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Privacy and Security Solutions for Interoperable Health Information Exchange

FINAL IMPLEMENTATION PLANS REPORT

Subcontract No. RTI Project No. 9825

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Table of Contents

I. Background

A. Purpose and Scope of this Report

The purpose of this report is to serve as the Final Implementation Report deliverable submitted by NJ-HISPC as required by the project contract. This report describes the process used by the New Jersey Implementation Planning Workgroup (NJIPW) to develop detailed plans for implementing specific solutions for the privacy and security and interoperability of HIE. We also offer our recommendations on the specific steps that might be taken to in furtherance of our recommendations.

NJ-HISPC does not see this final report as the end of this project, the alliance we have formed, nor our resolution to move forward with the development of safe and secure Electronic Health Records ("EHR") in New Jersey. Rather, we choose to see our current status as one of transition and recommitment. Also, we are mindful that we have much to be thankful for:

- We have done a great deal of very professional quality work in a short period of time;
- We have reexamined our goals, motives and assumptions;
- We have assembled a dedicated and qualified group of highly professional individuals who are committed to the advancement in New Jersey of safe and secure EHR and Health Information technology ("HIT") systems;
- We have established a cooperative working relationship with like-minded professionals from around the country;
- We have gained a good working knowledge of the current status of the HIT and EHR community in New Jersey and built a large list of interested stakeholders;
- We have identified specific projects that will offer early opportunities for success, demonstrating that our concrete plans for advancement warrant further investment of time and money;
- We have realistically analyzed many of the barriers that we are likely to face as we move forward and have carefully crafted practical and achievable solutions;
- Perhaps most valuable of all, we have focused the attention of New Jersey government, its people, the payers and the business community in general on the value, efficiency and cost savings that are achievable.

This report contains recommendations for implementation plans for solutions which are consistent with on-going and proposed projects that are considered to have a high priority for immediate action in New Jersey, namely:

1. The introduction of the use of a standard patient identifier, such as a master patient index (MPI), which can be used initially by New Jersey Medicaid and the New Jersey Department of Health and Senior Services as a part of the State's electronic Immunization Registry via an interactive web portal which can be expanded to other state entities, heath care encounters and activities.

2. Establish a standard set of EHR data elements which can be used initially by New Jersey Medicaid and expanded to other state entities, health care encounters, propagated statewide and to other states in our region.
3. Continue to interact with New York State Department of Health to lay the foundation for discussions on creation of a metropolitan area MPI and to harmonize the public health electronic reporting registries that currently exist separately in New York and New Jersey so that each system registry will synchronize with and between the two states.
4. Work with New York State Medicaid Services and New Jersey Department of Human Services (NJDOHS) to share the benefits of a Medicaid Transformation Grant awarded to New Jersey so as to create one single EHR for Medicaid covered children that will be interoperable over state lines. This grant has been awarded to NJ DOHS to create EHRs, and NJ DOHS has asked NJ DOBI to help with privacy, security and composition of EHRs. We also hope to work with New York so as to share the benefits of these EHRs and other the opportunities that will likely emerge. We have already conferred with our New York State colleagues and plan to meet with them in late May 2007.
5. New Jersey Hospital Association-Horizon BC/BS RHIO. This is a major effort funded by the Hospital Association and Horizon to develop a feasibility/business plan for a New Jersey Regional Health Information Network (RHIO). All the major stakeholders are involved and NJ DOBI is a member of the steering committee and chairs the governance work group. The goal is to determine the level of interest and to create a funding plan. Eventually, all the major stakeholders, including the state, will be asked to provide funding.
6. South Jersey Emergency Medical Record Exchange (SJ-EMRX) – The Jewish Family Services of Atlantic and Cape May Counties and other healthcare groups obtained Robert Wood Johnson funding to establish a local RHIO in Atlantic and Cape May Counties. Many of the NJ-HISPC core leadership group are part of this organization and will serve on the Board of Directors. Geographically this RHIO is well suited to undertake this effort. There are only a few large medical facilities, it is in a relatively isolated area, one major employer (the Casinos) dominates the local economy and there are only a few major payers. It is expected that this organization will develop and thrive, if properly supported, and will serve as a major incubator for HIT/EHR development in New Jersey. Eventually, it will be linked with other efforts statewide and become part of a larger network.
7. NJ DOBI is working on a joint project with Horizon and Our Lady of Lourdes Medical Center is to create an interoperable electronic health record network between hospitals and providers in the Camden and Willingboro areas. These are two lower income areas with many people that have chronic illnesses. The patients receive their medical care from local providers who could substantially increase the quality of care if they are given the necessary HIT/EHRs. NJ Medicaid is also interested in participating in this project. The Hospitals already have internal EHR networks and can share some hospital imagining and test results with provider offices. This project would open the hospitals' internal loop to share an interoperable EHR with the admitted providers. We have already assessed the set up costs and will be ready to determine the level of interest from funding sources.

8. The National Provider Identification Number Project is still evolving. With the recent CMS action permitting a year long breathing space for an expanded implementation period, we have set up meetings to create a state wide implementation plan and a central location for all payers' New Jersey based implementation plans. Several bulletins and enumeration implementation guides will be issued by NJ DOBI as warranted. Once again, we will endeavor to create a New Jersey wide implementation effort to ease the deployment of these federal mandates.
9. We hope to train and equip the NJ DOBI Speakers Bureau in the benefits of EHRs, HIT and NPI implementation. One of the major conclusions reached by NJ-HISPC is that we need to better educate providers, medical office staff and patients on the requirements and limitations of HIPAA privacy and security and the benefits of EHR and HIT. The Department's Speakers Bureau is ideally suited to appear statewide to present to consumers, providers and their staff on these important subjects. We hope to properly train and equip the Speaker's Bureau with power point presentations and literature to help lessen and eliminate many of the misconceptions and misapplication of HIPAA that we encountered during the HISPC study.
10. Application for AHRQ Ambulatory Care Grant - This is a partnership project with the NJ Department of Health and Senior Services, NJ DOBI, Clara Maas Medical Center, The Healthcare Quality Institute and several others seeking to obtain federal funds to develop an electronic healthcare network for the ambulatory care of asthma patients using an interoperable exchange of medical information between the hospital and providers.
11. Recently, NJ Assembly Bill # 4044 was introduced for discussion. The Bill could create a New Jersey Health Information Technology Commission and calls for the development of EHRs in this State. Coupled with the on-going legislative hearings, it appears that major advances in NJ EHR and HIT are on the threshold. Consequently, the various Departments of state government are engaged in a significant analysis and drafting effort designed to create a self-sustaining interoperable EHR structure.

B. Key Assumptions and Limitations

The specific NJ-HISPC implementation plans appearing in this report are those that, after a process of review and prioritization, are of the highest priority and most feasible for New Jersey. We used our original groupings of solutions into five categories to organize the planning work. The categories are: Interoperability, Workflow, Federal and State Law, HIPAA Security and Privacy, and Education. A set of solutions suggested by the Solutions working groups in previous stages of this project has been reviewed by members of implementation planning working subgroups. These groups completed the work of consolidating the solutions where appropriate and also created detailed plans for executing those solutions.

As described above, during the period of the NJ-HISPC project activities, several new initiatives and partnerships began to move the state toward interoperability of electronic health records. The implementation plans included in this report reflect this continuing evolution of stakeholders coming forward, projects undertaken and new resources being committed. The plans contained in this report will continue to evolve and become more specific as stakeholder entities commit resources.

We have also observed that these HIT and EHR projects of necessity involve many different state agencies, levels of government, trade associations, kinds of insurance coverage, private institutions, providers of every size and discipline, vendors and countless others. In this process we have engaged a very diverse and deeply very committed group of stakeholders. They all see and understand the potential cost efficiencies, reduction in waste and increase in the delivery of timely quality medical care. We have enlisted the payers, all the major trade associations, all necessary government agencies and providers in NJ-HISPC and other HIT efforts.

Our hope, and assumption upon which our future work is predicated, is that we will keep our team motivated and focused as we move from ideas, talk and planning into action and implementation. We have some very significant projects and ideas that we are working on now which we have listed above. However, we are still at a very precarious gap/transition period. For instance:

a) While there is legislation pending in the NJ Assembly to create an EHR Commission and EHR network there is no specific State funds have been budgeted for execution as yet. It is uncertain when this bill will be acted upon, while the state budget in New Jersey is facing large potential deficits. This is a continuing source of concern which leads to stakeholder uncertainty and hesitancy to commit private funds.

b) We are, in submitting this Report, offering a very substantial and well thought out Final Implementation Plan to move HIT forward in New Jersey, yet we really have no viable way to translate these plans into action without a firm commitment of funding. We have no firm economic commitment at this moment.

c) Every day groups and trade association are meeting in New Jersey to advance EHR but specific steps are not being taken on these positive items for lack of funding.

d) Most of the interested stakeholders in New Jersey are waiting to see if the State will invest in EHR before they commit their funds to any development projects involving the State of New Jersey.

Thus, it appears there are two distinct issues:

1. There is a need for interim/gap/transition goals, projects, activities and funding that will keep everyone invested in these projects and EHR while we are waiting for New Jersey legislation to provide new funding sources and related direct commitment of state health care payment and delivery systems. Ultimately, it appears that the State will commit economic and *de jure* authority to this work. That in turn is likely to lead to significant matching funds from the federal authorities, payers and others. From a strictly practical point of view, there is so much taxpayer money tied up in Charity Care, Medicaid, Medicare, the New Jersey State Health Plan and several other medical expense areas, the state needs to find ways to reduce medical costs. Eventually, funds could be appropriated for these HIT projects and systems to reduce costs such as charity care, veterans care, Medicaid, workers compensation, Personal Injury Protection coverage, inmate care and many other payments sources. For now, it is important that we keep all the stakeholders assembled and focused as these other income sources evolve. This work will ultimately benefit all branches of government, multiple states delivery systems, payers, providers, third party billing companies, third party administrator, federally based claims forms and processes used on a local level in Medicaid and Medicare, application

and local dissemination of federal mandate and expectations, conflicting social, political and economic interests. What currently emerges from this crazy quilt mix is very often poorly understood, misapplied and frequently ignored. Eventually, however, a unified system will emerge and all will share in the costs and the benefits.

2. If anything has been accomplished by this NJ-HISPC work, it is the recognition that New Jersey needs to have one central HIT/EHR Coordinator who is able to cross over those barriers that exists interdepartmentally, economically, politically, geographically and socially. The purpose and obligation of a State Coordinator will also be to serve as a focal point for all HIT/EHR policies and projects so as to avoid waste, misapplication and to encourage consistency of effort. Assembly Bill #4044 described above would create an HIT Commission and Executive Director. This represents a legislative acknowledgement that a central office to coordinate these efforts is essential.

All of the above mentioned activities and recommendations that are mentioned herein and every other HIT effort that emerges in the future will require the close coordination and cooperation of several interested Departments in State Government. Each of these projects deal with the health care system in very fundamental ways and the following needs to be understood and recognized:

- Insofar as these issues touch on the payment of claims, the terms of coverage and the financial soundness of health care payers, the NJ Department of Banking and Insurance (“DOBI”) is one of several critical components.

- The NJ Department of Health and Senior Services (“DOHSS”) is also essential in that it is responsible for all issues involving the public health; the quality and viability of hospital and ambulatory care; bio-terrorism; long term care facilities; catastrophic events; collection of large quantities of medical data used in various registries and health care studies and the impact of terrorist acts on the public health.

- Medicaid, charity care, mental and emotional health facilities and several other activities related to the delivery of medical care are managed by the Division of Human Services (“DOHS”).

- The Department of Law and Public Safety, Division of Consumer Affairs, Professional Boards (“Professional Boards”) licenses all medical providers and has served as an invaluable asset in working with all medical care givers.

- To a lesser extent, other Departments that handle EHRs and/or provide medical care should also be involved when necessary. This includes Military and Veterans Affairs that operates long term and assisted care facilities; Corrections that provides medical care to inmates, and Labor and Work Force Development that handles Workers Compensation and State Disability.

- The current New Jersey State Health Plan and any other follow-on health care payer will likely be subject to the direction of Treasury and therefore, that department should also participate.

- County and municipal governments and the joint insurance funds are employers and their representatives are directly involved in the payment of medical claims.

This project will require the cooperation and involvement of all interested state and local government agencies in order to spread the cost and benefits associated with the development and deployment of EHR systems. Finally, without the active participation of all the described agencies and entities, the timely achievement of success is unlikely. Thus, creation of a State Coordinator's Office and staff is deemed to be necessary and appropriate.

Pursuant to N.J.S.A. 17B:30-24 et seq., DOBI is required to adopt administrative rules for the implementation of the HIPAA Transaction and Codes Sets; the privacy and security of health care electronic networks and electronic health records. This work is done in consultation with DOHSS. Also, DOBI has for many years acted as an impartial broker for all EHR/HIT and HIPAA issues. Consequently, it appears appropriate that the State Coordinator's Office should reside in DOBI. Of course, no action or administrative rules should be undertaken or proposed without the participation and approval of DOHSS, DOHS and all other necessary aspects of government.

C. The Way Forward in New Jersey

The HISPC project has already had a profound impact on the overall level of interest in the promise of administrative simplification and EHR. While HISPC has joined many otherwise divergent interests in a study of the impact of HIT on the universally recognized significance of privacy and security, it has also triggered an immediate commitment to move forward with EHR in New Jersey.

In the last six months new alliances for the development of Regional Health Information Organizations (RHIOs) have formed; collaborations to submit applications for AHRQ HIT ambulatory care grants have submitted a response to an RFP ; the New Jersey Assembly has conducted hearings on NJ-HISPC, RHIOs, HIT and EHR; the New Jersey Department of Human Services was awarded a CMS grant to establish the first Medicaid EHRs for minors; New Jersey has adopted statewide enumeration guides for use in selecting NPIs; we have adopted rules for inclusion of NPIs on all paper medical forms and on all provider license applications; we have opened discussions and will meet with New York State representatives to discuss a metropolitan area master patient index, harmonization of electronic public health registries and a shares EHR for area Medicaid children and we have formed strategic partnerships in many areas for the further development of a self-sustaining RHIO and EHRs.

Now that we are in the final implementation planning phase, it is critical that we once again examine our history, goals, and expectations and determine the best way to proceed.

The people and the government of New Jersey have always believed in the principle that progress through technological advancement will result in cost savings and improvements in the quality of health care. Witness our cutting edge HINT study in 1993 that was able to academically quantify the savings that could be realized through the introduction of electronic systems into medical office administration and management. Many of the conclusions reached in the pioneering HINT study became the foundation upon which HIPAA's Administrative Simplification was based. In 1999, New Jersey adopted the Health Information Electronic Data Interchange Technology Act (PL 1999, c. 154 and 155), (referred to as "HINT") which directed the Department of Banking and Insurance (DOBI) to adopt rules for the use and implementation of the HIPAA transaction and code sets in New Jersey. Recently, HINT was amended to permit DOBI to adopt rules for the development and use of EHR. See PL 2005, c. 352, sec. 18 et seq.

We see the role of New Jersey State government as bringing all the competing interests together to solve common problems with mutually acceptable solutions. Unlike most states and the federal structure, the jurisdiction to adopt rules for the deployment and use of electronic transaction and code sets as well as EHR is not placed with Departments of Health or Professional Licensing Board which generally regulate health care providers. Rather, New Jersey's approach to HIT and EHR development under HINT has been to directly link the prompt payment of clean claims by state based health care payers with HIPAA's electronic transaction and codes sets and all aspects of Administrative Simplification. . Thus, DOBI is the agency directed to adopt rules in furtherance of Administrative Simplification and EHR and to foster the use of electronic technology in the health care field with the Department of Health and Senior Services (DOHSS) acting in a consultative role. As a consequence, New Jersey has addressed many of the issues encountered in this process from practical business juxtapositions. New Jersey uses the good offices of state government to bring all the competing interests together in a cooperative working structure to find mutually acceptable ways to achieve common goals for the benefit of all. Most of all, together, we seek to find economically self-sufficient common ground for all parties to develop a health care transaction that will foster the goals of HIT.

While New Jersey has always been forward looking and progressive, our consideration of the practical need to find financially sound solutions and structures for HIT has restrained our early involvement in the RHIO arena. Unlike some other states, before adopting rules for the use of EHRs, we have sought to identify a return on investment for all – individual and large providers, payers, and the taxpayers – as well as a business model that will be financially sound and capable of sustaining itself. Based on these practical requirements we have on a regular basis in the last several years used the NJ DOBI Task Force to mobilize all stakeholders to undertake improvements in the business of health care in various joint ventures.

Now we find ourselves at pivotal moment! The HISPC project has generated substantial interest and desire in all facets of the health care industry to take the next necessary steps in the long and difficult metamorphosis from paper based record systems to universal EHR. As we go forward and as we consider the impact and application of the various implementation plans that we will be considering, out considerations should be measured against the following basic questions:

- Will the implementation plan encourage and facilitate the development and deployment of EHR in New Jersey?
- With chronic budget problems, will state government be able to find the financial resources and political resolve to be a contributing member of the HIT community?
- Can HIT/EHR projects be undertaken without the economic support of the state?
- Will there be a proper balance between the essential requirements of individual privacy and security in the individuals' protected health information with the equally compelling imperative that critical health information must be readily available when and where needed to save lives?
- Will the plan impose an unfair economic burden on any party?
- Can we demonstrate that the plan will have a return on investment for all parties, or not offset the cost to those least able to bear it?
- Are all parties committed to the success of the plan?
- Does our plan create an infrastructure and a business model that will each stand on its own without constant or periodic infusions of outside capital?
- Will our plan allow us to proceed deliberately and in concert with the needs of consumers, industry best practices, federal standards, regional standards and protocols?
- Have we considered what assets and resources already exist that can be used in furtherance of our plan development and deployment?
- Will all stakeholders agree to link the payment of claims to the creation and use of EHRs as a means of creating a self-funded entity that is the focal point for interoperable exchanges?
- Can we implement a plan wherein the payment of claims for medical tests and other procedures will be denied where valid useable EHRs test results already exist and are reasonable available for use when needed?
- Have we learned from the successes and mistakes of others?

With these questions in mind and always concerned about the essential aspects of privacy and security of protected health information, we plan on taking the following steps forward in furtherance of our Final Implementation Plan:

1. Continue to obtain knowledge of all electronic health information networks currently operating in this state. The full extent and nature of all HIT resources and activities; what information is being exchanged; what formats and granular structure are in use; whether we can join any of these networks to obtain regional usage; and whether the parties are willing to share assets and lessons learned with others are all questions that must be resolved. In short, we need to know what resources and people are available and their willingness to join in a common undertaking. , As we more forward from the NJ-HISPC Final Implementation

Plan we continue to gain a full and complete understanding of all the assets and resources currently in use in this state.

2. Our Final Implementation Plan will allow us to continue to work with the New Jersey Hospital Association, Horizon Blue Cross Blue Shield of New Jersey and many other interested parties to develop a business plan for a self-sufficient RHIO in New Jersey.
3. This Final Implementation Plan recommends that appropriate sufficient funds be appropriated by the legislature for use by state governmental agencies to gather all stakeholders into working groups to develop and deploy HIT systems; to seek out and work with others to acquire and match federal and private foundation funds for EHR and RHIO development; to undertake all necessary steps to develop and increase public awareness of the benefits of EHR to all members of society; to participate in all necessary federal and regional activities and forums in recognition that all HIT systems and formats must be consistent with federal standards, as well as that many of the applied solutions will be regional in nature; and to fund Thomas Edison State College to continue to assess the academic studies necessary to determine the effectiveness of HIT.
4. This Final Implementation Plan clearly demonstrates the need to show a real return on investment for all parties, especially by investing in EHR systems. Even though it is often stated as a fact that HIT can reduce costs by eliminating the incidence of unnecessary and redundant medical tests, up to now there have been no processes suggested that would demonstrate the means by which payers would be able to actually see a reduction in these wasted funds. Our final Implementation Plan recommends specific ways to actually reduce and/or eliminate unnecessary testing. One such model would employ a single web portal where all medical tests could be ordered by all providers. The electronic order form would be patient centric and would be immediately linked to a central index of medical tests already performed, and would display the results of those tests. If no new medical necessity or clinical conditions existed, and the results of the previous test are still valid, authority to perform a new test would be withheld unless compelling reasons were shown to exist. Furthermore, making test results available in this manner would benefit the patient and give the physician immediate use of the medical information as needed. Such a model, while not the only one, could be developed using the state's ability to regulate state based payers and the structure related to the payment of medical claims. Lastly, if a provider were to perform a test without complying with the test ordering protocol, payers would be permitted to refuse payment for non-conforming tests. Such a system could be self-funding based on the savings from medical tests not ordered because useable result where readily available.
5. Rather than trying to create a costly and single system to accomplish all our goals at one time, the Final Implementation Plan will seek to take those basic and sequential steps that are attainable within a reasonable time, are economically feasible and do not raise unreasonable expectations of and burdens on the participants. There are several currently operating networks functioning in New Jersey. Medical data elements and test results are already being digitized in formats that are capable of transmission from hospitals, testing centers and

laboratories into the offices of individual and group providers. We will look to join all currently available assets where possible. Once we are comfortable with the simple task of moving test results among all the essential parts of our health care delivery systems, we will then advance to move difficult issues, such as interoperable EHR. This does not mean that we will adopt a rigid incremental approach, but simply that our progress will be measured and not raise unreasonable expectations nor burdens.

6. The plan requires that we endeavor to assemble the necessary parties to determine the costs and savings that might be realized by introduction of EHR into the New Jersey State Health Benefits Plan as well as the state funds expended in the delivery of charitable and uninsured medical care, Medicaid and Medicare. We will seek to join these facets of the industry together to find economically scalable solutions.
7. The plan will require that we continue to stress the importance of EHR to society as a whole and to each of us individually. It is essential that all aspects of society recognize the need for these systems and our plan will aggressively engage all concerned. Most of all, we will emphasize that these systems will preserve the privacy of PHI in a secure environment that is safe from misuse. Fundamentally, we will demonstrate with clarity what mechanisms will be used to ensure privacy and security.
8. The Final Implementation Plan contemplates use of DOBI's Speakers Bureau to achieve many of the goals set forth in 7 above. We plan on training and equiping our speakers group to address consumers, individual and small group providers and others on the value of EHRs, HIT and the real requirements of HIPAA's privacy and security rules.

II. Summary of Interim Analysis of Solutions Report

A. Summary of Solutions for Implementation Plans Included in Report

In the Interim Analysis of Solutions Report, the NJ-HISPC SWG identified five solution categories that will assist in developing the implementation plans for electronic information exchanges as required by the contract. The solutions categories are as follows:

1. Interoperability,
2. Workflow,
3. Federal and State Law,
4. HIPAA Security and Privacy,
5. Education.

1. Under Interoperability, which we defined as the ability of products, systems, or business processes to work together to accomplish a common task, the solutions working group identified the functionality needed to implement electronic systems in the near future. Key solutions suggested by work group members for this area included:

- Use of a standard patient identifier, such as a master patient index

- Minimum encryption standards for data in an EMR system, in email exchanges, and web portals
- Statewide mandated uniform security protocols and HIPAA minimum necessary policies and procedures for use in all health care institutions
- Minimum authentication standards and ability to stratify access to information in EMR system
- Statewide approved and mandated algorithm for the de-identification of data
- Standard Business Associate Agreement
- Secure protocols and controls for provider remote access to EMR, and other databases
- Definitions of access privileges for all categories of users

The two solutions within this category for which a preliminary implementation plan was developed and is covered in this report are:

- development of a standard patient identifier, such as a master patient index; and
- establishment of a standard set of data elements.

2. The Workflow category is defined as the movement of documents and/or tasks through a work process. More specifically, workflow is the operational aspect of a work procedure. Under this category, the primary solution identified by the SWG was the development of community standards and best practices. These guidelines would be developed through the use of community forums. Specific topics that would be discussed in the forums and responses later analyzed to create standards, include:

- Standardized request form to share medical information
- Standard forms of identification, including use of a National Provider Identifier
- Verification of clinicians
- RHIO or patient centric portal
- Secure, encrypted email
- User access agreements
- Standard procedures for law enforcement obtaining PHI
- Business Associate Agreements / Confidentiality Agreements
- Pharmacy, marketing, employer, and public health issues

One first solution within this category for which an implementation plan was developed and is covered in this report is development of a physician ID card with National Provider Identifier (NPI).

3. We have repeatedly reported that the primary issue in need of a solution under the State Law area is the level of confusion, misunderstanding, lack of knowledge, and multiple interpretations of laws concerning the sharing of health information by stakeholders. Throughout this process, NJ-HISPC has recommended a state initiated analysis of existing federal and state laws covering the following topics:

- Information sharing between state and local health authorities
- Sharing of information to identify lead poisoning cases and risk factors

- Medicaid law reform to permit data sharing
- IRB web portal
- State permission for data sharing / types of authentication
- Sharing of mental health information
- State / interstate data sharing agreements
- Comprehensive consent form for research
- Statewide health data information exchange
- Temporary access for first responders
- Family access to medical records

Previously, the SWG recommended that baseline policies and procedures be put in place outlining federal and state law requirements and mandates relating to the secure exchange of health information. Finally, using DOBI's Speakers Bureau, an educational campaign will be launched on federal and state laws and regulations to deal with the differing perceptions between providers, payers, and consumers and provide a uniform collection of information for distribution to NJ stakeholders.

The immediate and currently executable solution within this category for which an implementation plan was developed is covered in this report recommends the development of state and interstate mandates/agreements for display of patient name, DOB, gender during catastrophic events at hospitals. This process would be wide spread and would use any and all media to would readily and reliably disseminate patient and missing person data.

4. Our variations assessment has demonstrated that currently there is a great deal of confusion, misunderstanding, lack of knowledge, and breadth of interpretation of the HIPAA requirements in New Jersey. Once again, the failure to understand the application of current laws and regulations is a major barrier to progress and unnecessarily impedes the flow of PHI.

The SWG has suggested the following activities related to educating various state stakeholders about HIPAA security and privacy solutions:

- Additional investigation of areas of confusion among stakeholders not involved in the variations assessment. Some key areas are:
    - Patient rights, understanding, and education
    - Law enforcement – both HIPAA and NJ law impacts; understanding and education
    - Minimum necessary understanding and education
    - De-identification understanding and education
    - Use and disclosure of sensitive data – both HIPAA and NJ law impacts; understanding and education, including when authorization for disclosure is required and when not
    - Standard consent/release/authorization documents and management process defined and implemented

  - Standard forms and checklist for employee return to work
  - Standard authorization forms and authorization management defined and implemented

All of these issues could be addressed in any educational package assembled and disseminated by DOBI's Speakers Bureau.

- There needs to be consensus as to statewide, baseline policies and procedures in place for the HIPAA security and privacy mandates and requirements which should be documented, memorialized and agreed to by all stakeholders. There needs to a recognition that there are benchmarks that form the fundamentals of privacy and security and its application.

- Education, and continuing education, on the HIPAA law and regulations, and consensus policies and procedures to dispel myths needs to take place, dealing with cultural issues, and the differing perceptions between and among the provider and payer stakeholders, and how they may differs from consumer perceptions.

The initial solution within this category for which an implementation plan was developed and is covered in this report requires development of a predefined protocol of data sharing elements of EHR with other entities.

5. The NJ-HISPC SWG and NJ-HISPC have previously agreed that the NJ-HISPC education solutions are initial and critical foundation blocks to HIE and interoperability in New Jersey. An education package will be developed to assist with dispelling cultural and perception barriers. The federal / state / HIPAA laws and regulations and New Jersey consensus drawn and approved policies and procedures will be explained to the consumers and provider stakeholders, as well as all the other NJ-HISPC stakeholders for statewide understanding.

Many outreach and education approaches will be used, including individual meetings, community and town hall forums, teleconferences, newsletters, brochures, and website/portal posting to present information about the following specific topics:

- Notice of Privacy Practices
- Consent
- Authorization
- Minimum Necessary
- De-identification
- Law Enforcement

The initial solution within this category for which an implementation plan has been developed is covered in this report and involves education packages aimed at the standard elements of consent.

B. Descriptions of Solutions Presently Implemented in New Jersey

A number of state and private projects working on sharing medical and administrative data electronically are currently underway. Many of these are in the planning or pilot stages. The HIT core leadership team expects to gather more information about these efforts to identify solutions which might be expanded and utilized in statewide efforts. Some of the statewide efforts are focused on emergency preparedness, and these efforts are identifying barriers between agencies and creative ways to address them while maintaining essential safeguards on personal information.

III. Review of New Jersey Implementation Planning Process

A. Organization of New Jersey Implementation Planning Workgroup

1. NJIPW Charge

The NJIPW was charged with identifying, critically analyzing and facilitating the creation of a workable implementation project plans for the highest priority and most feasible solutions to barriers for interoperability of EHR that were identified by the NJ-HISPC. For each of the identified solutions, the implementation workgroups were asked to detail specific plan components to achieve a successful resolution including: project ownership, project scope, timeline, evaluation activities, impact on stakeholders, feasibility assessment, whether project is single or multi-state, and the importance of project.

2. NJIPW Leadership

The NJIPW was run by the core NJ-HISPC members, including all those named as presenters on this Final report. The project manager, assistant project managers and all necessary members of NJ-HISPC actively participated in the work necessary to create final implementation plans and complete this Report.

3. NJIPW Membership

For the development of specific implementation plans, the NJIPW reviewed the master list of all stakeholders who had been involved in various aspects of NJ-HISPC as well as those who had expressed interest but had not been involved to date. An e-mail Newsletter was sent to all those listed on our stakeholder group list. NJIPW leaders then reached out to stakeholders with expertise in one of the five solution focus areas, inviting participation on a specific workgroup. Those stakeholders who were available and willing, joined a workgroup and reviewed all of the suggested solutions within their topic area, for example, interoperability or education. The group works were presided over by a NJIPW member, using phone conferences, email, and face to face meetings. Many emails were exchanged, opinions expressed, disagreements discussed and resolved and consensus developed. This was a comprehensive and wide ranging process even though it was conducted in a relatively short period of time.

4. NJIPW Stakeholder Representation

Members of the Implementation Planning groups represented stakeholders of the following types: hospitals/health systems, long term care facilities and nursing homes, homecare and hospice, medical schools, state government, payers, consumers, attorneys, privacy and security experts, and technology companies and consultants. There were some individuals participating who had not done so before but no new stakeholder groups were represented that had not been represented in earlier phases of the project.
Also, NJ-HISPC, in conjunction with NJ DOBI, Rutgers Center for State Health Policy, Thomas Edison State College, Horizon BC/BS and other state agencies, conducted an open Public Forum on April 9, 2007 in which the public, interested parties and stakeholders were provided an opportunity to present their opinions in person or in writing regarding the barriers, solutions and implementation plans set forth in our work. All of the NJ-HISPC reports were published on the Department's website for review by all. Notice of the Public Forum was published in five well know newspapers throughout the state. An electronic newsletter was sent to all stakeholders announcing the meeting. Particular consideration was given to input from consumers who may not have familiar with the NJ-HISPC project. While the meeting was very sparsely attended, we are able to demonstrate that the entire NJ-HISPC process was open, transparent, and that all opinions were considered.

B. New Jersey Process to Formulate, Determine Feasibility of Implementation Plans

All implementation plans developed by the planning workgroups were submitted to the NJIPW team leaders. These plans were consolidated into one planning spreadsheet and reviewed by NJIPW members. Within each solution area, NJIPW members selected those plans that were most complete, detailed, and those identified by the work groups as most important and feasible. Specifically, we have focused on the CMS Transformation Grant awarded to the DOHS to establish the first Medicaid EHRs for minors. This will be through a web portal providing the opportunity to move ahead with the development of key activities related to future expansion of interoperable EHRs throughout other entities in New Jersey. This actual project gives us an excellent opportunity to put our work, concepts and partnerships developed during this process in to practical application.

C. New Jersey Implementation Plans, Organization, Prioritization, and Presentation

Selected implementation plans are presented in this report organized by the five domains defined previously. For each implementation plan, we present:

- A summary of the effective practice to be instituted
- Planning assumptions and decisions
- Project ownership and responsibilities
- Project scope and tasks
- Project timeline and milestones
- Means for tracking, measuring and reporting progress
- Impact assessment on all affected stakeholders
- Feasibility assessment
- Single or multi-state focus
- Importance, ease of accomplishment and order to be completed.

Additional implementation plans which were developed during the project are included in Appendix B attached to this report.

D. Specific Planning Methods and Tools

The NJIPW created a spreadsheet containing all of the solutions suggested in the prior project phase as well as cells for specific project objectives and plan details. Solutions in the spreadsheet were grouped by the five solutions categories. The workgroups were given condensed spreadsheets containing only those solutions related to their topic area, in addition to one model example provided for guidance. Once they were all submitted to the team leaders, the individual spreadsheets were combined again to facilitate analysis and prioritization by the NJIPW members.

IV. NJ-HISPC and Multiple State Implementation Plans

A. New Jersey Strategy and Coordination

As described above, the NJ-HISPC implementation team intends to involve all stakeholders in the development of a full-blown, comprehensive implementation project plan for each of the solutions suggested to overcome the barriers to interoperability of EHR. In that way, we believe we will ensure that the commitment from key stakeholders to participate in implementation – which the NJIWG readily believes is critical to successful implementation post NJ-HISPC – will be obtained.

NJ-HISPC has incorporated into its process for evaluating each solution and creating its relevant implementation project plan, a determination about whether the solution contemplates a single-state or multiple-state based approach for implementation. Thus, the NJIWG does not believe it is necessary, for purposes of this report, to create separate headings herein to identify that effort as a single- or multiple-state treatment.

B. Implementation Plans

1. Interoperability Solutions

a. *Solution: Development of a standard patient identifier*

Summary of effective practice(s) to be instituted or barrier(s) to be mitigated or eliminated by the plan

A standard patient identifier is needed to allow critical health care data maintained by different agencies for the same patient to be linked. The absence of a standard patient identifier severely restricts the ability for separate entities that retain critical health information from a patient from exchanging this data with this inability to exchange this data having a potential adverse impact on the health of the patient.

Attempts to establish a unique patient identifier under the Health Insurance Portability and Accountability Act of 1996 did not succeed to in large part due to concerns over patient privacy. At this time, there is no suggestion that opponents to a national patient identifier will permit the adoption of a rule that would establish this identifier. As a result, it will be left up to individual states or regions comprising multiple states to establish a process for the assignment and use of unique patient identifiers in order for this initiative to move forward.

It should be noted that legislative action may be necessary to move forward with some of the initiatives that are described herein. As a result, the necessary state departments should work through the State Coordinator’s Office (if established), involved Departments and the Governor’s Office to create the necessary foundation.

Planning Assumptions and decisions

Notwithstanding the foregoing conclusion that some legislative action is necessary, the state agencies are moving forward with some structures that resemble a Master Patient Index and which could be expanded in the future to include all covered lives. For instance, the state’s Immunization Registry creates a unique master patient identifier under very controlled circumstance. This Registry may be linked with the Birth Registry so as to provide for the creation of a unique patient identifier at birth. Most noteworthy is the EHR that is linked to the immunization registry which extends well beyond vaccinations and will also hold, or be linked to, any other appropriate medical record. This EHR may well become the foundation for rapid growth of these structures in New Jersey.

Also, without direct legislative authority, various state New Jersey agencies have already joined together and are meeting with our New York State colleagues to form a partnership to create common health multi-state registries, join patient indexing and interoperable health records for Medicaid children.

Project ownership and responsibilities (identify specific individual and/or organization names and titles)

DOBI is the logical state agency to spearhead this effort based on the regulatory authority over payers and third party health billers in this State. Also, in the past it has acted and continues to act as an honest broker to bring all parties together to solve common problems and to move HIT forward. Finally, DOBI was authority to bring payers into this process to create administrative rules that relate to the payment of medical claims. Relating claims payment to EHR development appears to be one of the most effective ways to create self-sufficient electronic medical record exchanges.

Clearly defined project scope with identification of tasks required, organized by work breakdown structure

The scope of this project will be to establish the regulatory authority, when needed, for the assignment of unique patient identifiers, develop automated mechanisms for enumeration of the existing population, develop the capability to assign unique patient identifiers to individuals new to the State and implement the use of this unique patient identifier within the health care community.

Major tasks are:

Select Project Manager
Identify Project Team Needs
Determine State Agency Ownership
Prepare/Submit Regulations for Legislative Action
Assemble Full Project Team
Develop Project Plan
Define Enumeration Strategy
Define Education Strategy
Prepare and Secure Approval of System Design Document
Develop/Test Application
Document Application
Conduct User Training
Implement Project
Post Implementation Project Monitoring

Project timeline and milestones with projected cost and resources required

A project schedule will be developed that will define two major phases of the project. It is anticipated that this project will take 24 months and will likely be coordinated with the work described above relating to the Immunization Registry and the New York State Collaboration.

The first phase of the project will focus on defining the project team skill set needed, the determination of which State agency is best suited to handle both the initial enumeration process as well as handle the identification and assignment of unique patient identifiers on an ongoing basis. Additionally, the final task to be completed as part of this first phase will be the crafting of legislation, if needed, for action on the part of the legislature to enact the legislation needed for the implementation and use of a new unique patient identifier for health care services.

The second phase of the project will be to define, develop and implement a system so support both initial enumeration of residents of the State as well as to develop the infrastructure necessary to assign unique patient identifiers to new residents on an ongoing basis. Business processes that will be defined and implemented surrounding the new system will be the development of the initial enumeration strategy as well as the development of the strategy for educating all users impacted by the new unique patient identifier.

In so far as this work will involve multiple Departments of government in New Jersey and also other States, there must be careful coordination with the necessary Departments and Governor’s Offices and drafting of acceptable Memorandum of Understanding.

For each work task on the project plan both the projected and actual start and completion dates will be maintained. In addition, required resources will be projected for each defined work task that will include the agency or entity that will be responsible for delivering the resource.

Means for tracking, measuring and reporting progress

The project manager, during both phases, will measure progress against the established project plan, tracking actual project schedule against proposed project schedule and actual resource utilization against projected project resource needs.

Microsoft Project or a similar tool will be used in all solutions as a tracking, measuring and reporting mechanism.

Impact assessment on all affected stakeholders in the state (including small and rural providers)

This project has a large number of stakeholders all of whom will be impacted to some degree by this project. The first stakeholder group is the general population of the State of New Jersey. State residents would ultimately be issued a unique New Jersey patient identifier that they would be expected to share with the health care provider community. The second stakeholder group is the health care provider community. Health care providers would be expected to report the new patient identifier on a variety of health care transactions. The third stakeholder group is the health plan community. This community would be expected to accept the new patient identifier on a variety of health care transactions in lieu of or in addition to patient identifiers that are specific to the health plan. The fourth stakeholder group is government agencies that are responsible for a myriad of administrative, regulatory and public health functions.

Feasibility assessment with identification of possible barriers that the implementation plan may face

There is no dispute over the feasibility and benefits of establishing a unique patient identifier to facilitate the exchange and matching of health care data between two or more entities. Ultimately the whole concept of a complete and comprehensive health care record that can “move” with the patient will demand a unique patient identifier in order to be truly effective. However, it can be expected that the same issues that have stalled attempts to establish a unique patient identifier at the national level will be presented as reasons why the State of New Jersey should not move forward with the initiative to assign a unique patient identifier to residents of the State.

Finally, we should all accept that there may be significant opposition to creating any unique identifier which permits assess to an individual’s entire health record. There are some within our society that will never agree with construction of these structures regardless of the degree and scope of the privacy and security safe guards. Ultimately, most of us will likely move forward with MPIs and EHRs as a necessary but acceptable personal information risk while other simply elect to “Opt Out.”

Single State/Multi State

Single State and Multi State

Importance, ease of accomplishment and order to be completed

Project Importance: High

Ease of Accomplishment: This project is an extremely complex project, affecting the general population, the health care provider community, the health care payer community as well as numerous state, county and local agencies. There will be many obstacles that will need to be overcome in order for this project to be successfully implemented.

The first task is to determine what State agency would be best suited as the agency responsible for the assignment of unique patient identifiers. Since a significant portion of New Jersey residents are born within the State and many of the significant health care events that need to be tracked are for children, it may make sense on a go forward basis to initiate the assignment of the unique patient identifier at the time that the birth of the individual is recorded with the State. It is likely that New Jersey’s MPI will grow out of the State's Immunization Registry which is maintained by DOHSS and may first appear in Medicaid records that fall under the jurisdiction of DOHS.

The second task is to establish the regulatory authority to establish a unique statewide patient identifier and to require the use of this unique patient identifier on all health care transactions. Due to the real potential that the establishment of a unique patient identifier will not be supported legislatively, no significant work should be done toward development of the system and supporting business processes for assignment or use of the unique patient identifier should be initiated until legislation establishing the new identifier has been enacted. Administrative rules for MPI and its application and use in New Jersey would be undertaken by DOBI.

b. Solution: Establishing a standard set of data elements

Summary of effective practice(s) to be instituted or barrier(s) to be mitigated or eliminated by the plan

A standard set of data elements will be established that constitute the reporting transaction that needs to be prepared and submitted by any reporting agency combined with the information linking demographics, medical data and epidemiology data. This standard set of data elements will become the baseline from which a standard electronic transaction can be defined for use. The standard set of data elements will become the baseline from which a web-enabled solution is developed to allow for the real time direct data test results by laboratories to the reporting State agency. Security of the web application is essential so that only authorized entities are permitted to record the results tests. The use of Logical Observation Identifier Names and Codes (LOINC) for the reporting of actual test results should be considered. It is expected the anticipated HIPAA electronic claim attachment rule will name this code set as part of the standard for communicating test results as part of a health care claim. It is logical to extend the use of this code set to other processes requiring the reporting of test results rather than attempting to establish a standard that uses a "proprietary" set of data elements to report test results. Without the establishment of a robust Health Information Exchange (HIE) and a standard patient identifier, the means for collecting and disseminating pertinent information will not be possible.

Planning assumptions and decisions

It would be helpful, and perhaps wise, if a single State owned and/or operated public service entity was created explicitly for collection of all patient, medical, laboratory and epidemiology records and results. This entity will be responsible for the design, development, implementation and operation of a web based solution that can collect all pertinent information and inform the proper entities. The assembly of EHRs into an interoperable data source should be linked to the payment of claims so that EHRs become available for general access as quickly as possible. Finally, such an entity, free of any suggestion of private ownership or interests, could be accredited as to privacy and security by a not-for-profit, national standard setting organization much the same as HIE clearinghouses are accredited for operation in New Jersey pursuant to N.J.A.C. 11:22-3.8. This kind of structure would instill a degree of confidence in the patient/provider community that will be necessary if these efforts are to succeed.

Project ownership and responsibilities (identify specific individual and/or organization names and titles)

As described above, DOHSS is the agency that is responsible for the public health, relation of hospitals, acquires and assembled public health registries and disseminates bioterrorism information. DOBI is required by statute to adopt administrative rules for the implementation of the HIPAA Transaction and Codes Sets; the privacy and security of health care electronic networks and electronic health records. This work must always be done in consultation with DOHSS. Finally, DOHS and the New Jersey State Health Plan are also a critical elements in that they handle Medicaid claims, Charity Care and the one million covered lives in the State's Health Plan.

Consequently, it is appropriate that DOBI act as the central coordinator for the development of a Health Information Exchange. The implementation of a Health Information Exchange will require the involvement of many state, local government agencies as well as private entities. But, without the active participation of all, success is unlikely.

Clearly defined project scope with identification of tasks required, organized by work breakdown structure

The scope of this project is to define, develop and implement a robust Health Information Exchange. A firm commitment from all stakeholders is necessary to create and operate this entity. The project must consider all business processes from the point that the information of the bioterrorism event is reported. Pertinent information is to be gathered to ensure that data included is standardized and available to all necessary entities. Major tasks are:

Assemble Project Team
Assess Legislative Limitations/Required Legislative Action
Develop Project Plan
Define Requirements for the storage of any PHI data
Define standard data content reporting
Define web pages (format and content)
Define web access security requirements
Prepare and Secure Approval of System Design Document

Develop/Test Application
Document Application
Conduct User Training
Implement Project
Post Implementation Project Monitoring

Project timeline and milestones with projected cost and resources required

A project schedule will be developed that will define all major units of work to be performed as part of this project.

It is anticipated that this will be a 24 month project.

Means for tracking, measuring and reporting progress

The project manager, during the initial phase, will measure progress against the established project plan, tracking actual project schedule against proposed project schedule and actual resource utilization against projected project resource needs.

Impact assessment on all affected stakeholders in the state (including small and rural providers)

All stakeholders will need to develop a means to support electronic reporting and collection of data to the HIE.

Feasibility assessment with identification of possible barriers that the implementation plan may face

The creation of a standard set of data elements to be reported by laboratories for all blood lead screening tests performed is feasible. Creation of both an electronic transaction for batch reporting as well as the development and deployment of a web based solution for laboratory reporting would give reporting laboratories the ability to select the method for submission of test results that they feel is most appropriate to their internal operations. Barriers to this solution could include the unwillingness to allow for the secure use of social security number to identify either the patient or the adult custodian of the patient based on confidentiality concerns or identity theft concerns. There is no other unique individual identifier that exists that could be used as an alternative to the social security number and there does not appear to be any interest at the national level to pursue the assignment and use of a unique patient identifier under HIPAA. Relying on use of non-unique secondary identifiers such as patient name, date of birth, gender and physical street address will have a significant adverse impact on the accuracy of reporting.

Single State/Multi State

Single State for the most part although it would be very helpful for neighboring states to agree on the common elements of an EHR.

Importance, ease of accomplishment and order to be completed

Project Importance: Very High.

Ease of Accomplishment: From both a technical and a business process perspective this project is complex.

Order to be Completed: There are several critical actions that need to be taken before significant effort can and should be invested in this project.

2. Workflow Solution

Solution: Development of a physician ID card with National Provider Identifier

Summary of effective practice(s) to be instituted or barrier(s) to be mitigated or eliminated by the plan

Development of a physician ID card with National Provider Identifiers would allow efficient identification of providers, especially when physician does not normally participate in organizations health care delivery.

Planning assumptions and decisions

1) Since New Jersey cannot dictate the requirements of provider identification in other states, it would be helpful to endeavor to reach agreement other contiguous states regarding common data elements of provider identification.

2) By NJ DOBI administrative rules, the NPI will be included on all paper transaction forms, including billing.

Project ownership and responsibilities (identify specific individual and/or organization names and titles)

1) For physician ID card, task force selection of state health officials, physicians, Health Information Management (Medical Records), hospitals, mental health professionals and other key stakeholders would be selected to make recommendation for standards.

Clearly defined project scope with identification of tasks required, organized by work breakdown structure

1) Development of statewide physician ID card. Card would be issued by Department of Health but move likely will re related to the license application and renewal process that is handles by the Department of Law and Public Safety, Professional Boards.
2a) Selection of planning committee with project manager
2b) Approval of project scope and timeline
2c) PM develops charter and base plan to be approved by committee
2d) Working committee defines draft form and instruction use
2e) 90 day 'comment period' for all organizations defined as 'covered entities' by HIPAA.
2f) Modifications as necessary
2g) six month period for preparation allowed for covered entities

Project timeline and milestones with projected cost and resources required

Developed by project leader as part of project deliverables. Process would take two year total, 3 months for initial work, 3 months for comment period, 1 year for modifications, implementation, 6 months to allow preparation by existing covered entities. Costs would include appropriate reimbursement for staff hired or assigned to participate in project, meeting costs including conference calls, legal assistance, and technology fees.

Means for tracking, measuring and reporting progress

Regularly scheduled project meetings shall be held, and reporting progress by workgroup members against the project plan. Allow for complaint process to DOHSS or the Professional Boards for violations. Audits shall be performed by DOHSS to ensure compliance.

Impact assessment on all affected stakeholders in the state (including small and rural providers)

Impact assessment on all affected stakeholders in the state (including small and rural providers:
Appropriate representation of stakeholders in design/implementation process and during the comment period will ensure all affected parties have necessary input.

Feasibility assessment with identification of possible barriers that the implementation plan may face

Any physician provider currently defined as a 'covered entity' under HIPAA law must follow HIPAA guidelines for electronic transmission of information, via ePHR, email, fax, phone or other.

Single State/Multi State

Single State at first.

Importance, ease of accomplishment and order to be completed

1) High importance.
2) Medium ease of accomplishment due to setup time needed to implement statewide process.

*** Finally, it should be noted that many of the same steps related to the creation of a provider identification card could also be applied to creation of a uniform patient identification card. Such a simple measure would eliminate a lot of wasted time and resources that occur when patient information is not correctly recorded or transcribed to electronic standard transactions from photo copies of insurance identification cards. Use of bar codes and magnetic strips is also recommended.***

3. State Law Solution

Solution: Development of state and interstate mandates/agreements for display of patient name, DOB, gender during catastrophic events at hospitals

Summary of effective practices:
During a catastrophic event, like the aftermath of the 9/11 attack; there are multiple stakeholders who may request information from area hospitals to determine whether family members were admitted. These stakeholders may include public health authorities such as DOHSS, state officials, media, law enforcement, Red Cross and other disaster relief agencies, next of kin, New Jersey hospitals and hospitals or authorities in other states if a national emergency is declared.

Maintaining a directory of patients in a centralized website accessible to family members during a catastrophic event will effectively reduce the burden of requiring family members to go to individual hospitals to determine whether their loved ones are inpatients. As set forth in the attached, there is express authority under HIPAA and no express authority under state law (N.J.S.A. 28:13-17) to prohibit hospitals from developing patient directories consistent with the standards of 45 C.F.R. 164.510(a). However, there is no express authority or procedure to permit a third party (not designated as a relief agency) to receive patient information and to disclose it on its website to aid in reporting the location of patients after a catastrophic event. In order for hospitals to make patient directory information available in a website during a catastrophic event and ensure compliance with patient privacy requirements, state and interstate agreements are needed. These agreements/mandates should establish express authority and proper procedures for development and maintenance of such a website by a third party involved in relief efforts.

In developing state and interstate agreements, the following should be taken into consideration: (1) clearly state the procedure for when or who has the authority to declare an emergency, (2) adopt a process whereby the governor or commissioner of health provide express authority (via a request or an executive order) to disclose limited patient directory information obtained by hospitals with organization such as NJHA assisting families locate family members in an emergency (this will help mitigate against any uncertainty that patient directory information can be maintained on a centralized website rather than just at individual hospitals), (3) establish a procedure for hospitals to enter patient directory information into a Web-based database; (4) establish a procedure for maintaining and updating the website information; (5) enter into interstate agreements to authorize the sharing of patient directory information for maintenance of other state web-sites; (6) provide a process for family members to access the database using patient name; (7) include capability for multi-state searches in case of a national disaster; (8) establish a process to disband the web-site after the national emergency is over; (9) establish authority to waive the notice and opt-out requirements under the HIPAA Privacy regulations (45 C.F.R. 510(a)) to patients during a catastrophic event; (10) research other state laws to determine if there are any prohibitions with sharing patient directory information interstate during an emergency; (11) provide a mechanism for hospitals to update the information on a website; (13) provide an alternate method to access patient directory information for the hearing or visually impaired (i.e. telephone, IVR, TDD).

Planning assumptions and decisions:

Assumptions:

- The goal is to provide central access to limited patient directory information (meeting the standards of 45 C.F.R. 510(a) or more limited information) on a website during a catastrophic event to family members to reduce the burden of having to call individual hospitals to determine whether a family member was admitted
- Access to patient directory information may need to be available in multiple states if a national emergency is declared
- HIPAA allows the maintenance of patient directory information (patient name, location and general condition) by hospitals, but does not specifically address a hospital's authority to provide this type of information in a central web-based data base
- NJ state law and the laws of other states would not prohibit the development of patient directories consistent with the standards of 45 C.F.R. 164.510(a).
- Access to patient name, DOB and gender via input of patient name would allow non-family members (i.e. media, relief agencies) who otherwise may not have authority to access this information under normal circumstances
- Express / regulatory authority for a hospital to disclose information to NJHA or another agency assisting in locating family members during an emergency

Decisions

- Representatives from a cross-section of hospitals (large, small, community) should participate in the development of a process for providing patient directory information to a secure web-site once an emergency is declared
- A meeting will be convened with the governor and/or the commissioner of health to include specific authority under existing state law or executive order issued by the governor to allow hospitals to share information with a third party

(like NJHA which is not designated as a relief agency) to maintain a web-site and disclose patient information during an emergency

- The planning committee will rely on a uniform/reasonable interpretation of HIPAA privacy regulations and state law with respect to authority to develop patient directory information
- Draft a state agreement/protocol for maintenance of a website of patient directory information
- Once authority and procedure are developed, meet with the same representatives from other states to discuss development of interstate agreements for sharing of limited patient directory information in a website
- Development of state/interstate agreements will include provisions to comply with patient privacy requirements, security provisions, maintenance/update of information on the website, return/destruction of website information after the catastrophic event or national emergency is over
- The planning will also include education of hospital staff and the public prior to the initiation of the website to address the notice/opt out requirements of HIPAA (is there consensus that the notice/opt out to patient directory information under the HIPAA privacy regulations does not apply because there is a presumption that all individuals admitted during a catastrophic event were admitted for an emergency). There may be famous or note worth individuals who would not want their names included on a website that is accessible by anyone who has their name –may need to be an alternate option developed to exclude the names of famous or noteworthy individuals from the website.
- A part of our ongoing contact with New York State we should full address this issue and reach the necessary agreement and understanding.

Project ownership and responsibilities (identify specific individual and/or organization names and titles)

Initial project ownership shall be with NJ State Coordinator (if established), DOBI, DOHSS and DOHS.

(1) For a state solution, dependency exists on the team development of a process that includes clear authority to allow hospitals to provide patient information in a web database maintained by a hospital or a third party.
(2) Team should also include legal SME, NJHA representatives involved in setting up the website after 9/11 (for process, lessons learned, challenges) to ensure development of state/interstate mandates/agreements are consistent with relevant law. The Team should also include consumers to ensure any concerns, privacy issues are addressed.
(3) A team comprised of a cross-section of representatives from hospitals, NJHA, lawyers, and consumers to help ensure that the process for developing the website and its functionality meet the goal of the project to ensure rapid access to uniform information to locate family members in a hospital following a catastrophic event.
(4) A team leader will need to be identified to facilitate team coordination and ensure work plan completion.

1) Clearly defined scope and milestones; 2) Projected cost and resources required

Scope: To develop a secure website (at least in NJ) that complies with patient privacy requirements and contains limited patient directory information accessible to family members by entering a patient's (first and last name) after a catastrophic event to reduce the burden of family members having to call individual hospitals to determine if a family member is an inpatient.

The project must include a process to include patient directory information from other states in case a national emergency is declared.

Tasks include:

(1) Identify a team leader.
(2) Identify members of the team taking into consideration the various stakeholders impacted by this business practice.
(3) Evaluate the practice/procedure adopted in NJ after the 9/11 attack to make patient directory information available on a website and identify any barriers/lessons learned. Obtain information about how other states dealt with the same issue to identify best practices.
(4) Draft a position paper on relevant HIPAA and other applicable state law. <u>See</u> NJHA position paper on "The Impact of the HIPAA Privacy Rule on Nihau's & Hospital's Emergency Response", dated August 25, 2004 and the NJHA "HIPAA Emergency Preparedness", both of which are instructive.
(5) Develop a procedure to implement input/sharing by all hospitals at least in NJ to share patient directory information.
(6) To the extent there is a need for a website with national access, develop a procedure for sharing patient directory information interstate.
(7) Draft template state/interstate agreements to allow input of patient directory information on a website and maintenance of the website.
(8) Train/educate hospital staff and public on the procedure to access patient directory information after a catastrophic event.

1) Project timeline and milestones; 2) Projected cost and resources required

Since processes implemented in New Jersey to allow family members access to patient directory information via a website in 2001 after a catastrophic event (the 9/11 attack), can serve as a framework for implementing the business practice. Once consensus is reached in terms of the necessary authority required to permit an entity (other than a public health authority or a relief agency) to receive patient information then the following milestones could be met within the next 12-18 months: assemble hospital representatives, commissioner of health, community representatives, SME for planning team, legal adviser to assist in drafting state mandates/interstate agreements, choose group leader, develop timeline for work, research best practices and procedures implemented in other states and identify any barriers that could impact implementation of a website accessible in multiple states if a national emergency is declared, draft policy/procedure documents, draft template state/interstate mandates or agreements, seek whole state adoption of the policy/procedure (at a minimum and interstate adoption to maximize impact); create steps for implementation once an emergency or national disaster is declared.

Projected costs would include: initial planning team meeting, meeting location or teleconference call and setting up of subsequent meetings/conference calls, legal costs in drafting state mandates/agreements, website set up and maintenance.

Means for tracking, measuring and reporting progress

The following steps can be developed to track project status, measure and report progress: (1) Team will develop a detailed project plan with deliverables and deadlines that is accessible to entire team to input status of assignments; (2) periodic conference calls convened by team leader for team discussion of progress, deliverables and co-dependencies; (3) Team members input status of tasks prior to conference calls with the team leader coordinating team sessions and updating the project plan; (4) team leader periodically reports to HISPC project team on status and progress, issues etc.; (5) final policy/procedure and template state mandate/interstate agreements provided to HISPC project team for implementation. Same process would apply if business practice is implemented in multiple states.

Impact assessment on all affected stakeholders in the state (including small and rural providers: Once authority is identified and a procedure is developed for disclosure of patient directory information into a web database, the expectation is that all hospitals (statewide) would follow this procedure. Once the procedure is implemented by a majority, if not all, hospitals (small, rural, large and community hospitals), it may provide a uniform approach for family members to access patient directory information in one place and eliminate the need to access this information at each individual hospital.

To the extent authority is identified and this procedure can be replicated in all states, then family members could access patient directory information in other states via a website in case of a national disaster/emergency. This will reduce the burden of family members having to contact individual hospitals in each state after an emergency, like Katrina, after which many New Orleans residents were displaced and relocated to other states.

1 Feasibility assessment;
2) Possible barriers that the implementation plan may face:

Given the 2001 process to provide access to patient directory information on a website that took place after the 9/11 disaster, it is very feasible that a statewide procedure could be adopted. Possible barriers may include: failure to properly identify the authority to allow an agency not designated as a relief organization to maintain the website; inability of hospitals to update the website; rejection of the adopted procedure by the public unless individuals maintain the ability to opt out of including information in website directory; consistent and confirmed participation by stakeholders; failure for designated team members to complete tasks timely; failure of a majority of hospitals in NJ to adopt the policy; failure to reach interstate agreements or prohibition under applicable laws in other states to share patient directory information to respond after a national disaster.

Single State/Multi-state: Multi-state as most catastrophic events have multistage implications.

1) Importance; 2) Ease of accomplishment; 3) Order to be completed

1) This business practice is of medium/high importance as it will reduce the burden of family members having to approach individual hospitals in NJ to locate a loved one after a catastrophic event. 2) Accomplishment in New Jersey should not be too difficult as there is a process that was adopted after the 9/11 disaster that resulted in some hospitals disclosing patient directory information via a web database. Proper authority and procedure need to be documented to allow DHSS or hospitals to disclose patient directory information to non-relief agencies. May be more difficult to implement in other states if unwillingness or legal impediment for sharing patient directory information interstate or if interstate mandates/agreements cannot be reached. 3) Need to first establish authority for establishment of a website of patient directory information by disclosure of patient information by hospitals to non-relief agencies. See tasks above.

4. HIPAA Privacy and Security Solution

Solution: Develop a predefined protocol or decision pathway on which elements of PHI can be shared with certain entities.

Summary of effective practice(s) to be instituted

Physicians, medical records staff and unit floor coordinators need to have a predefined protocol or decision pathway on which elements of PHI, particularly what levels and kinds of PHI can be shared with others. .

Planning assumptions and decisions

Assumption #1: Physicians and other healthcare providers do not have a good understanding of HIPAA.

Assumption #2: There are no current pathways in hospitals/institutions have adopted regarding which PHI can be shared and what cannot with and without consent.

Decision: Develop materials and scenarios that will lead to formation of decision trees (by NJ-HISPC group) that will lead to useable pathway documents.

Project ownership and responsibilities

Initial project ownership shall be with the State Coordinator (if established), DOHSS, DOHS and DOBI.

DOHSS, DOHS and DOBI should partner with provider societies and organizations (MSNJ, NJAFP, ACP NJ, AAP NJ, UMDNJ) etc., to develop CME materials for understanding and use of project generated pathway documents. Project ownership is by coalition of state agencies. This can be rolled into NJ Health Information Technology Commission or related entity (as in current bill A4044) if/when created.

Project scope and tasks required

Project Scope: develop CME/CE materials that providers can get credit for to enhance working HIPAA knowledge and situational decision making.
Tasks required:
1) Identify various levels of PHI as defined by HIPAA,
2) Identify various state mandates on health info privacy and security
3) Develop generic decision pathways for different provider settings.
Deliverable- CD/DVD with complete CME/CE and protocols included.

Project timeline

Timeline: 24 months.

Means for tracking, measuring and reporting progress

Tracking through how many CE/CME credits awarded to providers through respective organizations.

Impact assessment on all affected stakeholders

Once an HDIE (Health Data Information Exchange) is developed, monitoring an increase in the number of transactions would quantitatively give a rough idea that methods worked. Distributing surveys and doing qualitative analysis would also be of use in evaluation.

Feasibility assessment

Feasibility- assessment: depends on relative cost of the development of materials and gaining acceptance and sponsorship from provider societies/academies. Possible barrier to project is that there would be little voluntary support from provider organizations.

Single state/Multi state

Single state initially, multi-state if NJ HISPC standards to be adopted by other states.

Importance, ease of accomplishment and order to be completed

Importance- very important- key to increasing the number of electronic health transactions in an overall HDIE/RHIO by removing key cognitive barriers. Ease of accomplishment- achievable with support of key stakeholders. Order to be completed is when federal and state laws are adequately matched and coordinated.

5. Education solution

Solution: Education about common consent forms

Summary of effective practice(s) to be instituted

Drawing from Scenario ID#12, the common development of pathways where consent is needed can then be distilled into consent forms. The forms can have clearly defined subsets of permission to be given to different interests- providers, payors, public health officials, administrators.

Planning assumptions and decisions

Assumption #1: Consents can be legally re-formatted to include different conditions and sub-conditions.

Assumption#2: Paper obtained consents can be transported into an electronic format with eventual storage as part of an EHR. .

Project ownership and responsibilities

Initial project ownership shall be with the State Coordinator (if established) and with DOBI, DOHSS and DOHS. .

Project ownership- We should create a short educational package with power point support; train DOBI’s Speakers Bureau to be familiar with educational package and issues and send out speakers to meet with and address provider and consumer groups. Purpose should be to dispel most common HIPAA misapplications and to show all concerned the value of EHRs. We would need to drive a collaboration/consortium with public/consumer interest groups, provider groups, payors/insurers and state entities on development of specific consent forms. This would include NJ Hospital Association, MSNJ, Nursing Associations, NJ PIRG, etc.

Project scope and tasks required

Project Scope: Develop model consent forms and educational package based on various healthcare environments. Tasks required: 1) Development of decision pathways 2) Distill pathways into various versions of consents based on environment where forms are to be deployed i.e. hospital, nursing home, rehab facility, dialysis center, surgical center, ambulatory care office, mental health institution

Project timeline.

Timeline: 6 to 12 months.

Means for tracking, measuring and reporting progress

If a compensation model for the use of forms is instituted (organizations pay for consent toolkits to cover production costs) then the number of kits delivered would serve as a means of tracking on how many organizations are implementing the model forms. When an HDIE is implemented in the state, an increase in transactions and deposit of electronic consents into a consent database would help determine utilization.

Impact assessment on all affected stakeholders

Using surveys of patients, providers and payors with qualitative analysis would aid to assess the impact of these interventions. Lowering the latency in health information transactions would result in speeding the delivery of care and reducing costs.

Feasibility assessment

Feasibility assessment- A Pilot study can be employed with volunteer organizations in controlled settings to determine if deploying standard consent forms would decrease the latency of health information transactions- operations research analysis through workflow studies. Barriers would include a lack of volunteers to assist in such a pilot.

Single state/Multi state

Multi-state as consents would invariably need to identify out-of-state permissions to access PHI.

Importance, ease of accomplishment and order to be completed

Importance- High importance.
Ease of accomplishment- medium difficulty.
Order to completed- after HIPAA decision pathways are determined, then consent forms can be designed, tested, deployed.

Appendix 1

NJ-HISPC Final Stakeholder Grid (posted as a separate document)

Appendix 2

NJ-HISPC Implementation Plans Grid (posted as a separate document)