and one particular clinic B provider was associated with low rates of logging in (HR: 0.39).

Younger age was associated with a much higher rate of logins. Compared to individuals older than 65, patients less than 35 had 8.33 fold higher. Individuals with co-morbidities had a modestly increased rate of logging in. The rate of logging in was twofold higher during the 1 week period before or after a clinic visit. The relationship between the duration of the initial login and the rate of repeat use was bimodal. Short (<10 minutes) or long (>20 minutes) duration of the initial login was associated with lower rates of logging in compared to medium duration of initial login.

Table 3. Factors associated with repeat login

Factor	Hazard ratio	95% confidence interval
Clinic A providers		
A-1	0.7	0.31,1.56
A-2	1.51	0.86,2.65
A-3	2.51**	1.25,5.04
A-4	0.9	0.27,2.95
A-5	1.38	0.71,2.69
Clinic B providers		
B-1	1.73	0.83,3.61
B-2	0.39**	0.19,0.79
B-3	1.48	0.66,3.29
Age, years		
<35	8.33***	3.64,19.06
35-44	3.95**	1.71,9.13
45-54	2.28**	1.31,3.97
55-64	1.42	0.89,2.26
≥ 65	reference	
Sex, male	0.71	0.42,1.19
Duration first login, minutes		
<10	reference	
10-20	1.94*	1.15,3.28
20-30	0.86	0.46,1.60
30-40	0.5	0.21,1.18
>40 minutes	0.51*	0.28,0.95
Time after first re-login	8.19***	5.99,11.20
One week window around clinic visit	1.75**	1.23,2.50
Hypertension	2.08*	1.18,3.68
Chronic obstructive pulmonary disease	1.15	0.40,3.27
Congestive heart failure	1.06	0.48,2.35
Diabetes mellitus	1.49	0.87,2.56

* p<0.05

** p<0.01

*** p<0.001

Methods and Results for Aim 3

Patient activation and shared decision-making

Survey methods. A survey was administered to increase understanding of patient needs, healthcare behaviors, and experiences with the clinic. The survey was administered via a computer-assisted telephone interview of approximately 30-45 minutes duration. Patients were selected from two UHR clinics (clinics A & B) and two non-UHR clinics. Participants received

\$20 in compensation to reimburse them for their time. All procedures were approved by the appropriate Institutional Review Board (IRB). The survey questions focused on the patients' experiences in the clinic, relationship with the physician, patient activation, and patient health behaviors.

The survey included questions about clinic experiences— including whether clinic appointments were received as quickly as desired, the method used to make appointments, whether after hours consultation was needed, use of email to contact the clinic, and the clinic response to telephone questions during routine care hours and after hours, when applicable. The following types of questions were included: “in the last 12 months, did you phone this provider's office to get an appointment for an illness, injury or condition that needed care right away?”

Participants were asked about the quality and content of conversations with their physician. Patients reported whether they talked about diet, exercise, stress, and medications. In addition, patients were queried whether the information they received from the physician was understandable. Preferences and experiences with shared decision making were elicited, for instance, “in the last 12 months, did the doctor tell you there was more than one choice for your treatment or health care?”

The Patient Activation Measurement short form (PAM-13) was used to assess patients' self-reported knowledge, confidence, motivation, and skills for managing their health. Sample items included “Taking an active role in my own health care is the most important factor in determining my health and ability to function” and “I am confident that I can take actions that will help prevent or minimize some symptoms or problems associated with my health condition”.

Patients were questioned about health behaviors including health maintenance, preventive measures, and health improvement efforts. Health maintenance and improvement behaviors reported included following a healthy diet, monitoring body weight (e.g., “Do you weigh yourself regularly?”), and exercise habits and intentions. Patients reported disease prevention behaviors including immunizations received and screening tests, such as mammograms or prostate specific antigen (PSA) testing. For patients with selected chronic conditions, questions about maintenance behaviors including blood glucose testing and oxygen saturation tracking were included.

Patients rated their satisfaction with their medical care at the clinic during the most recent visit “Using any number from 0 to 10, where 0 is the worst medical care possible and 10 is the best medical care possible, what number would you use to rate the medical care you received during your most recent visit with this provider?”

The survey was conducted during the period of the phase two launch (October - December, 2009). Insufficient resources were available to repeat the survey as originally planned in our grant. The primary reason for this deviance was that we were unable to fully carry over first year funds.

Survey Results

A total of 811 patients participated. Survey respondents were 62% female and 90% non-smoking. Participants ranged in age from 18 to 74 and older with 40% of the sample between ages 45 and 64 and an additional 42% aged 65 or older. Patients with chronic illness were intentionally oversampled. Additional demographic details of the sample are presented in Table 4.

Table 4. Survey patient demographics

Category	Value	Responses
Gender	Male	312 (38.4%)
Gender	Female	500 (61.6%)
Clinics	UHR	405 (49.9%)
Clinics	Non-UHR	407 (50.1%)
Disease	Chronic	638 (78.6%)
Disease	Non-chronic	174 (21.4%)
Education	High school or under	241 (37.1%)
Education	At least some college	570 (62.8%)
Education	Wouldn't say	1 (0.1%)
Age	Under 45	289 (35.6%)
Age	45 or over	523 (64.4%)
Race	White	52 (92.6%)
Race	Asian	1 (0.1%)
Race	Nat Hawaiian/Pac Is	3 (0.4%)
Race	Other	37 (4.6%)
Race	Multiple race	14 (1.7%)
Race	Wouldn't say	4 (0.5%)
Race	Missing	1 (0.1%)
Hispanic/Latino Origin	Hispanic/Latino	37(4.6%)
Hispanic/Latino Origin	Non-Hispanic/Latino	773(95.2%)
Hispanic/Latino Origin	Wouldn't say	2(0.2%)

Respondents indicated a high level of satisfaction with their care. A majority (66%) reported that their provider was always thorough during their treatment. Satisfaction with care – with 0 meaning the worst medical care possible and 10 indicating the best medical care possible – was rated at 9.34.

Table 5. Survey responses

Domain & question	Percent Responding Yes
Patient Clinic Experience	
Care received right away when needed	55%
Received routine care during past 12 months	71%
Phoned with Question during Regular Office Hours	53%
Patient Relationship with Physician	
Received complete/accurate information from provider about tests	84%
Received complete/accurate information about choices for care	76%
Complete and Accurate information from provider about treatment	85%
Provider listened to what patient had to say	84% (always)
Provider treated patient with respect	88% (always)

Domain & question	Percent Responding Yes
Patient Activation Measure	
Patient responsible for managing own health	96% (almost always or always)
Active role for patient most important health factor	98% (almost always or always)
Patient confident can take actions to prevent or minimize symptoms	93% (almost always or always)
Patient Health Behaviors	
Patients exercise regularly	57%
Patients monitor body weight	62%
Patients know recommended body weight	50%
Patients follow healthy diet	50% (almost always or always)
Patients had flu shot preceding 12 months	65%

A series of additional analyses examined associations between facets of physician/patient relationship quality and patient preference for shared decision making. Shared decision making between patients and physicians is considered optimal for determining treatments that adequately address patient’s health needs. Shared decision making results in appropriate treatments for patient needs -determined by patient disclosure coupled with physician expert judgment. Treatments resulting from shared decision making can be incorporated successfully into patient’s lives, and mutually agreeable to physician and patient. In the survey, patients reported whether physicians had informed them about alternative treatment options, discussed varied options with them (pros and cons), and elicited their preference for care. In addition, patients reported their preference for how decisions regarding treatments are made. The range of response choices included patients preferring extremely independent decision making (e.g., “make the final selection about which treatment I will receive”) to very dependent decision making (“Leave all decisions regarding treatment to my doctor”) the mid-point represented collaborative shared decision making (“have my provider and I share responsibility for which treatment is best”). Consistent with the innate preference for relatedness in SDT, patients whose physicians asked them about their life circumstances (stressors in their lives and whether they had been depressed during the preceding 12 months) were more likely to endorse a preference for shared decision making.

We have also conducted a rigorous psychometric validation of the PAM-13 instrument in the rural patient population using Rasch analysis. Results indicated that PAM-13 performs well in some areas, but not in all. The items had excellent fit statistics and largely confirmed the unidimensionality of the instrument. The person and item reliability indices were high, suggesting that person and item orderings were both replicable. The instrument also demonstrated high convergent and divergent validities. However, the item hierarchy revealed considerable ceiling effects, posing several potential problems. This should be addressed in future tool refinement to better capture the responses of those patients with high activation, and track improvements.

Further analyses of survey responses to examine patient communication, patient knowledge, and electronic health record use are ongoing.

Patterns of Use

We analyzed the actions associated with 6,700 patient sessions with UHR. The actions were grouped into 13 categories (table 6). The mean number of actions per session was 15 (range 1-679). The sessions were partitioned into 10 groups using the k-means clustering method. For the shorter sessions, defined as 10 actions or less, the primary task was either E-visit or clinic review. For longer sessions--more than 20 actions—patterns were more complex. In many of initial sessions, the predominant action involved completion of health history items. Other type of longer session involved numerous actions in the medication section of the UHR including information look-up and medication reconciliation. Another type of longer session involved se of health maintenance trackers.

Table 6. Tabulation of actions in summed across sessions

Type of action	Count	Percent	Cumulative Percent
Account settings	19,448	19.22	19.22
E-visit	16,403	16.21	35.42
Medication	15,258	15.08	50.5
Family	9,510	9.4	59.9
Refill	4,978	4.92	64.82
Tracker	4,646	4.59	69.41
Checklist	4,203	4.15	73.56
Conditions	4,094	4.05	77.6
Procedures	3,958	3.91	81.52
Email	3,917	3.87	85.39
Allergies	3,833	3.79	89.17
Clinic record	2,494	2.46	91.64
Resources	2,349	2.32	93.96
Error	1,992	1.97	95.93
Documents	1,626	1.61	97.53
Reconcile	1,252	1.24	98.77
Lifestyle	1,064	1.05	99.82
Help	173	0.17	99.99
Feedback	7	0.01	100

An analysis of action sequences to discern goals and questions associated with individual sessions is underway. We are using the model of information foraging as a conceptual framework to guide this deeper assessment.

Results

In summary, we found that: 1) user feedback led to significant improvements in the design of decision support and medication management functions of UHR; 2) distribution of physician letters to patients was a potent method of recruiting UHR users, but other clinic interventions were less effective; 3) almost half of the individuals who used UHR once used it again, sometimes frequently; 4) communication functions and medication management tasks were associated with heavy use. Despite significant interest among residents of the rural communities in the use of PHRs and widespread access to the Internet, uptake of the UHR was variable. By the conclusion of the project, only a small minority of patients regularly used the UHR.

Taken together, the results provide support to the hypothesis that patient-centered informatics has the capability to enhance self-management and health communication. Moreover, the analysis of survey responses suggests that bidirectional communication and physician interest in the patients' emotional well-being foster optimal health care practices. However, our findings also point to the challenges of expanding adoption beyond a cadre of early users of electronic PHRs.

We believe that clinical staff engagement and clinic fit-to-workflow are key determinants of success, not just of clinic electronic medical records, but also of adoption of PHRs. Support for this assessment came in the form of feedback elicited from clinical staff during the exit interviews conducted at the end of the study. Notably, when UHR was implemented in a newly opened clinic in Salt Lake City in 2011, the experience with patient use was much different. Clinic staff actively recruited patients to use UHR to facilitate the process of pre-registration. The clinic staff recognized that use of the UHR would increase the efficiency of registration and save personnel time. The subsequent experience was that 85% of the 1,100 patients who started receiving care at the clinic logged into UHR and completed their health history.

Rogers' Theory of the Diffusion of Innovations yields useful insights about these disparate paths. Individuals are most likely to adopt innovations that they hear about them from members of their social network. Adopters gain knowledge about innovations, are persuaded by positive or negative attitudes, make a decision whether to use the innovation, implement the innovation by engaging with it, and confirm its continued use when it consistently meets their needs and values. In the rural communities which participated in our study, the UHR was inadequately visible to others. Not only was vigorous clinic staff promotion needed but it was necessary for the staff to recognize the relative advantage of patient use of the UHR for the clinic. Intensive support for adoption is likely to be even more critically important in rural communities than in urban areas. Users should have a social network member to whom they can turn for help. Trialability, especially for novice users who are unfamiliar with the Internet, should be enhanced. Social media and mobile technologies warrant further study as additional platforms for implementation of patient-centered decision support systems.

List of Publications and Products

Conference presentations

Snow LA, Morales J, Carter M, Bateman K, Samore M. Usability Testing in a Resource Stressed Environment: A model for Public Health System Testing. 2009 Public Health Information Network conference, Atlanta, Ga., Sept 1, 2009.

Snow LA moderator; Bateman K, Gibson B, Mackelprang G. Panel Presentation: Universal Health Care Resources—Uniting Provider, Patient and Public Health Information, Utah Public Health Association, Midway, Ut., May 20, 2009.

Edmunds M, Baylis G, Greene M, Fanberg H, Snow LA. Panel Presentation: Bridging the Trust Gap: Collaboration and Innovation in Health Information Exchange, American Medical Informatics Association, Spring Congress, Orlando, Fl. May 28, 2009.

Massoudi BL, Snow LA, Beitsch LM, Krist A, Bateman K. Panel Presentation: Fostering Collaboration between Public Health and Healthcare through Informatics, American Medical Informatics Association, Spring Congress, Orlando, Fl. May 28, 2009.

Carter M, Morales J, Snow LA, Smith A, Mackelprang G, Bateman K, Samore M. The ACCESS Project: Connecting Patients to Providers through an integrated EMR/PHR system called the Unified Health Resource. Poster presented at: Agency for Healthcare Research and Quality annual conference; Bethesda, MD; September 13-16, 2009.

Hayden C, Carter M, Morales J, Snow LA, Samore M, Dzierzon R, Bateman K. The Unified Health Resource:

Analysis of an Integrated Electronic Health Record and Personal Health Record System. Poster presented at Agency for Healthcare Research and Quality annual conference; Bethesda, MD; September 26-29, 2010.

Hung M, Samore M, Carter M, Butler J, Leecaster L, Morales J, Hayden C, Snow L, Dzierzon R. Psychometric assessment of the Patient Activation Measure Short Form (PAM-13) in rural settings. Poster presented at 32nd Annual Meeting & Scientific Sessions of the Society of Behavioral Medicine; Washington, DC; April 27-30, 2011

Morales J, Carter M, Hayden C, Snow LA, Dzierzon R, Smith A, Mackelprang G, Samore M, Bateman K. Using the Internet to connect rural patients to primary care clinics. Poster presented at 33rd National Rural Health Association Annual Rural Health Conference; Savannah, GA; May 18-21, 2010.

Morales J, Carter M, Snow LA, Samore M, Bateman K, Smith A, Mackelprang G. How Can Personal Health Records Help Us Achieve Health Equity? Poster presented at Hispanic Health Care Task Force 4th Annual Conference; Salt Lake City, UT; March 11, 2010.

Butler J, Berg CA, Carter M, Hung M, Hayden C, Morales J, Samore M. A white coat effect: Age, education, and shared decision making between patients and providers. Accepted for presentation at the 33rd Annual Meeting & Scientific Sessions of the Society of Behavioral Medicine, New Orleans, LA; April 11-14, 2012

Journal articles

Hung M, Carter M, Hayden C, et. al. (In press). Psychometric assessment of the Patient Activation Measure Short Form (PAM-13) in rural settings. *Qual Life Res*

Products

- Unified Health Resource (DirectMD)—available through our commercial partner, CaduRx
- Patient cohort phone survey—with 7 domains
 - Patient activation measure short form (PAM-13)
 - CAPHS_care
 - CAPHS_doc

CAPHS_staff

Self-management behaviors

Self-management knowledge

Control preferences scale

- Clinic workflow charts
- Usability scripts & questions