

Realizing the Potential of Community Health Information Networks for Improved Quality and Efficiency Through the Continuum of Care: A Case Study of the HRSA Community Access Program and the Nebraska Panhandle Partnership for Health and Human Services

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1. Community Health Information Networks –

A Brief History

With the growth e-commerce and managed care, new demands were placed on health care in the 1990s to establish information infrastructures that allow timely, accurate and secure access to patient information across the continuum of care.

Managed care organizations and integrated health systems responded by developing health information networks within their organizations to support internal information needs¹.

Hospital information systems have evolved from mainframe legacy systems to complex, integrated, PC-based clinical, financial decision support systems.

Organizations such as Kaiser Permanente opted to adopt electronic medical records to ensure information sharing across the continuum of care.

Similar electronic medical records software packages became available during the mid-90s to provide similar capabilities primarily to group practices. In the late 1990s, the flurry of dot com start-ups led to several on-line medical records solutions for providers unable or not wishing to support electronic medical records internally.

While adoption patterns of such technologies varied within the industry, one key issue could not be resolved by any of these solutions. With the exception of internet-based electronic medical records (EMR), clinical and financial information

was trapped within each organization's system and could not be shared through the continuum of care or with business partners. Data in EMRs often cannot be shared beyond the provider, though some do link to select labs, hospitals and pharmacies. Electronic data sharing is not possible between competitors even for the purpose of continuity of care.

The concept of Community Health Information Networks (CHINs) grew out of grassroots community efforts to streamline information among the myriad of partners with the end goal of better integration of care and increased cost savings^{1,2}. Many definitions are offered to describe CHINs. Common elements from these definitions include:

- Interorganizational information systems for data and information exchange among participants in the local healthcare delivery system. Members include physicians, clinics, hospitals, payers including managed care companies, community health centers, public health, laboratories and other diagnostic/testing companies, pharmacies, and educational entities including universities
- Objective to improve efficiency and effectiveness of healthcare delivery
- Operates independently of member organizations, and often initiated by grassroots or community-based not-for-profit organizations
- Some provide resources and educational tools for the community, and provide disease management and case management modules

Funding for CHINs was limited and sporadic. Much of the start-up funding came out of HRSA Rural Health Telemedicine Grants and other Department of Health and Human Services funding sources^{1,3}.

Some CHINs, such as the Wisconsin Health Information Network (WHIN) arose out of for-profit ventures and charge membership fees in addition to selling many value-added services such as web site hosting, practice management software and electronic medical records⁴.

With a few notable exceptions such as WHIN, most CHINs never made it off the ground or were developed but were not viable. Of more than 500 projects identified nationwide in 1995, more than 80% had not even begun discussions with all key stakeholders¹. It is difficult to find much information on current CHIN progress.

In addition to lack of funding, major stumbling blocks included the need to have connectivity to all partners through a Wide Area Network (WAN) and standardizations of data structure and transactions. With the maturation of the internet, connectivity is a much less significant issue as long as the partners can access the internet. As will be discussed later, transaction standards developed under HIPAA offer a unique opportunity for CHINs because code sets and transaction protocols for much health information are now uniform and can be exchanged much more easily. While minimum privacy and security requirements have been outlined under HIPAA, the regulations allow for significant variability in implementation practices.

1. HRSA Community Access Program

Several Federal grant programs are in place or have provided funds to increase community access to health services for vulnerable populations, place health care professionals in underserved communities, and provide support services for people with specific health needs. Few resources, however, are available to help health care providers coordinate these "safety net" services for uninsured and underinsured Americans. HRSA has begun to fund some forward-looking communities through the Community Access Program (CAP) to reorganize their health care delivery systems to provide better coordinated, more efficient care for uninsured residents. Currently, CAP grants support 136 communities in urban and rural areas and on tribal lands³. At the core of this model is a CHIN-like information system linking hospital, clinic, social and other services through state-of-the-art data systems that share information and create seamless transitions for uninsured patients. Another hallmark of this model is service integration, including the creation networks to share uncompensated care more fairly among local health providers. CAP is intended to

help communities and health care providers develop integrated, community-wide systems that serve the uninsured and underinsured. CAP grants are designed to increase access to health care by eliminating fragmented service delivery, improving efficiencies among safety net providers, and by encouraging greater private sector involvement.

Currently, CAP programs do not focus on payers and the insured because of federal grant funding stipulations but the infrastructure that will be established by these grants are a solid base for broader CHINs. There are no restrictions for excluding these entities now. In many cases they simply are almost non-existent or are not major players. In fact, one desired outcome of CAP and other rural health grants is the creation of rural managed care organization, which will undoubtedly become CHIN members.

In addition to HIPAA, this iteration of CHINs have a better chance at success because of environmental factors such as increased data and transaction standardization created by HIPAA which will simplify data exchange, and the ability to utilize the internet to provide a platform-independent applications and tools that will be more widely available to the community. As discussed later, other infrastructure funding opportunities from the federal level may offer additional opportunities for expansion and sustainability. Solid, ongoing, sustainable funding is essential for the long-term viability of CHINs.

2. Panhandle Partnership for Health and Human Services

The eleven counties of the Panhandle of Nebraska are located in the high planes bordering South Dakota, Wyoming and Colorado. The population of almost 100,000 live and work in a 14,000 square mile area dominated by farms and ranches. Population decline and the faltering agricultural economy have impacted the delivery of core healthcare and human services.

The Panhandle Partnership for Health and Human Services (PPHHS) is a 501(c)(3) community based collaboration comprised of for-profit and not-for-profit health and human services agencies and organization, and community members from the 11 county area that comprised the Panhandle region of western Nebraska. The mission of PPHHS is to create and sustain an integrated, caring, flexible, accountable, and competent health and human services system to achieve measurable outcomes for

all citizens. The organization was founded partially as a result of the lack of any public health infrastructure in 10 out of the 11 counties in the region. In addition, upwards of 60% of the Region's population are underinsured or uninsured⁵.

Through the development of a regionally-integrated service delivery system that will be developed with CAP funds from HHS, the Partnership is striving to create a network to share uncompensated care more fairly among local health providers and integrate and consolidate services among the partner organizations. The primary mechanism of doing this is to create a CHIN: a shared, secure, inter-agency Internet-based, patient-level, information, referral and case management system. The system will be used as a primary case management system for health care and human services providers throughout the Panhandle. (See Appendix A for Technical Requirements.) It is anticipated that the increased coordination possible through the use of this shared system will bring significant cost reductions in providing care and improved reporting capabilities regarding client outcomes for the area and all participating agencies

3. PPHHS CHIN Project Objectives and Activities

PPHHS has been an established collaboration for almost 5 years, and the members are committed to bringing a Panhandle CHIN to fruition. Prior to the implementation of the CHIN, a comprehensive community health needs assessment will be conducted to identify key health concerns by county and region-wide using the MAPP community assessment methodology developed under a partnership between the Centers for Disease Control and Prevention and the Association of State and County Health Officials⁶. The entire regional health system will be evaluated and realigned prior to the implementation of the CHIN, and ensure that support and infrastructure will be sustained. The CHIN will become central and integral to the integrated delivery system.

The community will be involved in identifying health concerns, health priorities and give input into the integration and distribution of services. The final implementation of the CHIN will reflect these priorities and will reflect the values of the people it will serve. Buy-in is already significant, thus removing one major obstacle of many CHINs. It will be important to keep all stakeholders involved in the process to ensure sustained support.

In addition to the community assessment, a technical assessment of existing technical

capabilities, links and resources throughout the Panhandle area will be conducted. The technical environment of the Panhandle's eleven counties will be assessed. Systems currently in place over large areas of the state, such as Nebraska's state-wide immunization registry system will be included in the study as a way to detect geographically-specific lessons learned regarding broad-spread technical applications in the Panhandle. All organizations and agencies impacting the public's health will be included in the assessment process, in order to understand capabilities, links, resources, as well as potential barriers.

The State of Nebraska has no established statewide health performance standards, nor does the State provide aggregate health statistical reports at the county or other community level for the Panhandle region. This poses problems for PPHHS because they do not have source of data that allows them to track quality through process evaluations or impact and outcomes of services provided. As a part of this project, appropriate performance standards will be developed for the region, based on national health performance indicators⁷ and priorities established by the community. The CHIN will allow data on these indicators to be gathered in one place for the entire Panhandle. An inventory will be taken to assess data currently available and data that will need to be collected for ongoing monitoring of performance indicators. The performance indicators will help PPHHS to establish baseline data and track quality of care and outcomes for the entire region. Standard data sets and definitions will be established within the CHIN to ensure data is being collected uniformly, with much of this standardization being complete through ongoing national initiatives such as HIPAA. The data will be utilized for decision support for the development, implementation and evaluation of targeted interventions for quality of care improvements, increased coordination and integration of information and care, and community health education and interventions.

4. Planning and Implementation

Based on the outcomes of the assessment activities above, PPHHS will take the following steps to develop a comprehensive Public Health Plan for the Panhandle of Nebraska including MS Project Implementation Plan:

- Prioritize community health needs to be addressed through integration and inclusion in the CHIN
- Formulate alternatives to meet community needs

- Develop Goals, Objectives, Strategies, and Action Plans to Proceed
- Prepare Budget and Timeline for implementation
- The inter-county strategic plan will show how needs can be satisfied through the shared resources and integration of services within the Panhandle health infrastructure, steps that need to be taken to improve the Panhandle public health and infrastructure, and detailed requirements and implementation for a Community Health Information Network.

Some initial requirements are already known (additional technical requirements available in Appendix A). The CHIN will be internet-based and will deliver the functionality required of a case management system. The initial system will link 260 user sites within multiple agencies. It is envisioned that the system will include the ability for all participating agencies to securely share a common intake form and corresponding database, enabling cross-agency statistical reporting on services offered, clients receiving and lacking services, and other information critical to the coordination of care and proper planning and funding of health and human services programs throughout the Panhandle. As the Partnership is a broad based collaboration of health care and human service providers the clients in the system will overlap significantly with those in existing health and human services databases. Integration with these existing systems will be a challenge, however, because HIPAA has not defined a national individual health identifier, which still leaves the significant challenge of matching clients across the many databases in use by the partner organizations. Additional resources and functionality for both providers and the community will be delineated during the assessment.

5. Challenges

a. HIPAA

Although HIPAA provides significant opportunities for integration of other systems with CHINs as a result of increased data and transaction standardization, significant other issues arise. HIPAA requires a myriad of privacy policies and procedures be in place by April 2003. Additionally, Security policies are expected to be finalized in the next few months. The Security regulation alone requires that 19 different policies and procedures be in place and implemented. The Privacy regulation requires access to data be limited by “need to know,” and that need must be defined in system access rights. This will require a complete evaluation of

different user “roles” in patient care, and agreed upon role definitions by all PPHHS partner organizations. This will require a significant effort on the part of the partner organizations to devote the time needed to complete the effort involved to define these roles. PPHHS members will also need to consider using common consent and authorization form across all partner agencies.

b. Infrastructure, Ownership and Ongoing Financing

Data currently being collected by each PPHHS member organization is being done independently by each organization. The data is owned by each organization, and the technology infrastructure is paid for by each organization. With the PPHHS CHIN, ownership is not so clear-cut. By design, patient records will be viewed and edited by users from perhaps several different organizations. The internet will support the CHIN, not a closed local area network or wide area network. Funding will still be needed for software, hardware, maintenance and support. Data quality audits will identify quality issues across many organizations and may lay bare internal organizational problems to the entire Partnership.

The Partnership members have begun to deal with these different issues. They believe the benefits in the form of increased efficiency and quality are worth the effort. The members must not underestimate the challenges outlined above. Each agency will need to ensure complete buy-in from the highest levels to guaranteed continued support and participation. Difficult policy and procedural issues will need to be tackled to reach consensus on ownership of data, and a detailed funding and infrastructure plan will need to be developed and approved by the membership. Adherence to these policies and procedures, and any fee schedules that might be developed must become a condition of membership in the PPHHS CHIN.

6. CHINs in the Age of Bioterrorism

Clearly the PPHHS CHIN developed under the HRSA CAP program will not be as comprehensive or fully implemented as a more mature CHIN, such as the Wisconsin Health Information Network (WHIN). The primary reason: funding. The WHIN has corporate funding behind it and is a for-profit company. The PPHHS CHIN is grassroots effort and is going to be maintained largely on funding from member organizations and grant funding. While the CAP program is still relatively new, many federal

funding sources that provided seed money to early CHINs has dried up.

Two potential funding sources for CHINs may become readily available but may be overlooked. Increased funding for state and local health departments was approved in the U.S. House of Representatives last week and appears likely to make it though conference committee intact. The funding includes almost \$ 425 million dollars for upgrading State and local capacity to respond to bioterrorism events. Included in this amount is \$90 million for early detection surveillance, including a secured web-based disease notification and surveillance system and the Health Alert Network; and \$100,000,000 for State and local preparedness planning. The remaining \$233,000,000 is for ongoing State and local capacity building, including augmenting laboratory capacity and other information technology infrastructure issues.

a. HAN

The Health Alert Network project is a project of the CDC Public Health Performance Standards Program Office. The project was established to:

- Ensure communications capacity at all local and state health departments (full Internet connectivity, training) ;
- Ensure capacity to receive distance learning offerings from CDC, and other agencies and organizations;
- Ensure capacity to broadcast and receive health alerts (about bioterrorism, communicable diseases, natural disaster, etc.) at every level of the health system, down to the community level⁷.

Recent reviews of the system indicate that these goals have not been met by HAN⁸. Additional funding is expected to be used by CDC, state and local health to identify all members of the health care systems that need to be contacted during a public health emergency, and ensure that internet access and a communication mechanism is in place for all members of the systems. CHINs are unique in that those in place are often the only “pipeline” to the vast majority of community health providers, and the community in general. Building on existing CHIN infrastructure can expedite the goals of HAN and will serve to enhance CHIN infrastructure, technology, functionality, scope and reach. Communities with existing CHIN infrastructure should leverage their current ability to reach the HAN target audience and

seek funds from this pot of money that may begin to be made available as early as January 2002. CHINs under development, such as the PPHHS CHIN, need to leverage existing partnerships and community relationships, planning already completed and projects underway to leverage HAN funding for expansion.

b. NEDSS

The National Electronic Disease Surveillance System (NEDSS) project is an initiative from the CDC National Center for Infectious Disease, and was established to provide a standards-based, integrated approach to disease surveillance, and to connect public health surveillance to clinical information systems infrastructure in the private sector. Once implemented, NEDSS should improve the nation’s ability to identify and track emerging infectious diseases (including potential bioterrorism attacks), investigate outbreaks, and monitor disease trends. Labs, hospitals, clinics, private providers and other will be able to report to NEDSS through a web-based application. CDC is developing a “base system” that will provide basic functionality, or states may chose to develop or purchase their own system. In addition, standards have been developed for additional modules, and funding has been made available for these additional modules⁹.

Yet again, CHINs are in a unique position to leverage their existing infrastructure and data to work collaboratively with state health departments on NEDSS development and implementation. Mature CHINs collect much of the data to be included in NEDSS and receive data from NEDSS data sources. For less mature CHINs, collaboration with NEDSS projects will increase partners and data sources, and may enhance capabilities and infrastructure. CHINs should be involved in NEDSS assessments and planning from the ground floor, and should keep abreast of ongoing funding activities at national, state and local levels.

In the absence of local public health infrastructure, the Panhandle Partnership for Health Human Services has begun initial meetings among its partners for emergency health infrastructure planning. PPHHS has also begun discussions with the Nebraska State Department of Public Health to integrate organizational capabilities for rapid notification within the state HAN plan. No discussions have yet occurred about NEDSS.

7. Summary and Conclusions

Limited success was realized from initial attempts to implement Community Health Information Networks, largely due to reliance on cumbersome pre-internet technology, lack of standardization of data, and insufficient funding sources. Most early CHINs also aimed high, often out of reach, by trying to include all stakeholders in the system from the beginning. The HRSA Community Access Program (CAP) is an opportunity for communities that still wish to develop a CHIN to begin on a smaller scale. Typically, smaller scale improves chances of success with complex information technology projects, and early success can be essential in leveraging later buy-in and funding.

While challenges in the forms of HIPAA, funding and infrastructure will need increased resolve to tackle policy and funding issues, savvy CHINs will begin to position themselves for opportunities on the horizon. As intended by the legislation, HIPAA actually provides many benefits because it significantly simplifies data sharing. The forward-thinking CHIN will take advantage of opportunities provided by HIPAA to improve data standardization and integration. The same forward-thinking CHINs will also look beyond CAP funding toward more substantial funding sources such as the Health Alert Network of the National Electronic Disease Surveillance System. Such integration with HAN and NEDSS is in the original spirit of Community Health Information Networks to provide a single infrastructure for data collection and sharing within communities, and will enhance and benefit all programs involved.

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Appendix A: PPHHS CHIN Initial Technical

Requirements

1. Internet access to allow any authorized agency easy access to a single, centrally controlled system.
2. Secure access to authorized agency staff through a personal login that would uniquely identify his/her capabilities in the system. All interactions across the Internet must be encrypted to protect against external visibility to client data. Each user is also directly associated with one and only one agency.
3. Standardized data entry forms for intake that can be used by all agencies.
 - a) Major components of the client data record include:
 - Demographic Profile
 - Capability of relating clients to other clients already in system.
 - File Attachments including photo identification
 - Assessment information
 - b) The ability to customize up to twenty-five fields in addition to the system wide fields.
4. Case management capabilities including case planning, tracking and follow-up. Detailed tracking of case events stored on a per-agency basis with the option, subject to both the client and the case manager sharing restrictions, to share with some or all other participating agencies.
5. Service provision records which indicate services usage and need.
 - a) Services the client has received and needs/gaps in services which have not been met.
 - b) Ability to track the costs of services on an agency basis and the source of funds.
 - c) Taxonomy for classifying services compatible with the PPHHS website www.nehelp.net.
 - d) Email referral capability to other agencies.
 - e) Separate security for service transactions from client security.
6. Utilization management capabilities for residential and resource settings. Each agency should have the ability to update resource availability and have that information available to participating agencies.
7. Field level security on a per client basis with agency -specific Access Control Lists.
 - a) The capability of uniquely identifying each client without revealing any that clients data elements.
 - b) Allows field -level security control on a client by client basis.
 - c) Allows each agency to specify which agencies data will be shared with.
 - d) Allows each client to specify which agencies he/she does or does not want to share which portions of his/her data with.
8. All restricted data in the system must be stored encrypted with the decryption keys available only to the appropriate authorized users.
9. Flexible, multi level reporting capabilities.
 - a) Built-in report writer
 - b) Data extraction from the centralized system into standard, off the shelf reporting tools (Microsoft Access, Microsoft Excel etc.) or other common reports. Describe how this data extraction is governed by the same data security rules as any other access to the system.
 - c) In addition to the basic data extraction system and the standardized report generation, a flexible report writing tool that is built into the system, that would allow almost any user, including those of limited technical skills, to easily report on data relevant to their program, subject to data security rules.
10. Easily defined and changed data interfaces to existing agency systems. Data interfaces need to follow the same data security rules as outlined above, including in some cases refusing to import restricted data that may accidentally attempt to be imported from outside systems.
11. Mobile access capabilities. Each authorized user should be able to access the system from any location that has telephone access.