HEALTH INFORMATION EXCHANGE SERVICES IN SUPPORT OF DISASTER PREPAREDNESS AND EMERGENCY MEDICAL RESPONSE

Assessment of Opportunity in California and the Gulf Coast

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Executive Summary

Over the last decade, a number of significant disasters have struck the United States, including hurricanes, tornadoes, pandemic flu, and terrorist attacks. Each of these events has resulted in evacuations and/or the treatment of patients outside of where they traditionally seek medical treatment. Consequently, care is often provided with incomplete information, which may impact the quality of care or cause harm to patients. As the nation has moved towards the digitization of patient health information, many initiatives have focused on how electronic patient data can be used during a disaster or emergency to improve care. Additionally, many have considered how health information exchange (HIE) can support healthcare professionals not only during disasters, but also during day-to-day emergencies. While significant progress has been made since one of the U.S.'s worst disasters, Hurricane Katrina, the country as a whole was recently given a grade of "C-" for disaster preparedness and a "D-" for access to emergency care, suggesting that additional work is needed.[1]

The Office of the National Coordinator for Health Information Technology (ONC), the federal agency that oversees the nationwide effort to transition to and meaningfully use health information technology (HIT), has sought to capitalize on the emerging HIT infrastructure. To address the challenges associated with providing care during emergencies, ONC contracted with Audacious Inquiry (Ai) to develop a report on this topic. Ai focused its efforts on two geographic areas that are vulnerable to a high number of natural disasters: California and the Gulf Coast (Louisiana, Mississippi, and Texas). Officials in both of these areas have spent considerable time developing disaster preparedness and response plans. Additionally, hospitals and emergency medical services (EMS) providers in both California and Louisiana are developing use cases and pilots for sharing of EMS data with hospitals. By focusing on these two geographic areas, Ai developed two initial use cases: 1) sharing of patient data between EMS providers and hospital emergency departments (EDs) through a health information organization (HIO) and 2) deployment of a disaster response medical history web portal.

Ai held virtual and in-person meetings with critical stakeholders, including: EMS providers and organizations, public health agencies, state health information technology (HIT) coordinators, health information organizations (HIOs), health systems, and emergency preparedness officials in California and the Gulf Coast. In addition, Ai met with National EMS Information System (NEMSIS) staff.[2] The meetings were used to solicit feedback on the two high level use cases, and used to further refine the use cases. Based on stakeholder input as well as the belief that incremental progress can and should be made, while working towards the ultimate goal of ubiquitous health information exchange (HIE), Ai recommends ONC pursue additional activities related to the following two use cases.

1) **EMS bidirectional data exchange with hospitals**: EMS personnel send data from their electronic patient care record (ePCR) to hospital EDs. The hospitals make patient data available to EMS personnel for query while in the field. Finally, patient outcome

[1] America's Emergency Care Environment: A State-by-State Report Card. American College of Emergency Physicians. 2014. http://www.emreportcard.org/uploadedFiles/EMReportCard2014.pdf
[2] NEMSIS is a national effort to standardize data collected by EMS providers.

information to support EMS quality improvement objectives is sent from the hospitals to EMS providers. The use case would be accomplished with the support of an HIO that is responsible for mapping and routing the data among EMS providers and hospitals.

2) **Disaster response medical history portal**: Using Integrating the Healthcare Enterprise (IHE) standards, connect health systems and HIOs to an interoperability broker that can be accessed via a web portal user interface. During a disaster (the definition of which is agreed upon by participants in advance), the web portal is activated. Healthcare professionals employed by health systems or participating with HIOs would be able to access patient records through their existing systems, and other healthcare professionals, and possibly first responders, would be able to access the portal through a URL.

Introduction

The continuously evolving capacity of various health information organizations (HIOs) around the country presents new opportunities to leverage health information exchange (HIE) infrastructure to support natural and man-made disaster response, as well as day-to-day emergency medical services (EMS) operations. Motivated by past experiences with major disasters such as Hurricanes Katrina, Rita, and Sandy and the unfortunate eventuality of future disasters, developing HIE capacity aimed at supporting clinical data exchange during disaster response, should be a national priority. The past decade of activity to develop a national framework for data exchange among HIOs, and importantly, with Federal Agencies, has created a model which is applicable to pursuing an initiative to support clinical data exchange during disaster scenarios.

Each state's emergency response plan includes local and federal components. Each state has a designated state-level official who is in charge of public health aspects of emergency response during declared emergencies. Local government agencies are involved with emergency response through mobilization of local assets and administration of particular components of state and federal emergency response plans. In addition to their role in disaster response, state and local officials and organizations have an important role to play in daily emergency operations. There are a number of opportunities for health information technology (HIT) and HIE to be used in support of emergency response. The opportunities for using HIT in support of emergency response range from daily emergency operations, through the phases of disaster preparedness, response, and recovery. The objective of the research effort leading to this report, was to assess the current state of both EMS agencies/providers' and HIOs' capacity and interest in collaborating to pursue EMS and disaster response oriented exchange services in California and the Gulf Coast.

As is the case with any HIE pursuit, there are significant complexities which must be grappled with in order to effectively enable this critical national use case. For example, our discussions found general consensus that a disaster response service used infrequently would be ineffective when actually needed. Those responsible for disaster preparedness and response, that the team interviewed, cautioned against a solution which would be rarely used and include foreign workflows and unfamiliar toolsets. Yet, the findings of this report suggest that the existing Integrating Healthcare Enterprise(IHE) standards associated with the eHealth Exchange and the collaborative willingness in key stakeholders in California and the Gulf Coast, create an environment in which a pilot is not only possible, but poised to become a successful demonstration.

While the initial focus of this effort was tilted towards exploring disaster response opportunities, it quickly became apparent that EMS agencies, HIOs, and hospital stakeholders see significant opportunities for HIE services focused on daily EMS operations. Indeed, a number of pilots and initiatives aimed at data exchange among EMS responders and hospitals already exist in California. The broad framing of these exchange efforts has been to extend the continuum of care into pre-hospital care, premised on the fact that information captured during EMS response is both relevant and valuable to subsequent hospital care. Holding that premise as true, if more effective interoperable exchange of pre-hospital information were possible, the transition to hospital care could be made in a more timely and effective manner.

The findings of this report suggest that the core ingredients are in place in certain areas of California and the Gulf Coast to support successful pilots on both the disaster response use case and EMS-to-hospital data exchange. Those core ingredients include a willingness among relevant stakeholders to jointly pursue the use cases, and the technical capacity to pursue pilot demonstrations. Ultimately the value associated with the HIE service must be great enough to justify financial support for and sustainability of the service. The remainder of the report will explore the details associated with the use cases, including the technical details on how the use cases could be accomplished as well as their application in areas of the Gulf Coast and California.

Geographic Focus Areas

The selection of the Gulf Coast and California as the focus of this assessment and report was based on the historic precedence of natural disasters, existing work on EMS-based use cases, and the array of HIE activities occurring in regions within each geography. The team engaged in discussions with leaders from state and local EMS, HIOs, state agencies, and other hospital and provider stakeholders throughout California and the Gulf Coast. These discussions, forums, interviews, and perspectives shared throughout the course of the effort are described below and organized into two separate overviews of how the work in each locality. While the team entered into the discussions with high-level use cases outlined, a free-flowing discussion was encouraged, this shaped both the discussion and the use case evolution that stemmed from those discussions.

California Overview

As the most populous U.S. state and one of the largest geographically, California has espoused an approach to HIE that is necessarily regional by nature. Both the role of the HIO and the HIE service offerings in each region vary greatly, with some HIOs acting in a coordinating capacity and others offering end-user HIE services. Importantly, there are significant enterprise HIE activities (i.e., those sponsored by a health system or integrated delivery network) throughout the state which enhance the overall opportunity by diversifying services beyond "public" or multi-stakeholder HIE efforts.

The assessment conducted in California included a series of phone calls and on-site visits with a number of stakeholders from the San Francisco Bay Area to San Diego. Organized through the State of California Emergency Medical Services Authority (Cal EMSA), four meetings were held over the course of four days, bringing together stakeholders in three geographic regions to discuss EMS related use cases and assess the viability of pursuing them as pilots in California. An overview of each session and key takeaways are outlined below.

State Government Entities

The team began the on-site visits by meeting in Sacramento with leadership from Cal EMSA, the Office of Health Information Integrity (OHII) within Health and Human Services, the Department of Health Care Services, and the Department of Public Health. Leadership from the Hospital Council of Northern and Central California also attended the meeting in Sacramento. Cal EMSA also currently serves as the coordinator of Emergency Function 8, Public Health and

Medical, as part of the State Disaster Response Plan, and works closely with Federal HHS partners in coordinating the ESF8 disaster preparedness component.

The level of coordination and interest in a collective pursuit of a collaborative EMS-related HIE use case was immediately apparent. Cal EMSA recently partnered with Lumetra to produce an HIE and EMS readiness assessment, which evaluated electronic patient care record (ePCR) adoption throughout the state and established a staged framework for ePCR adoption leading towards HIE participation.[3] Cal EMSA, in particular, has quickly escalated ePCR adoption and HIE participation as a critical component of their strategy moving forward. More information on ePCR can be found in this document under Use Case Descriptions. Cal EMSA leadership participated directly in the subsequent meetings throughout the state, assisting in generating a highly collaborative series of multi-stakeholder sessions evaluating specific HIE opportunities.

Emergency Response

Day-to-Day EMS Operations Use Case

The diverse set of participants in each session led to a range of perspectives on what would be most valuable in terms of near-term opportunities for EMS to leverage HIE services. There are basic challenges that exist within daily EMS operations that were raised, but not necessarily problems that were readily addressable through enabling an HIE service. For example, there is general awareness that the delay for an EMS advanced life support team to receive the necessary documentation from the hospital (and in many cases to transfer a patient off the gurney he or she arrives on) causes inefficient use of a given county or region's EMS capacity. It was determined that addressing this particular challenge may not be the best place to start in bringing HIE services to EMS.

In each session, the use case of transferring pre-hospital EMS data to the hospital emergency department (ED) was presented with a focus on enabling basic demographic, status, and chief complaint/observation information to the ED in a format consumable by hospital information systems. In fact, most participants in all of the sessions agreed that just transferring basic demographics to the hospital in advance or at the time of arrival could significantly improve the efficiency of the patient transition to ED care. An important point of agreement was that the notion of the continuum of care should be expanded to incorporate EMS. Furthermore, supporting the transition to ED care with electronic exchange of relevant information was universally agreed to be a high-impact aim.

The Contra Costa Emergency Medical Services Data Infrastructure Project, the Health Share Bay Area pilot in partnership with Kaiser Permanente and American Medical Response (AMR), the Inland Empire HIE coordination with the local EMS agency, and the San Diego Health Connect efforts each represent an opportunity to build reference implementations, and in the case of San Diego, to refine the business model, associated with pre-hospital to ED data exchange. Focusing

[3] Health Information Exchange Readiness Assessment/Survey. Prepared for Cal EMSA under Contract EMS 1324. Lumetra Health Care Solutions. December 2013. http://www.emsa.ca.gov/Media/Default/PDF/EMS%20Project%20Full%20Report%20FINAL%2012-19-13%20REVISED.pdf

on establishing basic data exchange by transferring patient identity information and core complaint (and STEMI, Stroke, or Trauma indicators) to the destination hospital could offer an important baseline from which to expand and improve on the interoperability between the NEMSIS and CCDA standards (described further below).

While much of the discussions focused on the pre-hospital to ED transfer of data, there was an overarching and loud chorus of EMS representatives (state and local levels) who, while supportive of pursuing this specific use case, emphasized the importance of receiving post-hospitalization outcome data to support quality improvement efforts. A further treatment of this issue is offered below.

Disaster Preparedness and Response Use Case

The disaster response use case discussion evolved in an important way over the course of the sessions. The initial use case presented focused on creating the lowest barrier opportunity to enable access across public and enterprise HIE organizations. As presented at the conceptual level in each session, by focusing on a basic single-sign on assertion (e.g., SAML 2.0), a basic website could establish pre-existing connectivity with participating HIOs to enable access under certain disaster declaration scenarios. The initial hypothesis was that avoiding the need to comply with IHE-based eHealth Exchange transactions could reduce the technical burden, costs, and overall barriers to participate. However, the following key points below, impacted the ultimate use case:

- Although simple access to other HIEs would be valuable, knowing how to navigate their technologies would be problematic in practice.
- The variety of formats in which data could be presented, could make it difficult for users, to effectively use the information, especially during the stress of disaster response.
- Many HIE efforts in California are already pursuing use of the eHealth Exchange transactions for broader exchange efforts.
- Most public and enterprise HIOs in California use an array of technologies including Mirth, Epic, and Orion; each of which have demonstrated effective use of the eHealth Exchange transactions.
- Use of a standardized format (Blue Button was referenced) could create uniformity of record structure when accessing data across various platforms.

A final key point from the discussion centered on the definition of a disaster. An important aspect of driving willingness to participate in the use case was the limited circumstances in which cross-HIE access would be enabled. While CaHIE and the HIOs throughout California coordinate to achieve the broader future objective of on-going exchange among HIOs, national experience suggests that smaller incremental steps can be valuable, while still working towards that goal. While this use case focuses on declared disasters, there is an opportunity to extend the use case to smaller emergencies, which still move patients outside of their normal system of care (e.g., trauma level care). The findings in this report suggest beginning with a focus on declared disasters in order to drive participation, expanding the scope to include the use of smaller, but still critical response situations, is a natural near-term evolution.

Organizations Represented in Regional Meetings

Bay Area

- California Association of Health Information Exchanges (CaHIE)
- Health Share Bay Area
- Contra Costa County Emergency Medical Services Agency
- Alameda County Emergency Medical Services Agency
- Kaiser Permanente
- California Hospital Association
- American Medical Response (AMR)

Los Angeles

- Inland Empire County Emergency Medical Services Agency (ICEMA)
- Orange County Emergency Medical Services Agency
- Los Angeles City Emergency Medical Services Agency
- Los Angeles County Fire Department
- LANES – Los Angeles HIE
- Orange County Partnership Regional Health (OCPRHIO)
- Inland Empire Health Information Exchange
- Hospital Association of Southern California

San Diego

- San Diego County Emergency Medical Services Agency
- San Diego City Fire-Rescue
- San Diego Health Connect
- San Diego Department of Health
- First Watch
- Riverside County Emergency Medical Services Agency
- American Medical Response (AMR)

Gulf Coast Overview

The U.S. Gulf Coast, home to millions of people, is subject to annual hurricane seasons that have the potential to bring damaging and deadly storms to highly populated urban areas like Houston, Texas and New Orleans, Louisiana. These storms cause significant injury and death and prompt large evacuations. All of these characteristics create an opportunity to leverage HIE to mobilize clinical data to new points of care and health care providers who may not have relationships with patients, enabling more effective treatment and improving continuity of care in adverse situations.

The team interviewed key stakeholders in Texas, Louisiana, and Mississippi. The stakeholders included representatives from state and local public health agencies, state health information technology departments, emergency preparedness representatives, private sector emergency service providers, and HIEs. The interviews were primarily conducted virtually.

Texas

The state-level HIE infrastructure in Texas includes a state-level HIE connectivity backbone (HIETexas) being developed by the Texas Health Services Authority (THSA) to connect HIOs throughout the state. In addition, the THSA has developed a state-level trust agreement, participation agreement, and business associate agreement to govern the legal aspects of exchanging clinical data between local HIOs and their participants. The local HIE infrastructure along the Texas Gulf Coast includes several local HIE operators, most significantly Greater Houston HealthConnect (GHH), which provides HIE services to health care providers in the Greater Houston area, including Galveston. Of additional note is the Health Information Network of Southeast Texas (HINSTX), which provides HIE services to providers in the Corpus Christi area. The local HIOs along the Gulf Coast (and throughout the state) are in the process of connecting to HIETexas.

Louisiana

The state-level HIE infrastructure in Louisiana includes the Louisiana Health Information Exchange (LaHIE), operated by the Louisiana Healthcare Quality Forum (LHQF), a state-level non-profit organization. LaHIE was the state-designated entity (SDE) for the state of Louisiana under the federally-funded ONC State HIE Program. As such, LaHIE received the federal State HIE Cooperative Agreement on behalf of the state and was responsible for developing and implementing a state-level plan for enabling HIE capacity throughout the state. LaHIE provides a number of HIE services across the state, including Direct secure messaging, a query portal, notifications for ambulatory providers, and public health reporting. Additionally, LaHIE is in the process of launching a patient portal in 2014. A second HIO in Louisiana, the Greater New Orleans HIE (GNOHIE) was developed under ONC's "Beacon Community" program. GNOHIE was established by the Louisiana Public Health Institute to connect and serve health care organizations in the Greater New Orleans area. GNOHIE's services include a query portal, notifications for ambulatory providers, and data analytics. Recently, GNOHIE and LaHIE began to evaluate ways to work together to provide valuable HIE services to the entire state, ensuring that patient records are available no matter where individuals receive care in the state.

Mississippi

Soon after Hurricane Katrina, Mississippi received federal funds that were used to establish the Mississippi Coastal HIE, which served the communities along the Gulf Coast. Under its State HIE Cooperative Agreement, the Mississippi Health Information Network (MS-HIN) was designated the statewide HIE and effectively absorbed the functions and operations of the Coastal HIE. MS-HIN is now connecting hospitals throughout the state and offers a query portal, Direct secure messaging, results delivery, and public health reporting services.

Emergency Response

Given their location on the U.S. Gulf Coast, Texas, Louisiana, and Mississippi must necessarily plan for hurricanes. The opportunities for using HIT in support of emergency response range from daily emergency operations, through the phases of disaster preparedness, response, and recovery. HIE can be used to transmit clinical data from EMS operators to EDs to improve the hand-off between EMS and the hospital and to provide ED providers with additional clinical information in support of better and more efficient care. In Louisiana, LaHIE and Acadian (a large EMS provider in the state) are currently working on this use case. Acadian is planning to

provide data from its electronic billing system to LaHIE, the data would then be available through the HIO's query portal. The second phase of the project could move towards real-time sharing of data with hospitals from EMS personnel in the field.

HIE services can also be used to support disaster preparedness and response in a number of ways. Large-scale disasters often require regional evacuations, including the general population and hospitals. Evacuees may relocate to family and friends (outside the region), general shelters, special-needs/medical shelters, and hospitals in other states (typically no more than 500 miles away). HIE services can support all of these types of evacuations. Data from an HIO can be used to identify individuals in the general population who may have special-needs or are medically vulnerable and need assistance to evacuate. This data would allow healthcare professionals to pinpoint and assist these individuals with evacuating. Hospitals are primarily responsible for having evacuation plans in place but depending on the circumstances of the disaster, hospitals may require outside assistance to evacuate their patients to hospitals outside of the disaster area. Currently, hospitals print the patient's care summary from their EHR and send it with the patient. HIE services can support record continuity, by providing electronic access to the patient's summary of care, reducing the likelihood the data will be lost in transit. HIO data can also be utilized to help reunite patients and evacuees with their families, once they reach a safe location. Additionally, receiving hospitals, special-needs/medical shelters, points of dispensing, and other patient care facilities can utilize HIE services to obtain patient data to support the appropriate treatment of the patient.

An important consideration is that hospital patients may be evacuated by plane to hospitals well beyond the disaster zone. This requires a patient movement plan with tools for patient tracking, such as Joint Patient Assessment and Tracking System (JPATS) operated by the U.S. Department of Health and Human Services, Office of the Assistant Secretary for Preparedness and Response (ASPR). The actual evacuations are facilitated by EMS who transport patients to the airport. At that point, federal agency partners (e.g., Departments of Defense or Veterans Affairs) or National Guard medics, take over the care and transport patients to other hospitals. There is a significant opportunity to make the patient data available electronically to all appropriate clinical personnel through an HIE platform.

Organizations Represented in Regional Meetings

- Acadian Ambulance Service
- Louisiana Health Information Exchange
- Louisiana State HIT Coordinator
- Louisiana Public Health Institute and Greater New Orleans HIE (GNOHIE)
- Metropolitan Hospital Council of New Orleans
- New Orleans Health Department
- Mississippi State Department of Health, Health Protection
- Mississippi Health Information Network (MS-HIN)
- Mississippi State HIT Coordinator
- Greater Houston HealthConnect (Houston HIE)
- Texas Department of State Health Services, Public Health Preparedness

Use Case Descriptions

Exchanging Data among EMS and Hospital Emergency Departments

Much like hospitals and practices, EMS providers are increasingly moving towards the use of electronic health records, which in the industry are typically called electronic patient care records (ePCRs). NEMSIS creates data standards for ePCRs, with a focus on sharing data between EMS providers and county and state agencies for reporting purposes. NEMSIS certified ePCR software as compliant with its standards, with version two being the current standard used by the majority of ePCR vendors.[4] NEMSIS has been developing version three of its data standard, and for version three has moved towards using HL7 clinical data architecture standards. As ePCR vendors move towards version three, the ability to share data with hospital emergency departments (EDs) and back to an ePCR will become more feasible.

There is a need for EMS personnel to share patient data with the hospital ED, prior to patient arrival. This allows the ED providers to appropriately prepare to receive the patient and adds to the patient's record across the full continuum of care. Conversely, EMS providers have a need for the hospital ED to share the patient's data back to their ePCR, once the encounter is closed. EMS providers and county/state agencies have a number of EMS Core quality measures they must meet, specifically for trauma, stroke, cardiac, and asthma events.[5] Without data from the hospital on the final disposition of the patient, EMS providers find it difficult if not impossible to assess their performance on these quality measures.

The envisioned use case is for EMS personnel to create an ePCR during transport and send the data to an HIO in the NEMSIS version three standard. The HIO would extract the most relevant data (as identified by hospital ED providers), translate it into the consolidated clinical data architecture (CCDA) format, and send it to the hospital ED that will be receiving the patient. A hospital using a 2014 certified EHR could integrate the CCDA data into the patient's record. Once the hospital ED provider closes the encounter with the patient or has a final disposition, they can create a CCDA summary of care and send it back to the HIO. The HIO would then translate the CCDA into the NEMSIS version three standard and send the summary to the EMS provider's ePCR.

Technical Considerations

The HIO transforming or translating the data will need to map the NEMSIS version three data fields to a CCDA format. HIOs will need a technology vendor that is capable of creating CCDAs and will need to determine how to map NEMSIS data that may not easily translate to the CCDA standard. Of note, in version three, NEMSIS has made an effort to utilize CCDA specifications where it could. However, a number of data elements could not be represented in the CCDA format. For example, EMS personnel typically make a preliminary diagnosis in the field, which is not the final disposition. ICD-10 codes cannot be used for the preliminary diagnosis, so

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[4] https://www.nemsis.org/v2/compliantSoftware/goldCompliant.html and https://www.nemsis.org/v2/compliantSoftware/silverCompliant.html

[5] California EMS System Core Quality Measures, Data Years 2012/2013, http://www.emsa.ca.gov/Media/Default/PDF/CM_2013_FINAL.pdf

NEMSIS has worked with the Regenstrief Institute to develop Logical Observation Identifiers Names and Codes (LOINC) specific to NEMSIS. These codes are used throughout the version three data standard. An HIO will need to determine how to map these codes to the CCDA format.

Additionally, the HIO will most likely require a master patient index (MPI) that can match the incoming record from EMS personnel with a patient in their HIO, and ideally include the hospital's medical record number (MRN) for the patient on the CCDA. The MPI would also be necessary for routing hospital ED CCDAs back to EMS providers. Potentially most challenging, the HIO will need a consistent and automated way to determine which hospital ED and the individual(s) within that hospital ED, to route the CCDA to. This data may be contained in the NEMSIS version three data sent from EMS personnel, but there may be situations where EMS personnel do not know which hospital ED the patient will be transported to, when data is sent to the HIO.

Policy Considerations

EMS providers, hospitals, and HIOs might work together to determine which information is most relevant for ED providers and what can be collected consistently in the field. This may be as simple as demographics so the ED can review the patient's record prior to arrival, or as advanced as an electrocardiogram (ECG) readout. All parties will need to come to an agreement on the base data that should be shared with the ED. This may be compounded by variations in hospital ED or EMS provider workflows.

There are concerns and issues that need to be addressed regarding the Health Insurance Portability and Accountability Act (HIPAA). EMS providers are a covered entity, as are hospital EDs, with HIOs acting as business associates. Consequently, when EMS providers send data through the HIO to the hospital ED, it is a covered HIPAA transaction, and all that would be necessary is a data use and reciprocal services agreement (DURSA) between the parties. Such an agreement would allow EMS personnel to query the HIO for patient data. However, sharing data from the hospital ED back to EMS is a concern for many hospitals. Specifically, hospitals are concerned about whether or not it is a covered HIPAA transaction, since it will be used to report quality data to county and state agencies. Cal EMSA has done some research into this particular concern and has proposed that county and state EMS agencies are not covered entities under HIPAA. They do, however, have specific obligations to analyze health information for quality measurement purposes. Cal EMSA's determination is that hospitals are legally allowed to share patient outcomes data with EMS providers and agencies.[6] Further research around this issue is needed, particularly around state laws for sharing protected health information.

[6] Cal EMSA Memorandum: Local EMS Agency HIPAA Responsibilities. February 2014. http://www.emsa.ca.gov/Media/Default/PDF/HIPAA_Local_EMS_Responsibility_for_Public_Health_Oversight.pdf

Disaster Response Medical History Web Portal

Patient Unified Lookup System for Emergencies (PULSE)

Disasters and large scale emergencies over the past decade have demonstrated the need to have immediate access to patients' medical histories when they are displaced from their communities. This was initially highlighted in the aftermath of Hurricane Katrina, as thousands of residents lost their medical histories in the flooding. Consequently, the industry created KatrinaHealth, a web portal that allowed physicians and pharmacists to search for a patient's medication history.[7] The site was available for a number of weeks, and was followed by the more permanent In Case of Emergency Prescription Database (ICERx). ICERx worked similarly to KatrinaHealth and was developed and run by the same organizations. It was used three times after Hurricane Katrina, but has since been shut down.[8] However, the industry recognizes the need to have easy access to patients' medical histories when they are displaced from their primary care physician and community hospitals.

For the purposes of this document, the disaster response medical history web portal has been named the Patient Unified Lookup System for Emergencies (PULSE). PULSE connects multiple data sources (HIOs and health systems) to an interoperability broker using IHE standards (XCPD/XCA or PDQ/XDS.b) that are currently supported by the eHealth Exchange. This allows each data source to create a single connection, rather than multiple, somewhat varied connections to each individual data source. Since healthcare professionals are unlikely to know which health system or HIO a patient's record exists in, a broadcast query to all data sources from the interoperability broker is the most efficient method for querying. PULSE connects to the interoperability broker and allows users to query for patient medical histories in two ways: 1) through a standalone web portal that can be accessed by healthcare professionals that are not connected to a participating HIO or health system (including first responders); and 2) through a participating HIO or health system's own web portal. PULSE would only be activated during a disaster or an emergency (the definition of which would be agreed upon by participants in advance). Since the user interface to PULSE is a URL, activating and deactivating PULSE could be accomplished by modifying the URL to point to either the login screen, or a message that indicates a disaster has not been declared and the page is currently unavailable. Likewise, HIOs and health systems participating in PULSE could create a hyperlink in their portal and use a Security Assertion Markup Language (SAML) assertion to allow their users to access the PULSE search screen through single sign on. The hyperlink could be modified to point to the currently unavailable page or the patient search screen as the situation dictates.

In addition to HIOs and health systems acting as data sources, organizations participating in the Blue Button+ project can also act as data sources. Blue Button+ builds on the original Blue Button concept by structuring the data file in the consolidated clinical data architecture (CCDA) format and using a RESTful API to "pull" data from the data source. These data sources can

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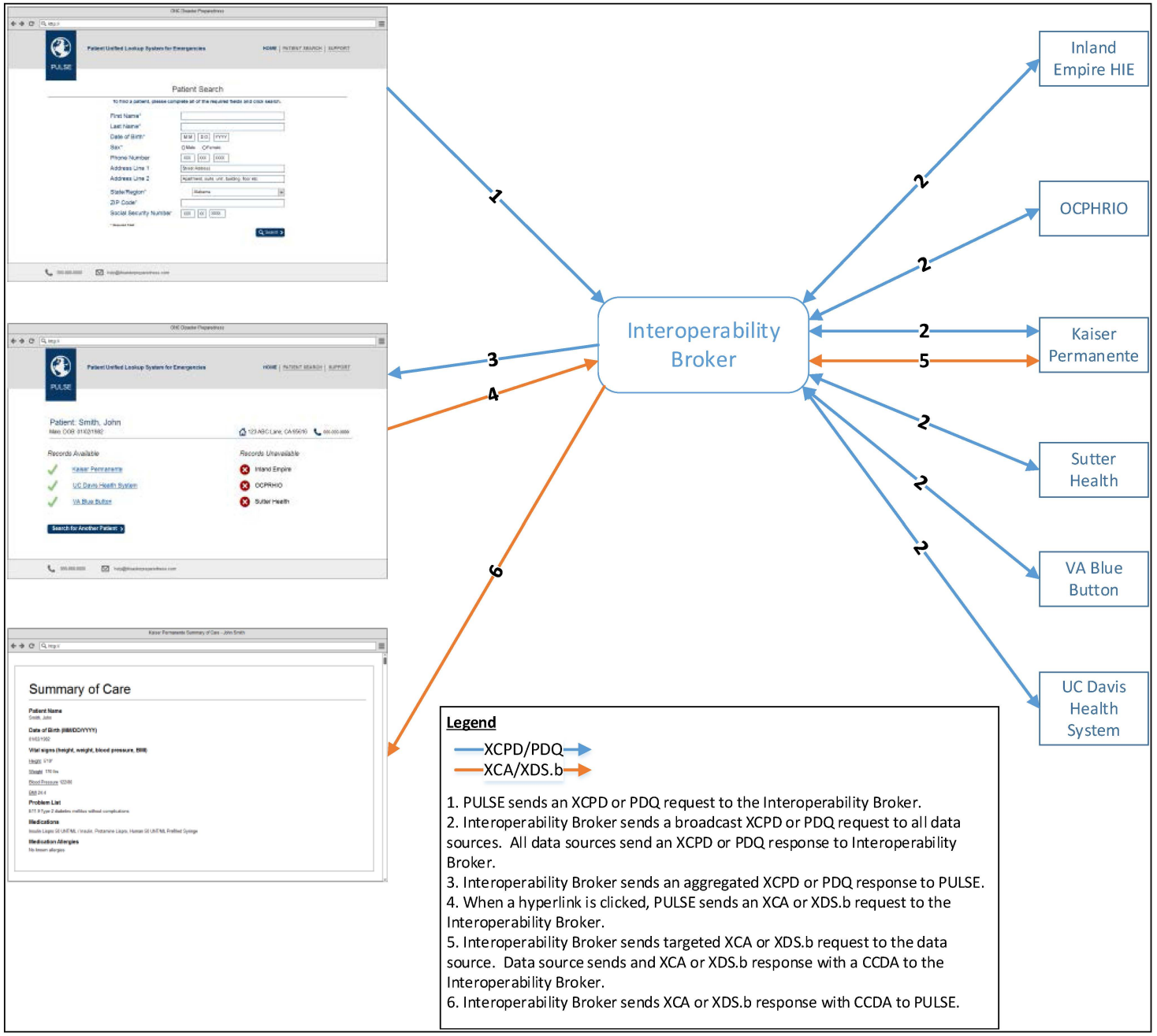
[7] Lessons from KatrinaHealth. Markle Foundation. June 2006. http://www.policyarchive.org/handle/10207/bitstreams/15501.pdf

[8] ICERx was limited to physicians and pharmacists. Based on interviews with organizations involved in running ICERx, it did not have high usage when activated. As noted by the Markle Foundation report, physicians typically did not have time to query the portal, while caring for patients, and participants believed that expanding the use of the portal to additional healthcare professionals would lead to higher usage.

connect to the interoperability broker via this API, rather than the IHE standards, and allow patient data to be queried by the healthcare professional providing treatment. Using Blue Button+ as a data source increases the likelihood that a healthcare professional will be able to obtain a patient's medical history, particularly for Medicare recipients and patients receiving treatment from a Veterans Affairs (VA) medical facility. Of note, Blue Button is primarily meant to be consumer facing. Consequently, this use case would likely need to be addressed in the organization's participation or privacy agreements. Figure A provides an overview of how PULSE could work, using California health systems and HIOs as an example.[9]

[9] Appendix A contains wireframe mock-ups of a potential user interface for PULSE.

Figure A: Diagram of PULSE functionality (California is used as an example)



Technical Considerations

Returning a CCDA

Since PULSE will be used during emergencies to provide immediate treatment to patients, it's believed that a summary of care in the CCDA format would be most helpful, particularly since for Stage 2, hospitals and providers will be producing these documents for their transitions of care, and the CCDA contains problems, medications, and allergies at a minimum. However, the IHE profiles suggested for PULSE, do not specify a specific type of document that should be returned to a user. To ensure a CCDA is returned, the data sources will need to build their systems in such a way, that when an XCPD or PDQ message is received from the interoperability broker, the document ID that is returned (when a document exists) is for a CCDA document in the data source's registry. When the interoperability broker then sends an XCA or XDS.b request, it will contain the document ID for the CCDA, and the data source will return the correct document type to PULSE.

System Redundancy

A major technical consideration is the location where PULSE components, specifically the interoperability broker and the user web interface, are hosted. Both items will require a disaster recovery server or location that is in a separate geography from the main infrastructure. This ensures that in the event of a disaster in the location where the interoperability broker and web interface are hosted, PULSE will have a fail over server and continue to be available. Similarly, hospitals and HIOs have their own disaster recovery plans, which typically include a second fail over environment and servers. For PULSE to have access to their data during a disaster, hospitals and HIOs may need to build two connections to the interoperability broker, one for their primary servers and one for their disaster recovery servers.

Policy Considerations

Types of Emergency Declarations

Since PULSE is only activated during an emergency, a primary consideration is defining which types of emergency declarations trigger the activation of PULSE. State laws dictate the circumstances under which a state of emergency is declared, the types of emergencies, and the individuals who can make the determination that an emergency should be declared. In states where different types of emergencies can be declared and where individuals other than the governor can declare an emergency (e.g., state health officers), each declaration has a different set of resources that are activated. Additionally, each declaration need not cover the entire state, but could be limited to a zip code(s), city, or county. Typically, local officials will declare an emergency first, and when their resources are exhausted state officials or the governor will declare a state of emergency. When state resources become insufficient due to the magnitude of the disaster (e.g., flood, tornado, pandemic, earthquake), the governor will request that the president make an official disaster declaration. Once the president declares a disaster, federal resources from the U.S. Department of Homeland Security's Federal Emergency Management Agency (FEMA) become available based on the needs of the state. Some emergency declarations are easily identifiable as situations that should activate PULSE (e.g., Hurricane Sandy); other declarations may not be as easily identified. States will need to define an activation plan for PULSE in their disaster Memoranda of Understanding (MOUs), Emergency Management

Assistance Compact (EMAC), local and state Emergency Operations Plans (EOPs) and other emergency policies and procedures.

HIPAA/Security

A major consideration for providing healthcare professionals with access to patient information is HIPAA compliance and the security of patient information. After Hurricane Katrina, Centers for Medicare and Medicaid Services (CMS) issued guidance for following HIPAA regulations during a declared disaster. Covered entities may always access patient data for treatment purposes, without requiring patient consent. Public health agencies and agencies, such as the Red Cross, may access limited patient data for treatment purposes and alerting next of kin. However, state laws may be stricter than HIPAA, particularly with regards to sensitive health data. A pilot project will need to explore the variance in state laws on access to patient health data. There may need to be limitations on the data shared in the summary of care, to abide by all state laws. In addition, providers may be concerned about liability associated with accessing or using clinical data obtained through a web portal that is outside of their normal experience. The liability context may be affected by any disaster declarations but should be analyzed and fully understood before establishing PULSE.

Data Use and Reciprocal Support Agreements (DURSA)

In order to provide PULSE with access to query data, HIOs and health systems will need to develop a DURSA that covers accessing data during an emergency or "break the glass" coverage. In 2012, the Southeast Regional HIT-HIE Collaboration (SERCH) recommended standard DURSA language that covers access between HIOs in the event of a disaster.[10] This language can be used by HIOs and health systems. Alternately, CAHIE developed the CalDURSA, which would cover California organizations for sharing information during a disaster but may require revisions to support inter-state exchange.[11] Finally, the eHealth Exchange DURSA does not currently contain "break the glass" language. [12] Potentially, the eHealth Exchange DURSA could be modified to include appropriate language that would enable organizations to immediate share data via PULSE in the event of an emergency.

Credentialing Users

There are two key aspects to credentialing users: 1) providing usernames/passwords to authorized users; and 2) determining who should have access, particularly across states, since state laws differ on access to patient health information. One of the lessons learned from KatrinaHealth was more than physicians and pharmacists need to have access to the patient's medical history. KatrinaHealth credentialed only licensed physicians and pharmacists to use the system, at that time these were the only two groups with a national database or registry that could be used to verify their licensure. Physicians, during Katrina, were rapidly triaging patients and they often did not have time to login to KatrinaHealth and find a patient. In fact physicians only represented 17 percent of the queries of KatrinaHealth. Additionally, technology that allows

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[10] ONC State Health Policy Consortium Project: Health Information Exchange in Disaster Preparedness and Response Final Report. RTI International. July 2012. http://www.healthit.gov/sites/default/files/pdf/SERCH-White-Paper.pdf

[11] http://www.ca-hie.org/projects/cadursa

[12] http://healthewayinc.org/index.php/exchange/dursa

individuals to use their credentials from one site to log in to another site (OpenID and OAuth), were in their infancy, requiring physicians and pharmacists to call toll-free numbers, be verified, and receive login credentials.

For PULSE to be successful and have a significant impact on patient care, access must be given to as many healthcare professionals as possible, including: first responders (including VA and National Guard medics, police officers, and firefighters), nurses, nurse practitioners, physician assistants, physicians, pharmacists, and other health professionals who would take part in the response. Additionally, credentials must be easily obtained or be reusable from other secure sites to make the login process as seamless as possible.

With the national registries available today, there are a number of avenues for credentialing healthcare professionals, including first responders, nurses, nurse practitioners, physician assistants, physicians, and pharmacists to provide easy access to PULSE in the event of an emergency.

- The National Registry of Emergency Medical Technicians (NREMT) provides certification for EMS personnel. [13] Some states require that all EMS personnel working in their state be registered with the NREMT, including Mississippi. California, Louisiana, and Texas have separate registries for EMS personnel, but work closely with the NREMT. NREMT issues usernames and passwords to individuals who are certified in the registry.
- The Emergency Service Advance Registry for Volunteer Healthcare Professionals (ESAR-VHP) is a national registry for individuals who want to volunteer to serve during an emergency or disaster.[14] ESAR-VHP verifies their credentials in advance, which allows them to immediately serve during a disaster, even across state lines. The registry issues usernames and passwords to individuals who are part of the registry. Of the states involved in the case study, Louisiana has the highest proportion of residents in ESAR-VHP, followed by California. Texas has very low registration, and Mississippi does not have any healthcare professionals registered.[15]
- The National Council of State Boards of Nursing (NCSBN) maintains Nursys, an online registry for verifying nursing credentials and licenses.[16] The registry includes both registered nurses (RNs) and certified nurse practitioners (CNPs). In addition to the registry, NCSBN runs the Nursys e-Notify service, which allows emergency response organizations to confirm a nurse's license and any disciplinary actions. Fifty-two Boards of Nursing (including states and U.S. territories) provide data for the e-Notify service.

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[13] http://www.nremt.org/
[14] http://www.phe.gov/esarvhp/Pages/default.aspx
[15] America's Emergency Care Environment: A State-by-State Report Card. American College of Emergency Physicians. 2014. http://www.emreportcard.org/uploadedFiles/EMReportCard2014.pdf
[16] https://www.nursys.com/Default.aspx

- The National Commission on Certification of Physician Assistants (NCCPA) maintains a national registry for certified physician assistants.[17] All states and U.S. territories utilize NCCPA for certification of physician assistants, meaning that this is truly a national registry. Certified physician assistants are issued a username and password to access the registry.
- Emergency responders including National Guard medics, VA medics, and EMS personnel participate in annual disaster response exercises. These exercises could include the use of PULSE and be used to issue usernames/passwords to participants.
- The Council for Affordable Quality Healthcare (CAQH) maintains the Universal Provider Datasource.[18] More than one million providers have registered with CAQH and provided documentation to support credentialing with health plans and hospitals. The database contains information that can be used to verify a provider's credentials prior to providing access to PULSE.

In addition to these systems, states and localities may have additional systems developed to manage medical volunteers (e.g., Medical Reserve Corps). There are a number of different methods for verifying an individual's credentials, licensure, or certification in order to provide access to PULSE. Ideally, a service such as OAuth could be used to allow individuals to utilize their registry's username/password to access PULSE. This would reduce the need for a manual identity proofing process. In lieu of using a single sign-on process, a manual process can be used to verify individuals' identities, including their credentials. The majority of the registries listed above provide access to search for and view records. The organization that maintains PULSE could request access to these registries and manually authenticate individuals, and then assign usernames/passwords. Finally, healthcare professionals who are already credentialed with a participating HIO or health system would use the same credentials to access PULSE and would not require any additional verification.

The second aspect relates to the legal issues of determining which healthcare professionals can access PULSE, particularly when they practice in a different state than where the emergency occurred. While ESAR-VHP alleviates some of the challenge, since all states recognize professionals registered with ESAR-VHP, the low registration rates, particularly in the Gulf Coast region, reduce its effectiveness. As noted earlier, state laws on who can access patient information vary. This challenge can be addressed several ways. If the governor declares an emergency, the EMAC can be activated. EMAC is an agreement between states to provide assistance after a state becomes overwhelmed to manage resources during an emergency.[19] EMAC requires states to recognize the certification/license of healthcare professionals from other states. This may allow healthcare professionals located in another state, who are treating a patient from the state where the disaster was declared, to access PULSE for treatment purposes.

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[17] http://www.nccpa.net/
[18] http://www.caqh.org/
[19] http://assets.opencrs.com/rpts/RL34585_20080721.pdf

Training, Use, and Incorporation into Disaster Response Exercises

Tools or procedures that are not used by medical professionals in their daily operations are less likely to be used in cases of emergencies or disasters. Conversely, there are many elements of disaster response that are only activated in case of an emergency or disaster. To the degree possible, access to and use of HIE services should be incorporated into the regular clinical workflows of health care providers in areas targeted for PULSE. However, some aspects of PULSE may not be capable of being activated or used on a day-to-day basis, absent the regulatory flexibility that accompanies a formal disaster declaration. Whether PULSE is used on a daily basis or not, training of individuals involved in responding to a disaster should be explicitly incorporated into formal emergency policies, procedures, and training and exercise plans. Overall the user interface of PULSE should be such that minimal training of individuals would be necessary.

Recommendations and Next Steps

As the hospital and ambulatory healthcare system become increasingly electronic and increasingly connected, there is a risk that the EMS community is not included as a relevant component of the continuum of care. Further, the continuous advances of HIE efforts within health systems and public HIOs has laid the foundation from which a national disaster response use case could be developed. Both California and the Gulf Coast have organizations and stakeholders that have demonstrated the readiness and willingness necessary to pursue pilot initiatives.

Based on the background research and direct stakeholder input that contributed to the overall assessment stemming from this effort, Ai recommends that ONC pursue the next steps below for each use case.

Disaster Response Use Case

The most apparent and actionable recommendation it to coordinate a pilot effort among enterprise and public HIOs in California and the Gulf Coast, as well as at least one organization working with Blue Button+, to pursue the technical approach described in the PULSE use case. The willingness of HIOs to participate, the leadership of state and local government, the limited number of underlying technology platforms involved, and the alignment with the existing national eHealth Exchange strategy all suggest that pursuing a multi-participant pilot could be a low barrier approach for the federal government to explore an extremely valuable opportunity. The most valuable ingredient in pursuing this pilot is the obvious collaborative nature of the relationships observed at both the community and state levels. Specifically, ONC should:

- Pursue a pilot of the disaster response use case described above;
- Identify five to nine California HIOs (both public and enterprise) to participate in a pilot;
- Identify an organization currently working on Blue Button+ and the RESTful API to participate in a pilot;
- Pursue the pilot in alignment with the core technical approach outlined above; and
- Coordinate the pilot with other relevant Federal partners.

EMS Bidirectional Data Exchange with Hospitals

There is further opportunity to support pilots in the major population centers in California that have seen high-levels of ePCR adoption and are poised to make significant progress on EMS to ED data exchange. There are a range of models and underlying technologies and workflows to support this data exchange, but it represents a foot in the door to exploring deeper exchange relationships among EMS agencies, ambulance providers, and the hospital community. While it may not ultimately be the most valuable use case to EMS agencies, it promotes an on-going level of coordination that creates trust and a set of partnerships, from which further work can successfully be accomplished. Specifically, ONC should:

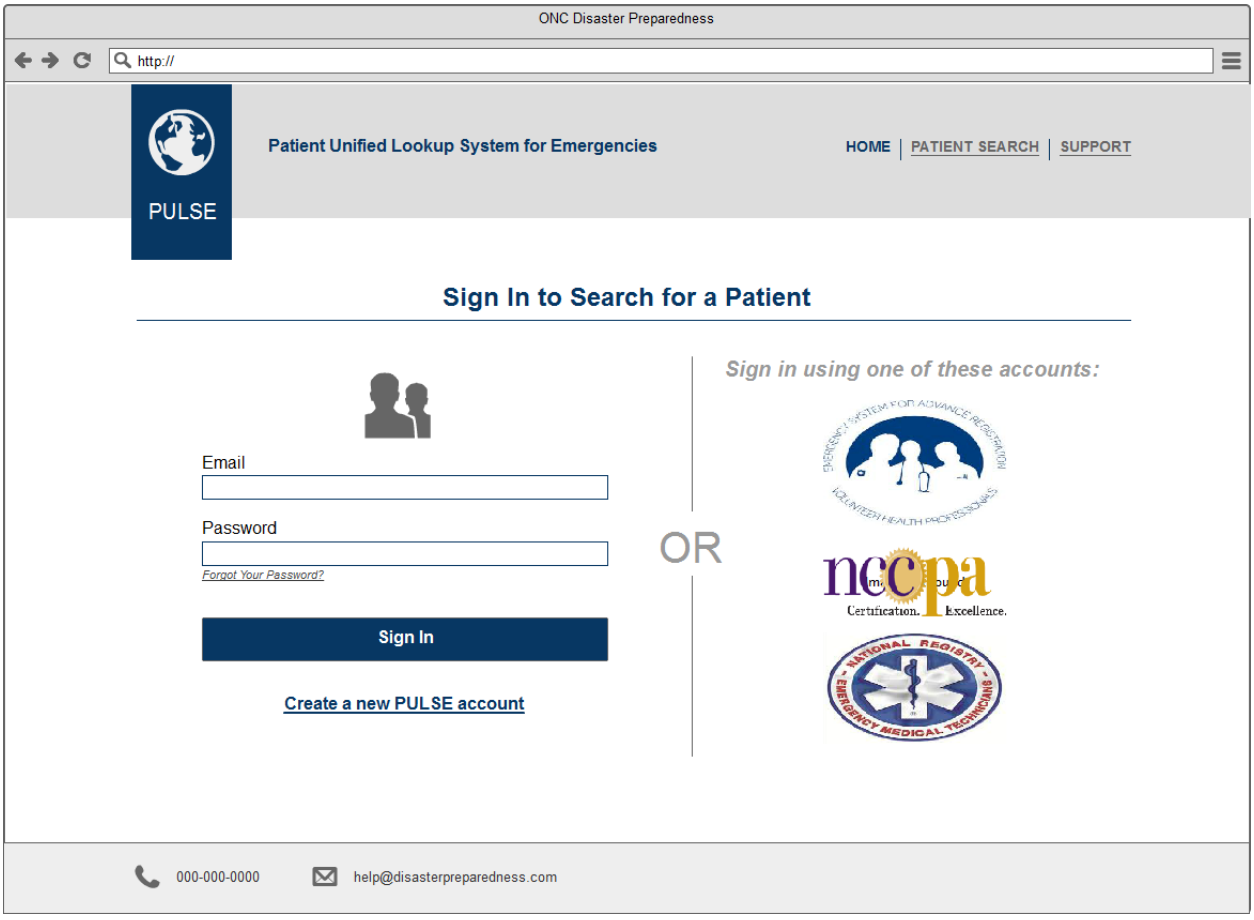
- Continue to encourage EMS leadership in major population centers to collaborate with HIE efforts;
- Generally encourage HIE efforts to pursue pilot activities with EMS agencies focused on practical service offerings, such as the pre-hospital to ED use case outlined above; and
- Identify two pilot locations to engage with more directly in establishing an ONC-sponsored pilot of pre-hospital to hospital data exchange.

Appendix A: PULSE Wireframes

Ai created the following wireframes as a tangible demonstration of how PULSE might look to end users. Every effort was made to make the interface easy to use, with minimal to no training.

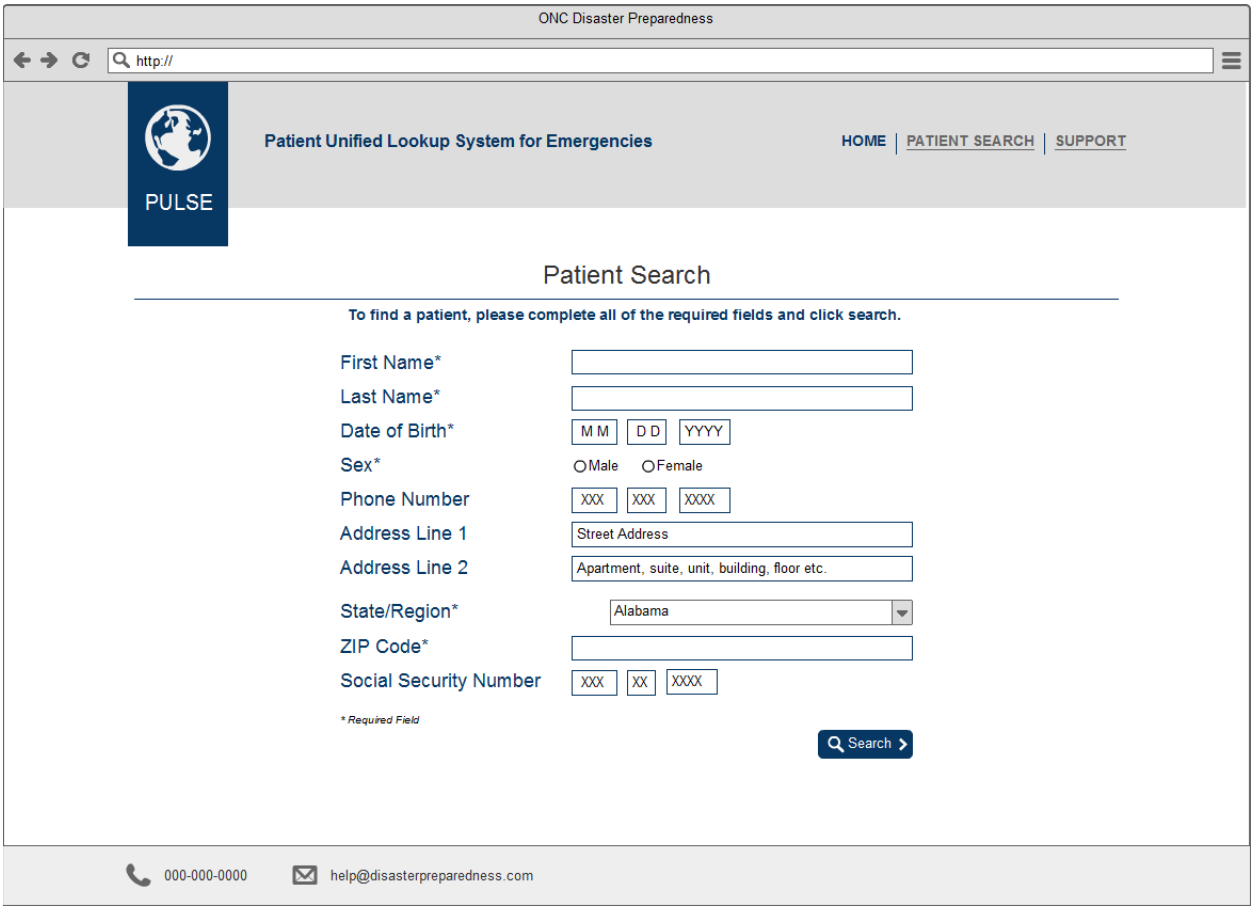
Landing Page

Healthcare professionals with existing credentials can login or click create an account. Individuals also have the option to use credentials from nationally recognized organizations to login.



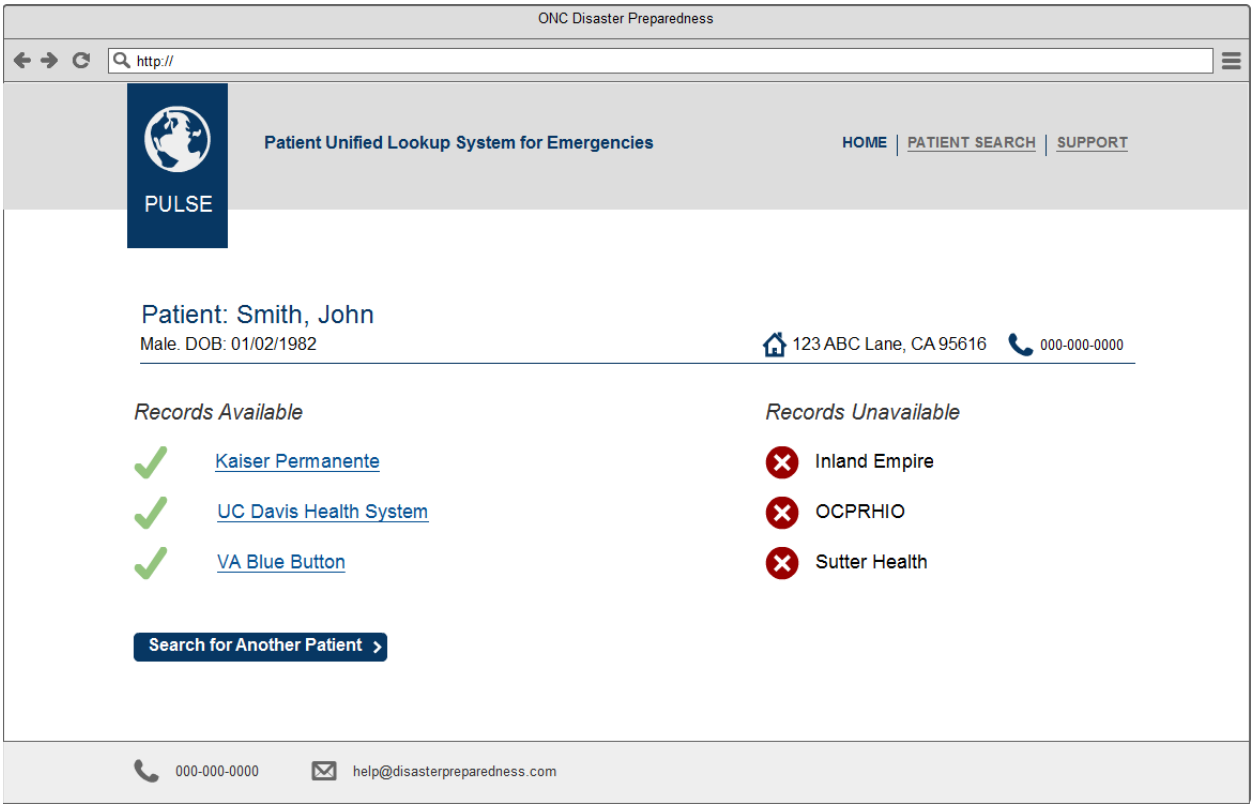
Patient Search Page

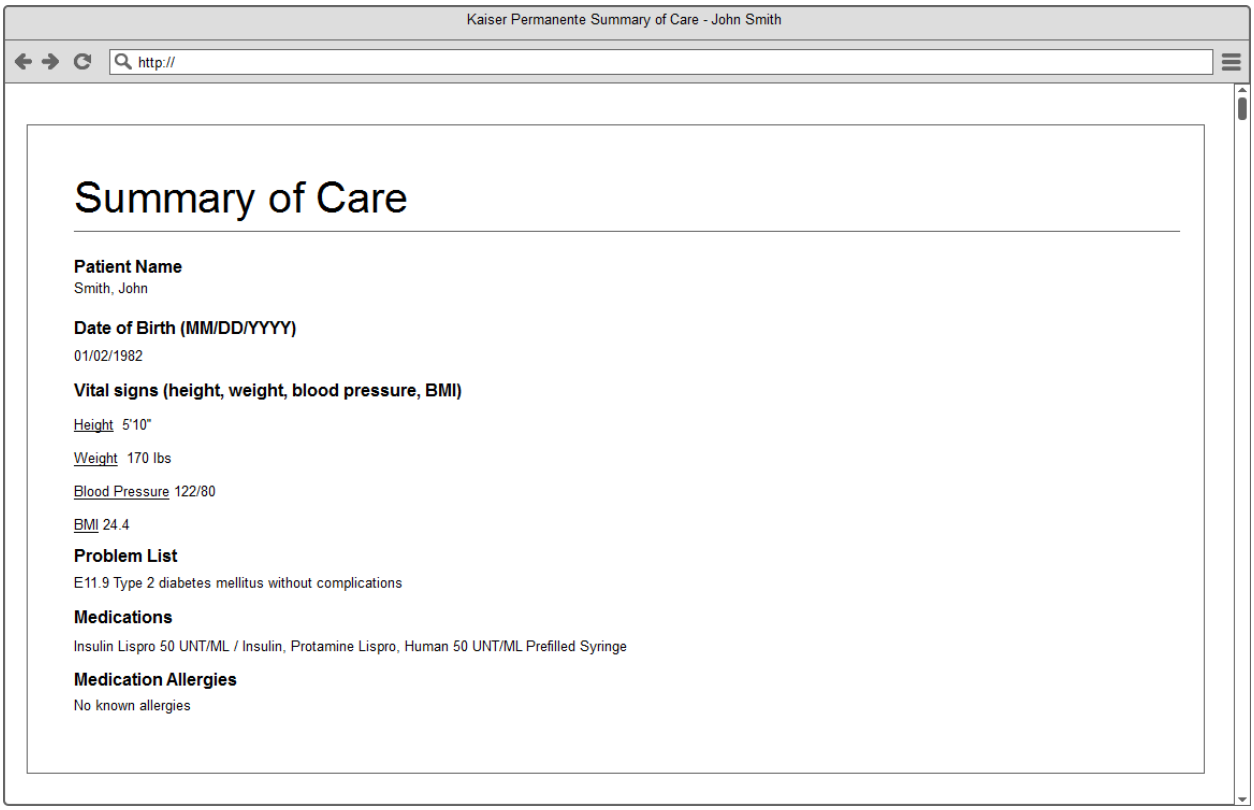
Users enter patient data for the required fields and click Search.



Response Page

An easy to interpret screen is returned. HIOs or health systems that have data for the patient are hyperlinked with a green check mark, and those without have a red "x" next to them. Users then click on each source to retrieve the summary of care.



Summary of Care

The summary of care is returned from the data source and an HTML style template is used to display the summary of care in human readable format in a new page.