FINAL ASSSESMENT OF VARIATION AND ANALYSIS OF SOLUTIONS REPORT

NEW HAMPSHIRE

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SUBMITTED BY THE NH INSTITUTE FOR HEALTH POLICY AND PRACTICE

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1.0 Background and Purpose

New Hampshire has few legal barriers to HIT/HIE. However, the historical and cultural context of New Hampshire to protect and regard privacy with the utmost care is not to be underestimated. In fact, the law in New Hampshire specifically states that the information within the patient medical record (note: not the medical record itself) is considered the property of the patient and falls under property law. The assumptions of the team, after multiple interviews and forums with key experts and provider groups became focused on the consumer engagement phase of the project. Much of the effort and focus of the project became, therefore, on one major component: determining how the HIT/HIE experts can most effectively engage providers and consumers in the pursuit of a seamless HIE environment which benefits patient care and clinical practice.

2.0 Assessment of Variation

2.1 Methodology

New Hampshire is a small state and we sought to work with providers and stakeholders in as non-intrusive a manner as possible to avoid "research participation burnout". As key informants are likely to encounter multiple demands on their time, and be involved in similar efforts across the state, we offered to meet individually and/or interview the staff rather than create a single forum for discussion at this time. It is our intention to craft a final "variations" assessment and meet with the stakeholders to gain additional qualitative information for the solutions and implementation phase. In addition, the NH HISPC team sought to streamline and facilitate the project in a way which produced a thorough review as possible but which capitalized on existing efforts and committees:

- Combined NH efforts with VT team and initiated weekly progress conference calls. Developed two state master scenario documents that included assumptions for each scenario (See Appendix B of previous report) although the final methodology varied between the states. We assumed that this approach would benefit RTI and the funder as it would standardize even further the data collected.
- The NH and VT team staff collectively interviewed an academic medical center that spans over both geographic regions. The team agreed to review scenarios 11 and 12 with the provider.

- The project team mapped each scenario(s) to stakeholder group(s) identified by RTI and revised based on NH landscape. (Table 1 of previous report) Project team identified specific key stakeholders to represent each group.
- Business practices and policies were identified double inputted into portal and spreadsheet. Spreadsheet sent to LWG for legal analysis.
- For the purposes of this report, a barrier was defined as a business policy or practice which, for interoperability to occur major legal or procedural changes must be developed and implemented.

2.2 Summary of Relevant Findings Purposes for Health Information Exchange

2.3 TREATMENT (SCENARIOS 1- 4)

2.3.a. Patient Care-Scenario A

The emergent transfer of health information between two healthcare providers when the status of the patient is unsure.

Patient X presents to emergency room of General Hospital in State A. She has been in a serious car accident. The patient is an 89 year old widow who appears very confused. Her adult daughter informed the ER staff that her mother has recently undergone treatment at a hospital in a neighboring state and has a prescription for an antipsychotic drug. The emergency room physician determines there is a need to obtain information about Patient X's prior diagnosis and treatment during the inpatient stay.

ASSUMPTIONS:

- Time is a factor, the injuries are serious.
- The patient is determined to be unable to give informed consent or to provide accurate, specific medical information and there is no ability to access or locate informed consent documentation if it does exist.
- Adult daughter is not a guardian or health care agent under an advance directive.
- The prescription was dispensed by hospital while Patient X received inpatient care.
- Neighboring state hospital's consent policy is unavailable.

STAKEHOLDERS:

Hospitals (ED personnel and pharmacists)

Consumers

2.3.b. Patient Care—Scenario B

The non-emergent transfer of records from a specialty substance treatment provider to a primary care facility for a referral.

A specialty substance abuse treatment facility wants to refer client X to a primary care facility for a suspected medical problem. The client has a long history of using various drugs and alcohol relevant for medical diagnosis. The information is being sent to the primary care provider without the patient's authorization. The primary care provider refers the patient to a specialist and sends all of their information (without patient authorization) including the information received from the substance abuse treatment facility to the specialist.

ASSUMPTIONS:

- Treatment is of a non-emergent nature.
- Each provider is a separate entity and the specialist is non-hospital based.
- The patient has consented to medical treatment.
- Client recall of medical history is unreliable.
- No inpatient admission, the substance abuse facility is free-standing.

STAKEHOLDERS:

- Physicians/Clinicians (includes Mental health/Specialty substance abuse providers)
- Community Health Center
- Consumers

SPECIFIC QUESTIONS:

- Is the sharing of information in this scenario a problem?
- Do you have special safeguards for the handling of substance abuse information?

2.3.c. Patient Care Security and Access—Scenario C

At 5:30pm Dr. X, a psychiatrist, arrives at the skilled nursing facility to evaluate his patient, recently discharged from the hospital psych unit to the nursing home. At the time of the patient's transfer, the discharge summary and other pertinent records were electronically transmitted to the nursing home.

Upon entering the facility Dr. X seeks assistance in locating his patient, gaining entrance to the locked psych unit and accessing her electronic health record to review her discharge summary, I&O, MAR and progress notes. Dr. X was able to enter the unit by showing a picture identification badge, but was not able to access the EHR. As it is Dr. X's first visit, he has no login or password to use their system.

Dr. X completes his visit and prepares to complete his documentation. Unable to access the long-term care facility EHR, Dr. X dictates his initial assessment via telephone to his outsourced, offshore transcription service. The assessment is transcribed and posted to a secure web portal.

The next morning, from his home computer, Dr. X checks his e-mail and receives notification that the assessment is available. Dr. X logs into the portal, reviews the assessment, and applies his electronic signature.

Later that day, Dr. X’s Office Manager downloads this assessment from the web portal, saves the document in the patient’s record in his office and forwards the now encrypted document to the long-term care facility via e-mail.

The long-term care facility notifies Dr. X’s office that they are unable to open the encrypted document because they do not have the encryption key.

ASSUMPTIONS:

- Each provider is a separate entity.
- Patient is a returning patient at the long term care facility.
- The physician has a business associate contract in place with the transcription services company.
- The correct patient records were transferred to Dr. X.
- Dr. X is verified to be who he states he is, he is a credentialed provider and contracted to provide services for the patients of the long term care facility.

- The long term care facility wants Dr. X to access the information.
- Patient consent has been obtained for Dr. X to access the information.

STAKEHOLDERS:

- Long term care facilities
- Physician groups/Clinicians (includes Mental health providers and Practice managers)
- Hospitals (includes Hospital Psych Unit)
- Other (Transcription Services Company)
- Consumers

SPECIFIC QUESTIONS:

- Are the practices described here adequate from a security and privacy perspective?
- How would you handle the request of the long-term care facility?

2.3.d. Patient Care—Scenario D

The non-emergent transfer of health information.

Patient X is HIV positive and is having a complete physical and an outpatient mammogram done in the Women's Imaging Center of General Hospital in State A. She had her last physical and mammogram in an outpatient clinic in a neighboring state. Her physician in State A is requesting a copy of her records and the radiologist at General Hospital would like to review the digital images of the mammogram performed at the outpatient clinic in State B for comparison purposes. She also is having a test for the BrCa gene because other family members have had breast cancer.

ASSUMPTIONS:

- Radiology department, laboratory and treating physician are under same health care operations and under the same policy constraints.
- The patient's HIV status is of relevance to treating physicians.
- The patient does not want to disclose her HIV status to the treating physicians.
- The patient cannot access her medical record directly.

STAKEHOLDERS:

- Physicians
- Hospitals/Clinics
- Public health department/lead agency
- Consumers

SPECIFIC QUESTIONS:

- What are your practices and policies surrounding HIV related confidentiality?
- Would this diagnosis (HIV positive) be forwarded to State A?

2.3.A. STAKEHOLDERS

The Community Health Access Network (CHAN) is a private non-profit membership organization consisting of federally qualified community health centers throughout New Hampshire. A strong penetration of HIT exists in the community health centers. All of NH's Federally Qualified Health Centers (FQHCs) adopted the Centricity EMR product, and have now had several years of active use. Through the Community Health Access Network (CHAN), five Community Health Centers (CHC's) in the southern part of the state currently exchange information with one another, and closely affiliated partners. In addition, 7 out of the 9 New Hampshire community health centers use the same EMR (the remaining 2 would be implemented on this EMR as part of the grant). The two remaining Health Centers without an EMR (Valley Regional and White Mountain) are interested in the technology, but currently do not have the resources to implement an EMR. The Members hold an inter-agency data sharing agreement that governs access to and use of the data stored by the Network on its shared central enterprise servers. 2 CHC's were interviewed for this project.

An academic medical institution was also among the stakeholders. The institution is an early adopter of health information technology with the automation of a "home-grown" electronic medical record. Today, the organization utilizes three EMR systems across the system. In every community the organization is involved with the local hospital to electronically transmit community specific information. In addition, each of the hospitals has established firewalls to access hospital data and some of data from referring nursing homes.

A community-based health delivery system was interviewed pertaining to these scenarios. Over the past several years the organization has focused on developing methodologies and processes to streamline the exchange of healthcare information across the transition points that improve the

care for the patients served. The Centricity EMR has been leveraged in several ways to facilitate HIE exchange across affiliations. In addition, the organization has developed a privacy policy to be signed by all personnel.

A public health agency is also represented under Scenario 4 regarding HIV status.

2.3.B. DOMAINS

Information Use and Disclosure Policy

Disclosure of Specialized Categories of Protected Health Information

Providers utilize a separate patient consent form and/or section in addition to a general release form to obtain authorization to disclose specific categories of PHI.

Legal Analysis:

As detailed in Appendix A, New Hampshire has enacted multiple medical record disclosure requirements, many specific to particular types of illnesses, particular types of testing, consent by legal representatives, and facility licensing. These requirements are in addition to medical record property rights. Illness-specific provisions include HIV, mental illness, communicable diseases, and alcohol and drug abuse. Disclosure requirements also apply to genetic testing, advance directives and guardianship, and patient rights in licensed facilities. Penalties and remedies attach too many of these requirements.

"Uses and Disclosures for Treatment, Payment and Healthcare Operations" Section 506 General Manual State of NH

Information Authorization and Access Controls

Interagency agreements, business associate agreements and/or contracts influence access to PHI. For example under Scenario3 – Patient Care C, if the community health center has a contract with the nursing home the center would have addressed the specifics of patient informed consent and information sharing.

2.3.C. CRITICAL OBSERVATIONS

Variation exists among processes and technology utilized in obtaining patient consent across provider types. Patient consent may not be fully understood by the patient, and signed as a matter of course. Information is exchanged more readily by provider groups who work together on a regular basis, and formal authentication can be lapsed as a matter of ease or habit in daily operations. The practice of obtaining consent is also dependent on the context of the interaction, for example in emergent situations consent may not be obtained until the crisis has passed.

2.4 PAYMENT (SCENARIO 5)

2.4 Payment Scenario

X Health Payer (third party, workers compensation, disability insurance, employee assistance programs) provides health insurance coverage to many subscribers in the region the healthcare provider serves. As part of the insurance coverage, it is necessary for the health plan case managers to approve/authorize all inpatient encounters. This requires access to the patient health information (e.g., emergency department records, clinic notes, etc.).

The health care provider has recently implemented an electronic health record (EHR) system. All patient information is now maintained in the EHR and is accessible to users who have been granted access through an approval process. Access to the EHR has been restricted to the healthcare provider's workforce members and medical staff members and their office staff. X Health Payer is requesting access to the EHR by its case management staff to approve/authorize inpatient encounters.

ASSUMPTIONS:

- Payer and physician have contract allowing payer access to medical records pertinent to claims payment.
- Access requirements are time sensitive (inpatient admissions).

STAKEHOLDERS:

- Third party payers
- Hospitals
- Physicians
- Consumers

Note: This scenario is applicable to all healthcare providers. (RTI)

2.2.A. STAKEHOLDERS

Two third-party payers represent national health insurance companies.

2.2.B. DOMAINS

Information Use and Disclosure Policy

Business practices are primarily based on national policies. The policies that would dictate the disclosure of the PHI indicated in the scenario would be those of the provider, not the health plan. Typically the provider policies that would safeguard the exchange would be: Use and Disclosure, Role Based Access/Access Control and Third Party Access policies.

In addition, contracts with providers mandate that the type of information described in the scenario must be supplied by provider for authorization. To date, one of the third party payers receive this information in paper format (typically fax). To date, providers have not offered to give our management staff access to their EHR's.

Legal Analysis:

In addition to medical record property rights and specific disclosure requirements, New Hampshire law limits the utilization reviewer's access to only that information in the medical records that is necessary to certify service coverage. Key statutory requirements include patient consent requirements relative to mental illness, HIV, and genetic testing information, as well as facility licensing requirements and patient property rights in medical records. (See Appendix A of previous report)

2.4.c. Critical Observations the issue of patient consent and information exchange remain the same in this situation; providers may, as a matter of administrative ease share information without per-episode authentication of the recipient. There may at times be a conflict between business policy and administration of daily operations.

2.5 RHIO (SCENARIO 6)

2.5 Regional Health Information Organization (RHIO) Scenario

The RHIO in your region wants to access data from all participating organizations (and their patients) to monitor the incidence and management of diabetic patients. The RHIO also intends to monitor participating providers to rank them for the provision of preventive services to their diabetic patients.

ASSUMPTIONS:

- RHIO has business associate agreement with providers as covered entities.
- The information will be distributed in an aggregate report to third party payers and employer groups as requested.

STAKEHOLDERS:

- Long term care
- Home health
- Hospitals
- Physician groups
- Federal health facilities
- Community clinics/health centers
- Consumers

Note: Each stakeholder should participate in this scenario keeping in mind the type of data their organization anticipates exchanging with a RHIO. (RTI)

2.5.A. STAKEHOLDERS

Currently, New Hampshire does not have an existing RHIO. However, during this process the project management team discovered a rural funded through the Bureau of Primary Health that started work in May 2006. Stakeholders involved in the grant include long term care, home

health, hospitals, the Veteran's Administration, the Visiting Nurses Association, community clinics, consumers and NH Department of Public Health. The overall goals of the grant are: 1. to develop a regional diabetic registry, 2. to develop a regional hypertension registry. Providers in project will have access to a registry portal by login/password privileges with a separate login/password for reading and writing privileges. The client will sign a release form that will include information about the project, and list providers that information will be shared with included in the project. Interagency Information Data Sharing Agreements will be signed by all agencies.

2.5.B. DOMAINS

To be determined

Legal Analysis:

As described in the analysis of patient treatment scenarios above, the medical record property right and disclosure requirements in New Hampshire law are important considerations in RHIO activity. Many requirements are specific to particular types of illnesses, particular types of testing, consent by legal representatives, and facility licensing. As also noted above, penalties and remedies attach too many of these. (See Appendix A of previous report)

2.5.C. CRITICAL OBSERVATIONS

To be determined

2.6 RESEARCH (SCENARIO 7)

2.6 Research Data Use Scenario

A research project on children younger than age 13 is being conducted in a double blind study for a new drug for ADD/ADHD. The research project is being reviewed by the IRB that presides over research protocols at the major medical center where the research investigators are located.

The data being collected are all electronic and all responses from the subjects are completed electronically in the same data base file.

The principle investigator was asked by one of the investigators if they could use the raw data to track the patients over an additional six months or use the raw data collected for a white paper that is not part of the research protocols final document for his post doctoral fellow program.

ASSUMPTIONS:

- The Institution is an academic medical center with an IRB process in-place.
- Parental consent was obtained for the project.
- Research subjects have given consent to participate.
- Data is not identifiable.

STAKEHOLDERS:

- Researchers/academic institutions (IRB)
- Hospitals
- Clinicians/Physician groups
- Consumers

SPECIFIC QUESTIONS:

- Does this scenario require a business agreement?

2.6.A STAKEHOLDERS

Non-Medical Academic Institution (No affiliated medical school)

Academic Medical Institution (Medical school)

2.6.B. DOMAINS

Information Use and Disclosure Policy

Institutional Review Boards (IRBs) are in place at both institutions. All research involving human subjects is reviewed and approved by an IRB. Each utilizes IRB protocols which outlines data collection and procedures for security and confidentiality to guide business practices in relation to the use of research data. In addition, the Academic Medical Institution is part of a privacy group that developed a Notice of Privacy Manuel for consumers.
Specifically, the scenario would require full research protocol to IRB in addition to consent from parents would be required and possibly assent from children. The IRB has to approve giving data to a third party. Consent would be obtained from subjects.

Legal Analysis:
State law provides that personal medical or other scientific data obtained for the purpose of medical or scientific research by the commissioner of the Department of Health and Human Services, or by any person, organization, or agency authorized by the commissioner, is confidential and may only be used for medical or scientific purposes. Under the law "data" includes, but is not limited to, all information, records of interviews, written reports, statements, notes, memoranda, or other data procured in connection with scientific studies and research conducted by the State Department of Health and Human Services, or by other persons, agencies, or other organizations authorized by the commissioner. Personal medical or other scientific data may not be exhibited, nor may the contents be disclosed except as may be necessary to further the study or research project to which they relate. The person who performs an unauthorized disclosure of any confidential medical or scientific data is guilty of a misdemeanor. (See Appendix A in previous report)

2.6.C. CRITICAL OBSERVATIONS

IRBs are critical to the rigorous regulation of research data use at academic intuitions. Research activities proposing to involve human subjects must be reviewed and receive written, unconditional approval from the IRB before commencing. There is no waiver from this policy.

2.7 LAW ENFORCEMENT (SCENARIO 8)

2.7 Scenario for access by law enforcement

An injured nineteen (19) year old college student is brought to the ER following an automobile accident. It is standard to run blood alcohol and drug screens. The police officer arrives in the ER in addition to the patient's parents. The police officer requests a copy of the blood alcohol test results and the parents want to review the ER record and lab results to see if their child tested positive for drugs. These requests are made to the ER staff.

The patient is covered under their parent's health and auto insurance policy.

ASSUMPTIONS:

- Details of the accident and whether a crime has occurred are unconfirmed.
- Patient has consented to treatment, which is emergent in nature.
- Patient has not consented to sharing of medical information with non-medical personnel.
- Patient has not consented to drug and alcohol screens.

STAKEHOLDERS:

- Hospitals (ED staff)
- Law enforcement
- Consumers/Patient's family

SPECIFIC QUESTIONS:

- How would you handle the complicating matter of the parent's health and auto insurance policy?

2.7.A. STAKEHOLDERS

City Police Department Chief
City Police Department Detective

2.7.B. DOMAINS

State Law Restrictions

The law is the policy. The county attorney sets policy as he or she determines how the police will follow the law. At this time, the law states that a subpoena must be obtained prior to receiving results of blood tests, whether or not a criminal act is thought to have occurred. Students' rights are well protected and the parents should not be given access to the results. The Family Educational Rights and Privacy Act (FERPA) (20 U.S.C. § 1232g; 34 CFR Part 99) is a Federal law that protects the privacy of student education records. The law applies to all schools that receive funds under an applicable program of the U.S. Department of Education.

Legal Analysis:

For law enforcement, the law defines practice more so than it does for health care practitioners and insurers. Public safety policy allows limited overrides of medical record rights. There are two particular provisions of relevance in New Hampshire law. The first is related to a provider privilege exception and the second to requirements in the Motor Vehicles code relative to alcohol or drug impairment.

While privilege extends to health care practitioners, such as physicians and nurses, exception is made relative to the blood sample and the blood alcohol test results of a person under investigation for driving a motor vehicle while under the influence of alcohol or controlled drugs. However, the law limits this constraint on privilege to the official criminal proceeding.

The Motor Vehicles code provision deems any driver on the roadways of the State to have given consent to tests and examinations for the purpose of determining whether the driver is under the influence of alcohol or controlled drugs, if the driver is arrested for an offense arising out of acts alleged to have been committed while the person was driving, attempting to drive, or in actual physical control of a vehicle, while under the influence of intoxicating liquor or controlled drugs or while having an alcohol concentration in excess of the statutory limits. Tests are administered at the direction of law enforcement, who also have access to test results. Additional consent allowances or overrides apply to people who are dead, unconscious, or who are otherwise in a condition rendering them incapable of refusing the test or in the event of a collision that results in death or serious bodily injury to any person.

As to adult children (over the age of 18), the New Hampshire rights to medical information privacy apply. However, the legal implications of the federal Family Educational Rights and Privacy Act should also be considered. (See Appendix A in previous report)

2.7.C. CRITICAL OBSERVATIONS

The law is clear on this issue although again, in a setting where the parties work together often, information may be informally exchanged prior to consent or a subpoena being obtained.

2.8 PRESCRIPTION DRUG USE BENEFIT (SCENARIOS 9 & 10)

2.8. Scenario A—Pharmacy Benefit

The Pharmacy Benefit Manager (PBM) has a mail order pharmacy and also has a closed formulary. The PBM receives a prescription from Patient X for the antipsychotic medication Geodon. The PBM's preferred alternatives for antipsychotics are Risperidone (Risperdal), Quetiapine (Seroquel), and Aripiprazole (Abilify). Since Geodon is not on the preferred alternatives list, the PBM sends a request to the prescribing physician to complete a prior authorization in order to fill and pay for the Geodon prescription. The PBM is in a different state than the provider's Outpatient Clinic.

ASSUMPTIONS:

- There is no state law prohibiting generic substitutions.

STAKEHOLDERS:

- Pharmacists
- Clinicians/Physicians (includes Psychiatrists)
- Third party payers (including Medicaid and PBMs)
- Consumers

SPECIFIC QUESTIONS:

- Do you access insurance formularies? How?
- How do you handle electronic interchange with a PBM?

2.8 Scenario B—Pharmacy Benefits

A Pharmacy Benefit Manager 1 (PBM1) has an agreement with Company A to review the companies' employees' prescription drug use and the associated costs of the drugs prescribed. The objective would be to see if the PBM1 could save the company money on their prescription drug benefit. Company A is self-insured and as part of their current benefits package, they have the prescription drug claims submitted through their current PBM (PBM2). PBM1 has requested that Company A send their electronic claims to them to complete the review.

ASSUMPTIONS:

- Individual employee information will be suppressed from reporting.

STAKEHOLDERS:

- Employers
- Consumers
- Third party payers/TPA
- PBM

SPECIFIC QUESTIONS:

- Would patient/employees be readily identifiable?

2.8.A. STAKEHOLDERS

Third Party Payer

2.8.B. DOMAINS

This scenario would be subject to provider policies rather than health plan policies. The health plan providers their formulary as well as benefit related electronic transactions to our providers through various channels.

Patient and Provider Identification

The scenario states that employee-specific information will be suppressed from the report. It was unclear whether the report would be 'de-identified' as described by HIPAA's Privacy Rule. (De-Identification Policy on file with Julie Ward)

Information Protection

Additionally, the disclosure of the information may reveal proprietary corporate information. In this case, it appears that the self insured group health plan wants the PBM to have the information in question but depending upon the situation the exchange may reveal corporate financial arrangements or other corporate proprietary information that the self insured group health plan would prefer to not disclose. (Standard P&S Agreement Template and P&S Agreement Policy) (On file with Julie Ward)

Legal Analysis:

In addition to medical record property rights and provider disclosure requirements, New Hampshire law limits the utilization reviewer's access to only that information in the medical records that is necessary to certify service coverage. Additionally, State law prohibits the transfer, use, or sale of prescription information, containing patient-identifiable information, for any commercial purpose. (See Appendix A in previous report)

2.8.C. CRITICAL OBSERVATIONS

Business policies and practice must be reconciled to allow for protection of corporate information which may be of competitive use. Again, patient consent, employee rights and business protections must be balanced and able to be administered in a manner not burdensome for daily operations.

2.9 HEALTHCARE OPERATIONS AND MARKETING (SCENARIOS 11 & 12)

2.9.a. Healthcare Operations and Marketing - Scenario A

ABC Health Care is an integrated health delivery system comprised of ten critical access hospitals and one large tertiary hospital, DEF Medical Center, which has served as the system's primary referral center. Recently, DEF Medical Center has expanded its rehab services and created a state-of-the-art, stand-alone rehab center. Six months into operation, ABC Health Care does not feel that the rehab center is being fully utilized and is questioning the lack of rehab referrals from the critical access hospitals.

ABC Health Care has requested that its critical access hospitals submit monthly reports to the system six-sigma team to analyze patient encounters and trends for the following rehab diagnoses/ procedures:

- Cerebrovascular Accident (CVA)
- Hip Fracture
- Total Joint Replacement

Additionally, ABC Health Care is requesting that this same information, along with individual patient demographic information, be provided to the system Marketing Department. The Marketing Department plans to distribute to these individuals a brochure highlighting the new rehab center and the enhanced services available.

ASSUMPTIONS:

- The data fields are accessible, the information available and the report can be pulled as requested.
- Integrated delivery system operates as single entity (provider is a wholly-owned subsidiary).

STAKEHOLDERS:

- Hospitals
- Consumers
- Third Party Payers

SPECIFIC QUESTIONS:

- Do you use PHI in support of operations and/or marketing?

- How?
- What are the policies you have in place regarding this practice?

2.9.b. Healthcare Operations and Marketing—Scenario B

ABC hospital has approximately 3,600 births/year. The hospital Marketing Department is requesting PHI on all deliveries including mother's demographic information and birth outcome (to ensure that contact is made only with those deliveries that resulted in healthy live births).

The Marketing Department has explained that they will use the PHI for the following purposes:

- To provide information on the hospital's new pediatric wing/services.
- To solicit registration for the hospital's parenting classes.
- To request donations for construction of the proposed neonatal intensive care unit.
- They will sell the data to a local diaper company.

ASSUMPTIONS:

- The data fields are accessible, the information available and the report can be pulled as requested.

STAKEHOLDERS:

- Hospitals (includes Clinicians and Marketing department)
- Consumers

2.9.A. STAKEHOLDERS

The NH HISPC team collaborated with the VT HISPC team to interview an academic medical center that spans over both geographic regions. The team agreed to review scenarios 11 and 12 with the provider.

2.9.B. DOMAINS

Information Use and Disclosure Policy

In 2003, the academic medical center created a Health Privacy Committee in conjunction with four other hospitals, two behavioral health systems and a medical school. The policies developed by the team were adopted universally, covering a large segment of New Hampshire's health care market. In the case of the hospital, the field operation is given latitude in adopting the corporate policies (samples are provided) but in most cases the privacy and security policies were adopted across the board.

Legal Analysis:

In addition to medical record property rights and provider disclosure requirements, New Hampshire law prohibits the release or use of patient identifiable medical information for the purpose of sales or marketing of services or products without written authorization by the patient.

2.9.C. CRITICAL OBSERVATIONS

Access to patient information including demographics is clinically generated. For example, patients are followed after a clinical encounter for regular checkups and treatment for the purposes of improvement of care.

2.10 PUBLIC HEALTH/BIOTERRORISM (SCENARIO 13)

2.10 Bioterrorism event

A provider sees a person who has anthrax, as determined through lab tests. The lab submits a report on this case to the local public health department. The public health department in the adjacent county has been contacted and has confirmed that it is also seeing anthrax cases, and therefore it could be a possible bioterrorism event. Further investigation confirms that this is a bioterrorism event, and the State declares an emergency. This then shifts responsibility to a designated state authority to oversee and coordinate a response, and involves alerting law enforcement, hospitals, hazmat teams, and other partners, as well informing the regional media to alert public to symptoms and seek treatment if feel affected. The State also notifies the Feds of the event, and some federal agencies may have direct involvement in the event. All parties may need to be notified of specific identifiable demographic and medical details of each case as they arise to identify the source of the anthrax, locate and prosecute the parties responsible for distributing the anthrax, and protect the public from further infection.

ASSUMPTIONS:

- Adjacent county is in same state.

STAKEHOLDERS:

- Local/State/Federal agencies (public health/emergency response/law enforcement/public health network)
- Providers
- Hospitals
- Consumers

2.10.A. STAKEHOLDERS

Public Agency

2.10.B. DOMAINS

Information Use and Disclosure Policy

Department may disclose PHI when acting as public health authority for purposes of preventing or controlling disease and conducting public health surveillance, public health investigations, or public health interventions.

Legal Analysis:

New Hampshire law requires the provider report communicable disease to the New Hampshire Department of Health and Human Services. The Department may release protected health information, relative to this provision, only with the informed, written consent of the individual or to authorized persons having a legitimate need to acquire or use the information and then only so much of the information as is necessary for these persons to provide care and treatment to the individual, investigate the causes of disease transmission in the particular case, or control the spread of the disease among the public. The physician-patient privilege does not apply in this situation. (See Appendix A in previous report)

2.10.C. CRITICAL OBSERVATIONS

Public health is almost always considered of greater importance than individual rights, especially in an urgent or emergent situation. Providers and law enforcement are clear that protecting public health is the primary responsibility.

2.11 EMPLOYEE HEALTH (SCENARIO 14)

2.11 Employment Information Scenario

An employee (of any company) presents in the local emergency department for treatment of a chronic condition that has exacerbated which is not work-related. The employee's condition necessitates a four-day leave from work for illness. The employer requires a "return to work" document for any illness requiring more than 2 days leave. The hospital ED has an EHR and their practice is to cut and paste patient information directly from the EHR and transmit the information electronically to the HR department.

ASSUMPTIONS:

- Company maintains employee handbook that includes work absence policies.
- The employee has requested the return to work document be sent to his/her employer.

STAKEHOLDERS:

- Hospitals
- Employers (Employer Handbook Policies)
- Mental health providers
- Consumers

2.11.A. STAKEHOLDERS

Large public sector employer (2500 FTE).

2.11.B. DOMAINS

2.11.C. CRITICAL OBSERVATIONS

Human resource management requirements under employment law may conflict with HIPAA in the case of medical leave. The information must be available to make a determination on medical leave, yet balance with patient rights.

Documentation requirements for medical absence and FMLA

The employee is required to fill out a medical leave form and supporting documentation must be supplied by the physician. This form is returned electronically to the human resource office, and only designated HR employees can access the information; anyone who reviews or even files the information must sign a privacy and confidentiality form. The employee may chose to disclose to his or her supervisor the specific medical information, but the company HR department will not. The information is maintained electronically and is password protected.

2.12 PUBLIC HEALTH (SCENARIOS 15-17)

2.12.a. Public Health - Scenario A--Active carrier, communicable disease notification

Active TB Patient has decided to move to a desert community that focuses on spiritual healing. The TB is classified MDR (multi-drug resistant). Patient purchases a bus ticket - the bus ride will take a total of nine hours with two rest stops. State A is made aware of Patient's intent two hours after the bus with Patient leaves. State now needs to contact the bus company and State B with the relevant information. State A may need to contact every state along the route.

ASSUMPTIONS:

- The patient is not aware of the notification practice of the state of origin.
- The patient did not consent to notification.
- The patient’s treating clinician has notified the public health authorities under state law.

STAKEHOLDERS:

- Physicians/clinicians
- Public Health agencies
- Consumers
- Private transportation companies
- Law enforcement

2.12.b. Public Health - Scenario B--Newborn screening

A newborn's screening test comes up positive for a rare genetic disorder and the state lab test results are made available to the child's physicians and specialty care centers specializing in the disorder via an Interactive Voice Response system. The state lab also enters the information in its registry, and tracks the child over time through the child's physicians. The state public health department provides services for this rare genetic disorder and notifies the physician that the child is eligible for those programs. One of the services that the mother uses from the state is regularly purchasing special food products for persons with PKU.

ASSUMPTIONS:

- Parent has consented to sharing of information among clinical care providers.
- The state lab is not considered a clinical care provider.
- Specialty care centers are located within same state.

STAKEHOLDERS:

- Public Health/Medicaid
    - Public Health Lab
- Physicians
- Specialty Care Centers
- Consumers

SPECIFIC QUESTIONS:

- Describe special tracking and reporting of rare diseases you are aware of in our state?

2.12.c Public Health Scenario C--Homeless shelters

A homeless man arrives at a county shelter and is found to be a drug addict and in need of medical care. The person does have a primary provider, and is sent there for the medical care, and is referred to a hospital-affiliated drug treatment clinic for his addiction under a county program. The addiction center must report treatment information back to the county for program reimbursement, and back to the shelter to verify that the person is in treatment. Someone claiming to be a relation of the homeless man requests information from the homeless shelter on all the health services the man has received.

ASSUMPTIONS:

- The man has consented to medical treatment.

STAKEHOLDERS:

- Public Health/County program
- Public/Private Service providers (Homeless shelter)
- Mental health providers (Drug treatment center)
- Community Health Center
- Patient's family
- Consumers

2.12.A. STAKEHOLDERS

Public Agencies

Community Health Center
Law Enforcement

2.12.B. DOMAINS

Information Use and Disclosure Policy

To protect the health of the public, public health authorities might need to obtain information related to the individuals affected by a disease. In certain cases, they might need to contact those affected to determine the cause of the disease to allow for actions to prevent further illness. The Privacy Rule continues to allow for the existing practice of sharing PHI with public health authorities who are authorized by law to collect or receive such information to aid them in their

mission of protecting the health of the public. Examples of such activities include those directed at the reporting of disease or injury, reporting adverse events, reporting births and deaths, and investigating the occurrence and cause of injury and disease.

"Section 507.4 Public Health Activities D General Manual NH" (On file with Julie Ward)
"The Department may disclose protected health information to a person who may have been exposed to a communicable disease or may otherwise be at risk of contracting or spreading a disease or condition, if the department is authorized by law to notify such a person as necessary in the conduct of a public health intervention or investigations"

Information Authorization and Access Controls

The release information to "someone claiming to be a relative of the homeless man" without his written consent would not be allowed. If he has not been declared incompetent, the patient is required to sign the consent for release of his information.

Legal Analysis:

As with Scenario 2, New Hampshire confidentiality provisions specific to substance abuse apply. Patient consent to release information is required. (See Appendix A in previous report)

2.12.C. CRITICAL OBSERVATIONS

New Hampshire operates by town and has a limited number of homeless shelters throughout the state mainly located in the larger cities such as Manchester or Concord. If client needed a referral from a rural site, transportation is an issue and most end up in the closest emergency room.

2.13 STATE GOVERNMENT OVERSIGHT (SCENARIO 18*)*

2.13 Health Oversight: Legal compliance/government accountability

The Governor's office has expressed concern about compliance with immunization and lead screening requirements among low income children who do not receive consistent health care.

The state agencies responsible for public health, child welfare and protective services, Medicaid services, and education are asked to share identifiable patient level health care data on an ongoing basis to determine if the children are getting the healthcare they need. Because of the complexity of the task, the Governor has asked each agency to provide these data to faculty at the state university medical campus who will design a system for integrating and analyzing the data.

ASSUMPTIONS:

- The State University is designated a quasi-state agency and has signed a confidentiality agreement with the State regarding use of data.
- Data will be used to check lead levels and screening rate compliance

STAKEHOLDERS:
Researchers/academic institutions
Public Health/Medicaid/State agencies (Child welfare agencies)
Consumers

2.13.A. STAKEHOLDERS

PUBLIC AGENCIES

Academic Institutions

2.13.B. DOMAINS

INFORMATION USE AND DISCLOSURE POLICY

Requires full research protocol to IRB which outlines data collection and procedures for security and confidentiality. IRB would waive individual consent from subjects based on purpose and level of risk.

INFORMATION AUTHORIZATION AND ACCESS CONTROLS

IRB PROCESS AND PRIVACY RULE.

Legal Analysis:

State law provides that personal medical or other scientific data obtained for the purpose of medical or scientific research by the commissioner of the Department of Health and Human Services or by any person, organization, or agency authorized by the commissioner is confidential and may only be used for medical or scientific purposes. Under the law “data” includes, all information, records of interviews, written reports, statements, notes, memoranda, or other data procured in connection with scientific studies and research conducted by the State Department of Health and Human Services, or by other persons, agencies, or other organizations authorized by the commissioner. Personal medical or other scientific data may not be exhibited, nor may the contents be disclosed except as may be necessary to further the study or research project to which they relate. The person who performs an unauthorized disclosure of any confidential medical or scientific data is guilty of a misdemeanor. (See Appendix A in previous report)

2.13.C. CRITICAL OBSERVATIONS

None

3.0 Summary of Key Findings from the Assessment of Variations Report

- The nature of consent in New Hampshire is an important issue. As noted in the legal analysis of the variations report, it is a critical point that medical records are considered property of the patient. The State of New Hampshire has a long history of the protection of privacy and property rights in general, and it is no different in regard to medical privacy. This approach is codified in state law, and also deeply embedded in the culture of New England independence and personal reserve. The project team does not consider consent to be a barrier, but a best practice and cornerstone to implementing a cross-system information exchange. Essentially, it must be determined how to balance the potential burden of unduly arduous administration of privacy rules and restraints with patient confidentiality and supreme confidence that information is closely guarded in both policy and practice.

- Consumer engagement will be a key element of establishing a successful, interoperable system of medical information exchange. State and federal laws do not provide insurmountable barriers, but addressing consumer perception of the protection of privacy and confidentiality is essential to the long term support and success of the HIT and HIE.

- The policies regarding the protection of patient privacy and security are well-developed and consistent across provider groups. However, it must be acknowledged that there may be inconsistency in field application of corporate policies regarding privacy and security. While most health care providers at a minimum have mandatory training on privacy and security annually, the informal exchange of information is an inevitable part of doing business. Most information exchange is informal as professionals from different organizations work together over a long period of time may not observe the formal implementation of policy. In addition, there may not be complete information given to the patient regarding specific components of consent at the time of a medical encounter; i.e., the administration of consent has the potential to be a rote and meaningless practice.

- New Hampshire has a high penetration of EMR technology and a strong commitment to implementation of a system-wide information exchange. However, the presence of technology produces a challenge of obtaining interoperability and standardized data systems.

4.0 Introduction to Analysis of Solutions Report

As noted previously, New Hampshire did not uncover substantial business and/or legal barriers to health information exchange. As such, the HISPC team worked with several organizations to further understand the current landscape across New Hampshire. This information is important to New Hampshire's bottom- up approach to the development of health information exchange across the state. The following is a summary of a survey conducted by the University of New Hampshire:

A survey of HIT penetration in New Hampshire indicates that as of September 2006 more than 40% of providers have some form of electronic medical record technology available in their practice (see Attachment A in previous report). The challenge remaining for wider implementation of health information exchange between these providers and others is engaging the wider consumer audience in a "layperson" dialogue to understand its benefits and importance. Key findings of this 2006 study, conducted in collaboration with major health insurance providers are as follows:

- Physicians and other health care professionals report being technologically sophisticated personally, but yet many have not fully implemented current technology into their practices.
- A larger percentage of respondents in the 55 and older age group describe themselves as unsophisticated computer users, compared to those in the younger age groups.
- Forty-six percent of respondents report using Electronic Health Records (EHR's). Of those, 43% have used them for 3 years or less.
- There is a significant relationship between users' level of sophistication in computer use and whether or not their practice has an EHR: 63% of very sophisticated computer users report having an EHR, compared to just 8% of much unsophisticated users.
- Eighty-two percent (82%) of practices with an EHR say they can easily or very easily generate a patient list based on a diagnosis or health risk, compared to just 45% of practices without an EHR.
- Only 16% of respondents report using technology assisted disease management.
- Although 45% of physicians and other patient care givers have PDA technology, 69% do not currently use the technology in their practice.

- Providers are particularly hesitant to use technology with patients. Currently, 70% do not use e-mail to communicate with their patients, and 42% are resistant to patients having access to their medical record. Others (41%) are open to the idea, likely dependent on level of access and function.
- The biggest barrier reported to increased use and adoption of EHR was the upfront cost of the hardware and software.
- Despite low adoption and mixed use, two-thirds of physicians and other patient care givers reported high levels of satisfaction with the current level and use of technology in their respective offices (79%).

5.0 Review of State Solution Identification and Selection Process

Given that there are no legal or business practice barriers to exchange in New Hampshire, this project focused primarily on assessing the barriers presented by consumer engagement and consent issues. Those were defined through a continuing consumer engagement process.

Consumer Engagement Phase

The consumer engagement phase of New Hampshire's HISPC process continues with additional focus groups completed and other groups being organized. In addition to the initial group that was organized in Concord, and summarized in the last report, two additional groups were held in North Conway and Portsmouth NH, on March 14th and 15th respectively. Recruitment in the more rural areas of the state has proven more difficult, and has necessitated more targeted efforts. In addition to the measures used to obtain broad based input for the earlier groups, we have also run ads in targeted local papers and turned to other local agencies to assist in recruiting for the final groups. The screening forms continue to be completed and returned by phone, fax, mail, or on-line. We anticipate completing 1-2 additional groups before competing the consumer focus group phase of the project and summarizing the findings overall. All focus groups have been completed within the 90 minute timeframe allotted, following a 30 minute orientation to the concepts that comprise electronic and interoperable health records.

The focus group moderator's guide (Appendix C of the previous report) has proven an effective means of structuring the consumer conversations and eliciting insights from consumers. As noted previously, the questions focus on the way potential changes will be viewed and experienced from the consumer's perspective, with a focus on how promoting their interests can be a key factor in facilitating adoption of the technology. Topics focus on what degree of

ownership consumers feel in their medical record information, how much control they desire, how much effort they are willing to expend, and how they expect they will identify the benefits (both personal and at the broader system level) of the new technology.

The results of all focus groups will be summarized in detail once the final group(s) is completed. Preliminary themes, elucidated from the three groups completed thus far, are outlined below.

- General acknowledgement that the move towards the new medical information technology was inevitable and that it will change how your information is stored even if you don't take advantage of the options
- Some of the risks (such as hackers) were present even if you 'opt out' of sharing, etc. so consumers should be engaged even if they don't advocate the technology
    - Some concerns about need for internet access and technology comfort to take advantage (elderly, poor).
- Frame of Reference
    - The comparison to on-line banking yielded a range of responses. The comments generally elicited information about the decision making process around new technology, adoption and trust.
    - Some felt that the online banking system was considerably simpler in terms of the type of information involved and the ability to control it. One person stated with regard to electronic medical information transfer (paraphrased), "We are not the customer in this system, and we are the money".
    - Some discussed existing systems, like the ability to get a prescription at any CVS in the country, as an example of how this could be functional and beneficial.
    - Some saw Google as an analogy to finding out everything about someone easily. Some saw this as a positive (in terms of access to information), others saw it as an example of what's potentially wrong
    - Most agreed that they would need to know much more about a system before they could decide if they would participate in it – Consumer education in terms they can understand was cited.
- Ownership of medical record was a complex issue. There was a clear sense that the patient SHOULD be the owner, but also sense that this currently is not the general practice or understanding

- Patients barred from reading their record or charged to get copies. Sense that you had to 'fight' to see it and that there was not much control over what happens to your record currently.
- Sense that the technology could potentially improve the ability to see and control the record, but that this places new responsibility on the patient.
- Some noted that there were parts of the medical record that the provider may want/need to track but not share with the patient – such as suspicions of alcohol or drug use (side notes to the record)
- Ability to easily see the medical record was a strong positive for most people, even if they had not wanted to review it in the past. This impacted a variety of areas beyond ownership, including accuracy, trust, control, etc.
- The issue of whether the average person can effectively read/interpret their medical record was also raised. Also, there was a sense that there was no process for a dialogue with the provider or for correcting perceived mistakes in the information.

- Some skepticism that technology will lead to a better interaction with the provider.
  - Concern that the electronic record will take the place of interaction with the patient – sense that the record can't fully represent the patient and that more information will mean more time for the provider with the record and not the patient
  - Some had already experienced situations where provider focused on a computer screen without interacting with the patient – perceived as negative even if all the information was there
  - Sense that there may be too much information and that the computer screen will get in the way of the provider actually reading all of it
  - Fear that it will benefit insurance companies or that it would be used to restrict care
  - Positive comment on provider patient interaction would be that providers might have to be more up front with patients if they knew the patient could review the record.
- Patient experience of benefits from the system
  - Most felt that the idea of having the information available if it was needed (i.e. in an emergency) was a strong positive. Preventing drug interactions or missing key diagnoses was commonly cited.
  - Ability to see, check, and even 'annotate' (but not change) your medical information was considered beneficial for those interested in doing so.
  - Software should do more than store a paper record – it should help prioritize and organize the information so the doctor sees what's relevant

- Generally if it is perceived as improving the quality or time with the provider it's a positive, if it places greater distance between the patient and provider it is perceived as negative
- Sense that using it for public health monitoring or medical research would be a good thing at the 'societal' level. Many felt that this must be 'de-identified' information … not able to be traced to a specific person.
- Strong sense that the system needs to be 'universal' to be beneficial – want their information available in other states/countries if they have an emergency. Several stated that the worst scenario was that it was partial so that you didn't know what was there and what wasn't and you couldn't count on it or you needed to repeat all the information anyway.
- Sense that it could lower costs if you are uninsured – not clear if it would lower costs for others
- Expectation that cost savings should accrue to the consumer – much skepticism that it would benefit the insurers only. One respondent felt that premiums or co-pays should be lowered if you share, but that you would have the option to pay more and not share.
- Benefits were considered a potential 'piece' of the puzzle in solving issues in health care but should be careful not to over-sell the role.

- Exercise of rights over privacy and sharing
  - Clear sense that the insurance companies and pharmaceutical companies should not be allowed to see the information. Don't want it used to make decisions to limit care or market drugs/treatments. Don't want it used for marketing.
  - Patients want a great deal of specificity of control over the record in terms of what is shared, with who, when, etc. This included diagnoses, medications, treatments, etc. There was a clear demand for the ability to 'opt out' but a simple yes/no was not sufficient. "It's not an all or nothing decision."
  - Participants wanted to be able to change their choices regarding authorization at any time – not just when they are at the provider's office. Some envisioned an internet-form type of screen where you could change your choices regarding authorization, etc.
  - Participants liked the idea of being able to move any of their information into a 'private' folder where it would not be shared with others. They acknowledged that they were responsible for any problems that caused in their treatment.

- Some felt they were not qualified to understand the clinical implications of hiding some of their information – felt that their provider should help in making those decisions but that the risk was ultimately theirs.
- Large variation in terms of what or how much each participant would restrict – ranged from full access to full sequestering. Much seemed to depend on trust (or lack thereof) in one's provider to make appropriate use of your information, and trust in technology in general.
- There was a clear dividing line between clinical and 'non-clinical' sharing (i.e., insurers, employers, schools, etc), with greater caution on the latter. Some cited patients currently paying out of pocket for mental health to avoid having the record in the insurance system.
- Recent changes to the government's ability to access information (Patriot Act) were cited by one participant as a factor that had soured his opinion of security and openness in terms of sharing information.

- A variety of factors were mentioned in terms of lowering the threshold for trusting the system and agreeing to participate
  - Ability to see data and have an audit trail of who had access was strong positive factors for many. Fewer, but some, expressed the desire to be asked before the data was shared each time.
  - Word of mouth (regarding the benefits and security) was the most commonly cited reason for adopting new technology. Many wasted for others to try it first.
  - Many wanted to 'test out' the system. One participant had done this with online banking, using a small amount of money in an account so see if she could 'mess it up'.
  - Patients wanted control over what organizations could see the information, but most wanted the provider to be responsible for assuring that the data was not released improperly.
- Structurally participants didn't care specifically where or how the information was stored – the real issue was how well the system was programmed in terms of finding the information when needed, providing control and access to the patient, and protecting the information from unauthorized use.
  - Those most concerned about security wanted personal control (carrying a chip, etc) as opposed to data sent over a network, internet, etc.
- Consumer Driven Adoption:

- When asked, many participants stated that they could see themselves choosing a provider based on whether they were participating in a data sharing system, however they were split about whether it would be a positive or negative factor in that decision.
- Cost-benefit was acknowledged by many in terms of whether they felt the benefits outweighed the risks.

We will further explore these themes in the additional focus groups to be conducted. The full findings from these groups will be integrated into the final report.

At present it has been determined that convening a Consumer Working Group would be premature at this time, as the group would not have specific options to review or comment on in terms of solutions or changes to the system. It was, however, determined that there needs to be a process for sharing the consumer perspective with the other stakeholders in the system, such that their needs can be integrated into the individual efforts currently being pursued. It was determined that the results of the consumer focus groups would be developed into a presentation to be shared at a meeting of the other 'system level' stakeholders in the state. This venue would provide the ability for those responsible for policy and organizational behavior to consider whether the processes they are adopting are consistent with what was gleaned in terms of consumer driven adoption of the technology and lend itself to activities developed during implementation planning.

With respect to implementation, the Legal Working Group will analyze results from consumer focus groups which will be provided in the final report. In addition, the group has identified potential New Hampshire bills in the 2007 legislative session that may have impact on health information exchange, include bills relative to:

- Requiring proposed bills and rules to include an analysis of their impact on personal privacy
- Access to confidential patient information
- Personal health and financial information privacy
- Establishing a committee to study a constitutional amendment to guarantee a right to personal privacy
- Electronic prescribing for prescription drugs
- An electronic controlled drug prescription monitoring program

- Advertisement of prescription drugs and establishing the pharmaceutical marketing disclosure law
- Notification by pharmacies to consumers when prescriptions need to be renewed
- Access to certain business records
- Establishing a health care fund, continually appropriating a special fund, and requiring certain employers to report certain information to the department of health and human services
- A commission to study establishing a statewide emergency communication system
- School emergency response plans
- Prohibiting unauthorized disclosure of social security numbers
- The office of information technology
- The powers of state government in the event of an incident or outbreak of communicable disease
- Exceptions to the confidentiality provisions for certain department of employment security records

6.0 Analysis of Proposed State Solutions

Health information exchange activities in New Hampshire are only now entering the planning phases. This has been purposeful as stakeholders expressed desire to develop a firm concept of what HIE would be and a vision and set of principals for participation. This project was especially important in assessing those related to privacy and security. Given consumer input, it is clear that consumers need to be engaged on two levels. One is that there needs to be clarity and synthesis of what consent means, primarily in the form of a uniform consent document. Second, any specific solutions will be directed at tangible exchange scenarios yet to be developed. Thus, the project team will be integrating the HISPC reporting outcomes and implementation phase with the priority of the NH Citizen's Health Initiative to implement several electronic health technology initiatives. The Citizen's Initiative, at the direction of the governor's office, has requested that the New Hampshire Institute of Health Policy and Practice at the University of New Hampshire develop a statewide HIT/HIE strategic plan. The following are the mission and priority of the planning team:

- To develop a vision statement for health information exchange in New Hampshire.
- To assess and insure national standards adoption for HIT for participation of HIE in NH.
- To assess and develop a sustainable business plan for HIE in NH.
- To develop a marketing and education approach for providers and publics around HIE.
- To develop and implement a pilot exchange project involving at least 3 distinct stakeholders in the NH health care community (such as health center, hospital, lab, pharmacy, etc)

Within this context and specific to the HISPC component, the solutions report identified the need to both understand in more detail the nature of consumer understanding and support around HIT/HIE and to integrate this with the creation of a standardized and simplified consent form. Such a form would need to be developed with the participation of consumers, providers, employers, and with legislative input. It would also need to be aligned with the medical record property rights of consumers. To complete this phase of work, a Consumer Engagement and Consent project is outlined below. Specific details of the work breakdown structure will be included in the final implementation report.

Key Workgroups:

Steering Committee (Consumer Working Group from the HISPC project)

Privacy Stakeholder Group (membership from HISPC implementation working group and others)

Citizen's Health Initiative membership (multi-stakeholder group from which all HISPC groups were formed) representing providers, business, consumers, and legislators, to serve as final evaluators of project deliverable

Major Work Tasks:

Consumer Focus Groups

Consumer Statewide Survey

Interim and Final Consumer Privacy and Security Report

Development of Unified/Standard Consent Form in conjunction with national efforts

Development of Marketing and Education Plan for Consent Form Implementation

Implementation Plan

The work for this project, begun under the HISPC project, will commence May 1, 2007 and extend until April 30, 2008. It will examine the creation of a unified consent form for statewide health information exchange, but also regional health information exchange as well as adhere to any national consent standards that are developed. It will integrate with the NH Connects for Health project which is developing a statewide strategic plan for HIE, as well as promoting the proliferation and use of both electronic medical records and electronic prescribing technology statewide, and is coordinating exchange efforts regionally with Vermont and potentially other neighbor states.

7.0 National-level Recommendations

State Recommendations – Uniform Consent Form

HIPAA clarification is needed and development of a uniform privacy and security act may be beneficial, including a uniform consent form. However, current New Hampshire policy, as well as consumer and provider input, should be reflected in laws adopted by the State Legislature and the final format of the uniform form if adopted in New Hampshire.

In New Hampshire, the uniform consent form should clearly reflect: the patient's property right in the medical record; provider confidentiality principles; and exclusive State legislative authority to determine consent policy. The form should address: general consent requirements; consent principles relative to condition-specific consent requirements; inter-state information exchange; information exchange with payers and employers; use of information for marketing; and waivers of consent when the patient's life is at risk and in public health emergencies. Information on these matters, relative to patient rights, should also be available to the consumer so that the consumer may make an informed decision relative to consent for health information exchange. The uniform consent form would ideally be modeled after health care directives, in that it would be a documented in the medical record, as well as presented and carried by patients with them from one provider to another.

8.0 Conclusions and Next Steps

Summary:

Key to implementation of health information exchange in New Hampshire is the understanding by the individual that they legally own their medical record. This puts obvious parameters on any exchange system from confidentiality and consent perspectives, and places the individual (here-in termed consumer) at the center of all solution and implementation activities. Business practices were found to present no formal barriers to the exchange of personal health information. That realized, and common to both business practice and consumer engagement, is the need to have a simplified and well understood process of consent. This is not inconsistent from findings in other states, and so key to the solutions developed through this project is the creation of such a systematic consent policy, whether done within New Hampshire or in conjunction with national efforts. Such efforts were being considered as of the national program meeting in March of 2007. Overall, consumers were found to be supportive of exchange, but interested that their records be kept secure in a trusted environment, and were positive that they would be able exercise input into the process.

Next steps:

Beginning in May of 2007, the project team will be integrating the HISPC reporting outcomes and implementation phase with the priorities of the NH Citizen's Health Initiative to implement several electronic health technology initiatives. The Citizen's Initiative, at the direction of the governor's office, has requested that the New Hampshire Institute of Health Policy and Practice at the University of New Hampshire develop a statewide HIT/HIE strategic plan. The following are the priorities of the planning team:

- To develop a vision statement for health information exchange in New Hampshire.
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HIT/HIE and to integrate this with the creation of a standardized and simplified consent form. Such a form would need to be developed with the participation of consumers, providers, employers, and with legislative input. It would also need to be aligned with the medical record property rights of consumers. To complete this phase of work, a Consumer Engagement and Consent project will be developed to include activities (3) that will mirror the specific exchange activities defined in the pilot (5), in keeping with the vision (1) and principles developed (2). Specific details of the work breakdown structure will be included in the final implementation report.

Projected Key Workgroups:

Steering Committee (Consumer Working Group from the HISPC project)

Privacy Stakeholder Group (membership from HISPC implementation working group and others)

Citizen's Health Initiative membership (multi-stakeholder group from which all HISPC groups were formed) representing providers, business, consumers, and legislators, to serve as final evaluators of project deliverable

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