

# **Bridging Care Communication and Health Management within Diverse and Underserved Populations**

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## **ABSTRACT**

As the US healthcare system becomes further impacted by factors such as the oncoming flood of aging baby boomers, increases in the amount of people uninsured or underinsured, higher occurrences of chronic illnesses (diabetes, hypertension, etc.), and a potentially insufficient pool of incoming healthcare workers, the burden of managing one's own health, therapy, and medical transactions will increasingly fall on the patient, their family and care managers. A multitude of new systems for personal health management are being developed and it will be critical that these systems are responsive to the unique and specific needs of all people and perhaps more importantly those who are the most at-risk. As an initial step toward identifying core system requirements, interviews with care managers and administrators of a personal health information system (PHIS) for use with migrant farm workers was conducted providing preliminary recommendations toward the development of a framework for effective use of PHIS within diverse and underserved populations. Initial findings indicate that PHIS within these types of communities will exist not so much as an isolated tool for health management, but moreover an artifact for bridging health information communication between patients and their healthcare providers.

## **Keywords**

Personal health information systems, diverse populations, care management

## **INTRODUCTION**

The overarching goal of this research is to identify whether access to and use of personal health information systems (PHIS) can assist underserved people in feeling more in control of their health and as a consequence toward feeling "healthier". While the relation between the effects of PHIS use on actual health outcomes might be difficult to reliably assess there is potential for describing the way in which engagement with PHIS may have a perceived effect on personal empowerment in relation to health. Before, however, this aspect of the research can be investigated it is essential to first determine how PHIS can be effectively used within these populations. Within the context of this study "underserved" in general refers to diverse communities of low-income status, who are often uninsured and at-risk of critical health problems due to fragmented healthcare. As a result of these challenges people experience increased difficulties in accessing and working with information technologies (IT). Described extensively within the digital divide literature, these difficulties include issues of limited access often due to income, lower-education, misunderstanding of value, misunderstanding of purpose and many others (Cherry & Edmondson, 1985; Brown, Barram, & Irving, 1995; Lievrouw & Farb, 2003).

Accordingly, the use of health IT (HIT) within underserved communities will experience the same challenges as described in the digital divide literature; however, they will be further exacerbated by adverse medical conditions and the complications of disabilities. It is proposed that successful utilization of PHIS within underserved populations will require a comprehensive HIT infrastructure delineated by technical, personal, organizational and policy-based factors. Each of these factors is then further described by HIT related constructs specific to working within vulnerable populations. Providing frameworks for designing systems that meet the needs of the most disadvantaged users can help to insure wider adoption of that system by providing accessible and usable functionality and resources (Shneiderman, 2000).

As part of a multi-phase research project, this report describes preliminary steps toward the creation of a conceptual and evaluative requirements framework that can be used by healthcare providers for designing, implementing and evaluating personal health and care management systems targeted for use within vulnerable populations. The full study will investigate three case studies that include 1) a PHIS being used within migrant populations, 2) current PHIS and care coordination

systems development for use within the safety-net and 3) experience and perceptions of leaders and administrators within community health environments. This paper will present elements of the first case study involving the use of PHIS within migrant populations and will address perceptions and experiences of care managers, outreach workers, administrators and involved community based organizations. Continued research will report specifically on patient experiences, but within this first phase of study it is important to first gain an understanding of the people, organizations and common issues that come into play in support of this population.

## **REVIEW OF THE LITERATURE**

### **Migrant Workers and Families**

This case examines aspects of providing health services to the “migrant” or “day laborer” community, the majority of which currently being predominately Latino immigrants (Department of Labor, 2005) who relocate frequently based on growing seasons and in search of work common to industries of agriculture, landscaping, and construction. Migrant families within the United States are a unique and historically misunderstood population of people. Migrants straddle a line between the status of documented workers of the U.S. and “illegal-alien”. Although they tend to the majority of U.S. agricultural needs, their status as citizens often raises questions regarding their rights to receive education and healthcare (Wolf, 2008). In this respect it is important to identify that studies by Wallace, Castaneda, & Gutierrez (2007) identified that although uninsured and employed within fairly dangerous work environments, the migrant population is relatively healthy and recent findings have indicated that their impact on healthcare is not the burden that is often perceived. With this said however, Wallace, et.al also note that due to occupational hazards Latino immigrants have the highest risk of death and disability and that often they do not take timely action on health problems due to fears of being fired or threatened, unwillingness to take time-off and lose wages or from being unknowledgeable about workers’ rights and compensation laws.

The need for health self-management resources for use within underserved populations cannot be overstated, especially in light of the growing amount of people who are uninsured. Within California alone there are more than 6 million people uninsured which accounts for more uninsured residents than any other state (44 million nationally). Less than 10% of adults who are uninsured qualify for public health insurance and relevant to migrant workers, the majority (32%) are of Latino ethnicity (California HealthCare Foundation, 2007). The consequence of being uninsured is that it makes one less likely to take advantage of preventive health services. In place of professional help people are left to their own devices for diagnosis and therapy of health problems, most likely relying on the advice of literature, friends and family if available. Adoption of PHIS within these populations has the potential for providing access to both general and personal health information resources that might not otherwise be accessible.

### **Health Information Technology and Health Outcomes within Underserved Populations**

It has been steadily identified that early intervention and access to quality outpatient care can assist in reducing morbidity and suffering of patients with treatable chronic conditions such as diabetes, hypertension and asthma, as well as providing significant reductions in healthcare costs (OSHPD, 2005). At the same time, however, there is an increasing number within the population suffering from fragmented health care practices and this problem is more frequently encountered within communities of lower socioeconomic status, the majority of which are often made up of racial and ethnic minorities (AHRQ, 2003). These and related findings are especially pertinent at a time when the U.S. works to make public programs such as Medicaid sustainable and consequently denotes efforts toward decreasing avoidable hospitalizations and costly inpatient expenditures as an area of high interest to legislators and policy makers (Clancy, 2005).

Accordingly, healthcare organizations are being encouraged to rethink the way they do business and are being lead to develop new processes and to implement new infrastructures that will allow them to electronically record, transmit and store patient health information. A great deal of this development however has yet to have been undertaken and it has been revealed that upwards of 53% of hospitals were still solely using a paper chart method for recording data and that 25% of the others utilized a combination of both computer-based and paper-based recording methods (Metzger, 2007). Similarly, within transition areas further studies have shown that ineffective communication of medical information can be attributed to as much as 50% of all medication errors and upwards of 20% of adverse drug complications in hospitals (ISMP, 2005). Within the community health setting similar findings indicated that upwards of 47 percent of community clinics surveyed were considering or in the process of adopting EHR systems, but that overall less than 5% had actually implemented an EHR system and that for many of those that did significant barriers to success were noted (CHCF, 2004). With such findings in mind it can be hardly doubted that improvements in health information reliability and efficiency will be critical to the next phase of HIT development.

Research to support adoption and implementation of PHIS has identified that access to health information resources and support can have a positive impact on the health of underserved patients (Chang et al., 2004). Significantly, it has also been reported that between 42-45% of patients in use of PHIS say that the use of PHIS has improved communications with their doctor and other health care professionals (California HealthCare Foundation, 2008). Personal Health Record (PHR) functionality findings have reported that representatives of underserved populations expressed a concern with privacy, noted that they want to decide who will access their health information and would want their PHR to be portable in some manner (Moreno, Peterson, Bagchi, & Ursin, 2007). Furthermore, it is related that general lack of access to e-health services and resources is further increasing the digital divide across racial and ethnic groups (Hsu et al., 2005). It would appear that this community has distinct perceptions and insight toward the use of PHIS and yet common digital divide issues of accessibility (technology access and healthcare access), usability and literacy (Berkman et al., 2004), education and outreach (Brodie et al., 2000; Martin, 2006; Tang, 2006) are prevalent within HIT and PHIS research findings. With this understanding comes a responsibility then to design systems targeted and unique to the education and skills of the populations who may potentially derive the most benefit from these resources.

### **Care System Redesign: A Consumer-centric Focus**

In light of the latter described challenges findings have reported that preliminary efforts in the use of HIT to assist the underserved in managing their health provided positive financial and health services efficiency results (Botts & Horan, 2007). One distinct aspect of the program studied was that inherent to the design of the program was work toward organizationally networking the clinics and medical center within that community in order to counteract preventable conditions that are the result of sporadic and fragmented treatment of chronic conditions. This is important in relation to the research being discussed here in that barriers, whether financial or chronic at the patient level, are exacerbated or possibly indicative of deficiencies in the healthcare system structure (Gardner & Kahn, 2006) and that it is within this space of integration, coordination and collaboration that a real impact on these communities can be achieved. Importantly, in order to better understand how to bridge efforts between health and social care organizations patients need to be innately involved so as to describe and help plan the network required to support their needs.

The Institute of Medicine (2001) outlined six facets for the redesign of healthcare systems in the twentieth century which included provision of safe, effective, patient-centered, timely, efficient and equitable healthcare. In reference to those six facets of redesign were ten design requirements which focused highly on the presence of patient-centered development practices. The Community Clinics Initiative (CCI), a joint program of the Tides Foundation and The California Endowment, identified that provision and effective implementation of an EHR is an extremely difficult process for clinics. In development of a framework for adoption and implementation of EHRs within the community clinic setting the CCI proposed six main objectives of which one describes the need for the promotion of consumer-centric care. Specifically, the framework notes that due to the unique populations served by community clinics that personal health information should be properly adapted for “diverse individual needs, cultural traditions, reading levels, or socioeconomic modulators of illness” and that the ability to personalize care through health information technologies is critical to their effectiveness (FullCircle, 2005).

### **The MiVIA Program**

The MiVIA program in Sonoma County, California provides a web-based application used as the vehicle to provide outreach, care coordination, and a PHIS for the migrant farm worker community. The application aspect of the MiVIA program is a web-based personal health record that allows migrant farm workers to update and keep track of their health information. MiVIA provides the ability to create a continuous record of health services and needs for migrants as well as providing access to healthcare providers (determined by patient permissions) who come into contact with these patients. Aguirre International (2006) conducted an evaluation of the MiVIA program as it began to rollout services into Napa County, California. This evaluation provided an overview of system needs and implementation considerations for the MiVIA program as it continues to expand. This report indicated that components essential to adoption of the MiVIA program include a strong provider support base, effective outreach efforts, farm worker education opportunities and inclusion of established health services as part of the implementation.

Building off of these findings, investigation of the MiVIA program as it is being used within St. Joseph Health System and Vineyard Worker Services of Sonoma County has been undertaken in order to better understand effectiveness of services for the migrant community. It is becoming obvious through research and general implementation findings that a better understanding of unique needs is necessary to effectively utilize personal health information systems and that it is within the details of these experiences that the greatest need for research resides. For it is that element, the inimitable difficulties that cannot be easily overcome by diverse and underserved communities, which greatly needs consideration.

## **METHODOLOGY**

This is a report of a single case within a multiple-case study derived from interview data. Use of these types of methods within this research is appropriate since its purpose is to explore and examine general impressions and experiences of healthcare workers as they work to assist the migrant population. It is posited that the most important aspects to this study are within the minute and at times formless interactions between migrant patients, their care managers and the associated community health and social service organizations. Neuman (2003) advocates the use of such research methods when assessing unique populations that may be otherwise difficult to reach. Semi-structured interviews were conducted in November 2007 with the director and MiVIA outreach worker of the St. Joseph Health System and an administrator and two case-workers of the Vineyard Workers Association of Sonoma County. An example of these questions can be found at <http://wfs.cgu.edu/bottsn/MiVIA-Interviews.pdf?uniq=4qs9c1>. Each of the interviewed participants is using or in charge of implementing the MiVIA application within the community health environment.

Yin (1989) states that general applicability, results from the set of methodological qualities of the case and the rigor with which the case is constructed. In efforts to make these and future case-study findings within this research as generalizable and representative as possible, interview data is analyzed through the use of Atlas ti 5.0, the qualitative data analysis software, in order to consistently code and draw inferences from interview data received. Initial coding constructs included aspects of adoption, integration, usability, design, and health outcomes. Significant unrealized themes within discussions and interviews were derived as well and reported herein.

## **CASE STUDY OVERVIEW**

### **The MiVIA Personal Health Information System**

The MiVIA program is a customized PHR application designed within an underlying framework called FollowMe. The FollowMe platform is developed by Access Strategies, Inc., a privately held health information technology firm focused on web-based IT strategies for the healthcare industry. The ability to hold the health information of migrant farm workers in a centralized place, through which they can access it, no matter where they move, is an important feature for this highly transient and often undocumented population. Of equal importance is the ability to keep track of any medical interactions that might occur throughout several different clinics in several different counties. Many of these field workers do not have medical insurance and so, in many cases, whenever they go to a clinic, doctors often have to start over again and again toward understanding and deciphering the health history of these patients.

### **MiVIA Study Setting**

Interviews were conducted during a two-day trip to Sonoma County where one of the MiVIA program implementations is taking place. Sonoma County is located a few miles above San Francisco and is most commonly known as a popular wine growing region. Sonoma is highly rural and consists of acres of vineyards used to grow grapes for wine. Consequently, farm workers are employed throughout the year in order to assist in the growing, harvesting and fermenting of grapes. While this keeps many farm workers employed on a continual basis there are off season times in which farm workers must migrate within and outside of the county in order to find further work.

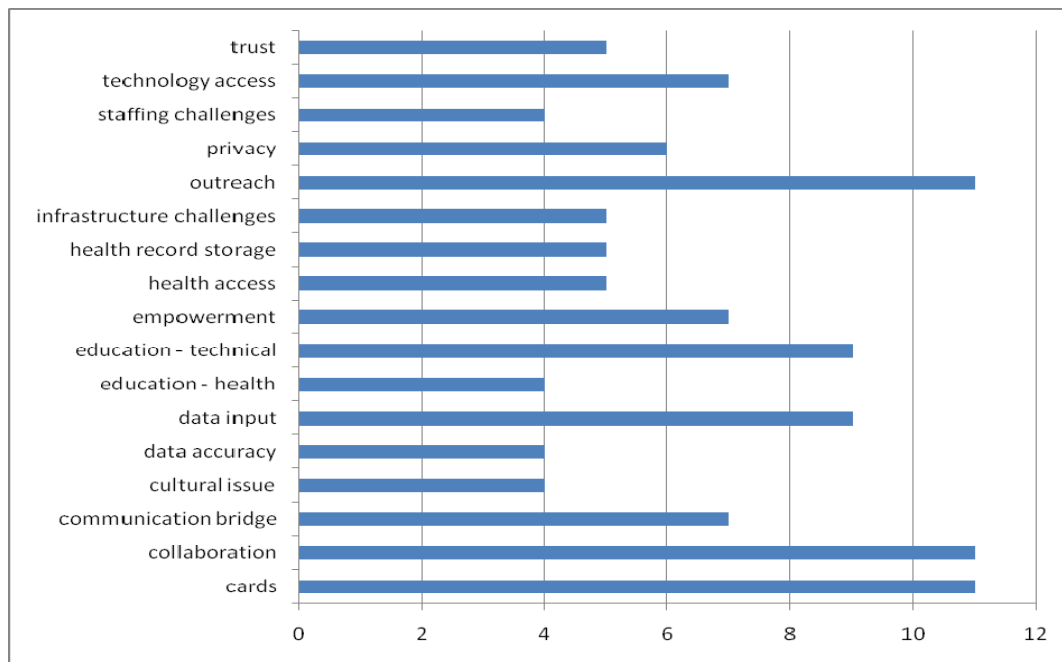
Two main sites were visited including a community center used as a mobile clinic site for St. Joseph Health System and an outreach center run by the Vineyard Workers Association. The mobile clinic site utilizes an "RV" in order to provide dental services on some days and health services on others. Staffing at these sites usually includes one to two primary physicians, nursing staff and a MiVIA outreach worker. It is the responsibility of the outreach worker to enroll patients into the MiVIA program and assist the physicians in populating the patient's PHR with updates to their healthcare. The role of the outreach worker is vital to patient and physician adoption of the MiVIA application. In discussions with the outreach worker it was identified that she often assists and trains patients in tasks which include learning how to use a computer, learning how to navigate the Internet and understanding how to log in and use the MiVIA PHR.

The Vineyard Workers Association (VWA) consists of an office in downtown Sonoma that is used as a drop-in site for migrant farm workers. Case managers there assist workers in a variety of social service tasks including the filling out of general paperwork, finding jobs, finding housing, dealing with social issues and accessing healthcare. Currently located at the VWA is one computer that can be used to train farm workers on computer basics and to enroll and train them in use of the MiVIA PHR. Significantly, VWA received a grant from the California Endowment in 2006 to enroll five hundred workers in the MiVIA program. The VWA were able to fulfill their enrollment quota and are now seeking opportunities for continued use and adoption.

## INTERVIEW ANALYSIS AND FINDINGS

### Analysis and Preliminary Findings

The interview between community clinic and social service administrators, outreach workers, and research staff spanned a time period of approximately one hour. The full interview was recorded and from this recording a transcript of the discussion was created. This discussion included approximately two hundred different communication exchanges between participants. Many elements were tagged with more than one code depending upon how many different relevant concepts were used within the quotation. A primary goal of this study is to determine implementation issues experienced within the community health setting when using PHIS. One way in which this was done was by identifying which coded variables arise within the conversation most often (Figure 1).



**Figure 1. Frequency of Coded Primary Perceptions and Experiences**

It is important to note that counting of qualitative coding elements is at times of limited value due to the subjectivity of the coding process. Equally, to some degree frequency and the origination of some concepts are influenced within these findings by the types of questions being asked. With those limitations in mind however, there is still value to be gained from making counts and comparing weights of concepts discussed (Miles & Huberman, 1994) and as follows, analysis of these weights can relate patterns and associations within the content of the discussions.

From a quick look at findings it can be identified that aspects of technology access, privacy, outreach, empowerment, technology education, data processing, communication bridging, collaboration and the use of health I.D. cards were a frequent part of people's experiences and perceptions (referenced in some capacity six or more times). Each of these concepts was found often throughout the discussion and indicate an important aspect of MiVIA use within these communities. Further issues of importance included trust, staffing and infrastructure challenges, health record storage, healthcare access, health education, data accuracy, and cultural issues. The concept of technology education, found upwards of nine times, referred often to training needs in use of computers for accessing information in people's MiVIA accounts. Expressed often was the idea that you cannot simply hand this community a PHR and think that they will begin managing their health. The only way for it to be effectively used within this group is through continuous trainings, education and assistance. This includes trainings about how to use a computer, use the Internet, and how to understand health information.

- *“When we started doing MiVIA we discovered that there is no point registering people if they had no education on the program. There was just no use for it. So I started doing training for everybody on how to use the computer, how to use the internet, and how to use the MiVIA program in general.”*

- *“Because just having a card is not enough [health ID card]...there is a lot of information to learn if you don’t have computer skills and we do want them to maximize the use of this tool to their benefit and their families benefit. So it does take continued interactions with them.”*

Another big issue in use of the MiVIA program with migrants was aspects of empowerment and often tied directly to that was the concept of the health ID card. Although the unintended importance of the health ID card had been related informally, it became obvious from this discussion just how big of an impact the introduction of this card had within the farm worker community. On further reflection this makes sense in that these people primarily consist of undocumented workers (Department of Labor, 2005) (even ones that have been living in the U.S. for up to ten years and more) and consequently obtaining valid identification can be very difficult and a great burden. By providing a health id card that includes a picture and physician validated information the MiVIA program significantly empowers farm workers in their ability to legitimately identify themselves. Obviously, of equal importance is the fact that the MiVIA health I.D. allows migrants to provide doctors with up to date health information including allergies, prescriptions, and chronic illnesses. Specific medical information can be hard to remember for anyone and is only intensified when added to language difficulties and a highly fragmented health background.

Below are a couple of the comments made in this regard:

- *“Another big thing is the communication barrier and not being able to remember the medications because the names are so crazy yet now they have something on them that carries that information and they can take it with them wherever they go.”*
- *“...not only that but even walking down the street and worrying about getting stopped by the police or somebody they are at least able to show that they are a part of Vineyard Worker Services and have recorded health information. Not only that, but without getting into liability issues it provides basic forms of information of what they are allergic to or medications.”*

A concept not related within interview questions that became prevalent within the findings was the concept of bridging communication between patients and health information. Again, this concept was most often related in terms of the health ID card and in being able to look up health information online. Having access to those initial resources seemed to provide people with enough information to spark their memory or enough confidence to ask their doctor or care manager further questions. It also recognizes that healthcare is not an isolated experience and that people who use PHIS will often be doing so through assistance with and in communication with family members, care managers and physicians.

Interview responses identified in relation to the concept of communication bridging included the following:

- *“Oh my gosh, it makes all the difference in the world. When I talk to the physicians about this they are excited because they don’t have to start from ground zero. Or have inaccurate information...they have an information resource they can trust. So often people come into contact with the system [clinic] and know that they have hypertension but don’t know the meds, or have diabetes but don’t know those medicines or describe it in a vague way, “Sugar problem”...”*
- *“This is a good base for us because when they come in and get their id they start asking more questions and asking for more resources that are out there and that is very important for us. Because on a lot of occasions, since we have this base [the card] and they know they can show the card, then even if they don’t understand the whole process they know they can come in and ask questions about health.”*

### **Conceptual Model Development for Community HIT Requirements**

Based on the frequency of concepts encountered within interviews a preliminary community HIT conceptual model is proposed (Table 1). The conceptual level column describes the domain at which concepts were discussed or referred to in interviews, the construct column identifies the coded concepts and the examples and instances column describes specific episodes in which these concepts were discussed. In consideration of space, the constructs noted here provide some examples of the most frequently discussed concepts and the instances or specific issues through which they arose in interviews.

Conceptual Level	Constructs	Examples and Instances
<b>Policy Level</b>	Healthcare Access	<ul style="list-style-type: none"> <li>Access to healthcare is a central and political issue in regards to this population and arose frequently in conversation.</li> </ul>
<b>Organizational Level</b>	Collaboration	<ul style="list-style-type: none"> <li>Noted often as a primary barrier to providing comprehensive and continuous care</li> </ul>
	Outreach	<ul style="list-style-type: none"> <li>Identified as one of the key aspects that an organization needs to be able to provide people</li> </ul>
	Communication Bridging	<ul style="list-style-type: none"> <li>Determining ways to bridge communication between patients, health information and their medical providers</li> </ul>
	Education	<ul style="list-style-type: none"> <li>Provision of education both technical and health related was identified frequently within conversations</li> </ul>
<b>Personal Level</b>	Access – Technology & Health	<ul style="list-style-type: none"> <li>Access to computers = low</li> <li>Access to healthcare is difficult due to mental and physical barriers</li> </ul>
	Privacy	<ul style="list-style-type: none"> <li>Inherent guarding of information due to citizenship</li> </ul>
	Empowerment	<ul style="list-style-type: none"> <li>Provides patients with a physical support mechanism (ID Card) as well as a virtual mechanism (PHIS) both of which are mobile</li> </ul>
	Cultural Issues	<ul style="list-style-type: none"> <li>Although not discussed as frequently, the weight of this issue was heavy within the discussion</li> </ul>
<b>Technical / Application Level</b>	Format	<ul style="list-style-type: none"> <li>Health card identified as one of the most valuable program components</li> </ul>
	Data Processing	<ul style="list-style-type: none"> <li>Described in terms of technical implementation issues</li> </ul>
	Infrastructure	<ul style="list-style-type: none"> <li>Lack of computers for use within community and healthcare settings.</li> </ul>

**Table 1. Conceptual Model for Community HIT Requirements**

Of note in regards to this framework is that currently few specific policy level constructs have been identified, most likely due to the grounded level of questions being asked. It could be hypothesized that some of the discussions in regards to collaboration ultimately point to policy level constructs, but within the context of the interviews themselves were more often discussed in regards to specific needs in collaborating with other local agencies.

*“what we are trying to do now is to say ok they don’t have health access and health education, well you know if you [other community based organizations] shifted some resources here or helped us in some certain way then we would be able to open some of those doors and create this channel.”*

This statement speaks both to an organizational and a policy level construct in that at an organizational level it can be simple to identify that some level of collaboration or resource sharing should take place, but at times policy level statements need to be in place in order to allow those decisions to happen. Likewise, although healthcare access was deemed accurately added to the policy level section due to general political barriers in regards to healthcare provision, at the same time, many of the conversations in which the issue of healthcare access was discussed was often related to mental and physical barriers of the population itself. The level at which those constructs occur, however, are hard to separate when it is likely that mental and physical barriers are at least in part due to the history of policy level decisions that have barred (comprehensive) access for so long. As further data is acquired future iterations of this framework will provide a more complex and exhaustive discussion of relations between constructs and conceptual levels.

A potentially interesting element that starts to become obvious while describing the conceptual model is the possible implication of the overarching domains that each of the sets might belong and how that relates to community-based organizations and their underlying priorities. Other than the need for assistance in data processing the top elements discussed by directors and outreach workers all had to do with how MiVIA affected social parameters. In other words the discussion centered on how MiVIA best supported patient education, patient empowerment, patient outreach, how to collaborate with other agencies, and how to provide useful resources. While the primary focus of the study is on how PHIS might affect

patients, the questions asked of providers were in regards to adoption and implementation factors within the community clinic setting and yet even the concept of data processing is often related to the needs of patients.

*“If we got someone who has already enrolled, we offer training for the day, you know either during their wait or we schedule another appointment, but for people who are just getting enrolled we sit down and show them how the program works, get all the information down, have them log in and give them their user name and passwords and take their pictures. We then either give them the ID card on the spot or send it to them by mail. And by the time the mobile gets here, I incrementally add the information; my whole thing is to get them enrolled so the doctors can have access to that patient...”*

When we start to look at the second set of concepts, those used three to four times we then seem to find concepts more focused on the needs of the overall clinical system (e.g. data accuracy, staffing issues, infrastructure challenges, etc.). Outside of any indication as to the unconscious goodwill of community health workers it is possible that this suggests that personal health system success is most reliant on successful coordination between the patient and the care managers trying to support them versus the technicalities of the system itself and would imply the need for a continued investigation of personal and organization level facets.

## CONCLUSION

Due to the differences to be found within underserved population sub-groups (Derose, Escarce, & Lurie, 2007), preliminary conceptual framework development suggests that further analysis of specific implementations will necessitate scales to indicate the degree to which particular constructs should be represented. Equally important will be incorporating a method for describing relations between constructs and across domain levels. Findings indicate the need for patient-centered approaches to personal health information system design and development within vulnerable populations. It would be expected that a patient's perspective of personal health systems would center further on their specific needs and yet is instructive when administrators and care managers of these systems identify the need for increased patient education and empowerment as well. Findings also indicate that the use of a health I.D. for bridging communication needs as it relates to health information and access to health services can be of great value and provides specific recommendations for use with PHIS in community health settings.

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