Qualitative evaluation of health information exchange efforts

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Abstract

Because most health information exchange (HIE) initiatives are as yet immature, formative evaluation is recommended so that what is learned through evaluation can be immediately applied to assist in HIE development efforts. Qualitative methods can be especially useful for formative evaluation because they can guide ongoing HIE growth while taking context into consideration. This paper describes important HIE-related research questions and outlines appropriate qualitative research techniques for addressing them.
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1. Introduction

A sign hanging in Albert Einstein's office at Princeton declared "Not everything that can be counted counts and not everything that counts can be counted." There are many important aspects of Health Information Exchange (HIE) efforts that are in need of exploration, yet they cannot be counted, or tabulated or quantified. Among the complex entities of local, regional or state organizations that might be making efforts toward organizing HIEs, there is a great deal that needs to be understood, yet little research has been conducted in this area. As new and undeveloped as some of these entities are, the evaluation need not wait until some future end point when objective outcomes can be clearly measured. Formative research, which can inform the process of HIE organizational development, can and should be conducted so that lessons can be learned along the way. This formative research can advise optimal course corrections earlier on in the process, contributing to a maturation of these organizations. This paper will describe some initial foci for assessment early in the development process, some evaluation questions that

might be asked at intervals after the project has started, an explanation of why qualitative methods might be an appropriate and preferred approach to evaluation, and guidelines for conducting interviews and observations in the course of qualitative research.

2. What are qualitative methods?

Qualitative research is an approach to scientific inquiry that relies on more naturalistic, humanistic and interactive processes. The methods are primarily language based, with data in the form of words rather than numbers. They take into consideration the larger context of a human situation, so often they are used at the site of activity, in the field. The design plan is generally iterative and flexible rather than tightly preconfigured, because as new discoveries emerge, the plan may need modification and redefinition to allow the collection of the richest data possible. The most common qualitative data gathering strategies include interviews, observation and document analysis.

3. The evaluation design

As in any project, the design for evaluation begins with articulating exactly what it is you want to know. What are

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the essential and specific questions you need to have answered? Lorenzi and others have outlined relevant broad organizational issues [1–3], including many surrounding development of HIEs that seem ripe for qualitative evaluation. These issues might be addressed by asking the following questions:

- Overall, what are the important barriers and facilitators to development of health information exchanges?
- What are the expected levels of leadership and commitment from the various actors, from the federal to the local level?
- What are the needs, expectations and motivations of the many different stakeholders?
- Consumers must have confidence in the accuracy and the confidentiality of protected health information. What are the issues that need to be addressed?
- When addressing the governance of these projects, what issues of control, power and politics arise?
- All of these subjective concerns are not static. How do the players' perceptions vary over the duration of these projects, and how does that affect the chances of success?
- The decision making structure must be initially outlined. How does the planned organization on paper compare to the reality in practice?
- Communication is essential. What communication channels exist and what are their levels of effectiveness?
- What are the levels of trust among stakeholder groups and what are the conditions and issues that affect this trust?
- How do the information systems fit with the workflow of all users—clinicians, public health officials, laboratories, payers and administrators?
- What are the user perceptions of the information systems in terms of usefulness or ease of use?
- What issues in the planning and project management processes are optimally effective?
- These efforts have been directed to be patient-centric. What are the patients' points of view, perceptions and needs?
- The improvement of health care quality ought to be paramount. What are the motivations, expectations and processes that are directed toward this goal?

These are questions that could be measured quantitatively, but what is the value of such a determination? The "thin" data of numerical assessment would not provide much detailed guidance about the directions the HIEs should follow in the formative stage. One needs richer, more subjective information to understand "what is really going on" in complex human environments.

4. Studying health information exchanges longitudinally

The eHealth Initiative Foundation's Second Annual Survey of State, Regional and Community-Based Health Information Exchange Initiative and Organizations (August 2005) identified six "stages of development" of HIEs (Table 1) [4]. There are obviously many specific research questions related to each of these. For some, an initial assessment done early in the development process could yield critical information about whether different entities are ready for this effort (Stages 1–3). Some possible foci for this initial assessment might include the following:

The plan and planning process

To what extent is there a shared mission?
How clear are the purpose and objectives?
Has a needs assessment been done?
What is the level of trust among the stakeholder groups?
Is there a mechanism for handling political issues, conflicts, and negotiation?
Is there a decision making process related to ownership of data and who should have access to what data?
Is there a process for identifying and agreeing on standards?

Cultural foundations

To what extent are the leaders and their organizations committed?
What is the history of collaboration within and among organizations?

Clinician involvement

How committed are the user clinicians?
What do the users anticipate will happen?

Table 1
eHealth initiative foundation stages of HIE development [4]

Stage 1	*Recognition of the need* for health information exchange among multiple stakeholders in your state, region or community (public declaration by a coalition or political leader)
Stage 2	*Getting organized*; defining shared vision, goals, and objectives; identifying funding sources, setting up legal and governance structure (multiple, inclusive meetings to address needs and frameworks)
Stage 3	*Transferring vision, goals and objectives to tactics and business plan*; defining your needs and requirements; securing funding (funding organizational efforts under sponsorship)
Stage 4	*Implementing* technical, financial and legal (pilot project or implementation with multi-year budget identified and tagged for a specific need)
Stage 5	*Fully operational health information organization*; transmitting data that is being used by healthcare stakeholders (ongoing revenue stream and sustainable business model)
Stage 6	*Demonstration of expansion of the organization* to encompass a broader coalition of stakeholders than present in the initial model