HEALTH IT AND HEALTH DISPARITIES

Healthshack Personal Health Record – connecting at-risk youth to health and social services

PREPARED FOR:

U.S. Department of Health and Human Services
Washington, D.C.

PREPARED BY:

NORC at the University of Chicago
4350 East-West Highway
8th Floor
Bethesda, MD 20814

JUNE, 2012
CONTRACT NUMBER: HHSP2337005T/OS38984

Case Study Report: Healthshack Personal Health Record – connecting at-risk youth to health and social services

"[Healthshack] assists in the development of independent and emancipated youth by providing a personal health information system that is designed with and for these youth, which provides resources as well as safekeeping and accessibility for important life documents." – Healthshack Purpose Statement[i]

Report Summary	
Intervention and Setting	Healthshack is an untethered personal health record (PHR) implemented at Wind Youth Services in Sacramento, CA, in collaboration with FollowMe, Inc., an electronic health information vendor, and University of California - Davis Children's Hospital. University of California - Davis conducted developmental research to understand the acceptability of a PHR among vulnerable youth.
Target Population	System-based and vulnerable youth, including the homeless and those aging out of foster care.
Technology Description	Healthshack PHR: A web-based, patient-owned repository for electronic health information, information on community resources, and other functionality.
Funding and Start-up	$50,000 start-up funding from the Sierra Health Foundation in 2007 $400,000 from the United Health Group and $125,000 from the Sierra Health Foundation in 2008 to design and implement Healthshack
Data and Analysis	Content analysis using NVivo for a series of in-person and telephone discussions with program administrators and participants including: • Director of Wind Youth Services • Case manager at Wind Youth Services • Healthshack Program Manager • Two volunteer public health nurses • Six youth health ambassadors • Director of FollowMe, Wind Youth Services' PHR vendor • Professor of Nursing at California State University – Sacramento • A member of the We Help Youth (WHY) collaboration • Two individuals from the Sierra Health Foundation • A former Assistant Professor of the UC Davis School of Medicine
Key Take-Aways	• Healthshack empowers vulnerable youth to find and access the health care and social service resources they need. • User-centered design and peer outreach can facilitate acceptance and buy-in. • Non-primary health care providers can effectively manage PHR projects, but interoperability, resources, and sustainability remain important challenges. • Despite limited resources, youth are eager and capable of using IT and are resourceful in their ability to find access to the Internet.

Introduction

Located in Sacramento, California, Wind Youth Services is a non-profit organization comprised of a 12-bed shelter and a separate day center (Wind Youth Center) providing an array of supportive services, including employment assistance, housing referrals, and on-site accredited education programs, to system-based youth (i.e., the homeless and those aging out of foster care) aged 11 to 22. They serve one of many groups at risk for lacking access to health care.

Nationally, homelessness touches 1.6 – 2.1 million youth aged 12 – 24 over a year period and California leads the nation in terms of children in foster care.[ii,iii] As these youth age out of the foster care system, they face new challenges in accessing and navigating health care, employment opportunities, training, education, housing and other services. For example, a longitudinal study of youth leaving foster care found "44% had problems accessing health care 'most of the time.'" The homeless face significant risk for experiencing learning difficulties and school problems, among other poor educational outcomes.[iv,v]

Potential benefits of using a PHR like Healthshack. If implemented correctly, some personal health records (PHRs) give patients more control and access to their health care information. Some patients who use PHRs note improvements in access to care and overall health. Untethered PHRs in particular, support access to health care and help highly mobile populations lacking a regular source of health care or geographic stability maintain and control their information, and grant providers access as appropriate.[vi] Applications similar to Healthshack, such as MiVia, an untethered PHR for migrant farm workers, demonstrate potential benefits PHRs bring to highly mobile groups regardless of computer ownership or access the Internet from home.[vii]

Key functionality and uses. Healthshack enables system-based youth to capture and maintain important information in a single, secure website they can access and update. It includes modules designed to capture personal information on health, education, employment and related areas. The health module captures information on medical history, including insurance information, emergency contacts, medications, allergies, information on doctor and hospital visits, immunizations received, and medical provider contact information. The health module also includes a pain and symptom guide where youth can track health events and learn about acute episodes such as asthma attacks and other common health issues. A public health nurse initially populates the health module's information on behalf of a youth upon intake at Wind Youth Services, and the youth can access the health module and edit their information thereafter. The patient's information resides on a secure site available only to the patients themselves and their authorized care providers, including clinicians, caseworkers, and other caregivers.

> **"We got an email from a pregnant girl who left Sacramento. She had collapsed in a grocery store and had medication allergies but she also had a Healthshack card on her. They were able to give her better care because she had her ID and had her allergy information listed there. She was really grateful that she had that and let us know."** *Youth Health Ambassador*

Healthshack also offers youth information on health and community resources, a resume-building function and a document management feature for maintaining scanned copies of critical

records, such as birth certificates, diplomas, social security cards, and immunization histories. Healthshack users receive a Healthshack identification card – essentially a picture-ID and emergency medical card including important health-related information (i.e., allergies to medications) – for use by medical personnel or by the youths themselves in situations where they need a picture-ID.

The success of Healthshack and similar initiatives targeting use of health IT among vulnerable populations relies on engaging members of the target population as champions and advocates. In this vein, Wind Youth Services hired "youth health ambassadors" from among their current and former clients. These ambassadors provided input and assisted with the development and implementation of Healthshack's PHR and accompanying website. Approximately 350 youth have enrolled in Healthshack from its inception (November 2008 through August 2011).

Sources of Start-up Funding

- $50,000 start-up funding from the Sierra Health Foundation in 2007
- $400,000 from the United Health Group and $125,000 from the Sierra Health Foundation in 2008

Encouraging Adoption & Implementation

In this section we outline findings related to the design, implementation, and adoption of the Healthshack PHR and website, including discussants' assessments of lessons learned from their experience.

User-centered design facilitates acceptance and take-up. From the project's beginning, the youth health ambassadors helped ensure the tool addressed the target population's needs. The Healthshack PHR vendor, FollowMe, Inc., leveraged the technological infrastructure of the existing MiVia PHR as a starting point in the design and development of Healthshack. To develop technical specifications for Healthshack, researchers from University of California-Davis Children's Hospital, conducted interviews and focus groups with the youth health ambassadors to identify the business requirements for the tool.

"…We could not make an assumption on what their lives were like or what their needs were." *Healthshack Administrator*

The design team met weekly during the development phase to ensure the tool was operating correctly and met the requirements specified by the ambassadors. Ultimately, the design team – Wind Youth Services, youth health ambassadors, and FollowMe – decided to model Healthshack's health record module after MiVia and include additional features, such as the community health resources, resume builder, and document management function to address the target population's particular needs. One Healthshack administrator provided the following anecdote when describing the design process: *"A youth said, 'It is very nice that you want to worry about where my last tetanus shot was, but that's not important. What's more important is to have a place to keep all my personal documents.'"* Case study respondents attribute focus on user-centered design as a reason for the wide acceptance of Healthshack among the target population.

Use of peer outreach helps overcome barriers to acceptance. In order to encourage adoption, Healthshack staff used a peer-to-peer approach to introduce the tool to youth and conduct outreach in the community. Youth health ambassadors engage with youth visiting Wind Youth Services, introduce them to Healthshack, and handle the initial enrollment in a manner sensitive to the youth's cultural preferences and needs.

> **"Youth engagement takes a lot of work and you have to have the right people. Simply because an agency serves young people doesn't mean they appreciate youth development or youth engagement in leadership and making decisions about the care they receive."** *Healthshack Stakeholder*

Peer-to-peer interaction between the ambassadors and youth who visit the center often overcomes the natural distrust some vulnerable teens feel towards enrolling in new programs or systems. The ambassadors introduce the concept of a PHR and Healthshack's functionality to the youth. As part of the introduction, they emphasize the tool's ability to facilitate easy access to essential documents. If interested, the youth meet with volunteer nurses to jointly input clinical and non-clinical user information into Healthshack. According to staff, approximately half of the youth approached at the Wind Youth Center by a health ambassador enroll in Healthshack. In addition to recruiting youth who visit Wind Health Services, the youth health ambassadors and volunteer public health nurses conduct outreach activities at schools and other locations where homeless youth gather.

Youth are resourceful in finding opportunities to access the Internet. When introduced to the tool by an ambassador, most teens embraced the application. Although some Healthshack administrators thought lack of consistent internet access might present an accessibility issue for Healthshack users, youth often access the tool at the library or on a smartphone. One staff member of Wind Youth Services suggested homeless youth may even forego food to have texting and time on the computer: "*This population is very computer/technology savvy… That is real important to youth. They will put all their resources into getting online.*"

Impact of Adoption and Consequences

Having explored strategies employed by Wind Youth Services to make Healthshack a useable, accessible, and accepted application, we next describe how they employed the tool to address the needs of its target population.

Healthshack provides youth instant access to critical information. System-based youth have specific needs and challenges due to the nature of their transient living situation. These adolescents face challenges with basic needs, such as remembering a social security number or demonstrating proof of their age to access available services. During the Healthshack enrollment process, youth can scan any valuable

> **"In the absence of Healthshack, if somebody went for a job, it would take a lot longer because of the absence of needed records like immunizations and not having documentation needed... It's usually something like transitional housing or programs like JobCorps or getting things like the California ID that requires them to have documentation. Otherwise, that process is delayed."** *Wind Youth Services Staff Member*

documents they have, such as a birth certificate or social security card, into the Healthshack system for secure, timely access to accurate information when they apply for jobs, school or benefits. In the absence of this resource, many youth could not keep track of this information, impairing their ability to apply for and access services they need.

In addition, Healthshack gives youth timely access to information through the Healthshack identification card – an emergency medical card is generated using the medication, allergy, chronic condition, and emergency contact information stored in Healthshack. In the case a youth needs to receive emergency medical services, the card gives them quick access to medication and allergy information needed by the treating provider.

Healthshack provides new avenues to access health professionals. The Healthshack intake process indirectly facilitates access to the volunteer public health nurse at Wind Youth Services and establishes an opportunity for building strong relationships between homeless youth and health care providers. Many homeless youth do not regularly access medical care and rarely talk to a health professional. In some cases, the youths' living situations present barriers to addressing their health needs. During the Healthshack intake process, the youths have a confidential and non-threatening conversation with a nurse, something they otherwise may not have the time or motivation to pursue. By helping build their profile on Healthshack, the nurses build trust with the youth; provide the opportunity to answer health education questions; refer youth to providers and schedule appointments; facilitate sign up with Medicaid; direct youths to clinics to get prenatal care and sexually-transmitted infection (STI) testing; provide counseling, and connect youth with other services related to specialty care needs, housing or employment. As one Wind Youth Services staff member explained, *"Sometimes when I meet with these kids they tell me things they can't tell anyone else, I often wonder what they would do if we weren't here."*

Healthshack also includes a community resource wheel – a directory of youth-friendly resources vetted by the youth health ambassadors. The wheel facilitates direct access to care for youths using Healthshack. The youth health ambassadors identify the resources included in the wheel and visit the sites themselves, writing up an honest review of the resource from a peer perspective. For each resource, the tool also provides a website link, address and phone number, services provided, hours, insurance options accepted, and directions via public transportation. A youth health ambassador described the wheel as *"invaluable"* and felt the feature drives adoption of Healthshack.

Healthshack can facilitate engagement and empowerment on health issues. In some cases, access to Healthshack and exposure to a volunteer public health nurse helped youth feel more empowered to address health issues. The nurses serve as an ally, helping youth construct case plans around their goals by emphasizing prevention and self-care. Sometimes, these discussions provoke meaningful action. For example, a Wind Youth Services staff member noted, *"One of the unexpected findings is that kids are coming back. At first they didn't really approach the nurses, but now [the nurses] are like a fixture."* Another explained, "*Without [the nurses], I don't know if a young person would utilize Healthshack as much, but they do because a nurse is there to help them navigate the process and break it down for them…"*

Supporting these observations, an initial evaluation of Healthshack conducted by the University of California-Davis concluded: "*Once runaway and homeless youth are engaged in the process of accessing healthcare, their ability to store health histories and important health documents in an electronic format may improve communication with their health care providers and lead to better medical management.*" [viii] Results from two pre-post surveys (one currently being analyzed and another in the development phase) will provide additional information on changes in health outcomes for Healthshack users and their perceptions of health.

"It [being a youth health ambassador] helped me grow as a person and opened my mind to the resources that were available… It was a great experience for me and ties into my major. Currently I am studying to be a pharmacy tech, but now want to be a pharmacist. I want to see how I can help [the community] after I am out in the field. It [being a health ambassador] was also a great support system for me." *Youth health ambassador*

Case study respondents mentioned the project's impact on the youth health ambassadors themselves as an unintended positive benefit. The ambassadors work, as part-time paid employees, can dramatically improve their own lives. The ambassadors learn how to communicate with their peers and others. As representatives of the program, many have presented to large groups and conferences. They also help their peers overcome life challenges and improve their community as a whole. Because of the income earned as youth health ambassadors, some now qualify for transitional housing and move out of a shelter. Their experience with Healthshack motivates many ambassadors to pursue community work, education or even a career in health care. According to one respondent, *"These are not the same kids that they were a year ago. I think Healthshack is important for what it's done beyond the technology. There is a transformative experience that they have had being involved in this project."*

Barriers to Use of Healthshack

While the case study offered several positive findings relative to the potential for PHRs following the Healthshack model to assist homeless youth, we identified some important barriers of relevance to similar projects. We highlight some of these barriers below.

Sign-up procedures make broader access difficult. Signing up for Healthshack requires a trip to Wind Youth Services. While making the physical visit provides an opportunity for engagement with service providers in an environment where the youth feels safe, it can pose a barrier for a population of homeless youth with limited access to transportation as well as those outside of Sacramento, CA. Staff pointed out *"the youth that don't use the program much at all are those that are on the streets."* Although these individuals could greatly benefit from the tool, they face considerable barriers in accessing Healthshack.

"I definitely think youth who have less immediate need in their lives are probably more able to focus on this and able to use it. I have had young ladies who are applying to college and they have brought me their transcripts. They are really interested in storing this information." *Wind Youth Services Staff Member*

Youth face competing priorities. Many Wind Youth Services staff members emphasized the basic needs of many youth who visit the facility, such as shelter and food. In many cases,

youth preoccupied with finding ways to meet these basic needs do not sign-up for Healthshack. As described by one youth health ambassador, *"For the people who say no (to Healthshack), it's because they are just in here trying to get lunch or find a place to live. They are not really worried about where their documents are because they don't have a place to live."* Promoting effective, ongoing use after sign-up also poses challenges. Most revisits to the Healthshack site happen when a youth visits the volunteer public health nurses at Wind Youth Services or when a youth who has moved away needs access to their information.

Even well designed applications can be challenging to use. Although respondents suggested the user-driven design approach greatly supported successful adoption, some users saw opportunities to make Healthshack *"(more) user-friendly and simpler."* One administrator noted many homeless youth also have mental health issues and cognitive deficits that affect their ability to navigate the website. Some noted glitches with using the tool through a browser.

Interoperability and provider use of Healthshack would improve its usefulness. Lack of interoperability with other electronic record systems and limited use of Healthshack by health care providers limits the application's usefulness. Healthshack does not automatically import information from other systems – instead a person needs to manually enter or scan all documentation on health conditions, history, and medications into the system. Although the tool includes capabilities allowing youth to provide trusted individuals and providers access to their records, providers outside of Wind Health Services generally do not use the system largely due to the increased time required to access the standalone system. As a workaround, some youth print out information from the Healthshack record to bring to medical appointments. While not a barrier unique to Healthshack, lack of interoperability currently limits the ability for the tool to address problems with fragmented care and services.

> **"I don't think providers have time [to access Healthshack]. They have their own health data base… The youth can give access to the health providers, but I don't know if that is happening. The reality of it is I don't see a provider opening their laptop and asking for their password and [entering] all this information in."**
> *Wind Youth Services Staff Member*

Funding and infrastructure constraints limit functionality. Like many health IT projects, particularly those targeting underserved populations, the Healthshack project faced and overcame barriers related to technology infrastructure and funding in the years since its inception. For example, having a reliable internet connection was an early a problem that Healthshack easily solved. Since FollowMe hosts the Healthshack application, the Wind Youth Center did not have the additional burden of supporting and maintaining the application. Healthshack stakeholders worked hard to secure sufficient grants for start-up. Obtaining additional funds into the future poses significant challenges largely because potential funders often prioritize direct support for basic needs over interventions like Healthshack. In addition, heavy programming costs make additional application development and configuration difficult. As one Wind Youth Services staff member explained, *"[There are] maybe 60 additional features that we want to add into the Healthshack product, but we can't because there is not*

> **"There is a huge gulf between the cost of technology and technology development and the cost of hardware and the ideas."**
> *Healthshack Stakeholder*

[enough] funding." Additional desired features include interoperability with other health record systems, adding additional videos, an appointment calendar function, and video conferencing capabilities.

Policy and Organizational Factors for Replicability

Finally, we present information on organizational factors that played an important role in the Healthshack project, particularly as they relate to replicability.

Partnerships can provide instrumental support. Respondents noted community partnerships with organizations as critical to Healthshack's success. A partnership with California State University - Sacramento enabled nurses working towards a Bachelor's degree to complete the clinical requirements of a community health nursing course as a volunteer public health nurse at Wind Youth Services. This increases awareness of system-based youth, the health of these youth, and technology like Healthshack among the nurses who play a critical role in the program.

Health IT plays into a broader program of support. Stakeholders thought of health IT applications as tools facilitating a broader program supporting the target population's needs. As one individual familiar with the program explained, "*Healthshack is a great tool, but by itself it's nothing. It has to be part of a larger picture."* This comprehensive approach includes the training and coordination of staff, the integration of Healthshack into the programs already offered at Wind Youth Services, as well as the development of a Healthshack website to provide additional information on the program. Specifically, the ambassadors created videos and blogs for the Healthshack site which provide additional information to potential users.

> **"In the absence of the hook, I believe youth would have very, very low likelihood of utilizing a PHR in and of itself."**
> *Healthshack Stakeholder*

Vision, partnerships and start-up resources affect sustainability. Although Healthshack relied on grants from foundations to become established, case study respondents mentioned financial self-sufficiency and project expansion as critical to Healthshack's future success. As one administrator explained, *"Foundations can only take it so far. They have invested in the development and initial implementation of this technology to see if it does work, but [foundations] can't take it to the next step."* From its inception, stakeholders envisioned Healthshack as a model that could expand to other organizations and locations allowing for economies of scale and lowering the cost of adoption. Healthshack continues to build collaborations with multiple organizations that support the target population as a strategy for enhancing the tool, but this requires active education and ongoing outreach.

Healthshack's collaboration with Sacramento's We Help Youth (WHY) collaborative, a network of social service delivery organizations, illustrates their approach to sustainability. WHY recently established an electronic referral form and interface through Healthshack to manage its case management process. Referrals made to WHY will automatically alert a case manager via text message and set up an account for the referred youth in Healthshack with information from WHY for the youth to access throughout the case management process. By preserving the

youth's ownership over the Healthshack account, but expanding access to other service delivery providers caring for the youth, Healthshack aims to achieve wider utilization.

Although other organizations expressed interest in the technology, they face important barriers. First many organizations lack the technology infrastructure (e.g., functional computers and laptops for street outreach) and human capital (e.g., project management staff and the employment of additional youth health ambassadors) needed to support the program. In addition, providing basic needs for this population often takes top priority. Administrators also noted issues with the *"comfort-level to support a system that is geared toward a consumer-driven platform versus one where it is system-driven and [the organization] would collect the information and [youth] would have access to it."*

Summary of Findings

The Healthshack case study demonstrates the potential for community-based, untethered PHRs to support the needs of special populations. Stakeholders emphasized the importance of working closely with the target population to design functionality that addresses problems they face in their daily life and embedding technology into a broader program that includes the use of peer-leaders to build buy-in and adoption. The case also demonstrates effective management and use of a PHR project by a non-health care entity, but shows that interoperability, resources, and sustainability remain as important challenges. Finally, the case illustrates the general eagerness and capacity to use health IT among disadvantaged youth regardless of the difficulties they face.

Project Background and Data Sources

The Office of the National Coordinator for Health Information Technology (ONC) and the Health Resources and Services Administration (HRSA) awarded NORC at the University of Chicago a project to conduct case studies examining lessons learned from community organizations using health IT to serve the needs of underserved groups or to address health disparities. The final report from this project will inform the Secretary of the Department of Health and Human Services' (HHS) work under these topics per Section 3001 of the Health Information Technology for Economic and Clinical Health (HITECH) Act passed as part of the American Recovery and Reinvestment Act of 2009 (ARRA). Findings are based on analysis of notes taken during a series of discussions with clients, administrators, providers, researchers and youth health ambassadors.

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