Community-wide Information Systems Design: Concepts and an Illustration

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Abstract

As health care migrates from institutions to the community, and as recognition that achievement of health and health care goals requires information systems that transcend institutional barriers, models for community-wide information systems design are needed. This paper reviews various approaches to community-based information systems design, draws design principles from the experiences of past innovations, and describes our team's experience in partnering with a community health planning group to create information systems innovations that support health in the community. Key themes that guide community-wide information systems design include (1) partnerships; (2) brokering and integrating existing initiatives; and (3) creating business models for sustainability.

Keywords:

Information Systems Design, Community Networks, computer communication networks, NHII

Introduction

Design strategies that facilitate institutional and enterprise information systems are insufficient for developing the infomation infrastructure needed to meet health and health care information management needs of the 21st century. In the United States, plans for a National Health Information Infrastructure [1] call for the development of the communications and information infrastructure necessary to support assessment of the public health, surveillance of and intervention in infectious diseases and bioterrorism events, and efficient coordination of care, including payment. Growing recognition of the two key dimensions, citizen participation [2] and public health, in achievement of health care goals demands creation of new kinds of information systems that not only link health care providing agencies to each other but also support monitoring and treatment of public health threats. [3] Emerging information systems must also provide the ability for citizens to access local and national sources of health information.

Methods

Presented in this paper is a review of models of community health information systems design, description of the experiences of our group in creating a partnership for community information systems design, and a discussion identifying general principles to guide community health information systems design.

Outreach Models

Many health care delivery systems, from small clinics to large medical centers, recognize the need to provide information and resources to their patients and customers. These approaches largely take the form of Web sites that permit access to information about the care services provided, how to locate and access these services, and special information related to the health needs of the population served. Columbia Presbyterian Medical Center provides one example of outreach, in that they created a suite of services and the infrastructure necessary for patients and physicians to access them [4,5]

Outreach models meet institution-specific goals and can be considered relevant to community-wide information systems design in so far as they extend the resources of a single institution into the geographic community wherein their constituents reside. Sustainability of these approaches results when the outreach resource contributes to generation of market, facilitating patient loyalty, and compensation for care services once provided by the institution.

Enterprise-wide Models

The past decade witnessed emergence of large health care enterprises in which several originally distinct organizations united under a common organizational structure. Each of these institutions generally had its own information system in place, yet achievement of the enterprise goal necessitated integration of some aspects of the clinical and operational information systems. Partners HealthCare, Boston, MA, created such an enterprise-wide health information system, permitting the local member groups to retain their internal information systems while establishing communication and messaging strategies to permit enterprise-wide sharing of critical clinical and business information. In Oregon, the PeaceHealth initiative [6] resulted from the creation of a common organizational alliance across several health care institutions that served a common geographic region. Interorganizational design [7] strategies permit the extension of E-commerce principles to selected health care operations. Other approaches create specific networks to serve focused purposes in health care. For exa mple, Navin [8] describes the development of a regional PACS system to support image capture, transmission, storage, and interpretation.

Enterprise-wide models are characterized by the implicit or explicit organization-to-organization agreements, sometimes mediated by a parent organizational structure. These approaches are

governed first by an organizational commitment to information integration that subsequently drives the design of the information systems.

Regional Health Information Systems

Appearing originally under the rubric of CHINs (Community Health Information Networks), various approaches to regional health information systems have been described in Edinburgh, Scotland [9], Wisconsin, USA [10] and Indianapolis, Indiana, USA. These approaches emphasize a business-to-business interaction model and facilitate sharing of purchasing, billing, or materials management data, and secure access to authorized clinical information. Clinical care goals, such as insuring access to a patient's medical record at the point of emergency care or surveillance to detect outbreaks of infectious disease, drive design in the regional approaches. Critical to the success of the design approach are the establishment of interorganizational agreements as a first step in the design pro cess.

The concept of community health information systems enjoyed great attention in the past decade. Initial efforts involved voluntary cooperation between and among specific organizations and participation in third-party alliances. Effective networks faced the challenges of adherence to commo n language and messaging standards, creation of sharable information objects, and scalability. Their long-term viability remains in question, in part due to changes in regulatory processes in the United States, which placed special responsibilities on organizations to insure patient privacy in data sharing, and the absence of business models, assuring financial viability of the information sharing effort for all participants. (Personal communication, J. Glaser, September, 2003.)

Community-wide Information Systems Planning

Initial attempts at true community-wide information systems planning generally emerge from the vision of a single organization desiring to serve a specific purpose. For example, the Net-wellness project [11] began at the University of Cincinnati as an attempt to open the health information resources of the University to the community as a whole. Involvement of community participants through boards of director appointments has successfully insured a broad-based response to a diverse community. An early example of multi-participant communitywide information systems is evident in the Dayton, Ohio experience [12] which allowed interorganizational sharing of data and relevant information.

Summary

Four approaches to community-wide information systems design have been identified: outreach from a single institution, enterprise-wide linking of geographically distant members of a single enterprise, regional health information systems, and community-wide information systems planning. Common themes found in all information systems design include (1) Identification and proper involvement of stakeholders; (2) Needs assessment and resource identification; (3) Generation of information systems goals and (4) development of sustainable business models. A challenge under each of these approaches lies in assuring representation of and attention to the needs of the governmental bodies (e.g. public health authorities) and individual citizens. Additionally, community-wide information systems planning necessitates a reconsideration of where the boundaries of the health care delivery system lie and determining to what extent social service agencies, schools and community groups have a stake in and therefore require explicit consideration during information systems planning.

One facet that distinguishes community-wide information systems planning from the outreach, enterprise, and regional health information design approaches is the absence of a single governing body to make decisions and set priorities. Thus, any commu nity-wide information systems design strategy must address governance and how one proceeds to balance stakeholder claims and available resources. No single design model will fulfill the needs of every community across long periods of time. Community boundaries, whether geographic or conceptual, change over time. Participants and stakeholder needs, values and resources also vary over time. It is appropriate, therefore, to conduct a variety of experiments to develop robust models of community-wide information systems d esign that incorporate local planning groups into the design process.

Developments in the consumer health informatics arena offer one direction for starting community-wide health information planning. Understanding the health information needs, behaviors, and resources experienced by citizens in their local geographic communities provides a foundation for creating a vision of a community health information architecture. Capitalizing on small demonstration projects and larger business-to-business initiatives affords a way to achieve community health information management goals and can provide generalizable learning to facilitate systematic, community-wide information systems design. In this spirit, then, we offer our experiences in fulfilling a vis ion of a community-wide information architecture through collaboration with a local health planning agency.

Results

Collaboration with the Dodge-Jefferson Healthier Community Partnership

Under the UW-Madison Integrated Advanced Information Management Systems (Wi-IAIMS) initiative, we created a plan for a regional health information architecture that linked the University, its research and service initiatives, local care providing facilities, the state and local public health authority, and community level groups. In one part of this initiative, our team established a relationship with a local community health planning organization, the Dodge Jefferson Healthier Community Partnership (DJHCP). DJCHP is a 501 c (3) charitable organization committed to develop regional health planning initiatives for a two-county area. DJHCP oversees health planning for a 170,000-citizen area of central Wisconsin. There are three hospitals, two public health authorities, 11 libraries and approximately 50 solo and small-group clinical practice clinics. The DJHCP Board consists of representatives from key health care providing institutions and community representatives and delegates from local businesses.

The initial Wi-IAIMS project established a general focus (complement DJCHP goals with the information technology planning

needed to achieve them) and a mechanism for undertaking joint projects. A key project was the development of a digital library resource that would provide Internet-access to local and national resources. Subsequent joint projects under this University-Community relationship included an evaluation of layperson's home health information management behaviors, an assessment of community health information resources that supported creation of the digital library resources (IADL). This paper documents the IADL planning process and uses this experience to highlight some of the generalizable learning arising from a university-community partnership approach to community-wide information systems design.

Purpose of this project

Funded by the National Library of Medicine (NLM) Digital Library initiative, the broad purpose of the DJCHP-IADL project was to deliver reliable, relevant, and understandable informational resources to support the health of the people who need them in the Dodge-Jefferson community. The University and the DJHCP Board jointly developed a proposal. Our evaluation of home health information management behaviors revealed two key challenges: storing contact information for health care providers and accessing problem-specific treatment instructions. In addition, we observed that over half of the participants had Internet access from home or work. We sought to develop a digital library approach to support com-munity-centered health information brokering. Applying Inter-net technology to this challenge would improve accessibility to local resources as well as organized information and re-sources in a structure that matched local need. Providing a community-level integrated access to a range of service-based and content resources relieved consumers of the burden to negotiate institutional barriers. The intended result is effective access to health information and support for achievement of personal health goals. Partners involved in this demonstration project acknowledged the changing role of consumers and therefore the need for a virtual (not physical) structure for health information delivery. [13]

DJHCP IADL Project Steps

The DJCHP Board identified a planning committee consis ting of three Board members, two community members, and a program manager and outreach specialist from the University. The project followed four steps: (1) Confirmation of community need; (2) Assessment of existing health and social service information providing and resource referral; (3) Technical Planning and (4) Business Planning and Sustainability.

1. Confirmation of Community Need. The planning committee reviewed the 2001 Community Health Assessment for Dodge and Jefferson Counties and Healthiest Wisconsin 2010: A Partnership Plan to Improve the Health of the Public. Based on these reports, they identified desirable features and services of the digital library that would meet the stated purpose. The committee identified two types of users (lay and professional) and created use scenarios that depicted their vision of how these different users might benefit from a digital library re-source.

(2) Assessment of existing health and social service information providing and resource referral. Guided by the program manager and outreach specialist, the planning committee examined existing databases and directories that contained local content and

referral information. Information and referral organizations (I & R) address the health and social service needs of a community by providing, on request or through public dissemination, specifics about what resources exist in a given region and how an individual qualifies to access those. A meeting of all Information and Referral stakeholders in the community was held to identify additional resources and potential partnerships. One important stakeholder group was the United Way organizations. These voluntary associations pro-vide information about, and many times also funding for, health and social service resources. There are three such agencies in our two -county area. As a result of this information meeting, these stakeholders shared their local databases, which existed in many formats. Additional input was also gathered by surveying the I&R stakeholders and DJHCP Board.

The planning committee was committed to avoiding replication of existing solutions. To this end, they examined existing initiatives that already provided citizens of Wisconsin Internet links to national health information resources, including those supplied by the NLM and other statewide resources. The process of bringing together various I&R stakeholders revealed the existence of parallel initiatives under the United Way umbrellas and another directed by the local Area Health Education Council (AHEC). The 2-1-1 resource, a telephone-accessed database referral system (http://www.kinetic-data.com/FCFHDane/Area.cfm) and the AHEC HealthyWisconsin (http://www.healthywisconsin.org/) website, both provided content and services similar to those which the planning committee had identified as important. The planning commit-tee assessed the match of the characteristics of these projects to their list of desirable features. The need was defined as facilitating citizen access to local health services and providers in the Dodge-Jefferson community and national resources, and the project goal was stated to develop the content and Webportal services needed to deliver locally-branded access to a suite of resources in place through efforts at the NLM, proxi-mate-county 2-1-1 databases, and AHEC resources.

(3) Technical Planning. The next step was to identify a potential host of the digital library and develop a business plan to sustain t he library. It was agreed that the local host needed to represent both counties. DJHCP seemed to be well matched in mission and representation; however, in order to host and sus-tain the digital library, DJHCP also had to make a commitment to evolve organizationally, including the addition of advisory committees to their structure.

The planning committee then took on the work of another phase, planning the technical aspects of the digital library. They identified technical operating and content criteria and required features of the Web-based digital library, keeping in mind the diverse nature of the local population. Some exa mples of features needed to address the diverse nature of the local population included assuring the availability of low-literacy and Spanish-language resources, content that addressed the health priorities of the Dodge-Jefferson communities, and recognition of the largely-rural nature of these communities.

(4) Business Planning and Sustainability. Six months prior to the exit of the University's presence in this project, the Outreach Specialist began working with the full committee to transition

roles. The committee members openly discussed the transition related to the project as well as the transition they would personally experience as they moved from a planning committee to a technology design committee to a program oversight committee for sustainability. The Outreach Specialist made use of group dynamics and business planning strategies to transfer key responsibilities to the community planning committee. A process for contracting support of the technical hosting of the digital library resource, content editorial responsibility, and funding and financing is now in place

Challenges During the Planning Process

Maturation of the Community Partner.

Approximately halfway into the IADL planning process, the DJHCP Board of Directors conducted a retreat and an internal audit of their agency systems, quality assurance and roles of the Board and the Director. The IADL planning proces s made explicit some aspects of the DJHCP Board functioning that interfered with the agency's ability to commit to long-term sustainability. As this challenge emerged, the University Outreach Specialist expanded her role to support the self-evaluation process of the DJCHP Board. Her expertise in community development provided the DJCHP Board with sufficient guidance to review and revise some of its foundational principles, including the articles of incorporation and the by-laws, the Board composition and committee structure, and the roles of agency employees. While this self-assessment and renewal delayed the IADL planning activity, it afforded stabilization of the DJHCP Board and insured a strong foundation for insuring that the IADL planning process would occur in an environ-ment likely to insure sustainability.

Changes in Key Personnel

During the course of the project, several key personnel left their positions and new ones were hired, including both the DJHCP Executive Director and the University's Project Manager. The continued progress in the IADL planning attested to the overall commitment of the University Team and the DJHCP Planning Committee, demonstrating that the success of the planning process did not rest on the presence of a single individual.

Themes of this community information system design

Several key themes emerged from this demonstration project:

1. Community-wide information planning requires involvement of stakeholders from government, health care providers, information and referral resources, and local voluntary agencies.
2. Assessing local needs and resources provides a basis for identifying opportunities for improving access to health information.
3. Brokering to provide integrated access to a suite of health information resources for the consumer pro-vides an efficient alternative to existing approaches that emphasize creation of entirely new initiatives.
4. Building community partnerships increases the capacity of the community to meet health information needs of all individuals in the community through access to shared resources and engagement of actual and p otential part-

nerships that are likely to insure sustainability. . Successful partnerships included the original DJHCP, the University-DJHCP alliance, creating linkages between local information and referral groups, and development of business relationships and financing streams that insure sustainability of commu-nity-wide, rather than institution-specific, information resources.

Discussion

Four models of community-wide information systems design were identified: outreach, enterprise, regional and community-wide. Our experiences with the Dodge-Jefferson Healthier Communities Partnership provide one example of a communitywide information systems design activity that holds lessons for other groups.

Collaboration in various forms of partnerships was essential to the success of this community-based project. The rigorous efforts served to promote joint ownership of decisions and shared responsibility for outcomes was the key element for leadership of design and sustainability.[14] There were three types of partnerships in this project, between organizations, among initiatives, and between consumers and information technology.

The University of Wisconsin and DJHCP collaborated to introduce the idea of a community-wide information system and to explain the concepts and design in this demonstration project. The University of Wisconsin also represented an internal partnering of the School of Nursing and the Health Sciences Libraries through a shared vision and expertise. Likewise, DJHCP itself represented a partnership of local hospitals, physicians, public health departments, local government and concerned citizens interested in health promotion. DJHCP uniquely represents all residents of two counties, and the planning committee for this project was similarly representative. The planning committee also formed a partnership with local I&R stakeholders. The partnership of the University of Wisconsin and DJHCP also serves as an example of The Wisconsin Idea, a research institution sharing expertise at the local level with a health organization. As suggested by [14], the most successful partnerships possess complementary strengths and therefore the ability to achieve results jointly that they could not achieve individually.

In addition to the grant-supported planning initiative to develop a digital library, two other initiatives occurred in parallel in the community. DJHCP was experiencing a predictable progression o f organizational transformation after seven years of existence.[15] This included increasing complexity in organization design, the evolution of the Board role from passive to active, and the need to manage dynamic change. A unique aspect of this illustration was the acknowledgment that DJHCP had to evolve in order for the o bjectives of the project to be met. Therefore, rather than an institution imposing the initiative on the organization and community, the partners truly col-laborated.[14] DJHCP's development occurred simu lta-neously and in consultation with the digital library development to result in seamless transition and full ownership by the host agency when the University's role was completed.

Effective involvement of consumers in community-wide health information planning is daunting. One must determine how to

effectively involve consumers at all points in the process. As a starting point, joining with the local community health planning group (DJHCP) provided a neutral, two-county-wide group for interaction. However, DJHCP is largely made of up of representatives of health care providers or public health authorities, so it likely represents the biases that might also be found in outreach, enterprise- or regional information systems planning. However, we were able to mitigate this bias by involving consumers in surveys conducted by our group, and by drawing from earlier-completed community-wide health needs assessment activities. Additionally, we have established a training and implementation plan that will solicit consumer feedback and evaluation of the system to insure that subsequent iterations meet the needs of this important constituency.

It remains relevant to address those aspects of communitywide information systems planning that did not get explicit attention in the project illustration offered here. The technical scope of the project was rather limited and did not require extensive investment in information systems technologies. The proposed community health information resource provides information and referral support and does not depend on interorganizational or public exchange of personal health information. Future development of a robust, comprehensive commu-nity-wide information system for this rural Wisconsin community will require both increased technical sophistication and interorganizational sharing of personal health information. The project progress to date had resulted in a process in which trust is established across multiple stakeholders, processes for identifying and making decisions is retained at the community level, and a partnership exists that will allow these more complex dimensions of information systems planning to occur.

Conclusion

The IADL planning process engaged in under a University-Community partnership demonstrates one approach to com-mu-nity-wide information systems design. The approach differed from other approaches to community information systems planning in that (1) it addressed community-identified needs through a broad-based partnership involving a multistakeholder group and (2) decision making and control were retained at the community level. It differed significantly, both from outreach community planning activities that arise on a project level between a small group of institutions and from information systems planning activities that emphasize the business-to-business arrangements.

Acknowledgments

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