

Healthcare Information Exchange (HIE): Considerations for Engaging North Carolina Consumers



Prepared by the NCHICA Consumer Advisory Council on
Health Information (CACHI)
for
The North Carolina Health Information Technology
Strategic Planning Task Force



Released: May 27, 2009

Intended Audience:

The audience for this document is the North Carolina Governor's Office and others who direct and manage initiatives which guide the future of healthcare information exchange in North Carolina.

Purpose of this Document:

The purpose of this document is twofold:

1. A Primer on HIE Basics: Sections of the document provide 'primer information' for what we see as the context for what healthcare information exchange involves. This includes providing definitions, advantages and disadvantages of HIE, and other information to guide discussions in a consistent context.
2. Ways to Engage Consumers to learn more about HIE and to become involved in HIE, whether through personal interactions with healthcare providers or in organized HIE efforts.

About NC CACHI:

The NCHICA Consumer Advisory Council on Health Information is a unique health care consumer group formed by NCHICA in 2006 for grassroots input and participation to explore ideas and issues surrounding health information, such as privacy and electronic health records. The purpose of the NC CACHI is to engage patients (health care consumers) in providing input and feedback on topics related to health information.

Healthcare Information Exchange Technology Definitions:

1. *PHR (Personal Health Record)*— “An electronic record of health-related information on an individual that conforms to nationally recognized interoperability standards and that can be drawn from multiple sources while being managed, shared, and controlled by the individual” (Halamka).
2. *EMR (Electronic Medical Record)*— “An electronic record of health-related information on an individual that can be created, gathered, managed, and consulted by authorized clinicians and staff within one health care organization” (Halamka).
3. *EHR (Electronic Health Record)*— “An electronic record of health-related information on an individual that conforms to nationally recognized interoperability standards and that can be created, managed, and consulted by authorized clinicians and staff, across more than one health care organization” (Halamka).
4. *HIE (Healthcare Information Exchange)*—The standardized electronic exchange of health records (typically EHRs) between healthcare providers to enable continuity of care.
5. *NHIN (National Health Information Network)*—The infrastructure (standards, protocols, network, and technology) which supports HIE across the United States.

The Importance of Healthcare Information Exchange (HIE):

The nature of healthcare is evolving due to advances in technology which allow health records to be electronically exchanged between providers. This electronic exchange of information has the potential to improve the quality of healthcare. Health records can be transmitted between patients, doctors, hospitals, and other providers at the time of service. With accurate and complete records at the time of care, it is anticipated that providers will be able to make better medical decisions.

Advantages of and Challenges with HIE:

To guide discussions in how consumers can become aware and engaged in healthcare information exchange, we have compiled a list of the advantages of and challenges with healthcare information exchange. This list is based on our experiences with the healthcare system, or working in healthcare or IT, by reading articles and attending workshops. These lists are not all-inclusive or listed in priority order.

Advantages of HIE:

1. ***Better Healthcare.*** The assumption is that providing health records from various sources to a provider at the time of care will enable the provider to make better medical decisions, resulting in better quality of healthcare. Better healthcare will be enabled through more information at the time of care; real-time test ordering; real-time receipt of test results, and up-to-date medication lists. It has been found that fewer medical errors are made due to electronic ordering of tests and medications. For example, pharmacists no longer need to struggle to read the handwriting on physician scripts. Electronic health record exchange is also an advantage to specific populations of people. For example, those who live in rural areas; people who are caregivers to others and need access to their health records; and people who care for foster children.
2. ***Consumer Control.*** The capability of technology such as PHRs allows consumers to control and manage their own health information. The capability of HIE technology has the potential to allow consumers to choose which doctors will be able to access information in their health records. It also has the potential to allow consumers to decide which information in the health records can be viewed. This allows information that the consumer feels if very sensitive to be kept private.
3. ***Certification Standards.*** CCHIT (Certification Commission for Healthcare Information Technology) is an organization which has developed criteria for certification of electronic health records. This enables organizations who are purchasing these systems to make a comparative analysis based on specific and standardized features (CCHIT website).

Challenges with HIE:

1. *Privacy and Security Concerns.* The privacy and security of health records can be vulnerable as they are gathered, stored, transmitted, shared, and maintained.
2. *Inconsistent Policies and Laws.* Policies and laws between healthcare provider offices, hospitals, regions, and states are not consistent and need to be standardized.
3. *Too Much Information.* The fear of medical malpractice suits by patients because physicians feel they will have a lot more information to sort through and may miss important facts when making medical decisions.
4. *Complete and Accurate Information?* The assumption is that more information to make medical decisions doesn't ensure that the information is accurate or complete. Who will be responsible for correcting inaccurate information that is received from referring physicians, for example? Who will be responsible for medical decisions made based on inaccurate or incomplete information?
5. *Cost.* They can be expensive to implement, especially for smaller practices. Not only the cost of the technology is an issue, but also the costs of training and maintenance are not well known.
6. *Disruption to Workflows.* Many providers' office have expressed concern that adopting and installing HIE technology will cause too much disruption in their current workflow processes.
7. *ROI?* There is no proven ROI (Return on Investment) in monetary terms. Another concern is if it will actually enable providers to make better medical decisions. The assumption is that electronic sharing of information will benefit consumer by allowing for better healthcare. Few studies have examined long-term impacts of electronic healthcare information exchange.
8. *The Impact of Socially Stigmatizing Conditions.* Some patients with socially stigmatizing conditions may feel that their sensitive information may be used inappropriately and may avoid seeking care due to privacy concerns. For example, some consumers have been discriminated against because they have been diagnosed with certain illnesses.
9. *Role of PHRs?* Personal Health Record (PHR) technology is not designed to interact with the health record systems that physicians install. How will PHRs play a role in the exchange of information? PHRs also rely on consumers to maintain their own medical records. This is critical to ensure that medication lists and other information is accurate and up-to-date.
10. *Inadequate Adoption of HIE for Widescale Information Exchange.* There aren't enough providers that have adopted HIE technology to enable health information to be exchanged on a regional basis much less at a national level.
11. *Lack of Initiatives for Consumer Education and Engagement.* Consumers aren't aware of many of the disadvantages of exchanging health records. While they may have the right to control how their information is gathered and shared, this entails an associated responsibility to be informed about the decisions that need to be made. This requires a 'marketing campaign' to educated consumers.

Who are Consumers?

- We believe that patients are consumers of healthcare.
- We believe that caregivers of patients (such as caregivers of elderly parents or parents of children who are patients) are also consumers of healthcare.

Why Should Consumers Be Involved?

The electronic exchange of information has implications for how consumers may provide consent to share their health records. Due to this, we feel that, at a macro level, representative consumers should be involved in initiatives which plan for the adoption and implementation of health information exchange technology in North Carolina. At a micro level, consumers should be involved in HIE by understanding how it is used and asking questions.

We feel that consumers need to be invited to the governance structure for North Carolina. An adequate representation of consumers is a goal to ensure that a variety of consumer perspectives is provided.

Before Consumers Can Become Involved:

We believe that consumers need to be aware that HIE technology is emerging and will be utilized in the healthcare industry. After consumers become aware that it exists, they need to then become educated in HIE terminology; how the general technology works; the different consent options for sharing their health records; and the implications for privacy and security of their health records. Consumers can then be informed at a level at which they are comfortable making decisions to become engaged in HIE technology. This can range from asking their provider questions about how their information is shared to becoming involved in HIE initiatives and workgroups to provide a consumer perspective. Therefore, there are three steps that consumers should experience to become involved in HIE:

1. Awareness
2. Education
3. Engagement

Ways to Involve the Consumer:

Marketing Campaigns. The public at large can learn more about HIE through brochures, radio announcements, newsletters, fact sheets, television and video ads, workshops, conferences, and through searching for information on the Internet.

Public School Curriculum. In the future, if HIE technology is implemented on a wide scale level, education of consumers could be integrated into the public school system curriculum. It could be incorporated as a consumer education component, similar to the way we now teach our students about financial consumer education (i.e. how to reconcile a bank statement and manage our finances). Adult education classes are also a possible effective means to communicate information about HIE.

Contacts. The public can be informed through the marketing campaigns through professional, fraternal, civic, and religious organizations. One example is for churches to insert a small brochure into their programs. Consumers can also be educated through information given to them by their providers and employers. At a more macro level, specialized organizations such as AARP (American Association for Retired Persons), NCHICA (North Carolina Healthcare Information and Communications Alliance), NAMI (National Alliance on Mental Illness), and other advocacy groups are excellent ways to reach out to consumers.

What Role Can CACHI Serve in Consumer Involvement?

As one of these contact groups, CACHI is willing to fulfill its role as a collaborator with other consumer groups in the state to funnel ideas to the governance structure. If requested by the governance structure, CACHI will provide at least one meeting annually as an open invitation to these types of groups. This meeting can serve as a way to network, collaborate, and educate one another on HIE topics.

CACHI members are also willing to serve as representatives on governance structure task forces which discuss the future of HIE in North Carolina.

Sources:

CACHI (Consumer Advisory Council on Health Information). Accessed May 2009 at <http://www.nchica.org/CACHI/main.htm>.

CCHIT (Certification Commission for Healthcare Information Technology). Accessed May 2009 at <http://www.cchit.org/hie/>.

Halmanka, John. (March 23, 2009) *Life as a Healthcare CIO*. Accessed May 2009 at <http://geekdoctor.blogspot.com/2009/03/healthcare-it-primer.html>