



Data Use Domain Workgroup Charter

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1 Overview

The North Dakota Health Information Network (NDHIN) is committed to implementing a secure statewide health information exchange of “protected health information”(PHI) that is consistent with state and federal privacy and security laws as well as the Principles articulated in the Office of National Coordinator for Health Information Technology’s, *Nationwide Privacy and Security Framework for Electronic Exchange of Individually Identifiable Health Information* (Privacy and Security Framework).

The Data Use Domain Workgroup of the NDHIN will review a number of issues that must be addressed in order ensure that a comprehensive approach for data use is in place, while leveraging the NDHIN to meet the data needs of its stakeholders.

2 Introduction

2.1 Purpose of this document

The purpose of the document is to define the charter, statement of work, and scope for the Data Use Domain Workgroup.

2.2 List of Related Documents

The following documents are important to this project and provide additional information for review.

Table 1: Related Documents

Document Name	Version/Date
Health Information Exchange Strategic and Operational 2012 Plan Update	July 24, 2012
Health Information Exchange Strategic and Operation Plan	December 6, 2010

2.3 Acronyms

Table 2: Acronyms

Acronym	Description
AHRQ	Agency for Healthcare Research and Quality
CDC	Centers for Disease Control and Prevention
CFR	Code of Federal Regulations
DHHS	Department of Health and Human Services
DURSA	Data Use and Reciprocal Agreement
GINA	Genetic Information Nondiscrimination Act
HIE	Health Information Exchange
HIPAA	Health Information Portability and Accountability Act
HITAC	Health Information Technology Advisory Committee
HITECH	Health Information Technology for Economic and Clinical Health
NDHIN	North Dakota Health Information Network
PHI	Protected Health Record
RTI	Response to Intervention
NwHIN	Nationwide Health Information Network

3 Data Use Domain Workgroup

The Health Information Technology Advisory Committee (HITAC) has formed a Data Use Domain Workgroup to provide assistance to HITAC during the implementation and operationalization of the North Dakota HIE Strategic and Operational Plan (SOP).

In Section 13.1.4 of the SOP, under Legal and Policy Issues (also included in the Legal and Policy Domain Workgroup Charter), the following is stated:

The HIE will also need to determine how and for what purposes the protected health information (PHI) in the HIE will be used. The HITAC recommends the NDHIN be initially limited to uses and disclosures of PHI for treatment and continuity of care purposes. Limiting the initial uses and disclosures to treatment purposes makes it easier for entities to comply with federal laws and it helps to build trust and gain confidence in the NDHIN. Once entities participating in the NDHIN get comfortable with using it for these purposes, HITAC may want to consider expanding the purposes and uses of PHI in the NDHIN to potentially include public health reporting, health surveillance, quality measure reporting, research, and law enforcement.

In March 2012, the HITAC approved several policies and agreements for the operation of the NDHIN. [Appendix I](#) is an example of a policy that specifically guides the appropriate use and disclosure of PHI, but comprehensive recommendations are required to continue development of NDHIN procedures.

3.1 Charter

The Data Use Domain Workgroup has four areas of responsibility:

- Review federal, state, and other pertinent regulations/guidance
- Develop recommendations for how PHI in the NDHIN will be used
- Recommend applicable changes to HITAC policies and procedures
- Coordinate with other HITAC workgroups

3.2 Primary Work Activities

The primary work activities of the Data Use Domain Workgroup are as follows:

- Identify data use requirements and needs
- Recommend changes to policies and procedures for management of access, use and disclosure of PHI

- Review and recommend changes to policies and procedures to achieve harmonization of state and federal laws
- Define and agree upon accountability and enforcement for noncompliance of policies and procedures
- Obtain legal opinions as required to complete the workgroups work
- Coordinate with the Clinical, Communication & Education, Legal & Policy, Technical Infrastructure, Finance, and Governance Domain Workgroups

3.3 Key Deliverables

Key deliverables and expected outcomes from the Data Use Workgroup are as follows:

- Recommendations for how PHI in the NDHIN will be used
- Recommendations for if, and how, PHI should be accessed by non-clinical participants and who should have that access (i.e. Payers, researchers etc.)
- Recommendations to the Legal and Policy workgroup for changes to HITAC policies and procedures based upon how data will be used or accessed
- Recommendations for changes to North Dakota laws to meet federal standards and guidelines
- Recommendations to the IT domain workgroup regarding process changes for their incorporation into the technology platform

4 Data Use Issues

The following issues will need to be addressed by the Data Use Domain Workgroup. Resolution of these issues will require the expertise and input from one or more of the other domain workgroups, with final decisions made by HITAC.

4.1 Access and Use (how will PHI be used)

1. With the advent of Accountable Care Organizations, Home Health, MediQHome and other payment reforms, how does the HIE support these endeavors? Some sample questions include the following:
 - a. What data does a provider/payer need to be able to enter into a risk-based contract?
 - b. How often does the information need to be accessed?
 - c. Who should have access to data?
 - d. Is the information needed in a de-identified state or identified?

- e. Is there a need for a data warehouse?
 - i. Who will accumulate the data?
 - ii. Who will create reports?
 - iii. How will reports be requested, created and made available?
 - iv. Who has access to the reports?
 - v. What information should be available?
 - vi. What types of reports are needed?
 - f. As services are provided, how does this information get back to a provider that has accepted a consumer under a risk based contract?
 - g. How is consumer choice handled?
 - i. What would a payer/provider have to produce to show that they have a relationship with the consumer to access the information?
 - ii. What consumer releases are required?
 - iii. How are they tracked within the NDHIN platform?
 - h. Assuming they enter into a contract assuming risk, what information does a provider/payer need access to, how often and to what degree?
 - i. How does Opting out of the NDHIN affect this data?
 - j. What authorizations are currently available from a consumer/patient to allow a provider/payer to access the clinical information to assess whether they want to enter into a risk based contract on behalf of the consumer?
 - k. If authorizations are not currently available, what authorizations are required before the information can be released?
 - l. To assist the Legal and Policy Domain Workgroup, what policies and procedures would need to be updated and what other agreements would need to be developed?
 - m. How the usage of this data would be monitored for reporting to recipients?
 - n. Should there be changes to the sustainability plan identified in the SOP be updated for this type of information?
 - o. What risks are there for using information in this manner
 - i. Consumer Trust
 - ii. Eligibility determination for health insurance
 - iii. Employment
 - iv. Etc...
2. Availability of PHI data to the consumer
- a. What information should be available to consumers?
 - b. How should that data be made available?
 - c. How should it be displayed?

- d. What needs to be available for Meaningful Use Stage 1, 2 and 3 and how can the NDHIN help providers meet those requirements?
3. If an individual “opts out” of the NDHIN, is that individual’s information still stored somewhere in the Network, i.e., in the server of the provider that treated the individual?
 - a. What are the best practices for providers to use when an individual opts out?
 - b. How are other providers notified?
 - c. What business or information technology processes need to be changed?
 4. Develop common agreed upon definitions that all payers and providers can use relating to access of data for each type:
 - a. Payment
 - b. Treatment
 - i. Medical necessity
 - ii. Quality of care
 - c. Operations
 - d. Misuse of data

4.2 Issues from other HITAC Workgroups and Current HITAC Policies and Procedures

There are several issues regularly discussed in other HITAC Domain Workgroups that may need to be referred to the Data Use Domain Workgroup for further analysis, including existing policies and procedures.

The Data Use Domain Workgroup will review these and similar issues then provide recommendations back to the applicable Workgroup for action. Some of these issues include, but are not limited to:

4.2.1 Data Ownership

“Who owns the data?” is an important policy determination because it establishes responsibilities related to the information (e.g. for purposes of complying with HIPAA) and who would be liable for any potential breaches. The HITAC recommends this issue be addressed in any legislation that may be developed.

4.2.2 General Data Issues

The NDHIN will also need to determine how and for what purposes the PHI in the NDHIN will be used. The HITAC recommends the NDHIN be initially limited to uses and exchange of PHI for treatment and continuity of care purposes. Limiting the initial uses and exchange for treatment purposes makes it easier for entities to comply with federal laws and it helps to build trust and gain confidence in the NDHIN. Once entities participating in the NDHIN get comfortable with using it for these purposes, HITAC may want to consider expanding the purposes and uses of PHI in the NDHIN to potentially include public health such as public health reporting and surveillance, quality measure reporting, research, and law enforcement.

4.2.3 Patient Access to NDHIN

The Data Use Domain Workgroup will need to recommend solutions for the issue of whether patients should have direct access through the NDHIN into their EHR or PHR. Under HIPAA, patients have a right to access and have copies of their medical records. However, that does not necessarily mean they should have direct access through the NDHIN like a personal health record.

The HITAC recommends patients not be given direct access through the NDHIN because doing so creates additional security risks and increases the operational burdens of establishing and monitoring passwords. Participating providers should permit patients to see their records and obtain copies if requested. The NDHIN may direct patients to provider sites where more complete health records may be found. Additionally, individual healthcare providers or entities

participating in the NDHIN may choose to give patients direct access into their medical records systems.

4.2.4 Current Policies

The existing list of HITAC policies is located at <http://www.ndhin.org/policies>.

- [NDHIN Policies \(Printable PDF\)](#)
- [Introduction](#)
- [Individual Participation](#)
- [Security](#)
- [Participant and Authorized User Authentication](#)
- [Audits](#)
- [Enforcement](#)
- [Breach](#)
- [Uses and Disclosures of Health Information](#)
- [Accounting for Disclosure and Use](#)

4.3 Harmonization with State and Federal laws

The Data Use Domain Workgroup will review and recommend changes to NDHIN policies and procedures to achieve harmonization of state and federal laws.

Some of the pertinent laws are as follows (refer to the work of the Legal and Policy Domain Workgroup for the most current needs for data use analysis):

- Privacy and Security Rule of the Health Insurance Portability and Accountability Act of 1996 (“HIPAA”)
- Health Information Technology for Economic and Clinical Health Act (“HITECH”): The HITECH Act was passed to rein in any adverse use of patient medical and health information. The target of this legislation was—and remains—hospitals, physicians, pharmacies, and other providers to enable coordination and connectivity while preserving private, secure transfer of information.
- Federal 42 CFR Chapter 1 Public Health Service, DHHS, Part 2 Confidentiality of Alcohol and Drug Abuse Records (“42 CFR Part 2”)
- Other Federal Statutes
- Neighboring State Laws

5 Data Use Domain Workgroup Risks

Understanding how changing environmental factors may impact any strategy is crucial to creating a plan that is supported by diverse stakeholders. Therefore, it is important to examine potential risks and develop mitigation strategies to minimize any impact. Risks for the Data Use Domain Workgroup are identified in the Strategic Plan and Project Plan; they should be reviewed regularly and risk responses identified.

Appendix I – Uses and Disclosures of PHI

<http://www.ndhin.org/resource/policies/uses-and-disclosures-health-information>

Uses and Disclosures of Health Information

Policy Statement: Individual Health information may be accessed only by Authorized Users through the North Dakota Health Information Network (NDHIN) for only the purposes consistent with this policy.

Compliance with Law

All disclosures and uses of health information through the NDHIN must be consistent with all Applicable Laws and the NDHIN Policies, and may not be used for any unlawful or discriminatory purpose. If applicable law requires that certain documentation exist (such as an authorization) or that other conditions be met prior to using or disclosing health information for a particular purpose, the requesting Participant shall ensure that it has obtained the required documentation or met the requisite conditions and shall provide evidence of the documentation and conditions at the request of the disclosing Participant.

Participant Permitted Purposes

A Participant may request and may disclose individual health information through the NDHIN only for purposes of treatment, payment, health care operations, to comply with public health reporting requirements, and as required by law.

Each Participant shall provide or request Individually Identifiable Health Information through the NDHIN only to the extent necessary for the permitted purpose.

Any other use of Individually Identifiable Health Information data is prohibited.

NDHIN Permitted Purposes

NDHIN may use and disclose Protected Health Information (PHI) for the following purposes:

1. for the proper management and administration of the Business Associate, in accordance with 45 C.F.R. § 164.504(e)(4);
2. subject to the Participation Agreement, NDHIN Policies and Procedures, and 45 C.F.R. §§ 164.504(e)(2)(i) and 164.504(e)(2)(i)(B), provide data aggregation services related to the health care operations of the covered entities with which NDHIN has a Participation Agreement;
3. manage authorized requests for, and disclosures of, PHI among Participants in the network;

4. create and maintain a master patient index;
5. provide a record locator or patient matching service;
6. standardize data formats;
7. implement business rules to assist in the automation of data exchange;
8. facilitate the identification and correction of errors in health information records;
and
9. subject to the Participation Agreement and the NDHIN Policies and Procedures, aggregate data on behalf of multiple covered entities.

Prohibitions

Except as permitted by the Health Insurance Portability and Accountability Act (HIPAA) privacy rule, Patient Data may not be used by a Participant or NDHIN for marketing, marketing related purposes, or sales without the authorization of the individual to whom the information pertains.

Information Subject to Special Protection

Certain health information may be subject to special protection under federal, state, or local laws and regulations (e.g., substance abuse). Each Participant shall identify any information that is subject to special protection under applicable law prior to disclosing any information through the NDHIN. Each Participant is responsible for complying with all applicable laws and regulations.

Minimum Necessary

Participants shall disclose and use only the amount of information reasonably necessary to achieve a particular purpose.

Each Participant may share health information obtained through the NDHIN with and allow access to the information by only those workforce members, agents, and contractors who need the information in connection with their job function or duties.

This “Minimum Necessary” policy does not apply to the disclosure of PHI to health care providers for treatment.

Treatment and Insurance Denial Prohibition

A health care practitioner may not deny a patient health care treatment and a health insurer may not deny a patient a health insurance benefit based solely on the provider’s or patient’s decision not to participate in the NDHIN.

Participant Policies

Each Participant shall have in place and shall comply with its own internal policies and procedures regarding the disclosure of health information and the conditions that shall be met and documentation that shall be obtained, if any, prior to making any such disclosure.