

DRAFT INTRODUCTION AND PRINCIPLES FROM GOVERNANCE WG SMALL GROUP

What is the Nationwide Health Information Network (NHIN) and what is its purpose?

“A set of policies, standards and services that enables the Internet to be used for secure and meaningful exchange of health information to improve health and health care”

What is NHIN governance and why is it necessary?

Governance is the mechanism that ensures that the necessary policies, standards and services that enable the use of the Internet for secure and meaningful exchange of health information to improve health and health care are adequately and appropriately established, coordinated, overseen and enforced. The governance functions, taken together, must improve health while ensuring public trust, and enable interoperability while stimulating innovation. Trust and interoperability can only be achieved at a national level with the development of specified information policies, the adoption of some common technical approaches and standards and the establishment of clear oversight and enforcement mechanisms. Today a patchwork of these elements exists to varying levels and is developed and overseen by many different public and private bodies creating overlap in some areas and gaps in others. For trust and interoperability at national scale the roles of these bodies must be clearly specified and coordinated through a framework of governance that adheres to sound principles. Only with a sound governance framework in place can NHIN serve its intended purpose and deliver sustainable solutions.

What are sound governance principles?

1. Transparency and openness
2. Inclusive Participation and Adequate Representation
3. Effectiveness and Efficiency
4. Accountability
5. Distributed governance and devolution
6. Clarity of mission and consistency of actions
7. Fairness and Due Process

SUPPLEMENTARY LISTS OF PRINCIPLES TO CONSIDER

1. List of Preliminary Principles From Initial ONC Governance Discussions

- **Transparency and openness.** Open and transparent processes are essential to building trust. The degree, type, and mechanisms for openness may vary depending on the function and stakeholder needs. To the extent possible, the process of developing governance mechanisms for the NHIN should be open and transparent, with an explicit preference for processes that favor inclusion over exclusion. This should include transparency about the NHIN standards, services and policies themselves, what information sharing they support, and the oversight mechanisms.

- Form should follow function. Choices among the many possible forms of governance mechanisms should reflect the functions over which authority will be exercised and the needs of the relevant stakeholders.
- Accountability. Participating stakeholders should be held accountable and able to hold their governance mechanisms accountable. Because of the important role to be played by the NHIN in the nation's health agenda, those involved in exchange using NHIN, as well as the NHIN governance mechanisms, must also be accountable to the public at large.
- Minimization. Governance mechanisms should operate so that authority is exercised only over those issues whose resolution is necessary for the successful implementation and operation of the NHIN and the accomplishment of its goals. To the extent the governance mechanisms can build upon existing processes and procedures they should do so.
- Distributed governance and devolution. Governance should not be centralized, but distributed among entities with the requisite expertise, capabilities, and standing. Decisions about an issue and should generally be made by those closest to the issue and with the greatest stake in its successful resolution. As a matter of principle, users should have the autonomy to make decisions about what they do and how they do it rather than being told what to do
- Representative governance. The governance mechanisms should permit and encourage robust participation by the diverse set of stakeholders whose interests are affected by the decisional processes.
- Clarity and consistency. Rights, responsibilities, and obligations must be well documented and clear to all stakeholders. Consistency in decision making is helpful, for planning by stakeholders but should not be an obstacle if change is necessary.
- Prescriptive rules. The degree of specificity of rules and the consequences for non-compliance should be directly related to the criticality of the issue. More general guidance allows greater freedom and encourages innovation but may be inappropriate for issues that require uniform treatment. Administrative burdens should be reduced to the absolute minimum and voluntary agreements should, in principle, be preferred.
- Standardization. The degree of uniformity in policies and standards should reflect the requirements of the particular issue. In some instances, such as in enabling electronic health information exchange across institutional and jurisdictional boundaries, standardization is necessary to enable innovation; in other instances premature standardization may inhibit innovation. Standards should not be used to make policy decisions, but should support and be in service to policy goals.
- Retention or delegation of authority. While Congress has provided ONC with broad authority regarding the establishment of a governance mechanism for the NHIN there appears to be considerable leeway as to the degree of authority that can or should be delegated by ONC. Some initial thinking regarding the retention and delegation of authority suggest that:
 - The Federal government should retain functions that are inherently governmental. Federal governmental involvement is essential in certain areas to maintain public trust and to ensure that the NHIN meets the stated goals of the national HIT agenda. Given the Congressional mandate the ONC should retain the right to exercise its authority over

governance in the future to ensure that the goals of the NHIN are met and critical public interests are protected. The retention of that right should not be equated with the intention to exercise this authority if other user driven approaches can accomplish the same purposes.

2. From *Governance of the Operational NATIONWIDE HEALTH INFORMATION NETWORK: Functions and Activities*. Submitted to the Office of the National Coordinator for Health Information Technology by the National eHealth Collaborative Nationwide Health Information Network Governance Framework Planning Working Group, June 26, 2009,

What are the overarching principles of effective NHIN governance?

Governance takes many forms depending upon the nature and structure of the activity that is being governed. It is important to avoid misconceptions about what the NHIN governance model will ultimately look like since the very idea of the NHIN is novel. There is no single model of governance that can simply be adopted “as is.” The Governance Work Group has identified the following as foundational principles to guide the development of NHIN governance.

Distributed Governance: The Governance Work Group anticipates that governance of the NHIN will not be vested in any single organization or group. The complexity of the governance functions and the diversity of core competencies required to execute these functions make it very clear that effective NHIN governance will require the active participation of multiple organizations, individuals and groups, including consumers. Governance of the “network of networks” is and will continue to be inherently complex and requires a diverse range of competencies and perspectives thus making it very clear that effective NHIN governance requires active participation by and distribution among public and private organizations.

Representative Governance: One of the hallmarks of the NHIN is its diversity in terms of those who participate in the exchange of health information. The ONC Strategic Plan affirms that this diversity is purposeful and should be encouraged. As discussed above, currently, participation in and use of the NHIN is voluntary. One major implication of this fact is that the governance model should be designed to balance the collective needs of the NHIN with the unique needs of individual stakeholders, thus promoting stakeholders’ continued use of and participation in the NHIN. Many stakeholders including, but not limited to governmental stakeholders, are subject to specific legal requirements that govern their participation in the NHIN. Any eventual governance structures should take these requirements into consideration.

Transparency and Openness: The foremost basis for establishing trust is engaging in governance activities that are transparent and open to stakeholders. The degree, type and mechanism for openness and transparency will vary in accordance with the specific functions or activities.

Responsive: It is important that NHIN governance exist for the benefit of diverse stakeholders. This concept has many implications and challenges for governance but among the most significant is that the

governance process be responsive to the needs and concerns of both governmental and non-governmental stakeholders. This responsiveness includes giving timely attention to address governing issues and remaining flexible enough to accommodate other legitimate issues.

Accountability: Those charged with NHIN governance occupy a position of public trust. The NHIN is a vital component of the national infrastructure as part of both the healthcare system and the electronic health information exchange infrastructure. Individuals and organizations who participate in the governance process must recognize that they, as well as the actual governing authority(ies), are accountable to the stakeholders, and the public more broadly, in the discharge of their duties. To the extent that multiple groups are involved in governance, their individual interests may at times be in conflict with the interests of the NHIN. There will need to be processes to address such conflicts.