Lessons From KatrinaHealth

Markle Foundation
American Medical Association
Gold Standard
RxHub
SureScripts

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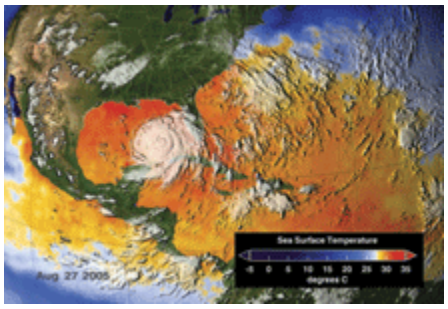


NASA/SVS

"Katrina will likely be recorded as the worst natural disaster in the history of the United States."

— U.S. National Hurricane Center

KatrinaHealth was an online service that was established to help individuals affected by Hurricane Katrina work with their health professionals to gain access to their own electronic prescription medication records. Through a single portal, **KatrinaHealth.org**, authorized pharmacists and doctors were able to get records of medications evacuees were using before the storm hit, including the specific dosages. Having this information helped evacuees renew their medications, and helped healthcare professionals avoid harmful prescription errors and coordinate care. With the assistance of federal, state, and local governments, **KatrinaHealth** was made possible by a national foundation, several private businesses, and national organizations of physicians and other health professionals.

This report is based largely on the proceedings of a meeting of principals involved in **KatrinaHealth** that was held by the Markle Foundation on November 18, 2005. It contains the following topics: a description of the storm and its impact, the primary hurdles **KatrinaHealth** faced, concerns about national disaster response, the context for disaster response, details of the KatrinaHealth story, and set of recommendations in anticipation of future disasters.

The Gathering Disaster

Just after 6:00 a.m. on Monday morning, August 29, 2005, a Category 4 hurricane bearing gusts of up to 155 mph hit southern Louisiana near New Orleans, a major U.S. port city whose metropolitan area includes some 1.4 million residents. At 10:00 a.m., it made landfall a second time further north, as a Category 3 storm, devastating the Mississippi-Louisiana border region with a storm surge up to 28 feet high. Nearly 10 million Gulf Coast residents experienced the storm's hurricane-force winds, and the official death toll for the several affected states was over 1,800, with approximately as many missing but not confirmed dead.

Katrina's awful impact was not fully revealed until the following day, when the breached levees and burst canals of New Orleans allowed the waters of Lake Pontchartrain to surge into the town. Water filled up the city's low-lying areas—many of which are 7-10 feet below sea level—as if it were a giant punchbowl. Within hours, three-fourths of greater New Orleans lay under water.

Many New Orleans residents who could evacuate before the storm did so, but perhaps 100,000 people who may not have had the resources to evacuate, did not. They were now stranded, with rising water and decreasing evacuation options. The breakdown in emergency services, food and water supply, sanitation, and law and order that ensued was an unprecedented event on the nation's consciousness.

More than 1 million people evacuated Louisiana and Mississippi either before or, eventually, after the storm. As they arrived in recipient communities—Baton Rouge, Houston, Dallas, and Atlanta—an entire region rallied to cope with the aftermath of the tragedy. Many residents found refuge in even more distant harbors—New Jersey, New York, Utah, and California. Eventually every state in the union would house at least some of Katrina's evacuees, and 44 areas sheltered significant numbers.

But this was not the end. A mere 25 days later, another hurricane approached. After entering the Gulf of Mexico, Hurricane Rita rapidly intensified from a Category 2 to a Category 5 hurricane in 24 hours. Although it weakened as it moved toward Galveston, Rita frightened nervous Gulf Coast residents. Houston was evacuated. Tens of thousands of Louisianans sheltering there were displaced for the second time in less than a month. Rita made landfall at about 2:30 a.m., September 24, just east of the Texas-Louisiana Border as a Category 3 storm. Its 120 mph winds caused serious wind and water destruction and produced a storm surge that again flooded portions of New Orleans, but spared Houston its worst.

Within days of the first storm, Americans haunted by the televised images and personal stories emerging from the chaos sought the best ways they could help Gulf Coast communities and their scattered people. Water rescue teams arrived with boats and rafts to collect stranded residents; doctors and nurses set up tent clinics to provide emergency medical services; and animal rescue organizations worked to save the city's pets. People expert in health information technology were no exception. Many in this latter group joined together to create **KatrinaHealth**. Participants represented an ever-enlarging group of key players: medical software companies; pharmacy benefit managers; chain drug stores; local, state, and federal agencies; and doctors. Eventually 150 public and private organizations would provide data and support for **KatrinaHealth**.

KatrinaHealth grew out of the clear understanding that, in the midst of all the destruction and displacement, residents and evacuees would have become perhaps permanently separated from their personal medical records. An obvious need was to reconstruct at least some portion of those records, particularly the medication history—the drugs people are taking to control and manage both acute and chronic conditions. In fact, an estimated 40 percent of evacuees used one or more prescription medications before the storm hit. Afterward, as a result of both routine medical needs and disaster-related problems caused by exposure, lack of food and clean water, and physical and mental stress, many more evacuees would require medical assistance. Under emergency conditions, tracking their personal records would be difficult, if not impossible.

KatrinaHealth was conceived as a way to fill in at least some of that missing information. For doctors working with evacuees and residents, it would be a useful reference for understanding the medical history of their new patients. For pharmacists, it would help reconstruct customers' medication records.

Disaster planning has long included consideration of likely health services needs. But little effort had previously been put into reconstructing personal medical records. Perhaps this is because, in the past, the job was virtually impossible. A person's medical history existed in highly decentralized paper form in the offices of their several doctors or clinics, testing laboratories, the corner drug store, the local hospital, the health department, and so on. Today, as the U.S. health care system inches toward broader deployment of electronic health records (EHRs) and other electronic information systems connected and interoperating over the Internet, what was impossible has become more feasible. And, in some parts of the system—particularly the insurance and payments parts—electronic administrative data systems are well developed.

Details of the KatrinaHealth Story

The Genesis of KatrinaHealth

As early as Friday, September 2, queries were going out among a network of health information technology experts to explore ways to help. For Markle Foundation executives, figuring out a way to pull together medical records, particularly pharmacy records, had immediate appeal, because of the acute nature of the need and because it was known that the medication history data was accessible outside of the affected areas by key players in pharmacy data management. Calls to the American Red Cross corroborated such interest in medication data.

Over Labor Day weekend, Markle executives called the heads of several companies that held pharmacy data, such as the National Association of Chain Drug Stores (NACDS). Craig Fuller, NACDS president and chief executive officer, knew immediately that Gold Standard, a Tampa-based company, would be an essential part of any response because of their experience with a similar situation after Florida hurricanes. Fuller suggested that Gold Standard executives work toward this effort, and that same day calls were also made to SureScripts and RxHub. Most people in this group knew each other and had worked together on the Markle Foundation's **Connecting for Health** project. There was immediate willingness to give this effort priority within their companies.

Over the next 12 hours, partly in response to an email sent to a large group of colleagues in the health information technology community from Mark Frisse, MD (director of regional initiatives for the Vanderbilt Center for Better Health), a conversation began amongst colleagues. Sparked by the health information community's collective desire to assist those in need, the federal Office of the National Coordinator for Health Information Technology, headed by Dr. David Brailer, suggested a conference call in which he asked many of the thought leaders in health information technology to brainstorm ideas about how to harness information technology in the emergency. Additionally, Dr. Brailer contacted and engaged the appropriate representatives within the federal health information technology community. On Sunday, Dr. Brailer held the first call. During the discussion, several participants suggested the pharmacy records project. Anticipating the key issues that would arise in implementation, work groups were established, led by individuals from the public and private sectors:

- evacuee registration (Carol Diamond and Lori Evans)
- information access (Carol Diamond and Dale Nordenberg)
- field medical records (Janet Marchibroda and Robert Wah)
- dissemination and communication (Dana Haza)
- security and authentication (Lori Evans and Scott Wallace)

Initially, there also was a group monitoring coverage issues that provided periodic updates.

The group planned a series of daily 1:00 p.m. conference calls in order to move the project forward, keep participants informed of progress and problems, and collectively brainstorm solutions and workarounds. Participants represented an ever-enlarging group of key players: medical software companies; pharmacy benefit managers; chain drug stores; local, state, and federal agencies; and doctors. Eventually 150 public and private organizations would provide data and support for **KatrinaHealth**.

The Veterans Health Administration's Information Technology Commitment

The nation's largest integrated health system, the Veterans Health Administration (VHA), has invested heavily in information technology as a way to ensure accountability for quality of care and to improve system efficiency. The VHA's automated information system has operated in all its medical facilities since 1985, and its computerized patient record system for clinicians became operational in 1997. The system contains information on medications, procedures, x-rays and imaging, laboratory tests, and so on, and serves a wide variety of professionals, regardless of setting. It can be viewed remotely from other VHA and some Department of Defense medical treatment facilities. Within VHA, all information for all Veterans was available through the VHA's EHR, allowing the VHA to access records for any of its patients who found their way from the Gulf Coast to other veterans' facilities around the nation. After the storm, the VHA's Wide Area Network was down for a short time, and records could not be accessed. Within 24 hours, this problem was solved. The VHA also was able to use an existing "identity management" system to verify the identity of evacuated employees as well as patients. **KatrinaHealth**.org provided a tool for VHA physicians, acting as emergency responders, to see the medication history of non-Veteran patients.

Where were the data?

The ad hoc team that worked on KatrinaHealth worked with several key organizations involved in handling pharmacy information:

- **Gold Standard**—managed Medicaid prescription information for Mississippi with an existing, secure online medication information portal for doctors, and had agreements in place prior to Katrina to do the same in Louisiana. They also had the experience of setting up a very similar system in Florida during the 2004 hurricane season.

- **Rx Hub**—electronically routes up-to-date patient medication history and pharmacy benefit information to physicians in their offices and at hospitals on behalf of several large pharmacy benefit managers (PBMs) (including Caremark, Express Scripts and Medco). They currently manage the information for over 150 million individuals with pharmacy benefits in their virtual network.
- **SureScripts**—manages an e-prescribing network covering more than 90% of the nation's pharmacies. SureScripts pooled data from numerous chain pharmacies including Albertsons, CVS/Pharmacy, Kmart, Rite Aid, Target, Walgreens, Wal-Mart, and Winn Dixie.
- **Veterans Health Administration**—with its own national system of electronic records for veterans who seek care through its system.

KatrinaHealth was able to leverage the tremendous investments these organizations have made over the past several decades in developing sophisticated data systems and communications capabilities for managing the supply chain, identity, and pharmacy information. KatrinaHealth resulted when these organizations effectively leveraged their individual resources and created a single, secure portal.

KatrinaHealth was structured with two architectures. One was to query the original source of data over a secure network, the other simpler method was to capture a single snapshot of data from the source system and move it to Gold Standard. There were advantages and disadvantages of both. Capturing a snapshot of data meant that the timeliness of the data was limited to the date and time when it was captured and moved, but the technical solution was available sooner and with less technical effort than the real-time network queries to the source of the data. However, real-time network queries, when enabled, had the advantage of returning data that was accurate up to the time of the query and avoided the need to centralize all of the prescription history data, leaving it in its source system when possible. The benefits of this flexible architecture were that it allowed multiple solutions to be adapted in line with the capabilities of different participating entities and supported a policy approach that was mindful of privacy and security protections.

Ultimately, both strategies enabled prescription data from any source (Medicaid, Veterans Heath Administration, commercial payers, and community pharmacies) to be retrieved via a single web portal. In doing so, **KatrinaHealth** succeeded in enabling access to patient medication data for evacuees by any authorized physician or pharmacist caring for them. This response was operational at a pace and scale never before attempted.

RxHub, SureScripts, and Gold Standard made available the information their systems contained for residents of the affected ZIP codes (192 for Hurricane

Katrina and 82 for Hurricane Rita), as defined by the Federal Disaster Management Agency (FEMA), covering some 90,000 square miles. Personnel from these three organizations and the chain pharmacy headquarters organized by SureScripts put existing work on hold and focused enormous energy on clearing the technical hurdles involved in linking to the **KatrinaHealth** portal. Current business models and competitive relationships were set aside. And they did this work pro bono.

How was the privacy and security of the data protected?

Protecting the privacy and security of the data was a paramount concern for all involved. Under ordinary circumstances, HIPAA privacy rules would have required formal, written "business associate agreements" among **KatrinaHealth** participants before they could exchange medical information, and many of the participants already had these agreements in place or were able to do so rapidly during that first week in September. Almost in parallel, relief also came on September 9 when the Department of Health and Human Services (DHHS) Office for Civil Rights (which oversees HIPAA) issued a special bulletin clarifying that, considering the emergency circumstances, organizations that did not comply with the usual business associate requirements would not be penalized as long as they showed "good faith efforts" to protect the privacy of health information "and to appropriately execute the agreements required by the Privacy Rule as soon as practicable."

In addition to HIPAA, many states have laws that restrict sharing of information on sensitive health care conditions, such as mental health, substance abuse, or HIV/AIDS. Since **KatrinaHealth** might be used by doctors and pharmacists in every state for patients from several states, the **KatrinaHealth** team could not quickly resolve these interstate differences at a technical or policy level, and therefore took the most conservative approach: all data that might be deemed sensitive by laws in any state were removed from the database.

Organization	**RxHub**	**SureScripts**	**Gold Standard**	**Veterans Administration (VA)**
Having data for	All states	All states	Mississippi & Louisiana	All states
Specialty	Pharmacy benefits management	Community Pharmacies	Medicaid claims processor	Medical care provider
Had data on	Medicare & privately insured patients	Patients of all types	Medicaid patients	VA patients

How were the data structured to protect privacy?

In addition to avoiding centralization where possible, KatrinaHealth was structured in such a way as to prohibit access to aggregate data. Authorized physicians and pharmacists had the ability to dispatch a query for one patient at a time only (such as when they encountered the patient for care or when a patient presented to renew a prescription) and their query could not be successfully submitted unless they were authorized and had obtained specific information about the patient.

All activity on KatrinaHealth.org was closely monitored. System audits were in place and Gold Standard and RxHub established real-time monitoring of the queries to Katrina Health so that any unusual activity could be assessed and disrupted if necessary.

Who could access the KatrinaHealth portal?

KatrinaHealth was piloted in a dozen shelters in Louisiana, Mississippi, Dallas, and the VA system, starting Tuesday, September 12. Every day more data were linked into the system, more sites were added to those having access, and the team made revisions to the site based on feedback from the field. Select shelters and community pharmacists were able to access the data through their secure IP connection. Initially no one was credentialed to use the system outside of the handful of shelters and the community pharmacies—but for rollout, the team had to solve the problem of allowing doctors and pharmacists in 50 states to access the system.

A telephone call secured the aid of the American Medical Association (AMA) in establishing a system in which potential physician users could call an 800-number to be authenticated. An AMA staff member would verify their identity using the AMA's Physician Masterfile information; in effect asking physicians to prove they were who they said they were (by answering a series of detailed questions) and to have a medical license in good standing. The AMA would only then would provide a username and password from a list provided by Gold Standard. Daily, the AMA advised Gold Standard of the "credentials" that had been given out, and that batch of users was cleared to use **KatrinaHealth**.

Similarly, the National Community Pharmacists Association (NCPA) authenticated and provided access for independent pharmacy owners seeking access to **KatrinaHealth**.org, and SureScripts authenticated and provided login information for community pharmacies on behalf of the National Association of Chain Drug Stores (NACDS). The community pharmacies were able to validate IP

addresses from the computers used by pharmacists in their chains in order to authenticate this group of users.

KatrinaHealth was officially rolled out nationwide on September 22. For doctors and pharmacists, the system was simple to access. Once they were authorized and authenticated, they could then sign in, type in identifying information for their patient, and **KatrinaHealth** would query the various systems for prescriptions filled during the previous 90 days. Exactly matching data from any or all of the sources were delivered to the health care professional in a uniform format.

Because the need for data security required absolute assurance that users of **KatrinaHealth** were authenticated, one great disappointment was that it was not possible to make the system available to many other categories of health professionals—nurses, nurse practitioners, and physician assistants, and even hospital pharmacists for example—for whom a definitive and simple authentication mechanism was not readily available during the crisis.

How were patient identities verified?

Although some information technology experts have advocated a national system of unique patient identifiers usable across health care settings, privacy concerns have stalled the actual development of such a system. The Connecting for Health report, *Linking Health Care Information: Proposed Methods for Improving Care and Protecting Privacy* http://www.connectingforhealth.org/assets/reports/linking_report_2_2005.pdf, seriously questions whether a system of universal identifiers is either desirable or feasible. It argues that as long as there is a lack of agreement about implementing such an identifier, other reliable methods of linking information about a patient based on probabilistic matching need to be developed and deployed.

Having in place a secure system to manage patient identities across a large population was essential to handling requests for medication history where data may reside in different places. The medication history information from the PBMs was accessed directly through the RxHub network. RxHub does not store any of the medication history data themselves. Rather a finely tuned probabilistic matching algorithm is used to query the source data held separately by each of the PBM's. The team maximized this resource by networking it to the **KatrinaHealth.org** portal, which avoided the need to move or centralize any of the pharmacy benefit records. In the following weeks, when Hurricane Rita was imminent, the teams once again had to respond. Because the PBM data was already networked through RxHub, the team could expand **KatrinaHealth** to include residents from the Hurricane Rita ZIP codes almost immediately.

Similarly, the retail pharmacy chains once again pulled their resources together to respond to the pending disaster and again dedicated efforts to rapidly pool their data over the 48 hours prior to the hurricane.

The retail pharmacy, state Medicaid, and VA records, however, had not been previously linked. To develop **KatrinaHealth,** the team had to quickly put in place an alternative method of linking records for the same individual. This method put a priority on avoiding incorrectly linking information; therefore, it linked records based only on an exact match of five key pieces of demographic information. For these records, the probabilistic algorithm and the standard methods used in the industry to correct for misspelling or transposition of digits had to be forgone since there was no time to tune or test them. The result of this conservative approach was that, on the one hand, a doctor or pharmacist querying **KatrinaHealth** was never given records that did not belong to the specific patient they were seeing. But on the other hand, their query may have failed to produce records more often than necessary. In an effort to reduce to reduce the possibility of having records linked incorrectly, the team had to accept the attendant consequence, which is that they may not have linked records that should have been linked—estimated to be about an additional 5% of the total number of records.

What information did health professionals receive?

Medication history for a period of 90 days was, where possible, provided for this population from all sources. In addition to medication history, the community pharmacy data pooled by Surescripts often contained additional information about the medications such as indication and dosage, administration, interactions, dose and quantity, and whether refills were available on existing prescriptions. It also included information on known drug allergies, who wrote the prescription, and, in some cases, the pharmacy where it had been filled.

Sensitive information as defined by state laws in the areas of mental health, substance abuse, and HIV/AIDS was not available from any source.

How were people made aware of KatrinaHealth?

Once **KatrinaHealth** was near completion, word about it had to get out quickly, especially to pharmacists, doctors, and shelters. SureScripts worked with the National Association of Chain Drug Stores and the National Community Pharmacists Association to leverage their numerous communication vehicles to get the word out to community pharmacists nationwide.

Doctors were more dispersed. However, the AMA aggressively promoted the service on its web site, in its various widely distributed electronic and print

publications for members and affiliated organizations, and discussed it in speeches and presentations to medical groups.

Surprisingly, there was no master list of shelters, so reaching them was sometimes impossible or a complicated two-step process, going through other entities.

A news conference launched the **KatrinaHealth**.org web site, and information about the site was distributed to almost 500 journalists covering the hurricanes, health, and information technology, as well as to web sites offering other information for evacuees.

KatrinaHealth team members distributed information to their own diverse constituencies as part of the overall effort to increase awareness of the service among the affected public. For example, the National Council of Churches distributed materials to more than 160,000 people, and 22 organizations posted the **KatrinaHealth**.org link on their web sites for professionals and the public. Time did not allow a thorough analysis to determine the best way to convey information about the service to the public. However, a survey conducted in late September 2005 underscored public concern about data privacy and validated **KatrinaHealth**'s emphasis on system security.

From October 10 through November 11, the **KatrinaHealth**.org outreach team increased the pace of outreach to all organizations, individuals, and governmental agencies that received **KatrinaHealth** information to ensure they had what they needed to post to web sites and distribute through their networks. The team also reached out to groups associated with evacuee support and disaster relief in the 44 major resettlement areas across the country, focusing on the highest-impact areas.

During November, the outreach team continued to work with national and local media in the Gulf Coast and major resettlement areas in order to make people aware that evacuees' prescription drug information was available.

KatrinaHealth Timeline

Aug 26	Louisiana declares state of emergency
Aug 28	New Orleans's Mayor orders mandatory evacuation
Aug 29	Katrina hits Gulf Coast; President declares disaster
Aug 30	Flood waters rise First **KatrinaHealth** planning call
Sept 4	Technical work begins
Sept 6	HIPAA enforcement statement Community Pharmacy (via Surescripts) & Medicaid data integrated
Sept 9	Pilot tests begin in La., Miss., Tex., and VA system
Sept 11	Decisions made about filtering out sensitive data AMA's MD authentication process and RxHub-Gold Standard data exchange operational
Sept 13	***KatrinaHealth launched*** 82 doctors & 27,000 pharmacies have access Expanded marketing effort begins
Sept 18	
Sept 21	
Sept 22	
Oct 3	
Oct 10	

What were the results?

Within the first 60 days, **KatrinaHealth** had fielded nearly 5,000 queries from doctors (17 percent of total queries) and pharmacists (83 percent). Patient-specific results were successfully obtained for 1,500 of these queries. Approximately 1,100 of the successful searches were from the community pharmacy (SureScripts) database, 250 were from RxHub, and 160 were from the LA Medicaid data. Improving patient identity matching could have had a somewhat positive boost on the number of queries that produced results. Some numbers of queries failed because patients were not from the FEMA-designated ZIP codes and, by definition, their data were never included in **KatrinaHealth**.

More than 100 doctors from 30 states requested authentication to use **KatrinaHealth**. Over 16 chain pharmacies, representing thousands of pharmacists, and over 100 independent pharmacists were authenticated. If access to **KatrinaHealth** could have been expanded to nurses and other clinicians, it might have been seen as a time-saver for doctors, and use of it probably would have increased.

Because the PBM data was networked, real-time queries yielded accurate medication histories up until the time of the actual query. For the remainder of the data, the result of a query to **KatrinaHealth**.org would yield a 90-day medication history as of approximately September 10, based on the one-time snapshot created when the data was pulled.

What's the future of KatrinaHealth?

The web site **KatrinaHealth**.org, created to respond to an emergency situation, was available, as intended, for just a short 90 day period. But **KatrinaHealth**—the project—was more than just "a triumph of good will," as one participant said, it also demonstrated a feasible, pragmatic strategy for gathering personal health care information from multiple sources quickly and (relatively) easily, without creating a massive centralized database. In this regard, it was a poster child for the concept of interoperability. The **KatrinaHealth** experience and aspects of the technical model it used were important demonstrations of a viable approach to the broader goal of sharing health information with authorized patients and clinicians over a secure network—something necessary for the provision of high quality health care in the routine and emergency situations.

Finally, and more generally, **KatrinaHealth** established what one federal official called a "new benchmark" for public and private sector collaboration around health information technology that has prompted many involved in current efforts to ask how they can move faster.

The Hurdles KatrinaHealth Faced

To design, construct, test, and prepare **KatrinaHealth** for use in less than three weeks, the project team confronted numerous technical, policy, and organizational hurdles. The specifics of the team's process are described in some detail at the end of this report. Many of the hurdles were overcome, some were not, but did not derail the project, and others remained sticking points. Contrary to expectations, the technical hurdles, although significant, were easier to work around, and sometimes solve, than were some of the policy, business, and organizational issues.

Some of the hurdles described were specific to the development of **KatrinaHealth**, but others plagued the post-Katrina health care response as a whole. In some cases, these challenges overwhelmed the efficiency and effectiveness with which a narrowly defined project like **KatrinaHealth** could be implemented. One of the primary hurdles that kept **KatrinaHealth** from having maximum exposure and impact was that it was conceived and implemented after-the-fact, when all the displacements and disruption of the hurricane absorbed the attention even of those clinicians and evacuees who could have been helped by it.

Technical Hurdles

KatrinaHealth showed that it's possible to work around many of the technical challenges to electronic health information sharing.	In less than three weeks, the most ambitious effort yet undertaken to make patient health care data securely and widely accessible to accredited health care providers was up and running smoothly, using a web-based portal that allowed an authorized professional to request for medication history for a particular patient from multiple data sources containing prescription information for Katrina evacuees.
KatrinaHealth demonstrated the value of networked systems.	The importance of having worked on the challenge of accurately linking information about the same person from various data sources was highlighted by the experience of **KatrinaHealth**. Health information today is scattered across many information systems—a reflection of our highly decentralized health care delivery system. Routine care and disaster responses demand a way to link information and do so "on the fly," so that information about an individual can be brought efficiently to the clinical encounter. Without a method to reliably do this, manually cutting files from

	multiple databases, pulling the data together, and trying to link them appropriately—initially and each time a change in the target population occurred—proved very challenging.
Effort spent forging business arrangements and creating technical standards pays dividends during an emergency.	Organizations that had worked together in the past and had brought their information systems into alignment were able to respond much more quickly to the disaster. For example, Louisiana's Medicaid program had a business agreement already in place with Gold Standard that enabled it to quickly provide patient medication records into **KatrinaHealth**.
Policy Hurdles	
The HIPAA framework did not complicate putting KatrinaHealth together.	HIPAA privacy rules set the "floor" for national health-data privacy. They are designed to be flexible in emergencies and permitted information disclosure for treatment purposes in the post-Katrina situation. The Department of Health and Human Services' Office for Civil Rights (OCR), which oversees HIPAA, issued two bulletins to clarify HIPAA's policy in emergencies. These clarifications helped **KatrinaHealth** participants by allowing them to put business associate agreements in place in a way that did not delay the project. The OCR took into consideration the emergency situation and acknowledged "good faith efforts" to implement privacy protections and written agreements as soon as was practicable. The HIPAA framework is well understood by businesses involved in health care, and the **KatrinaHealth** team was able to use this familiar mechanism to quickly establish relationships among its participants. In addition to HIPAA however, several other privacy and security measures had to be put in place, including audit and monitoring measures, establishing authentication methods for community health professionals, restricting access to any aggregate data, and assuring compliance with many state laws restricting access to data for sensitive conditions such as mental health, substance abuse, and HIV/AIDS.

KatrinaHealth used a collaborative decision-making model.	The team that developed **KatrinaHealth** kept the health information technology community informed about the progress of the project through a series of daily hour-long conference calls. The Office of the National Coordinator for Health Information Technology **(**ONC) took the lead on setting up the calls for the first month, after which Markle staff organized and supported them throughout the duration of the project. Several work groups were established for efficiency, and these groups also conducted multiple conference calls daily—in order to move the project forward. The number of planning partners and supporters eventually numbered 150. Any large, complex project involving multiple parties needs a locus for making decisions—one who understands and respects the capabilities of each player, and who keeps them on a timeline by being an effective problem solver and cheerleader. In **KatrinaHealth**, the sense of urgency created by the disaster, and the positive group dynamic established by the conference calls, encouraged team members to set aside many organizational competitive interests and work together effectively as a team.
By contrast, the broader disaster relief effort was* not *well coordinated.	One early decision the **KatrinaHealth** team had to make was, "Whose records should **KatrinaHealth** include?" Different governmental agencies and private organizations like the American Red Cross defined the disaster's "affected areas" differently. These definitions had enormous implications for local residents and the benefits and services for which they were eligible. Ultimately, the team adopted the Federal Emergency Management Agency's (FEMA) designation of affected ZIP codes.
Practice Hurdles	
KatrinaHealth could assist doctors and pharmacists only about one third of the time.	**KatrinaHealth** linked records from community pharmacies, state Medicaid, and VA data using an exact match of five pieces of identifying information. The pharmacy benefits records were left in their own databases and networked using RxHub's Master Patient Index (MPI), which was networked to the **KatrinaHealth** portal. Overall, the system matched and delivered information for about 30 percent of queries. Given that the population mix

	was either largely uninsured, or covered under Medicaid, the hit rate to RxHub's MPI was low. While the successful searches more often came from the community pharmacy records, the success rate might have been even higher if a method to link and match records had been in place for the community pharmacy records—something now being worked on by SureScripts.
A broader range of professionals needed access to KatrinaHealth.	**KatrinaHealth**'s pharmacy records were available only to doctors who could be authenticated by the American Medical Association (AMA), and to community and independent pharmacists who could be authenticated by their IP addresses. In practice, midlevel practitioners (nurse practitioners and physician assistants) and nurses need access to patients' prescription information, so that they can call it up, print it out, put it in front of the physician, or, in some cases, write a prescription themselves. In the emergency, doctors were seeing 50 or more patients a day, and did not have time to access even easy-to-use online systems.

Concerns About National Disaster Response

The **KatrinaHealth** experience has prompted thoughtful reflection on some more general concerns among policymakers, practitioners, and the public—based on their experience with the Katrina and Rita disasters.

General Concerns	
We need to continue working collaboratively to anticipate and solve a range of health information sharing and access problems.	While **KatrinaHealth** overcame many hurdles, described herein, its impact and effectiveness were compromised by the emergency conditions under which it was created. To design, create, test, implement, and publicize an information system that has maximum benefit and impact it must be established, understood and communicated well in advance of an actual disaster hits.
We need a new, more flexible way of planning for different kinds of emergencies that stresses integration across systems and clear lines of authority.	Different kinds of emergencies require various types of responses. For example, a tornado is a highly localized event, whereas a hurricane generally affects a large region, and an epidemic like SARS or avian flu may be fast-spreading over multiple cities and states. The larger the potentially-affected area, and the greater the rate of onset, the greater the need for coordination, cooperation, and clear lines of authority to ensure that everyone involved knows "who is in charge of what." Unfortunately, most emergency planning happens in isolation—either by governments or private institutions—creating islands of policy, practice, and information. This is as true among health care providers in a single city as it is across neighboring communities and counties—or among governmental levels in a single state, or across state boundaries. Lack of coordination even in non-emergency policies can cause problems in emergency situations. For example, variations across states (and between institutions) on issues like privacy and credentialing create havoc when disasters, evacuees, and volunteer providers cross jurisdictional boundaries.

Our emergency communications systems must be easy to use, reliable, and anticipate breakdowns.	Recent crises and disasters (for example, 9/11, anthrax scares, or hurricanes) have repeatedly demonstrated failures and breakdowns in communication systems. In a crisis, people do not have time to learn how to use an unfamiliar technology, and even familiar technologies won't always work. Thus, emergency communications plans must include multiple communications channels and multiple ways to distribute information. Communication about an event needs to be planned and executed accordingly for the various event stages. Communication should specify: how warnings are issued, how to disseminate accurate and useful information in an ongoing incident, who is in charge of what, and how to handle questions about recovery.
Before the hurricanes and even today, planning for the health care needs of evacuated and now returning citizens has received minimal attention.	Crisis planning specific to health care proved particularly weak before, during, and, now, after the hurricane disasters, according to people on the front lines. As a result, as **KatrinaHealth** began to take shape, it was almost impossible to determine whom to go to for what information. In Louisiana, it was reported that two weeks before Katrina, a disaster response plan exercise was run, but health care records were not even considered. Likewise, Texas had no proactive planning regarding how to develop and manage a medical information system—or, for that matter, *any* kind of information system—for evacuees.
Communities had difficulty taking full advantage of the outpouring of volunteer assistance.	While large numbers of volunteer health professionals streamed into evacuee areas, there were no mechanisms for coordinating their efforts. Similarly, communities that received large numbers of evacuees, while not facing the same infrastructure devastation as New Orleans and the Gulf Coast, also had difficulty coordinating health care workers. In Dallas, the emergency medical providers, who by default had the lead in providing evacuee care, ultimately called in their chits with private providers to "create a new care network on the fly." In Houston, emergency personnel over time began to solve its coordination and communication problems in a novel way:

	they simply used the medical school's existing open-source courseware to post messages and exchange information. Ordinarily, the sharing of state resources and personnel is handled through the congressionally ratified Emergency Management Assistance Compact, a state-to-state mutual aid agreement. In this instance, participating states deployed more than 1,000 doctors, nurses, emergency medical technicians, dentists, ambulances, and medevac helicopters to affected areas. However, because of the scope of the Katrina/Rita disaster, the Department of Health and Human Services (HHS) created a federalized system that allowed health care professionals to register their intent to volunteer for disaster relief assignments. More than 33,000 health care personnel and relief workers registered and were brought on as short-term, non-paid federal employees, with their travel, malpractice premiums, and workers' compensation coverage paid. However, in Sue Dillon's experience (a doctor who worked in three different shelters and makeshift clinics in Mississippi for a total of 34 days), these measures did not solve the coordination issues on the ground.
Policymakers' Concerns	
The lack of coordinated l leadership responding to the hurricane disasters affected medical care providers.	The question of how the Hurricane Katrina disaster could have been better handled by local, state, and federal government entities is beyond the scope of this document. What is essential during recovery efforts, and was lacking in this episode, said one doctor who participated in recovery efforts, is a "chain of health information command"—a coordinating agency that could provide communications tools and necessary information technology (IT) support.
Emergency systems and procedures don't have to be perfect; they just have to be "good enough."	What policymakers have yet to adequately define are "acceptable levels of fallback" from normal policies and practices in emergencies. Most states require greater confidentiality and privacy of patient data on, for example, mental illnesses, substance abuse history, or HIV status by requiring individual patients to consent to any transfer of their information. Since there was no time to analyze or adjudicate all these differences among jurisdictions,

	KatrinaHealth adopted the most conservative solution, which was to omit all information on sensitive conditions from the system. Whether this decision rule always served patients' best interests could be argued.
Practitioners' Concerns	
In order to reap full benefit from health information technology systems, physicians' practice styles and expectations will have to accommodate or change.	Ironically, some physicians who treated evacuees are so accustomed to the current fragmented medical information system that they simply expected *not* to have any medical records when seeing a new patient. Emergency medicine practitioners, in particular, are taught not to expect any records on the patients whom they see and to skillfully extract the information they need on the spot. This long-standing approach may also work against their taking full advantage of whatever information systems do exist—like **KatrinaHealth**.
It was impossible to get the right records to the right place at the right time using the right technologies (even paper).	Anticipating that in the future Katrina/Rita evacuees will have difficulty accessing information about their emergency treatment, in Dallas, every encounter generated a paper summary given to the patient. The Dallas County public health agency now holds paper copies of some 8,500 records of medical services provided to hurricane evacuees. Today, however, these individuals are scattered across the country. Even if systems for creating and storing electronic health records existed, the people they are attributed to need to be found—so that records can be transferred to their current providers. The 2005 hurricanes created such disruption and displacement that one Louisiana official simply lamented, "Where are our citizens?"
Doctors needed better support to practice efficiently in difficult conditions.	The decline in availability of public health resources, particularly nurses, was another serious problem facing emergency responders. Even when doctors had nursing support, there were limits on how much help the nurses were allowed to provide. For example, in Mississippi, the State Board of Nursing would not allow nurses to dispense medications, which meant that hard-pressed physicians had to expend precious time to deal with issues that could have been served by other professionals.

At the community level, providers' ongoing confusion about HIPAA requirements was not effectively resolved.	Even though the rules established under HIPAA served the organizers of **KatrinaHealth** well, at the practice level, physicians and health care workers remain confused about the scope and potential applicability of HIPAA in the hurricane emergency—just as they are in everyday practice. (In an extreme example, one doctor described an ambulance crew that would not reveal the name of the patient they had just brought in—out of fear of violating HIPAA). To harried professionals, the perceived additional HIPAA requirements seemed impossible to meet. For example, in a 3-week period in Houston, emergency health teams used more than 47,000 volunteers to enter medical information in temporary records. Volunteer training was minimal, and there was no absolute way to preserve privacy. Even some of the volunteers worried whether HIPAA would apply to them, and whether they could be sued for some privacy breach. A further challenge is that a variety of additional and differing state-specific privacy laws and regulations are constructed on top of HIPAA's "privacy floor." As noted previously, it is too cumbersome to reconcile these discrepancies in an emergency situation when dealing with patients, providers, and records from multiple jurisdictions. A framework for reconciling these differences in state policies must be established in advance for both routine and emergency care.
The Public's Concerns	
Public information must be calibrated to user needs.	Meeting participants, many of whom were responders in the crisis, said that local Gulf Coast residents, like people in any community responding to an emergency, valued information that was *specific* to their locale. In some instances, they suggested that there was too much information available. Multiple, competing web sites or overly complex information are hard for stressed-out individuals to comprehend and assimilate.

People need to know where to obtain reliable information.	Information systems for the public must be readily accessible. Even in emergencies, people seek out their usual and familiar information sources: television, radio, the Internet, and so on. The virtues of a "911"-type system are that it is both simple to use and familiar—because it has been in place and regularly reinforced over a long period of time.
Plans for using the information media in emergencies need backups.	During the Katrina/Rita crisis, television broadcasts ran emergency public service announcements and were the primary news source used by local officials. Generally, people say that in a crisis they would rely on television for their information. Of course, after the power went out in New Orleans, television didn't work. By contrast, radio stations continued to broadcast, but officials reportedly underutilized them.
People need to know what medical information may be needed in emergencies.	For many evacuees, getting medical care and renewing prescriptions took a backseat to obtaining food and shelter. Even if they had sought care, people generally do not know what medical record information may be needed in an emergency or how to obtain it. Certainly, they may not have anticipated the almost complete disruption in the local health care system that made their records unavailable, and for some, irretrievable. Electronic personal health records may at some point resolve this problem. These are Internet-based tools that allow people to access, control, and coordinate their lifelong health information and make appropriate parts of it available to those who need it. Some have described them as "communication hubs" controlled by the patient. Personal health records are not yet a viable solution in disasters, however, because too few people have them and they exist on multiple platforms that may not be compatible with one another. A person completing an electronic form that contains basic health information is an easy first step. Much more difficult will be achieving automatic, electronic transfer of their data from health care providers into their personal health records.

We haven't had a national discussion about access to personal medical information in emergency situations.	Although national surveys indicate that most Americans believe access to their health information can make a life-and-death difference in emergencies, they remain concerned about the security and privacy of their information and their control over it; and they don't want others to have access to it without their permission. How people's personal health care information flows through increasingly digitized and interoperable systems will remain an important issue. We must be able to reassure them that "privacy is an integral part of the process"—as a representative of the Office of Civil Rights said.

The Context for Disaster Response

In responding to hurricanes Katrina and Rita, the region's health system—much less the **KatrinaHealth** initiative—had only partial control over its own destiny. It had to operate within a number of other environmental and organizational frames that either helped or hindered its operation. The conclusions described here reflect participants' views on how the following frames affect the future application of health information technologies in disaster situations.

- The basic community infrastructure (electric grid, phone system, roads)
- The health care infrastructure (policies, practices)
- The governmental infrastructure (FEMA, state finances)
- The social infrastructure (poverty, community cohesion, media role)

The Challenge	
Americans have difficulty maintaining a sense of urgency.	The challenge posed by Dr. David Brailer, National Coordinator for Health Information Technology, to the group was "Why can't we replicate **KatrinaHealth** for America in a year?" This almost presumes that we cannot, and is indeed reflected in Dr. Brailer's follow-up question: "How do we develop systems of unyielding urgency?" Part of the reason we cannot lies in the discussion of the following four frameworks.
We need pragmatic, doable solutions.	But this is a good place also to ask a slightly different question: Why was **KatrinaHealth** successful? Portable health information had not been on the disaster planning agenda, yet the project put together the necessary pieces in remarkably short order. One conference participant attributed success to both the project's ambition—"it was national in scope"—and its fundamental approach—"it was simple in design." This latter feature especially needs to be borne in mind for future projects.
The Basic Community Infrastructure	
Health care had to be delivered in an environment of complete chaos.	In the New Orleans area, flooded cable boxes, downed electrical and telephone lines, deactivated DSL circuits, and felled cell towers meant that in large portions of the city, almost no phone or Internet service was possible. Dr. Sue

	Dillon never practiced in a place that had electricity—much less Internet access. Only providers who had created solid disaster plans and backup systems—and were lucky enough to be out of the worst of the flooding—remained in operation. But even where communications systems were working, the scale of the disaster was such that frontline workers were too hard-pressed to check their email or phone messages.
The Health Care Infrastructure	
We have to make good connections and information exchange among providers the norm, not the emergency exception.	In fast-changing emergency environments, inter-hospital communications systems would enable local health officials to quickly conduct simple surveys pinpointing resource needs. This is an example of a type of system that would be useful every day, as hospitals work close to capacity. Generally, emergency services, procedures, and systems must be normalized. They won't be used if they are relegated to unusual situations, organized outside the daily work routine, or require special equipment. Market competition and lack of cross-institutional cooperation in health care has built walls that are hard to break down. Even in emergencies, different organizational cultures may be hard to meld in a coordinated effort. Despite these challenges, **KatrinaHealth** was up-and-running quickly, perhaps because it involved working with relatively few major partners, and with individuals who, in many cases, knew and trusted each other.
The Governmental Infrastructure	
Federal rules and state finances hinder improvements in emergency response.	After a disaster, many private companies are willing to donate hardware, software, and training. However, the federal government is prohibited from accepting such donations, and it has not determined how to identify entities that can accept and use them effectively. In general, forming public-private partnerships is difficult

	because of a tangle of government regulations and restrictions, as well as mistrust among the parties. Some of the nation's poorest states were affected by the 2005 hurricanes, and these same states are at high risk for future storms. Many U.S. states have suffered financially in recent years, but the poorest states do not have the resources to devote to significant expansion of emergency preparedness and health information technology systems. This is especially true for the Gulf Coast states, leaving them vulnerable to a repetition of the difficulties experienced in Hurricane Katrina. Moreover, many other states could encounter similar difficulties should a severe emergency—earthquake, epidemic, or bioterrorism—occur.
The Social Infrastructure	
Gulf State poverty exacerbated the logistical and social difficulties.	More than two million residents of Alabama, Louisiana, and Mississippi live in poverty, and the patterns of care many of them receive contributed to the difficulties of tracking their health information. Before the hurricane, 40 percent of Louisiana residents were either uninsured or receiving state-financed health benefits. Patients without insurance, by definition, are not part of commercial databases that monitor insurance claims, and safety net providers rarely have electronic records. Fortunately, some of these patients are captured in medication history databases from community pharmacies and Medicaid records. However charity pharmacies and other community-based organizations were not integrated into the KatrinaHealth effort.

Recommendations in Anticipation of Future Disasters

Below are summarized a set of policy recommendations derived from the "after actions" meeting discussion.

Recommendations

1. Engage in Advance Planning and Put Pieces in Place Now
   - Invest in realistic advance planning and analyze actual disasters for lessons.
   - Conduct a realistic emergency simulation that includes health information management, analogous to TOPOFF (the congressionally mandated series of role-playing exercises involving TOP federal, state, and local officials who would direct crisis-management responses in actual situations).
   - Determine in advance which agency is responsible for definitively identifying affected areas and for creating registries of affected people.
   - Establish business agreements that will allow information sharing in disaster response situations. If these are in place prior to any emergency, then coordination, communication, and access move much faster and more effectively.
   - State public health departments' emergency management teams should build relationships not only with federal agencies and local hospitals and providers, but also with non-governmental organizations and faith-based groups who may serve as unofficial first-responders.
   - Plan "backups to backups," for when technology inevitably breaks down.

2. Take Advantage of Existing Resources
   - Examine the potential of Regional Health Information Organizations (RHIOs) to provide information coordination and surge capacity.
   - Although private information technology companies generously come forth with resources—offers of equipment, software, training, and technical support—in times of emergency, at that point organizations and systems are too stressed to make the best use of them. The assistance of these companies should be sought prospectively.

3. Address System and Electronic Health Record Design Issues
   - Private industries interested in helping design, develop, and deploy health information systems should use open standards.
   - Create health information systems that are simple, interoperable, and resilient—and that accommodate the reality that data may be in different formats.
   - Develop a comprehensive record-linking strategy, using probabilistic algorithmic matching of commonly-available identifiers, building on the

experience with the five-element matching system used in **KatrinaHealth**.
- Establish a secure method to authenticate doctors, pharmacists, other health professionals—and patients themselves—to enable access to health information for clinical treatment and care to all who need it.

4. Integrate "Emergency" Systems into Daily Routine
   - Integrate emergency response mechanisms (and people) into non-emergency settings and care.
   - Ensure that communications systems set up for emergencies are useful in broader circumstances—and their use regularly reinforced.

5. Create Systems that are Simple to Access
   - Enable the electronic health information record to be accessible to nurse practitioners, physician assistants, and nurses working with physicians and clinics.
   - Establish standards for laboratory results, health claims, and so on, so that more currently digitized data can be easily accessed in emergencies.

6. Improve Communications Strategies
   - Help people understand what is involved in their taking responsibility for at least some portion of their own records—especially people with chronic and life-threatening conditions—in both everyday and emergency situations, and facilitate their doing so.
   - Develop multiple communications channels:
     - for different audiences (practitioners, the public)
     - using different technologies (not just the Internet) and
     - engage third parties that are respected in the community.
   - Make sure these user groups know about information resources and how to use them.
   - Find out in advance what types of information people want via the Internet, recognizing that some information is better than none.
   - Develop and promote an analog to the 911 system (e.g., ".stat") now, rather than waiting for the next emergency. Sponsors must make clear what the service is capable of offering.
   - Identify and leverage people's normal communications channels. For example, ask web search engines to ensure that the most reliable emergency web sites pop up first in searches.

7. Overcome Policy Barriers
   - Engage the public and private sectors in identifying barriers to working together, and start working on those now, at the highest levels.
   - Reeducate communities on public policies, like HIPPA, that are still poorly understood and have unintended consequences magnified in emergent

situations. Notably, the Research Triangle Institute (RTI) had received $11.5 million from the Department of Health and Human Services to assess and develop plans to address variations in organization-level business policies and state laws that affect privacy and security practices which may pose challenges to interoperable health information exchange. The National Governors Association's Center for Best Practices, a program partner, will fund efforts in up to 40 states.

- State privacy officers should clarify how privacy rules apply in emergency situations.

Appendices

Appendix 1. KatrinaHealth Supporters, Contributors, and Participants

Appendix 2. Maps of the FEMA-Designated Zip Code Areas Affected by Hurricanes Katrina and Rita

Appendix 3. The 44 Major Evacuee Recipient Areas

Appendix 4. Further Reading

Appendix 1.

KatrinaHealth Supporters, Contributors, and Participants

Major Participants

American Medical Association

The American Medical Association (AMA) helps doctors help patients by uniting physicians nationwide to work on the most important professional and public health issues. Working together, the AMA's quarter of a million physician and medical student members are playing an active role in shaping the future of medicine. For more information on the AMA, please visit www.ama-assn.org.

Gold Standard

Tampa-based Gold Standard is a leading developer of drug information databases, software, and clinical information solutions. The company's products are developed by a staff with extensive experience in pharmacy practice, electronic publishing, and software development. Gold Standard's customers include hundreds of hospitals, the nation's largest retail pharmacy chains and consultant pharmacy organizations, state and federal agencies, the country's top pharmacy and medical schools, and hundreds of thousands of health care professionals and consumers worldwide. Additional company information is available at www.goldstandard.com.

Markle Foundation

Emerging information and communication technologies possess enormous potential to improve people's lives. The Markle Foundation works to realize this potential by accelerating the use of these technologies to address critical public needs, particularly in the areas of health and national security. The Markle Foundation's overarching goal in the health area is to accelerate the rate at which information technology enables consumers and the health system that supports them to improve health and health care. For more information on the Markle Foundation visit www.markle.org.

RxHub LLC

RxHub electronically routes up-to-date patient-specific medication history and pharmacy benefit information to caregivers at every point of care. Its end-to-end solution enables doctors to prescribe the most clinically-appropriate and cost-effective prescription to be sent electronically to the patient's pharmacy of choice. RxHub's mission is to work with all stakeholders in the prescribing industry to improve patient safety, increase workflow efficiency, and reduce the overall cost of health care delivery. RxHub was founded in 2001 by the then three largest PBMs: Advance PCS (acquired by Caremark Rx), Express Scripts,

and Medco Health Solutions. RxHub is based in St. Paul, MN. For more information, please visit www.RxHub.net.

SureScripts
SureScripts, the largest network provider of electronic prescribing services, is committed to building relationships within the health care community and working collaboratively with key industry stakeholders and organizations to improve the safety, efficiency, and quality of health care by improving the overall prescribing process. At the core of this improvement effort is the SureScripts Electronic Prescribing Network, a health care infrastructure, which establishes electronic communications between pharmacists and physicians and enables the two-way electronic exchange of prescription information. Today, 90 percent of all pharmacies in the United States are certified on the SureScripts network. More information about SureScripts is available at www.surescripts.com.

Contributors and Participants

American Medical Association

American College of Physicians

American Health Information Management Association

American Health Quality Association

American Medical Group Association

American Medical Informatics Association

American Red Cross

Association of American Medical Colleges

Blue Cross and Blue Shield Association of America

Blue Cross and Blue Shield of Louisiana

Center for Health Transformation

Computer Sciences Corporation

eHealth Initiative

Electronic Health Records Vendors Association

Gold Standard

Harvard School of Public Health

Healthcare Information Management Systems Society

Healthworks Louisiana

Hospital Corporation of America

Louisiana Healthcare Review, Inc.

IBM

International Rescue Committee

Manatt, Phelps and Phillips

Markle Foundation

National Association of Chain Drug Stores

National Community Pharmacists Association

National Alliance for Health Information Technology (the Alliance)

National Opinion Research Center

Pharmaceutical Care Management Association

Regenstrief Institute

Robert Wood Johnson Foundation

RxHub, LLC

State of Louisiana, Department of Health

State of Mississippi, Department of Health

SureScripts

Swandivedigital

U.S. Department of Commerce

U.S. Department of Defense

U.S. Department of Health and Human Services

- Office of the National Coordinator for Health Information Technology (ONC)
- Centers for Disease Control (CDC)
- Centers for Medicare and Medicaid Services (CMS)
- National Institutes of Health (NIH)
- Federal Drug Administration (FDA)
- Agency for Healthcare and Research (AHRQ)

U.S. Department of Homeland Security

U.S. Department of Veterans Affairs

Verizon

Chain Pharmacies

Albertsons

CVS/Pharmacy

Kmart

Rite Aid

Target

Walgreens

Wal-Mart

Winn Dixie

Pharmacy Benefit Managers

Caremark

Express Scripts

Medco Health Solutions

Pilot Site Participants

Shelter staff at Reunion Arena and Dallas County Convention Center in Dallas, Texas

Special Needs Shelters in Louisiana

Sparks Regional Medical Center

University of Mississippi Medical Center

University of South Alabama College of Medicine

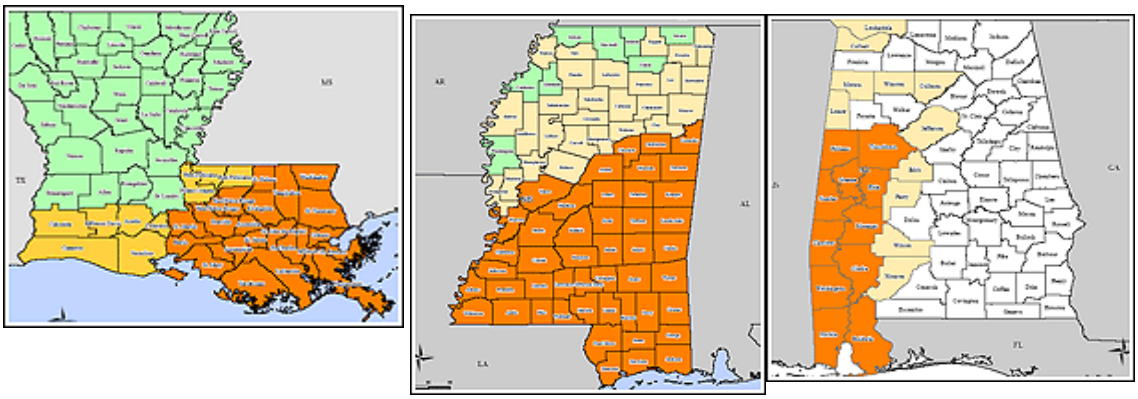
University of Texas at Houston

University of Texas Southwestern

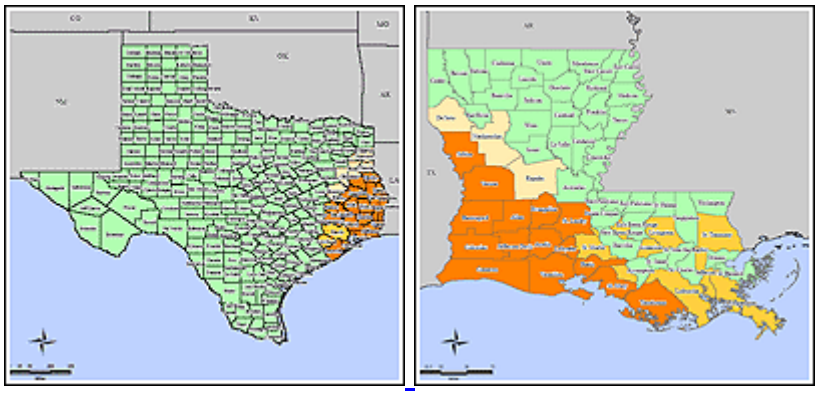
Appendix 2.

Maps of the FEMA-Designated Zip Code Areas Affected by Hurricanes Katrina and Rita

Hurricane Katrina



Hurricane Rita



Source: US, Federal Emergency Management Agency, http://www.fema.gov/library/drcys.shtm

Appendix 3.
The 44 Major Evacuee Recipient Areas

Huntsville, Alabama
Mobile, Alabama
Phoenix, Arizona
Los Angeles, California
San Francisco, California

Denver, Colorado
Washington, DC area (Maryland)
Miami, Florida
Tampa, Florida
Jacksonville, Florida

Atlanta, Georgia
Chicago, Illinois
Indianapolis, Indiana
Louisville, Kentucky
Baton Rouge, Louisiana

Shreveport, Louisiana
Boston, Massachusetts
Detroit, Michigan
Minneapolis/St. Paul, Minnesota
Jackson, Mississippi

St. Louis, Missouri
Kansas City, Missouri
Omaha, Nebraska
Las Vegas, Nevada
Santa Fe, New Mexico

New York City, New York
Raleigh, North Carolina
Charlotte, North Carolina
Oklahoma City, Oklahoma
Philadelphia, Pennsylvania

Charleston, South Carolina
Columbia, South Carolina
Memphis, Tennessee
Nashville, Tennessee
Austin, Texas,

Corpus Christi, Texas
Dallas, Texas
El Paso, Texas
Fort Worth, Texas
Houston, Texas

San Antonio, Texas
Richmond, Virginia
Seattle, Washington
Milwaukee, Wisconsin

Appendix 4.
Further Reading

1. **Connecting for Health**, A Public Private Collaborative. Various reports available from The Markle Foundation.
2. Linking Health Care Information: Proposed Methods for Improving Care and Protecting Privacy, Working Group on Accurately Linking Information for Health Care Quality and Safety, The Markle Foundation **Connecting for Health** project, February 2005.
3. "HHS Enters into Agreements to Support Digital Health Recovery for the Gulf Coast," DHHS News Release, Nov. 17, 2005.
4. "Hurricane Katrina Bulletin #2: HIPAA Privacy Rule Compliance Guidance and Enforcement Statement for Activities in Response to Hurricane Katrina," DHHS, Office for Civil Rights, September 9, 2005.
5. "Statement by Mike Leavitt, Secretary of Health and Human Services, About the First Meeting of the American Health Information Community," DHHS News Release, Oct. 7, 2005.
6. Perlin, JB, Kolodner, RM, and RH Roswell. "The Veterans Health Administration: Quality, Value, Accountability, and Information as Transforming Strategies for Patient-Centered Care." *The American Journal of Managed Care*, November 2004, pp. 828-836.