

# **Internet Platform for Public Health**

An Information Architecture for a Next Generation of Health Policy Research

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## **Project Summary/Abstract**

We propose a research program directed toward the innovative use of the public Internet to support Public Health Policy research and population health management initiatives. The nature of the proposed research is to look beyond the current “first generation” of Internet-based “personal health record” applications to a next generation that will move the focus from its current institution-centered “strategic” value proposition to a public-policy value proposition. Such a shift will be enabled by the identification of key infrastructure components that need to be constructed as a government-sponsored public work for the health care system as a benefit to all entities, just as the interstate highway system was constructed as a public work that benefited the auto industry.

We propose a two-pronged approach: first, to undertake a clear articulation of a *new vision for health policy research* using a public Internet. Second, we propose a careful analysis and exploration of the concept in Internet2.

We envision the following phases of the research program, which we think will take approximately 8 months.

- (1) Formulation of the vision;
- (2) Assessment of Internet2 technology initiatives;
- (3) Exploration and presentation of the concept to key decision makers in government, academia, and the health care industry.

Key to this research agenda is the interdisciplinary approach being proposed by the expertise of the senior investigators.

## **Proposed Budget – Spreadsheet Detail**

Please contact the authors for budget details.

## **Proposed Budget - Notes**

The research proposal contemplates the budget items defined on the spreadsheet on the preceding page. The specifics for each item are addressed below.

- (1) Druseikis – summer support
- (2) Woods – summer support
- (3) Graduate student – 1 year
- (4) Travel for investigators
- (5) “Software Licensing Fee” acquires exclusive rights to HealthCompass for nominal down payment and promise of negotiated future royalty; license to be held by South Carolina Research Foundation with rights to derived works; rights to commercialization must take place in a specific term (which may be several years in the future and are beyond the scope of this proposal.) Should no commercialization take place in the specified term, both the property and derived-works reverts to copyright holder.

## **Biographical Information**

### ***Frederick C. Druseikis***

Dr. Druseikis is Research Associate Professor of Computer Science and Engineering at the University of South Carolina College of Engineering and Information Technology. A computer scientist by training, Dr. Druseikis has spent almost his entire career in the development and application of information technology.

Prior to joining the USC faculty in the fall of 2001, Dr. Druseikis was a co-founder and principal of a South Carolina-based health information technology consultancy, which was subsequently sold. Dr. Druseikis spent over 20 years in the various research and development positions at AT&T/NCR, AT&T Bell Laboratories, the RCA David Sarnoff Research Center, and divisions and subsidiaries of Adventist Health Systems/Sunbelt, where he held various positions as a contributor or manager to advanced development projects that lead to commercial deployment. Prior to his career as an industrial computer scientist, Dr. Druseikis held an academic appointment in the Department of Computer Science at the University of Arizona.

Most recently he held the position as chief software architect for one of the first examples of an Internet-based “first generation” personal health record system (trade-named HealthCompass) build by the former HealthMagic subsidiary of Adventist Health Systems/Sunbelt. This application was first deployed in late 1997 at the Celebration Health clinic operated by Florida Hospital (near Orlando) for residents of the planned community of Celebration, FL. (The town of Celebration, Florida, is a planned community developed by the Walt Disney Company.) Subsequently the HealthCompass application was subsequently marketed to health plans and providers during late 1990’s,

and contracted for use by the Internet portal drkoop.com (but not deployed.) The Smithsonian Institution recognized HealthCompass in the Spring 2000 as one example (among several) of the most innovative information technology applications of the 20<sup>th</sup> century.

Dr. Druseikis' research interests include applications of the public Internet to health care, e-commerce in health care, information security and privacy, and distributed object technology. Dr. Druseikis' contributions to information technology include the contributions to the development of Object Management Group (OMG) CORBAsec international standards for information security in distributed object systems, and for CORBA interface standards for master-patient indexing systems used in health care.

### ***John R. Woods***

Dr. Woods is Associate Professor of Family and Preventive Medicine at the University of South Carolina School of Medicine, and Director of the Center for Health Services and Policy Research at the Norman J. Arnold School of Public Health. An experimental psychologist by training, Dr. Woods has spent the bulk of his career in clinical and health services research.

Prior to joining the USC faculty in 1998, Dr. Woods spent 21 years at the Methodist Hospital of Indiana, a large teaching and research facility associated with the Indiana University School of Medicine, where he founded and directed the Methodist Center for Health Services Research. He also held an adjunct faculty appointment at the Indiana University School of Public and Environmental Affairs, and was an Affiliate Research Scientist with Indiana University's Bowen Research Institute, an organization dedicated to health services research in primary care and community medicine.

While at Methodist Hospital, Dr. Woods organized and directed the Health Status and Health Risk Survey, a statewide population-based health measurement program sponsored by the North Indiana Conference of the United Methodist Church. He also developed and subsequently directed the Medicare Heart Bypass Demonstration Program at Methodist Hospital, one of six such research and demonstration programs in the United States. In the mid-1980's he participated in the design and analysis of the FDA-supervised trial of the renal lithotripter, an investigational technology designed to treat kidney stones non-invasively using high-pressure shock waves. As a result of this work, he subsequently participated in the NIH Consensus Conference on Kidney Stone Disease, co-authored the first publication analyzing the cost-effectiveness of lithotripsy technology, authored the Report to the Indiana State Board of Health on renal lithotripsy, and co-authored a textbook on emerging technologies in the treatment of kidney stone disease.

Dr. Woods has served as a member or consultant to a number of national organizations, including the Provider Payment Panel of the Health Care Financing Administration Office of Research and Demonstrations, the National Performance Measurement Panel for Coronary Artery Disease sponsored by the Foundation for Accountability and the U.S. Agency for Health Care Policy and Research, and the Urological National Database Project sponsored by Boston Scientific, Summit Medical Systems and the National Urological Society.

In his current position at the University of South Carolina Dr. Woods serves as a member of USC's Intellectual Property Committee, and is on the Advisory Board of the South Carolina Center for Innovation in Public Mental Health. He is also a consultant to

the Palmetto Health Alliance Quality Improvement Coordinating Committee and a member of the Statewide Systems Development Work Group of the Head and Spinal Cord Injury Division of the South Carolina Department of Disabilities and Special Needs.

Dr. Woods' research interests are in the development and use of economic and health status outcome measures, and the use of statistical quality improvement methods in medical care. He is the author or co-author over 60 peer-reviewed journal articles, abstracts, and book chapters.

## **Narrative Description**

### ***Background***

In 1995 with the advent of the so-called “new economy” it became clear that the phenomena called the public Internet would have many implications for the gathering and dissemination of information. With the metaphorical equivalent of an on-line library of global scope, use of the public Internet grew at exponential rates. The public Internet was and still is a vehicle for extraordinarily efficient dissemination of information.

During that period many essential features of the public Internet came into the public mind – for example, that it was for publishing information, that it needed to be searched, but, significantly, the user of it – not unlike the user at the public library – was effectively anonymous. There were risks to using it, possibly including the loss of personal privacy. The use of the Internet for applications in which the identity of the user is known with significant access controls for personal content was and still is a challenge in the public mind.

Like all things of unbounded promise, the public Internet has come to facilitate what is easy to do, and to leave undone, unfinished or untouched those things that require significant planning to fulfill a beneficial vision. We believe there is great potential for the use of personally identifiable health care information in the furtherance of public health research and practice.

Earlier in the 1990’s the Institute of Medicine published a seminal study on the Computerized Patient Record [1]. The IOM study articulated a vision for health care based on comprehensive longitudinal information model. (A recent example of the IOM vision in Europe is described in [10].)

These two ideas – the public Internet and the Computerized Patient Record – show great promise if they can somehow be combined in a manner that delivers value. That such combinations were possible was clear, but it was not obvious as to how value would be derived.

To that end, several projects by different organizations<sup>1</sup> (see, for example, [3], [5], [6], [7], and [11]) were undertaken to create a patient record that would be useful in ways that were reflective of the IOM's concept. A first generation of such integrated offerings were actually built and deployed during the "Internet Boom" of the late 1990's. Realizing value sounded easier than it turned out to be. "Build it and they will come," a catch phrase of the era, proved once again to be as vacuous as it always was.

The concept of a personal health record has emerged during the interval. What might be called a "first generation" of such information repositories emerged in an attempt to fulfill a "strategic" niche. Strategic initiatives are often undertaken because they are believed to be essential to the survival of an organization, even though there will be economic cost sustained during the interval in which investment is made.

The characteristics of such a personal health record system are that: it is "consumer" centric, meaning that it reflects the needs and desires of a class of "health care consumers", a broader class of persons than those being patients, i.e., those persons having a current disease and who are being treated. The needs and viewpoints of health care consumers are distinctly different from those of health care providers. This appears to be a unique twist on the original IOM notion, which appeared to be distinctly provider

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<sup>1</sup> The principal investigator was involved in one of the first of such projects, which was undertaken by Adventist Health Systems/Sunbelt of Orlando, Florida, and became known under the trade name of HealthCompass.

centric. Healthcare consumers may be concerned not only about their own health but also the health of spouses, aging parents, children, extended family and so forth. The first generation systems address significant concerns for privacy and security of information – sometimes in a legal context that was at best undefined or certainly moving into new territory (see, for example, [4]).

The first generation systems maintain content that was distinctly *personal* – about a person’s specific health experiences; *synoptic* – reflecting the fact that specific details were suppressed because of the favorable outcome of treatment; and *life-long* – in that the repository covered the entire lifespan from birth to death.

These systems proposed agendas that often-reflected strategic imperatives for their sponsor be they providers, payers, or even employers (see, for example, [8].) The strategic imperative stated how the combined systems would service some proprietary business advantage making the sponsor either more competitive in their specific markets, or better able to contain costs. The strategic potential had to exist for a favorable return on investment that could be measured in increased market share and therefore increased revenue. To that end such systems offered a variety of features that ranged from diet calculators to health risk assessments to repositories to reams of qualified (and sometimes unqualified) health care information.

By mid 2000, with the sudden recession of the new economy at “Internet speed,” the pressure for rational economic justification increased. The old economy raised its annoying, annual questions about profit, and the imperative for a proprietary strategy, if not vanished, certainly faded.

## **Research Agenda**

This research proposal starts with the hypothesis that these two technologies – the public Internet, and the personal health record evolving as it did from the concepts in the IOM report – have been melded successfully into a technically and conceptually consistent offering that we called a personal health record. This much is known. Further, this combination creates the possibility of a new tool to develop and measure public health programs, particularly those seeking to better manage the health of populations and to design better health policy. The essential vision for this research is to go beyond the “strategic imperative” driving a proprietary advantage for a single organization in its pursuit of profits to a broader imperative for realizing public policy. With such a combination the collection and dissemination of protected health information can take place in a well-understood public infrastructure.

But we need to note what this research proposal is *not*. It is not about creating web sites for departments of public health, or in anyway concerned with the dissemination of public information in a new media – as much merit as this may have. This research is intended to address the technological issues that need to be in place to deal with protected health information in order to be of value in a public health mission.

This research project proposes to address the following questions:

- What is a vision for the use of the public Internet in the design and implementation of Public Health policy?
- How successful have the first generation of personal health applications for the public Internet been?

- If one could shape a next generation of software tools available on the public Internet, what would the choices be?
- What are the barriers to implementing the vision?
- What kind of infrastructure needs to be put in place to enable the collection of data most efficiently?
- In what ways does Internet2 meet the requirements? In what ways is it inadequate? Are the information security services of Internet2 [2] adequate for this work?
- Do information technology standards presently exist to support this vision?
- Is there a common infrastructure that can benefit the proprietary interests of health care providers and payers as well as the broader interests of public policy?
- Should such an infrastructure be built and maintained using public funds? What technology drivers need to be in place?
- Are there strategic imperatives for the health care industry that make such an infrastructure impossible?
- What would be the engineering cost of realizing and operating such an infrastructure?

We propose to acquire rights to HealthCompass, a first generation personal health record. It can be made available under very favorable terms with low initial cost with the

promise of future royalties to the copyright holder should future events lead to commercialization. The South Carolina Research Foundation would hold the software license with rights to any derivative works created. The acquisition of this intellectual property provides a legal basis for addressing technological issues by example.

The purpose of acquiring this software is not to enter into the business of operating a personal health record; rather, to provide a point of reference. We propose to use it to establish a working demonstration of the concepts especially in the context of Internet2 security middleware.

### ***Potential for an Incubator Company***

The purpose of this research proposal is to balance the right combination of technical and infrastructure requirements with the needs of public health. We believe that infrastructure initiatives in the state of South Carolina ultimately could create an opportunity for an incubated company poised to deliver on the fruit of this research at the national level. Creating an incubator company, however, is not the primary focus of this early research.

## Bibliography

[1] The original IOM Study on the Computer Based patient record [The Computer-Based Patient Record: An Essential Technology for Health Care \(1991\)](#) (ISBN 0309044952), Richard S. Dick and Elaine B. Steen, Editors; Committee on Improving the Patient Record, Institute of Medicine. An update on the Computer-based Patient Record report is described in <http://www.nap.edu/html/computer/> (Also published in hardcover as: *The Computer-Based Patient Record: An Essential Technology for Health Care*, Revised Edition (1997)).

[2] The Internet2 is described in <http://www.internet2.edu/>. The middleware initiatives of Internet2 are of specific interest to this research.

[3] An example of a commercially available, first generation, personal health record is <http://www.capmed.com/>. Another example of a first generation personal health record is [http://my.webmd.com/my\\_health\\_record](http://my.webmd.com/my_health_record).

[4] Some issues of privacy rights in the personal health record are addressed in [http://www.medrecinst.com/resources/pat\\_right/index.shtml](http://www.medrecinst.com/resources/pat_right/index.shtml)

[5] Recent conference proceedings touching on personal health records are described in <http://www.medrecinst.com/conferences/tepr/2001/program/final/special/astm.shtml>

[6] A discussion of Personal Health Records appears in <http://www.informatics-review.com/records.html>

[7] A proposed standard for patient medical information being considered by the National Committee on Vital and Health Statistics is cited in

<http://ncvhs.hhs.gov/010319p8.htm>

[8] An overall assessment of the current state of health informatics standards is

<http://www.chim.org/Members/Standards.asp>

[9] An assessment within the last year of the general prospects of consumer health records appears in <http://www.fcgdoghouse.com/company/news000711.asp>

[10] Technical issues with creating a comprehensive patient record in Europe on the public Internet are considered in <http://www.jmir.org/2001/1/e7/>.

[11] K. Armstrong, F. C. Druseikis, N. Hazeltine, "Case Study, HealthCompass: Providing Direction in the World of Health Care", *1998 Guide to Health Care Resources on The Internet*, J. W. Hoben, Ed., Faulkner & Gray, New York, 1997, p. 39.