

CONNECTING FOR HEALTHSM

MARKLE FOUNDATION *A Public-Private Collaborative*

July 30, 2007

P. Jon White, MD
Health IT Director
Agency for Healthcare Research and Quality
540 Gaither Road
Rockville, MD 20850

Dear Dr. White,

Connecting for Health is pleased to submit this response to your Request for Information regarding a national health data stewardship entity. This response reflects a collaborative view of the diverse spectrum of stakeholders that make up the Connecting for Health public-private collaborative. The Connecting for Health Steering Group, consisting of more than 70 health care leaders representing the range of stakeholder views, is actively engaged in extending its foundational work on information sharing for the clinical setting into the area of population health. In doing so, we seek to build a framework for private and secure data sharing to achieve better decision-making in the areas of:

- Health research
- Quality and safety, and
- Public health.

We are encouraged that the AHRQ/AQA Request for Information (RFI)¹ embraces the potential of health IT to transform “healthcare performance measurement and the way healthcare data is aggregated, processed and transmitted from which measures of health care quality may be derived and to which the measures could be applied.” Connecting for Health has published a “Common Framework” of technical and policy resources for private and secure health information exchange (HIE) over the Internet based on a “network of networks” model. A network of networks model is now also the core architectural design of an emerging Nationwide Health Information Network (NHIN), as described by the HHS Office of the National Coordinator for Health Information Technology (ONC). Information about the Common Framework can be found at <http://www.connectingforhealth.org/commonframework/>.

Information technology offers new opportunities to foster rapid learning and an evidence-based approach to high-quality decision-making to improve quality,

¹ Federal Register: June 4, 2007 (Volume 72, Number 106), Page 30803-30805

Connecting for Health Response
AHRQ Request for Information on National Health Data Stewardship

research, and public health. Each of these areas faces similar challenges in analyzing information from many electronic data sources that are distributed across a complex and, often, uncoordinated system. We encourage, therefore, a common approach to guide the uses of population health data in a networked environment, with necessary protections to promote trust, prevent misuse, and maintain privacy.

We encourage AHRQ and AQA to develop systems for nationally uniform performance measurement with a humble recognition of our limited and evolving understanding of what information users will seek in order to make better decisions and of the many other activities that make use of similar data. A robust policy and technology infrastructure will support all of these legitimate purposes, earn the public's trust, and allow continued innovation in how we apply health information to improve quality.

We look forward to a continuing dialogue with you and with the AQA leadership in developing an appropriate infrastructure to support quality improvement and other critical goals throughout our health system.

We appreciate the opportunity to provide this input.

The Connecting for Health Steering Group*

Connecting for Health wishes to thank a core team of volunteers who worked together on the preparation of this response: Deven McGraw of the National Partnership for Women and Families, Christine Izui of the Blue Cross Blue Shield Association, Rick Ratliff of Surescripts, Hindy Shaman of PricewaterhouseCoopers LLP, and Thomas Sullivan, MD of Dr. First. Without their diligent review, thoughtful discussion, and careful assessments we could not have achieved this result. In addition, we thank the Markle team; David Lansky, Josh Lemieux, and Adam Wright for their adept preparation of the manuscript in capturing the views and ideas expressed by the Steering Group.

*See page 6 for a list of Connecting for Health Steering Group members

The Connecting for Health Response to the
AHRQ/AQA Request for Information Regarding
A National Health Data Stewardship Entity
Summary

The Connecting for Health Steering Group does not recommend the creation of a new national health data stewardship entity to address quality reporting at this time. Careful consideration must be given as to whether additional functions are required and whether they can be fulfilled by extending the role of existing data stewardship entities.

We make the following observations and recommendations:

1. **Public values must guide the policies and technologies deployed to support quality reporting as well as other critical uses of health data.** Quality measurement and reporting is but one of several important goals of the nationwide health information network. A foundational set of policies regarding patient and provider access and control, handling of sensitive information, notification and audit, appropriate use, commercialization, and data integrity should be common and consistent across all uses of personal health information. Such policies should be set through a transparent and accountable public process. If the quality measurement applications require additional policies, those should be developed as supplements to the foundational policies that apply to the entire network.

2. **The policies and technologies deployed to support quality reporting should reflect the requirements of all appropriate and authorized users.** First, the infrastructure should enable the use of valuable information by those who can act on it to improve health and health care. These include not only the health plans and employers who have implemented public quality reporting and pay-for-performance, but also the many physicians, managers, and provider institutions who need to be motivated and enabled to make systemic improvements and the consumers who need quality and outcome information to weigh treatment options, choose providers and be active participants in their health care.

Second, we believe that the current RFI focuses primarily on the mechanics of data acquisition and less on anticipating the needs of diverse users of performance information. The measure of success for such efforts should reflect the ability to get the right data to the

Connecting for Health Response

AHRQ Request for Information on National Health Data Stewardship

full range of users at the right time, and, ultimately, the effect of these information transactions on health outcomes.

3. **The policies and technologies deployed to support quality reporting should fit within a broader strategy to enable connectivity across a network.** In a “network of networks” model of data exchange, all participants must adopt a minimum, uniform set of information policies and technical standards in order to leverage existing information sources, protect privacy, and maintain public trust. These policies form the foundational layer for all population-level information services; they are not specific to quality measurement and reporting. A well-designed network will allow a diverse set of authorized users to take advantage of timely, high-quality data with appropriate protections for personal privacy and civil liberties.
4. **A distributed but coordinated approach to set measurement and aggregation policies could stimulate innovation and better meet user needs.** The RFI describes a number of functions, such as data collection, aggregation, risk adjustment, weighting, etc., which are associated with some approaches to performance reporting. These are functions of specific applications but they are not intrinsic to the network itself. The network infrastructure should permit multiple approaches to innovate and adapt to progress in measuring and improving quality. A distributed but coordinated approach is a better way to meet the legitimate and evolving needs of consumers, purchasers, clinicians, and health care administrators to identify and address quality variations and deficiencies.
5. **A single data repository for aggregating and reporting quality data could ultimately fail to meet user needs, increase the risk of large scale privacy violations and undermine public trust.** Connecting for Health does not believe that the evolving nationwide health information network should seek to support each of the myriad of information functions (like quality reporting, public health and research) through the creation of large, centrally operated, single-purpose databases of personal health information.
6. **The research and quality improvement agenda should include a comprehensive assessment of the policies and architectural requirements needed to support the use of**

population-level information by diverse users to improve quality and safety.

7. **A distributed and non-hierarchical network will require governance mechanisms to set common policies and technologies, monitor their implementation, coordinate the various efforts, and guide “good network citizenship.”** These mechanisms should coordinate and define a common framework; guide user behavior; resolve disputes; ensure compliance; and facilitate learning and constant improvement. A governance model that conducts these functions will require sufficient authority and influence with both the general public and with health sector participants to overcome existing unease and resistance.

STEERING GROUP MEMBERSHIP

Antoine A. Agassi
Director and Chair
State of Tennessee eHealth Council

Peter A. Andersen, MD†
Public Health and Clinical Informatics Officer and Relationship Manager
Lockheed Martin Corporation

Zoë Baird
President
Markle Foundation (ex-officio)

Robert B. Bogin, MD
Managing Director
Strategy and Collaborations Health Promotions Department
American Cancer Society

William R. Braithwaite MD, PhD
Health Information Policy Consultant
Braithwaite Consulting

Carolyn M. Clancy, MD*
Director
Agency for Healthcare Research and Quality

Janet Corrigan, PhD, MBA
President and Chief Executive Officer
National Quality Forum

Robert M. Cothren, PhD
Technical Fellow and Chief Scientist, Health Solutions
Northrop Grumman Corporation

Rex Cowdry, MD
Executive Director
Maryland Health Care Commission

Mike Cummins
Chief Information Officer
VHA, Inc.

Mary Jo Deering, PhD*
Director for Informatics Dissemination
Center for Bioinformatics
National Cancer Institute
National Institutes of Health, USDHHS

Carol Diamond, MD, MPH
Managing Director, Health Program
Markle Foundation
Chair, Connecting for Health

Connecting for Health Response

AHRQ Request for Information on National Health Data Stewardship

David A. Epstein
Director, Public Sector Solutions
IBM Software Group

Colin Evans
Director, Policy and Standards
Digital Health Group, Intel Corporation

Stefanie Fenton†
Senior Business Leader, Quicken Health
Intuit, Inc.

Mark Frisse, MD, MBA, MSc
Director, Regional Informatics
Vanderbilt Center for Better Health

Daniel Garrett
Managing Director
PricewaterhouseCoopers LLP

J. Peter Geerlofs, MD†
Chief Medical Officer
Allscripts Healthcare Solutions

John P. Glaser, PhD
Vice President and Chief Information Officer
Partners Healthcare System

Janlori Goldman, JD
Director
Health Privacy Project

John D. Halamka, MD
Chief Information Officer
CareGroup Healthcare System

Douglas M. Henley, MD, FAAFP
Executive Vice President
American Academy of Family Physicians

Joseph M. Heyman, MD
Chair-elect, Board of Trustees
American Medical Association

Gerald Hinkley, JD
Partner
Davis Wright Tremaine LLP

Kevin Hutchinson
Chief Executive Officer
SureScripts

Connecting for Health Response

AHRQ Request for Information on National Health Data Stewardship

Michael Jackmant
Chief Technology Officer, Health Imaging Group
Eastman Kodak Company

Charles Jaffe, MD, PhD
Chief Executive Officer
Health Level Seven, Inc.

William F. Jessee, MD
President and Chief Executive Officer
Medical Group Management Association

Michael L. Kappel
Senior Vice President, Government Strategy and Relations
McKesson Provider Technologies

Brian F. Keaton, MD, FACEP
President, American College of Emergency Physicians
Chair, Northeast Ohio Regional Health Information Organization (NEO RHIO)

Linda L. Kloss, RHIA, CAE
Chief Executive Officer
American Health Information Management Association

Allan M. Korn, MD, FACP
Senior Vice President, Clinical Affairs
Blue Cross Blue Shield Association

David Lansky, PhD
Senior Director, Health Program
Executive Director
Personal Health Technology Initiative
Markle Foundation

Jack Lewin, MD
Chief Executive Officer
American College of Cardiology

Stephen H. Lieber, CAET
President
Healthcare Information and Management Systems Society (HIMSS)

J. P. Little
Chief Operating Officer
RxHub, LLC

John R. Lumpkin, MD, MPH
Senior Vice President, Director, Health Care Group
Robert Wood Johnson Foundation

Janet M. Marchibroda
Executive Director, Foundation for eHealth Initiative
Chief Executive Officer, eHealth Initiative

Connecting for Health Response

AHRQ Request for Information on National Health Data Stewardship

Philip Marshall, MD, MPH†
Vice President, Product Strategy
WebMD

Howard Messing
President and Chief Operating Officer
Meditech

Arnold Milstein, MD, MPH
Medical Director
Pacific Business Group on Health, The Leapfrog Group

Farzad Mostashari, MD, MSPH
Assistant Commissioner and
Chair Primary Care Information Taskforce
New York City Department of Health and Mental Hygiene

Margaret E. O'Kane*
President
National Committee for Quality Assurance

Dennis S. O'Leary, MD
President
Joint Commission on Accreditation of Healthcare Organizations

J. Marc Overhage, MD
Director, Regenstrief Institute, Inc.
President and Chief Executive Officer, Indiana Health Information Exchange (RHIO)
Professor of Medicine, Indiana University School of Medicine

Herbert Pardes, MD
President and Chief Executive Officer
New York-Presbyterian Hospitals, University Hospitals of Columbia and Cornell

Carol Raphael, MPH
President and Chief Executive Officer
Visiting Nurse Service of New York

Alison Rein*
Senior Associate
Academy Health

Craig Richardson
Vice President, Health Care Strategy and Development
Johnson & Johnson Health Care Systems, Inc.

Wes Rishel*
Vice President and Research Area Director
Gartner, Inc.

John Rother
Group Executive Officer of Policy and Strategy
AARP

Connecting for Health Response

AHRQ Request for Information on National Health Data Stewardship

Peter A. Schad, PhD*
Health Informatics Coordinator
National Cancer Institute
Division of Cancer Control and Population Sciences

David Schulke
Executive Vice President
The American Health Quality Association

Steve Shihadeh
General Manager, Health Solutions Group
Microsoft, Inc.

Clay Shirky
Adjunct Professor, New York University
Graduate Interactive Telecommunications Program
Chair, Consumer Authentication Work Group

Ellen Stovall
President
National Coalition for Cancer Survivorship

Barry M. Straube, MD*
Chief Medical Officer
Director, Office of Clinical Standards & Quality
Centers for Medicare & Medicaid Services

Steven J. Steindel, PhD
Director, Data Standards and Vocabulary
Centers for Disease Control and Prevention, USDHHS

Thomas E. Sullivan, MD
Past President, Massachusetts Medical Society
Partner, Women's Health Center Cardiology
American Medical Association, Council on Medical Service
Chief Strategic Officer, DrFirst.com

Paul Tang, MD
Chief Medical Information Officer
Palo Alto Medical Foundation (PAMF), Sutter Health

John Tooker, MD, MBA, FACP*
Executive Vice President and Chief Executive Officer
American College of Physicians

Micky Tripathi
Chief Executive Officer
Massachusetts eHealth Collaborative

Charlene Underwood, MBA
Director, Government And Industry Affairs
Siemens Medical Solutions

Connecting for Health Response

AHRQ Request for Information on National Health Data Stewardship

Dennis J. Van Liew
Senior Director, Strategic Management Group
Pfizer Global Research and Development
Pfizer, Inc.

Robert Wah, MD
Chief Medical Officer and Vice President
Computer Sciences Corporation

Andrew M. Wiesenthal, MD
Associate Executive Director
The Permanente Federation

Marcy Wilder, JD
Partner
Hogan & Hartson LLP

Robert B. Williams, MD, MIS
Director, Healthcare Practice
Deloitte Consulting

Hugh Zettel
Director, Government and Industry Relations
GE Healthcare Integrated IT Solutions

* **Abstaining from this response**

† **Could not participate in review of this document within allotted time frame**

Introduction

- Our health care sector is made up of some 6,000 hospitals, a large number of clinicians including 750,000 physicians, over 2 million nurses, health professionals and other care providers, and myriad public and private insurers at national and local levels. In this complex and pluralistic environment, the more narrowly conceived and centrally controlled the data collection system (no matter how well-intentioned), the less likely that we'll see a far-reaching, widely distributed participation and impact on quality.
- Structured performance information gathered from providers can help improve the safety and quality of health care if the approach is right. We focus on two purposes here: to help providers and patients improve care and to help consumers and purchasers evaluate and reward quality (either through selection or payment). We believe these two purposes are closely aligned, and that the information infrastructure should strengthen – not weaken – that alignment.
- Indeed, we believe that a 21st century health information environment should empower a rich variety of users, instead of creating new information “stove pipes” and silos.
- In the 21st century, the United States must have an information-sharing environment that enables a variety of users to generate knowledge and make better health and health care decisions by analyzing data from disparate sources. This approach must be based on principles that support the efficient exchange of accurate information as well as the protection of individual privacy and personal choice.
- Some of the most serious challenges facing health care today — medical errors, inconsistent quality, lack of timely drug safety research, bio-security concerns, rising costs, and lack of access to high quality care — can be addressed, in part, through better information analysis and sharing through the effective application of information technology (IT), coupled with leadership, rational incentives and clear priorities.

A Distributed, Networked Approach

- Leaders within the highest levels of government and the private sector consider the creation of a more connected health care system as an important pillar of needed health reforms.

Connecting for Health Response

AHRQ Request for Information on National Health Data Stewardship

- The broad goal of a connected health care system must be to get the right information to the right person at the time of decision-making in a private and secure way in order to improve health and health care. This requires appropriate sharing of data across authorized entities, communities, regions, specialties and sectors.
- Over the last five years, the Connecting for Health collaborative has concluded that only a distributed, networked approach can reasonably meet the needs of our large, fragmented, and complex health care system.
- The potential advantages of such a distributed, networked approach for providing an information exchange environment include:
 - Broadly distributed and secure access to information;
 - Broadly distributed value, facilitating the use of information resources for multiple uses and decisions;
 - Broadly distributed opportunity for innovations and applications that derive value for end users;
 - Improved transparency, accountability and legitimacy, and
 - Improved data quality and integrity — with cleaner data at the edges of the network.
- We caution against a national centralized data repository as “the” approach to quality measurement. There are many reasons for this caution, including:
 - It is not plausible to believe that a single repository or entity will be able to satisfy all necessary uses and analysis of health data for quality assessment or other population health objectives.
 - Public trust is critical for major aggregate data initiatives, and the public is more likely to support keeping the most sensitive data close to where it is captured.²
 - Timeliness, accuracy and validity of data are harder to address as data are maintained farther from their source.
 - The creation of such a single repository creates a significant risk of catastrophic breach.
 - Building and maintenance costs for developing this kind of centrally controlled infrastructure on a national scale are enormous and have the potential to generate unnecessary and redundant resource requirements.

² California HealthCare Foundation: *National Consumer Health Privacy Survey 2005*.

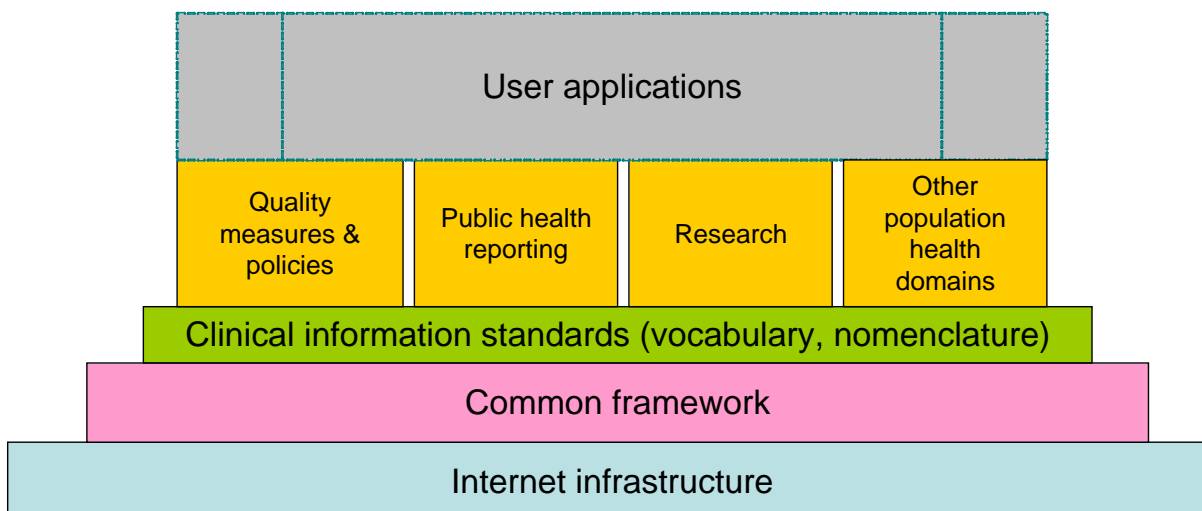
Connecting for Health Response

AHRQ Request for Information on National Health Data Stewardship

- In many respects, the quality area is not exceptional compared with other uses of de-identified data drawn from across the network, such as public health. We believe that all such uses should adhere to certain basic, uniform open standards and policies (or a “common framework”) to create trust and reduce inefficiencies in the network.
- If, in the quality arena, a group of stakeholders (e.g., the AQA or NQF) wishes to define a set of operating rules for a particular application, such as physician performance reporting, it is logical that it would want to set up a structure to do so. However, as described in Table A below, there are certain policies that are best handled commonly across the network, and certain functions or policies best left to individual applications. If the network-wide rules are well-established and trusted, then the policy requirements of each application (such as AQA quality requirements) are more appropriately narrowed and easier to achieve. The quality initiative can build upon a network-wide foundational policy layer. It is particularly important that any quality reporting applications help, rather than hinder, the direct provision of patient care. For example, we expect that a network-based approach would allow clinicians and patients to compare the quality of care they are giving or receiving based on outcomes.
- The implications of all of the above are:
 - The attempt to drive health care quality should be viewed as an “application” that runs atop a common distributed information infrastructure (i.e., a network of networks) and which fulfills other aggregate data needs (e.g., public health, research, and other quality efforts).
 - The core focus should be on the creation of such a distributed infrastructure, using a common framework of policies and standards for data transmission, messaging and privacy protection.

The diagram below depicts the “stacks” that enable applications for better decision-making across several population health domains:

Connecting for Health Response
AHRQ Request for Information on National Health Data Stewardship



- Many of the RFI questions are application-related, such as data attribution and analysis. As a multi-stakeholder collaborative, we remain agnostic about end-user applications and encourage ongoing innovation in this area. We therefore do not answer each specific question of the RFI.

The Connecting for Health Common Framework

- Connecting for Health has worked for three years to develop the key attributes of a Common Framework for health information exchange – identifying both the technical and policy features that can build public trust in an effective health information environment. The components were placed in the public domain at www.connectingforhealth.org in April 2006.
- A foundational component of the Common Framework architecture is the protection of privacy, because privacy and confidentiality are core public values in the handling of personal health information.
- To date Connecting for Health has proposed a nationwide framework for a secure environment based on a “network of networks” to enable the sharing of personal health information where and when it is needed for patient care while protecting privacy. This framework includes mechanisms for authentication, consent, and trust relationships.
- Similarly, a distributed “network of networks” must also support critical needs to evaluate and improve health care and the health of the nation’s population.
- In this early phase of our exploration into how the Common Framework can be applied to address the requirements related to population health

objectives such as quality improvement, research and public health, we have drafted the following set of “First Principles.”

Connecting for Health First Principles for Population-Level Data Analysis and Decision-making

A. Designed for Decisions

A 21st century health information environment will focus on improving the decision-making ability of the many actors in the health sector. Information technology provides value to health and health care by bringing timely, accurate, and appropriate information to a decision-maker at the right time and in the right way. Data collection alone does not lead to better decisions – indeed, too much or poorly organized data can distract us from filtering up to the most useful information upon which to base a given decision.

B. Designed for Many

A 21st century health information environment should empower a rich variety of users. The network can feed analytic tools in many settings and provide value to millions of users – to consumers, families, health professionals, policy makers, public health officials, scientific investigators, and many others. The technical and policy framework for the network should anticipate the diverse requirements of this array of users – much like the Internet itself.

C. Shaped by Public Policy Goals and Values

A 21st century health information environment should achieve society’s goals and values – such as to improve the health of individuals; to make the care delivery system more effective, safe, and efficient; to reduce and manage threats to public health; to respect confidentiality; and to increase scientific knowledge. The network serves both the personal care setting and public needs and values. It is obliged to respect and further public values such as individuals’ ability to control the use of their information. Such policy and public values must be made explicit and subjected to public discussion, and then architected into the technology at the outset.

D. Boldly Led, Broadly Implemented

A 21st century health information environment should be guided both by bold leadership and strong user participation. The

Connecting for Health Response

AHRQ Request for Information on National Health Data Stewardship

network's value expands dramatically with the number of needs it can meet and the number of participants it can satisfy. The network is not bound, for example, by a hospital's walls or the parameters of a research grant. A forward-looking generation of health care leaders will know that they are not building information systems to keep data from competitors or to deprive others of the opportunity for insight, but that they are contributing to a diverse, flexible, and expansive body of knowledge. Value will be created by those who are most skilled at accessing the right information, applying the right intelligence, and solving the right problems. New health care leaders must come together with a common vision to develop an architecture and policy framework that facilitates this kind of information environment.

E. Possible, Responsive and Effective

A 21st century health information environment should grow through realistic steps. Overly complex or ambitious technology can exacerbate the problems we face, or introduce new ones. It is therefore essential to seek realistic steps towards the ultimate vision of a responsive, nimble system to enhance decision-making.

F. Distributed but Queriable

A 21st century health information environment should be comprised of a large network of distributed data sources. It should be possible to query across all of these sources without needing a central structure. We must avoid replicating (or even exacerbating) the current problem of uncoordinated health data silos, which result from duplicative efforts to build repositories and analytic systems, often drawn from the same data sources. We must also avoid the temptation to create a single repository of health information for each population health purpose.

G. Trusted through Safeguards and Transparency

A 21st century health information environment should earn and keep the trust of the public through policies that provide safeguards and transparency. Americans will support sharing their sensitive health information across the Internet if they trust in the security, privacy, and appropriate uses of the network. Such trust can be established through a combination of safeguards (including both technical and non-technical approaches) and transparency (of both decision-making process and practice). The technical architecture will include tools to protect data against break-ins and theft, to provide anonymization, and to

prevent data corruption or errors. The policy architecture will develop clear rules and guidelines through an inclusive and transparent ongoing process.

H. Layers of Protection

The 21st century health information environment should protect patient confidentiality by emphasizing the easy movement of queries and responses, rather than of raw data. The level of protection should be scaled to the risks, with identifiable data subject to the highest levels of protections. Many classes of authorized users should be able to send standardized queries across the network, allowing appropriate data sources to respond with aggregated or anonymized “answers” without compromising personally identifiable data. When requirements for additional identifiers are appropriate, additional levels of protections should be applied.

I. Accountability and Enforcement of Good Network Citizenship

A 21st century health information environment should encourage and enforce good network citizenship by all participants. Health sector leaders should take steps to increase the appropriate movement of health information and discourage those who pursue unauthorized uses. To receive public funding or to be welcome in various information exchange initiatives, participants must abide by both the technical and policy rules that permit the larger national network to function. The data-sharing infrastructure must include accountability and strong mechanisms for policy enforcement, auditing of data uses, assignment of liability for data misuse, and mechanisms for redress.

Implications

- These principles of population-level data use suggest a separation between the standards and rules needed to support any particular application – such as performance measurement, and the standards and rules required by any and all applications that wish to access health information across the network. While there may be a need for an entity to set standards and rules specific to performance measurement, we believe that such an entity would need to operate within and subordinate to the broader policy regime and architecture of the network as a whole.
- We have identified network policies (which we will address) vs. information use or “application” policies (which we won’t address).

Connecting for Health Response

AHRQ Request for Information on National Health Data Stewardship

- The table below illustrates how each of the stewardship functions identified in the RFI should be addressed in a way consistent with a “network of networks” approach:

TABLE A

Function	RFI Proposed Scope of Work	Connecting for Health Comment	Related RFI Questions
Data aggregation	<p>“Should address various data aggregation issues including required characteristics of aggregators (e.g., they should be trusted and respected entities), transparency of aggregation processes, control and ownership rights of the data, potential liability within data aggregation processes, and issues that arise when competing aggregation efforts are in a single market area; should ensure that the experience of existing aggregation efforts are leveraged.”</p>	<p>Centrally operated databases are often impractical and face a difficult time satisfying a necessary pluralism of demands.</p> <p>If key stakeholders in the performance measurement arena find it necessary to create an entity that defines methods or policies for data aggregation, those methods and policies should not preclude other uses of the nationwide network, including other approaches to the analysis of quality data.</p> <p>A single national aggregator is not needed to support the availability of comparative performance data.</p>	<p>1, 2, 3, 4, 5, 6, 7, 10, 13, 16</p>

Connecting for Health Response
 AHRQ Request for Information on National Health Data Stewardship

Function	RFI Proposed Scope of Work	Connecting for Health Comment	Related RFI Questions
<p>Data collection (includes identification of data sources)</p>	<p>“Should set policies, rules and standards for collecting public and private sector data from relevant stakeholders, including providers, employers, health insurance plans and others based on an agreed-upon measurement set; should assess the pros and cons of using data derived from administrative data (e.g., claims, pharmacy and lab data), medical record review and surveys, and develop policies that prioritize data sources based on various dimensions.”</p>	<p>Same as above. No one entity should be the only one to have access to, analyze or act on the data.</p> <p>A separation of roles is important: an appropriate entity may have the authority to require reporting and disclosures, and parties may enter into contracts to enable such disclosures. The network is designed to enable such disclosures, but the appropriate authorizations come from another entity – not the network itself.</p>	<p>1, 2, 3, 4, 5, 6, 7, 10, 13, 16</p>
<p>Attribution</p>	<p>“Should address at what specific level(s) data should be aggregated (e.g., individual physician level or group practice level). When making this determination, should consider sample size issues and physician/practice identifier issues.”</p>	<p>See answer above for “Data Collection.”</p> <p>This is an application, not a network function.</p> <p>This is part of making questions standard. This does not need to be decided in the design of the system. Different users will have different needs.</p>	<p>1, 2, 3, 4, 5, 6, 7, 13, 16</p>

Connecting for Health Response
 AHRQ Request for Information on National Health Data Stewardship

Function	RFI Proposed Scope of Work	Connecting for Health Comment	Related RFI Questions
Methodologies	"Should set methodological rules and standards for aggregating data, including those addressing risk adjustment, measure weights and sample size."	Same as above.	1, 2, 3, 4, 5, 8, 11, 13
Data analysis	"Should set data analysis rules and standards, including those relating to trending, benchmarking, distribution, outlier analysis, correlation analysis and stratified analysis (variance between regions and states)."	Same as above.	1, 2, 3, 4, 5, 8, 13
Data validation (audits)	"Should set policies, rules and standards to ensure that the validity of the data submitted is independently audited."	Same as above. In addition, there needs to be a mechanism to ensure that an entity performing an aggregation function maintains the integrity of the data from the source.	1, 2, 3, 4, 5, 9, 10, 13, 14, 15

Connecting for Health Response
 AHRQ Request for Information on National Health Data Stewardship

Function	RFI Proposed Scope of Work	Connecting for Health Comment	Related RFI Questions
Uses of Data	"Based on current law, should recommend allowable and non-allowable uses of data. Allowable data uses may include quality and efficiency improvement, consumer reporting, accountability, and pay for performance programs; also should, address allowable secondary uses of raw/primary data."	All of these proposed uses should occur consistent with a common framework of network rules, developed through a transparent and accountable process. The Connecting for Health policy framework provides one such starting point.	1, 2, 3, 4, 5, 8, 9, 10, 13
Data access	"Should specify who should have access to data and applicable limitations, such as confidentiality and privacy rules; should consider policies which allow contributors, including both public and private sector entities, to have access to their own data as well as information which allows them to compare their data against benchmarks."	Same as above.	1, 2, 3, 4, 5, 13

Connecting for Health Response
 AHRQ Request for Information on National Health Data Stewardship

Function	RFI Proposed Scope of Work	Connecting for Health Comment	Related RFI Questions
Data sharing and reporting	"Should develop guiding principles for public reporting and reporting back information to clinicians. Screening processes to ensure valid reporting also should be addressed."	Reporting of performance data occurs as part of an application, not as a network function. Plurality is better. Various users should be able to receive the most useful and appropriate outputs to support the decisions they must make. Formats for clinical managers, front-line clinicians, and consumers can all appropriately vary and innovators should be encouraged to add value to the raw performance information.	1, 2, 3, 4, 5

- Bottom line: Our goal is to have a performance information system that reflects the First Principles outlined above (particularly design for decisions and pluralism). We believe that such a system can accomplish the quality goals described in the RFI and serve as a catalyst for the development of, and increase participation in, such an effort.
- We are hopeful that such a performance information system will not be designed purely for retrospective measurement, but instead, to enable prospective approaches to quality improvement, such as the capacity to provide information to authorized users capable of acting on it at the point of decision making, and the capacity for providers and patients to initiate queries, collaborate and provide feedback as a way to encourage people to cooperate while improving the use and quality of the data. We refer to this as the "virtuous circle" of data reporting. In a well-designed network, as data are collected and analyzed in a quality-supporting clinical system, new knowledge is created and fed back to clinicians and data sources, analysts and managers. As the cycle repeats, knowledge grows and quality can improve.

Implications for governance

- A networked model of information flow represents a significant departure from the historical way of doing business. It is distributed and non-hierarchical. A health information network will require more than a common framework integrating common policies and technical standards. It will require governance mechanisms that determine those common policies and technologies, monitor their implementation, coordinate the various efforts, and guide “good network citizenship.” Governance must include mechanisms to ensure compliance with rules and guidelines that protect security and privacy and to allow the system to adapt to changing circumstances. A governance mechanism that conducts these functions will require sufficient authority and influence with both the general public and the health and other sector participants to overcome existing unease and resistance.

- Connecting for Health has previously described (in 2005 when it participated in the Collaborative Response to the NHIN RFI³) the following functions and characteristics as essential for a successful and trusted governance regime; they do not necessarily have to fall to a single entity:
 - **Coordinating and defining a common framework** – It must provide a uniform coordination mechanism for a distributed national health information exchange network, identifying and recommending the “common” information policies, technical and data standards essential for establishing privacy, security and interoperability.

 - Given its public importance, and the possibility that its authority will influence activities beyond its initially prescribed scope, any governance regimes should:
 - Have a bounded and well-defined mission;
 - Receive strong strategic direction from public interest leadership;
 - Facilitate and encourage strong participation by all affected stakeholders on recommending standards and policies that support the strategic goals;
 - Ensure equal representation of key interest groups, including support for consumers and patients;

³ Available online at:
http://www.connectingforhealth.org/resources/collaborative_response/collaborative_response.pdf

Connecting for Health Response

AHRQ Request for Information on National Health Data Stewardship

- Provide for accountability to affected stakeholders, including effective independent review procedures, and
 - Promote openness and transparency, including procedural and financial transparency.
- **Guide user behavior** - It must guide user behavior through clear, consistent guidelines that are issued promptly but evolve over time as more is learned. Guidelines should especially cover privacy issues. Quality training on guidelines and policies and the use of incentives to encourage the correct behavior are also essential to ensuring appropriate behavior within the national health information exchange environment.
 - **Resolve disputes** - It must have a systematic, workable mechanism for quickly and consistently resolving disputes between and among entities and individuals about information sharing. Over time, a “common law” of decisions should develop to guide resolution of future disputes.
 - **Ensure compliance** - It must ensure compliance with the common framework and ensure accountability for misuse through a system of ongoing compliance monitoring and rigorous oversight. The compliance monitoring must rely on automated and manual reviews of real-time audit log information to determine whether guidelines are understood and being applied correctly, and take immediate action to correct errors that are discovered. Oversight must come from within and outside of entities and enforce a clear, calibrated, and predictable system of accountability.
 - **Facilitate learning and constant improvement** - It must provide mechanisms to upgrade and adapt the environment to changing circumstances and to leverage information in support of decisions and challenges that were unforeseen at the time of creation.