



The Design of a Holistic mHealth Community Library Model and Its Impact on Empowering Rural America

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Abstract. Healthcare delivery in rural America poses additional challenges than its urban counterpart. Rural locations more commonly face shortage of physicians, a lack of high-paying jobs with adequate insurance benefits, transportation, health literacy, a stigma with health conditions due to lack of anonymity and difficulties accessing specialty care. Rural communities see higher rates of suicide, heart diseases, respiratory disease, stroke, social isolation, and public health crisis such as the opioid epidemic. More than 46 million Americans, or 15% of the population, live in rural areas within the United States.

Communities play an important role in the health of their residents, as social and economic factors, physical environment, and healthy behaviors make up 80% of an individual's overall health, while clinical care accounts for only 20%. Chronic disease doesn't occur in isolation. Conditions such as diabetes, asthma, heart disease, and obesity are all tied very closely to the environments, culture, and behaviors that surround individuals. Therefore, a significant amount of human health is determined beyond clinical care. For many individuals who are at an elevated risk of developing chronic disease, episodic care that begins and ends inside a hospital or clinic is not adequate to accurately treat the patient.

We propose a holistic mHealth community model for residents to overcome significant barriers of care in rural America by providing an application capable of integrating multiple health and safety data sources through a mobile digital personal health library application. Users are able to securely share their health data with others (e.g. primary care physician, caregiver). Artificial Intelligence (AI) algorithms can strategically connect residents to community resources and provide customized health education aimed at increasing the health literacy, empowerment, and self-management of the user. Communities can use de-identified population health data from this model to improve decision-making and allocation of community resources.

Keywords: Interoperability · Machine learning · Personal health library · Medical privacy and security

1 Introduction

Healthcare delivery in rural America poses additional challenges than its urban counterpart. Rural locations more commonly face shortage of physicians, a lack of high-paying jobs with adequate insurance benefits, transportation, health literacy, a stigma with health conditions due to lack of anonymity and difficulties accessing specialty care [1]. Rural communities see higher rates of suicide, heart diseases, respiratory disease, stroke, social isolation, and public health crisis, such as the opioid epidemic [2]. More than 46 million Americans, or 15% of the population, live in rural areas within the United States [3].

Communities play an important role in the health of their residents, as social and economic factors, physical environment, and healthy behaviors make up 80% of an individual's overall health, while clinical care accounts for only 20% [4]. Chronic disease doesn't occur in isolation. Conditions such as diabetes, asthma, heart disease, and obesity are all tied very closely to the environments, culture, and behaviors that surround individuals [5]. Therefore, as a significant amount of human health is determined beyond clinical care for many individuals who are at an elevated risk of developing chronic disease, episodic care that begins and ends inside a hospital or clinic is not adequate to accurately treat the patient. Advanced technologies aimed to significantly lower these barriers of care provide an opportunity for a substantial positive impact in rural healthcare.

Past work has investigated the association of patient empowerment with improved health [6], and the negative impact of powerlessness [7]. According to work conducted by Shulz and Nakamoto, they found patient empowerment to be desirable due to three variables stemming from traditional thought [8]. First, the increase of personal autonomy in patients regarding decisions made in their health. Second, there is a growing interest in patient empowerment with the view that citizens should participate and take responsibility for their health care in efforts to help control healthcare costs [9]. Third, patient empowerment is advocated as improving health outcomes [10]. The increase in patient empowerment is also linked to increasing one's health literacy, which carries the potential to not only positively affect the individual, but also the community. An example of a lack of health literacy can be seen in the refusal of parents to vaccinate their children against infectious diseases, leading to serious health consequences for not only the child but also the community. By improving the mechanisms in which users feel empowered in managing their health, while simultaneously providing enhanced health literacy knowledge and the communication within the environment in which they live, health outcomes can be improved for individuals and the community population as a whole.

We propose a holistic mHealth community library model to overcome significant barriers of care in rural America by proposing a solution capable of coordinating data for a user's physical health, behavioral health, social and economic factors information, healthy behaviors, and physical environment information. Our proposed model permits users to securely share their health data with others (e.g. primary care physician, caregiver). Communities can use de-identified population health data from this model to improve decision-making

and allocation of community resources. The model also serves as an open-source platform to develop tools for accurate assessment of individuals or populations in areas such as disease progression, risk stratification, care management, bio-surveillance, telemedicine, etc. Machine learning algorithms can be developed to accomplish many of these tasks, including to strategically connect residents to community resources and provide customized health education aimed at increasing the health literacy, empowerment, and self-management of the user.

2 Related Work

Over recent years, discussions having been prevalent regarding research and development of patient facing applications with the ability to exchange health information and improve the self-management an individual's health. This ecosystem has seen self-interest and participation from both commercial organizations and academic institutions.

Commercially, an importance has been placed on providing the patient with their own data and its impact to improve health outcomes, literacy, engagement and empowerment. The field continues to attract more developers to this space, including large and well-known commercial companies. Apple Health Records API for example, permits users to aggregate health data where the company has established partnerships with EHR vendors and health providers to allow patients to store their health records collectively [11].

Academically, there exists numerous papers describing the need and theoretical elements of such a model for patients to access their health data and descriptions of the value of incorporating patient generated health data (PGHD) within this system [12–14]. However, we could find no publications that present a holistic mHealth community library model, containing inclusive data surrounding the integration and mapping of health data from multiple sources, identity management provisions, privacy protections, and proposed scalability methods.

3 Background: Integrated Data Source Health Information Exchange and Security

Interoperability, security, and privacy has been widely recognized as an integral requirement for the success of healthcare information exchange. While linking data across various sources within a health system is a challenge, added complexity results when integrating data from multiple systems and devices. Creating an architecture capable of successful interoperability, security, and privacy delivers economic value and more importantly a form of patient safety, as the clinical value of information is enhanced when the best information is available for treating patients [15]. To help ensure a consistency and interoperability of health data, the United States' federal government has taken steps over the past decade to outline requirements and standards in third-party platforms which are critical in the development of proposed models such as ours.

3.1 Interoperability

The Health Information Technology for Economic and Clinical Health (HITECH) Act of 2009 presented incentives for providers to invest in EHRs with a defined minimal set of standards, known as Meaningful Use (MU), in which incentive payments would offset a substantial part of the cost of these systems. As a result, EHR adoption with MU standards exceeds 97% of the United States' hospitals and 74% in physician practices [16]. Stipulations from MU encouraged interoperability between systems along with patient access to their medical records. MU was developed in three stages. The first required patients seen by a provider within a reporting period to have access to an electronic clinical summary in a reasonable amount of time. The second stage required patients to have the ability to view, download, or transmit their health information to a third party. The third and current stage, requires patients to have the ability to connect third-party applications to their medical records through Application Programming Interface (API) technology. APIs are a tool for software applications to communicate with EHRs and other sources of health data [17]. The 21st Century Cures Act of 2016, extends interoperability further, as it “enables the secure exchange of electronic health information with, and use of electronic health information from, other health information technology without special effort on the part of the use” and provides an explicit API set of requirements for EHRs to obtain certification [18].

As a result of the 21st Century Cures Act, Health Level Seven (HL7) released the International Argonaut Project in 2017. The project included major EHR vendors who released industry-developed open APIs built on HL7's latest version called Fast Healthcare Interoperability Resources (FHIR). Shortly after, the U.S. Department of Veterans Administration, along with a consortium of providers and vendors, signed the Open API pledge to expand the set of data resources available to patients, physicians, and care teams through APIs standardized by the HL7 Argonaut Project.

The Office of the National Coordinator (ONC) for Health IT is responsible for EHR certification criteria, which includes requirements for APIs. The ONC's Common Clinical Data Set (CCDS) includes 21 data fields for clinical data, such as demographics, medication lists, lab results, and problem lists [19]. The CCDS does not currently include key data, such as provider notes, imaging, appointment information and cost or payment information.

3.2 Security

Data security and patient privacy requirements for health provider organizations is fairly well-known. While implementation may have more degrees of freedom, the specific laws and regulations, such as HIPAA, are more clear. However, when patients are able to obtain and store their own health information outside of the provider organization, security regulations and monitoring are not as clear. As an example, HIPAA's privacy rule does not include consumer applications, social media, fitness trackers.

With patient's authorized release of their digital health data from the EHRs of provider organizations to third-party applications, the provider organizations relinquish liability to secure, monitor, and audit that data. Many health applications struggle to have consistent security and privacy policies. And some have no policies regarding privacy of data. While this is problematic even in cases where the patient's data is an isolated subset of their health, such as a BlueTooth glucose monitoring application for a diabetic user, this problem gets much worse when patient health data from varying sources is integrated, with the aim of providing a longitudinal record of the patient. Therefore, it is critical, not only for security and privacy, but also for data accuracy, that a robust, secure, and scalable identity management solution is used to ensure security and privacy, monitoring, and auditing of user's data.

4 Model Design and Development

In this section we describe the proposed model, its architecture and its elements of health data exchange, interoperability, security and access. We then provide a discussion regarding the model's replication to other communities within the United States.

4.1 Proposed Methodology in Overcoming Barriers to Care in Rural Health

To help overcome barriers of care we link challenges in rural healthcare to one's health factors. This overlapping of health factors to the challenges of rural health care in Fig. 1, illustrate the importance of providing a platform which can holistically offer health and safety information to the patient and the community.

Data integration, including information regarding a user's health behaviors, physical environment, clinical care, PGHD, and social and economic factors, are key in holistically assessing the user and determining correct course of action. Figure 2 depicts the application's holistic approach to health and safety data integration.

Our model creates a personal health library (PHL) for each resident who downloads and registers with the application. A individual's PHL connects the user to their different data sources of care via secure APIs to retrieve information. For health factors which do not contain previously stored information, such as healthy behaviors and social determinants of health for example, the application requests this information using straight-forward questions. Users are provided the opportunity and are encouraged to update this information as needed.

Participating community health organizations, such as provider organizations, police and fire, food banks, shelters, and local public health departments, are able to keep residents updated on available education and resources, such as free screenings for breast cancer and dental, fire safety and workshops regarding healthy eating on a budget. Participating health and safety organizations are able to review HIPAA compliant de-identified data within this model to better

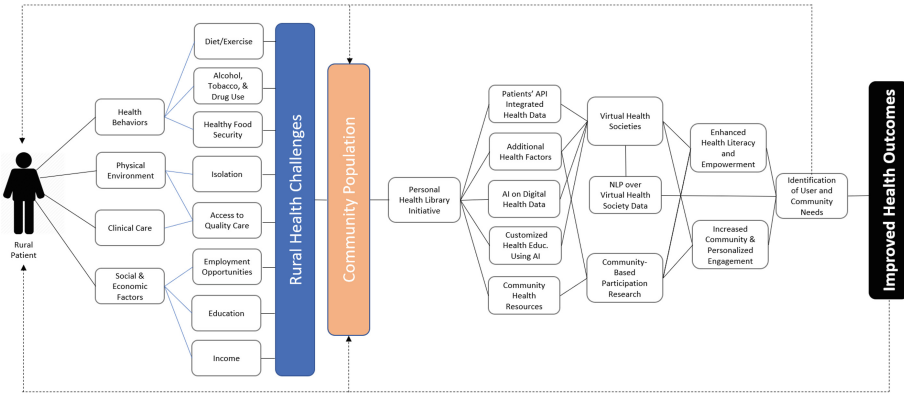


Fig. 1. Rural health challenges and Roadmap to solve these challenges through mHealth community library model

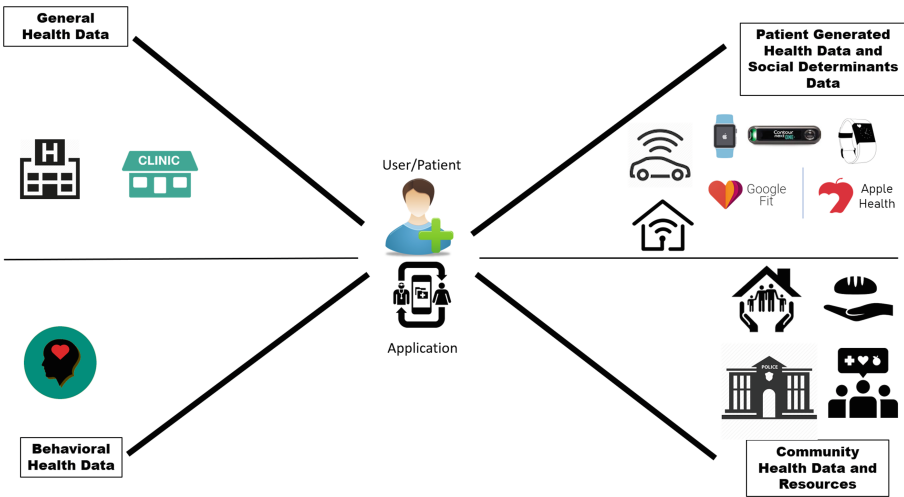


Fig. 2. Coordination of health and safety information for community residents

understand the community population, helping to better utilize their resources and meet the needs of its residents.

AI techniques, such as machine learning, can be used on the collected data to provide insightful information. We have begun developing customized health education algorithms that utilize the National Library of Medicine’s MedlinePlus API [20] to provide customized health and safety education reflective of each user’s collected data.

4.2 Data Coordination and Interoperability

The open-source mHealth community-centered library application consists of an interoperable backend database server structure to ensure the organization and security of user’s health data, and a front-end application server, available as a mobile application and web interface for users to access, share, analyze, and select which data sources they wish to include within their PHL. Figure 3 depicts an example community architecture.

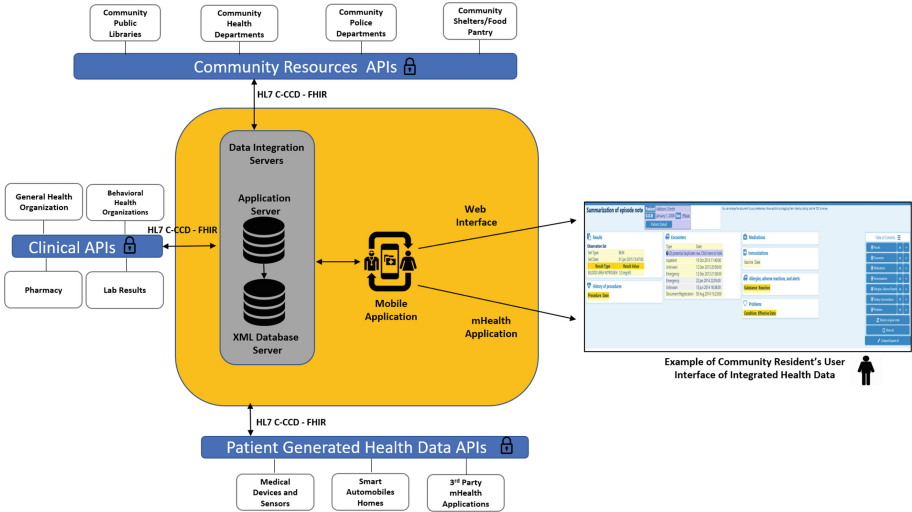


Fig. 3. mHealth community library architecture example

Interoperability exists through within the open-source eXist backend extensible markup language (XML) database mapping mechanism we have developed. Health and safety information received from the APIs or directly from the application’s user front-end (e.g. social determinants of health) are placed into the individual’s secure table where XML transform algorithms are able to tag each document header to establish accurate mapping of data and ensuring interoperability. Data stemming from the clinical APIs are in the form of Continuity of Care Document(CCD), as most EHRs are required to produce a CCD. An example CCD in raw form can be seen in Fig. 4.

FHIR has emerged as the standard mHealth applications and EHRs are now working to be in compliance with this standard. Scripts were created within the eXist database to map CCD data into the new FHIR standard using guidelines provided by the ONC’s CCDS, allowing user’s to see an organized, readable, and user-friendly interfaces of their data and providing them the capability to gain much more insight through the development of software tools to accomplish such tasks as customized education, drug to drug alerts, medication adherence reminders, and local community resources available to them.

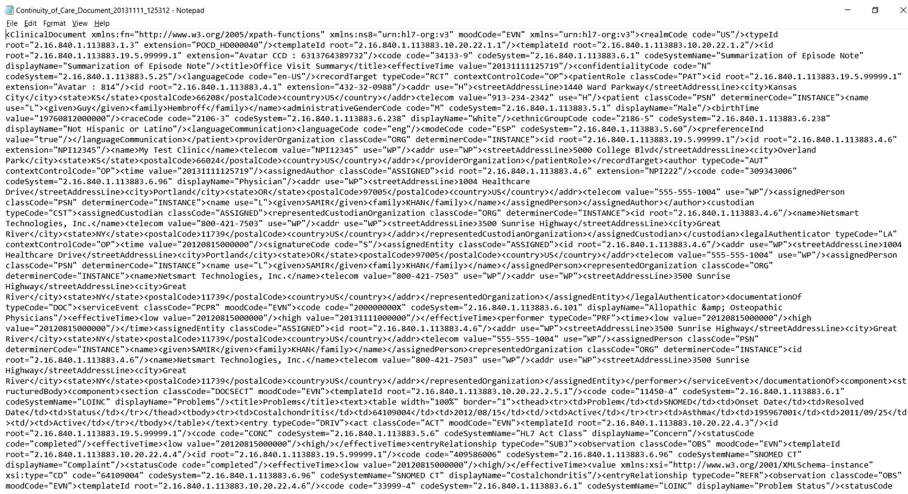


Fig. 4. Example continuity of care document in Raw format

4.3 Security and Privacy

Security and privacy elements have been implemented to protect the confidentiality and integrity of user's data. While authorization and access to the application can be achieved using standard username and strong passwords, there is an option to use biometrics as part of the identify management within the application. The lead author of this paper has developed a biometric solution called Unique Medical Biometric Recognition of Legitimate and Large-scale Authentication (U.M.B.R.E.L.L.A.), which developed an algorithm over touchless fingerprints to produce and secure a unique health identifier (UHID) for each individual [21]. Facial recognition is then used as the second factor of identification. As a result, usernames and passwords are not required but can still be used if needed. Figure 5 demonstrates using UMRELLA's biometric solution within the application for identity management. The UHID for an individual has the potential to be cross-matched to the internal master patient identifier (MPI) of a healthcare organization, enhancing the accuracy of identifying the correct patient's data, while also increasing the efficiency of exchanging data. It can be used on most devices (e.g. smart phones, tablets, PCs, laptops) with cameras as it is hardware agnostic.

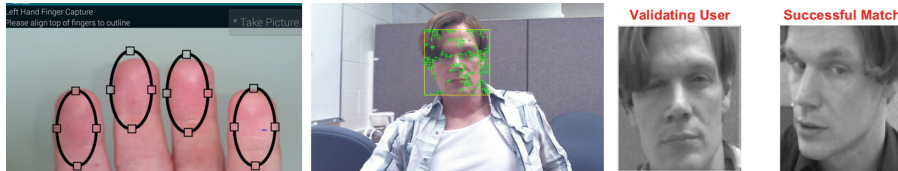


Fig. 5. UMRELLA's biometric identification solution

User information, its privacy, and integrity are managed through attribute-based access control (ABAC), which consists of an authorization policy engine and a RESTful authorization server. The Java API provides an extensible control markup language (XACML) policy decision point (PDP) engine, while the Web API uses an HTTP/REST API and PDP and policy administration points (PAPs) to manage policies and request authorization decisions. Throughout this architecture, access and control is enforced to establish strong user authorization and authentication techniques to achieve security and privacy of user data. To accomplish this, we incorporate elements of open-source AuthZForce into our solution [22].

5 Experimental Setup

To test the model, we established a front-end interface and used the architecture design illustrated in Fig. 3 to assess the application’s functionality. We used a variety of servers and virtual machines to simulate both physical and cloud attributes and their respective API connections to the data sources. A view of the application’s front-end graphical user interface can be seen in Fig. 6. Bluetooth blood pressure cuffs and smartwatches were used, along with a mhealth mood tracker smartphone application to simulate patient generated health data. Test CCD documents were added to simulate the clinical environment. Users testing the system completed social and economic determinants of health, environmental factors, and health behavior questions upon downloading and logging into the application for the first time. A total of 50 participants were asked to test the system and complete a user satisfaction survey after ten hours of use.

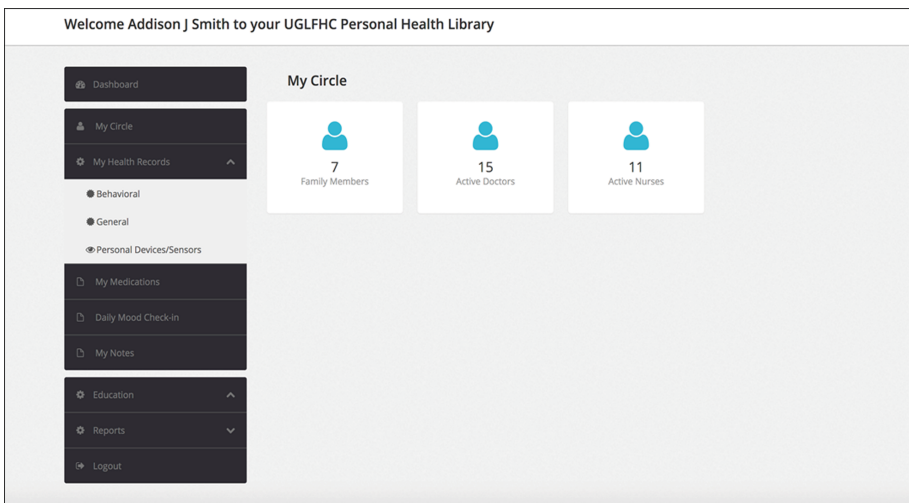


Fig. 6. Application Front-End displaying User’s Secure sharing of Health information they wish to share in the MyCircle feature

The population of users testing the system were between the ages of 19 years and 72 years. Ten were primary care physicians, ten were population health quality improvement (QI) personnel, and thirty were students associated with the university where the study was being conducted and used to simulate patients. All participants evaluated the model's application from a *patient's perspective*. Additionally, primary care physicians and population health QI personnel provided feedback regarding their respective roles in the clinical field.

6 Results and Discussion

To determine users' satisfaction with various aspects of this model's application, we asked all 50 respondents, in the role of patients, to indicate their level of agreement or disagreement with each of the following 10 general functionality statements, using the scale Strongly Agree, Agree, Neutral, Disagree, and Strongly Disagree. Below are the patient survey statements used:

1. The mHealth Library Community Model application is easy and intuitive to use.
2. I felt comfortable with choosing from the list of available API connections to link the test application's health data.
3. The method of obtaining a patient's social and economic factors, physical environment, and healthy behaviors data was reasonable.
4. I would feel comfortable with my own health data on this platform.
5. I like having a choice of using biometrics and not having to use usernames and passwords.
6. I feel my data is more secure using biometric authentication and authorization.
7. I would use the share data functionality to share my health data with my primary care physician.
8. I can better track and manage my own health through this application.
9. By using this application, I feel more engaged in community health.
10. I feel more empowered in addressing my health using this application.

Results from the survey are summarized in Table 1. Overall, the user satisfaction results from the users were positive. In terms of using the application to manage health, it is interesting to note that 72% *Strongly Agreed* in feeling more empowered about addressing one's own health. While 62% *Strongly Agreed* they would be able to better track their health with the functionality of this application. A total of 76% either *strongly agreed* or *Agreed* on the application's use of increasing community engagement. In terms of security, a combined 58% of *Strongly Agreed* and *Agreed* to a comfort level of placing their own health data on the application. When evaluating whether the user felt more secure using the biometric option, 88% of users *Strongly Agreed*.

Primary care physicians were asked to complete an additional physician users' satisfaction survey, using the scale Strongly Agree, Agree, Neutral, Disagree, and Strongly Disagree. Below are the physician survey statements used:

1. As a physician, the application is intuitive in letting me see my patients' data.
2. I trust data from other sources.
3. Having data from other health factors, beyond clinical care, is important to holistically diagnose and treat the patient.
4. Patients using this application will be better aware of community health and safety resources available to them.
5. This application will help patients better self-manage their health.

Results from the survey are summarized in Table 2. Primary care physician user satisfaction was overall positive. In the category of using other health factor data (i.e. environmental, social and economic, and healthy behaviors), 80% of physicians *Strongly Agreed*. This reinforces the problematic nature of only using clinical care data to diagnose and treat patients. Reflecting on this application's ability for patients to better self-manage their health, 70% *Strongly Agreed* while 20% *Agreed*. An area of concern is the overall trust of data from other sources. 40% of responses were either *Disagree* or *Strongly Disagree*, signaling there is still much work to be done in this domain to provide physicians confidence in using data from other sources.

Table 1. Patient satisfaction survey results by percentages.

Patients' Survey Statements Abbreviated	Strongly Agree % $N = 50$	Agree % $N = 50$	Neutral % $N = 50$	Disagree % $N = 50$	Strongly Disagree % $N = 50$
1. Easy and intuitive	28%	44%	26%	2%	
2. Comfort level connecting data	36%	28%	22%	10%	4%
3. Reasonable time to obtain additional health factors	32%	38%	26%	4%	
4. Comfort level with placing own health data on system	22%	36%	38%	2%	2%
5. Like choice of biometric security	68%	18%	12%		2%
6. Feel biometric option is more secure	88%	8%	4%	2%	
7. Use share option	54%	32%	8%	2%	4%
8. Better track own health	62%	24%	8%	6%	
9. Increased engagement in community health	34%	42%	16%	6%	2%
10. More empowered in addressing my health	72%	24%	2%		2%

Table 2. Physician satisfaction survey results by percentages.

Physicians' Survey Statements Abbreviated	Strongly Agree % N = 10	Agree % N = 10	Neutral % N = 10	Disagree % N = 10	Strongly Disagree % N = 10
1. Application is intuitive	10	70%	10%	10%	
2. Trust data from other sources	20%	30%	10%	20%	20%
3. Patient data beyond clinical care is important	80%	10%		10%	
4. Improved patient awareness of community health and safety resources	30%	40%	20%		10%
5. Improve patient self-management of health	70%	20%	10%		

Finally, we asked population health QI personnel to complete an additional user satisfaction survey pertaining to the model's evaluation in population health, using the scale Strongly Agree, Agree, Neutral, Disagree, and Strongly Disagree. Below are the population health QI personnel survey statements used:

1. Data from this application provides strong potential to improve community population health monitoring.
2. I would trust data from this application in population health assessment.
3. Data from this application will provide an enhanced mechanism in planning and distributing community health and safety resources.
4. This application's data will improve defining strategic public health initiatives in our community.
5. This application can provide improved methods of communication for public health emergencies.

Survey results reflect a an optimistic outlook on use of the model to improve community population health. QI personnel, like physicians, responded with similar concerns regarding the trust of data from other sources for population health assessment with 20% who *Disagree* and 10% who *Strongly Disagree*. Users reported 70% in the category of *Strongly Agree* the model's use of improving community health and safety initiatives, and 40% of *Strongly Agree* in improving the communication of public health emergencies to citizens (Table 3).

Table 3. Population Health QI Personnel satisfaction survey results by percentages.

Population Health QIs' Survey Statements Abbreviated	Strongly Agree % <i>N</i> = 10	Agree % <i>N</i> = 10	Neutral % <i>N</i> = 10	Disagree % <i>N</i> = 10	Strongly Disagree % <i>N</i> = 10
1. Improved view of community population health	30%	20%	30%	20%	
2. Trust data for population health assessment	20%	40%	10%	20%	10%
3. Enhanced mechanism for community health and safety	40%	30%	20%	10%	
4. Improve community health and safety initiatives	70%	20%	10%		
5. Improve methods of communicating public health emergencies	40%	30%	20%	10%	

7 Conclusion

In this work we presented the design and testing of a mHealth community library model to assist in overcoming barriers to care in rural America and to empower residents and their community to better manage their health and safety. Innovative methods of data retrieval, interoperability, security and privacy were discussed. Development of the model was done using open-source software, helping this model to be replicated in other communities. Patients, primary care providers, and population health QI personnel reported overall positive experiences using the model's application. Specifically, a high percentage of patients felt empowered to track and manage their health, while also increasing their community engagement. A large percentage of physicians surveyed felt health factor information, beyond clinical care, was important to treating and diagnosing patients and that patients would overall benefit in the self-management of their health. Clinical personnel associated with population health QI were favorable to the application's potential to improve communication of health emergencies and community health and safety initiatives. The highest concern from the survey results was trust of outside data sources.

8 Future Work

Due to the responses regarding trust of health data resulting from other sources, one initiative of future work is to investigate methods which can be used to validate data to the users of the system. Since there remains a significant percentage of the population of both rural and urban environments that do not

have access to technology, such as smartphones, computers, or Internet access, this model and its application does not directly help them. As almost 96% of America's population has close proximity to public libraries, which are typically equipped with technology to access a mHealth application such as ours. We feel there is a tremendous opportunity to provide an access point to those who do not have this technology through the public library medium. Our future work, includes working with the National Library of Medicine and public libraries to create an initiative to provide this service to communities across the nation.

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