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Linda Gordon Date

Cloud Computing Solutions for Newborn Screen Data Disruption by Hurricane Disasters

By

Linda Gordon, MD
Master's Thesis for the Degree of MPH, Informatics
Emory Rollins School of Public Health

Committee Chair, Mark Conde, B.A. Date

Field Advisor: Fred Grant PhD., MPH, MBA Date

Director, EMPH Program, Melissa Alperin EdD, MPH, MCHES Date

Cloud Computing Solutions for Newborn Screen Data Disruption by Hurricane Disasters

By

Linda Gordon, MD

University of Chicago-Pritzker School of Medicine, M.D
awarded 1997

Thesis Committee Chair: Mark Conde, B.A.

An abstract of
A thesis submitted to the Faculty of the
Rollins School of Public Health of Emory University
in partial fulfillment of the requirements for the degree of
MPH in Informatics 2019.

Abstract

Cloud Computing Solutions for Newborn Screen Data Disruption by Hurricane Disasters

By

Linda Gordon, MD

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Purpose Statement:
The purpose of this thesis is to provide a systematic literature review of Newborn Screen system components, the newborn screen information flows and disaster planning considerations, which result in operational improvements during hurricanes. This thesis reviews the 2005 Hurricane Katrina as a pivotal weather event where health information was significantly disrupted.

Methods: This thesis followed a systematic literature review presenting analysis from those articles and data gathered to address the questions of how best to improve health information flows for the Newborn Screen, during disaster planning and utilizing modern technology available that being cloud computing. periodical literature, government documents and grey literature were contrasted and compared for content and bias.

Results:
The selected literature for review gave important insight as to the evaluation of health information for the Newborn Screen in times of disaster and emerging technologies so as to improve resulting health outcomes. The literature highlighted the importance of collaboration among health professionals, federal agencies, and public private partnerships. The adjunct use of the emerging technology of virtual cloud computing was also deemed an effective use of a health IT systems that would ensure effective delivery of Newborn Screen services in times of disaster.

Conclusion:
Virtual cloud computing is the modern technology solution to delivery of uninterrupted Newborn Screen services during hurricanes. This may be achieved via amplification of existing cloud structures in at risk regions through public private partnerships. Moreover, lessons learned from Japan, Australia and France indicate that virtual computing can be applied to the health care infrastructure for disaster planning or national health care the potential for greatly improved health outcomes.

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To faculty and staff of Emory University Rollins School of Public Health, thank you for the opportunity to grow personally and professionally in the Executive Master of Public Health Program. I am deeply grateful for the knowledge gained, a wealth of experience.

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CHAPTER 1: INTRODUCTION

Problem Identification

Lessons learned from Hurricane Katrina with interrupted health care delivery have led to advances in the emergency management and disaster preparedness planning with regard to health information (Weiner, 2011). The problem of how best to manage the Newborn Screen in time of an extreme weather event will be presented in the context of health records including demographic and laboratory management for emergency preparedness.

Purpose Statement

The purpose of this thesis is to provide a systematic literature review of Newborn Screen system components, the newborn screen information flows and disaster planning considerations, which result in operational improvements during hurricanes. This thesis reviews the 2005 Hurricane Katrina as a pivotal weather event where health information was significantly disrupted. A revision of the workflow path will explore the various cloud components to address the information technology requirements of medical records access, creation and maintenance. As well, the use of cloud components including communications support and backup servers will be explored.

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Rationale

The Newborn Screen is a test collected in the first forty-eight hours of life for all newborns to identify endocrine, metabolic and hematologic disorders that present early in life with the potential for intervention and referral (Communications, O. 2017).. In some cases, the early intervention be it change of diet or medical therapy is lifesaving. In times of hurricane disaster, the information flows that preserve data collection, testing and reporting are therefore time sensitive and if interrupted have untoward consequences.

Problem Statement

Traditional Newborn Screens were a collection with a blood sample placed on a card and sent to a regional state lab by mobile transport for testing. Standards dictated by the Clinical and Laboratory Standards Institute, established guidelines for emergency operations plans to address the hazards of mass weather events such as natural disasters including hurricanes. These operations include quality management of laboratory systems that maintain service through the use of coordinated systems (Pass, 2009). Historically, these systems have included collaborative agreements with neighboring hospitals, public health laboratories and personnel. Health or laboratory information was transmitted by fax or with information technology advances EMR. This is a system of information flow that

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requires functional hospital operations, mass transit, and EMR across facilities that may not be interoperable. It is during normal hospital operations, Newborn Screens have followed up reporting within 5 days (Kim L.-P. T., 2003) . However, this system was noted to be flawed with 31% of medical homes reporting a delay of greater than 10 days. It is the assertion of this thesis that during extreme weather events, such as hurricanes there can be a significant disruption to this essential medical testing process further placing infants at risk. Moreover, that modern technology such as cloud computing is the solution to this problem.

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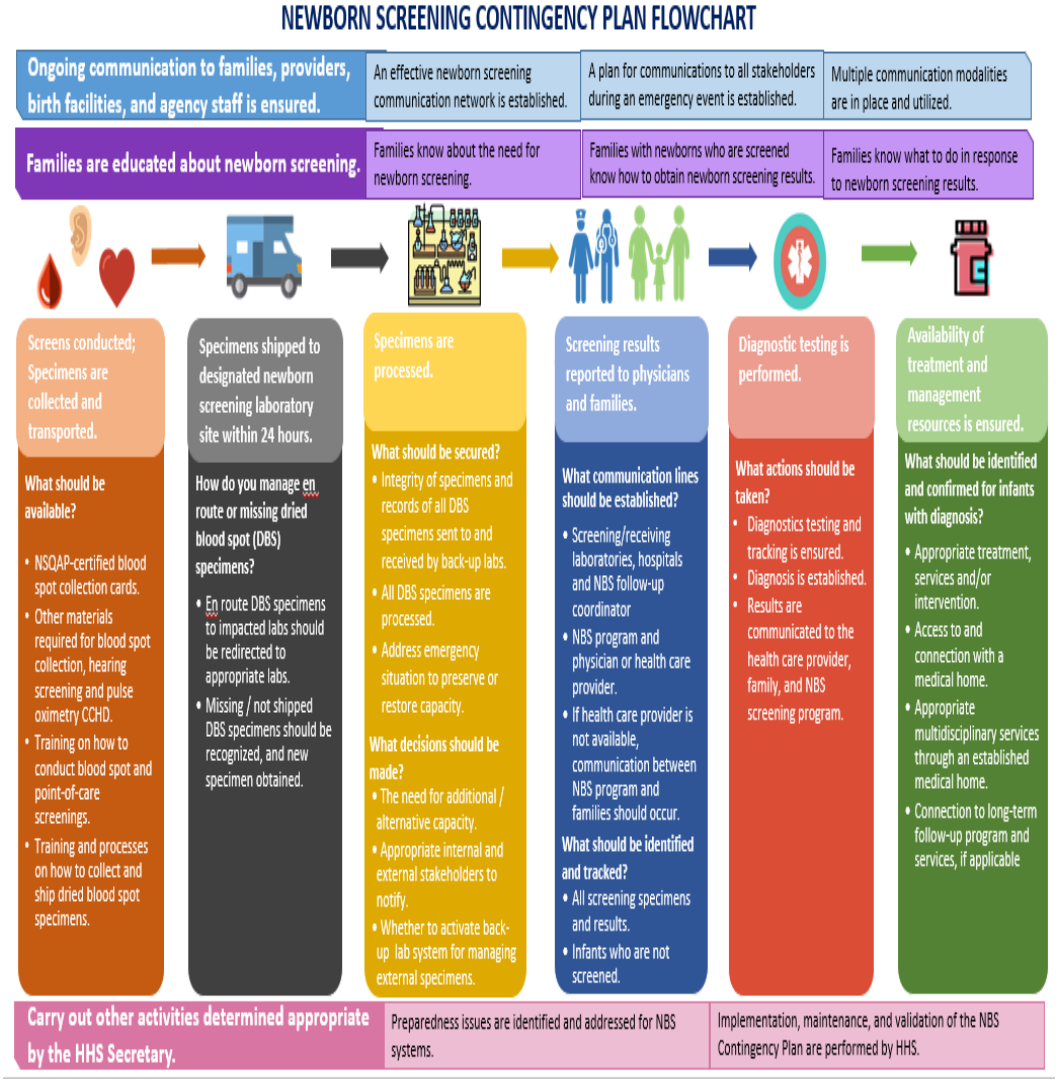
Fig 1. NewBorn Screen Contingency Plan



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Research Question

It was during Katrina, that the loss of patient health information was superseded by the mass exodus of population with displacement of providers, ancillary personnel and patients. The resulting negative impact on the maintenance of existing patient data is such that patients were lost to follow up and time sensitive information including results of the Newborn Screen were delayed or not reported. The research questions are thus: 1) What advances in technology have taken place to overcome any potential disruptions to Newborn Screen operations during hurricanes? 2) Is cloud computing a solution to IT disaster preparedness for the Newborn Screen in mass weather events such as hurricanes?

Significance Statement

Public Health is an evidence-based practice. New technology and new applications of information technology systems such as cloud computing in the phases of disaster response, by means of virtual information flow and data governance may permit adaptable and timely response for clinical care of patents such as those awaiting results of the Newborn Screen in hurricane disasters. A systematic literature review may suggest areas for improvement and standardization.

Cloud Computing Solutions for Newborn Screen Data Disruption by Hurricane Disasters

Virtual cloud computing systems offer a solution in part to the absence of infrastructure. This was evident in Hurricane Harvey in 2017 where 49% of medical records were retrievable within hours of patient identification via cloud computing (Goldstein, FedTech, 2018). In this regard, health information technology is benefitting from modern information flows that are timely, adaptable and scalable and these technologies are virtual. Virtual or cloud computing is such a technology and with the benefits of accessibility, maintenance and cost. The cloud model consists of five characteristics, three models for data management, and four models of data exchange.

The characteristics of cloud computing are accessibility, scalability, timeliness, adaptability. Timeliness is notable by on demand service, adaptability is evident by the ability to open service at any location, and scalability is notable by the capacity for resource pooling, establishing public private partnerships and governance of regional geography. The models of data management are cloud infrastructure as service (IaaS), cloud platform as service (PaaS), and cloud software as service (SaaS) (Velev Z. , 2012). The data exchange models are private cloud, community cloud, public cloud, and hybrid cloud. The DHS is utilizing a combination of public and private cloud. Among the organizations of DHS using cloud systems is the Federal Emergency Management Agency (FEMA) for disaster recovery in hurricane management. FEMA is in use of the Web Content Management as Service (WcMaaS). Cloud system. This system was

developed in 2010 as a result of the:" Restore the Gulf" initiative ordered by President Obama to revive the Gulf ecosystem, industry and infrastructure (Council, 2017).

The evolution of cloud support for disaster recovery by DHS and in particular by FEMA is relevant given the increase in natural disasters. Climate change and its untoward effects has led to natural disasters of greater frequency and severity. The United States Gulf Coast has witnessed this phenomenon with the Hurricane Katrina in 2006 and in 2017 Hurricane Harvey. These natural disasters however, are. distinguished by the presence of cloud computing and its impact on pediatric patient outcomes. Hurricane Katrina was without cloud computing and suffered disruption of EMR information flows, while in contrast Hurricane Harvey had the benefit of cloud computing and preservation of patient records with resulting continuity of care. Moreover, the timeliness of the Newborn screen is generalizable to the needs of health care delivery in times of disaster and success of cloud application with this service and may provide insight into success with healthcare for disaster preparedness in a larger context.

Thesis Organization

This thesis opens with Chapter 2, providing a background and framework for the important concepts associated with the New Born Screen. Chapter 2 presents the themes for the thesis in question namely periodic, government

document and grey. An extensive systematic literature review is included in the thesis as well to discusses the questions raised by the information flows of healthcare data for the Newborn Screen during the 2005 Hurricane Katrina, and place into context of information technology disaster planning, contrasting current EMR technologies with emerging cloud computing. The peer review articles reference Hurricane Katrina, and subsequent hurricanes such as Sandy and Harvey. As well they reference health information technologies and emergency management system evolutionary changes. Government documents highlight policy advances in disaster management. Grey literature provides real time changes in emergency management. Literature review will discuss the themes of Hurricane relevance, Newborn Screen, Disaster Planning, and the Evolution of Cloud Technology. The history of the Newborn Screen will be detailed as well as context will be reviewed with regard to Hurricane Katrina and lessons learned from loss of health care service as described in the literature. Disaster Planning discussion will begin with discussion of hurricane trends and patterns, followed by the history of disaster preparedness as outlined in the literature and government documents. Organizational data will define the relationships required for disaster planning. Thereafter is a general discussion of information technology in disaster planning introduced with attention to relevant government and NGO partners such as DHS, hospitals and CDC. IT is then presented in its role in disaster planning historically as traditional and emerging technologies with

comparison of EHR and cloud computing, and for their potential role in disaster planning. This is followed by an introduction to health information technology as it relates to disaster planning and the evolution of health IT in emergency management. Chapter 3 Results and Outcomes will describe best practices for health information technologies of the Newborn Screen in times of hurricane as dictated by the analysis of Chapter 2. Chapter 3 outlines the systematic literature review methodology used in this study. The systematic literature review covers newborn screening information management since Hurricane Katrina. Literature around IT disaster planning and technology for hospitals is identified and presented to revisit Hurricane Katrina with the project of designing a more timely and adaptable information system. Chapter 4 provides Results and Discussion around the systematic literature review. There is a discussion of the technology broader application as the literature's references to global and national health care IT systems are contrasted and compared. In doing so, the Chapter will open with discussion of the Southeast Region HIT-HIE Collaboration for context regarding modernization of IT post Katrina for the region. The attributes of this system and application to a Hurricane Katrina will be highlighted as well compared to methods of IT disaster planning currently in place for hurricane prone Japan and Australia. Chapter 4 Discussion gives a synthesis of the thesis and application of principles with reference to the French Dossier, a successful example of national cloud health services application with comment on applications for similar

program in the United States in times of mass weather events. Chapter 5 will outline the public health implications of these emerging virtual technologies and future research needs for disaster planning and improved Newborn Screen outcomes.

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Definition of Terms and Abbreviations

Abbreviations:

AAP: American Academy of Pediatrics

Organization of member pediatricians dedicated to the health of children, this to include primary care providers and geneticists who interpret the Newborn Screen.

ACA: Affordable Care Act

ACLS: American Society for Clinical Laboratory Science

Advocacy group of clinical laboratory scientists who guide safety, regulatory and quality control recommendations practices including those for lab testing during emergency planning.

ACCA: Asia Cloud Computing Association

BIA: Business Impact Analysis

CDC: Centers for Disease Control

The nation's health protection agency that coordinates care between federal and state agencies including health care services and disaster management.

COCA: Clinical Outreach and Communication Activity

CONPLAN: Concept of Operations Plan

The Concept of Operations Plan is an organizational tool in concept form ready for deployment in times of emergency; regional and federal collaborations and disaster plans for implementations during hurricane events.

COOP: Continuity of Operations Plan

The development, testing and training of procedures to restore operations in times of disaster, IT operations plan a component of such a hospital disaster plan.

DHS: Department of Homeland Security

The cabinet level department of the Federal Government responsible for the safety and security of the interior.

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DoD: Department of Defense

EMCA: Emergency Management Compact Act
The disaster relief agreement mandated by law among the 50 states for intrastate relief for support with or without federal aid.

EMR: Electronic Medical Record
Patient health information stored and shared in a digital format.

FEMA: Federal Emergency Management Agency
A DHS agency with the purpose of coordinating federal response to natural or man-made disaster that overwhelms local or state authorities.

FISMA: Federal Information Security Management Act

GIS: Geographic Information System

GSA: General Service Administration

HAN: Health Alert Network

HIPAA: Health Insurance Portability and Accountability act

HITECH: Health Information Technology for Economic and Clinical Health Act.
Legislation of 2009 designed to stimulate the adoption of EHR technologies, this includes the nation's health care information systems.

HRSA: Health Resources Service Administration

HUD: Housing and Urban Development

IaaS: Infrastructure as Service

IT: Information Technology

ITCP: Information Technology Contingency Plan
A pre-established plan for restoration of services after technology disruption of information technology such as a hospital IT disaster plan.

LRN: Laboratory Response Network

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MNT: Maintenance Agreement

NARA: National Archives and Records Administration

NIST: National Institutes of Standards and Technology

NDRF: National Disaster Recovery Framework

NBS: NewBorn Screen
A genetic blood test collected in the newborn period to screen for metabolic and inherited diseases, consisting of mandated and optional screens to facilitate early intervention for life threatening conditions and those requiring specialty care.

NMS: National Medical Service

NMSA-HRSA: National Medical Service Association, Health Resources Services Assoc.

NGO: Non-Governmental Organization

OMB: Office of Management and Budget

PaaS: Platform as Service

RA: Risk Assessment

REC: Recovery Plan

SaaS: Software as a Service

SLA: Service Level Agreements

WcMaaS: Web Content Management as Service

Additional Definitions:

Cloud Systems: A cloud operating system is an information technology system of virtual exchange with data governance, storage and processes including software and hardware infrastructure.

Public Health Informatics: The application of computer science technology to public health principles of surveillance, public health prevention and public health preparedness and health promotion defines public health informatics.

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CHAPTER 2: REVIEW OF LITERATURE

Introduction

Purpose Statement:

The purpose of this thesis is to provide a systematic literature review of Newborn Screen system components, the newborn screen information flows and disaster planning considerations, which result in operational improvements during hurricanes.

This thesis reviews the 2005 Hurricane Katrina as a pivotal weather event where health information was significantly disrupted.

Problem Statement:

Historically, the Newborn Screen developed when infants with the metabolic condition PKU, phenylketonuria, were discovered to improve in child development with the feeding of specialty formula[1]. It was this testing of newborns for genetic diseases of morbidity and mortality, so as to initiate therapy at birth, that led to the evolution of Newborn Screen. The Newborn Screen is now a test of inheritable, metabolic and chronic conditions. In 2002, the American College of Medical Genetics, ACMG, standardized testing across all states for

[1] See (Communications 2017) "NICHD's …early research efforts were a study of the effectiveness of the PHE-restricted diet for children diagnosed with PKU. This research showed that children with PKU who followed a diet with limited amounts of Phe were healthy at age 7 years…"

newborn screen testing so as to include 29 core conditions and 25 secondary conditions. As of 2016 this list has expanded to 36 core conditions and 26 secondary conditions (NIH, 2017). Infants screened at birth for the condition, traditionally had a blood sample placed on a card and sent to a regional state lab by mobile transport for testing. Standards dictated by the Clinical and Laboratory Standards Institute, established guidelines for emergency operations plans to address the hazards of mass weather events such as natural disasters including hurricanes. These operations include quality management of laboratory systems that maintain service through the use of coordinated systems. Historically, these systems have included collaborative agreements with neighboring hospitals, public health laboratories and personnel. Health or laboratory information was transmitted by fax or with information technology advances EMR. This is a system of information flow that requires functional hospital operations, mass transit, and EMR across facilities that may not be interoperable. It is during normal hospital operations, Newborn Screens have follow up reporting within 5 days [2]. However, this system was noted to be flawed with 31% of medical homes reporting a delay of greater than 10 days. It is the assertion of this thesis that during extreme weather events, such as hurricanes there can be a significant disruption to this essential medical testing process

[2] See (Kim L-P.T., 2003, pg 121) "26% of pediatricians were not routinely notified of results nad28% interpreted the lack of report as negative results…?

further placing infants at risk. Moreover, that modern technology such as cloud computing is the solution to this problem.

Research Questions:

The research questions are: 1) What advances in technology have taken place to overcome any potential disruptions to Newborn Screen operations during hurricanes? 2) Is cloud computing a solution to IT disaster preparedness for the Newborn Screen in mass weather events such as hurricanes?

Review of Literature

Hurricane Trends and Significance:

Information technology exchange and data governance has become a necessity of the Federal Emergency Management Agency, FEMA, given its need for rapid response to extreme weather events and the desire to attend to large scale populations ((Scientists, 2017)). In 2017 disasters were marked by increased demand for technology that was adaptable to scalable response for millions of survivors, regional geography and coordinator first response[3]. Furthermore, advances since 2005 suggest that cloud computing may be the preferred platform disasters as it offers a technology that enables continuous operations--and this is most relevant for extreme weather events such as hurricanes which affect the East and Gulf Coast of the United States.

[3] See (Goldstein 2017). Goldstein states, "The 2017 disasters …required a concurrent increase in technology infrastructure. The challenge this year is scalability…"

Cloud Computing Solutions for Newborn Screen Data Disruption by Hurricane Disasters

With climate change the frequency and intensity of hurricanes has worsened in the last five decades, necessitating technologies for disaster preparedness. Storms that occurred once every 100 years now (Scientists, 2017) occur every seventeen years and with greater residual destruction. The number of Category 4 and 5 hurricanes has nearly doubled. (Please see the figure below for the grading system for hurricanes and the Atlantic Ocean storm trend.)

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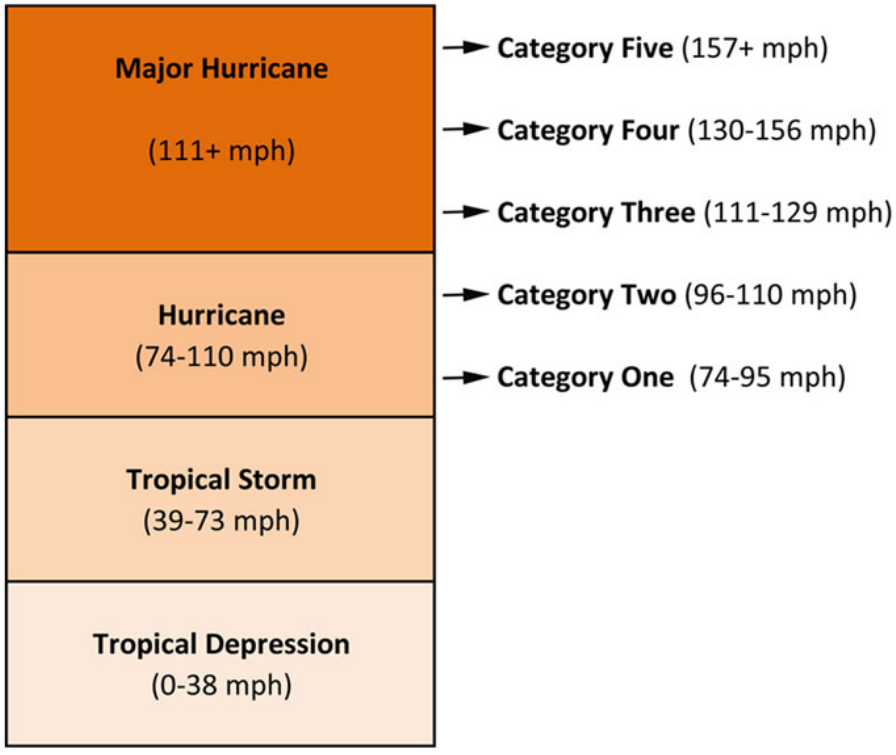
Fig2. Hurricane Categories



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Review of Hurricane Katrina, Events and Lessons Learned

As we consider the need for cloud technology to aid FEMA response to larger scale extreme weather events, it is important to revisit a time when technology was not available (AAP, 2015). If one reviews the events of Category 5 Hurricane Katrina in 2005, we observe an emergency response system that did include hospital information technology planning lacking the attributes of adaptability, scalability, timeliness and data governance. Hurricane Katrina, which led to land damage of the Louisiana, Alabama and Mississippi Coasts, relied on hospital EMRs (Browning-Floyd, 2013). These EMR were not interoperable, lacked back up services, and were unable to overcome system and institutional failures due to power outages and hospital closure. Moreover. Those functional facilities were challenged by displaced patients and providers, thus interrupting the exchange of health care information. Loss of information exchange was most exemplary for the most vulnerable of patients, the newborns receiving the test of the Newborn Screen. Per institutionalized agreements at the time of Katrina, the Emergency Management Compact Act, the Newborn Screen was tested by the neighboring state of Iowa, with a differing panel of tests to run, and with the expectation of one to two positive results per week (Lobato, 2017). However, also with the fear of lack of follow up on results reporting for the reasons given. This stated, the thesis will transition from disaster planning concepts using cloud technologies to application of those technologies for Newborn Screen management in hurricane disasters.

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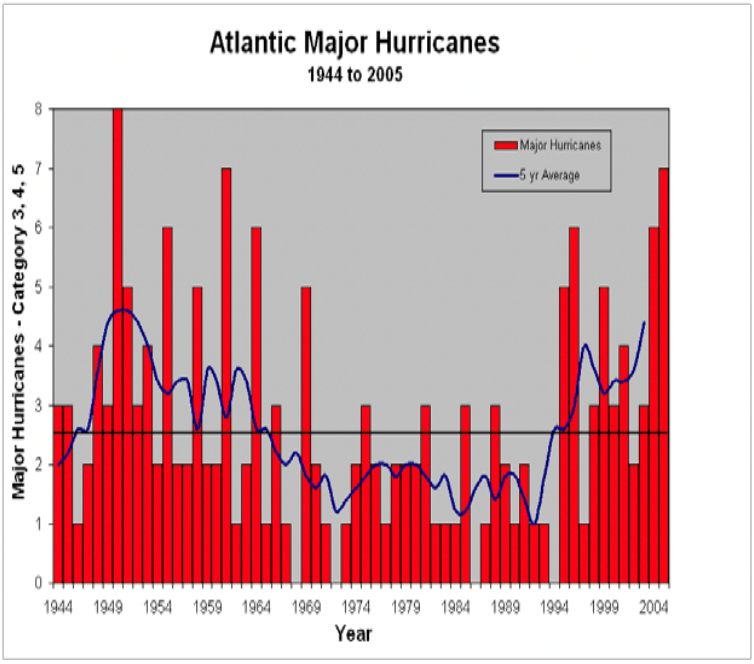
Hurricane Sandy and Improvements in Information's Delivery for Newborn Screen:

Moreover, a review of Category 3 Hurricane Sandy on the New Jersey Coast also serves to highlight the challenges of Newborn Screen delivery of services with crude technologies (ASTHO, 2013). The disaster planning systems for this hurricane led to preservation of NBS laboratory testing. Disaster planning did consist of using first responder and emergency support personnel to transport specimens to the state lab. Approximately 100,000 lab specimens are processed annually of which 1/368 will include an abnormal newborn screen, a low margin for error. As well, it was during Hurricane Sandy that with UPS services suspended, 1,000 newborn screens were processed, delivered to that state lab by law enforcement. NBS services were therefore maintained with continuity of lab testing. As such, Hurricane Sandy did not result in the same population displacement of providers and patients as did Katrina, likely contributing to preservation of the medical home and health information exchange.

Cloud Computing Solutions for Newborn Screen Data Disruption by Hurricane Disasters

Fig3 Hurricane Trends.



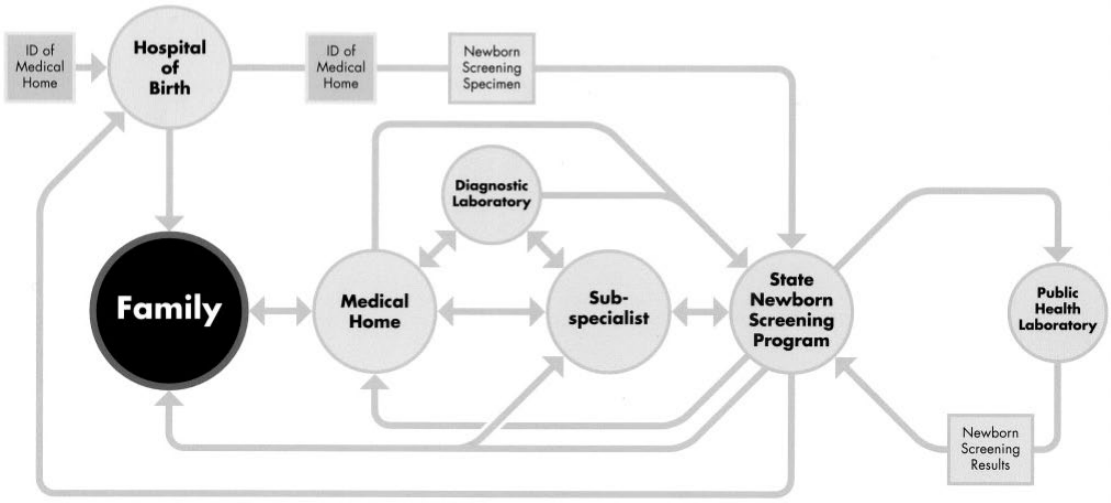
The History of the Newborn Screen:

The Newborn Screen is a state mandated screening test for inheritable and treatable diseases of infants born in the United States. Under the guide of the American College of Genetics, states test for 29 diseases and may test for up to an additional 25 secondary conditions. Newborn screening identifies some conditions that if not treated in the immediate period are life threatening. Hence the requirement for timeliness and data quality. Moreover, the data flows in Newborn screening require continuity in communication among health care providers and patient (Kim L.-P. T., 2003).

Cloud Computing Solutions for Newborn Screen Data Disruption by Hurricane Disasters

The Newborn Screen is genetic information, which in times of weather stability has redundancy built into its data governance. Patient health records redundancy has been maintained with the goal of testing, results, follow up and specialty referral supported by EHR (electronic health records.

Figure 4. Newborn Screen Data Flow



The disruption of data flows in the Newborn Screen can occur at several points along this process as noted in Figure 6.

Newborn Screen Health Information Flow:

From this data flow one denotes that Newborn screening includes the components of parents and newborns, as well professionals to deliver results. In addition, data must flow through laboratories engaged in testing and diagnosis. Health information exchange includes demographic data collection, specimen collection and results reporting. Stakeholders in this process are such that the laboratories include hospital lab, state regional lab and public health departments.

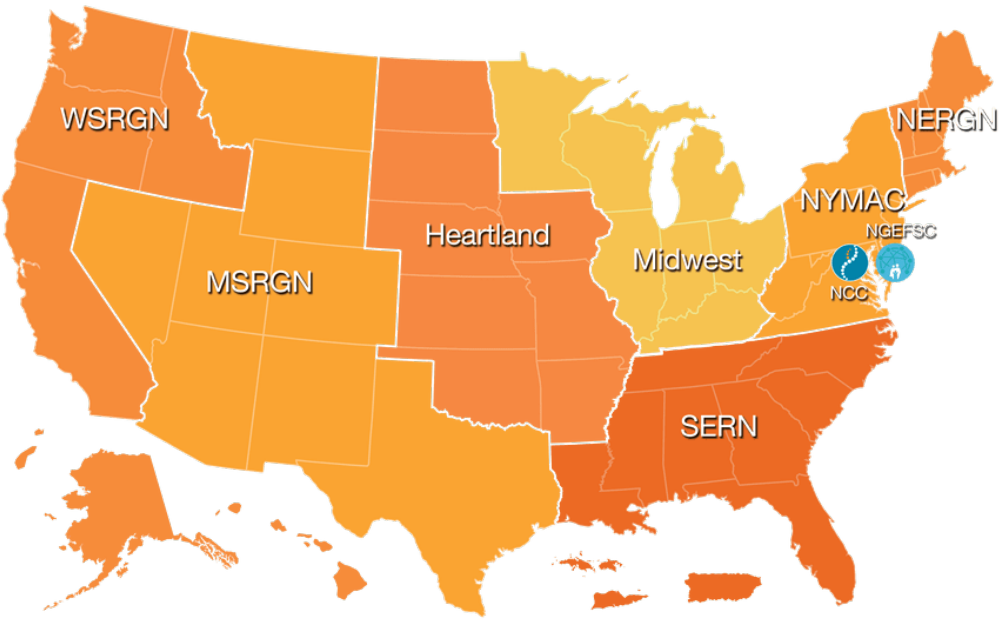
As well, professionals include primary care providers, and specialists (Pass, 2009).

During Hurricane Katrina, hospital closings, displaced families, displaced medical providers, hindered transport of laboratory samples to backup labs in Iowa, and lack of interoperable EHRs among providers all served to contribute to 20% of Newborn Screens lost to follow up (Lobato, 2017)).. Services were interrupted from 8/15/05-9/21-05, interim period of Hurricane Katrina (Lobato, 2017)). Post Katrina survey examined the magnitude of service disruption via hospital survey and found of the 58 hospitals surveyed 10% had laboratory processing disruptions and 6% had those due to a combination of laboratory, labor and delivery. Laboratory processing disruptions did include specimen handling and storage. Moreover, of the 5,958 specimens submitted post hurricane, 20.3% of the results were missing or invalid. An additional18% of the results were forwarded to the primary physician. Thirty percent of specimens were invalid due to receipt greater than 14 days post collection. Specimens collected by private laboratories were protected from these errors but only comprised 8 percent of the total sample.

In times of weather stability information flows are complicated by a lack of interoperability among health care centers for migrating patients and communicating providers as well as irretrievable data. Yet, in times of weather instability such as the disaster of a hurricane, the attempt to preserve the

redundancy of data reporting is met with challenges. Hence the work of the regional collaboratives of genetic care resources to improve the delivery of NewBorn Screen health services. In total there are seven total regional collaboratives designed to enhance the screening capacity of neighboring states (Lloyd-Puryear, 2005). In the context of disaster preparedness and post Hurricane Katrina, this has evolved to provide backup services.

Fig5 Genetics Collaborative Regions.



NERGN	New England Region
NYMAC	New York Mid-Atlantic Region
SERN	South East Region
Midwest	Midwest Region
Heartland	Heartland Region
MSRGN	Mid-States Region
WSRGN	Western States Region

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Genetics Collaborative Group

The Regional Genetics Collaborative groups, funded by the Health Resources and Services Administration's Maternal and Child Health Bureau has developed programs for emergency preparedness to improve access to health care services, The Southeast Region Collaborative has made efforts to enhance COOP, continuity of operations through support of NBS programs, genetic center health care teams, patients with genetic diagnosis (Anderson P. B.-B., 2011). In implementation of COOP, it is of note that health information is registry listed in the www.southeastgenetic.org/directory, with patients able to access virtual records via the directory listing. This is for diagnosed patients however but did prove to be an intact system in the 2010 SERC(SERN) meeting 'mock exercise' of evacuated patients seeking to re-establish a medical home (Anderson, 2011).

Evolution of Disaster Planning, Concepts and Organization:

Efforts to learn from the mistakes of the 2005 Hurricane Katrina led the state of Louisiana to adopt the 2008 Newborn Screening Saves Lives Act and the 2008 CDC/HRSA Workshop to adopt the 2010 Newborn Screening Contingency Plan CONPLAN with enhanced preparedness plans developed. (DHS, 2010). The CONPLAN has since been updated in 2015. The Newborn Screening Saves Lives Act was signed into law in 2005 by President George Bush (110th, 2008). Section 6, Laboratory Quality and Surveillance which seeks to establish regional centers

to in coordination with the CDC to develop screening methods. Section 7, Contingency Planning that mandates the CDC to establish a disaster preparedness for national emergencies.

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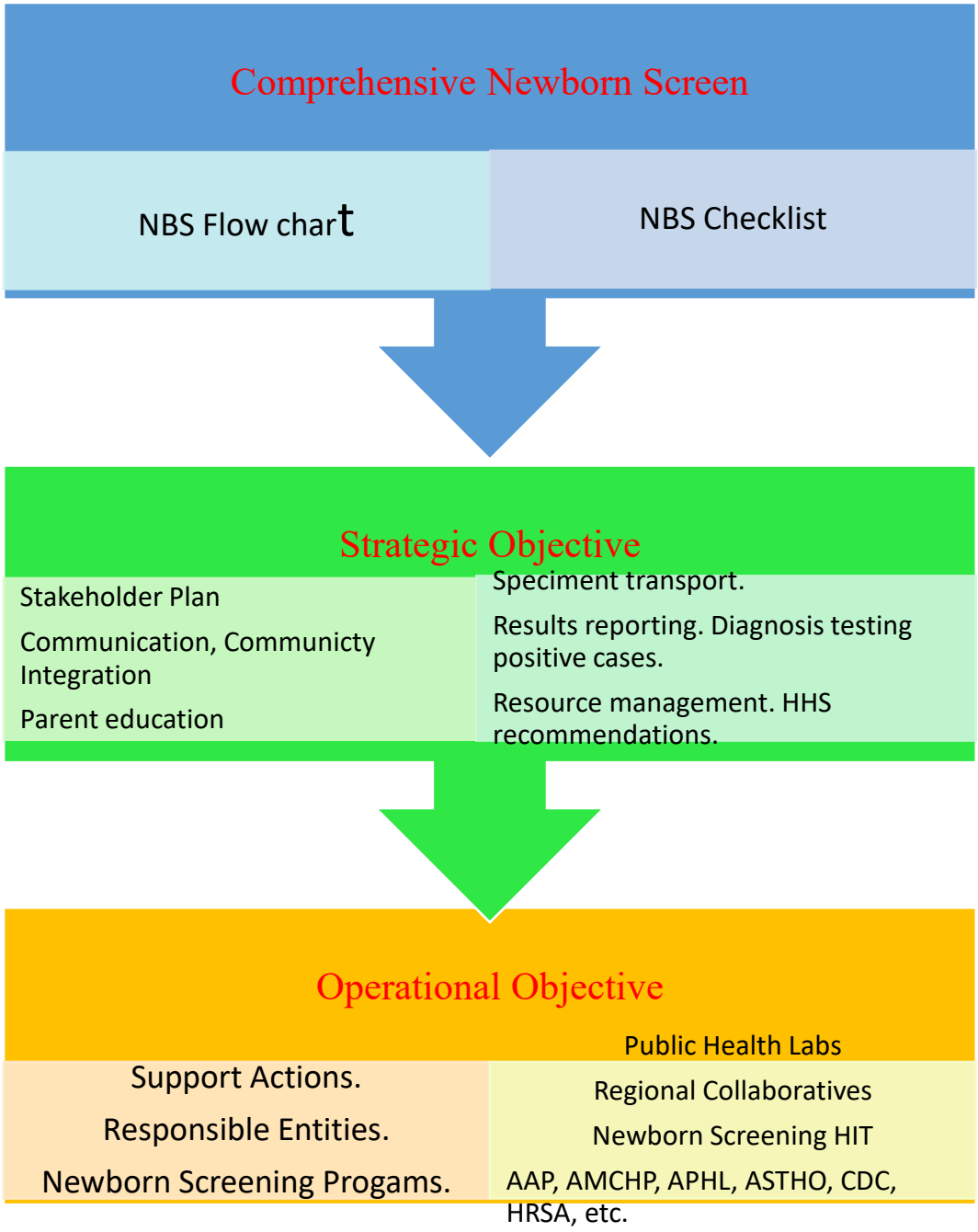
Figure 6 CONPLAN requirements



CONPLAN requirements fulfill the criteria needed for execution of a functional NBS system so as to identify lapse in lab processing, clinical reporting, diagnosis and treatment. CONPLAN updates as well have placed an emphasis on family support. With regard to Newborn Screening during hurricane disasters, CONPLAN serves to mobilize the necessary stakeholders for coordination of plans and resources needed to maintain Newborn screen services at those various points listed in the Newborn Screen Data Flow of Figure 3. It is the formalized organization and planning of these services that prevents disruption of the Newborn Screen health care delivery in times of hurricane disaster.

Foundational Concepts of Disaster Preparedness:

The history of disaster preparedness of the present day begins with the integration of FEMA (est. 1979) into the Department of Homeland Security in 2001. Prior to this disaster plans were decentralized, adopted by business and universities, and with some oversight by FEMA's National Incident Management System (Mische, 2016). Post 9/11 terrorist attacks however, the federal government has prioritized national coordination of preparedness efforts for all institutions. Preparedness is now a process of planning, assessment and problem solving through coordinated response. The goal of disaster preparedness is to protect and preserve life and health. Health promotion in this era requires information exchange, and it is the need for adaptable technologies that are now required in present day disaster preparedness. As mentioned in the preface,

required are the need to scale to time, mass population and regions of geography. With regard to information exchange preparedness refers to electronic health records and the information technology plan for their data governance.

Information Exchange in Emergency Management and the Evolution of Cloud Computing:

Emergency Management refers to the organization and coordination of responsibilities to humanitarian and community resources for disaster response. Disaster Recovery refers to those IT processes used to protect and recover information technology in times of emergency including due to natural disaster. IT processes for health information exchange and for disaster planning are not new, yet cloud computing a modern application of technology in disaster management. Cloud origins date to the 1950s[4] central mainframe designed for the singular user. This design was transformed in the 1970s with software advances that enabled multiuser virtual computing. Moreover, the 1990s witnessed the expansion of cloud computing with offerings to the public and private sector. Private sector use of the cloud was in grid and utility industries. Market expansion has led to public access and public private partnerships with network-based subscriptions offering in some cases unrestricted access[5]. Consequences for

[4] See (Neto, 2014) "Neto asserts that '…the VM operating system that originated in the 1950s took the shared access mainframe to the next level, permitting multiple distinct computing environments to reside in one domain..?"

Disaster Recovery IT are logically for enhanced use in health information exchange.

Emergency Preparedness, Health IT and *CONPLAN, COOP:*

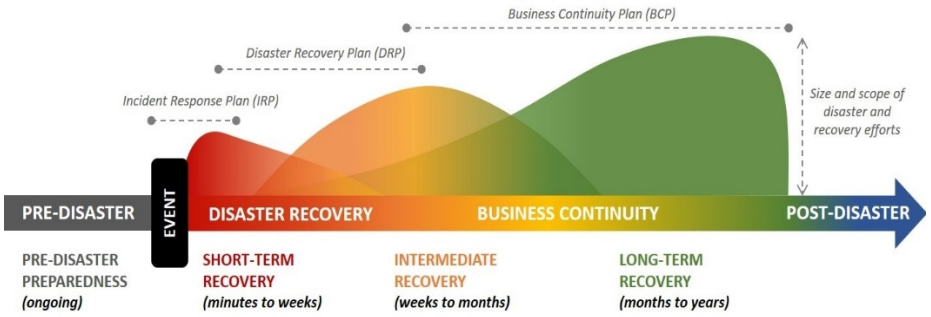
Disaster Recovery for health IT is included in the Emergency Preparedness Sequence (Andersson, 2011) for the NewBorn Screen CONPLAN. In this preparedness effort, the priority is to first create a hierarchy of personnel with duties. These personnel should develop and in-act the plan at the appropriate time. As well, the plan should include and activate business agreements with partner health centers with capabilities of performing patient care and health information exchange. The plan should conclude with the resumption of services as disaster recovery takes place.

Business agreements with partner health care institutions support information exchange are part of an IT Disaster plan. These business agreements have been formalized in the Continuity of Operations (COOP) and represent the union of public health and federal partnerships for the purposes of contingency planning (DHS, 2010). For the purposes of this thesis we will discuss those agreements the fundamental entities participating in COOP are:

Cloud Computing Solutions for Newborn Screen Data Disruption by Hurricane Disasters

Table 1. 2. COOP Stakeholders

A Continuity of Operations Plan (COOP) is designed to provide a holistic approach to both disaster recovery and business continuity. Our COOP address (1) pre-disaster preparedness, (2) disaster recovery operations, (3) business continuity operations and (4) post-disaster activities.



Stakeholders included in the COOP for the NewBorn Screen are as follows:

Pre-Disaster	Disaster Recovery	Business Continuity	Post-Disaster
HRSA	CDC	Insurance	NMS-geneticists
NMSA	NMS	Pharma	Clinicians
Advocacy	APL	Advocacy	CDC
Hospital	Hospital	Hospital	Hospital

In this regard, health information technology is benefitting from modern information flows that are timely, adaptable and scalable and these technologies are virtual.

Cloud computing is such a technology and with the benefits of accessibility, maintenance and cost. The cloud model consists of five characteristics, three models for data management, and four models of data exchange.

Cloud Computing Solutions for Newborn Screen Data Disruption by Hurricane Disasters

Characteristics of Cloud Computing:

According to ((Zong, 2016))[5], the characteristics of cloud computing are described by accessibility, scalability, timeliness, adaptability. Timeliness is notable by on demand service, adaptability is evident by the ability to open service at any location, and scalability is notable by the capacity for resource pooling, establishing public private partnerships and governance of regional geography. The models of data management (Velev, 2012)[6]are cloud Infrastructure as service (IaaS), cloud platform as service (PaaS), and cloud software as service (SaaS). The data exchange models are private cloud, community cloud, public cloud, and hybrid cloud. The DHS is utilizing a combination of public and private cloud. Among the organizations of DHS using cloud systems is the Federal Emergency Management Agency (FEMA) for disaster recovery in hurricane management. FEMA is in use of the Web Content Management as Service (WcMaaS) (Kundra, 2011). Cloud system. This system was developed in 2010 as a result of the:" Restore the Gulf" initiative.

Cloud requirements in emergency planning include confidentiality, integrity and availability; compliance; data encryption; and crisis management processes (USDHS, 2011). Additional. objectives include ranging scales of

[5]See (Zong, 2016), "Zong states, pg. 179, The integrated (platform) management of natural disasters is the more effective and advanced means and ways for natural disaster prevention, mitigation and management.,
[6]See (Velev, 2012) "Velev states page 189, Cloud computing handles resources in a better way since the user no longer needs to be responsible for storage…they may request it, stop the use of it or release it…".

geography; adaptability to mobile devices, and partnership with NGOs, the private sector and social networks.

To date, cloud computing has been primarily used for its communication properties, such as alerts: SMS, MMS, email, for buildings, of safety and remote controls. As well the offsite data storage has been used to warehouse business information. However, if. one considers the data of cloud computing is not limited by geography or government partnerships, there if the potential for benefit to the healthcare system, in particular for EMR data storage and exchange. Moreover, for EMR use in clinical care where lab data is accessed, assessed and reported. This start to finish process is discussed for the Newborn Screen in general and in time of hurricane event. Moreover, the IT requirements for this process are highlighted to demonstrate the clinical use of IT in disaster planning and the benefits of cloud services over traditional EHR data exchange. Hospitals may in coordination with FEMA provide disaster relief and preserve patient health care records with the aid of such cloud computing. FEMA which had $306 billion in damage (Goldstein, 2018) from extreme weather events had made an effort to increase its technology infrastructure so as to permit scalability to the millions. Contract obligations were expected to increase by 32 percent in 2018 for a high of $6.5 billion with the federal market public private clouds and multicloud environments expanding (Goldstein, 2018). This suggests both the need and

potential for improved healthcare in times of emergency management with cloud systems.

Summary

There has been a significant evolution in technology and emergency planning since 2005. The evolution of cloud support for disaster recovery by DHS and in particular by FEMA is relevant given the increase in natural disasters (Little, 2017). Climate change and its untoward effects has led to natural disasters of greater frequency and severity. The United States Gulf Coast has witnessed this phenomenon with the Hurricane Katrina in 2006 and in 2017 Hurricane Harvey. These natural disasters however, are. distinguished by the presence of cloud computing and its impact on pediatric patient outcomes. Hurricane Katrina was without cloud computing and suffered disruption of EMR information flows, while in contrast Hurricane Harvey (Vesely, 2017) had the benefit of cloud computing and preservation of patient records with resulting continuity of care.

Cloud Computing Solutions for Newborn Screen Data Disruption by Hurricane Disasters

CHAPTER 3: METHODOLOGY

Introduction

Purpose Statement

The purpose of this thesis is to provide a systematic literature review of Newborn Screen system components, the newborn screen information flows and disaster planning considerations, which result in operational improvements during hurricanes. This thesis reviews the 2005 Hurricane Katrina as a pivotal weather event where health information was significantly disrupted.

Problem Statement

Traditional Newborn Screens were a collection with a blood sample placed on a card and sent to a regional state lab by mobile transport for testing. Standards dictated by the Clinical and Laboratory Standards Institute, established guidelines for emergency operations plans to address the hazards of mass weather events such as natural disasters including hurricanes. These operations include quality management of laboratory systems that maintain service through the use of coordinated systems. Historically, these systems have included collaborative agreements with neighboring hospitals, public health laboratories and personnel. Health or laboratory information was transmitted by fax or with information technology advances EMR. This is a system of information flow that requires

functional hospital operations, mass transit, and EMR across facilities that may not be interoperable. It is during normal hospital operations, Newborn Screens have follow up reporting within 5 days (Kim e. a., 2003). However, this system was noted to be flawed with 31% of medical homes reporting a delay of greater than 10 days. It is the assertion of this thesis that during extreme weather events, such as hurricanes there can be a significant disruption to this essential medical testing process further placing infants at risk. Moreover, that modern technology such as cloud computing is the solution to this problem. The research questions for this thesis are: 1) What advances in technology have taken place to overcome any potential disruptions to Newborn Screen operations during hurricanes? 2) Is cloud computing a solution to IT disaster preparedness for the Newborn Screen in mass weather events such as hurricanes?

Literature Search Methodology

Data Type: Systematic Literature Review, Methodology:

Regarding methodology, this thesis used a Systematic Literature Review (SLR), or Systematic Review. This method was used to identify, evaluate and summarize the relevant themes in the literature in a manner that was critical and reflective of historical and timely data. SLR allows for scientific analysis that justifies current research and allows for future study. SLR permits a lower bias than the traditional reviews (Cooper, 2018).

To perform the systematic review a search was conducted with the inclusion and exclusion criteria according to language, database, and publication.

A search was conducted with the PubMed data base and that of Library of Congress as well the Internet. Eight-nine (89) articles were found with this method which were further narrowed in scope to twenty (20) articles. The systematic literature reviewed followed the methodology of screening literature by inclusion/exclusion criteria as outlined in Figure 1 and BiSLR Bioinformatics Systematic Literature Review as noted in Table 2 below.

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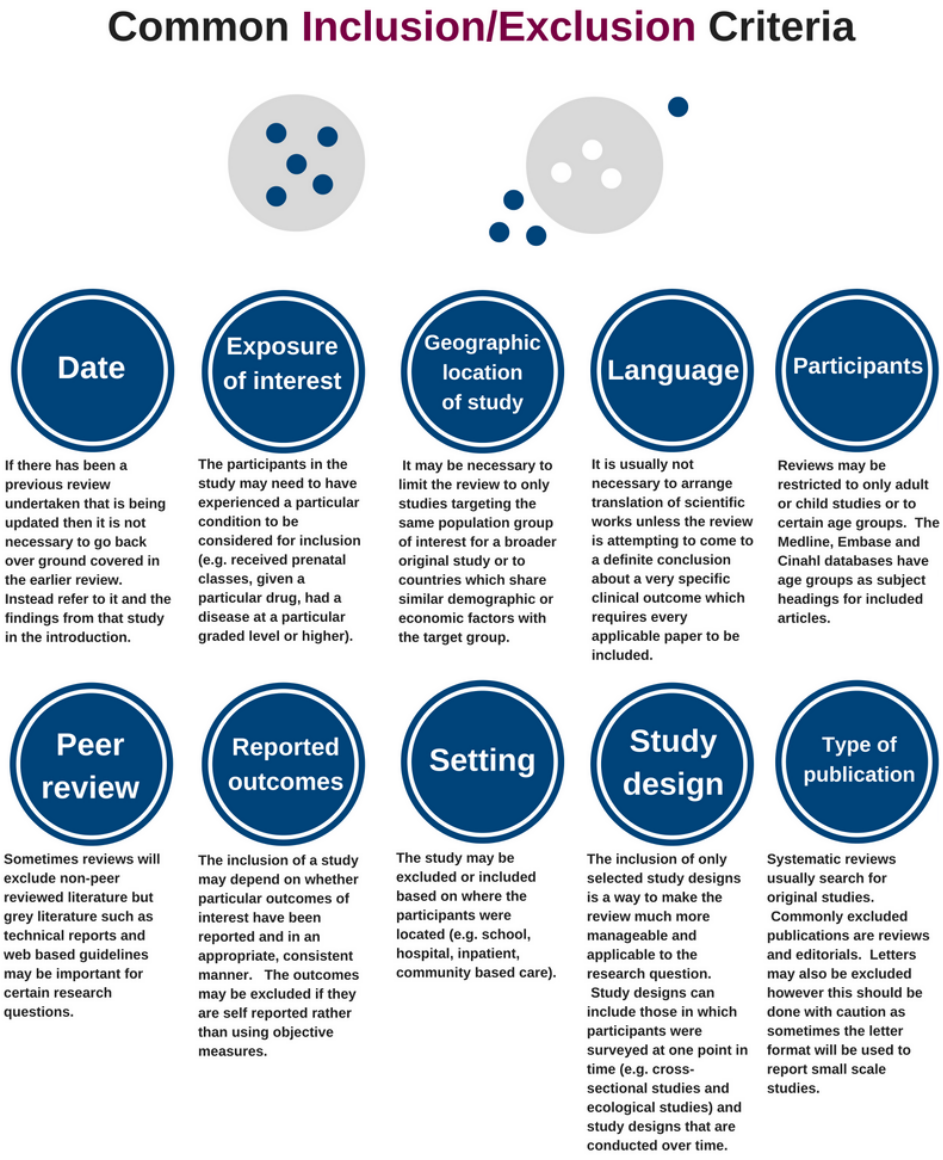
Figure 7. SLR Inclusion/Exclusion Criteria



The Literature Search was conducted using inclusion and exclusion criteria. Articles were selected for data post 2003 given periodic review of Newborn Screen systems in the literature at this time and Hurricane Katrina in 2005. Exposures and Geographies were limited to those regions affected by Hurricanes Katrina, Sandy and Harvey. English language articles were selected.

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Participant stakeholder terms most utilized in key word searches were newborns, geneticists, FEMA, and Government. Peer Review literature was queried in PubMed and on the internet. The internet a source of periodic journals, nonscientific literature and op ed journalism. The setting for literature review chosen included that of case study, peer review and government publication. Study design was reflective of retrospective cohort, observational, qualitative review and descriptive analysis. This analysis was as stated in periodicals, scientific, blog publications and government document.

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Table 2. Literature Search Criteria

Inclusion/Exclusion	Criteria Met
Date	prior to 2003
Exposure, Geography	Hurricanes Katrina, Sandy, Harvey Gulf Coast, East Coast
Language	English
Participants	Newborns, Geneticists, FEMA/Government
Peer Review	PubMed Internet web journal
Setting	Descriptive, Analytic, Opinion
Study design	Survey, Retrospective cohort, Qualitative, Editorial
Type of Publication	Journal article, Government Publication/Law/Testimonial, Blog,

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Project Design and Procedures

Of the articles selected in the English language, several of the Pediatric Journal and Emergency Management periodical publications are from this initial period of 2005-2010. Thereafter an effort to obtain comparative data on Hurricanes Sandy and Harvey led to three articles of grey literature (internet sourced periodicals) dating from 2009-2017. Grey literature consisting of documents produced and published outside of the body of work led by academic and publishing institutions. These articles were selected for their narrative and objective analysis of health information system flows during hurricane disaster. Periodical journal articles dedicated to the Newborn Screen were varied in source and did include established scientific journals, numbering three. These articles satisfied the Cochrane criteria and did include descriptive survey studies, descriptive qualitative and cross-sectional analytic publications. FEMA and Disaster Planning data sources varied in source given references in journal articles, grey literature and government documents. Journal articles referencing Disaster Planning were one in number with grey literature three studies and government publications from DHS totaling five. The grey literature articles were thus from internet source scientific journals. The government publications did include department media and official document. These references were selected for qualitative description of organizational content of government structure as

well as objective assessment of current trends in policy and decision making. To follow, on the subject of EHR and Health IT Disaster Planning, two journal articles were selected. These descriptive qualitative articles were selected for historical background information. Cloud computing and hurricanes yielded a single descriptive qualitative article. Cloud computing and government yielded a single official government publication, two grey literature articles and two descriptive qualitative articles in periodicals. The cloud subject articles were selected for technical expertise, policy perspective and global insight as provided by comparison with other nations.

(Twelve articles are discussed in the Literature Review.)

Data Selection

BiSLR Method and PRISMA Results:

SLR, Systematic Literature review is a method to 'identify, evaluate and summarize the state of the art of a specific theme in the literature…by methodological analysis ' (al M. e., 2017). BiSLR is the Bioinformatics Systematic Literature Review, and accounts for the diversity of professions in the field with the resulting potential for selection bias in literature search. The BiSLR and PRISMA diagrams below further detail the method of document selection for literature review. The spiral model as noted below defines the BiSLR sequence. The BiSLR model is divided into four main steps. 1) (A) Deciding on the study objectives and research questions. (B) Deciding what to include in the literature

search. (C) Data evaluation: consists in assessing each study collected in the SLR and define the list of papers included in the SLR. (D) Interpreting the findings consists of analyzing the papers covered in the SLR, group, summarizing, evaluate the SLR, collect data for construction of curated databases and construct a narrative synthesis to summarize everything. This method provided the final inputs into the PRISMA Diagram.

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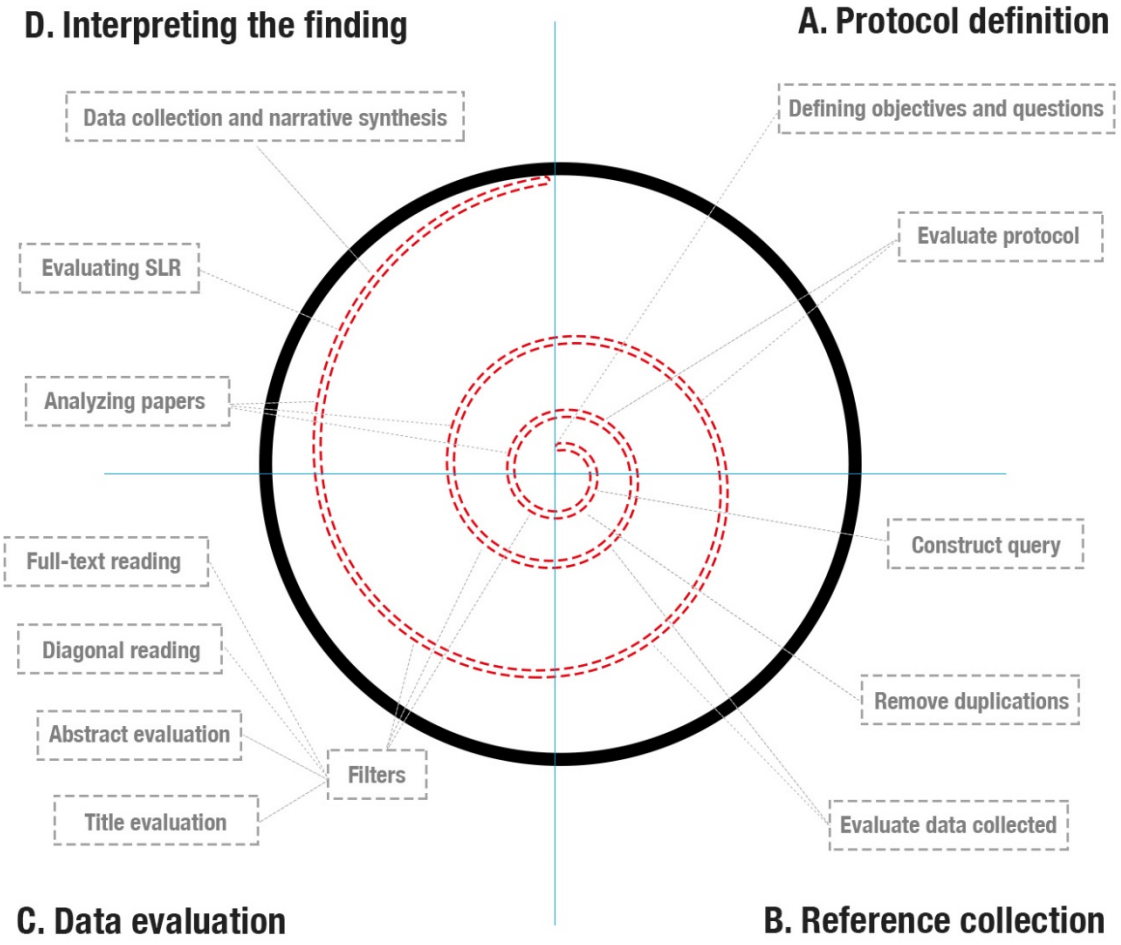
Figure 7. BiSLR spiral model.



Following protocol definition by research question, reference collection began with data collection in PubMed, Library of Congress and Internet. Query led to group with Newborn Screen, Hurricane and Information Technology results number 3,556. Also query with Newborn Screen, Hurricane, Cloud technology, ER Management and FEMA number 370. Data evaluation led to filtering of studies by title, abstract, and full text reading. Second query produced NewBorn

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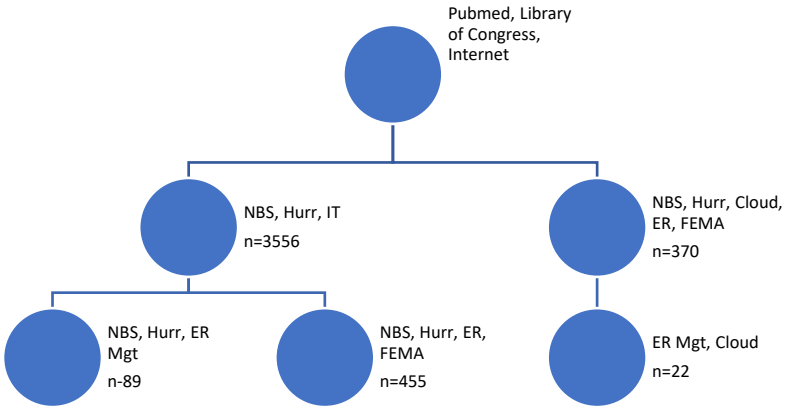
Screen, Hurricane, and ER Management number 455. Interpretation of findings through analysis of papers led to final number of

89 for Newborn Screen, Hurricane, ER Management and number 22 ER Management and Cloud technologies.

Figure 8 PRISMA Diagram



Key
NBS-Newborn Screen
Hurr-Hurricane
IT-Information Technology
ER/ER Mgt-Emergency Management
FEMA-FEMA
Cloud-Cloud or virtual computing

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The PRISMA results are expanded to include the articles referenced and classify them according to their source, method and impact on the literature review. Articles are numbered, titled, and listed by author. As well, the study type is listed. Study types include study designs descriptive survey and qualitative as well as the analytic cohort study. Also listed is the editorial or opinion publication. Grey literature, that of nonreviewed scientific publication is listed. Government documents are listed. With regard to impact, the impact categories have been arbitrarily chosen and include qualitative description, qualitative observation or policy description and policy information.

Table 3 PRISMA Results.

Article	Title	Author	Study Type	Insight
1.	**Hurricanes and Climate Change**	**Union of Concerned Scientists**	**Grey Literature**	**Qualitative**
2.	**Impact of Hurricane Katrina on Newborn Screening in Louisiana**	**Lobato et al**	**Descriptive Survey**	**Qualitative**
3.	**Public Law 100-204**	**US Congress 110**	**Government Document**	**Policy Information**
4.	**Examination of the Communication Practices…**	**Kim et al.**	**Descriptive Survey**	**Qualitative**
5.	**Disaster and Contingency Planning…**	**Mische**	**Descriptive Qualitative**	**Qualitative**

6.	**Emergency Preparedness for genetics centers…**	**Anderson et al**	**Descriptive Qualitative**	**Qualitative**
7.	**Newborn Screening: A National Snapshot…**	**Floyd-Browning et al**	**Descriptive Qualitative**	**Qualitative**
8.	**Newborn Screening Goes on In Spite…**	**Grey Literature**	**Descriptive Qualitative**	**Qualitative**
9.	**National Disaster Recovery Framework**	**FEMA**	**Government Document**	**Policy**
10.	**Principles of Cloud Computing Application in Emergency Management**	**Velev et al.**	**Descriptive Qualitative**	**Qualitative**
11.	**CONPLAN 2010**	**CDC**	**Government Document**	**Policy Information**
12.	**Overview of the Federal Interagency Operational Plan, 2016ederal Cloud Computing Strategy**	**DHS**	**Government Document**	**Policy Description**
13.	**How the Cloud Helps FEMA Scale and …**	**Goldstein**	**Grey Literature**	**Qualitative**

14.	**Electronic Health Records Access During a Disaster**	**Florshan et al.**	**Grey Literature**	**Editorial**
15.	**Federal Cloud Computing Strategy**	**Kundra**	**Government Document**	**Policy information**
16.	**How the Cloud Helps FEMA Scale and …**	**Goldstein**	**Grey Literature**	**Qualitative**

17.	**Strengthening the Federal Emergency Management Agency's Disaster…**	**Canon et al**	**Grey Literature**	**Qualitative**
18.	**Health system disaster preparedness and data backup: Are hospitals….**	**Vesely**	**Grey Literature**	**Editorial**
19.	**Health Information Technology Can Make Disaster Seem ….**	**Stevens et al.**	**Descriptive Qualitative**	**Qualitative**
20.	**How Will Federal Cloud Use Evolve in 2019?**	**Goldstein**	**Grey Literature**	**Qualitative**

Cloud Computing Solutions for Newborn Screen Data Disruption by Hurricane Disasters

PRISMA Table Analysis and Discussion:

Articles on the subject of hurricane trends were source from grey literature with the impact to give contextual background and historical data. Those articles from clinical journals detailing the NewBorn Screen services during Katrina, genetics oversight, and emergency management served to provide historical review and analysis, as well as through survey study determine the prevalence of ineffective delivery in health care services. Those Government Documents listed provide organizational context for those agencies referenced in the role of emergency response for hurricane disasters. As well, policy was reported and defined in the documents that detail the federal investment in cloud computing.

Cloud Computing Solutions for Newborn Screen Data Disruption by Hurricane Disasters

Both periodicals and grey literature gave insight into the evolution of cloud computing as a means of health information and its role in disaster preparedness. Data obtained was technical, consisting of definition of terms, as well consisting of assessment of current technological advancements and prediction of emerging technological trends. There was little experimental quantitative review data to describe the practical use of the cloud in hurricanes and in particular for delivery of Newborn Screen services, as expected with this emerging technology. Moreover, there was a plethora of grey literature consisting of non-scientific expert opinion on the benefits of cloud computing in emergency services and these articles were discarded during literature review.

Summary of Data and Methods

Analysis of the literature search qualified data by article title, author, study type and impact. Study type is significant for its characterization of data analysis. Data is interpreted as objective peer reviewed, expert opinion, or professional guideline. Given the disciplines that impact NewBorn Screen Health IT during hurricanes, it is important to have diversity of literature from professional communities in genetics, emergency management, information technology, government policy, and da disaster planning

Cloud Computing Solutions for Newborn Screen Data Disruption by Hurricane Disasters

CHAPTER 4: RESULTS

Introduction

Purpose Statement:

The purpose of this thesis is to provide a systematic literature review of Newborn Screen system components, the newborn screen information flows and disaster planning considerations, which result in operational improvements during hurricanes.

This thesis reviews the 2005 Hurricane Katrina as a pivotal weather event where health information was significantly disrupted.

Problem Statement:

Traditional Newborn Screens were a collection with a blood sample placed on a card and sent to a regional state lab by mobile transport for testing. Standards dictated by the Clinical and Laboratory Standards Institute, established guidelines for emergency operations plans to address the hazards of mass weather events such as natural disasters including hurricanes. These operations include quality management of laboratory systems that maintain service through the use of coordinated systems. Historically, these systems have included collaborative agreements with neighboring hospitals, public health laboratories and personnel.

Health or laboratory information was transmitted by fax or with information technology advances EMR. This is a system of information flow that requires functional hospital operations, mass transit, and EMR across facilities that may not be interoperable. It is during normal hospital operations, that Newborn Screens have follow up reporting within 5 days. However, this system was noted to be flawed with 31% of medical homes reporting a delay of greater than 10 days. It is the assertion of this thesis that during extreme weather events, such as hurricanes there can be a significant disruption to this essential medical testing process further placing infants at risk. Moreover, that modern technology such as cloud computing is the solution to this problem. The research questions were: 1) What advances in technology have taken place to overcome any potential disruptions to Newborn Screen operations during hurricanes? 2) Is cloud computing a solution to IT disaster preparedness for the Newborn Screen in mass weather events such as hurricanes?

This thesis was designed to update and inform public health as to the benefits of cloud computing for delivery of Newborn Screen health care information in times of hurricane disaster. Emerging themes from the literature and lessons learned are as follows. Results are grouped by research question.

-Question 1: What advances in technology have taken place to overcome any potential disruptions to Newborn Screen operations during hurricanes? -

Hurricanes and Disaster Planning for the Newborn Screen:

The literature suggests that climate change will lead to an increase in the frequency and severity of hurricane weather events, Category 3, 4 and 5. These mass weather events will likely guarantee land mass destruction that will interrupt the traditional information flows of the Newborn Screen rendering the original contingency plans obsolete. Moreover, that these events will require regional Collaboration of the medical community in conjunction with federal, state and local agencies who partner in coordinated disaster planning efforts.

Federal Interagency Disaster Operations Plan:

Under the guise of the DHS is the FEMA National Incident Management System as mentioned which includes Federal Interagency Operational Plans, which "describe operations for integrating and synchronizing existing national-level capabilities to support local, state, tribal, territorial, insular area, and federal plans and are supported by federal department -level operational plans, where appropriate..[7]" This consists of four mission areas protection, mitigation, response and recovery of hazards and attacks, including mass disasters and terrorist incidents. The following is a graph of core capabilities and coordinating activities with information technology an integral part of prevention, protection, mitigation and recovery. Specific to the FIOP, is the National Disaster Recovery Framework

[7] See (DHS, 2016) Recovery Federal Interagency Operational Plan page 1. Additional resources from fema.gov. Retrieved from: https://www.fema.gov/media-library-data/1471451918443-dbbb91fec8ffd1c59fd79f02be5afddd/Recovery_FIOP_2nd.pdf.

(NDRF), which addresses disaster response, linking local, state, and federal governments with the private sector and community organizations. The NDRF is

the evolution of the 2009 President Obama DHS and HUD Long-Term Disaster Recovery Working Group with a resulting Web portal that permits relevant stakeholders to reference a descriptive document of duties and resources for disaster recovery (FEMA, 2011)

With regard to health services FEMA, NDRF must ensure timeliness and adaptability in restoration of health services as well as public health planning. Health care infrastructure must be maintained and or restored with the aid of the public /private sector. This includes the creation of communication and information sharing for health and social services within a state and or community also scalable to coordination with federal resources. This information sharing must include data quality that allows for metrics analysis of effectiveness and for ongoing impact as well as continued public health intervention.

Table 4. Federal Interagency Disaster Operational Plan

Prevention	Protection	Mitigation	Recovery
Planning	Planning	Planning	Planning
Public Information	Public Information and Warning	Public Information and Warning	Public Information and Warning
Operational Coordination	Operational Coordination	Operational Coordination	Operational Coordination

Forensics and Attribution	Access Control Identity Verification	Community Resilience	Economic Recovery
Intelligences and Information Sharing	Interdiction and Disruption	Long-term Vulnerability Reduction	Health and Social Services
Interdiction and Disruption	Screening, Search Detection	Risk and Disaster Resilience	Housing
Screening, Search, Detection	Physical Protective Measures	Threats and Hazards Identification	Infrastructure Systems

-----	Risk Management	-------	Natural and Cultural Resources
-----	Cybersecurity	-------	---------
-----	Supply Chain Integrity/Security	-------	---------

Cloud Computing Solutions for Newborn Screen Data Disruption by Hurricane Disasters

The four phases of disaster recovery, prevention, protection, mitigation and recovery are presented in the context of federal duties (DHS,2016). Some commonalities exist including planning and informing the public. Of note and relevance to IT Disaster planning is the Information Sharing component of Prevention, Cybersecurity component of Protection and Health and Social Services Component of. Recovery. Health Information Technologies are thus inclusive of all phases of Disaster Operations Plans.

Cloud Computing Solutions for Newborn Screen Data Disruption by Hurricane Disasters

-Question 2: Is cloud computing a solution to IT disaster preparedness for the Newborn Screen in mass weather events such as hurricanes? -

Newborn Screen Information Exchange in the SouthEast Regional Collaborative:

Listed in the Recovery Phase is Health and Social Services and to that regard, the literature highlights the regional health informatics operations plans of the SouthEast Regional Collaborative. A review of the Southeast Regional HIT-HIE Collaboration (International, 2012) document denotes the efforts to transition from the poor outcomes in health service due to paper-based health records from 1992 to 2007. Review of VA hospital IT performance during Hurricane Katrina also revealed a superior system due to the present of virtual computing.
Their recommendation thus inspired a statewide HIE as an effort to implement the Nationwide Health Information Direct network and remains pending. This is a cloud-based system. Plans for this system were to phase in from 2011-2014.

Cloud Computing Solutions for Newborn Screen Data Disruption by Hurricane Disasters

Table 5 Phased Approach to HIE of NwHIN

Phase 1	Phase 2	Phase 3
Sept 2011–June 2012	July–Dec 2012	Jan 2013–June 2014
• Encourage enrollment • Leverage cloud-based EHR systems • Leverage EHR vendor data aggregation • Identify, publicize, and enable access to data • Capture and house data from point-to-point data	• Increase use • Integrate with other secure messaging platforms • Integrate provider directories across States • Improve capabilities of State HIE Networks • Evaluate, develop, and deploy data access services	• Continue use • Deploy fully functioning State HIEs • Implement cross-State physician credentialing services • Implement cross-State identification of patients • Evaluate need for data access services

This table highlights the phased in HIE of the Southern Regional Collaborative with efforts to establish and increase use of services for physicians and access for patients. The objective is interoperability and statewide use of cloud services with needs assessment for ongoing development. To date the region has developed Health Exchanges for its providers and established best clinical practices as dictated by payors but no cloud system for disaster preparedness is in place (Budniak, 2018).

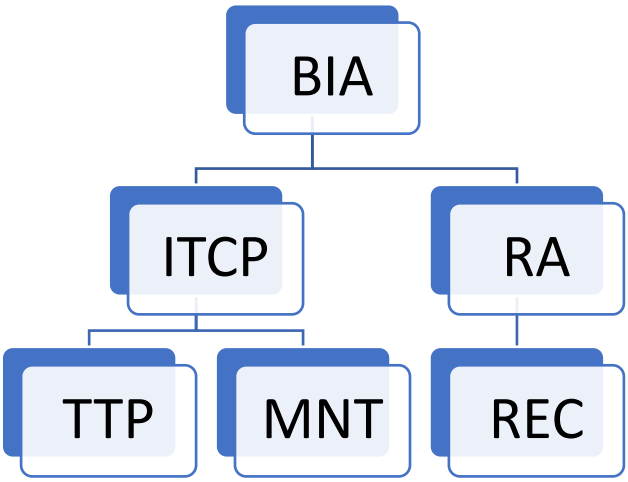
Cloud Computing Solutions for Newborn Screen Data Disruption by Hurricane Disasters

Hospital Information Exchange and Disaster Planning:

Health information IT in disaster planning includes those recovery measures for hospital systems with an organized protocol for recovery. The protocol is a comprehensive assessment of the disrupted systems and networks with the intention of limiting disruptions in normal operations. Formalized documents sequence the process of prioritizing risk, identification of critical systems and initiated recovery These documents are under the head Business Impact Analysis, Risk Assessment, Contingency Planning Policy, Testing and Revision Policy, Data Backup Plan Policy, Training and Awareness Standard (Supremus Group, 2016). Hospitals must have an IT recovery plan in place to both protect information and mitigate the average cost of $5,000 loss per minute for loss of critical applications (Vesely, 2017). The Business Impact Analysis serves to highlight critical systems, Risk Assessment reduce disruptions, Contingency guide and restore damaged systems, Training, and aid in recovery. This plan is essential for the traditional EHR system with components as mentioned including physical servers, IT staff and back up data. However, the availability of cloud computing mitigates the many requirements of the Hospital Disaster Plan (Supremus, 2016).

Cloud Computing Solutions for Newborn Screen Data Disruption by Hurricane Disasters

Figure 9. Hospital IT Disaster Recovery Plan



- BIA
  - Define critical IT systems
  - Develop a contingency plan
- ICP
  - TTP
    - Test the contingency plan, prepare for recovery
  - MNT
    - Plan maintenance
- RA
  - Identify measures that reduce disruptions
    - REC
      - Develop recovery strategies

Model Hospital IT Disaster Recovery Plans seek to "protect life, protect assets, and protect the organization.."[8]. In this regard, business functions are utilized to

[8] See (Council on Foundations, 2019) "This plan outlines the organizations strategy…provides information essential for continuity.. and identifies resources…" Obtained from cof.org. Retrieved from: https://www.cof.org/content/disaster-preparedness-and-recovery-plan

promote safety as resources essential for emergency resources are identified and delivered. As well the stakeholder relationships that facilitate this process are supported by information technology that is maintained and restored. Figure 9 presents a general view of these relationships needed for services vital to the hospital, stakeholders and community at large. With regard to information technology, the BIA, Business Impact Analysis is established to determine business, operational and financial impact of disaster on IT systems (Supremus, 2016) This is followed by a RA, Risk Assessment with resulting REC, Recovery Strategies produced. The BIA as well will produce an ITCP, IT Contingency Plan from which the TTP, Technology Test Plan and the MNT Maintenance Plan. The Technology Test Plan includes and Audit Checklist of the Business Unit, Network, Database and Disaster Recovery. The Maintenance Plan includes completed documents and a final audit report.

[8] See (Council on Foundations, 2019) "This plan outlines the organizations strategy…provides information essential for continuity.. and identifies resources…" Obtained from cof.org. Retrieved from: https://www.cof.org/content/disaster-preparedness-and-recovery-plan

Cloud Computing Solutions for Newborn Screen Data Disruption by Hurricane Disasters

Table 6 Business Process Matrix for IT Hospital Disaster Recovery Plan

Objectives	Bus. Rules	Trigger	Task Set	Input	Output	Outcome
Business Impact Analysis Analysis of critical applications and data with financial, operational and legal impact.	**Risk Assessment** Facility risk assessment.	**Contingency Program** Disaster Recovery document for disaster event with hospital data back up and storage plan	**Recovery Strategies** To implement application, network, database, server, recovery plans.	**Testing and Revision Plan** Test schedule and audit checklist.	**Final Reports** Completed Data Backup Plan, Recovery Plan, Final Audit	**Metrics** Type of Tests Completed Emergency Operations Plans

The Business Process Matrix outlines the sequence from objectives to outcome for IT Hospital Disaster Recovery Plan. This is important given the role of hospitals as a stakeholder in the Newborn Screen process. They are a central provider of patient data collection and dissemination. Cloud data warehousing of Newborn Screen data still requires a referencing hospital. Thus, the return to a freestanding medical facility is important in disaster recovery. Within the Business Matrix, Business Impact Analysis defines the financial impact of data loss and interruptions. Risk assessment details the system deficits and needs for return to full function. Contingency Program details those backup and recovery measures in place to restore data, minimize loss of information. Recovery strategies begin the act of data retrieval and restoration of function. Testing and revision audit the recovery process. Final reports document the testing and

revision process, auditing the disaster and recovery process. Metrics documents the types of tests utilized in operations plans. Based upon this matrix it is clear that cloud computing provides ongoing health care services that allow for the hospital or health care center to assess and repair traditional EHR capabilities. Moreover, cloud services may serve as an auxiliary support in system testing and analysis of function while providing health care information.

Cloud Computing Solutions for Newborn Screen Data Disruption by Hurricane Disasters

CHAPTER 5: DISCUSSION

Introduction

Purpose:

The purpose of this thesis was to provide a systematic literature review of Newborn Screen system components, the newborn screen information flows and disaster planning considerations, which result in operational improvements during hurricanes.

This thesis reviews the 2005 Hurricane Katrina as a pivotal weather event where health information was significantly disrupted.

This chapter will review the key findings of the thesis with regard to virtual cloud services as a means of health information exchange, attributes and challenges. A dissuasion is to follow detailing current cloud computing use in emergency services abroad with examples in Australia and Japan. The French use of cloud computing in their nationalized health care system will also be reviewed.

Summary of Key Findings

Health Information Exchange as Cloud Services:

This thesis served to give an overall description of cloud technologies and their context in hospital information's systems with regard to Newborn Screen health care delivery during hurricanes. Electronic Health Record (EHR) systems

and Cloud computing systems are methods of healthcare records data storage. EHR has been the traditional method of health care data storage but is now being replaced by cloud storage due to its advantages as outlined in Figure 8. These advantages are of particular importance in hurricane disasters and for exchange of the Newborn Screen. First EHR stores data on a physical location either on site or off site warehoused in a server with files maintained by an Information Technology staff for backup and recovery. This is costly and a security risk for theft and cyber-attack. As well, with regard to hurricane there is risk of physical damage to the site. In contrast cloud data is stored on the internet by a vendor as a Software as a Service (SaaS) service with fees that include maintenance, backup and updates. There is no risk of physical damage, less risk of theft and cyberattack. HIPAA compliance is challenging with cloud exchange, and the risk remains of inability to access data with loss of internet service. Typically, the cloud service is less expensive to maintain than EHR with savings for hospitals of 20%. (Adair, 2019)

Cloud Attributes:

Additional attributes of the cloud include adaptability with the cloud data capacity much greater than that of the EHR allowing for the scalability required of disaster events. Moreover, the timeliness required of disaster events is also better provided by the cloud computing services. Data is immediately accessible and available at all hours of the day.

This is important for the Newborn Screen during hurricanes as adaptability in the presence of high category storms requires accessibility to health information for

displace patients and providers. As well, hospital information technology disaster plans may include cloud technologies as an initial component of their recovery plan, transitioning to the more conventional EMR with recovery of infrastructure such as personnel and power. Future study is needed to determine the most effective public private partnerships for the cloud in times of emergency as hurricane disasters are regional events that evoke the engagement of a diversity of corporate and civic stakeholders.

Cloud Computing Definitions and Requirements:

Definition.
Cloud computing is a virtual, on-demand internet access shared computing network accessed via service provider.

Five Characteristics

1. On-demand self-service-One can purchase server time and storage prn.
2. Broad network access-Network services accessed through standard procedures.
3. Resource pooling-Multiple consumers serviced by provider.
4. Rapid elasticity-Rapid scale out and quick scale in to meet consumer demands which may be unlimited in need or quantity
5. Measured service-Service caps offered, and resources monitored by provider.

Varied purchase agreements for availability and access to data, data storage capacity and data network maintenance operations For the NewBorn Screen Health IT needs during hurricanes, resource pooling would be most beneficial as the provider, VaMED/RHIO is accessible by public and private stakeholders, both in health care, the private sector and in government.

Data Management

1. Cloud Infrastructure as a Service (IaaS)-data processing, storage, networks provided with consumer control over operating systems and networking components.

2. Cloud Platform as a Service (PaaS) consumer created or acquired applications are available as provided by the provider
3. Cloud Software as a Service (SaaS) the consumer has limited user application features as sported by the provider.

Data applications with varied consumer control as provided and supported by the provider. The Newborn Screen Health IT cloud service would be best served by SaaS as the VaMed and RHIO provide the cloud service and limit use to select users and only in times of hurricane.

Data Exchange

1. Private cloud-service owned by an organization
2. Community cloud—shared ownership by several organizations
3. Public cloud-available to the general public
4. Hybrid cloud-unique entities sharing a cloud

Data exchange is defined by the population with ownership or access to the cloud services. The Newborn Screen HIT cloud for VaMed/RHIO would be and Hybrid or multi-cloud with the unique entities previously defined sharing cloud services.

Security for the Cloud:

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The DHS private cloud model security is founded in the Defense-in-Depth strategy and following the HIST definition of private cloud computing. This includes technologies such as OneNET, Trusted Internet Connections, and Policy Enforcement Points. The public cloud model security is bolstered by technologies such as FedRAMP, and business agreements that reduce the “visibility gap” that clearly defines the responsibility of provider and client.

Cloud Computing Solutions for Newborn Screen Data Disruption by Hurricane Disasters

Table 7. EHR vs. Cloud Attributes

Attribute	EHR	Cloud
Cost	Startup	Maintenance
Maintenance	IT staff manual updates	Software updates, less manpower
Adaptability	Limited data storage	Scalability
Timeliness	Delays	Approximates real time
Security	Theft, Cyberattack	No HIPAA guarantee

Table 6 contrasts the attributes of EHR and Cloud computing technologies. EHR has a minimal startup cost, yet cloud has a lower maintenance cost. Maintenance is facilitated by the need for less staff and hardware as well the ease of software updates. The cost withstanding, the cost benefit is gained with the scalability of the cloud and unlimited data capacity. Moreover, timeliness with the cloud extends to real time functionality. However, as EHR is subject to theft and cyberattack, the cloud is challenged by the virtual network inability to guarantee privacy protection.

Practical Application/Anecdotal Evidence

It was observed that cloud systems were superior in health care delivery for Hurricane Harvey vs. Katrina. As well, it is the conclusion of this thesis that a multicloud hybrid system would have been of benefit to Katrina. A description follows:

The consequences of adopting cloud computing as suggested in this thesis lie in the full integration of cloud computing for hospital networks. If as

suggested, states use RHIO existing cloud services and prepare to merge with VaMed in times of disaster as well Medicaid. In this regard military mothers register under VaMed and all other mothers and children are registered as Medicaid patients during time of evacuation for cloud registry and tracking. Patients are therefore not lost to follow up and health care data information flows are maintained. Moreover, providers in these states may have an emergency Medicaid provider number for accessing patient data. This scalability as a needed design alleviates the need for elevated costs and maintenance. Some HIPAA and cybersecurity challenges may remain. It is with this adaptation in mind that Newborn screen patient lab data is obtained, tracked and reported without patient lost to follow up or provider and in a timely manner. This is irrespective of land mass destruction, mass evacuation, and hospital closing.

A similar cloud base HIE should be implemented in in preparation for Katrina if one were to revisit the events of 2005. This would HIE cloud technology udder public private business agreements (Memorandum of Understanding among Consortium States) that allow for hybrid multiload functionality to assess public health needs, conduct disease surveillance, coordinate medical personnel, and coordinate health care delivery. With regard to the Newborn screen, states of the SouthEast Region would have SaaS service access to this cloud for providers of all member states. As well patient demographics feasibly could be registered pre and post weather event, tracking

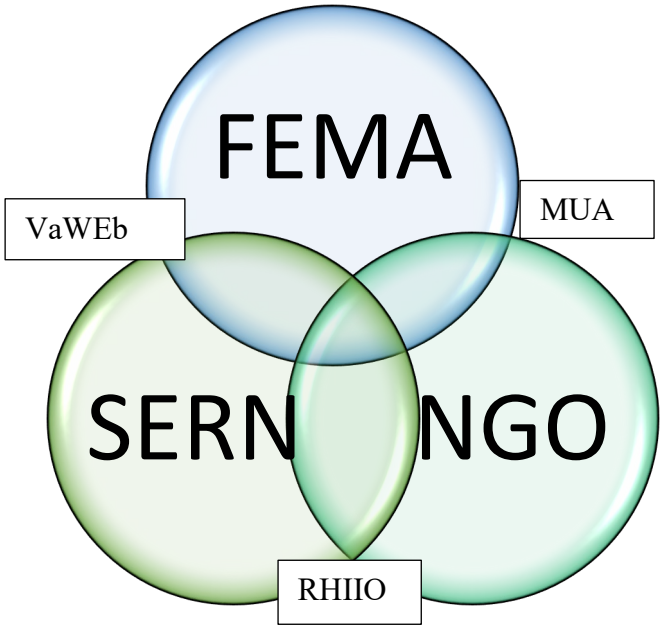
pre and post displacement. Health care delivery is then trackable within the region. This design with cloud computing is scalable, timely, and adaptable. Scalability is achieved as the HIE cloud data governance is under the guide of federal and state agencies, in particular with FEMA coordination. Timeliness is gained by the public private partnerships and multicloud platform used. Adaptability is enabled with the HIE cloud technology coordinated use with mobile apps and other internet services (pharmacy vendors such as SureScripts and federal health care such as Medicaid)

A review of the Nationwide Health Information Network (Godby, 2016) gives some insight as to the success of this proposal. NHIN adopted in 2004 by the Office of the National Coordinator for Health Information Technology does allow for information exchange among CBC, CMS, DoD etc., for sharing of personal health records, EHR, and public health records. However, is underutilized. The 2010 Direct Project increased used of information exchange of encrypted information. Information exchange intrastate, known as RHIO has a $19.2 (pg150) billion-dollar investment since 2009 for increased used. It is this RHIO that should be implemented if one were to revisit Hurricane Katrina. Barriers to implementation include cost, inability to guarantee confidentiality and HIPAA compliance, unauthorized access of data for public health and risk of cybercrime.

Cloud Computing Solutions for Newborn Screen Data Disruption by Hurricane Disasters

In 2009 41% RHIOs were not meeting the cost of revenue and a fraction of these were limiting their data exchange to clinical data. Given the Federation of Cloud Computing Strategy of President Obama in 2011 which examined the merits of cloud computing in disaster recovery, it is my suggestion that in times of hurricane disaster a hybrid cloud of RHIO combine with VistaWeb to provide health care information exchange. In this regard federal coordination with state and local resources is optimized and existing cloud services can be scaled according to circumstance.

Fig 10 New Schema for SaaS for Katrina, Public-Private MultiCloud



Cloud Computing Solutions for Newborn Screen Data Disruption by Hurricane Disasters

The new cloud schema for emergency management of Hurricane Katrina includes FEMA, SERN and NGO collaboration. Cloud virtual computing for military personnel, families and providers would continue via VaWEB, and for civilians would occur by urgent scale up on RHIO. VaWEB is the Veterans Administration virtual cloud computing HIE. RHIO is a Regional Health Information Organization (which includes EHR, HIE, and personal health records). MUA medically underserved and to benefit from the business agreements of public private partnerships that would facilitate the multicloud needed for the military and civilian cloud scaling in times of emergency.

Implications

The systematic review of each of above categories established a progression of knowledge which informs public health informatics practice. This review timeline extends from 2005 to the present 2019 and as such is characterized by periodic literature as well as government document and grey literature. It is therefore subject to scientific insight and bias. Among the knowledge gleaned from the literature review is the progress in information exchange and. Emergency management as noted by technological advances, public policy and practical application with hurricanes subsequent to Katrina. There has been measurable progress in health information exchange for the Newborn Screen and in particular in times of hurricane. Moreover, the bias of the

literature review, that of selection bias from grey literature materials limited to subjective industry op eds, and expert analysis is tempered by the objective reporting of journals and government data from established federal agencies actively engaged in emergency management or cloud use. More literature is needed on this subject in the United States as it seeks to define cloud computing use in health care services and in particular in emergency management.

As a national policy, the effort has been underway to modernize information exchange to cloud services with the understanding that this technology is the best practice of information exchange (Valle, 2016).

Recommendations and Next Steps:

A view of the use of cloud services across the globe suggests the United States should aggressively pursue ongoing expanded use of cloud technologies in disaster planning. International use of cloud computing in disaster response has proven beneficial. Two examples of this are in Japan and Australia. In 2013 Japan's Ministry of the Interior signed a Business Agreement with NEC (Kato, 2013) for a cloud disaster and emergency information system. Prior to the SaaS agreement, each municipality operated its own information system, however coordination and consolidation of services as well as GIS applications were offered. The NEC sys included services for disaster situation management, on-site response with mobile applications, and network notifications with local

reports to and from the public to government, utilities, etc. This nation's support of cloud services has been due to the Asia Cloud Computing Association (ACCA) with Japan the top country in the market. Government investment has been led by the Digital Japan Creation Project established in 2009 with moderation in 2015. Australia's Victoria State Emergency Service has partnered with Microsoft's Public Cloud and domestic Data #3 (Data#3, 2017) in a hybrid partnership in 2017. This is with the intention of addressing emergencies including bushfires, floods, storms, etc. with attention to GIS data, and communications. This builds on the information technology strategy initiated in 2014 with IasS agreement initiated with Microsoft Azure[9]. As well, France has successfully adopted a national HIE and this is a model to be studied. In 2004 the Dossier Medical Personnel (Grady, 2012) was initiated by the French government in an effort to coordinate health care. In France, the combination of fee for service and government funded health care provides for a Carte Vitale which is an electronic health insurance card (pg. 385). This Carte Vitale was converted to an electronic format, SESAM-Vitale with access to the Dossier HIE. The French had privacy concerns which delayed the implementation of full interoperability of the system and similar concerns exist in the United States. This has been alleviated in part by granting citizens some control over their health records. This includes notification of information exchange, deletion, and review with third parties and other clinicians. This is in part granted in the US under HIPAA, however, conflicting

[8] Data#3 (2017) states that "Private Cloud IaaS service managed applications for emergency services operations…"

state and federal privacy laws, however, confuse guidelines regarding patient and institutional rights.

Note Bene

The Emory Center for Public Health Preparedness and Research since 2008 has engaged in the analysis of public health systems so as to improve health care delivery during disasters. There work for pediatric diseases has primarily focused on vaccination delivery systems, however, their experience in this realm provides support for the implications of this thesis.

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