A Culturally Appropriate, Web-Based Technology for Anonymous Data Collection for Public Health Research in Culturally Diverse Populations

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EXECUTIVE SUMMARY

This case study describes how a Web-based technology helped a small nonprofit cancer education and research organization collect data anonymously from Native American cancer survivors from across the North American continent. The system described herein, known as the Privacy Broker System, is adaptable to different cultures and languages. The Privacy Broker System made cancer education and research, which was previously infeasible due to high costs and regulatory constraints, possible.

Keywords: cultural differences; database capture; patient data management system; privacy

PROJECT BACKGROUND

The Privacy Broker System is a project created by the Institute for Dynamic Educational Advancement (IDEA) in response to the needs and challenges that a Native American health organization faced in its nationwide studies. The Privacy Broker System was designed to address two primary issues faced by the organization, namely:

1. How does a small education and research organization leverage its financial resources and staff skills to reach culturally diverse Native populations in disparate geographical locations throughout the North American continent? Native Ameri-
cans are a heterogeneous population, with a dramatic range of diversity in culture and location. A technology was needed that would allow for the customization of research and educational materials that would be appropriate for the many cultures represented in Native America.

2. How does a small educational and research organization collect research data on individuals from across the North American continent in a consistent and efficient way, while protecting individual privacy and complying with stringent government regulations concerning patient confidentiality? Research involving human subjects is strictly regulated by federal laws. The most important of these laws—in terms of the impact it has had on research—is the Health Insurance Portability and Accountability Act (HIPAA). While HIPAA has played an important role in protecting research subjects’ privacy, it also has hampered many types of research and made some types of research impractical. In the pre-HIPAA era, it would not have been unusual for a researcher to collect the names, addresses, and even Social Security numbers of these subjects, so that the subjects could be recontacted at a later date to determine if a given intervention had an effect on quality of life. However, in the current environment, obtaining these types of identifiers would require also implementing the informed consent process and then obtaining written informed consent from each study participant. This would not be practical for a small health research organization, due to the expense and logistics of obtaining consent from hundreds of people located across the continent. The Privacy Broker System allowed the Native American research project to perform long-term studies by using culturally appropriate pseudo-identifiers that did not require written informed consent, because no personal identifiers were linked to the participants’ responses.

The competitive landscape is bare, and this project fills an important void. While there is a large industry devoted to helping organizations comply with a range of HIPAA regulations and its ancillary requirements, the authors know of no projects that directly address the challenges of protecting patient privacy, while also allowing longitudinal data collection and also meeting the needs of providing culturally appropriate anonymous identifiers.

This case study reviews the implementation of the Privacy Broker System for the organization’s Native American Cancer Education for Survivors (NACES) project.

**SETTING THE STAGE**

**Cancer Ravages the Native American Community**

Approximately 1.4 million people in the United States will be diagnosed with cancer this year (American Cancer Society, 2005). In 2005, more than 570,000 people were expected to die from cancer in the United States, which translates to more than 1,500 people dying from cancer each day. Despite these dismal statistics, cancer mortality rates have been generally declining in recent years. The drop in cancer mortality is largely attributable to better treatments and increases in early detection (American Cancer Society, 2005).

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