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_____ _____

Shahidah Q. Mallay Date

Use of Mobile Health Technology to Inform on End-of-Life (EOL) Public Health Intervention

By

Shahidah Q. Mallay

Master of Public Health

Applied Public Health Informatics

Laura M. Gaydos, Ph.D. Date

Committee Chair

Frank Manja, PMP, FAC-COR Date

Committee Member

Melissa Alperin, EdD, MPH, MCHES Date

Chair of Academic Affairs, Executive MPH Program

Use of Mobile Health Technology to Inform on End-of-Life (EOL) Public Health Intervention

By

Shahidah Q. Mallay

B.S., Clayton State University, 2013

Thesis Committee Chair: Laura M. Gaydos, Ph.D.

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Abstract

Use of Mobile Health Technology to Inform on End-of-Life (EOL) Public Health Intervention

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Shahidah Q. Mallay

Introduction: Currently, the U.S. population is using mobile health applications to capture real-time health data on things like chronic diseases, nutrition, and fitness. However, there is uncertainty about the current rate of usage on apps for end-of-life (EOL) care.

Many Americans are adapting to EOL planning due to an increase in life expectancy by some 30 years. In such a technologically advanced age, there is, therefore, great potential for use of EOL apps. Use of this technology can contribute largely to gathering EOL data aimed at informing on specific public health interventions such as: improved communication between health care providers, patients, and family members about EOL. Using EOL application to gather such data requires data sharing between the app and components of the Electronic Health Record (EHR) system. Data sharing between these systems necessitates interoperability standards and compatibility, while adhering to the privacy and security standards set by the U.S. healthcare system.

Background: While there are existing challenges with privacy, security and integrative use of EOL mHealth applications, there is great potential to improve interventions for EOL care planning that will make a difference for millions of Americans. This project, therefore, demonstrates how a new mHealth app (LifeSynergy) could potentially improve data sharing of EOL documents across time, settings and healthcare providers, and how data from this app can be used to inform on EOL public health interventions.

Objective: This project-based thesis develops a prototype for the "LifeSynergy" app, which has potential to improve electronic access to EOL documents, and facilitate sharing of EOL preferences and health information between patients, family members and providers. The project was achieved by collecting data from multiple sources including key stakeholder interviews, literature review, EOL apps analysis, and the design of two detailed interoperability process flow diagrams.

Conclusion: The creation of the LifeSynergy prototype provides visual insight to how this app will function to collect EOL data, and integrate with EHR (Patient Portal) systems. Once implemented, LifeSynergy will have the potential to garner key clinical, policy and public health implications that affords great benefit to public health. Healthcare providers having immediate access to EOL documents is key to improving patient-centered care, as this will help them understand precisely the type of treatment their patients desire, and also remove the burden from family members having to make these critical and often very difficult life decisions.

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Chapter 1

Introduction

Today in the U.S., mobile health technologies are becoming widely used among the varying age groups. Although the aging population may not be early adaptors to this technology, the gap is gradually shrinking due to their increased use and ownership of smartphones and other mobile devices. Mobile health technology has the potential to capture a large pool of population-based health data, on and from people across the age continuum. Currently, the U.S. population is using mobile health applications (apps) to capture real-time health data on things like chronic diseases, nutrition, and fitness. However, there is limited information about the current rate of usage on apps for end-of-life (EOL) care. One reason for this uncertainty may be the limited availability of EOL apps in the technology market.

Many Americans are adapting to EOL planning due to an increase in life expectancy by some 30 years. In such a technologically advanced age, there is therefore great potential for use of EOL apps. Use of this technology can contribute largely to gathering EOL data aimed at informing on specific public health interventions such as; improved communication between health care providers, patients, and family members about EOL. Using EOL application to gather such data requires data sharing between the app and components of the EHR system. Data sharing between these systems necessitates interoperability standards and compatibility, while adhering to the privacy and security standards set by the U.S. healthcare system.

What is Mobile Health?

Mobile health or mHealth is the term used to describe the delivery of clinical, medical and public health interventions, and health messages by use of multiple wireless devices like mobile phones, tablets, patient monitoring devices, and personal digital assistants [1, 2]. The usage of these devices allows for real-time monitoring of chronic diseases, asynchronous exchange of short messages as a method for following up on medication, reporting and exchanging of data, capacity building and educational interventions [2]. In addition, mobile health apps are user-centered and serve as a method for self-managing of chronic diseases, monitoring vital signs, counting calories, logging nutritional and fitness workout data, as well as a variety of other health related concerns [3,4]. Mobile health apps also allow patients to further engage in the advancement of their health care by accessing personal health data. Overall, the capability of mHealth devices and apps are designed to improved health researches, health outcomes, and health care services [5], which may inevitably be of substantial benefit to the patient and the public. mHealth apps may also help with achieving the HealthyPeople 2020 goal for Health Communication and Health Information Technology [6] because of its potential to improve the way health information is viewed [used] in health care, public health and by the overall American population.

In recent years, the use of mHealth technology has grown exponentially [4]. This uptake in usage is seen as having direct connection to the proliferation of mobile phones and other mobile device ownerships. According to a Pew Research Center survey, conducted in January 2017, 95% of adult Americans own some type of a cellphone, with 77% of those being owners of a smartphone. The increase in smartphone ownership has more than doubled the 35% reported in the 2011 Pew survey [7]. The demographic spectrum of smartphone owners, within the adult

U.S. population, shows difference between gender and race, but the vast difference is evident within the age groups. Ninety-two percent of the millennial population (ages 18-29) owns a smartphone, compared to 42% of the aging population (ages 65+). There is also great variation, in current smartphone ownership, from both the economic and educational perspective. Only 64% of those earning less than $30,000 own smartphones, compared to 93% who currently earn over $75,000. Respectively, 54% of current adult Americans whose education level is less than high school own a smartphone, compared to 89% that are college graduates [7].

The rapid growth and adoption in the use of mobile devices and mobile health technology shows potential for the advancement of patient-centered care, and the increased ways patients are accessing their health information [8]. About 92% of the current U.S. adult population has considered accessing their personal health information online, which indicates the growing interests for using patient-facing health IT tools like personal health records, patient portals, and mobile health apps [8, 9]. This shows great potential for the American population to be more engaged with the self-management of their health [9]. Further, mHealth has the potential to capture a large pool of population-based surveillance data that can contribute to informing on public health interventions for the improvement of population health outcomes and health care quality [6].

mHealth for End-of-Life (EOL) Care

One specific area in which mHealth applications have not been widely applied, but have great potential is in EOL care. EOL care is a means of providing support, comfort and care to patients who are in their last months or years of life. In many instances, palliative and hospice are service options available to dying patients in hopes of improving their last days and supporting family.

Palliative care services focus on providing treatment for seriously ill patients, and can start at any stage of the illness. The goal of providing palliative care is to improve the patient's quality of life and to help them and their loved ones understand the choices of medical care available [10]. Hospice, however, is a service offered to patients with terminal illness and is specifically designed to reduce pain and bring comfort to the patient and family during the last days or months of the patient's life. This service brings together a multifaceted skilled team of individuals like doctors, nurses, spiritual advisors, and social workers that each provides treatment and significant medical care at the patient's home or in a facility such as nursing home [10].

EOL care ensures the treatment patients receive is individualized and specifically tailored to meet their needs, while relieving unnecessary suffering, and having improved quality of life and health outcomes [11]. To ensure the care and wishes people prefer at the end of their life are honored, a comprehensive care plan or advanced care plan should be considered [11, 12]. Advanced care planning has become a necessary means to ensure these wishes are known. In many instances, this type of plan integrates the health, cultural, spiritual and social wishes which may provide better understanding of decisions that may be challenging for the family and caregivers to make, if the patient is unable to speak or make such decisions for his/herself [12, 13].

Today, there are a variety of options and types of documents available to the U.S. population for recording their EOL or medical wishes. Some of the common documents, called advanced directives, include Living Will, Medical Power of Attorney, Do Not Intubate (DNI), Do Not Resuscitate (DNR), Physician Order for Life-Sustaining Treatment (POLST) and Healthcare proxy [14]. According to Institute of Medicine (IOM), the most effective benefit of having an

advanced directive is to incorporate the wishes detailed in the document into the advanced care planning of patients during their EOL care [15].

The Impact of Advanced Care Plan on Patients, Health, Health Care and Public Health

The need for improved quality of life for patients has a direct connection to the unprecedented gain in life expectancy of the U.S. population. Life expectancy in the United States has increased by some 30 years during the last century; this is according to a Healthy Aging article published by the CDC [16]. Today, with the contributions of medical and public health advancements, the average person in the United States will live to about 80 years old [17]. However, many seniors face a mix of chronic and acute illnesses that may require special consideration for both treatment and EOL care. As such, new approaches in dealing with death and dying are needed to ensure the wishes of terminally ill persons are honored [16].

The growing number of Americans that are living longer has created substantial burden on population healthcare spending for both Medicare (senior health services) and Medicaid (long-term care) [15]. Spending on patients with chronic conditions, accounts for approximately 84% of U.S. health care cost [15]. In addition, the role family members play as caregivers may be difficult to sustain because many are unable to leave their jobs. This creates a decline in family caregiving capacity and would potentially increase the need for care through Medicare and Medicaid funding [15]. Advanced care planning has the potential of reducing this burden of healthcare costs for terminally ill patients, by aligning care treatment with patient preferences. This is a key component to lowering cost for healthcare unit utilization.

In the past, they were several publicized cases of terminally ill people being kept alive by artificial means while their families debate over the type of care treatment best suited for the patient [16]. Today, use of advanced care planning has the potential to reduce many uncertainties around the wishes of patients. Many people record their medical wishes with the intention of having it presented to their healthcare provider, loved ones or healthcare agent. It is important to note that a proactive approach can be taken to start the advanced care planning process, which can begin at any age or state of an individual's health [13].

Disparities in End-of-Life Care Planning

Although a large percentage of Americans (71%) believe enhancing the quality of life of seriously ill patients is of most importance (which may mean a shorter life), 23 percent believe it is most important to explore every possible medical intervention in order to extend the life of seriously ill patients [16]. The disparities of age, race, culture, religion and socioeconomic standing within the U.S. population has created a divide among people that have EOL care plan(s) and those that don't, even in cases where there is equal access to healthcare [13].

According to the IOM, conversation surrounding EOL wishes should occur frequently with family members and caregivers, and copies of these plan wishes and other relevant materials should be stored electronically to ensure improved access and effectiveness of care [13]. In addition, further public health interventions and awareness building; like educating healthcare professionals and community outreach, are needed to understand and reduce the gap of these disparities, and to create sustainable health outcomes for EOL care patients [13].

Given the importance of reducing the disparity gap between people with EOL care and those without, it is extremely important for there to be concurrent technical consideration along with

increased awareness of EOL planning. Implementation of any electronic source to store, share or access EOL documents requires technological input that is directly impacted by privacy, security and interoperability among systems.

Technical Considerations for EOL Technology

Interoperability

Interoperability describes the ability for systems to communicate with each other, exchange data and interpret the shared data [18]. HIMSS describes interoperability in healthcare as the ability for different health information systems and software applications to share data within or across organizational boundaries to enhance and advance the delivery of healthcare for individuals and communities [18]. Further, an interoperable system reduces waste of material, cost, time (delays and repetition) and errors.

Non-interoperable health information systems continue to be an on-going challenge for sharing electronically stored health data [18]. As public awareness and education for advanced care planning increases, there will also be a need for increase capacity on data sharing. For some patients with advanced directive plans, these documents tend to be stored in the electronic health record (EHR) system of a specific healthcare provider, and remains to be separate (or unknown) from other healthcare specialist overseeing their care. While there is rapid growth in the use of mobile health applications and there is increased availability of EOL mobile apps, it is essential for this data to be integrated into the EHR system.

Data sharing between health information systems requires a set of standards and expectations to allow interoperability to occur [18]. Moreover, the variation in system software, hardware, coding, terminology, and differences in data interpretation, creates potential barriers for

achieving health data interoperability [19]. To combat these problems a framework of international standards, guidelines and methodologies, called Health Level Seven or HL7, were developed to facilitate how electronic health data is exchanged, integrated, shared and retrieved among various health care systems [20].

In recent years, the HL7 organization developed a much-improved API (Application Programming Interface) for interoperability standard called Fast Healthcare Interoperable Resource or FHIR [20]. FHIR (pronounced "Fire") was designed for the web and focuses on specification through a defined set of "Resources" that provides distinct fields and data types to facilitate the integration, security and authentication capabilities between EHR, mHealth applications and cloud based communication [21]. In addition, FHIR provides RESTful web services, which allows it to perform CRUD (Create, Read, Update, Delete) functionalities [21

In addition to the recent milestones in electronic standard advancement, mHealth application now has the capability of using platform specifications to run third-party applications on EHR systems. This technology platform called Substitutable Medical Apps and Reusable Technologies (SMART), allows app developers to create mHealth apps that can securely run (plug-and-play) across varied healthcare IT system [22]. The SMART standard allows mHealth app users the ability to choose and replace a variety of health related apps that may improve their health [22].

Sharing EOL mobile health data within and across organizations requires highly interoperable standards and infrastructure compatibility. Further, integrating EOL mobile data with the EHR patient portal will require SMART, which uses the combination of HL7 FHIR standards [18]. HL7 uses medical interoperability standards to maintain the FHIR infrastructure. SMART is integrated with FHIR to create a dynamic way to extend EHR capabilities via "pluggable" app

functionality [23]. Further SMART on FHIR is an open-source API that is free for public use [24], however data transmitted in this format has to be secure as it contains Personal Health Records (PHR). The 2017 Interoperability Standards Advisory released by the Department of Health and Human Services' Office of the National Coordinator for Health Information Technology (ONC) includes essential standards and implementation specifications for health IT vendors and clinicians to use as a roadmap in accomplishing SMART on FHIR and other interoperability goals [23]. ONC is a huge proponent of SMART on FHIR interoperability specifications, and supports having aggregated health data from different sources, stored in one secure application [23].

Privacy and Security for Mobile Health Technologies

Across to the U.S. healthcare system, privacy and security of health information is extremely important. With the exponential increase and use of mobile health technology there was a need for privacy and security standards to be developed for this new form of health communication. In March 2012, the Department of Health & Human Services (HHS) conducted a Mobile Device Roundtable to formulate HIPAA Privacy Rule that will protect privacy and security of health data transmitted on mobile devices [25].

The HIPAA Security Rule established a national set of security standards for the confidentiality, integrity, and availability of electronic protected health information (e-PHI) [25]. In general, the security standards require all covered entities "to maintain reasonable and appropriate administrative, technical, and physical safeguards for protecting e-PHI" [25]. This allows protection for all e-PHI created, received, maintained or transmitted [25]. Further, covered entities must ensure all e-PHI are identified and protected against anticipated threats to data

security, data integrity, and impermissible uses or disclosures [25]. Workforce compliance is also an integral requirement to enforcing e-PHI security standards [25].

Mobile health applications and other technologies should adhere to the privacy and security of HIPAA regulations to ensure data is protected against potential breeches. In addition to the established HIPAA Security Rules for electronic protected health information, further steps like secure logins, encrypting data at rest, and encrypting data in transit should be used to protect Personal Health Information stored on mobile devices. Further, incorporating HIPAA Security Rule Mapping provides an additional level of security through use of a defined set of formal control family designations. Some such designations are; Access Control, Awareness and Training, Audit and Accountability, Security Assessment and Authorization, Configuration Management, Contingency Planning, Identification and Authentication, Incident Response, Maintenance, Media Protection, Planning, Personnel Security, Risk Assessment, System and Service Acquisition, System and Security Protection, and System and Information Integrity [26].

An alternative form of storage and security for PHI data could be the cloud environment. The cloud environment is a computing model used to storage large amounts of data, and by use of efficient authentication to protect the privacy of PHI data; security breaches could be significantly reduced.

Conclusion

While there are existing challenges with privacy, security and integrative use of EOL mHealth applications, there is great potential to improve interventions for EOL care planning that will make a difference for millions of Americans. This project therefore proposes to demonstrate how mHealth application would be most applicable to improve access to EOL documents across time,

settings and healthcare providers, and how this data can be used to inform on EOL public health interventions.

Problem Statement

Inadequate access to EOL documents has contributed to individuals not receiving the level of care they desire, which consequently affects the quality and cost of healthcare.

Purpose Statement

This project-based thesis will develop a prototype for improving electronic access to EOL document, which will potentially help health outcomes through informed public health interventions.

Specific Aims

Aim 1: Identify and describe the challenges of delivering person-centered health outcomes for patients in EOL care

Aim 2: Describe the impact and benefits mobile health technology has in expanding access to care and improving healthcare through public health interventions

Aim 3: Identify and analyze the general features of existing EOL mobile applications and whether or not a new application, that can aide in collecting population-based data, needs to be developed.

Aim 4: Develop a process flow to demonstrate how SMART on FHIR is used to securely share data between a mHealth app and components of the EHR system

Aim 5: Develop a prototype of a new EOL mHealth app that has the functionality to integrate with EHR systems

Definition of Terms:

Terms	Definitions
End-user or User	This person will actually be using the EOL app. This may be the patient, a proxy or another authorized person.
App	Within this paper, the term is interchangeably used with the word application. This refers to an application that a user downloads to a mobile device.
Living Will	This is a document or statement that details a person's wishes regarding life-sustaining treatment in circumstances where they are no longer able to express informed consent.
Medical Power of Attorney	This person will make medical decisions for you in an emergency. This person can make decisions not covered in most end-of-life documents.
Do Not Resuscitate (DNR)	This indicates that a person [terminally ill or with serious medical conditions] wishes not to have cardiopulmonary resuscitation (CPR) attempted in the event their heart or breathing stops. This indication is typically stated in most end-of-life documents.
Do Not Intubate (DNI)	This indicates that a person [terminally ill or with serious medical conditions] wishes not to have breathing tubes placed in the event their heart or breathing stops. However, chest compressions and cardiac drugs may be used.

Terms	Definitions
Physician Order for Life-Sustaining Treatment (POLST)	This document includes specific medical orders to be honored by health care workers during a medical crisis. The objective of this document is to improve end-of-life care in the U.S.
Healthcare Proxy	This person will make medical decisions for you in an emergency. This person can make decisions not covered in most end-of-life documents.
Protected Health Information (PHI)	Protected Health Information is also called Personal Health Information. This type of information refers to patients' demographic information, medical history records, test and laboratory results, insurance information and other data collected by a healthcare professional.
HIPAA	HIPAA (Health Insurance Portability and Accountability Act of 1996) is legislation mandated by the Unites States to provide data privacy and security provisions for safeguarding medical information.
Meaningful Use	Meaningful use is using certified electronic health record (EHR) technology to meet set objectives that eligible professionals (EPs) and hospitals must achieve to qualify for Centers for Medicare and Medicaid Services (CMS) incentive Programs.

Chapter 2: Methodology

Introduction

We collected and analyzed data to determine whether there is a need for improved access to patient EOL information and whether or not a mobile health application will facilitate EOL interventions. The study was reviewed and approved by Emory's University Institutional Review Board and the determination was made that it does not require IRB review because it does not meet the definition of human subjects' research as set forth in Emory's policies and procedures federal rules.

Interviews to Determine Current Usage of End-of-Life Mobile Apps in Healthcare Facilities

To meet the federal standards for meaningful use of health information technology, many hospitals and healthcare systems have begun optimizing the use of technology and health data to provide cost-efficient, patient-centered care to their patient population [28]. Over the years, the Hospital & Health Networks (H&HN), in collaboration with the American Hospital Association (AHA), has completed and published results from annual surveys that display technology and health data. This data was compiled in the form of a "Most Wired List," for U.S. hospitals and health systems that are advancing in their efforts to utilize information technology to connect with patients [28].

To determine the current usage and capacity of EOL mHealth apps in healthcare facilities, we decided it was important to conduct interviews with a sample of hospitals in the Metro Atlanta area that were measured at a high level for IT adoption. We selected the convenience sample of

hospitals from the H&HN 2015 *HealthCare's Most Wired List*. We reviewed each hospital's website and selected providers from the Palliative Medicine, Emergency Medicine and Chaplin Service departments. By way of phone calls or emails, we contacted six providers and requested the opportunity to conduct interviews to help us determine the current usage of EOL mobile apps in their respective healthcare entity. We were subsequently able to schedule and conduct individual phone and in-person interviews.

As a primary data collection method, one member of the project team conducted separate phone interviews with each of the six representatives from the healthcare entities. At the beginning of the interview, we informed the interviewees that their participation was confidential, and their identity and that of their respective healthcare entity will not be disclosed in the research paper. In addition, we informed the interviewees that we would use the information gathered during the interview process to form a consensus on the current use of EOL apps among healthcare entities.

We outlined this scope statement (To gather data from healthcare entities to determine if they currently use EOL apps) and used it as a guide, to ensure the interview questions capture specific data related to the current usage of EOL mobile apps in healthcare facilities. Seven overarching questions were developed, two of which had sub-questions to aid us in gathering further data to fulfill the scope statement. The questions followed a progressive pattern to understanding each entity's current method of receiving EOL documents, the effectiveness of that method, and the interviewees' thoughts on both the entity and patients utilizing mobile apps to transmit EOL documents efficiently.

Systematic Review to Develop Mobile App Rating Scale on Existing End-of-Life Apps

The methodology used for identifying study data for this section was replicated from the 2015 PubMed literature review study *"Mobile App Rating Scale: A New Tool for Assessing the Quality of Health Mobile Apps"* [27]. Between March and April 2017, we conducted a systematic search, in the Apple iTunes and Google Play stores, in an effort to gather data to determine what EOL applications currently exist on iOS and Android smartphones and to evaluate their features. We created a thorough list of EOL related mobile apps by utilizing the following search terms: "Advanced Directive" OR "Advanced Care" OR "End of Life" OR "Living Will" OR "POLST" OR "DNR" OR "Dying Wish" OR "Final Wishes" OR "Power of Attorney" OR "Palliative" OR "Hospice." We selected specific app inclusion criteria based on an extensive review of the description and information included within the apps. The inclusion criteria were: (1) category – for this criterion, we included apps that were categorized as Medical, Health and Fitness, and Lifestyle, and excluded apps categorized as finance, business or gaming; (2) types of documents included within the app – for this criterion we included apps that had one or multiple EOL documents available within the app. We excluded apps that did not include any EOL document(s); (3) cost – for this criterion, we included apps that had no cost associated with downloading or use of the actual app. We excluded apps that had a cost associated with it ; (4) language – for this criterion, we only included apps that had its text displayed in English. We excluded apps with text displayed in any other language; (5) customer review – this criterion had minimal impact on the selection process. We excluded apps that customers stated had "in-app" costs associated with it. All other apps were included.

Of the twenty apps reviewed, we selected nine by only considering the inclusion criteria "cost" and "language", and removing all duplicate apps. We evaluated the cost criterion and only selected free apps. We then evaluated the language criterion and removed all non-English apps. We trailed the apps for a minimum of 20 minutes each, and then independently reported on each apps, using these four dimensions; Functionality, Engagement, Aesthetics and Information. We selected the dimensions from the Mobile Application Rating Scale (MARS) [27]. ***See appendix 1***. We used the MARS 5-point rating scale from "1. Inadequate" to "5. Excellent", to classify and assess the quality of each app.

During the analysis process, we excluded two of the 9 apps because they were beyond the scope of the app review process. One app required a separate online account before allowing the user to access the app. The other app served as an informational database, and was basically designed to prompt users to get an Advanced Directive. No forms were included on this app, nor does it allow for storing EOL information. The final analysis was conducted on 7 apps.

We then analyzed the 7 apps using the validated MARS evaluation criteria. We excluded two questions from the quality ratings because they were considered irrelevant and not applicable to the analysis of the EOL apps being reviewed in this study. The first question ("Entertainment: Is the app fun/entertaining to use? Does it use any strategies to increase engagement through entertainment) was included in the "engagement" criterion section. The second question ("Evidence base: has the app been trailed/tested; must be verified by evidence (in published scientific literature)") was included in the "information" criterion section. In order to keep the reviews objective during the analysis process, we decided to remove two subjective dimensions (App Subjective quality and App-Specific) from MARS.

Understanding the Interoperability Process – Integrating with EHR systems

To gather data on the current use of FHIR interoperability with EHR systems, we conducted a comprehensive online search of the ONC website by searching the site's browser for these key words; "FHIR" OR "SMART" OR "SMART App" OR "Interoperability" OR "Interoperability Standards Advisory" OR "ISA" OR "App Challenge." From this search, we were able to identify a list of health IT innovators and developers that are currently utilizing the 2017 Interoperability Standards Advisory, and those working towards implementing HL7-FHIR integration with EHR systems [23]. From this list, we found the names of the three Consumer Health Data Aggregator Challenge winners. The objective of the Consumer Health Data Aggregator Challenge is for contestants to "address a common consumer need to easily and electronically access and securely integrate health data from different health care providers using a variety of health IT systems" [29]. Of the three winners, we selected the first place winner (PatientLink Enterprises) to conduct a more in-depth online research of their solution (MyLinks) because their cloud-based application allows for ease of use when gathering, managing and sharing patient data using FHIR and direct messaging. The solution also adheres to HIPAA guidelines and provides encrypted transmission of PHI to and from any direct address [29]. These features are closely related to the requirements of our EOL app.

To help us understanding the FHIR interoperability process flow between EHR, mHealth apps and cloud-based communication, we conducted a careful review of an online webinar for the MyLinks solution [30]. We played and listened to the entire webinar on three different occasions. The first was to allow us the opportunity to gather general knowledge on the PatientLink Company and their partners, the purpose of the MyLinks tool and to get information on the overall functionality and features of the tool. We allow for 24 hours before listening to the

webinar a second time. On this occasion, we focused on gathering information on two distinct aspects on the MyLinks tool; the functions and the features. We carefully listened to the presenter, paused and replayed sections of the webinar recording, whenever needed, to ensure we captured (by note taking) precise information. From the webinar, we were also able to retrieve a sketch drawing of the FHIR interoperable flow of data between the patient, all their providers and the EHR system. The final listening instance occurred on day 2 as well, but approximately 20 minutes after the previous listening occurrence. Again, we focused the final listening instance specifically on the functionality and features of the tool. This allowed us the opportunity to review our notes and to make edits as needed.

During the course of searching the ONC website, we discovered the existence of a platform architecture that was developed by Children's Hospital Boston and Harvard Medical School [31]. The platform, called the SMART platform, is publicly available to App developers and innovators to build apps and test them in a virtual EHR/EMR environment. In addition, the platform aims "to transform the way health IT supports health care by facilitating the development of medical applications that are scalable and substitutable; that will drive competition, innovation, and increased efficiency in the functionality of technology for improved health care" [31].

To give us the visualization of the interoperability workflow process, we connected to the online environment of the SMART platform [32]. We then created an online account that allowed us to use the SMART Health IT Sandbox. The SMART Sandbox "is a virtual testing environment that mimics a live EHR production environment, but is populated with sample data" [33]. Within the Registered Apps section of the Sandbox, there are Apps publicly available for App developers

and others to use for testing and demonstration of the SMART on FHIR interoperability process with the EHR portal.

In order to grasp a better concept of the EHR/mHealth app integration process, from the end user's perspective, we conducted a simple test of the "Growth Chart" App. The "Growth Chart" App is a provider-facing app, which pulls specific patient data from the EHR and uploads it onto the app. This app allows providers to complete graphs and grids that are very helpful in the care of their patients. In April 2017, we launched the app within the testing environment to review its functionality. After launching the app, we randomly selected a patient from the list of patients available. The list displayed patient names, gender and age. Before the app was able to integrate with the EHR and access patient data, we were prompted to complete an authorization request. After completing the request, we were then able to access the growth chart within the app and visually review patient data in both graphs and table (grid) format.

For us to better understand the integration process flow from the app developer's perspective, we sent an email message to the SMART on FHIR team requesting information on the SMART on FHIR integration workflow process and also information on how to get started building an app within the SMART platform. We received an email response that included links to the information we requested.

Capturing the Requirements – User Stories and Functional Requirements

In developing the features for a new application, it was important to capture at a high-level, the details of what the application will be capable of doing. To ensure we did not miss any of the functionality details, we used the approach of capturing the user's perspective in the form of "user stories". Within the software industry "user stories" is a common term used to describe the

functionality of a product in simple language and follows the format of "*As a <type of user>, I want <some desired outcome> so that <some reason>"* [34].

We collected a convenience sample of individuals [friends and family of our team] to participate in gathering these "user stories". Each team member explained to the sample of individuals that we would like them to participate in an exercise where they would write a list of sentences stating what they would want to be included in a mobile app geared towards storing EOL information. For this exercise, we selected the first seven individuals willing to participate. We provided the selected seven participants with a more detailed set of information that explained our need to capture specific details of how each of them would interact with the app, given a hypothetical scenario. We randomly assigned seven categories of end-users, to each participant. The categories included; (1) The spouse, (2) The child of an elderly parent living in a different State, (3) The child of an elderly parent living in the same State, (4) The caregiver, (5) The patient (owner of an EOL document; (6) The family member, (7) The healthcare provider. The scenarios were for them to imagine that they were the end-users and had to use the EOL app and its content as a means to contribute vital information related to the care of their loved one. We allowed each participant 2 hours to formulate a "user story" for his or her given scenario and present it using the "user story" format.

After gathering the "user stories", we determined the need for further elaboration of each statement in order to capture very specific details to describe how the software should act. We decided to create a list of detailed requirements from the "user stories". To do this, we carefully examined each "user story" presented by the seven participants, and extracted the *desired outcome* section. With this section, we were able to convert these into a list of very detailed functional and non-functional requirements using "The system shall…" format.

Summary

Using the methods detailed above, we were able to gather and analyze a substantial amount of data on existing EOL mHealth applications, and the usage and capacity of EOL mHealth apps within Metro Atlanta area hospitals. In addition, we used these methods to help in determining the best industry practice for integrating mobile applications within EHR systems, and to capture functionality details for a new EOL mobile app, from the end user's perspective. The methodology we used within this project created the foundation for, and provided the adequate resources needed to, create a prototype of an EOL mHealth app that can improve access to patient EOL information.

Chapter 3: Results

Key Findings

Healthcare Facilities Interview – Current usage of EOL apps

The information gathered during the interview process helped us to form a general consensus about the current use of EOL apps among healthcare entities within Metro Atlanta area. As specifically identified and noted within this paper, the rationale for individuals to have and use EOL mHealth apps is to create an environment where patients, family and healthcare providers can have real-time access to a patient's EOL documents.

This fundamental concept is currently lacking within some healthcare entities including those that are considered technologically advanced. We found this to be especially true, as 100% of our interviewees reported that patients typically do not bring their EOL documents with them at the time of their visit. It was further reported that in emergent patient care situations, the providers are aggressively trying to complete an advanced directive document for patients, since the patient does not have one as part of their medical records. The providers noted this approach as being very ineffective and unreliable, and it does have severe impact on fulfilling the patient's EOL wishes.

Only one of the six providers interviewed indicated that the idea of utilizing mHealth apps to access and transmit EOL documents to their healthcare facilities is now gaining traction. Although they don't currently utilize or recommend their patients to use mHealth apps for this purpose, there may be plans for this in the future. There was however, overall consensus that

patients having the ability to electronically store and share their EOL documents will be of great benefit to the patient and an advantage to the healthcare industry.

Providers identified having real-time access as a critical piece of the rationale for having patients complete EOL documents, and not delay until confronted with EOL issues. Overall, the providers recognized that there is need to improve the old system of completing EOL documents at the bedside in care institutions. They see the EOL mHealth app as a viable alternative, but it must be specifically designed to appeal to a wide age group (which includes the older population) by emphasizing user-friendly designs that boosts simplicity, security and accessibility across platforms and environment.

MARS Rating Scale

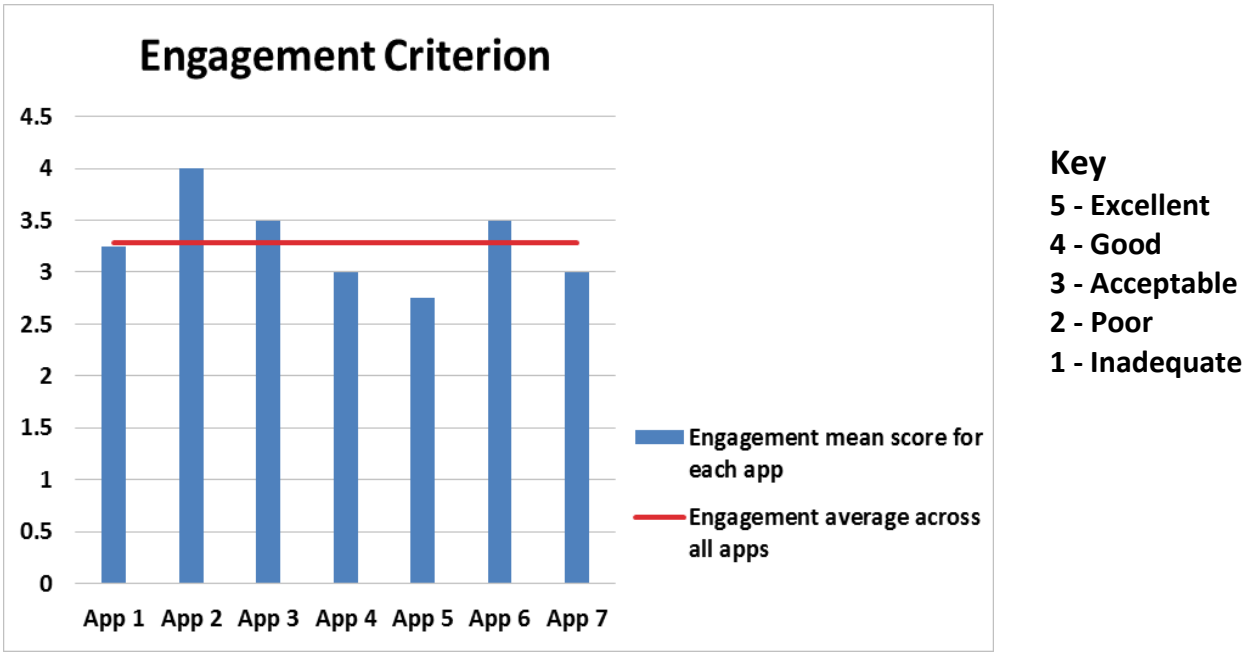
Given these requirements, useful EOL applications must be usable by seniors. EOL discussions are age appropriate for teens as much as they are for seniors. With this in mind, mHealth apps must be designed to appeal to users of all ages, and with varying levels of cognition and skills set. Mobile health apps have come at a time when most 3-40 year olds are interacting with mobile applications of one form or another. Unfortunately, the technological age is light years beyond most of America's seniors – who must confront EOL issues sooner rather than later. For this reason, mHealth Apps must satisfy the four criteria included in MARS (see Appendix 1): 1. **Engagement** – the app must be user-friendly, interactive, fun, interesting and customizable. 2. **Functional** – the app must be easy to learn, navigate and have a logical flow. 3. **Aesthetic** – the app must have overall visual appeal and stylistic consistency and 4. **Information** – the app must contain high quality information from a credible source.

Using MARS 5-point rating scale to assess the quality of the 7 apps, our analysis yielded the following as displayed in figures 1 – 4 below. The mean score results are indicated on the y-axis, and are representative of the MARS 5-point rating scale (1 – Inadequate, 2 – Poor, 3 – Acceptable, 4 – Good and 5 – Excellent). The information displayed on the x-axis is representative of the 7 apps analyzed (App 1 to App 7).

Summary of the Engagement Criterion

Figure 1 demonstrates a large percentage of the apps examined had an average quality rating for the "engagement" criterion. The highest mean score was 4, and represents "Good" according to MARS. Two apps within this category had mean scores of 3, which indicate they are merely "Acceptable". The overall engagement average mean score for all seven apps is 3.28.

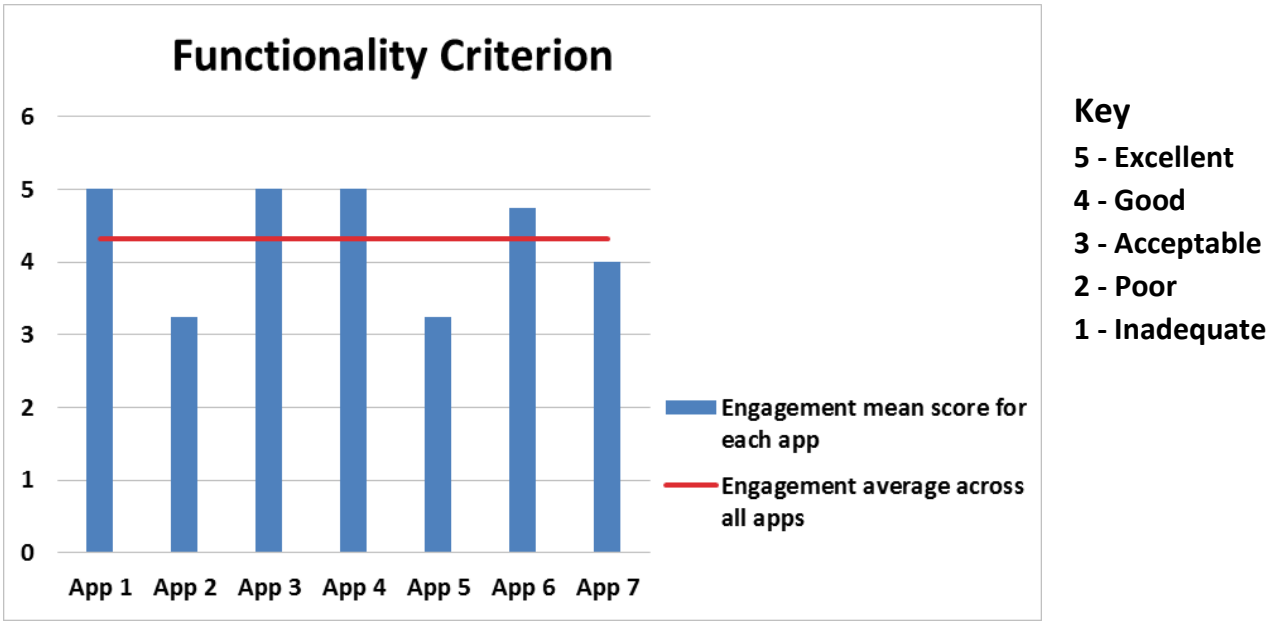
Figure 1: Engagement Mean Score



Summary of the Functionality Criterion

The functionality criterion yielded three of the seven apps as having "Excellent" quality rating, with mean scores of 5. There were also two apps with mean scores between 4 and 4.75. None of the apps had quality rating of 3 or below. Of the four MARS criteria, functionality produced the highest mean scores overall, which indicates that most of the apps were relatively easy to learn and easy to navigate. (*see figure 2*). The overall functionality average mean score for all seven apps is 4.32.

Figure 2: Functionality Mean Score

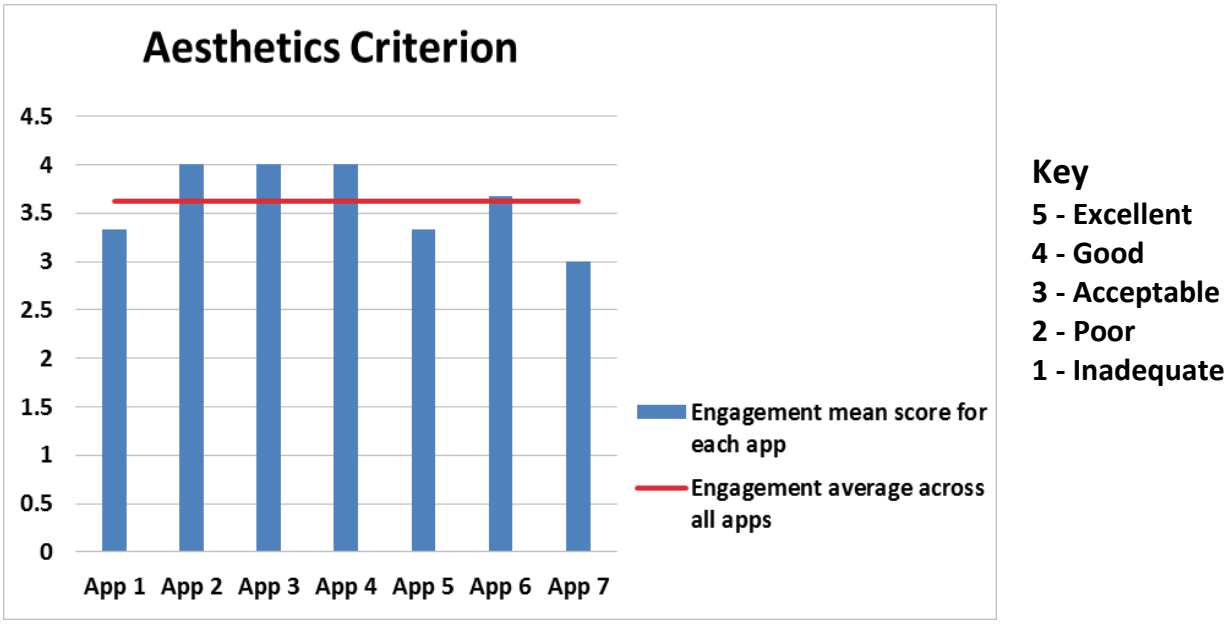


Summary of the Aesthetic Criterion

Aesthetically, most apps were thought to be of a fairly high standard, although none were rated as "Excellent." Three of the 7 apps had mean scores of 4 which indicates a rating of "Good" quality for visual appeal, color scheme and stylistic consistency. The other four apps have mean

scores that ranged between 3.67 and 3, which are relatively "Acceptable" (*see figure 3*). The overall aesthetics average mean score for all seven apps is 3.62.

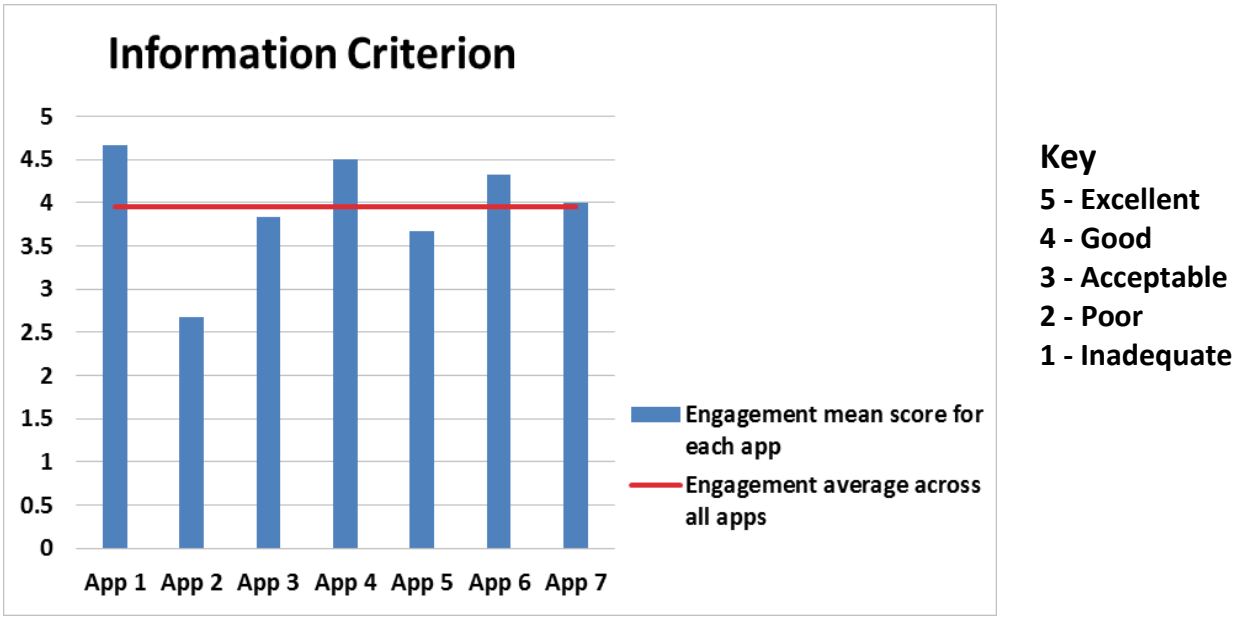
Figure 3: Aesthetics Mean Score



Summary of the Information Criterion

Six of the 7 apps rated between "Acceptable" and "Excellent" with regards to the quality of information they contained. These mean scores were between 4.67 and 3.67. Only one app scored an "Acceptable" rating quality, with mean score of 3. This app lacked visual explanation of concept. It included only text information, and had no images or videos to assist with navigating the app or understanding its content (see figure 4). The overall information average mean score for all seven apps is 3.95.

Figure 4: Information Mean Score



Overview of Findings

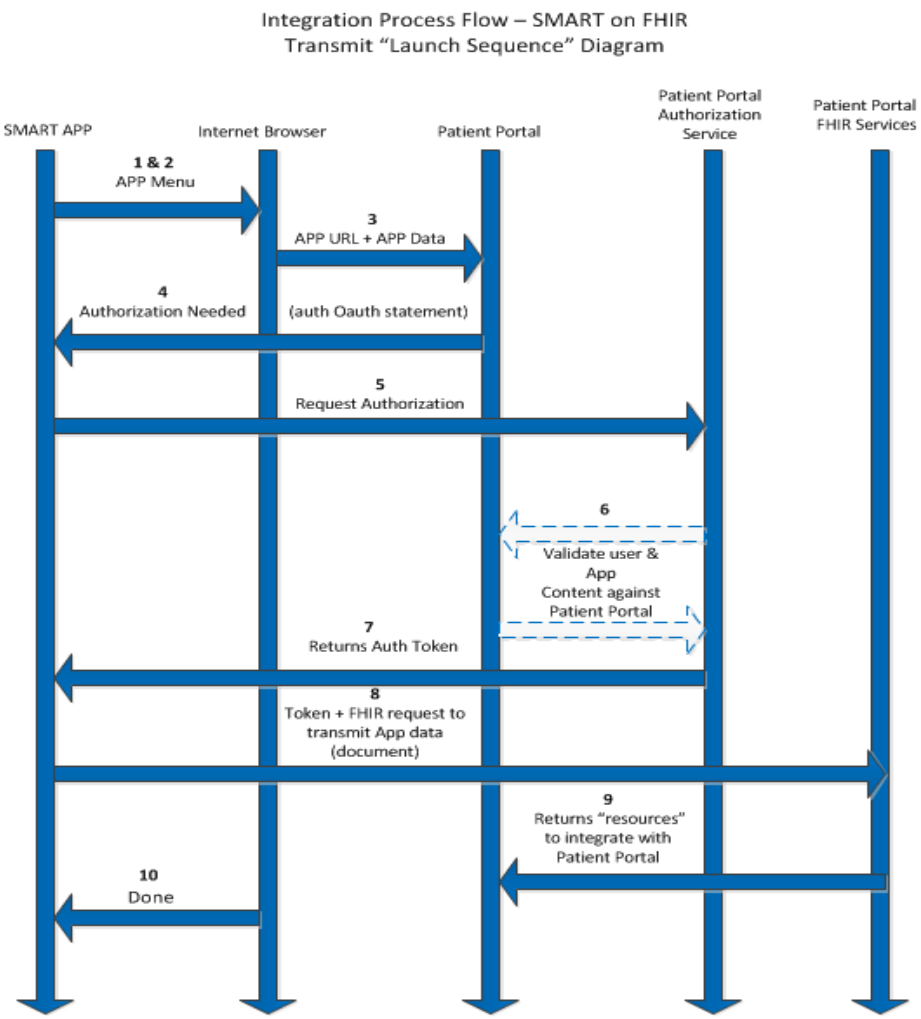
As an overall measure of quality, the 7 apps reviewed surpassed minimum expectations; they rated among "Acceptable", "Good" and "Excellent." While reviewing the "engagement" criterion of all the apps, we paid very specific attention to the apps' interactive and customizable functionality. With this, we found a few of the apps do allow for users to share EOL documents via email. However, none of the 7 free apps included the functionality that will allow them to integrate with EHR systems. Given this, and the other findings above, EOL mHealth apps on the market appears to be relatively good with regards to the way they function, their aesthetics and their content. There is still however the lack of interoperability among systems.

Integration Process Flow – SMART on FHIR "launch sequence"

The depth of information provided by the SMART on FHIR team allowed us to construct two sequence diagrams (Transmit Sequence and Retrieve Sequence) and step-by-step description of the launce sequences. These sequence diagrams, shown below in Table 3 and Table 4 respectively, demonstrates the overall process flow between the mHealth App and components of the EHR system. Each sequential flow represents a standalone launch of the App from outside the Patient Portal or EHR session.

SMART mHealth APP Transmit "launch sequence" to the Patient Portal

Figure 5: Transmit Launch Sequence Diagram

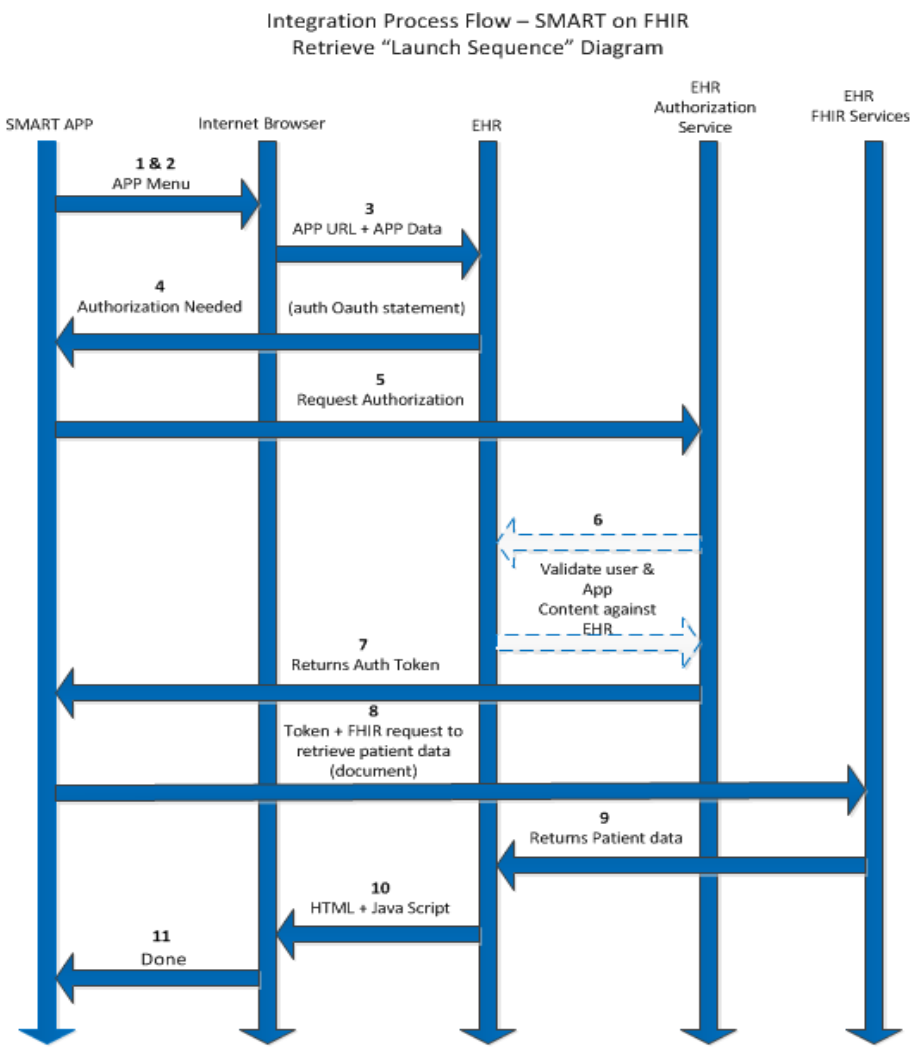


Transmit Launch Sequence Steps:

1. The user selects the EOL app by clicking on the app icon on a mobile phone home screen
2. The app will launch from its registered URL without a launch ID
3. The app attempt to access and transmits content (data/documents) to the Patient Portal
4. The app discovers the Patient Portal authorization service (OAuth – authorization and token)
5. The app sends a request for access to the Patient Portal
6. The authorization service validates the user and app content against the Patient Portal
7. The authorization service returns an authorization token to the app
8. The app uses the authorization token and makes a FHIR request to the FHIR service
9. The FHIR service returns "resources" which allows for app integration with the Patient Portal
10. The sequence flow is complete after the document is transmitted securely and is integrated into the Patient Portal

SMART mHealth APP Retrieve "launch sequence" to the Patient Portal

Figure 6: Retrieve Launch Sequence Diagram



Retrieve Launch Sequence Steps:

1. The user selects the EOL app by clicking on the app icon on a mobile phone home screen
2. The app will launch from its registered URL without a launch ID
3. The app attempt to access and retrieve content (data/documents) to the Patient Portal
4. The app discovers the EHR authorization service (OAuth – authorization and token)
5. The app sends a request for access to the EHR
6. The authorization service validates the user and app content against the EHR
7. The authorization service returns an authorization token to the app
8. The app uses the authorization token and makes a FHIR request to the FHIR service
9. The FHIR service returns "resources" which allows for app integration with the EHR
10. Data is retrieved and populated into the app using HTML and Java Script
11. The sequence flow is complete after the document is securely integrated into the Patient Portal

Requirements

By capturing very specific details to describe how the EOL mHealth app should act, we created the below document which lists detailed functional and non-functional requirements (*Table 1 and Table 2 resp*.). The document further categorizes the requirements by "Priority" to indicate those requirements that are "Must have" and "Nice to have". The "Must have" represent those expectations detailed in the user stories, and also those that would meet the scope (objective) of developing the EOL mHealth app. The "Nice to have" are optional requirements that can be used to possibly enhance or complement the overall development of the app.

Scope Statement: To develop a prototype for a mobile health application that will allow users the ability to create, store and securely share EOL documents with their healthcare provider.

Table 1: Functional Requirements

Req ID	Description	Priority
FR 1.0	The system shall contain a repository of writable PDF End-of-Life (EOL) documents as listed; Living Will, Medical Power of Attorney, and Physician Order for Life-Sustaining Treatment (POLST)	Must have
FR 1.1	The system's repository shall include only State authorized EOL documents	Must have
FR 1.2	The system shall categorize each EOL document by State from which users can select	Must have
FR 2.0	The system shall provide the user the ability to save EOL documents	Must have
FR 3.0	The system shall provide new users the ability to create a new account	Must have
FR 4.0	The system shall require returning users to sign in before accessing their account	Must have
FR 4.1	The system shall have the functionality for returning users to use Touch ID as an option to access their account	Nice to have

Req ID	Description	Priority
FR 5.0	The system shall have the capacity to auto-populate the current date and time as part of the file name whenever the EOL document is saved	Must have
FR 6.0	The system shall allow cloud-based storage for both Apple and Android platform	Must have
FR 7.0	The system shall provide the user the ability to EDIT EOL documents.	Must have
FR 8.0	The system shall provide the user the ability CLOSE EOL documents.	Must have
FR 9.0	The system shall have the capacity to generate the alert statement “Want to save changes? The content in this document will be permanently lost if cancelled without saving”	Must have
FR 10.0	The system shall provide the user the ability to PRINT EOL documents.	Must have
FR 11.0	The system shall have the capacity to import documents	Must have
FR 11.1	The system shall have the capacity to import PDF documents	Must have
FR 11.2	The system shall have the capacity to import emailed documents	Must have
FR 12.0	The system shall have the capacity to share documents	Must have
FR 13.0	The system shall have the capacity to export documents to email servers	Must have
FR 13.1	The system shall provide functionality to send EOL documents securely via email	Must have
FR 14.0	The system shall provide 2 Factor Authentication for all documents sent via email	Nice to have
FR 15.0	The system shall have the capacity to export documents to EHR Patient Portal	Must have
FR 16.0	The system shall have read only functionality for EOL documents exported into the patient portal of the EHR system	Must have
FR 17.0	The system shall store demographic information for each person with end-of-life information collected as listed: First Name, Last Name, Middle Name or Initial, Date of Birth, SSN, Address, Phone Number	Must have
FR 18.0	The system shall have the ability to access complete medication information from the EHR platform. This functionality can be done with SMART on FHIR integration capabilities.	Nice to have
FR 19.0	The system shall have the capacity to store up to two Emergency Contact Persons information as listed: First Name, Last name, Phone Number, Address	Must have
FR 20.0	The system shall have the capacity to store demographic information for healthcare providers, as listed; First Name, Last Name, Specialty, Entity Name, Phone Number, Fax Number, Email, Address	Must have
FR 20.1	The system shall have the capacity to add new (multiple) healthcare provider demographic information	Must have
FR 21.0	The system shall provider user the ability to record messages in the form of audio or visual.	Nice to have

Req ID	Description	Priority
FR 21.1	The system shall allow 15 minutes of recording time for each audio or video message	Nice to have
FR 21.2	The system shall have the capacity to add new audio and video messages	Nice to have
FR 22.0	The system shall have the ability to take photos	Nice to have
FR 23.0	The system shall use HL7 standards for interoperability with all certified EHRs	Must have
FR 24.0	The system shall use SMART on FHIR technical standards for interoperability with all certified EHRs	Must have
FR 25.0	The system shall have e-signature capability for signing EOL documents	Must have
FR 26.0	The system shall have thumb scan capability as an option for signing EOL documents	Nice to have
FR 27.0	The system shall have functionality to authenticate the user by barcode. This functionality can be used if the user in incapacitated and unable to log into the App.	Nice to have
FR 27.1	The system shall allow the user to use the barcode to gain restricted access to the app	Nice to have
FR 28.0	The system shall be compatible with mobile platforms	Must have
FR 28.1	The systems shall be compatible with the iOS platform	Must have
FR 28.2	The system shall be compatible with the Android Platform	Must have
FR 28.3	The system shall be compatible with the Windows Mobile platform	Nice to have
FR 29.0	The system shall provide different level of access for each type of user	Must have
FR 29.1	The system shall provide full access to the registered owner	Must have
FR 29.2	The system shall provide full access to the Proxy	Must have
FR 29.3	The system shall provide restricted access to authorized persons	Must have
FR 29.4	The system shall allow the registered owner to determine level of access and functionality of additional users	Must have
FR 30.0	The system shall have the capacity for users to optionally complete the “Quick Form”	Must have
FR 30.1	The “Quick Form” shall allow the user the ability to enter the user’s name, date of birth, and address	Must have
FR 30.2	The “Quick Form” shall allow the user the ability to enter their health care Agent and alternative’s full name. address, phone number, relationship to user	Must have

Req ID	Description	Priority
FR 30.3	The "Quick Form" shall contain the following and allow the user the ability to select one healthcare choice: **My Agent is to honor my healthcare choices as delineated below:** **Section 2 (choose one)** **____ I want my Agent to make decisions that sustain my life using all possible medical means** **OR** **____ I want my Agent to make decisions that do not introduce any mechanical or medical means of sustaining my life** **OR** **____ I want my Agent to make decisions in consultation with my medical team that will/may provide me with the best quality of life**	Must have
FR 30.4	The "Quick Form" shall contain the following and allow the user the option to populate the user's name and select a choice from the dropdown menu: **Section 3 (optional)** **I your name have executed a** select ▼ **.** **This document is stored select** ▼ **other .**	Must have
FR30.5	The select option within the "**I your name have executed a** select ▼ **.**" section of the "Quick Form" shall contain the names: • Advanced Directive • DNR • Living Will • Medical Power of Attorney • POLST	Must have
FR 30.6	The select option within the "**This document is stored select** ▼ **other .** " section of the "Quick Form" shall contain the following name: • LifeSynergy Or allow the user to enter text in the "other" filed	Must have

Table 2: Non-Functional Requirements

Req ID	Description	Priority
FR 31.0	The system shall adhere to all security policies designated by Stakeholders	Must have
FR 32.0	The system shall support a session-based approach to internet mobility	Must have

Req ID	Description	Priority
FR 33.0	The system shall adopt an Enterprise Mobility Management (EMM) Solution to support secure connectivity without implementation of session-based (VPNs)	Must have
FR 33.1	The system shall work while coverage is intermittent. This functionality will allow the system to work in areas with low bandwidth and provide minimum connection speed (2G or 3G).	Must have
FR 33.2	The system shall wherever possible reduce battery drain	Must have
FR 33.2.1	The system shall NOT default to push, instead 'Fetch' to ensure minimum battery drain	Must have
FR 34.0	The system shall support Data on Demand (DoD) platform connectivity	Must have
FR 34.1	The system shall have user notification – push, fetch and synch technology	Must have
FR 34.1.1	The system shall work when user is offline	Must have
FR 34.1.2	The system shall push full enterprise data content to the application or leverage a "poke and pull" method in which the user is notified that device synchronization is needed	Must have
FR 35.0	The system shall use Geo-location services	Must have
FR 36.0	The system shall encrypt data in transit	Must have
FR 36.1	The system shall adhere to HIPAA regulations for encrypted data in transit	Must have
FR 37.0	The system shall encrypt data at rest	Must have
FR 37.1	The system shall adhere HIPAA regulations for encrypted data at rest	Must have

A New EOL mHealth App - LifeSynergy

Improving access to patients' EOL information can be critical for continuity of care and improved quality of life, especially at the end of a person's life. Our interviews with healthcare providers, within the Metro Atlanta area, further suggested having and using a mobile app to store and securely share EOL information with healthcare professionals could be extremely beneficial. Our research further determined there is great need for an EOL mHealth app that has the ability to securely integrate with EHR systems. Having this knowledge, we determined it was important to develop the prototype of a new EOL

mHealth app. We called this new app **LifeSynergy**. We used the four criteria (Engaging, Functional, Aesthetic and Information) from the MARS rating scale as part of the guidelines to develop the prototype for LifeSynergy. We also incorporated some of the functional requirements listed in *Table 1* (See the extracted requirements listed in Table 3 below).

Table 3: Functional Requirements Used in Prototype

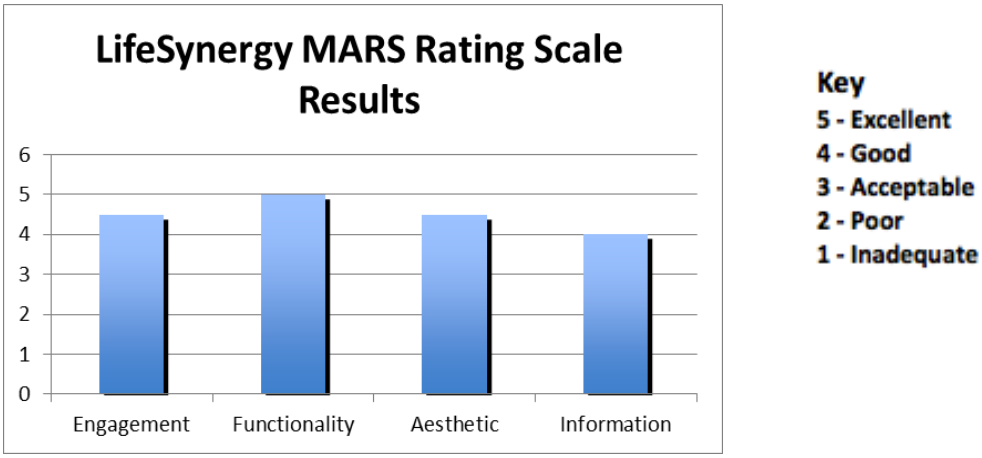
Req ID	Description	Priority
FR 1.0	The system shall contain a repository of writable PDF End-of-Life (EOL) documents as listed; Living Will, Medical Power of Attorney, and Physician Order for Life-Sustaining Treatment (POLST)	Must have
FR 1.2	The system shall categorize each EOL document by State from which users can select	Must have
FR 2.0	The system shall provide the user the ability to save EOL documents	Must have
FR 3.0	The system shall provide new users the ability to create a new account	Must have
FR 4.0	The system shall require returning users to sign in before accessing their account	Must have
FR 7.0	The system shall provide the user the ability to EDIT EOL documents.	Must have
FR 8.0	The system shall provide the user the ability CLOSE EOL documents.	Must have
FR 9.0	The system shall have the capacity to generate the alert statement “Want to save changes? The content in this document will be permanently lost if closed without saving”	Must have
FR 10.0	The system shall provide the user the ability to PRINT EOL documents.	Must have
FR 11.0	The system shall have the capacity to import documents	Must have
FR 13.0	The system shall have the capacity to export documents to email servers	Must have
FR 17.0	The system shall store demographic information for each person with end-of-life information collected as listed: First Name, Last Name, Middle Name or Initial, Date of Birth, SSN, Address	Must have
FR 18.0	The system shall have the ability to access complete medication information from the EHR platform. This functionality can be done with SMART on FHIR integration capabilities.	Nice to have
FR 19.0	The system shall have the capacity to store up to two Emergency Contact Persons information as listed: First Name, Last name, Phone Number, Address	Must have

Req ID	Description	Priority
FR 20.0	The system shall have the capacity to store demographic information for healthcare providers, as listed; First Name, Last Name, Specialty, Entity Name, Phone Number, Fax Number, Email, Address	Must have
FR 29.0	The system shall provide different level of access for each type of user	Must have
FR 30.0	The system shall have the capacity for users to optionally complete the "Quick Form"	Must have
FR 30.1	The "Quick Form" shall allow the user the ability to enter the user's name, date of birth, and address	Must have
FR 30.2	The "Quick Form" shall allow the user the ability to enter their health care Agent and alternative's full name. address, phone number, relationship to user	Must have
FR 30.3	The "Quick Form" shall contain the following and allow the user the ability to select one healthcare choice: **My Agent is to honor my healthcare choices as delineated below:** **Section 2 (choose one)** **____ I want my Agent to make decisions that sustain my life using all possible medical means** **OR** **____ I want my Agent to make decisions that do not introduce any mechanical or medical means of sustaining my life** **OR** **____ I want my Agent to make decisions in consultation with my medical team that will/may provide me with the best quality of life**	Must have
FR 30.4	The "Quick Form" shall contain the following and allow the user the option to populate the user's name and select a choice from the dropdown menu: **Section 3 (optional)** **I your name have executed a** select ▼ **.** **This document is stored select** ▼ **other .**	Must have
FR30.5	The select option within the "**I your name have executed a** select ▼ **.**" section of the "Quick Form" shall contain the names: • Advanced Directive • DNR • Living Will • Medical Power of Attorney • POLST	Must have

Req ID	Description	Priority
FR 30.6	The select option within the "**This document is stored select other .** " section of the "Quick Form" shall contain the following name: • LifeSynergy Or allow the user to enter text in the "other" filed	Must have

Before we completed the prototype, we first developed a wireframe (*see Appendix 2 below*) to ensure we captured the four criteria and the prototype requirements. Developing the wireframe provided us with a high-level visual design draft that demonstrated aesthetics, information and certain functional aspects of LifeSynergy. To capture how LifeSynergy's functional interface engages with users, we developed the final prototype (*see Appendix 3 below*) and had an independent app developer analyzed the app using the MARS rating scale. LifeSynergy was rated as follow: **Engagement – 4.5, Functionality – 5, Aesthetic – 4.5 and Information – 4**. **LifeSynergy** represents the ideal EOL mHealth app and would be of great benefit to the public; including patients, healthcare professionals and public health professionals.

Figure 5: LifeSynergy MARS Rating Scale Results



Descriptive Functions of LifeSynergy Prototype

Understanding that people have varying levels of technological interest and capabilities, we designed LifeSynergy to meet the unique needs of older adults as well as younger people. With this app, the user has the option to utilize only a few sections or maximize the full potential of LifeSynergy. At the minimum, the user can choose to only complete the My Choice section of the LifeSynergy app. Here users have the ability to quickly express their choices, by completing pertinent information about their Healthcare Agent, Alternate Agent and the agent's duties. In addition, the user has the option to truly take advantage of the LifeSynergy, by utilizing as many or as little of the multiple categories described below in **Table 4**.

Table 4: LifeSynergy Prototype Categories and Description

Categories	Description
Quick Form	This section allows the user the option to quickly select Healthcare Agent and/or Alternative, by completing a two page semi pre-populated form.
My Profile	This section is where the user has the ability to create and store their personal demographic information and also upload their photo. In addition, the user has the option to create and store personal demographic information of other individuals. This is perfect for situations where family members prefer to secure their EOL information within a single app download. Example, an elderly person and their child OR a husband and wife
Emergency Contact	Here the user has the option of creating and storing the emergency contact information for multiple individuals. A photo of the emergency contact(s) can also be uploaded here. For this prototype, we demonstrated an alert feature which prompts the user to save or discard the emergency contact information before leaving the page. ***Note:*** *The alert notification only appears if the user attempts to leave the page without saving or cancelling.*

Categories	Description
Repository	The Repository section is where the user has a variety of options to securely retrieve, store or share their EOL documents. **Online Search** – allows the user to select a State and type of EOL document they would like to search for online. Within this section, the user has the ability to retrieve, open, complete and save any writable pdf EOL document. **Import** – allows the user the ability to import pdf copies of previously completed EOL documents. **Export** – this allows the user to send a completed copy of their EOL document to their patient Portal or an email address. **Print** – allows the user to print a copy of their EOL document(s) **Edit** – allows the user the ability to open, make changes and save their EOL document
My Users	For this section, the user has to option to create new accounts for their health care Agents. Here the user decides what level of access to grant to their agent. After the new account is created, the health care Agent becomes a secondary user and must download the LifeSynergy app onto their smartphone. The Agent must use the username and password credentials allocated in order to sign in and view assigned sections of the primary user's account. For this prototype we were able to demonstrate the specific sections (access) the user granted to their health care Agent. Here, the Agent was unable to access the **Manage User** section
Medication	Within this section the user can manually add new medication and the dosage for each. The section also allows the user the ability to securely import a list of medications from their patient Portal

Chapter 4: Discussion

Introduction

There are big issues surrounding the care patients receive at the end of their lives. Many of these issues are directly related to the existence and accessibility of EOL documents. Moreover, although data sharing is somewhat prevalent for mHealth apps, sharing predominantly occurs through email and text messages methods that are relatively insecure, and give rise to the need for a more secure channel of data exchange. Aligning accessibility and security bridges the gap between the patient and the care they receive at the end of their lives. The goal of this project was to develop the prototype of an EOL app that will effectively bridge this gap.

Summary of Project

Americans are steadily adapting to EOL planning, as more are aware of the need to make their care preferences known. However, inadequate access to EOL documents has contributed to individuals not receiving their care preference at the end of life when they may not be able to advocate for themselves personally. Consequently, this may have tremendous negative impact on care patients receive at the end of their lives. This project proposed an option that shows how mHealth applications could transcend across time, settings and healthcare facilities to create an environment where patients, their families, and healthcare professionals can share and access EOL documents in real-time.

Our research suggests that the uptake for using mHealth apps as a formal tool to transmit EOL documents among patients and healthcare professionals is somewhat limited. As the

use of technology in health care becomes increasingly prevalent more and more healthcare entities and healthcare professions will utilize wireless electronic devices like the EOL app. Effectively, using EOL apps in the healthcare industry can become an integral part of the continuity of care for patients at the end of their life journey.

As the healthcare industry propels into utilizing EOL apps, the Apple iTunes and Google Play market places may need to catch up to the demand for apps that allow more than email sharing of EOL documents. From the apps we analyzed none had the functionality of integrating with EHR systems. [Secure] Integration is such a vital function within the sphere of sharing real-time data between the patient and their healthcare provider. Furthermore, patients and their families will have peace of mind knowing that their EOL documents can be securely transmitted and immediately accessible by their healthcare provider.

In order to ensure that the EOL app and EHR system integration process is an achievable goal, we focused on understanding the process flow that would be required to incorporate the SMART on FHIR interoperability. This type of interoperability is a new and innovative way of securely transmitting data between systems, while adhering to HIPAA guidelines. We were then able to construct two step-by-step descriptive launch sequence diagrams to demonstrate how EOL documents are transmitted and retrieved between the app and the EHR system.

Forming the realization that there is indeed need for a new app that has the potential to improve access to EOL documents, we created a list of requirements molded from end-users' perspective of what features and functionalities they would like to be included in a new EOL app. Each requirement provided vivid details of what the app should include,

and subsequently how it should performance. We called this new app LifeSynergy. Using some of the functional requirements and the MARS criteria, we developed a wireframe followed by a prototype to demonstrate the visual design and functional interface for the LifeSynergy app.

Implications

The creation of the LifeSynergy app prototype was based on data collected from multiple sources including key stakeholder interviews, literature review, EOL apps analysis, and the design of two detailed interoperability process flow diagrams. As part of the implications for this project, we have laid out both key and novel components of the LifeSynergy app that includes clinical and policy implications.

Clinical Implications

Real Time Emergency Access to EOL Documents

Once LifeSynergy is implemented, access to EOL documents will be significantly improved. Having immediate access to EOL documents is key to improving care. With this, healthcare providers will know precisely the type of treatment their patients' desire. In emergent cases, and especially in cases where the patient cannot communicate their wishes, it is of vital importance that the healthcare providers understand their patients' preferences on things like: Do Not Resuscitate, organ donation, who can make healthcare wishes on their behalf (their healthcare proxy) and other EOL decisions. This scenario is somewhat similar (but more advanced) to an organ donor indication on someone driver's license. They have both noted specific preferences.

Removing the Burden from Family

The families and loved ones of patients undergoing EOL care also stand to benefit greatly from LifeSynergy, as information from the patient's EOL document will be readily available to their healthcare provider. Furthermore, having specific detail and clarification on the treatment plan, for terminally ill patients, immediately available to the care providers will remove the burden from family members having to make these critical and often very difficult life decisions. Our research show, many people have the desire to explore every possible medical intervention in order to save their loved one's life. However, doing so may further contribute to undo stress within the family circle although such an approach may not even be the wishes of the terminally ill patient.

Policy Implications

Patient Self Determination Act – A Boost to EOL App Engagement

Since Congress passed the Patient Self Determination Act (PSDA), healthcare facilities and providers have been mandated to inform patients about their rights to consent or refuse treatment, and to formulate EOL documents like Advanced Directives. The advancement of wireless technology offers a way for healthcare providers to better increase compliance with existing PSDA legislations. Facilities and providers will be able to engage with their patients beyond what is currently mandated. As providers discuss and assist their patients with formulation Advanced Directives, further discussion can be had about the benefits of utilizing an app to securely create, store and transmit these EOL documents to multiple specialists. Having this enhancement to the current PSDA mandate can even eliminate silos among multiple healthcare specialists that provide treatment to

terminally ill patients. By doing this, the app can be used as a universal source of informing specialists of their patients' EOL preferences.

At the healthcare facility level, policies and procedures should be created that will allow for proper training for health professions so they can effectively engage patients about utilizing EOL apps. In addition, patient engagement of this nature should be continuous and available at every provider-patient encounter. The current reimbursement system set in place by PSDA will allow healthcare providers to be compensated, by Medicare/Medicaid, for this level of patient engagement.

Public Health Implications

Reducing Healthcare Cost

Population health will become more patient-centered as more people utilize mHealth apps like LifeSynergy. Allowing patients the ability to access and share their EOL documents in real-time creates a sense of empowerment for the patient and encourages them to participate in their own care plan. As patients' participatory care increases, population health literacy on EOL care would potentially grow, leading to more Americans understanding and communicating their desired health needs. These key components can redirect both Medicare and Medicaid healthcare cost spending to pay for services patients desire.

Project Strengths

This project used an innovative approach for dealing with some of the issues Americans have with administratively managing their EOL documents. With only a few clicks on

their EOL mHealth app, a healthcare agent, a family member or even the patient can share their EOL documents with healthcare provider across all U.S. States and even internationally, in some instances. This innovative approach allowed us to build upon existing technology to create a tool that triangulates three separate entities; the EOL mHealth apps, the Internet and EHR systems. An EOL app like LifeSynergy alleviates the historical burden patients and their families bear of always remembering to have and produce a physical paper copy of an EOL document at their doctor's visit.

Limitations

Skewing the EOL App Usability Search

For this project, interviews were only conducted with informants at Metro Atlanta area hospitals. Metro Atlanta is the healthcare hub of the southeast and has a high number of providers that were easily accessible and willing to participate in the research. Consequently, finding participants in technologically advanced hospitals outside of this area were difficult. Exclusion of other statewide or nationwide hospitals may have likely skewed the findings and impacted our ability to truly measure the current usability of EOL apps within the healthcare industry. By expanding the sphere of the interviewees to include hospitals and other healthcare facilities outside the Metro Atlanta area we may, or may not, have found that this type of technology is being used currently. If this type of technology was indeed found, there may have also been opportunities to explore how these apps are currently being used to further benefit patients at the end of their lives.

Although we were unable to expand our research to include hospitals outside the Metro Atlanta area, our selections only included hospitals that are considered cutting-edge in its

adaptability to health information technology. This unique sample may have indeed been a good enough proportion to use in determining the current usability of EOL apps within the healthcare industry.

App Analysis Restrictions

About 75 percent of the EOL apps we identified had a cost associated with it. In addition, there was a relatively large amount (about 30%) of EOL apps that displayed in languages other than English. Restricting our search criteria to only analyzing EOL apps that are free and those displayed in English, may have had significant impact and limited our search results. The probability exists that some EOL apps within the app market places have more features and the functionality to share data with EHR systems. If such apps do exist, there needs to be future research that directly focuses on population usage and population benefit, and the contribution [if any] such apps make to the healthcare industry.

More Advanced Technical Skills Needed for Testing

Testing one of the applications within the SMART Health IT Sandbox allowed us to conduct the "Growth Chart" test. This gave us visual insight, from the end-user's perspective, of how specific patient data is retrieved from the EHR system and pushed onto an app to allow providers to further manipulate before displaying grids and graphs. Although this was successful, we were unable to utilize this resource more effectively to build an app prototype within the SMART Health IT Sandbox that was capable of interacting with a virtual EHR system. To do this, we needed a set of more advanced technically skilled individuals. As an alternative we developed a prototype of the EOL

app and displayed some of its features and functionality. We were also able to create SMART on FHIR interoperability process flow. Both of these bodies of work will be of great benefit to the research community.

Next Steps

All Cost and Language Inclusion in Future Research

To fully understand the capability, features and functionality of EOL apps within the app market place, the search criteria for future research should be expanded to include all EOL apps and not just those that are free and displayed in English. Including such criteria will give researchers a macroscopic insight to the demographic population that uses [or not uses] EOL apps and the benefits they currently receive. By understanding these variables, researchers then have the opportunity to provide recommendations on what approaches to use to create awareness and inclusion of the marginalized population. In this technologically progressive age, the health IT industry will receive significant benefit from large-scale data collection on how current EOL apps function for data sharing and data security.

Technological Advancement

Developing, testing and launching of LifeSynergy are achievable next steps for this app that will be accomplished. At the development phase a more interactive prototype will allow targeted users to view more tangible features of this app. After we have developed a finished version of LifeSynergy, the app will then go through the beta-testing or user testing phase. During this phase, users will have a better opportunity to test the functional

capabilities of LifeSynergy under various platform environments and conditions to ensure major bugs and crashes are fixed before release (launch). The beta-testing phase also allows us to get real feedback from our target customer in areas such as the user's comfort level with using the LifeSynergy app. Some of this feedback will be incorporated before launching.

We plan to integrate an analytics tool before launching LifeSynergy. This tool will give us a comprehensive overview of how many people used LifeSynergy, how they arrived on our app's website and subsequently how we can improve customer engagement. For some market places, like iOS, we plan to send LifeSynergy for a manual review and may need to make changes before launching. Finally, at launch, we will employ a strategic plan, schedule and a set of control approaches to release from testing to live environment.

It is important to note that there are many technological additions that can be included to LifeSynergy to further assist patients with EOL issues. The inclusion of wearable devices that interfaces with LifeSynergy is one such additive. Another is the inclusion of a web robot within LifeSynergy to assist visually impaired users with completing their EOL documents. These tools can be extremely useful to further engage the patient population (including the vulnerable groups) and will be implemented in future versions of LifeSynergy.

Recommendations

English Only Apps – Available in Multiple Languages

It is equally important to have EOL apps available in multiple languages even within the United States. The U.S. healthcare system treats patients of varying nationality

backgrounds, many of whom uses the English language as a secondary or even tertiary language, while some do not speak or comprehend English at all. The healthcare industry should, therefore, have health technology devices and apps available in multiple languages in order to provide significant benefit for its consumers. With many EOL mHealth apps being available in a single language, many people may be at a huge disadvantage in utilizing this technology to document their healthcare wishes and sharing these documents. Such disadvantages can contribute to patients receiving undesired care at the end of their lives.

Repository for Providers

The concept of using LifeSynergy or an app of this kind, to transmit EOL documents into the Patient Portal can be transformed into a solution for storing EOL documents for all people within the same local or national area. With this type of solution, people will be able to complete their EOL documents via the app and securely send it to a state or national repository. This will be a repository where healthcare professionals can securely retrieve EOL information on their patients, even if the patient was unable to send a copy to their Patient Portal. A solution of this nature can improve continuity and quality of care for patients.

Education and Awareness

From the interviews conducted, we found that a large pergentage of the providers were concerned that there is still great need for patient education and awareness about the importance of completing and having some form of EOL document. It is fundamental to understand that fostering education and awareness goes beyond the patient’s hospital

bedside. Contributions to this cause must also be done at the community level and also at a public health level. This is an area that requires continued research and resources in order to combat its shortcomings.

Community Support

Moving beyond creating policies at the healthcare level, awareness on the use of LifeSynergy (or apps of this kind) should be propagated throughout the communities as a benefit to improving the quality of care and health from a public health perspective. Involvement of senior living facilities, churches, health insurance companies and other institutions like AARP and churches can facilitate opportunities of informing its members on the benefits of using this app.

In addition, inclusion of such institutions can further bridge the gap between the population that has and uses EOL plans, and those that does not. This can be of great benefit to specific groups like minorities, women and millennium. Informing and encouraging all groups within the community to use EOL mHealth technology can significantly reduce the disparities among these vulnerable groups.

Conclusion

As the use of smartphones rapidly increases, people will continue to use wireless connectivity to access their health information. Using an app like LifeSynergy to securely transmit EOL documents into the Patient Portal ensures patient-centered care for patients at the end of their life. Beyond this, there are implications for healthcare facilities, insurance companies, senior living facilities and other institutions like AARP to use LifeSynergy as a means to generate awareness and have more people completing and

having their own EOL document(s). Additionally, there are opportunities for technological advancement where LifeSynergy can work in conjunction with other forms of technology to further engage the public to use the app and therefore bring awareness to EOL plans and its benefits.

Chapter 5: Executive Summary

Introduction

Today in the U.S., mobile health technologies are becoming widely used among the varying age groups. Currently, the U.S. population is using mobile health apps to capture real-time health data on things like chronic diseases, nutrition, and fitness. However, there is uncertainty about the current rate of usage on apps for end-of-life (EOL) care.

Many Americans are adapting to EOL planning due to an increase in life expectancy by some 30 years. In such a technologically advanced age, there is therefore great potential for use of EOL apps. Use of this technology can contribute largely to gathering EOL data aimed at informing on specific public health interventions such as: improved communication between health care providers, patients, and family members about EOL. Using an EOL application to gather such data requires data sharing between the app and components of the EHR system. Data sharing between these systems necessitates interoperability standards and compatibility, while adhering to the privacy and security standards set by the U.S. healthcare system.

Background

While there are existing challenges with privacy, security and integrative use of EOL mHealth applications, there is great potential to improve interventions for EOL care planning that will make a difference for millions of Americans. This project therefore demonstrates how a new mHealth app could potentially improve data sharing of EOL

documents across time, settings and healthcare providers, and how the data from this app can be used to inform on EOL public health interventions.

Objective

This project-based thesis will develop a prototype for improving electronic access to EOL documents, which will potentially help health outcomes through informed public health interventions.

Process

We collected and analyzed data to determine whether there is need for improved access to patient EOL information and whether or not a mobile health application will fill that need to inform on EOL interventions. To determine the current usage and capacity of EOL apps in healthcare facilities, we conducted interviews with a convenience sample of hospitals in the Metro Atlanta area that were considered “Most Wired” because of their high level of IT adoption.

To determine what EOL apps currently exist on the iOS and Android platforms and to evaluate their features, we conducted a systematic search in the Apple iTunes and Google Play stores. Further, we conducted a comprehensive online search of the ONC website to gather data on the current use of FHIR, and SMART on FHIR, interoperability with EHR systems. Here we were able to identify a list of health IT innovators and developers that are currently utilizing the 2017 Interoperability Standards Advisory, and those working towards implementing HL7-FHIR integration with EHR systems.

In developing the features for a new application, it was important to capture at a high-level, the details of what the application will be capable of doing. To ensure we did not miss any of the functionality details, we used the approach of capturing the end-user's perspective in the form of "user stories". All of the methods we used within this project created the foundation for, and provided the adequate resources needed to, create a prototype of an EOL app that can improve access to patient EOL information.

Conclusion

This project demonstrated how mHealth apps could transcend across time, settings and healthcare facilities to create an environment where patients, their families, and healthcare professionals can share and access EOL documents in real-time. Our research suggests that the uptake for using mHealth apps as a formal tool to transmit EOL documents among patients and healthcare professionals is somewhat limited. As the use of technology in health care becomes increasingly prevalent more and more healthcare entities and healthcare professionals will utilize wireless electronic devices like EOL apps. Effectively using EOL apps in the healthcare industry can become an integral part of the continuity of care for patients at the end of their life journey.

From the apps we analyzed none had the functionality of integrating with EHR systems. [Secure] Integration is such a vital function within the sphere of sharing real-time data between the patient and their healthcare provider. Furthermore, patients and their families will have peace of mind knowing that their EOL documents can be securely transmitted and immediately accessible by their healthcare provider.

In order to ensure the EOL app and EHR system integration process is an achievable goal, we focused on understanding the process flow that would be required to incorporate the SMART on FHIR interoperability. This led us to construct two step-by-step descriptive launch sequence diagrams to demonstrate how EOL documents are **transmitted** and **retrieved** between the app and the EHR system. Using some of the functional requirements and the MARS criteria, we developed a wireframe followed by a prototype to demonstrate the visual design and functional interface for the new APP we named LifeSynergy.

Next Steps

To fully understand the capability, features and functionality of EOL apps within the app market place, the search criteria for future research should be expanded to include all EOL apps and not just those that are free and displayed in English. Including such criteria will give researchers a macroscopic insight to the demographic population that uses [or not use] EOL apps and the benefits they currently receive.

Developing, testing and launching of LifeSynergy are achievable next steps for this app that will be accomplished. Furthermore, technological additions like wearable devices and a web robot, for the visually impaired users, can be included to LifeSynergy to further assist patients with EOL issues. These tools can be extremely useful to further engage the patient population, including the vulnerable groups.

Key Recommendations

1. The U.S. healthcare system treats patients of varying nationality backgrounds, many of who uses English language as a secondary or even tertiary language,

while some do not speak or comprehend English at all. It is therefore equally important to have EOL apps available in multiple languages as a benefit to the U.S. population.

2. The concept of using LifeSynergy, or apps of this kind, can be transformed into a State or National repository where all people within the same local or national area can store EOL documents. From this repository healthcare professionals can securely retrieve EOL information on their patients. A solution of this nature can improve continuity and quality of care for patients

3. We found that a large percentage of the providers interviewed were concerned that there is still great need for patient education and awareness about the importance of completing and having some form of EOL document. It is fundamental to understand that fostering education and awareness goes beyond the patient's hospital bedside. This is an area that requires continued research and resources in order to combat its shortcomings.

4. Moving beyond the healthcare level, awareness on the use of LifeSynergy (or apps of this kind) should be propagated throughout the communities as a benefit to improving the quality of care and health from a public health perspective. Involving senior living facilities, churches, health insurance companies and other institutions like AARP can facilitate opportunities for informing its members on the benefits of using this app. Including such institutions can further bridge the gap between the population that has and uses EOL plans, and those that does not. This can be of great benefit to specific groups like minorities, women and millennium. Informing and encouraging all groups within the community to use

EOL mHealth technology can significantly reduce the disparities among these vulnerable groups.

For more information contact Shahidah Mallay @ shahidaha@yahoo.com

Appendix

Appendix 1:

Mobile App Rating Scale

Appendix 2

LifeSynergy - Wireframe

Appendix 3

LifeSynergy – Prototype Version for iPhone 6

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