

Grant Final Report

Grant ID: UC1HS016160

The Holomua Project: Improving Transitional Care in Hawaii

Inclusive dates: 09/30/05 - 09/29/09

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Submitted to:

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Abstract

Purpose: Increasingly, healthcare is becoming a shared, community-based responsibility involving diverse care providers, providing services to a common population of patients. The Holomua Project piloted an endeavor to bring together the community health centers (CHCs) and tertiary centers (TCs) in the state of Hawaii by developing and implementing the Holomua Master Visit Registry (HMVR). The HMVR sought to improve coordination of care that patients receive when transitioning between CHCs and hospitals through health information technology.

Scope: This demonstration project involved selected CHCs and TCs throughout Honolulu, Hawaii. Community Health Centers serve a vulnerable patient population who are at high-risk during their transition between healthcare facilities. There was currently no mechanism to share data among the facilities. The HMVR serves as a connection broker between institutions by identifying the type of service and who provided that service within the health system for a particular patient for two community health centers and two hospital systems. One of the CHCs was unable to contribute patient data due to financial constraints.

Methods: The methods focused on (1) increasing the accuracy and timeliness of shared patient information during transitional care between primary care and tertiary care facilities; and (2) increasing participation and involvement in decision making by patients or family on health related matters. The intervention was the HMVR; a record locator service that relies on a Master Patient Index to identify the correct patient across multiple health care institutions. Several types of data were collected to determine the impact of the HMVR on patients' coordination of care between the CHCs and the tertiary hospitals (e.g., HMVR usage, end-user satisfaction surveys and audit logs). Focus groups were held among healthcare provider groups, high-risk patient groups, and community.

Results:

- Developed and implemented a live health information exchange.
- Involved approximately 150 clinician users, 250,000 patients, & 500,000 visits.
- Trained over 100 HMVR end-users across three healthcare facilities.
- Enhanced relationships between participating CHCs and the TCs.
- Demonstrated a strong need for data standardization.
- Developed common transitional care policies & procedures for transitioning patients.
- Increased awareness of independent transitional care processes adapted by colleagues.

- Increased partners’ awareness of managing patients who visited multiple facilities.
- Illustrated patient, community member and providers’ perspectives on linguistic/cultural barriers, transitional patient care, use of electronic records obtained, and privacy and security issues related to records accessed.
- Evolved a community-participatory method to assess multicultural patients’, providers’ and community members’ perception of the impact of electronic health records
- Evolved guidance on privacy and security issues related to use of shared data systems
- Developed shared documents related to patient data sharing and business agreements

Key Words: transitional care, registry, data sharing, health information exchange, community health centers

Table 1. Abbreviations used in this report

Abbreviation	Meaning
AHRQ	Agency for Healthcare Research and Quality
CHC	Community Health Center
CPOE	Computerized Physician Order Entry
ED	Emergency Department
EMR	Electronic Medical Record
EPIC	EpicCare EMR
EPM	Enterprise SharePoint Project and Workforce Management
HHIE	Hawaii Health Information Exchange not-for-profit
HIE	Health Information Exchange
HIPAA	Health Insurance Portability and Accountability Act
HL7	Health Level Seven Standard
HMVR	Holomua Master Visit Registry
HPCA	Hawaii Primary Care Association
HPH	Hawaii Pacific Health (consists of KMCPM and KMCWC)
ICD-9	International Statistical Classification of Diseases and Related Health Problems
IRB	Institutional Review Board
IT	Information Technology
KKV	Kokua Kalihi Valley Comprehensive Family Services (community health center)
KMCPM	Kapiolani Medical Center at Pali Momi (tertiary center)
KMCWC	Kapiolani Medical Center Women & Children (tertiary center)
KPHC	Kalihi Palama Health Center (community health center)
MMDI	Master Physician Index
MPI	Master Patient Index
MVR	Master Visit Registry
PCP	Primary Care Physician
QMC	The Queen’s Medical Center (tertiary center)
TC	Tertiary Center

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Final Report

Purpose

The Holomua Project addressed two study aims. These are to:

1. Increase accuracy and timeliness of shared patient information during transitional care between primary care and tertiary care facilities;
2. Increase patient participation and involvement in decision making by patients or family on health related matters.

Secondary aims, which were addressed anecdotally, are:

3. Reduce incidence of medical errors that may occur due to linguistic and/or cultural barriers between patients and providers;
4. Reduce occurrences of duplicated diagnostic procedures performed;
5. Determine mechanisms by which information resources, information systems, and other IT initiatives can best support the Holomua Project.

This study tested the ability of the HMVR to link information on patients' care when they transition between selected CHCs and TCs. It also described multicultural patients' perspectives of using electronic medical records and their satisfaction with the outcomes.

Scope

Background

Over 50% of the CHC patients in Hawaii do not speak English as their first language. This population is the most indigent and at the highest health risks. Because the CHC patient cannot speak use English to communicate their experiences, when many CHC patients are admitted to a TC facility, the admission event leaves multiple questions about the diagnostic events, the health care administered, and continuity of follow-up directions rendered. Also because the CHC patient cannot speak English to communicate their experiences, there is limited follow-through available when they return to the CHC after their TC or emergency department (ED) admission.

Context

There was no search mechanism to link the health care experiences of patients who seek care between the CHCs and TCs in terms of either planned or unplanned visits to the ED and/or inpatient (IP) services. The HMVR is the proposed search mechanism which is envisioned to link a patient's medical records across selected CHCs and the TCs. While not a data repository, the HMVR will function as a "google" system to search for patient records across the selected health care institutions. It will provide the most probable medical records linkages for the patient. This type of medical record linkage may help develop continuity between the CHC patient's health care events at the TC or vice versa. In the past, the CHCs relied on patients' families to translate for them, but this option has quickly diminished due to the Hawaii's economic strains, necessitating most extended families to take on more than two jobs per household. For non-English speaking patients, the continuity of care will be further decreased unless a way is found for the CHC clinicians to learn what happened during the TC or ED admission. Patient safety and quality and continuity of care may continue to be decreased during transitional care for our most vulnerable populations in Hawaii.

Settings

The Holomua Project sought to use health information technology to improve the quality of care a patient from the community health center (CHC) receives when seeking health care between the CHC and tertiary care hospital (TC). This type of care is called transitional care. In September 2005, the Hawaii Primary Care Association received funding from the Agency for Healthcare Research and Quality (AHRQ) to design and pilot test the Holomua Master Visit Registry (HMVR) using selected CHCs and TCs within Honolulu, HI. The HMVR contains health information technology to improve the flow of information between patient/family, community health centers and hospitals.

Participants

Over 100 individuals from the CHCs, TCs, and community were identified over the last three to five years to participate in the Holomua Project. They served as executive committee members, workgroup members, focus group participants, and HMVR end-users. There were six active work groups: Information Technology, Healthcare Providers, Research and Evaluation, Patient and Community Advocacy, Privacy and Security, Administration. The focus group members were patients, providers and community members. The HMVR end-users included emergency room physicians, primary care physicians, nurse practitioners, physician assistants, nurses, medical assistants, front desk and registration personnel.

Incidence and Prevalence

Discontinuity of care exists almost 100% of the time when multicultural patients who speak do not speak English speak English as a second language transition between the CHCs and TCs. Two community health centers and two major hospital systems were involved and identified as the healthcare facilities that would provide data sharing information (quantitative) and focus

group (quality) information. The HMVR was developed via a collaborative effort among these partners with institutional agreements in place. The Hawaii Primary Care Association served as the lead agency in the collaborative. The two CHCs involved are Kokua Kalihi Valley Comprehensive Family Services (KKV), Kalihi Palama Health Center (KPHC), and the two TCs are The Queen's Medical Center (QMC) and Hawaii Pacific Health (Kapiolani Medical Center at Pali Momi (KMCPM) and Kapiolani Medical Center Women & Children (KMCWC). As we prepared business and privacy/security agreement during the course of the project, one of the CHCs and both hospital systems were able to contribute patient data in the HMVR. Due to financial constraints, the other CHC elected to withdraw from participating in the data-sharing component of the Holomua Project.

Methods

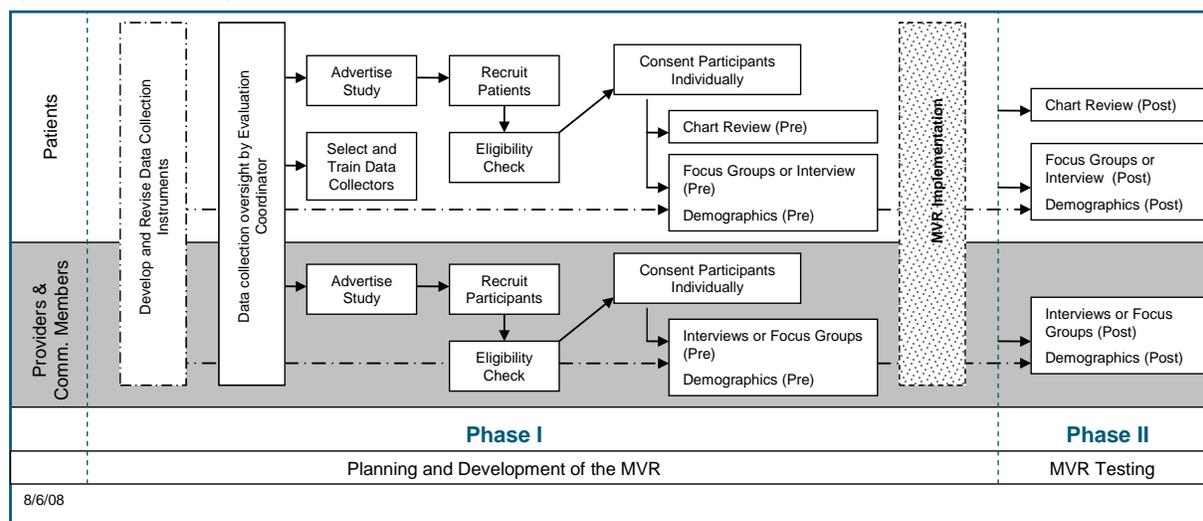
Study Design

The HMVR was developed with input from the four partnered organizations. The HMVR served as the connection broker, which maintained a log of patient records from disparate sources and allowed providers to access the following:

- A Master Patient Index (MPI), which identifies what types of services the patient has had in the past, who provided it, and where it was provided using a matching patient algorithm; and
- A Master Physician Index (MMDI), which is a list of all physicians in the Partnership who enter data into their organization's respective registry, each with a unique identification number. The HMVR allows the treating provider to review a list of the patient's visit history, identify which visit is pertinent to his/her case and contact the host Partner, via phone or electronically to request the patient's medical record.

Community-participatory focus groups were held before and after the HMVR was implemented. Focus group members included healthcare providers, high-risk patients, and community members from the four partner organizations. Demographic information was collected from the research subjects.

Figure 1. Study design *



* Chart reviews were not done, due to time constraints.

Data Sources/Collection

1. Workgroup notes (extracted from workgroup meetings held regularly throughout the duration of the Holomua project) to provide formative and summative reporting.
2. Notes of the software developer, Sun Microsystems and the information technology team (documentation of the planning, developing, implementing of the HMVR).
3. Audit logs (measures of HMVR use) collected and prepared by the information technology and software developer, Sun Microsystems for evaluation of the HMVR architecture and implementation.
4. Electronic surveys (measures of use and satisfaction) prepared and sent to the Holomua end-users at three different times during the Holomua Project: after training, after one-month implementation of the HMVR, and after six-months implementation of the HMVR.
5. Community-participatory focus groups (measures of health information technology perception) involving providers, patients and community members were held before (Time 1) and after (Time 2) the HMVR implementation and demographic information was collected. The demographic characteristics of the respondents at Time 1 are shown in Table 1.

Patients (n = 63 [Time 1]; n = 28 [Time 2]) were males or females over 18 years old who received care their general health care from the CHC and received care at the TC for either planned or unplanned visits. Patients had diagnoses related to chronic cardiovascular and peripheral vascular/neuromuscular conditions: (e.g., hypertension, coronary artery disease, diabetes (Type I and II), peripheral vascular disease, congestive heart failure, chronic obstructive pulmonary disease and neuromuscular disorders). The rationale for selection of these conditions

is they represent situations where patients have a higher probability of transitional care between a TC and the CHC. The pre-HMVR implementation data was collected via focus groups using English or one of the three (3) major languages (Ilocano, Chuukese, Samoan); all post HMVR implementation data was collected in English because obtaining certified translations into the other languages required too much time and was too costly.

Providers (n = 25 [Time 1]; n = 11 [Time 2]) were recruited from the CHCs and TCs (mostly from the ED). They were physicians (personnel providing medical care), nurses (personnel providing nursing care), other personnel (clerical and administrative) and outreach workers. All were required to interface with the HMVR. All provider interviewing was done in English.

Community members (n = 15 [Time 1]; n = 9 [Time 2]) who represent agencies that interface with the CHC as “stakeholders” (e.g., family members and community leaders such as pastors, personnel of agencies servicing patients from the CHC and local cultural leaders) participated in English speaking focus groups.

Table 1. Demographics: pre-HMVR (time 1) focus group participants

	Patients	Community Members	Providers
Average Age	60 years	69 years	47 years
Ethnicities	Micronesian, Filipino, Samoan, Chinese, Caucasian	Samoan, Filipino, Caucasian, African American	Mostly Caucasian, Filipino, Chinese, Japanese, Indian
Employment	Mostly unemployed, housewife, senior or respite companion	Mostly retired, unemployed	Nursing, Social Work, Public Health, Internal Medicine, Emergency Medicine

Selecting and training Data Collectors was a critical step in assuring the Project’s success. In addition to the Holomua Evaluation Team, each CHC designated Research Facilitators who are fluent in the native languages of their participants (Chuukese, Samoan and Ilocano). The Research Facilitators were the Project’s contact with the patient and community subjects. The Research Facilitators performed the data collection functions under the supervision of the Evaluation Coordinator and/or Evaluation Director. To achieve consistency in the data collection, the evaluation coordinator provided interviewing training to the Research Facilitators. We had planned to provide other opportunities for additional data collectors (e.g., performance of chart reviews) by medical students or other students who are participating in student practica with HPCA. However, time constraints prevented us from doing the chart reviews. Prior to data collection all of the investigators, co-investigators, and other research personnel completed the training in Protection of Human Research Subjects. All Research Facilitators were also trained on interviewing and data collection techniques by the Research Director.

The following procedures were used for inviting patients to join the Project and participate in the focus groups:

- Each research facilitator is a facility-trained medical interpreter. The research facilitators, which the Holomua Project trained, also direct a variety of patients’ activity groups. They contacted each individual to inform them that a focus group will be assembling, and that the patients are invited to join the focus group.
- Research Facilitators were able to piggy-back the Holomua focus group activities onto the existing CHC group activities (e.g., the Hodge-Podge, Exercise, or Elderly Groups).

- While recruiting patient participants for the focus groups, we realized that most of the CHC's patients come from a collectivistic orientation where the focus is on the group's activity rather than the individual's. The challenge laid in meeting IRB requirements to consent each person on an individual basis to participate in this project. All patient participants wished to consent as a group. Thus the idea of the project was discussed with the entire group; feedback was solicited and questions answered to the entire group. To honor the participant's collectivist orientation, prior to beginning the focus groups, the research facilitators first assembled the entire group, individually consented each individual, and returned everyone back into the large group.

Interventions

The implementation of the Holomua Master Visit Registry was the intervention in the project.

Measures

1. Workgroups

- The healthcare professional workgroup provided valuable input for preparing the transitional care guidelines that helped to streamline hand-off processes between healthcare facilities. They also provided input in determining the data points that were included in the HMVR. Additionally, they assisted in identifying the over 300 potential end-users by position that determined that the HMVR would be useful in their workflows.
- The privacy and security workgroup provided their expertise in developing many critical data-sharing documents. They also determined the actual HMVR end-users that would eventually be provisioned, just over 100, allowing certain positions to have full access to the HMVR, and others to have restricted usage.
- The patient and community advocacy work group provided perspectives from their viewpoints about patient-centeredness in the project. They provided input on how to recruit patients and community members for the focus groups.
- The information technology workgroup provided technical expertise in data validation, interface development, and architecture building. Their expertise was also enlisted in making a key decisions about a secured collocation site for the hardware.
- The research and evaluation outcomes workgroup diligently followed the requirements of the two institutional review boards, trained and recruited community-based research facilitators and data collectors, and provided data analysis expertise.
- The administration workgroup worked to examine sustainability models and worked in conjunction with the Hawaii Health Information Exchange, which is in the process of establishing 301c non-profit status.

2. HMVR architecture was built by the Holomua team, executive committee members, software developer, and information technology members. Planning, testing and production graphic user interfaces (GUI) were prepared for the different phases of the build. There were four screens developed: login screen, enter patient information screen, patient search screen, view patient information screen (and a link to partners' web portals and contact information).
3. End-user usage was collected using audit logs prepared by the software developer. Information was aggregated to examine usage over the six months of production of the HMVR, and separated by end-user position and restricted usage. There were 108 end-users provisioned to use the HMVR. A total of 68 end-users accessed the application (72% were KPHC end-users, 24% were QMC end-users, 4% were HPH end-users). The 68 end-users logged in 251 times in total, and accessed 780 HMVR screens. A total of 124 patients' data was accessed, and a total of 174 medical encounters/visits were viewed. Electronic surveys were sent to collect information about satisfaction with HMVR training, usage after one month HMVR implementation, and after six month HMVR implementation. The first electronic survey that was prepared to measure HMVR training satisfaction was sent to 50 end-users, with 18 respondents. The second electronic survey was sent one-month post HMVR go-live was sent to 107 end-users, with 19 respondents. The third electronic survey was sent six-months post HMVR go-live to all 108 end-users, with 6 respondents.

A. Training Survey questions:

- Overall training experience
 - 66.7 % strongly agreed that training goals were achieved
 - 72.2% strongly agreed that the information presented was well organized
 - 61.1% strongly agreed that the information presented was useful
 - 70.6% strongly agreed that the format of the training was effective
 - 72.2% strongly agreed that that training materials were useful
- Value of the training modules
 - 66.7% found the need for the Holomua Project very valuable
 - 55.6% found the overview of the Holomua Project very valuable
 - 55.6% found the overview of the Holomua MVR very valuable
 - 61.6% found the hands-on training very valuable

- 50.0% found the question/answer time very valuable
- User-friendliness of the HMVR
 - 55.6% found the "log-in" screen very user-friendly
 - 61.1% found the "enter patient information" screen very user-friendly
 - 66.7% found the "patient search" screen very user-friendly
 - 61.1% found the "view patient" screen very user-friendly
 - 61.1% found the link to partner's web portals/contact information very user friendly

B. One-month post-MVR questions:

- When do you use the HMVR?
 - I use it if I want to find out where and when patient was seen.
 - To find out where a specific test or procedure was done and when OR if patient was seen somewhere else besides our clinic.
 - Records for ED patients.
 - Would use in the ED/ED visits/to obtain info regarding ED visits at other facilities.
 - ED discharge or to know which CHC a patient belongs.
 - Check if patients kept clinic appointments.
- What do you think about the HMVR?
 - For patient safety and very useful.
 - I would say Yes; at least I know where to call for records; it helps to see diagnosis and date of service.
 - It is useful, but it would be great if we could get a result through HMVR besides dates and place of service.

- Useful, due to the fact that I can check on what ED/hospital patients have been recently treated. However, medical records are not accessible. It takes an extra step (via phone call) to obtain medical records.
- Too soon to tell.
- Currently, no, since there are no results or other useful info accessible; we are restricted from information we need.
- The registry was more useful when we could see (at least) a diagnosis for ED visits.
- Will be more useful when we can access things such as meds they were given and discharge prescriptions.
- It would be much more useful with all the island hospitals on HMVR.
- What information is most useful?
 - Finding the place where the service was done, doctor's name and the date.
 - Diagnosis and date/frequency of visits.
 - The date of visit old records.
 - Where they were seen, and the diagnosis. If an inpatient, how long they were admitted.
- What features would you like to see that would be more useful?
 - Obtaining the results online, i.e. ED report, etc.
 - I would like to see if I could get access to pull out/print patient medical records like inpatient, ED notes or any test result.
 - I would like to see and obtain results on each test and visit from HMVR.
 - Ability to see the entire clinical notes for an encounter.
 - It would be nice if other health centers participated.
 - Full access of the medical record, i.e. patient seen at Queens ED; it would be very helpful if we could access the medical.
 - Access to visit dates at each ED & initial diagnosis & secondary diagnosis.

- More hospitals participating.
 - Accessibility and usefulness.
 - I would like to say thank you, I think it's nice to have an access to a different facility or to know if a patient has been to other facility in order to provide good service to all patients.
 - I think this is a very useful tool and hope it expands.
 - So far so good!
- C. Six-month post-HMVR questions were: Do you use the HMVR?; Was it easily accessible?; Where do you access it?; How many times have you accessed it?; What type of access to you have?; Any logon problems?; and Overall score of helpfulness of HMVR in current patient workflows? At this point, there was very little response to this survey, so these results will not be presented in this report.
4. Evaluation outcomes as documented in the Evaluation Plan; the Evaluation Plan is on file with AHRQ; selected outcomes are shown below and organized according to project Aims.

Aim 1. Increase Accuracy and Timeliness of Shared Patient Information during Transitional Care between Primary Care and Tertiary Care Facilities

1.1: Understand the workflows that influence transitions at all the chc and tc organizations. Workflows on file.

1.2: Develop policies and procedures that would improve transitional care, data and information sharing. Policies and procedures developed and on file. CHC providers indicate there is adequate information on the patient during the transitional care process. Key themes from interviews from the providers 3 months post HMVR implementation document improvement of transitional care, data and information sharing:

- Has improved over time but could stand to improve more. Definitely QMC and HPH on Epic has helped. Particularly if a CHC has hospital credentials and therefore has remote access to the hospital systems. When a patient is transferred from the hospital back to the CHC, this remote access is of great value.
- TC Transfer Hotline – lots of issues raised here. Patients are triaged from CHC to hotline (where take diagnostic tests) before they show up in the ED with the exception of trauma patients. CHC providers in a pretty consistent way say that since the hotline, it has been more difficult to gain access to an ED provider to discuss a patient case which has resulted in a decrease in communication.

- Quality of transfer depends on the hospital. Some better than others.
- Lack of information when a patient is transferred from a hospital to a CHC happens very often. Consistent comments that one TC's providers better discharge data than other hospitals.
- Seeming increase in the discharge summary some providers received from hospitals. (This should be a natural occurrence with the implementation of Epic).
- If a PCP is not identified, hospitals send patient records to the wrong place. The HMVR would be helpful in identifying and providing contact information to the right place.
- Particularly with TC-privileged providers that work at the CHCs, transitional care is aided with their remote access to the Epic system.
- TC's implementation of the triage center has impeded a direct doctor-to-doctor conversation on a patient which has decreased the quality of care transitional care some patients receive.

1.3: Improve institutional mechanisms responsible for the ongoing assessment, enhancement and improvement of information, communication, and data sharing. Key provider interview themes demonstrating improved communication between service providers to increase the timeliness and appropriateness of treatment and reduce inefficiencies were:

- I think working in the ED, one of the things that really delayed some of the treatments, is the timeliness of the primary care provider in responding to the calls. Sometimes we have to wait before they return a call.
- Many visits in the ED are unplanned so the patients don't show up with information. Usually the ED provider makes a call to the PCP if known.
- Faxing is the most common way patient information is shared between facilities during transition.
- Offering materials and interpreters that are certified for that certain population – they're not getting the best care, because if you get a family member, you cannot guarantee that all the information is getting sent from what you are telling the patient.
- Generally better discharge information from TC.
- Need to focus on getting it more linked up and more organized, so that the interpreters go to where that need is. More organization, more streamlined, making it more available so that patients transitioning will have better service, interpreter services.
- For ED fax over the information from the CHC and develop a standard guideline to send over.

1.4: Implement the Holomua Master Visit Registry (HMVR) that will allow KKV, KPHC, QMC and HPH to share health information and data. The HMVR was created to share health information and data. All elements of the HMVR were functional/operational 6 months before the end of our funding period. The frequency (# of hits) by providers/nurses etc. users of the HMVR continued over the 6 month time period.

Table 2.

	04/09-05/09 HPH	04/09-05/09 KPHC	04/09-05/09 QMC	06/09-07/09 HPH	06/09-07/09 KPHC	06/09-07/09 QMC	08/09-09/09 HPH	08/09-09/09 KPHC	08/09-09/09 QMC
Grand Totals	0	0	0	0	0	0	0	0	0
# of Users	3	14	1	0	27	15	0	8	0
View Functions*	3	111	0	0	290	131	0	245	0
Logins	5	25	0	0	110	48	0	63	0

Note: HPH=TC¹; KPHC=CHC¹; QMC=TC²

* listing patients, viewing patients and visits

Over this 6 month HMVR use period, the majority of end-user providers and staff have not solidified their impressions about the impact of the HMVR on quality of transitional care:

- The proliferation of silo EMRs does not mean we can share data with each other. EMRs are internal to a facility so effective transitional care is still limited.
- Provider still expressed that when the patient shows up in the ED, information is not readily available.
- Overall, the healthcare industry is now more willing to give information about their patient before they are sent to the hospital. Likewise the expensive healthcare bills is motivating the patient to ask questions to the Provider on the necessity of tests, cat scans, etc...
- I expect more than what the HMVR has given me. Lab tests etc. A state wide data network that really promotes healthcare delivery that saves money and promotes quality of care will hopefully happen in the near future.
- In my limited experience these last two months for the two patients that had hospitalizations, that's an enormous improvement, but I have a limited, a small "n" (number of subjects).
- Facilities are paying more attention to medication summaries. At Queens, definitely. Queens' really is paying attention to it. They're interested in the whole meds coming in; they're interested in discharge medicines going out.

1.5: Widely disseminate, locally and nationally, information gained regarding performance (outcomes), lessons learned, and recommendations for future

directions/exploration based on the Holomua Project experience. The dissemination activities were broadly distributed in terms of geographical coverage, audience groups/ stakeholders. A minimum of 5 presentations and/or resources were developed and disseminated during each project year (see List of Publications and Products).

Aim 2. Increase Participation and Involvement in Decision Making by Patients or Family on Health Related Matters

Focus group interviewing was performed with the patients and community members. Reliability and validity of the qualitative data analysis was determined by an iterative process involving constant comparison of the themes from the interview data. This type of process allowed verification of the consistency of data over time and across interviews.

2.1: Solicit patient and community feedback regarding their perceptions of how transitional care is handled between systems. The pre-HMVR and 3 months post-HMVR implementation patient and community focus groups revealed the following themes:

Table 3.

Themes	Pre-HMVR	3 months post HMVR
Don't understand what's going on – told by provider what to do; just show papers from ED visit	X	
Wasting my time/too much time spent waiting for f/u after ED	X	
Faxing reports saves my time	X	
Computerized documents will negate waiting time	X	X
Frustrating not knowing what is going on	X	
Gaps between care provided from different entities	X	
Need to have family present – support and translation and recall of info	X	
Cannot get to referred provider – frustrating/worried	X	
Felt overwhelmed by information	X	
Interpreters needed – embarrassed by repeating, no understanding	X	
Access to transportation makes care satisfactory	X	
Leave CHC to see specialist - thought specialist to replace his PCP	X	
No transportation -- cannot get to care (ED, CHC), cannot get back home	X	
Don't understand why referred to specialist/wrong referral	X	
Doesn't understand need to go between systems	X	
Long wait time	X	
Too much duplication of questioning	X	
Don't come to clinic; God takes care	X	X
Services need to be made more cultural		X
Uses CHC infrequently (3-4 yrs apart)		X
Never any duplication between systems; each time asks new information		X
Little duplication of questions (surgery done); CHC seems to talk better with tertiary center/specialist at tertiary center		X
Tertiary center seems to accept CHC patients better		X
Staff at CHC gives priority to patients needing f/u from tertiary centers		X
Incorrect information shared; wrong meds given	X	X
Patient should be able to hand carry information between CHC and others (to prevent mix-ups)	X	X
Use of duplicate questions confirms patient identity; no records mix up		X

2.2: Solicit patient and community feedback regarding their perceptions of factors that influence their willingness and ability to seek treatment and follow up with discharge recommendations. The pre-HMVR and 3 months post-HMVR implementation patient and community focus groups revealed the following themes:

Table 4.

Themes	Pre-HMVR	3 months post HMVR
Provider attitude and expression; feel not welcomed, or welcoming	X	X
Provider reminders assists with follow up	X	X
Language Barrier: do not understand directions/instructions in English	X	
No f/u – no transportation; need shuttle buses	X	X
Forgot what to do	X	X
Forgot where to go, unfamiliar places	X	X
Need encouragement to follow d/c instructions		X
Providers to do contacting between systems; nurse set up the appointment to follow up, appt. reminders		X
No understanding of hospitalization		X
Inadequate f/u instructions		X
Systems coordinated the f/u – no problems		X
Problem has to do with the individual; not the system		X
Must bring own interpreter; have to work around family schedule to have someone accompany to CHC	X	X
Misunderstand or skip treatment, misinterpret directions, fear		X
Provider unavailable for asking questions afterwards		X
Doctor needs to speak simple language	X	
Translate doctor's directions into native languages	X	
Need written information for follow up	X	
Involve family in patient's care – recall; family understands what's going on	X	
Waiting time is a problem	X	X
Must tell someone about health concerns or you die	X	
Reluctant to go without knowing if there would be an interpreter available		X
Shame in appearing in public with medical appliances		X
Appointments are too early in the AM		X
System does not accept walk-ins		X
Follow instructions; does exactly what doctor says	X	
Length of waiting time is deterrent to going for care	X	
Clinic refused to provide care	X	
Transportation is a problem; walk, bus	X	X
Need to know and understand all medications before discharged	X	
Treatment is against my religious value; verses medical needs.		X
Financial responsibility is a barrier	X	X
Avoid going b/c unable to pay (shame)		X
Avoid going b/c first question is to show insurance card (has none)		X
Doctor must discuss care to be provided	X	
Needs information written down	X	
Problem in telling doctor what's wrong	X	
Need to cooperate and follow doctor's instructions	X	

2.3: Solicit patient and community feedback regarding concerns, issues and fears about sharing of health information and privacy. The pre-HMVR and 3 months post-HMVR implementation patient and community focus groups revealed the following themes:

Table 5.

Themes	Pre-HMVR	3 months post HMVR
What if the computer is down	X	
Worried about my identity being stolen	X	
Only for the appropriate persons /want my privacy to be exposed only my doctor and me	X	X
No privacy--my information could be seen by all at CHC/hosp	X	X
People will gossip or discussing it among each other or around the table	X	
Fear related to lack of privacy and security issues; confidentiality especially due to people know your identity	X	X
Hard copy documents to be used and hand carried	X	X
Nothing is secure anymore; Negative health information will be available for all to see; available on Internet	X	X
Understanding of privacy/security regulations	X	X
No concerns; helps the physician to make a determination about my problem,	X	X
Shame if others find out	X	
Differential treatment due to health problems	X	
Quick electronic transfers gets there before patient does	X	
The system SHOULD record your SSN; can't give care without that	X	
Good to share for the benefit of others so that they can learn	X	
Too many individuals seeing your records causes incorrect interpretation of information	X	
Each provider should be individually authorized by patient to view records		X
Only trust specific doctors to not share patients information with other people		X

2.4: Educate patients and their families about electronic health information data sharing. The pre-HMVR and 3 months post-HMVR implementation patient and community focus groups revealed the following themes:

Themes	Pre-HMVR	3 months post HMVR
My identity will be stolen	X	X
OK to share if computer system & technology make easier for doctors ; is more educational, and benefits to the provider	X	X
Speeds up treatment and care; better care coordination; good if you can't speak (emergencies)		X
My record must be safe and protected from public		X
Less need to go back and forth		X
Computer is better than paper work; no need to repeat each time and safe from fires, losing records, floods	X	
Inconvenient, staff lined up to use the computer	X	
Computer can transmit wrong information about/to patient which affects subsequent care	X	
Computer can provide patient reminders	X	
Computerized information to educate and be beneficial for the others		X
Timely access information 24/7		X
Can't lie about health condition anymore		X
Improved continuity in monitoring patient status		X
All results captured into one location		X
No control over this issue – all on internet now	X	X
Nothing is confidential anymore	X	X

Comparison of Patient and Community Member Themes between Time 1 (pre-HMVR) and Time 2 (post-HMVR) Implementation

It became evident that patients and community members initially were not aware they had a voice in their health care. The questions asked at Time 1 stimulated these participants to begin thinking about their role in the health care process. We noted that the interactivity amongst the focus group participants began to evolve a collective perspective. Since patients' opinions and perspectives were being sought, this must indicate there is some value in what patients have to contribute. Over a year passed before the post-HMVR focus groups were held. By this time, the HMVR had been in place and was in use for at least 3 months. It was during the Time 2 interviews that the patients indicated they noted some changes in the continuity of care they received. Namely, there was less duplication of care, and the duplication of questioning by the provider was necessary to affirm the patient's identity for safe provision of care. They also suggested some other uses for the HMVR in terms of providing patient reminders and tracking appointments. Joining ideas together in the focus group gave the patient and community members a new voice over time.

The staff at the CHC's who ran the focus groups were bilingual translators speaking English and one of the other languages (Chuukese, Ilocano or Samoan). By Time 2, when patients noted that their opinions had some "weight," they began to ask the focus group leaders to help them make changes in the system. However, the staff indicated that this was not within their job responsibilities to do so. This scenario indicates the importance of understanding that patients view all staff as representing the CHC without taking into consideration differentiation of job responsibilities. In order to provide successful infrastructure for information technology continuity of care, attention must be given to nurture the "human" capacity for successful reception of IT technology in the health care arena.

Although there were no direct benefits to the participants, this community participatory study increased patient safety, and quality and continuity during transitional care for vulnerable populations in Hawaii by (1) improving the flow of information between patient/family, community health centers and hospitals using health information technology; and (2) stimulating patient/community awareness of their power to effect changes in how their health care may be administered.

Limitations

1. The Privacy and Security workgroup proved to be invaluable in providing their knowledge and expertise about institutional and Holomua Project compliance to HIPAA related rules, policies, regulations, procedures. These as well as federal and Hawaii State law were continuously being considered. Due to recent concerns with the anticipation of increased regulations over the sharing of health information, the privacy and security group had expressed concern about the job positions that have been identified and previously approved to be end-users of the HMVR. After much discussion, the PS group agreed to reduce the number of positions of end-users who will have access to the HMVR. There were approximately 100 potential end-users that had finally been approved for access to the HMVR, down from the 300 potential end-users who initially stated that they would find the HMVR useful in the patient workflows.

2. An issue had arisen that has been brought up by the privacy officers regarding restricted vs. unrestricted users. Originally, the last screen on the HMVR (also known as the fourth screen) shows both patient visit information and ICD-9 codes. Initially, end-users who had unrestricted access were providers (physicians, physician assistants, and nurse practitioners). And non-providers were not to have access to ICD-9 codes and visit information. The ICD-9 codes and visit information are on the same (4th or last) screen. After some discussion, it was agreed upon that non-providers will have access to the HMVR as restricted end-users. For example, medical assistants and Case Workers will be able to see patient demographic and visit information but not ICD-9 codes. The new definitions were changed to the following:
 - Unrestricted: access to all information, including visit information and ICD-9 codes
 - Restricted: access to everything, including visit information), except ICD-9 codes

These new definitions were a slight deviation from the previous definition, i.e. restricted users were not able to see any information on the last screen (patient visit information and ICD-9 codes) and unrestricted users were going to be able to view everything in on the last screen.

1. Working with two different institutional review boards (IRBs) from two hospital systems was somewhat difficult to manage at times. It was difficult for the project to convince the IRB's that the HMVR was not a data repository. This resulted in numerous revisions of the application for human subjects approval to administer the focus groups. There were numerous changes to the study protocol when agreement was not made among the IRBs.
2. Due to the composite of multi-cultural groups in our target patient populations, translations were sought out to translate the patient informed consent form into the top three languages spoken among the patient groups (Samoan, Chuukese, and Ilocano). However, it was difficult for both the Holomua Project and the IRBS to find consistent professional translation companies with certified translators in a timely manner. This delayed the focus groups greatly at both the pre- and the post-MVR phases of the research project.
3. Concern was expressed by the IRBs surrounding the community-based participatory research methodology used to obtain informed consent. With the cultural groups that we worked with, there is great value placed on completing activities in a group setting. Thus, when we obtained informed consent, we did so in a group, rather on an individual basis. The corrective action was to re-consent the research subjects on an individual basis and to submit a modification of the study protocol to the IRB, which was subsequently approved. This is a reflection of the challenges of conducting culturally-based research in a western academic environment.
4. Continual and consistent “buy-in” from all of the partner institutions staff was very important in the continuing success of the Holomua Project. Enthusiasm often waned due to the consistent delays in the project.

5. The persistent perception of the Holomua Project is that it yielded only limited data, mostly demographic in nature, offering only one piece of clinical information which is the ICD-9 code field (including text of the diagnosis). There was a need for continuous efforts to maintain the “buy-in” from others involved in the Holomua Project, including the end-users (particularly the physicians), the institutional IT staff, and the privacy and security members. This is especially true for a project whose computer application has been significantly and repeatedly delayed.
6. The Holomua project remained a “priority C” project for staff members at the CHCs and tertiary facilities. The staff had existing workloads that demanded their immediate attention (i.e. patient workload, implementation of electronic health records, etc...) that often prevented them from giving consistent attention to the Holomua Project.

Results

The Holomua Project resulted in:

- Implementing a live health information exchange as of March 2009 with approximately 150 clinician users, 250,000 patients, & 500,000 visits.
- Training of over 100 HMVR end-users across three healthcare facilities.
- Fostering institutional collaboration through active participation of key stakeholders who had the power to affect change within each of the key partners. The key community institution stakeholders were integrated into the Holomua infrastructure from the start of the project and actively participated as members of the Executive Committee through being appointed into the functional workgroups.
- Assigning consistent professional staff, which could make decisions on behalf of the Project, to support the key stakeholders’ work in the functional workgroups.
- Increasing awareness of the infrastructure needed to provide continuity in patient transition between the CHCs and the TCs.
- Stimulating awareness of the need for data standardization across the disparate partners.
- Developing common transitional care policies & procedures for transitioning patients.
- Bolstering awareness of the need for all clinical colleagues to independently adopt similar transitional care processes.
- Achieving an immediate positive impact on the improvement of transitional care as a result of agreement of key transitional guidelines by clinical project participants.

- Increasing Partners' awareness of managing patients visiting multiple facilities via regular interactive meetings with consistent staff support.
- Incorporating Patient, Community member and Providers' perspectives and key insights into the challenges on linguistic/cultural barriers, transitional patient care, use of electronic records obtained, and privacy and security issues related to Health IT implementation.
- Developing a collective perspective among the Patient and Community Members in terms of having a voice in the health care they receive. This was due to the repeated asking of similar questions about self care and technologies.
- Enhancing understanding of Privacy and Security guidance on use of shared data systems.
- Developing several key shared documents related to patient data sharing and business agreements.

Principal Findings

- Disparate and at some level competitive community participants can unify to produce a shared product, the HMVR;
- Patients/community and providers were cautious about health IT and wanted security measures to limit risks; patients noted a decrease in amount of duplication of provider questioning,
- Highlighted was the importance of the role of family members as translators & care coordinators;
- The use of electronic technologies is a promising strategy for promoting efficiency in health care.
- While the HMVR is the "technical" solution to improving continuity of care for our shared transitional patients, the Transitional Care Guidelines are the "non-technical" solution. Thus far, the implementation of this "non-technical" solution appears to assist in making a small impact in the improvement of dialogue and communication between/among providers at the CHCs and at the EDs.
- Some members of the Healthcare Professionals workgroup have stated that there has been "great improvement" and "dramatic changes" in the way that providers communicate with one another. For instance, the CHC providers now expect that ED providers will receive their incoming phone calls regarding a patient that is being sent to the ED. Also, ED providers are now expecting a certain amount and level of information that is scripted in the Transitional Care Guidelines.

- Comments have continually been made by providers that there has been noticeable improvement in provider-to-provider communication, i.e. CHC provider to ED provider. Many have commented on the cultural changes and attitudes are changing in regards to the adoption of health information technology. Some have commented on the changes in their individual provider practices and workflows.
- The project recognized that information technology is only a tool, and therefore relies also on non-technological solutions to advance improvements in transitional care, and involves identifying the challenges in the transitional care process, improving work flow policies and procedures relative to transitional care, and using dialogue and communication to facilitate transitional care.
- Strong partnerships, open communication and enabling tools can be built among committed healthcare providers to overcome existing technical challenges and to improve transitional care processes for shared patients. Collaborative efforts need to continue to improve the quality of transitional care during the patient hand-off process.

Outcomes

- A major milestone is that there have been over 50 HMVR end-users that have been using the computer application since the go-live date. Another is the success of all partner institutions agreeing on a common data set for health information exchange. We successfully held meetings to determine the minimal matching algorithm accepted by all sites. We completed four data extracts from all three healthcare systems during the development and testing phase of the HMVR, which resulted in a successful integration and acceptance testing. HL7 interfaces were deemed stable, and daily batch file interface updates were scheduled and tested daily. Successful interoperability with the HMVR occurred with the hospitals providing HL7 feeds and the CHC is providing batch feeds. The Holomua Project reached other key milestones for HMVR go-live, including: 1) finalizing extensive testing of the four-screen Master Visit Registry application with our developer, Sun Microsystems, 2) preparing end-user training materials, 3) identifying over 300 potential end-users at each of the partner institutions, and 4) initial review of the data sharing agreement by all institutions. While the Holomua Project continues to be considered a “low priority” (known as a “C” project at one institution) for the partner institutions’ IT staff, as some are kept busy with their CPOE, EPM, and EMR preparations and implementations, we consider the accomplishments made thus far as extraordinary.
- A functioning Master Visit Registry for 6 months that shared patient health information that met federal and state HIPAA regulations,
- HIE-focused and standardized privacy and security policies and procedures,
- HIPAA-related forms, policies and procedures to include the development and authorized Business Association Agreement and Data Sharing Agreement,

- HMVR application training materials,
- Patient, community and provider perspectives, from focus groups.
- Standardized multi-facility transitional care guidelines,
- Clinic workflow analysis to determine the front-end needs of the HMVR implementation,
- A detailed HMVR decommission plan executed at project close-out,
- Committed Holomua stakeholder participation throughout project,
- Success in the Holomua Project positively contributed to the formation of the HHIE as the state-designated entity for statewide HIE planning.
- A collective voice from the patients and community members to shape the care they receive from the CHCs and TCs.

Discussion

- The project was a success because of the huge collaborative efforts among the community, providers, patients, IT developers and the project staff.
- We organized periodic Research Facilitator speak out sessions in which the research facilitators provided guidance to the project by sharing their observations on the progress of the focus groups. The research facilitators also received some technical assistance from the project on how to build community capacity for enhancing patient voices.
- Initially we front loaded the project with community input and then developed a satisfactory and usable system based on their input.
- Expanded the breadth and depth of the Holomua project by submitting another grant application to include other (non-Honolulu based) CHCs and incorporation essential services such as linkages to patient's laboratory results

Conclusions

- It is possible to involve community input to design systems to share information
- Significance: no registry existed linking patient transitions between CHCs and TC's.

Implications

- Data registry is needed to support development of things like the patient medical home.
- Improved continuity of care, population health outcomes
- Patient-provider relationships are important.
- Efficiency & decreased costs of providing health care can be achieved.

Sustainability

The legacy of the Holomua Project has played a strong part in shaping the development of Hawaii's health IT infrastructure. For example, the PI of the Holomua Project is assuming a lead role in the Hawaii Health Information Exchange (HHIE), Inc. The HHIE is a nonprofit corporation recently formed by key stakeholders in the Hawaii health care community including representatives from various hospitals, health insurers, physician organizations, and other health care providers. HHIE is dedicated to the formation and operation of a health information exchange system in the State of Hawaii, which would allow a secure and rapid exchange of medical information.

List of Publications and Products

Publication

Chin, BJ; Sakuda, CM; Balaraman, V. Transitional Care: Opening Communication between Community-Based and Tertiary-Care Healthcare Providers. *Journal of Health Information Management* 2008 23:46-49.

Posters

Sakuda, CM; Chin, BJ; Tse, AM. "Methodological Challenges and Supportive Factors Contributing to Community-Based Participatory Research in a Western Academic Research Partnership Infrastructure". Accepted for poster presentation at the Agency for Healthcare Research and Quality Annual Conference, 2008, Sept 8 – 10; Bethesda, MD.

Giesting, E; Sakuda, CM; Chin, BJ; Tse, AM; Song, S. "The Holomua Project: Improving Transitional Care and Health Disparities in Hawaii". Accepted for poster presentation at the National Association of Community Health Centers Annual Conference, 2009 Aug 23-24; Chicago, IL.

Conference Presentations (Podium)

Hawaii Primary Care Association annual conference 2008,
Data Integration and Continuity of Care: The Holomua
Project

Hawaii Primary Care Association annual conference 2009
Health Information Technologies: The Impact on HPCA
and its Members

Local Presentations

Kokua Kalihi Valley Comprehensive Family Services,
Kalihi Palama Health Center, Waianae Coast
Comprehensive Health Center, Diagnostic
Laboratories/Clinical Laboratories of Hawaii; Queens
Medical Center and Hawaii Pacific Health (Emergency
Department physicians/nurses, ancillary staff); patients at
community health centers; community members

Hawaii Health Information Exchange not-for-profit
(regular updates)

Statewide: Maui - Clinical Directory Management
Training Conference, Big Island informal talks

CHC week activities: health education initiatives

Hawaii Legislature: 2008 House and Senate Health
Committees

Electronic Resources Developed (Products of the Workgroups)

HIE RFP to Vendors

HMVR Technical Survival Guide

HMVR Input Record Format

Holomua User Provisioning Form

HMVR Detailed Scope Document

User Confidentiality Agreement

Data Sharing Agreement Phase 1 (planning and testing
period)

HMVR Role-based Access List

Data Sharing Agreement Phase 2 (production and
implementation period)

Holomua MVR User Manual

Holomua MVR Technical Reference

Business Associate Agreement

HMVR Architecture and Deployment

Colocation Security Management Contract

HMVR Decommissioning Plan

Clinical Transitional Care Guidelines

Holomua Project Poster

Holomua Hawaii Health Center Directory

Community-Participatory Infrastructure Developed

Research Facilitator speak out sessions

Medical/MPH Student Summer Internship

A second year medical student and public health student from the Northwestern University
Feinberg School of Medicine, Chicago, IL, was selected for a 3 months summer internship in

2009. The goal of the internship was to further refine what had been identified and documented as linguistic and cultural barriers that CHCs and TCs encountered in the course of each patient's transition and care. Once the problems were identified, the intern, who has an undergraduate engineering degree, worked with the Holomua staff, project coordinators, providers, and the patient community to propose low tech IT solutions to facilitate and improve communication between the CHC and the patient.

Further Information

Additional information may be obtained from the AHRQ quarterly progress reports (on file with AHRQ) or from the Holomua Project (Hawaii Primary Care Association, 345 Queen Street, Honolulu, HI 96813-4715; (808) 536-8442; www.hawaiiipca.net)