

**Testimony to  
Health IT Policy Committee  
Governance Workgroup**

by  
Maggie Gunter, PhD  
President and Executive Director  
LCF Research  
Albuquerque, New Mexico  
September 28, 2010

**Introduction**

My name is Maggie Gunter. I am honored to have been invited to testify to the Health IT Policy Committee's Governance Workgroup. My main focus will be thoughts concerning the governance issues we have encountered in developing and operating New Mexico's health information exchange in the following topic areas:

- Trust
- Privacy and Security
- Interoperability
- Respective Roles of States vs. the Federal Government

First, as context for my remarks, I would like to provide you some background concerning our organization and its involvement in leading the state's HIE. I am a health services researcher and medical sociologist, and I lead LCF Research, a non-profit applied health research and innovation institute located in Albuquerque, New Mexico that created, manages, and staffs the New Mexico Health Information Collaborative (NMHIC), the state's designated entity for health information exchange. LCF's interest in initiating the health information exchange stemmed from our pioneering work in disease management in the early 1990's in a large integrated system and our recognition that such work would have been even more effective and sustainable if full electronic medical records and associated performance data had been available then and if there had been the capacity to have a patient's electronic health data follow them across the community and across health care organizations. Key steps in our HIE development have been:

- Beginning in 2004 with a 3-year award from the Agency for Health Research and Quality, LCF has received a series of federal grants and matching state and community funds that have allowed us to work with numerous community stakeholders to develop and operate New Mexico's health information exchange network and to promote electronic health records adoption in our state.
- In the 2004-2007 period, NMHIC developed the initial community governance structure (the NMHIC Steering Committee and its various workgroups), built a Master Patient Index and other components of the HIE technical architecture, and implemented several pilot HIE pilot programs in the Albuquerque and Taos communities.
- In late 2007, LCF received one of the first 9 ONC contracts awarded nationally to participate in the Nationwide Health Information Network Trial Implementation Project, which allowed NMHIC to make significant developments in the HIE technical infrastructure.
- In 2009, Governor Richardson designated LCF/NMHIC as the State-designated Entity for ARRA purposes, a major milestone.
- In 2010, LCF was awarded two ONC cooperative agreement to (1) expand the State HIE and (2) to develop and operate the New Mexico HIT Regional Extension Center and received one of 15

contracts awarded nationally by the Social Security Administration to use the HIE to expedite the current cumbersome and paper-based process to apply for SSA disability.

- New Mexico was the first state to have an ONC-approved State Strategic and Operational HIE Plan and the first to be awarded State HIE implementation funding.
- An e-reporting initiative with the NM Department of Health is now live and channels lab results on notifiable conditions as well as emergency department utilization data from health systems to the Department of Health using the HIE.
- The Master Patient Index now contains 1.3 million unique patients (out of a state population of about 2 million). Data suppliers include 13 hospitals, the two largest testing laboratories, the two largest medical groups. Virtually all of the major health systems in the state and a number of rural facilities and medical groups are participating. The University of New Mexico Health Sciences Center is expected to join as a data supplier by the end of 2010.
- Operational clinical use is anticipated by the end of 2010.

## **Evolution of NMHIC Governance**

NMHIC's governance structure has evolved along with our health information exchange network. Our governance structure has evolved from an advisory group of community stakeholders in support of the initial NMHIC project in 2004-2005 to a formal statewide Board of Directors that now has true oversight over LCF as a whole including specific committees monitoring its HIT and research functions (2009-2010).

From NMHIC's inception, LCF was always aware that broad participatory governance was very important, and this was facilitated by AHRQ's wise decision to require that all AHRQ HIE funding be 100% matched by community organizations. This requirement facilitated community engagement from the proposal stage and led to the creation of a broadly representative NMHIC Steering Committee in 2005, a public/private advisory group consisting of 35 community stakeholder organizations including the major health plans, medical groups, and health systems, employers, professional associations, testing labs, employers, the State Department of Health, the State's CMS-designated Quality Improvement Organization, the state Primary Care Association (safety net providers), other HIT initiatives such as telehealth, the University of New Mexico Health Sciences Center, and consumers. When the NMHIC Steering Committee was replaced by a statewide Board of Directors, key additional stakeholders were added to the membership, most notably, the NM Medical Assistance (Medicaid) Division and representatives of a number of rural hospitals and medical groups. Coordination among the various HIT initiatives in the state and inclusiveness have always been of key interest in our governance design.

## **Trust and Governance**

Governance structures that engender trust are critical to the success of an HIE. Frankly, trust was an issue in the initial years of NMHIC's development, since LCF was at that time known as Lovelace Clinic Foundation and had been closely associated with Lovelace Health System, a major integrated system headquartered in Albuquerque. We at LCF recognized from the first that neutrality in leadership and governance was important with such a new and innovative enterprise, so we provided support to establish a new neutral 501 (c) (3) organization that would be led by a separate community-based Board and would take over from LCF to run NMHIC after the initial incubation period. With legal and other support from LCF, a new non-profit, the RHIO Grande, was established, along with a new Board of Directors. As this process progressed, LCF/NMHIC continued to develop the HIE infrastructure and work with the NMHIC Steering Committee, and there was growing community trust in NMHC's collaborative leadership team. NMHIC leaders reached out to other HIT initiatives in the state to assure coordination and lack of duplicative effort. Presbyterian Health Services, the largest health system in the state, provided initial leadership as a data supplier to NMHIC, which was a significant and positive sign since Lovelace was and is a major competitor of Presbyterian's.

Over time, the NMHIC team, which is comprised of professionals with a collaborative spirit, established sufficient community trust that in late 2008, the Board of the nascent RHIO Grande non-profit decided to merge into the LCF/NMHIC structure, which was a major milestone for the HIE and its governance. In turn, Lovelace Clinic Foundation decided to do business under a neutral name, LCF Research, and to establish a large and inclusive statewide Board of Directors to govern the whole organization, with a powerful Board Committee, the HIT Committee, to govern NMHIC and the HIE specifically. The new Board of Directors and HIT Committee became operational in January, 2010, and includes representation from the State Medical Assistance Office (Medicaid) as well as several rural hospitals and rural medical groups.

In summary, the steps the NMHIC team took to establish trust through governance were:

1. Establishment of a Board of Directors to provide oversight and governance to the HIE
2. The ByLaws establish a large and diverse Board to help assure broad community input across the state, require notification of conflicts of interest, policies for public announcement of upcoming Board meetings, and distribution of agendas prior to each meeting.
3. A special Board committee with significant decision making power was established to provide oversight specifically to the NMHIC/HIE Division.
4. The management of LCF and the HIE are accountable to the Board.
5. The management and staff of the HIE provide regular reports to the Board to facilitate transparency, including strategic and operational business plans and budgets.
6. Accountability and transparency are further promoted by management reports to the Board of threats and weaknesses as well as achievements and strengths.
7. Members of the Board were invited to review the strategic and operational plans and make recommendations for changes and corrections. It is noteworthy that a significant number (8-10 of the Board reviewed the entire lengthy HIE plan and provided meaningful and thoughtful questions and suggested revisions, which were incorporated.
8. At management's request, a **Sustainability Task Force was recently authorized by the Board to further engage the Board and non-Board community leaders in identifying those HIE services that are of priority value to the New Mexico community so key stakeholders would pay to receive those services. We view NMHIC as a public utility** that is the joint responsibility of the Board, management, and the community to work together to support. We think this will help solidify the sense of "ownership" of the process that is important for community stakeholders to have if the HIE is to be sustainable in its operational phase.
9. **Consumers** have been involved in NMHIC's governance since the inception—indeed, it was a non-health community leader who first voiced the need for sharing of data across competing health care organizations as an important need in New Mexico. While consumers are actively involved on the Board, we are still working to further engage a range of consumers in even more meaningful ways, especially as we educate the public concerning the benefits of the HIE, the privacy and security protections which are in place, and their right to opt-out and how to do so.

## **Privacy and Security Issues in Governance**

Privacy and security issues have emerged over the past several years as much more difficult and significant issues than the NMHIC team had initially anticipated. We had initially thought that limiting the exchange of data to treatment purposes only would streamline privacy concerns since HIPAA allows such sharing of PHI without written patient consent. The problem in New Mexico, and numerous other states, is that there are state laws which provide more restrictive protections for various sensitive conditions than HIPAA, thus requiring written consent for sharing of this sensitive information, even for treatment. At the governance level, we have identified privacy and security as important policies. Such policies are executed at the operational management level, where specific policies, practices, agreements, and technologies are developed and implemented. However, key

data sharing agreements and their specific privacy and security provisions have been vetted through numerous open meetings of stakeholders to allow extensive input, and significant revisions to these documents have been made as a result. The NMHIC management team worked with the Board, the State HIT Coordinator, and other stakeholders to pass new state legislation (the 2009 Electronic Medical Records Act) to authorize electronic medical records as legal documents and to address privacy and security issues relating to the operation and use of the HIE. This was a key factor in reducing legal concerns of data suppliers and smoothing the way to development agreements.

## **Respective Roles of State HIEs and the Federal Government in HIE Governance**

We are all still in the midst of sorting out the appropriate respective governance roles of the federal government vs. those of the states in developing and implementing health information exchanges, and it is obviously a sensitive issue in key areas, such as privacy and security and interoperability, among others. Some of my thoughts from the perspective of one who has been in the trenches of developing and operating a state HIE:

**Federal provision of Guidelines, Tools, and Incentives vs. Mandates to allow flexibility at the state level.** There is clearly a need for federal guidance and tools as states pursue their planning, development, policy setting, and implementation or there will never be rapid progress nor the degree of interoperability among HIEs and among states that we need to establish an effective nationwide HIE system. A few of the areas that come to my mind where we could use guidance would be:

- **Effective methods of mapping and translating** the lagging standards typically used in many of our local health systems into approved federal interoperability standards
- **Models for uniform patient consent and/or a process of harmonizing the conflicting levels of consent required under different state laws.** We in New Mexico were active in creating and signing the initial version of the DURSA to allow for sharing of information across HIEs in different states, but realize that New Mexico (whose laws require written patient consent for certain sensitive conditions even for treatment) could not readily share data with another state that does not require written patient consent, unless there were a feasible process to assure such consent had been accomplished. Numerous other states also have state laws that are more restrictive than HIPAA.
- **Provision of sample communication messages concerning HIE benefits, privacy and security issues, etc.** tailored for different stakeholders and audiences that could be adapted to the specific needs of various states and locales by the local HIE management and their Boards. Updates on emerging data and credible studies showing the effectiveness and benefits of HIEs and EHRs tailored for different audiences would be very helpful. This area of marketing and communications is often an area of weakness in local communities and is expensive to develop and fund. I remember well a supportive health plan CEO who told me a number of years ago that he thought the idea of sharing of data across organizations had great promise, but asked if there was a “petri dish” somewhere that could demonstrate its value in a real-world setting. (See my comments below on the need for evaluation).
- **Careful and creative evaluation of our existing processes and outcomes** is key to continuous improvement and to stakeholder engagement and sustainability. Both federal and state governance should require (and hopefully fund) strong evaluation of programs, to guide further improvements and to provide credibility to support the value of HIE services. Examples of strong evaluations from early adopter HIEs will be extremely valuable for those still in the planning stage, although local stakeholders are often most impressed by data on initiatives in their own local areas that show benefits or at least progress/promise. I have to emphasize how important such evaluation is to both local and national HIE success. I have

- long been concerned that there often seems to be funding to establish new health programs, but evaluation funding to assure that they are effective and to guide needed revisions is often lacking or insufficient. Evaluation should be a key concern of both local and state governance. A national effort should be undertaken and funded to identify and study lead prototypes of health information exchanges which have established effective processes and governance and/or have demonstrated positive impacts on quality and efficiency outcomes.
- **Methods of facilitating the use of HIE data for purposes beyond treatment, while protecting privacy.** In our state, our initial emphasis has been to use HIE data only for treatment purposes, since treatment seemed like an appropriate and relatively non-controversial place to start (and HIPAA permitted the sharing of PHI for purposes of treatment). However, there is increasing interest in the many valuable applications of such data beyond treatment with major ramifications for health care transformation, e.g., to fill the substantial gaps in our public health indicators, to provide true population-based data for surveillance, the identification and addressing of disparities, quality and public reporting, the data support needed to support the emerging Accountable Care Organizations, and other uses. These broader “secondary data” uses are also important because they can help provide funding to sustain the HIE as a public utility, since broadly applicable business models continue to be an issue for HIEs. We recognize the sensitivity of such uses in some communities and the need to protect the privacy of such information, but the federal government could help establish the national task forces needed to develop recommendations for supporting such valuable secondary use.

Thanks to the Governance Workgroup for the invitation to provide this testimony. I look forward to talking with you further at the September 28<sup>th</sup> hearing and to answering any questions you may have.