

March 31, 2009

Health Information Security and Privacy Collaboration

Summary Report of Lessons Learned

Prepared for

RTI International

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Consumer Education and Engagement Collaborative
Kansas HISPC III Consumer Education and Engagement Team

Health Information Security & Privacy

COLLABORATION



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Contents

| Section | Page |
|------------------------------|------|
| 1. Project Goals and Purpose | 1-1 |
| 2. Background | 2-1 |
| Appendix | |
| A: Acknowledgments | A-1 |

1. PROJECT GOALS AND PURPOSE

The overall purpose of the Health Information Security and Privacy Collaboration (HISPC) III Kansas consumer education and engagement (CEE) collaborative project was to educate consumers in rural Kansas on health information exchange (HIE) and health information technology (health IT) privacy and security issues. In this phase, a majority of the activities were geared towards planning for the delivery of educational information. The project began with a needs assessment and concluded with the development of a communication and evaluation plan. Throughout the project, an online toolkit was updated with materials that could be customized, used as resources, or used “as is” by those seeking to educate the Kansas target audience.

2. BACKGROUND

Successful strategies for communicating these concepts require an in-depth understanding of local populations, specifically focusing on the identified target audience. Kansas chose to focus on rural consumers because a large portion of the state is rural and has many frontier counties. Rural and frontier health care consumers have distinct educational needs regarding patient privacy and electronic health records which are different from their urban counterparts. These differences can be attributed to rural demographics and rural health care systems as well as the fact that the health care needs and services in frontier counties can be different from the needs and services in rural counties. In this document, “rural” includes the frontier population.

In Kansas, 90% of all counties are characterized as rural or frontier (frontier is characterized as less than 6 persons per square mile, rural as 6–19.9 persons per square mile, and densely settled rural as 20–39.9 persons per square mile¹), making Kansas one of the most rural states in the United States. Furthermore, based on the 2006 U.S. Census Bureau population estimates and using the peer group definition adopted by the Kansas Department of Health and Environment, of the 46 counties in western Kansas, 29 counties are designated as frontier (63%), 12 counties are designated as rural (26%), and 5 counties are designated as densely settled rural (11%). The variation of population density and health care services is substantially different in each of these designated settings with significant implications for the need for different health care solutions and effective communication programs. Approximately one-third of all Kansans live in a rural or frontier county. Individuals living in these settings tend to be older, sicker, and poorer than those living in urban areas. Residents of rural and frontier areas face health care challenges that their urban counterparts do not, because rural, and especially frontier, counties and areas are typically medically underserved. For these reasons, the educational and outreach efforts for rural and frontier consumers are unique compared to those for urban health consumers.²

Another issue that underlies the differences between urban and rural or frontier health care is the structure of rural and frontier health care systems. In general, there are fewer providers and hospitals in these areas and they operate with comparatively fewer financial resources. Individuals residing in rural and frontier counties are more likely to be uninsured

¹ The Frontier through Urban Continuum Definition, Frontier and Rural Committee of Mental Health Services for Children and Families, 2008, [http://www.socwel.ku.edu/occ/projects/articles/Frontier to Urban Continuum Definition.pdf](http://www.socwel.ku.edu/occ/projects/articles/Frontier%20to%20Urban%20Continuum%20Definition.pdf)

² What is Rural? U.S. Department of Agriculture Economic Research Service, 2007, <http://www.ers.usda.gov/Briefing/Rurality/WhatIsRural/>

and have fewer health services available. Consequently, a larger proportion of residents obtain care in safety net community clinics as compared to urban residents.³

Health care consumers in these areas are also more likely to be economically disadvantaged than their urban counterparts. In Kansas rural and frontier counties combined, 32% of children live in poverty.⁴ Among patients treated at safety net clinics, 92% live in family arrangements whose income is less than 200% of poverty and 56% are uninsured.⁵ External economic forces can contribute to stresses not applicable to urban systems. Cyclical commodity prices contribute to regional income fluctuations. Rural businesses are generally smaller and often do not provide health insurance. Approximately 1 in 5 patients (19.5%) in rural Kansas communities is covered by Medicaid or HealthWave and about 1 in 10 (10.5%) has Medicare coverage. Only 13% of patients seen in Kansas safety net clinics have private health insurance, and some of them may not be able to afford their deductibles and copayments.⁶

Migrant workers have additional unique educational needs as this group includes a relatively disadvantaged and mobile workforce. On average, hired farm workers are younger, less educated, more likely to be foreign-born, and less likely to speak English. They also have additional barriers to access health care.⁷

In summary, rural and frontier health care consumers present unique educational needs associated with the demographics of rural communities and limited access to medical care. Across Kansas, rural inhabitants tend to be older, sicker, and poorer than those living in urban areas. In addition, nearly all rural and frontier areas are medically underserved. These factors combined create challenges which are unique to rural and frontier health care consumers and require focused, innovative approaches to obtaining health information, education, and health care services. While there are many related issues, this information was sufficient to guide our selection of target subpopulations (specified in the communication plan) and justified our focus on rural consumers in Kansas.

³ Kansas Health Center Fact Sheet, National Association of Community Health Centers, 2007, <http://www.nachc.com/state-healthcare-data.cfm?State=KS>

⁴ Kansas KIDS COUNT Data, Kansas Action for Children, 2008, <http://www.kac.org/kac.aspx?pgID=886>

⁵ The Importance of the Health Care Sector to the Economy of Allen County, Kansas Rural Health Options Project, Kansas Rural Health Works, 2006, <http://www.oznet.ksu.edu/krhw/reports/rural.html>

⁶ Anthony Wellever, Building Medical Homes: A Strategy for Improving Health Care Quality, Reducing Cost, and Enhancing Access (White Paper), Kansas Association for the Medically Underserved, 2008, <http://www.kspca.org/pdfs/2008%20KAMU%20White%20Paper.pdf>

⁷ William Kandel, Profile of Hired Farmworkers: A 2008 Update, U.S. Department of Agriculture Economic Research Service, 2008, <http://www.ers.usda.gov/Publications/ERR60/>

Key Lessons Learned

- *Know your target audience* by getting input from the audience and those familiar with the audience and through literature reviews. In Kansas, statistics were useful in providing facts about the rural and frontier consumer population. Advisory group members (inclusive of individual consumers) familiar with the population also informed the project team on facts about the target population.
- *Focus on sub-populations within a broader audience.* In Kansas, the rural and frontier consumer population is large. Through research and recommendations, we identified several sub-populations to target, and these were included in a documented communication plan. They include the Hispanic/Latino population (migrant workers inclusive of the low German-speaking Mexican Mennonite farm worker population), the elderly, the medically underserved, and populations with disabilities.
- When planning for education and engagement activities, *involve those able to reach the target audience, and plan to educate your target audience to reach others.* In Kansas, the CEE workgroup formed during this phase of HISPC will be a channel for outreach to the sub-populations identified in the communication plan. They proved to be a key source of advice and guidance in the development of the communication plan. The communication plan also extends the scope to legislators, for example. Educating legislators can impact policy that then impacts consumers. Additionally, educated and convinced consumers can impact health IT policy positions through their legislators and other government officials.
- *Avoid re-inventing the wheel and search for existing resources.* In Kansas, a toolkit of materials was developed to jumpstart education of the target audience. The online toolkit was developed as a central location to consolidate existing education materials. The development of the toolkit was informed by an inventory matrix developed through HISPC that identified relevant existing resources. Sample materials were developed and customized through this project. Materials will continue to be developed and revised in alignment with the communication plan. In an evaluation plan, the HISPC team recommended pilot testing the materials with a pilot group inclusive of the target audience, prior to broader dissemination. As Kansas implements the communication plan, materials already available will also be considered for customization.
- *Document a communication and evaluation plan for education.* In Kansas, stakeholders were involved in developing and vetting a communication and an evaluation plan. These documents will be extremely useful in implementing a future education campaign and for assessing effectiveness of the communication. The communication plan described themes for messaging, strategy, tactics and action steps. The evaluation plan described how to measure the effectiveness of the communication.
- *As you plan for education, identify communication priority areas.* In Kansas, this HISPC project was the first state initiative seeking to educate rural consumers on

health IT and HIE privacy and security issues. Results from a needs assessment, results from research and recommendations from consultation with the CEE workgroup members enabled us to identify general education areas to focus messaging on. The following areas of education were identified, and some sample messages were developed during this phase, and will continue to be developed and revised upon implementation of the communication plan.

The areas of education identified include education on

- Basic health information flow
 - Health IT (personal health records, electronic health records, community health record, and e-prescribing), HIE and related privacy and security matters
 - The use of healthcare data for population health (public health, research, and quality improvement)
 - Relevant legislation (such as the American Recovery and Reinvestment Act, HIPAA Privacy Rule changes) and legislative issues
 - Patient rights and preferences
 - Patient HIE participation issues such as patient consent
 - Protecting sensitive health information
 - The national, state, and regional health IT and HIE initiatives
- *Develop a flexible communication plan.* The plan should be flexible enough to incorporate new ideas and opportunities which may arise. However, the plan should maintain a focus area on the initial specific target audience. In Kansas this would be the rural consumer. Secondary audiences able to be reached by consumers or able to reach or impact consumers were also included, such as legislators, other government officials, and health care providers. As more consumers become aware of the value of health IT/HIE, they are expected to make their opinions known in their community. This in turn will influence health care providers' and policymakers' positions on health IT and policy.
 - *Leverage other on-going efforts.* Leveraging other similar on-going efforts proves to be cost-effective and minimizes redundancy in activities. In Kansas, leveraging existing state efforts such as an ongoing consumer health Web development project (Kansas Health Online), enhanced project progress. In particular, it allowed us to reach some consumers across Kansas through focus groups and surveys. Materials developed through HISPC are also being posted on Kansas Health Online.
 - *Collaborate.* Collaboration is beneficial to all those involved. Collaborating with other states on similar issues provided maximum utilization of knowledge and talent as well as produced a rich array of education tools which could not have been achieved in such an accelerated approach without the team work. Together we were able to accomplish so much more than as an individual state. Kansas was in the planning phase of rural consumer education, and many of the developed tools and lessons learned from states will advance rural consumer education on health IT and HIE in Kansas. Work completed by the Kansas team also informed other states.

- *Identify a broad stakeholder group.* HISPC provided an avenue and incentive to bring together a large stakeholder group around a common goal “to increase utilization of health IT/HIE in the state and across state lines.” As a result of the HISPC project, Kansas enjoys the benefit of an established broad expert stakeholder group which shares many overlapping interests and provides a springboard for future statewide coordinated health IT work.
- *Develop working relationships.* Working relationships established and developed in the state and with other states provides a robust and extensive network of experts who are ready and willing to work together on future endeavors related to health IT/HIE. The Kansas team benefited greatly from collaborating with other states and working with stakeholders within the state.
- *Seek volunteers or volunteer.* Volunteerism from key stakeholders and stakeholder groups is critical to success. It is important to engage these individuals and groups early and to build trust in the relationship. In Kansas, the support from the HISPC steering committee and CEE workgroup was critical in ensuring success.
- *Tell the story.* The work completed through HISPC has been presented to audiences in Kansas and outside Kansas. Sharing lessons learned with other states and within the state has informed them and allowed us to learn from others.

APPENDIX A: ACKNOWLEDGMENTS

Kansas HISPAC Consumer Education and Engagement Team

- Helen Connors, RN, PhD, Dr PS (Hon), FAAN—University of Kansas Medical Center (Kansas HISPAC Steering Committee Chair)
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Kansas HISPC Steering Committee

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