

**IT TAKES A WHOLE COMMUNITY OF CARING TO IMPROVE  
HEALTHCARE QUALITY AND CONTAIN RISING HEALTH COSTS!**



**GREATER LOUISVILLE E-HEALTH RESEARCH REPORT 2007**





## Full Research Report

The full research report is available on <http://www.louhie.org>.

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LouHIE, Noblis' Center for Health Innovation, and University of Louisville School of Public Health and Information Sciences, Department of Health Management and Systems Sciences, worked together to conduct the Greater Louisville e-Health Survey 2007.

## About this REPORT

The Greater Louisville e-Health Survey 2007 Report is intended to present current perspectives of the consumers and organizations of the Greater Louisville area, including interests, benefits, concerns, and payment choices as they relate to the deposit and withdrawal of electronic health information from a community-wide health record banking service.

## About the AUTHORS

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## ACKNOWLEDGEMENTS

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**A Community’s Interest in a Health Record Bank**

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**Need: A way to improve healthcare quality and reduce rising healthcare costs**

Early in 2007, the Louisville Health Information Exchange (LouHIE) Board of Directors decided to commission a research study to understand the real perspectives of the Greater Louisville area community regarding the development of a community health record banking service. The study was to be performed by an objective third party, Noblis, Inc., working in partnership with LouHIE with support from University of Louisville School of Public Health and Information Sciences, Department of Health Management and Systems Sciences (UofL).

The challenge facing the research team was how to engage the community quickly so that the research could be accomplished in a timely manner and in the most cost effective way possible. In just a few weeks, the research approach, instruments, community notices, press conferences, booths at the State Fair, outreach to the different stakeholders, and outreach to the community occurred. This was definitely an excellent example of what can be accomplished when a whole community works together. LouHIE has seen a number of successes along those lines over the last few years of working together.

The findings of this research provide LouHIE with better insight and thus better direction for the future. As you read this report, hopefully you will see the depth of insight this research was able to uncover and can understand the conclusions reached. For LouHIE to succeed and be the catalyst to improve healthcare quality and reduce rising health care costs for the members of the Greater Louisville area, LouHIE has a great deal of work ahead.

But it's not just about LouHIE, it's about you, the Community. It is time for the community to continue to come together and take action!

Our thanks to everyone in this community!



Judah Thornewill, LouHIE



Barbara Cox, Noblis



Robert Esterhay, UofL

## Research Approach: Using our community to engage people to participate

The LouHIE Board of Directors authorized the development of a research study that was conducted from August through September 2007. The research plan is available at <http://www.louhie.org> (select research reports).

### *Research Objective*

The objective was to gain a level of understanding about stakeholder and consumer interests, perceived benefits, issues, and payment interests related to participating in a community-wide Health Record Bank.

### *Research Methods*

The research approach involved the use of mixed-mode research methods. The methods included consumer telephone research, organizational web surveys, consumer web surveys, stakeholder focus groups, functional committee focus groups, and consumer focus groups. Each research method had its own research instrument prepared for gathering the data. Examples of the research instruments can be found in the research plan.

### *Population Frame*

The research workgroup determined early in the process that it needed participation from individuals and organizations from across the greater Louisville area. Ten counties were selected, defined as the “Kentuckiana Regional Planning and Development Agency” (KIPDA) plus Spencer County.

The list of counties that participated in both the telephone and web surveys included:

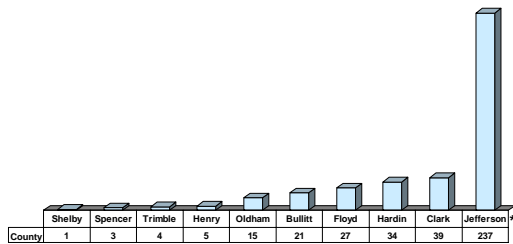
Bullitt	Jefferson
Clark	Oldham
Floyd	Shelby
Hardin	Spencer
Henry	Trimble

*In addition, health information technology product and service providers from across the country were invited to participate in the “Health IT” survey.*

### *Consumer Telephone Research*

For the telephone survey, households were randomly selected from the ten counties. A random sample was selected large enough to deliver a yield of 386 completed telephone surveys. Based on the population of 1.2 million, and the responses, this provided a .05 confidence interval. The telephone survey lasted twelve minutes and respondents were asked to answer twelve questions. Respondents were educated part way through the survey. The intent was to measure their level of understanding and interests before and after the education. The education focused on describing the health record banking model. The overall survey questions were designed to measure the “lay of the land”, and identify similarities and differences between the perspectives of the Louisville population and other US populations regarding e-health.

Telephone Survey - County Responses



386 survey responses came from 67 zip code locations within the Greater Louisville ten county area.



\* Jefferson county has 61% of the total population and is represented by the larger number of responses.

Paper Surveys

A non-random sample of consumers was given paper surveys through several channels. These included a booth at the Kentucky State Fair, and a number of physicians' offices which handed the surveys out to patients on a clipboard. The paper surveys included two sections. One was the general survey and the other, an optional section, was a sign-up form for participation in a consumer focus group.

Web Surveys

A set of thirteen web-based survey instruments were created, one for consumers and one for each of the twelve organizational stakeholder categories. Each of these instruments was accessed through a special website set up for the purpose: [www.louhie.org/research07](http://www.louhie.org/research07).

Individuals	
<ul style="list-style-type: none"> <li>Healthcare consumer survey</li> </ul>	
Organizations and Health Care Professionals (choose the survey which fits best)	
<ul style="list-style-type: none"> <li>Public Health Director or Program Manager</li> <li>Physician Office or Other Healthcare Practice</li> <li>Nurse or Other Practitioner</li> </ul>	<ul style="list-style-type: none"> <li>Employer (includes HR departments in healthcare organizations)</li> <li>Taft-Hartley Benefits Fund</li> <li>Medicaid and/or SafetyNet</li> <li>Senior and/or Medicare Service</li> </ul>
<ul style="list-style-type: none"> <li>Hospital or Other In-Patient Provider</li> <li>Pharmacy or Other Medical Products Retailer</li> <li>Pharmaceutical or Medical Product Firm</li> </ul>	<ul style="list-style-type: none"> <li>Health Plan, Payor or TPA</li> <li>Educator or Trainer of Healthcare Workers</li> <li>Health Information Technology Related Products or Service</li> </ul>

Prior to answering web survey questions, each respondent was asked to read a brief description about the health record banking model. The consumer survey had two parts. The first part asked a set of questions about the health record banking concept. The second part, which was optional, was filled out if the respondent was interested in being considered for participation in a focus group. The organizational surveys also had two parts. The first part, again, asked general questions about the health record banking idea as it pertained to the organization. The second part provided opportunities for the respondent to volunteer to attend a focus group, distribute consumer surveys to a consumer group or join the LouHIE mailing list. Organizations such as physicians' offices, upon agreeing to distribute surveys to their consumers, were automatically directed to a special website where a consumer survey, tagged to them as a source, could be downloaded, printed and/or e-mailed to their consumer populations.

*Web Survey Recruitment:*

A broad based effort was conducted to recruit organizations and consumers to participate in the web survey. The recruitment methods used to communicate with the community about the LouHIE research study included press conferences, press releases, community leadership announcements, phone calls from organizational sponsors to their employees, web communications and a booth at the Kentucky State Fair.

Public service announcements from Jerry Abramson, Mayor of Louisville, Mark Birdwhistell, Secretary, The Kentucky Cabinet for Health and Family Services, and Adewale Troutman, MD, Director, Louisville Metro Public Health and Wellness, provided public communications and leadership support for the LouHIE research survey. The message they conveyed was strong encouragement to all area employers, health care organizations, and government organizations to participate in the research study. The following research communications had occurred as of August 22, 2007:

- National Press Release went to over 478 media outlets
- 22 websites and publications had picked up the story as of 9/13/07
- Nine television stories on two stations
- Two radio stories on two stations
- Front-page business section story in the Courier-Journal
- The total number of media impressions for the coverage exceeded 700,000

*Organizational & Consumer Web Surveys*

The illustration below indicates the types of organizations and the number of surveys completed.

Research Grouping	Number Responded
<b>Consumer</b>	
Telephone	386
Individual (web-site)	355
<b>Organization</b>	
Public Health and Public Education	9
Physicians and Healthcare Professionals	92
Nurses and Other Practitioners	54
Hospitals and Other In-Patient Providers	9
Retail Services - Pharmacies and Other Retailers	2
Medical Products, Pharmaceuticals and Medical Devices	4
Employers, Benefits Trust Funds, HR/Benefits	24
Medicaid and SafetyNet	4
Seniors and Medicare	1
Health Plans, Payers and TPAs	2
Educators	11
Health Information Products and Services	40

*Focus Groups*

Recruiting for the focus groups occurred through the web and paper surveys, as well as through phone calls and e-mails by various LouHIE board and committee members.

Focus groups were broken into three major categories. These were stakeholder focus groups, functional committee focus groups and consumer focus groups.

A seven minute video was produced describing the health record bank (<http://www.louhie.org/research07>). The video was developed to ensure that a consistent message was delivered to the community and the respondents. This video was played to each focus group in advance of the research sessions.

The three types of interactive focus groups were organized to gather responses to a series of group-specific questions:

- There were 18 stakeholder focus groups, 3 consumer focus groups, and 5 functional focus groups.
- The health record banking video was played for each group at the beginning of the session.
- Each focus group was up to 2 hours in length.
- Each focus group had one facilitator and one scribe for notes; detailed notes were taken; summaries were created from the detailed notes; a digital recording was made to support verification of data.
- The data gathering tool for the focus groups was based on responses to a discussion agenda.
- At the end of each day, a discussion was held with several researchers to review the responses for the day.

The number of people who participated included over 209 participants spread across 26 different sessions.

The web/paper survey reached 355 respondents; the organization survey reached 252 respondents. The focus groups reached 209 and the telephone survey reached 386 respondents. The telephone survey sample size provided a .05 confidence level.

Research Groups	
<b>Quadrant 1: CONSUMER</b>	<b>Quadrant 3: PRODUCER</b>
▪ Consumers (3)	▪ Hospitals (2)
▪ Employers (3)	▪ Retail Services Committee
▪ Medicaid / Safetynet	▪ Health Products Committee
▪ Seniors Committee	
<b>Quadrant 2: RESOURCE</b>	<b>Quadrant 4: CAREGIVER</b>
▪ Payers (2)	▪ Public Health
▪ Health Educator (Workforce)	▪ Physicians (2)
▪ Health Info. Tech. Products & Services (2)	▪ Nursing & Allied Health
<b>Functional Groups</b>	
▪ Privacy and Security	▪ Executive Committee
▪ Technology	▪ Kentucky eHealth Network
▪ Research	

## Research Limitations

While the phone survey participants were selected randomly, participants in the web survey and the focus groups were self-selected. As a result of the self selection, it is likely that these groups were made up of members with greater knowledge of the concepts and technologies involved in the LouHIE plans than the general public. In addition, self selected participants were likely to either be more strongly in

support of or more strongly opposed to the concepts that LouHIE is proposing than a random selection would have been. Self-selection bias notwithstanding, review of the responses from across the focus groups found that many groups shared common ground with each other and with consumers on a number of the key issues such as trust, privacy and medication information.

## Value Achieved: What did the community say?

The research identified several common themes that pertain to health record banking (HRB) services and to the overall community's interest in participating in a HRB. The most prevalent and important theme identified by the community was the need for a **trusted environment** for electronic health information exchange. As the community discussed, an individual's health information is considered deeply personal and private. Consumers expressed a high degree of concern about being harmed by others who may inappropriately access their private information. Organizations expressed commensurate concerns about potential liabilities that could be created for them by privacy violations or uncontrolled personal health information sharing. Therefore, a second theme that emerged included the notion of **privacy and security**. The community wants LouHIE to assure that appropriate levels of security will be put in place to insure against intrusion or unauthorized use. The third theme that emerged was **consumer choice**. The consumers want the ability to control access to their information, make choices on whether or not to participate in various research programs, determine whether personalized messaging adds value to themselves, and to choose the types of services that they want to use. Another theme is that the majority of stakeholders indicated a **trusted not-for-profit community organization** like LouHIE would be needed to establish a foundation for a community-wide health record banking service. The community would trust a dedicated community not-for-profit more than government or private-sector organizations. Regarding types of

services, there was broad agreement that **sharing of medication information** was most important to save time and costs, and improve patient safety across the community in the short term. The community was generally concerned that the health record banking service should be **accessible** to those who do not have the means to pay especially since those are the people who need the service most. Uninsured, under-insured and low-income populations were essential to include. The community is willing to **pay for value received** and to off-set the expenses of the operations with other revenue streams. **Portability** was discussed as an essential aspect of the health record bank. The use of **cellular telephones** and handheld devices to reach many of the residents would be of interest. Many community members discussed the need to **expand** beyond the 10 county area, into the state, and across the nation. Based on consumer consent, the consumers support providing access to public health and medical researchers for **research** purposes. Lastly, the concept of LouHIE using its excess revenues to **invest in the community** to provide additional health related services to those most in need was seen as an honorable mission.

For a complete, summarized list of interests, benefits, concerns, payment choices indicated by the community stakeholders, refer to the research results summary located in the appendix.