

# HISPC II

The Nebraska Health Information Security and Privacy Committee II Workgroup

## **Phase Two**

### **Summary Report January 1 to December 31, 2008**

**February 2009**

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## HISPC II WORKGROUP MEMBERS

The HISPC II workgroup of the eHealth Council (as directed by the Nebraska Information Technology Commission (NITC)) is made up of individuals who have an interest in health information security and privacy. This diverse group brings many backgrounds and points of view together to review, discuss important issues related to this topic, and provide guidance to the public of the State of Nebraska.

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## **EXECUTIVE SUMMARY**

The Nebraska Health Information Security and Privacy Committee II Workgroup (HISPC II) was originally formed by Lieutenant Governor Rick Sheehy in 2005. The HISPC II Workgroup became a workgroup of the Nebraska Information Technology Commission (NITC) eHealth Council in January 2007. The workgroup is made up of a diverse group of individuals with an interest in health information security and privacy. The HISPC II workgroup realized the need for cross-collaboration and learning from the wide range of experts participating in studies completed by the original HISPC. Specific concepts were developed by the workgroup and used to guide the interactions and action item development.

### **Vision Statement – Workgroup is a Learning Community**

The workgroup will function as a learning community about health information technology and its uses; created and nurtured by a broad collaboration that shares knowledge widely, focused on creating a health information flow that is visible and understandable to all citizens, research-based and community appropriate, credible and focused on essentials, and provides a blueprint for improvement.

### **Guiding Values**

- ◆ We believe that each citizen owns his or her own personal health information and should be provided a reasonable opportunity and capability to make informed decisions about the collection, use, and disclosure of their individually identifiable health information beyond that permitted by law for treatment, payment, operations and public health reporting purposes.
- ◆ We believe that citizens should be involved in and partner with the designers of all health models, electronic health models, and with the devised distribution plans for these models.
- ◆ We believe in citizen involvement with the HISPC workgroup, their committees, and with other key stakeholders in the work to design a process for the creation of a health information exchange structure that maintains security and privacy of their health records.
- ◆ We believe that citizens, their health care providers, and other stakeholder organizations should be working in partnership/collaboration to ensure a statewide, interoperable, health care environment.

### **Activities of the HISPC II Workgroup**

Consumer involvement is commonly identified as a key element in the development of health information exchange. The National eHealth Initiative identified focusing on consumers as one of six common principles for effective health information exchanges. The eHealth Initiative recommends that health information exchanges enable consumers to make informed choices and address health information security and privacy needs of consumers. It is this concept that governs the two key work areas: consumer education and issues in security and privacy.

During 2008 the HISPC II workgroup formed the legal committee to complete an in-depth study of existing laws and regulations and an education committee to address the need for health information security and privacy education. As part of this work two projects were funded through the Nebraska Information Technology Council (NITC) in June of 2008. These projects included:

- ◆ Health Information Security and Privacy Consumer Education
- ◆ Health Information Privacy and Security Website.

Additionally, Nebraska participated in a multi-state collaborative project to address authentication and audit requirements as part of the national Health Information Security and Privacy Collaborative.

By focusing on consumer education as a priority this workgroup continues to move forward in developing educational materials for consumers regarding health information exchange as well as related privacy and security concerns. To aid in consumer education the HISPC II Workgroup Education Committee identified a list of references for consumers and providers (Appendix A – HISPC II Education Resources). Several members of the HISPC II Work Group were also involved in a Deliberative Discussion on Sharing Health Information Electronically. The Deliberative Discussion, facilitated by the University of Nebraska Public Policy Center, found that Nebraska consumers generally have positive views toward sharing health information electronically, although they do have some concerns about health information security and privacy.

In addition to the consumer education component, the HISPC II Workgroup Legal Committee completed an in-depth study of existing laws and regulations, with the guidance from representatives from health professions, health educators and health organizations to develop solutions on how to overcome barriers. The committee also assessed areas where confusion may exist about whether health information disclosure is permissible. The committee offers several recommendations to facilitate electronic health information exchange across the state of Nebraska:

## **Recommendations and Actions**

### **Education Committee**

Recommendations and future actions of the Education Committee include:

- ◆ Completion and sustainability of the Health Information Privacy and Security website
- ◆ Development of consumer materials
- ◆ Continued work to add education materials to the website which will be operational by late spring 2009
- ◆ Identify and/or create mechanisms for consumer engagement statewide with use of these materials. Two major foci are to assist consumers with
  - Personal health management
  - Involvement in ongoing public policy development

## Legal Committee

### Recommendations and future actions of the Legal Committee include:

Neb. Rev. Stat. 71-8401: Authorizations for Release of Information are valid for a maximum period of 180 days after date of execution. Health Insurance Portability and Accountability Act (HIPAA) permits the individual to state an expiration date or expiration event, providing the individual with greater access and disclosure rights over their protected health information.

1. Recommendation: Delete the 180-day restriction from Nebraska statute, so statute is silent, permitting the individual to determine the length of the time the authorization is valid. This change in law would eliminate the necessity for individuals to sign authorizations multiple times for continued release of information.

Action: HISPC II representatives met with staff of the Governor's Policy Research Office to discuss the 180-day restriction. Initial discussions were held with the Nebraska Medical Association (NMA) Executive Vice President and legal counsel about the potential for including the proposed revision to the authorization statute in legislation NMA planned to sponsor. However, the Department of Health and Human Services clean up bill (LB288) was deemed to be a better fit. An amendment was proposed at the hearing before the Health and Human Services Committee on Jan. 28, 2009.

2. Recommendation: Obtain feedback from the Nebraska Psychiatric Association about recommending a change to Nebraska law to be consistent with HIPAA standards. Since HIPAA provides the individual with greater rights of access, it preempts Nebraska law. Changing Nebraska law would eliminate confusion and reduce HIPAA violations when access is denied for improper reasons.
3. Recommendation: Create a model authorization, similar to the Nebraska Strategic National Implementation Process (NE SNIP) authorization contained in the Nebraska Health Information Management Association (NHIMA) Guide, to facilitate disclosure of health information. If Nebraska Department of Health and Human Services (NE DHHS) identified the form as meeting relevant regulations, then the form may be widely used and accepted. The model authorization could be placed on the eHealth Health Information Security and Privacy Committee website being developed. The model authorization could be amended if the 180 day restriction is subsequently eliminated through legislation.

Action: At the 2008 NHIMA conference on September 11, 2008 attendees were asked if a written model authorization form, supported by the eHealth Council, similar to the authorization created by the NE SNIP group and contained in the NHIMA Guide would be helpful. Sixteen attendees responded. Fifteen participants thought a standard form would be helpful. One respondent was not sure.

4. Recommendation: Identify additional ways this change can be publicized to health care professionals, such as placement on the eHealth Health Information Security and Privacy Committee website as an Frequently Asked Questions (FAQ), and communication to Nebraska health care professional associations.
5. Recommendation: The HISPC II committee will obtain a legal opinion describing how sensitive information may be used and disclosed. The HISPC II will use the legal opinion to create educational materials for Nebraska providers.

## BACKGROUND

The Nebraska Health Information Security and Privacy Workgroup Phase 2 (HISPC II) was formed by the eHealth Council based on recommendations from the original 2006-2007 Health Information Security and Privacy Committee (HISPC). These recommendations were from studies completed during 2007 by surveying Nebraska:

- ◆ Health/Licensure/Certification and Facilities Oversight Board Managers
- ◆ Health Professions Organizations Leadership
- ◆ Consumers

The *Security and Privacy Barriers to Health Information Interoperability* Reports generated by the first Health Information Security and Privacy Committee (HISPC) can be found on the Creighton Health Services Research Program (CHRP) website: <http://chrp.creighton.edu>.

The HISPC II Workgroup was tasked with completing an in-depth study of existing laws and regulations, with the guidance from representatives from health professions, health educators and health organizations to develop solutions on how to overcome the barriers determined in finding 5 of the *Security and Privacy Barriers to Health Information Interoperability Recommendations and Summary: Final Report for the state of Nebraska June 2007* report:

**Finding 5:** Our HISPC study of security and privacy issues is consistent with the same concerns and areas of work needing to be addressed within our state and its communities as a most recent cross-sectional study of the nation revealed.<sup>1</sup> The issues are embedded in complexity and confusion associated with state and federal level inconsistencies, conflicting business practices, and varying consent policies and approaches. These issues must be untangled and addressed. This will require a sustained commitment to achieve.

### **Recommendation:**

- ◆ **The e-Health Council should explore the development of a sustainable system for monitoring our progress in studying and addressing the security and privacy issues within the state of Nebraska.**
- ◆ **An in-depth study of existing laws and regulations, with guidance from representatives from health professions, health educators and health organizations is needed to develop solutions on how to overcome these barriers.**

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<sup>1</sup>Dimitropoulos, L.L. Interim assessment of variation: privacy and security solutions for interoperable health information exchange. December 29, 2006. RTI Project No. 0209825.000.004.002. RTI International, Chicago, Illinois. (ref. 16)

<sup>2</sup> Health Information Security and Privacy Committee State of Nebraska. *Security and Privacy Barriers to Health Information Interoperability Recommendations and Summary: Final Report for the state of Nebraska June 2007*: pp 4-5.

The workgroup was also tasked to address the need for health information security and privacy education determined in finding 6 of the *Security and Privacy Barriers to Health Information Interoperability Recommendations and Summary: Final Report for the state of Nebraska June 2007* report:

**Finding 6:** Based on the three research reports from this committee and our discussions, we believe there is a need for further research needed about implications to consumers, health professionals, health systems, educators, private and public care providers, and payers. Examples of important research questions that the committee has thought about, but are not limited to include:

- ◆ How are consumer's health and safety outcomes affected by the sharing of health information?
- ◆ What processes are necessary for consumers to participate in the sharing of health information?
- ◆ How will consumers concerns about the risks they perceive with health information sharing be "stewarded" as the processes emerge, and who will "steward" them?
- ◆ How are small business health care providers, health systems and large health care organizations, affected by the impact of sharing health information: What is the impact on workload? What is the impact on workforce considerations?
- ◆ How will the educational needs of the young, middle age, young-old and old-old adults be met as these processes develop?
- ◆ What is the impact of a partial adoption of health information sharing on patient security and privacy?

**Recommendation:**

- ◆ **The NHHS should pursue further research in the area of how to obtain needed technical information and employ effective processes of applying this information to assist health boards and facility boards with the ongoing process of staying current in and facilitating adoption of future rules and regulations that advance secure, private health information and interoperability approaches.**
- ◆ **Further research should be conducted by professional organizations about the on-going impact of health information and exchange and interoperability on provider and patient security and privacy issues.**
- ◆ **Further research should be conducted to better understand consumer viewpoints and needs.<sup>3</sup>**

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<sup>3</sup> Health Information Security and Privacy Committee State of Nebraska. *Security and Privacy Barriers to Health Information Interoperability Recommendations and Summary: Final Report for the state of Nebraska June 2007*: p 5.

## **2008 – 2009 HISPC II WORKGROUP DEVELOPMENT**

During 2008 the workgroup developed:

- ◆ Process – Organizational Principles to guide the workgroup
- ◆ Vision and Mission Statement Concepts for the HIT Learning Community
- ◆ Values to guide the workgroup
- ◆ Action Items

Two committees were formed to accomplish the tasks given the workgroup:

- ◆ Legal
- ◆ Education

Two funded projects were developed by the HISPC II Workgroup to facilitate the workgroup actions, gaining approval from the Nebraska Information Technology Council (NITC) in June of 2008.

- ◆ Health Information Security and Privacy Consumer Education
- ◆ Health Information Privacy and Security Website

As a direct result of the HISPC II workgroup a health information security and privacy website is being developed which will include resources for both consumers and providers. An extensive list of health information security and privacy resources has been compiled. Links to many of these resources will be available from the website. The website will be operational by late spring or early summer 2009. The development of the website is being funded by a grant from the Nebraska Information Technology Commission Community Technology fund.

For additional information on the process see pages 17 to 30 of this report.

## LEGAL COMMITTEE FINAL REPORT

The Nebraska Health Information Security & Privacy (HISPC) II Legal committee conducted a review of Nebraska laws related to health information disclosure to identify laws that may be a barrier to electronic health exchange. The committee also assessed areas where confusion may exist about whether health information disclosure is permissible. The committee offers several recommendations to facilitate electronic health information exchange across the state of Nebraska.

The committee utilized the 2006 Nebraska Health Information Management Association “Guide for Privacy, Retention and Disclosure of Health Information in Nebraska” as a resource to analyze laws related to health information disclosure. Committee members identified Nebraska laws requiring written individual authorization for disclosure of information when federal Health Insurance Portability and Accountability Act (HIPAA) laws do not. The committee also identified areas where confusion about disclosure rules exists. Additional education and clarification of disclosure rules to the health care community may facilitate electronic health information exchange in these areas.

The following Nebraska laws create potential barriers to electronic health exchange in Nebraska and should be considered for amendment.

### **Access to Medical Records**

Neb. Rev. Stat. 71-8401: Authorizations for Release of Information are valid for a maximum period of 180 days after date of execution. HIPAA permits the individual to state an expiration date or expiration event, providing the individual with greater access and disclosure rights over their protected health information.

Recommendation: Delete the 180-day restriction from Nebraska statute, so statute is silent, permitting the individual to determine the length of the time the authorization is valid. This change in law would eliminate the necessity for individuals to sign authorizations multiple times for continued release of information.

Action: HISPC II representatives met with staff of the Governor’s Policy Research Office to discuss the 180-day restriction. Initial discussions were held with the Nebraska Medical Association (NMA) Executive Vice President and legal counsel about the potential for including the proposed revision to the authorization statute in legislation NMA planned to sponsor. However, the Department of Health and Human Services clean up bill (LB288) was deemed to be a better fit. An amendment was proposed at the hearing before the Health and Human Services Committee on Jan. 28, 2009.

Neb. Rev. Stat. 71-8403: Designated mental health professionals may deny access to medical records if the provider determines it is not in the best interests of the patient. Under HIPAA, access can be denied only if the access requested is reasonably likely to endanger the life or physical safety of the individual or another person. (45 CFR 164.524(b)(2))

Recommendation: Obtain feedback from the Nebraska Psychiatric Association about recommending a change to Nebraska law to be consistent with HIPAA standards. Since HIPAA provides the individual with greater rights of access, it preempts Nebraska law.

Changing Nebraska law would eliminate confusion and reduce HIPAA violations when access is denied for improper reasons.

Model Authorization form. HIPAA contains several required elements for a valid authorization. As a result, some authorizations received by covered entities are not complete and must be returned. Also, some covered entities will not accept authorizations from other organizations.

Recommendation: Create a model authorization, similar to the Nebraska Strategic National Implementation Process (NE SNIP) authorization contained in the Nebraska Health Information Management Association (NHIMA) Guide, to facilitate disclosure of health information. If Nebraska Department of Health and Human Services (NE DHHS) identified the form as meeting relevant regulations, then the form may be widely used and accepted. The model authorization could be placed on the eHealth Health Information Security and Privacy Committee website being developed. The model authorization could be amended if the 180 day restriction is subsequently eliminated through legislation.

At the 2008 NHIMA conference on September 11, 2008 attendees were asked if a written model authorization form, supported by the eHealth Council, similar to the authorization created by the NE SNIP group and contained in the NHIMA Guide would be helpful. Sixteen attendees responded. Fifteen participants thought a standard form would be helpful. One respondent was not sure.

### **Professional Licensing Statutes**

Current Nebraska professional licensing statutes at Neb. Rev. Stat. 38-179(8) contain a definition of “unprofessional conduct” with several examples. One of the examples is “knowingly disclosing confidential information except as otherwise required by law.” Effective December 1, 2008, the language will be changed to read “knowing disclosing confidential information except as otherwise permitted by law.” This licensing statute change should facilitate health information exchange because several categories of disclosure of confidential information are permissible under HIPAA, but not required. Health care professionals will no longer be concerned that they could be engaging in unprofessional conduct if they disclose confidential information for permissible purposes (for example, to another health care provider treating the patient without written patient authorization).

Recommendation: Identify additional ways this change can be publicized to health care professionals, such as placement on the eHealth Health Information Security and Privacy Committee website as an Frequently Asked Questions (FAQ), and communication to Nebraska health care professional associations.

### **Disclosures Mandated for Public Health/Health Care Oversight Purposes**

The committee reviewed Nebraska laws related to disclosure of protected health information for public health and health care oversight purposes, including but not limited to disclosures to disease registries, reporting of health screening results, health care licensure laws, abuse reporting, and vital records. The Nebraska statutes clearly state reporting requirements, and often provide immunity to reporters of information against specific claims. These statutes facilitate health information exchange and the committee does not have any recommendations for change.

## **Areas Where Confusion May Exist**

The committee identified areas where confusion may exist among health care providers about whether or not protected health information may be disclosed, and under what circumstances. While the committee does not believe proposed amendments to state laws are needed, additional education to the health care community would be beneficial to facilitate health care exchange in these areas.

## **Personal Representatives**

HIPAA permits personal representatives of the individual to have access to the individuals protected health information. Health care providers often have questions about who is the personal representative, and under what circumstances. Questions arise about who is the guardian of minor patients, especially in divorce and foster care situations; durable power of attorney for health care; and access to deceased patient information.

*Release of “sensitive information” such as HIV and mental health information.* There are differing standards among health care providers and facilities about release of sensitive information. For example, Nebraska HIV testing statutes limit information disclosure, but the statutes do not extend to any HIV information. Inpatient behavioral health records have a heightened privacy requirements for disclosure but outpatient behavioral health records do not under state law.

*Minors.* Clarify circumstances under which minors can consent on their own behalf for treatment. Under these circumstances, the minor’s personal representative does not have access to the minor’s Personal Health Information (PHI) related to the care received within the scope of the minor’s consent. Under Nebraska law, minors can consent on their own behalf for sexually transmitted diseases (STD) testing and treatment only. Prior to 2006, minors could consent on their own behalf for substance abuse testing and treatment, but the law was changed. Minors cannot consent on their own behalf for pregnancy testing and pregnancy-related care.

*Disclosures for law enforcement purposes.* HIPAA provides several categories of disclosures to law enforcement, when Nebraska law is silent. Health care providers should generally follow HIPAA. The committee has no recommendations for statutory changes in this area, but believes additional education to the health care community would be beneficial.

Recommendation: The HISPC II committee will obtain a legal opinion describing how sensitive information may be used and disclosed. The HISPC II will use the legal opinion to create educational materials for Nebraska providers.

## **Additional Research on Special Health Records**

A legal review specific to mental health, behavioral health and genetic information on electronic medical records was requested. This review would help determine any state laws, regulations or statutes that address those specific areas. This is an area that was not specifically covered in previous legal reviews, and it is an area of national concern related to privacy and security of electronic medical records. We hope to learn of barriers, on no barriers, and recommendations to make Nebraska laws, regulations and statutes consistent with other states yet protect Nebraska's citizens. The findings will be reported out as part of our final work with HISPC III and passed to

the standing HISPC committee and the eHealth Council for disposition. We anticipate a short contract and short work period due to limited focus. We expect to complete this work before March 31, 2009.

### **Members of the HISPC II Legal Committee**

- ◆ Sheila A. Wrobel, Chief Compliance/Privacy Officer, UNMC; Chair
- ◆ Charlene Dunbar, MBA, RHIA, Director of Health Information, Nebraska Heart Institute Hospital
- ◆ David Lawton, eHealth Coordinator, Public Health Informatics/Community Health Planning, Nebraska Department of Health and Human Services
- ◆ Dennis Berens, Director, Nebraska Office of Rural Health, Nebraska Department of Health and Human Services
- ◆ Joseph Acierno, M.D., Deputy Chief Medical Officer, Nebraska Department of Health and Human Services
- ◆ Kimberly A. Galt, PharmD., Associate Dean, Creighton University SPAHP
- ◆ Joni Cover, Executive Vice President, Nebraska Pharmacists Association
- ◆ Roger Brink, Legal Counsel, Nebraska Department of Health and Human Services
- ◆ Ron Hoffman, RHU, Enterprise Privacy Office, Mutual of Omaha Insurance Company
- ◆ Kim Hazelton, MA, RHIA, President, Nebraska Health Information Management Association

## EDUCATION COMMITTEE FINAL REPORT

The Nebraska Health Information Security and Privacy Education Committee was formed to respond to finding six (6) of the *Security and Privacy Barriers to Health Information Interoperability Recommendations and Summary: Final Report for the state of Nebraska* Report published in June, 2007 (Available at: [http://chrp.creighton.edu/Documents/Final\\_HISPC\\_Report\\_Recommendations\\_Summary.pdf](http://chrp.creighton.edu/Documents/Final_HISPC_Report_Recommendations_Summary.pdf).) Specifically, the Education Committee was charged to address the need for health information security and privacy education.

The HISPC II Education Committee reviewed educational resources available from federal, state and private organizations. These resources included documents, toolkits and videos, all of which were available on the World Wide Web. Topic areas included personal health records, e-prescribing, privacy and security, and health information exchange. An evaluation of each of these resources resulted in a listing, HISPC II Educational Resources - 2009.

### Outcomes

- ◆ Created a list of security and privacy references for consumers and providers
  - **Appendix A: HISPC II Educational Resources - 2009**
- ◆ Secured funding from the Nebraska Information Technology Commission (NITC) Community Technology Fund to develop educational resources which will be included on the Health Information Privacy and Security Committee website. In addition, the project will include funding for a brochure and a card promoting the Health Information Privacy and Security Committee website.
- ◆ Collaborated with the University of Nebraska Public Policy Center on a Deliberative Discussion on Electronic Health Records which was funded by the NITC upon recommendation of the eHealth Council.
  - **Appendix B: Sharing Health Records Electronically: The Views of Nebraskans - 2009**

### Future Actions

- ◆ Completion and sustainability of the Health Information Privacy and Security website
- ◆ Development of consumer materials
- ◆ Continued work to add education materials to the website which will be in the spring of 2009
- ◆ Identify and/or create mechanisms for consumer engagement statewide with use of these materials. Two major foci are to assist consumers with
  - Personal health management
  - Involvement in ongoing public policy development

## **Members of the HISPC II Education Committee**

- ◆ Karen A. Paschal, PT, DPT, MS, Associate Professor of Physical Therapy and Faculty Creighton Health Services Research Program, Creighton University; Chair
- ◆ Anne Byers, Community Information Technology Manager, Nebraska Information Technology Commission; Co-chair
- ◆ David H. Filipi, MD, Vice President, Medical Affairs, Physicians Clinic
- ◆ James Harper, MD
- ◆ Ellen Jacobs, College of St. Mary
- ◆ Renee Rowell, MS, RHIA, CCS, Program Director, Management of Health Informatics Bellevue University
- ◆ September Stone, RN, Nebraska Health Care Association

## PROCESS – ORGANIZATIONAL PRINCIPLES

The HISPC II workgroup identified two committees to address goals, issues, and opportunities. The committees selected a coordinator to facilitate tasks work and report(s). The workgroup coordinates the work of each committee and approves proposals/action steps that are sent to the eHealth Council for their review and action.

All materials prepared are available to the citizen, health care providers, the Governor, the Legislature, and agencies. The following principles and organizational model guide the workgroup and the two committees:

### Principles:

1. Citizen Focused process/model(s) drove the workgroup discussions
2. The prioritization of HISPC #1 recommendations
3. Continued work on a sustainable action plan
4. Identify and utilization of non-workgroup member expertise
5. The workgroup's operational value(s) were explicitly identified and guided the workgroup's effort

### Organization Model:



Background from meetings:

January 4, 2008

The workgroup discussed their role, opportunities and challenges. They also discussed the values and beliefs guiding their work/process and the need for a new type of "map" to show their efforts. Listed below is a brief summary of the comments:

- a. The organizational process model should have arrows moving in both directions
- b. The Learning Community vision and mission model is important for all of our work
- c. We will need to identify strong public and private partnerships for our work
- d. Do we connect with the citizen or the citizen as a member of a community?
- e. People with a need are aware and interested. How do we capture them and their ideas for our work?
- f. What can we expect from government as we develop recommendations?
- g. What are the "upstream" issues that we must consider as we identify priorities?
- h. Our model will go from bottom up. The issue of opening communication lines will be most important.
- i. Should our model be inter-connected circles?
- j. Our first assumption is that we want a totally interoperable infrastructure. Or is it to remove barriers to interoperability. How do we prevent "mission creep"?
- k. What is our core set of values that we will use to create our priorities?
- l. What is the KEY privacy issue that we should address?
- m. Should our focus be in the context of Government priorities/DHHS or should it be the citizen?
- n. Conceptual approaches are fine for our group but government wants specifics.
- o. We must do scenarios if we are to be successful with our recommendations.
- p. We need to put our end goal up front for everyone to know
- q. We need to consider the real and perceived issues/costs of our recommendations.
- r. There are political and cost issues. We will need capital for both.

February 22, 2008

Members reviewed the revised Process-Organizational principles, vision and mission document and value statements. It was noted that the issues are constantly changing and that some general statements may be appropriate in the document to give some flexibility. Minor revisions were suggested and recorded for the vision and mission statements. Most of the time was spent reworking the VALUES draft from the January meeting. Members worked hard to clarify terminology, roles and work intent in the revision.

April 22, 2008

Members reviewed the changes to this document after the last meeting. No comments were received. Members discussed the interoperability issue found under Values (F).

The group discussed whether the issue of advocating for an ongoing operational committee that addresses interoperability at the state level. This is part of what the NITC is charged to do. Ongoing monitoring will be a need as will be the educational components of this effort. The HISPC II want to recommend to the eHealth Council and the NITC that an ongoing focus and operational work be done that focuses on identifying the many health interoperability issues that arise each year in Nebraska and share that information with all stakeholders.

This draft organization plan will stay in that form until the group makes it permanent.

## **HISPC II WORKGROUP AS A HEALTH INFORMATION TECHNOLOGY (HIT) LEARNING COMMUNITY**

The HISPC II workgroup realized the need for cross-collaboration and learning from the wide range of experts participating. Mission concepts were developed by the workgroup and used to guide the interactions and action item development.

### **Vision Statement Concepts for the HIT Learning Community:**

The workgroup will function as a learning community; created and nurtured by a broad collaboration that shares knowledge widely, focused on creating a health information flow that is visible and understandable to all citizens, research-based and community appropriate, credible and focused on essentials, and provides a blueprint for improvement.

Background from meetings:

April 22, 2008

Members reviewed the changes to this document after the last meeting. No comments were received. Members discussed the interoperability issue found under Values (F).

The group discussed whether the issue of advocating for an ongoing operational committee that addresses interoperability at the state level. This is part of what the NITC is charged to do. Ongoing monitoring will be a need as will be the educational components of this effort. The HISPC II want to recommend to the eHealth Council and the NITC that an ongoing focus and operational work be done that focuses on identifying the many health interoperability issues that arise each year in Nebraska and share that information with all stakeholders.

This draft organization plan will stay in that form until the group makes it permanent.

July 23, 2008

The group reviewed the mission and vision (with goals) document to begin the committee work and recommendations. It was determined that the work should reflect the agreed upon principles and values. In addition, the workgroup reviewed the HISPC#1 set of recommendations. It is important to continue reminding the eHealth Council and NITC about the recommendations from the past and present.

The workgroup suggested the following plan for our work in 2008:

- a. Complete a legal review, a consumer education project and a website.
- b. Unsure how to address the training of boards at DHHS. If provider associations are educated will that information then flow into the boards?

- c. The legal review is geared to identify gaps and recommend needed changes this year
- d. Need to help the health associations gain knowledge of health information security and privacy (HISP)
- e. Need to review the HISPC#1 recommendations and identify the next steps.

### **Mission Statement Concepts for the HIT Learning Community:**

This mission statement assumes the different levels of citizen understanding of HISPC II issues. We strive to identify a level of privacy and security for all citizens as we work to identify regulator barriers and solutions to these barriers.

#### The workgroup mission

1. Clarify what learners will need to learn.
2. Clarifies how we will know if learners have learned.
3. Clarifies how programs, “educators,” and trainers define and implement programs to meet the educational needs of all stakeholders.
4. Clarifies the linkage between community knowledge needs and sources/trainers of that knowledge.

Background from meetings:

July 23, 2008

The group reviewed the mission and vision (with goals) document to begin the committee work and recommendations. It was determined that the work should reflect the agreed upon principles and values. In addition, the workgroup reviewed the HISPC#1 set of recommendations. It is important to continue reminding the eHealth Council and NITC about the recommendations from the past and present.

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- d. Need to help the health associations gain knowledge of health information security and privacy (HISP)
- e. Need to review the HISPC#1 recommendations and identify the next steps.

## Values

- A. We believe that each citizen owns his or her own personal health information and should be provided a reasonable opportunity and capability to make informed decisions about the collection, use, and disclosure of their individually identifiable health information beyond that permitted by law for treatment, payment, operations and public health reporting purposes.
- B. We believe that citizens should be involved in and partner with the designers of all health models, electronic health models, and with the devised distribution plans for these models.
- C. We believe in citizen involvement with the HISPC II workgroup, their committees, and with other key stakeholders (insurance companies, information technology companies, all health provider associations, all community development organizations), in the work to design a process for the creation of a health information exchange structure that maintains security and privacy of their health records.
- D. We believe that citizens, their health care providers, and other stakeholder organizations should be working in partnership/collaboration to ensure a statewide, interoperable, health care environment.

Background from meetings:

January 4, 2008

VALUES: What do we want to be our core set of values?

- a. Do we value education of our citizens?
- b. Should that education be in real time or handed out by professionals incrementally?
- c. Should citizens design the system or be educated to understand a system?
- d. Will our value be shaped by a focus on the desire to improve the quality of care or to reduce the cost of care?
- e. Is our goal tied to a vision of sustainability?
- f. Will our goals be tied to a belief in the need for strong collaboration and cooperation or to individualism?

February 22, 2008

Members reviewed the revised Process-Organizational principles, vision and mission document and value statements. It was noted that the issues are constantly changing and that some general statements may be appropriate in the document to give some flexibility. Minor revisions were suggested and recorded for the vision and mission statements. Most of the time was spent reworking the VALUES draft from the January meeting. Members worked hard to clarify terminology, roles and work intent in the revision.

April 22, 2008

Members reviewed the changes to this document after the last meeting. No comments were received. Members discussed the interoperability issue found under Values (F).

The group discussed whether the issue of advocating for an ongoing operational committee that addresses interoperability at the state level. This is part of what the NITC is charged to do. Ongoing monitoring will be a need as will be the educational components of this effort. The HISPC II want to recommend to the eHealth Council and the NITC that an ongoing focus and operational work be done that focuses on identifying the many health interoperability issues that arise each year in Nebraska and share that information with all stakeholders.

This draft organization plan will stay in that form until the group makes it permanent.

### **Action Items**

Action: Develop a sustainable action plan to facilitate progress (present and future) in assuring privacy and security protections in the exchange of health information for and by each of our citizens.

Rationale: The complexity of the rules and regulations creates confusion in the arena of privacy. Because HIPAA preemption rules are complex, individuals in a position to potentially disclose protected health information sometimes are unsure if the Personal Health Information (PHI) may be disclosed without written individual authorization. Health care providers and payers who are faced with potential civil and criminal HIPAA fines and penalties, state law causes of action for invasion of privacy, and reporting to licensure board for breach of confidentiality, may often decide not to disclose PHI, when it is otherwise permissible to disclose. Variations in interpreting HIPAA and other laws may impede the exchange of health information. Currently work is being done by states, federal entities, health care providers, eHealth initiatives, and other stakeholders to address privacy and security issues. A process needs to be developed to monitor and respond to developments in this area to ensure the private and secure exchange of health information.

Lead: Health Information Security and Privacy Committee (HISPC)

Participants: eHealth Council, Nebraska HISPC II Workgroup, the Department of Health and Human Services (DHHS) legal department, the Attorney General's Office, the Office of the CIO, other state agencies that would become involved with PHI, and other stakeholders

Funding: Funding or in-kind contributions may be required for implementation.

Timeframe: Recommendations for the issues and model design should be ready by summer, 2008.

Action: Develop a plan and resources to inform stakeholders—particularly consumers and health professional associations—about issues related to health information security and privacy and involve them in policy discussions.

Rationale: In order to effectively address health information security and privacy issues, key stakeholders need to be informed and engaged in policy discussions. The first Nebraska Health Information Security and Privacy Committee surveyed consumers and health professional associations in year one of the initiative. The surveys found that these stakeholders are not well informed about health information security and privacy issues, but are generally supportive of health information exchange efforts. Citizen viewpoints and purchasing choices are critical to the design and use of health information technology (HIT) systems in the community, region, state and nation. A larger and broader representation of community and citizen viewpoints and needs is needed to help in the creation of a Nebraska model of HIT and its deployment and use. A model for understanding the needs of the community and its citizenry is needed to enable government, health providers, information technology (IT) providers and health product vendors to appropriately respond to identified needs. The unique knowledge and expertise of health care practitioners, facilities in which health care is provided, organizations involved with health issues at the societal level and educators of health professions students are needed to address how current laws, rules and regulations related to their disciplines affect and are affected by the electronic exchange of health information. Associations play a key role in seeking additional information and helping their members to become involved in these processes.

Lead: HISPC II Education Committee

Participants: HISPC II Education Committee, eHealth Council, Department of Health and Human Services (DHHS), health professional associations, DHHS health/licensure/certification board managers, and other stakeholders—possibly including University of Nebraska Extension, American Association of Retired Persons (AARP), the League of Municipalities, the Nebraska Association of County Governments, and service organizations

Funding: Funding or in-kind contributions may be required for implementation of the educational plan.

Timeframe: The eHealth Council should start this dialog immediately and then establish a tight time frame for completion of this work in 2008.

Action: The eHealth Council should ensure that an in-depth short-term study of existing laws and regulations, with guidance from representatives from the health professions, health educators and health organizations, be done in order to identify and solve electronic health privacy and security issues.

Rationale: Past Nebraska Health Information Security and Privacy Coalition research on state privacy and security issues has begun to reveal issues that are unique to Nebraska and those that are similar to other states. The issues are embedded in complexity and confusion associated with state and federal inconsistencies, conflicting business practices and varying consent policies and approaches. These issues must be untangled and addressed. This will require sustained commitment to achieve.

Lead: HISPC II Legal Committee.

Partners: eHealth Council, HISPC II Legal Committee, Department of Health and Human Services (DHHS) legal staff, professions and facility managers, health care associations and citizens.

Funding: It will probably be necessary to contract with a law firm or legal expert to address these issues (Est. \$50,000).

Timeframe: This needs to start immediately and be finished by August, 2008 in order to assist with other deadlines in HIT/grants/legislation/etc.

#### Background from meetings:

April 22, 2008

The eHealth Council has approved 7 action plans submitted by council members and committees. The Council has around \$250,000 available for grants to work on some of these action plans. Three of them are from the HISPC II workgroup. A formal application is due by May 12 and approved grants will need to be completed by June 2009. The group reviewed our group's three proposals and decided that we should work on Action Plan #3 and #4 (education/legal ideas). Members expressed the need to have a central location (website) with information and quality assurance about privacy/security issues. It should include most often asked questions and it should be available to both providers and citizens. The use of scenarios with good legal review would be helpful. This project must plan for sustainability. It should also be able to handle a broad range of issues for citizens and providers. The group pondered if privacy agencies could be lined together and what the role of the eHealth Council and DHHS is?

Members believe that interoperability issues will continue as providers and patients identify the ways and means of delivering patient health information. It may be valuable to create a single site where questions could be listed and "qualified" answers given and shared with everyone. The liability of the purveyor of this information/website provider needs to be explored. Members reach agreement that we should try to link action plans 3 and 4 because we need to provide reviewed answers to questions asked. Members also suggested that we model this after the SNIP model housed at the NHA to address past issues thru a list serve type of model. This may necessitate a "2nd" review by an outside legal entity of our work which can be then be posted on the site. Members are asked to review our discussions and submit model ideas to Dennis for incorporation in the application for funding. It was also brought up that Newborn Screening Board is addressing our state consent law that addressed the saving of blood from Newborns for a hearing issue that could develop past the 90 day disposal law. This proposed website model could help educate, inform and support knowledge transfer and appropriate actions.

## **FUNDED PROJECTS**

Two projects were developed that initiate the consumer information education effort of the HISPC II. The first project is centered on the design of consumer education materials about health information security, privacy and exchange. The second project provides a web-based mechanism for dissemination and sustained public access to consumer information developed or vetted by the HISPC II workgroup.

For additional information on the projects please contact:

eHealth Council  
C/O: Anne Byers  
[Anne.Byers@nebraska.gov](mailto:Anne.Byers@nebraska.gov)

For additional information on the projects see pages 27 to 30 of this report.

## **Project 1: Health Information Security and Privacy Consumer Education**

The project will develop educational materials for consumers regarding health information exchange as well as related privacy and security concerns. Consumer involvement is commonly identified as a key element in the development of health information exchange. The eHealth Initiative has identified focusing on consumers as one of six common principles for effective health information exchanges. The eHealth Initiative recommends that health information exchanges enable consumers to make informed choices and address health information security and privacy needs of consumers. The Nebraska eHealth Council has also identified consumer education as one of its priorities.

### Goals:

- ◆ To facilitate the exchange of health information by addressing the educational needs of consumers related to health information exchange and security and privacy issues.
- ◆ To increase consumer knowledge of health information exchange.
- ◆ To increase consumer support of health information exchange.

### Project activities:

- ◆ Identifying and prioritizing one or two educational pieces that should be developed.\*
- ◆ Providing input into the design of a health information security and privacy website.
- ◆ Identifying educational pieces and resources from Nebraska eHealth initiatives, other states, and national organizations that could be used.
- ◆ Evaluating existing educational pieces and resources.\*
- ◆ Developing a resource library of educational materials which will be made available from the Health Information Security and Privacy website.
- ◆ Drafting educational pieces.
- ◆ Reviewing and evaluating educational pieces.\*
- ◆ Finalizing educational pieces.
- ◆ Developing preliminary consumer marking plan.\*
- ◆ Distributing educational pieces to consumers.\*

\*Indicates activities in which health information exchange representatives will be involved. Representatives are welcome to participate in other activities. However, since many representatives of the health information exchanges have limited time, their participation is not expected.

### Accomplished:

- ◆ Created a list of security and privacy references for consumers and providers
- ◆ Collaborated with the University of Nebraska Public Policy Center on a Deliberative Discussion on Electronic Health Records which was funded by the NITC upon recommendation of the eHealth Council

## **Project 2: Health Information Privacy and Security Website**

The initial design of the website will link to the present eHealth Council website found inside the Nebraska Information Technology Commission (NITC) webpage:

<http://www.nitc.state.ne.us/init/ehealth.html>. This governmental site is desired because this information will need to be vetted, liability issues will be easier to address and because the underlying focus of this proposal is to have a sustainable delivery model.

### Goals:

- ◆ The initial information on the site will come from the research done by and collected by the HISPC I and II Workgroups. The information on state laws and regulations about health information privacy and security will have been vetted by the workgroup and most likely by an outside legal review.
- ◆ Funding will be needed to develop a user friendly website, gather all pertinent information, enter it in the site, create a management and vetting model, create an information transfer model, and develop a sustainability plan for this website these funds will be needed to cover labor, consultant help, capacity support and website promotional modeling.
- ◆ The site will allow the blending of the legal research that has presently been completed and the need to clarify what is state privacy and security issues and what are HIPAA/federal issues that citizens and professionals need to be aware of and to address. It can provide access to educational materials for citizens and professionals as well as a place to ask questions that need to be answered.

### Project activities:

- ◆ Working with the CIO personnel and the web designers to get quotes for this website model.
- ◆ Collect vetted health privacy and security information that can be placed on the website.
- ◆ Complete the review of Nebraska state laws and regulations affecting electronic transfer of information and place that vetted information on the website.
- ◆ Collect HIPAA/Federal information pertinent to our website development goals.
- ◆ Work with health provider stakeholders and consumer stakeholder groups to identify health privacy and security information questions to be placed on the website.

### Accomplished:

- ◆ The health information security and privacy website is under development and will be operational by late spring 2009.
- ◆ Created a list of security and privacy references for consumers and providers.
- ◆ The HISPC II Legal Committee utilized the 2006 Nebraska Health Information Management Association “Guide for Privacy, Retention and Disclosure of Health Information in Nebraska” as a resource to analyze laws related to health information disclosure.
- ◆ Committee members identified Nebraska laws requiring written individual authorization for disclosure of information when federal Health Insurance Portability and Accountability Act (HIPAA) laws do not.
- ◆ The committee also identified areas where confusion about disclosure rules exists. Additional education and clarification of disclosure rules to the health care community may facilitate electronic health information exchange in these areas.

## Background from meetings:

May 30, 2008

The eHealth Council had received \$388,000 worth of applications for the \$277,000 fund. The Council will do a voting process to reach the allowed amount. Two proposals from our Workgroup were included at this point in time. A) Education for the consumer using a website. The members would collect vetted educational materials and position it on the site for education and Q/A. It was also noted that in the reviews this proposal questions were raised as to why consumers needed this amount of attention; and B) The workgroup proposed the creation of a state government website that would allow the legal committee to place vetted privacy and security information on this site and also be the location for the educational materials listed above. This would also have a quality assurance potential. The NITC Tech Panel will meet on June 10 to review the Council's applications and the NITC will approve them on June 18, 2008 at their regular meeting.

July 23, 2008

Both of our proposals were accepted by the eHealth Council. The approved proposal include: A) Creation of a website that HISPC II materials and education efforts can be displayed and utilized. The legal team's review and other vetted material will be placed on this site; and B) Consumer materials will be found or created to be shared with consumers and providers. The website being created (and web hosting supported for 2 years under this grant) will be utilized. The collection of educational materials is being placed in an inventory model and reviewed.

September 19, 2008

It was proposed that a public engagement model be completed in two phases. A survey of (randomly selected) citizens in one or more counties which will determine what citizens know about HIT. The second phase would be a Deliberative Model discussion with citizens. Members suggested using a non metro county vs. Lancaster county. Members also asked about the types of questions to be used because of survey concerns of past models.

November 10, 2008

Website development is underway. The Education Committee pulled together a list of educational resources for consumers and providers and divided them into types and topics. Members are asked to review these resources.

December 16, 2008

A report was given on the Deliberative Discussion model. The involved citizens expressed some concerns about privacy and security but felt that with more information/education that could be overcome. The citizens wanted the state to address privacy and security issue on their behalf. This process provided our workgroup some affirmation on our focuses: education and legal reviews. It was noted the ideas presented matched some of the ideas Sec. Leavitt presented yesterday in a conference. The toolkit list can be found at: [www.hhs.gov/healthit/privacy](http://www.hhs.gov/healthit/privacy). The present focus is on the consumers and what they want. This will require a very flexible model and more of an

immediate focus on the PHR model. It was noted that consumers seem to really want access to their medical records. There is resistance to having insurance companies having all available information. It is believed that citizens want coordination of care. We lack good info on the wants, needs and knowledge of our rural citizens. Research should help fill in some of that gap, along with the Policy Center's work.

## STATE LEVEL RESEARCH TO INFORM THE HISPC II

Recent projects that study consumer knowledge and viewpoints about health information exchange, security and privacy issues have been used to inform the HISPC II and eHealth Council of the current status.

2008

The article entitled “*Privacy, Security and the National Health Information Network: A Mixed Methods Case Study of State-Level Stakeholder Awareness*” conducted by the Creighton Health Services Research Program (CHRP). “This study examines the knowledge, understanding, and awareness of 25 health board/facility oversight managers and 20 health professional association directors about privacy and security issues important to achieving health information exchange (HIE) in the state of Nebraska.”<sup>4</sup> The article can be found in *Advances in Health Care Management*, Volume 7, pp 165-189.

March 2007

The article entitled “*Privacy, Security and the National Health Information Network: A Mixed Methods Case Study of State-Level Stakeholder Awareness*” used findings from the *Security and Privacy Barriers to Health Information Interoperability Reports* generated by the first Health Information Security and Privacy Committee State of Nebraska. The specific reports include:

- ◆ Report 1: Survey of Health/Licensure/Certification and Facilities Oversight Board Managers
- ◆ Report 2: Survey of Health Professions Organizations Leadership

These reports can be found on the CHRP website: <http://chrp.creighton.edu>

February 2009

The report entitled “*Exploring the Interactions of Nebraska Community Infrastructures, Health Professionals and Organizations, and Consumers about Personal Health Data and Health Information*” conducted by the Creighton Health Services Research Program (CHRP). “This project is designed to study the consumers point of view about how they keep track and seek health information via the availability and use of their local community infrastructure including religious affiliations, health information technologies, health professions, organizations; and their viewpoints about privacy needs regarding their own personal and sensitive health information. There are powerful contrasts between what patients know and experience, what health professions and health organizations offer, and what community infrastructure provides.”<sup>5</sup> The report can be found on the CHRP website: <http://chrp.creighton.edu> on February 15, 2009.

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<sup>4</sup> Galt, K.A., Paschal, K.A., Abbott, A., Drincic, A., Siracuse, M.V., Bramble, J.D., and Rule, A.M. (2008). Privacy, security and the national health information network: a mixed methods case study of state-level stakeholder awareness. *Advances in Health Care Management*, 7, 165-189

<sup>5</sup> Creighton Health Services Research Program (CHRP): Exploring the Interactions of Nebraska Community Infrastructures, Health Professionals and Organizations, and Consumers about Personal Health Data and Health Information February 2009: p 1.

December 11, 2008

The report entitled “*Sharing Health Records Electronically: The Views of Nebraskans*” conducted by the University of Nebraska Public Policy Center. “The overall goal of the project was to learn about consumers’ attitudes towards electronic sharing of medical information; related concerns about privacy, access, and security; and opinions about what the policy role of the State of Nebraska should be in the development of electronic health information exchange in the state.”<sup>6</sup> The report can be found in Appendix B of this report.

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<sup>6</sup> University of Nebraska Public Policy Center: *Sharing Health Records Electronically: The Views of Nebraskans* December 11, 2008: p 2.

## APPENDIX A – HISPC II EDUCATION RESOURCES

### Personal Health Records

AHRQ Personal Health Record Video  
<http://www.ahrq.gov/consumer/phrvid.htm>  
Agency for Health Care Research and Quality

My PHR  
[www.myphr.com](http://www.myphr.com)

Florida Personal Health Record Toolkit  
<http://www.fhin.net/PHR/index.shtml>

Arizona PHR Info  
<http://www.azhec.org/personalHealth.jsp>

Project Health Design  
<http://www.projecthealthdesign.org>

### e-Prescribing

Arizona e-Prescribing Info  
<http://www.azhec.org/ePrescribing.jsp>

Florida e-Prescribing Clearinghouse  
<http://www.fhin.net/eprescribe/>

Learnabouteprescriptions.com  
[www.learnabouteprescriptions.com](http://www.learnabouteprescriptions.com)

### Privacy and Security

My PHR  
[http://www.myphr.com/rights/your\\_privacy\\_rights.asp](http://www.myphr.com/rights/your_privacy_rights.asp)  
American Health Information Management Association (AHIMA)

The Center for Democracy and Technology  
<http://www.cdt.org/healthprivacy/>

Myths and Facts about the HIPAA Privacy Rule from Health Privacy Project (5 pages)  
<http://www.cdt.org/healthprivacy/20080311mythsfacts.pdf>  
[http://www.healthprivacy.org/usr\\_doc/Myths\\_and\\_Facts.pdf](http://www.healthprivacy.org/usr_doc/Myths_and_Facts.pdf)

Health Privacy: Know Your Rights from Health Privacy Project (2 page flyer)  
[http://www.cdt.org/healthprivacy/2008\\_KnowYourRights.pdf](http://www.cdt.org/healthprivacy/2008_KnowYourRights.pdf)

[http://www.healthprivacy.org/usr\\_doc/KnowYourRights.pdf](http://www.healthprivacy.org/usr_doc/KnowYourRights.pdf)

How to File a Health Information Privacy Complaint from Health Privacy Project (2 page flyer)

[http://www.healthprivacy.org/usr\\_doc/Privacy\\_Complaint\\_Form.pdf](http://www.healthprivacy.org/usr_doc/Privacy_Complaint_Form.pdf)

[http://www.cdt.org/healthprivacy/2008\\_Privacy\\_Complaint\\_Form.pdf](http://www.cdt.org/healthprivacy/2008_Privacy_Complaint_Form.pdf)

What you can do to protect your privacy

[http://www.healthprivacy.org/usr\\_doc/WhattoDo.pdf](http://www.healthprivacy.org/usr_doc/WhattoDo.pdf)

Key Health Privacy Issues

[http://www.healthprivacy.org/usr\\_doc/34225.pdf](http://www.healthprivacy.org/usr_doc/34225.pdf)

eHealth: Putting Patients First

[http://www.healthprivacy.org/usr\\_doc/hpp-chcf-ehealth.pdf](http://www.healthprivacy.org/usr_doc/hpp-chcf-ehealth.pdf)

Health Privacy Project:

<http://www.healthprivacy.org/>

Health Privacy Project--CONSUMERS & E-HEALTH: A GUIDE

<http://www.healthprivacy.org/content2310/content.htm>

Secure Electronic Health Information Exchange: A Guide for Consumers

<http://toolkit.ehealthinitiative.org/assets/Documents/eHIGuideforConsumersonHealthInformationExchangeJan2007.pdf>

Arizona Privacy and Security Info

<http://www.azhec.org/privacySecurity.jsp>

HIMSS Privacy and Security Toolkit

<http://www.himss.org/ASP/privacySecurityTree.asp?faid=78&tid=4>

**A PATIENT'S GUIDE TO THE HIPAA PRIVACY RULE: When Health Care Providers May Communicate About You with Your Family, Friends, or Others Involved In Your Care**

[http://www.hhs.gov/ocr/hipaa/consumer\\_ffg.pdf](http://www.hhs.gov/ocr/hipaa/consumer_ffg.pdf)

**A HEALTH CARE PROVIDER'S GUIDE TO THE HIPAA PRIVACY RULE: Communicating with a Patient's Family, Friends, or Others Involved in the Patient's Care**

[http://www.hhs.gov/ocr/hipaa/provider\\_ffg.pdf](http://www.hhs.gov/ocr/hipaa/provider_ffg.pdf)

Your Health Information Privacy Rights

[http://www.hhs.gov/ocr/hipaa/consumer\\_rights.pdf](http://www.hhs.gov/ocr/hipaa/consumer_rights.pdf)

Privacy and Your Health Information

[http://www.hhs.gov/ocr/hipaa/consumer\\_summary.pdf](http://www.hhs.gov/ocr/hipaa/consumer_summary.pdf)

HIPAA FAQs

<http://www.hhs.gov/hipaafaq/>

EHR Today Consumer Brochure  
<http://www.ehrtoday.org/CMSuploads/LHCR-ConsumerBroch-sm-09843.pdf>

EHR Today Provider Brochure  
<http://www.ehrtoday.org/CMSuploads/LHCR-ProviderBroch-sm-09881.pdf>

Health Information Technology--Consumer Principles  
National Partnership for Women and Families  
[http://www.nationalpartnership.org/site/DocServer/HIT\\_20-20Consumer\\_20Principles\\_20FINAL\\_20March\\_202006.pdf?docID=990](http://www.nationalpartnership.org/site/DocServer/HIT_20-20Consumer_20Principles_20FINAL_20March_202006.pdf?docID=990)

Your Health Information Privacy Rights  
[http://www.hhs.gov/ocr/hipaa/consumer\\_rights.pdf](http://www.hhs.gov/ocr/hipaa/consumer_rights.pdf)

Privacy Rights Clearinghouse  
<http://www.privacyrights.org/medical.htm>

Patient Privacy Rights  
<http://www.patientprivacyrights.org/>

WYHIR—Wyoming’s Health Information Resource  
<http://wyhir.org/Browse.aspx?S=4>

## **Health Information Exchange**

Greater Rochester RHIO Brochure  
[http://grrhio.org/pdf/patient\\_trifold.pdf](http://grrhio.org/pdf/patient_trifold.pdf)

Louisville Health Information Exchange  
<http://www.louhie.org/>

Oregon’s Health Information Security and Privacy Collaboration video:  
<http://video.google.com/videoplay?docid=6764524539952681192&hl=en>

## **Videos**

AHRQ Personal Health Record Video  
<http://www.ahrq.gov/consumer/phrvid.htm>

Oregon’s Health Information Security and Privacy Collaboration video:  
<http://video.google.com/videoplay?docid=6764524539952681192&hl=en>

National Medical Report: AHIMA American Health Information Management Association Video – Added on April 8, 2008.  
<http://www.youtube.com/watch?v=TZzIw6RpQVg>

Louisville Health Information Exchange  
<http://www.louhie.org/>

## Frequently Asked Questions

AHIMA MyPHR.com FAQs

<http://www.myphr.com/faqs/index.asp>

Greater Rochester RHIO

[http://grrhio.org/pat\\_faq.shtml](http://grrhio.org/pat_faq.shtml)

EHR Today Consumers FAQ

<http://www.ehrtoday.org/home/section/1-5/faq-consumers>

EHR Today Providers FAQ

<http://www.ehrtoday.org/home/section/1-25/faq-providers>

HIPAA FAQs

<http://www.hhs.gov/hipaafaq/>

Patient Privacy Rights FAQs

<http://www.patientprivacyrights.org/site/PageServer?pagename=FAQs>

## Patient Educational Fact Sheets/Brochures

[http://bhix.org/Downloads/BHIX\\_EducationalFactSheet\\_ENGLISH.pdf](http://bhix.org/Downloads/BHIX_EducationalFactSheet_ENGLISH.pdf)

(Available in 18 languages)

Secure Electronic Health Information Exchange: A Guide for Consumers

<http://toolkit.ehealthinitiative.org/assets/Documents/eHIGuideforConsumersonHealthInformationExchangeJan2007.pdf>

Greater Rochester RHIO Brochure

[http://grrhio.org/pdf/patient\\_trifold.pdf](http://grrhio.org/pdf/patient_trifold.pdf)

Health Privacy Project--CONSUMERS & E-HEALTH: A GUIDE

<http://www.healthprivacy.org/content2310/content.htm>

What you can do to protect your privacy

[http://www.healthprivacy.org/usr\\_doc/WhattoDo.pdf](http://www.healthprivacy.org/usr_doc/WhattoDo.pdf)

Key Health Privacy Issues

[http://www.healthprivacy.org/usr\\_doc/34225.pdf](http://www.healthprivacy.org/usr_doc/34225.pdf)

eHealth: Putting Patients First

[http://www.healthprivacy.org/usr\\_doc/hpp-chcf-ehealth.pdf](http://www.healthprivacy.org/usr_doc/hpp-chcf-ehealth.pdf)

A PATIENT'S GUIDE TO THE HIPAA PRIVACY RULE: **When Health Care Providers May Communicate About You with Your Family, Friends, or Others Involved In Your Care**

[http://www.hhs.gov/ocr/hipaa/consumer\\_ffg.pdf](http://www.hhs.gov/ocr/hipaa/consumer_ffg.pdf)

A HEALTH CARE PROVIDER'S GUIDE TO THE HIPAA PRIVACY RULE:  
Communicating with a Patient's Family, Friends, or Others Involved in the Patient's Care  
[http://www.hhs.gov/ocr/hipaa/provider\\_ffg.pdf](http://www.hhs.gov/ocr/hipaa/provider_ffg.pdf)

Your Health Information Privacy Rights  
[http://www.hhs.gov/ocr/hipaa/consumer\\_rights.pdf](http://www.hhs.gov/ocr/hipaa/consumer_rights.pdf)

Privacy and Your Health Information  
[http://www.hhs.gov/ocr/hipaa/consumer\\_summary.pdf](http://www.hhs.gov/ocr/hipaa/consumer_summary.pdf)

EHR Today Consumer Brochure  
<http://www.ehrtoday.org/CMSuploads/LHCR-ConsumerBroch-sm-09843.pdf>

EHR Today Provider Brochure  
<http://www.ehrtoday.org/CMSuploads/LHCR-ProviderBroch-sm-09881.pdf>

## **PSAs and Advertisements**

InformationSTAT™ Public Education tools  
<http://www.ehealthinitiative.org/toolkit/getOrg/InfoSTAT.msp>

## **Reports/Surveys**

Creighton Health Services Research Program  
Report 3: Consumer Views about Privacy and Electronic Health Information Exchange  
[http://chrp.creighton.edu/Documents/HISPC\\_Report\\_3.pdf](http://chrp.creighton.edu/Documents/HISPC_Report_3.pdf)

eHealth Initiative Releases Results of 2007 Survey on Health Information Exchange  
December 19, 2007  
<http://www.ehealthinitiative.org/2007HIESurvey/>

Attitude and Opinion Research – Executive Summary  
Supported by the eHealth Initiative Foundation  
Released May 2, 2007  
<http://toolkit.ehealthinitiative.org/assets/Documents/eHISummaryofResearchonHealthInformationExchange05.01.07Final001.pdf>

Harris Interactive Survey—Feb. 2007  
<http://www.harrisinteractive.com/NEWS/allnewsbydate.asp?NewsID=1174>

The 2008 Health Confidence Survey: Rising Costs Continue to Change the Way  
Americans Use the Health Care System--October 2008  
[http://www.ebri.org/publications/notes/index.cfm?fa=notesDisp&content\\_id=3987](http://www.ebri.org/publications/notes/index.cfm?fa=notesDisp&content_id=3987)

Fixing Health care: What Women Want—March 2008  
[http://www.aafp.org/online/etc/medialib/aafp\\_org/documents/press/fixhealthwomen/fixhealthwomendoc.Par.0001.File.tmp/Executive%20Summary%20-%20Fixing%20Health%20Care%20-%200408.pdf](http://www.aafp.org/online/etc/medialib/aafp_org/documents/press/fixhealthwomen/fixhealthwomendoc.Par.0001.File.tmp/Executive%20Summary%20-%20Fixing%20Health%20Care%20-%200408.pdf)

Consumer Use of the Internet to Manage Care, Harris Interactive, May 2008  
<http://www.chcf.org/topics/view.cfm?itemID=133641>

Greater Louisville eHealth Research Report--2007  
<http://www.louhie.org/Downloads/LouHIE%20research%20report%20v9%20Final%20Exec%20Summ.pdf>

Harris Interactive Survey—Sept. 2006  
<http://www.harrisi.org/news/allnewsbydate.asp?NewsID=1096>  
Kansas Rural Consumers Health Information Technology (HIT) Needs and Preference Summary Report  
<http://www2.kumc.edu/healthinformatics/HISPC/KSSummaryReport.doc>

National Consumer Health Privacy Survey 2005, Forrester Research, Inc., November 2005  
<http://www.chcf.org/topics/view.cfm?itemID=115694>

The State of Health IT in California: Consumer Perspective, California Health care Foundation, 2008  
<http://www.chcf.org/documents/chronicdisease/HITConsumerSnapshot08.pdf>

CareSpark Survey 2006  
<http://carespark.com/images/stories/Documents/General%20Survey%20of%20Patient%20Attitudes.pdf>

## **Toolkits**

Toolkit for Consumers in Rural Kansas  
<http://www2.kumc.edu/healthinformatics/HISPC/Toolkit.htm>

**APPENDIX B – SHARING HEALTH RECORDS  
ELECTRONICALLY: THE VIEWS OF NEBRASKANS**

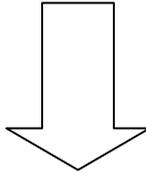
## APPENDIX C – BACKGROUND

### Telehealth Committee

The Telehealth Committee was created in 2000 by the Nebraska Information Technology Commission (NITC) to identify issues affecting the deployment of the telehealth/HIT services in Nebraska, especially rural areas of the state. This committee was instrumental in the creation of the Nebraska Statewide Telehealth Network which was the first statewide telehealth network in the nation (88 hospitals, 19 public health departments). When the NITC created the eHealth Council, the committee's role and focuses became a part of the work of the Council. Some of the founding members became members of the Council upon its creation.

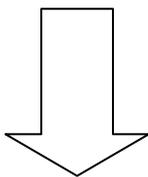
### First Health Information Security and Privacy Committee (HISPC)

The first HISPC was created in 2006 by the Lt. Governor for the State of Nebraska and reviewed key documents related to the state statutes that address, movement of personalized health information to assist in the treatment and care of a patient. They also conducted surveys of three stakeholder groups in Nebraska. The surveys assessed stakeholder security and privacy issues as they relate to stakeholder knowledge and perception about health information exchange, technology, and quality and safety of patient care.

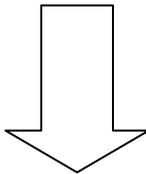


### eHealth Council

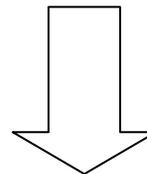
The eHealth Council was created on February 22, 2007 by the Nebraska Information Technology Commission (NITC) to facilitate discussions among eHealth initiatives in the state and to make recommendations to the NITC regarding the adoption and interoperability of eHealth technologies. eHealth technologies include telehealth, electronic health records, electronic prescribing, clinical decision support, computerized provider order entry, and health information exchange. The eHealth Council formed workgroups (three are listed below).



HISPC 2 Workgroup



PHR Workgroup



e-Prescribing Workgroup

- ◆ Legal Committee
- ◆ Education Committee

## **APPENDIX D - FINDINGS FROM THE FIRST HISPC COMMITTEE**

*Security and Privacy Barriers to Health Information Interoperability* Reports generated by the Health Information Security and Privacy Committee State of Nebraska

- ◆ Report 1: Survey of Health/Licensure/Certification and Facilities Oversight Board Managers
- ◆ Report 2: Survey of Health Professions Organizations Leadership
- ◆ Report 3: Consumer Views about Privacy and Electronic Health Information Exchange
- ◆ Final Report for the state of Nebraska: June 2007
- ◆ Recommendations and Summary: Final Report for the state of Nebraska: June 2007

These reports are available at the following website:

CHRP website: <http://chrp.creighton.edu>

## APPENDIX E – HISPC II WORKGROUP SHARED MATERIALS

Members of the workgroup have identified important materials and articles related to health care privacy and security. Those materials are cited below.

<b>Date information provided:</b>	<b>Information provided by:</b>	<b>Item</b>
01/24/08	Dennis Berens	HITSP Standards approval
02/01/08	Dennis Berens	HRSA to offer \$4.5 million in rural hospital technology grants
02/21/08	Dr. James Harper	Google to Store Patients' Health Records, Raising Concerns
02/25/08	Sheila Wrobel	NAHIT Draft Report on Defining Key Health IT Terms
02/26/08	Sheila Wrobel	HIE in the News
02/28/08	Dennis Berens	eHealth narrative and action items
03/05/08	Dennis Berens	Massachusetts – State wants universal e-medical records
03/14/08	Dennis Berens	Virtually all U.S. states now use IT-based e-health strategies
03/25/08	Dennis Berens	VA's mobile pharmacies hit the road
03/26/08	Dennis Berens	Health IT Executives Call for PHR Policies to Ease Privacy Concerns
04/03/08	Dennis Berens	E-Prescribing Final Rule
04/08/08	Dennis Berens	A National Web Conference on Practical Solutions for Engaging Consumers in the Design and Use of PHRs
04/22/08	Dennis Berens	Information and communication technology to revolutionize telemedicine's future
04/24/08	Dennis Berens	Individual Control of Sensitive Health Information Accessible Via the Nationwide Health Information Network for Purposes of Treatment (National Committee on Vital and Health Statistics)
04/28/08	Dennis Berens	Microsoft Explains HealthVault Strategy
04/29/08	Dennis Berens	CMS awards \$50 million in IT grants to aid Medicaid access
05/06/08	Dennis Berens	Kaiser completes nationwide installation of system for outpatient electronic medical records
05/08/08	Ron Hoffman	Benefits of PHRs will eclipse privacy concerns
05/09/08	Dennis Berens	More Who Need Major Surgery Are Going Overseas Audio: Insurers Eye Savings from Treatment Overseas
05/13/08	Dennis Berens	New Report: Home Telehealth and Remote Patient Monitoring
05/15/08	Dennis Berens	Leahy, HELP Leaders Reach Deal on IT Privacy Accords
05/19/08	Dennis Berens	Interesting HIPAA Privacy Development
05/20/08	Dennis Berens	Nation's uninsured embrace online prescription services
05/22/08	Dr. James Harper Dennis Berens	EHR grand rounds topic
05/22/08	Dennis Berens	CBO Report: Evidence on the Costs and Benefits of Health Information Technology

<b>Date information provided:</b>	<b>Information provided by:</b>	<b>Item</b>
06/02/08	Dennis Berens	UNMC Internal Medicine Grand Rounds
06/03/08	Dennis Berens	ONCHIT's strategic plan 2008-2012
06/09/08	Dennis Berens	Oklahoma Senate Bill 1420
06/10/08	Dennis Berens	Kaiser, Microsoft to launch PHR pilot program
06/13/08	Dennis Berens	E-prescribing by doctors skyrockets, but more barriers must be overcome
07/01/08	Dennis Berens	Health care, technology and insurance firms approve PHR privacy framework
07/09/08	Dennis Berens	Markle Foundation
07/17/08	Dennis Berens	Ohio Supreme Court Creates New Tort for Attorney's Unauthorized Disclosure of Medical Records
07/18/08	Dennis Berens	More IT in hospitals mean happier patients, better quality of care
07/23/08	Dennis Berens	NAHIT Key Health IT Terms 022108
07/23/08	Dennis Berens	Top Line Changes Between H.R. 6357 and the Amendment in the Nature of a Substitute to H.R. 6357
07/24/08	Sheila Wrobel	PRO(TECH)T Act Update
07/28/08	Dennis Berens	GHIT – CCHIT will focus on privacy in certifying PHRs
08/28/08	Kim Hazelton	<a href="http://www.ehnac.org">www.ehnac.org</a> Electronic Health care Network Accreditation Commission
09/02/08	Dr. Kimberly Galt	New Inventory of Colorado health care workforce programs and initiatives
09/24/08	Dennis Berens	State Alliance Issues Inaugural Report
09/29/08	Dennis Berens	GAO Report on HIT Privacy
10/07/08	Dennis Berens	HIT Digest: October 6, 2008
10/10/08	Dennis Berens	Press Release: Health care Compliance with New FTC Red Flag Rules (Corrected)
10/21/08	Dennis Berens	Wall Street Journal Article on HIT
10/23/08	Dennis Berens	FTC Will Grant Six-Month Delay of Enforcement of 'Red Flags' Rule: Baird Holm LLP Health Law Alert & FTC Release
10/24/08	Dennis Berens	Electronic Medical Records in Nebraska Security, Privacy, and Health Care Quality
10/30/08	Dennis Berens	Considerations on information and systems protections
11/04/08	Dennis Berens	Use of health IT could go long way toward preventing infectious disease outbreaks in U.S.
12/02/08	Dennis Berens	PQRT: FYI: Oklahoma: Standardized medical authorization from
12/08/08	Karen Paschal Dennis Berens	Electronic Medical Records: The Views of Nebraskans
12/10/08	Dennis Berens	Summary of State HIT laws (NCSL)
12/15/08	Dennis Berens	Deliberative Discussion on Electronic Health Records – Sharing Health Records Electronically: The Views of Nebraskans
12/16/08	Dennis Berens	Leavitt's Comments at yesterday's Keynote address

<b>Date information provided:</b>	<b>Information provided by:</b>	<b>Item</b>
01/30/09	Kimberly Galt	Privacy, Security and the National Health Information Network: A Mixed Methods Case Study of State-Level Stakeholder Awareness
01/30/09	Dennis Berens	Joint Commission HIT
01/30/09	Anne Byers	Pritts State Medical Record Access Report
01/30/09	Dennis Berens	Rethinking the Role of Consent in Protecting Health Information Privacy – January 2009
02/10/09	Dennis Berens	VA Secretary Shinseki vows departmental switch to EMR-based claims system by 2012
02/10/09	Dennis Berens	Stimulus Plan DRAFT