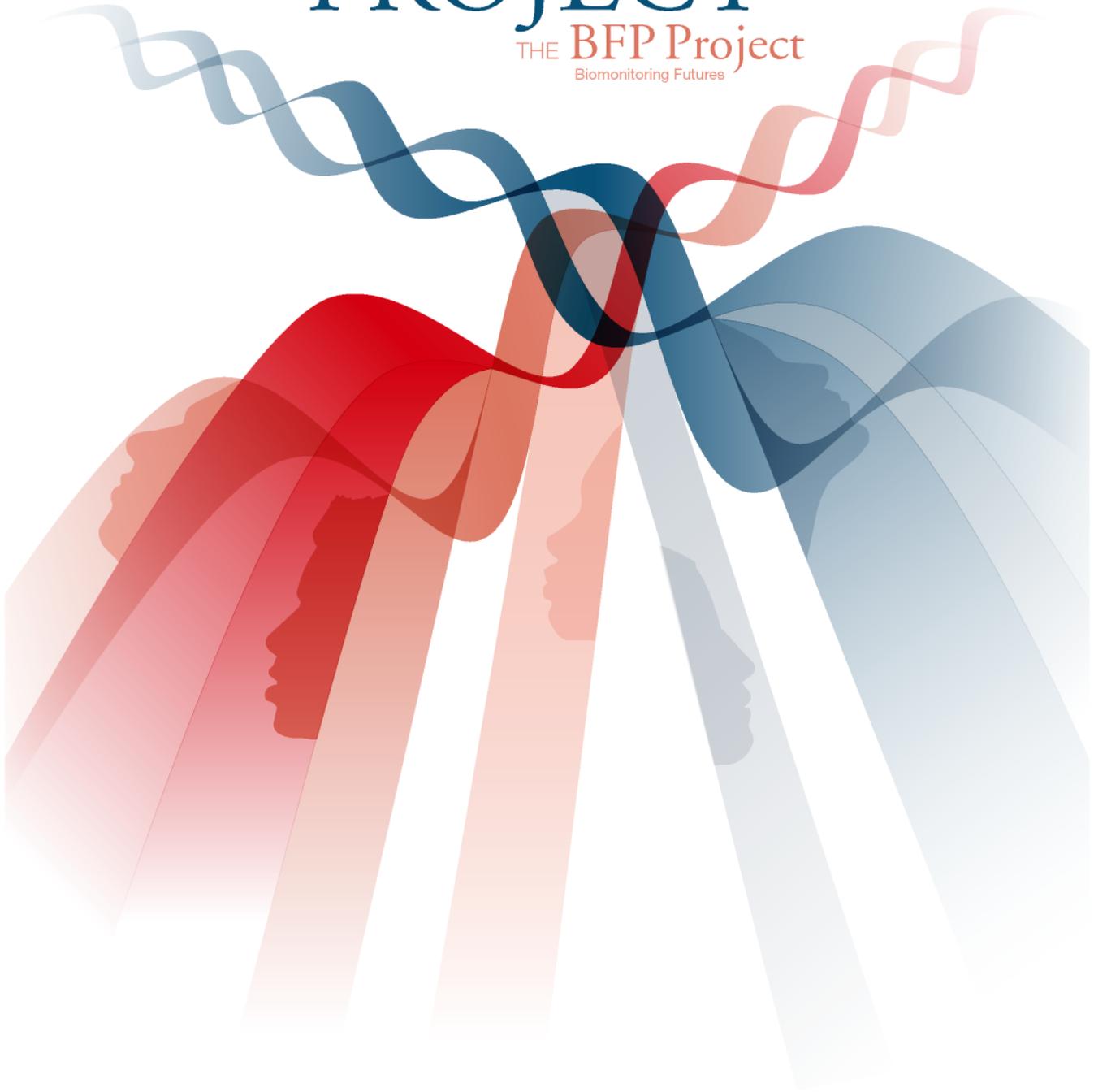


THE **DRA** PROJECT
Accelerating Disparity
Reducing Advances
THE **BFP** Project
Biomonitoring Futures



Health Information Systems

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THE BFP Project

Biomonitoring Futures

Health Information Systems 2015

Introduction	3
Diffusion of Technology	4
Access to the Internet and Cell Phones	5
Electronic Medical Records and Personal Health Records	7
Moving to a National Health Information Infrastructure	10

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Health Information Systems 2015

Introduction

This report is part of the Biomonitoring Futures Project (BFP). BFP is considering the future of biomonitoring for prevention and treatment of cancer and diabetes and its potential for reducing health disparities. Biomonitoring will be used in the context of health information systems. This report considers likely developments over the next decade in health information systems – for health care providers, for patients and for consumers of self-care.

There are many types of health care providers. For the Biomonitoring Futures Project and the larger Disparity Reducing Advances Project (DRA Project) the health care providers that will be considered as our modal delivery systems are federally qualified Community Health Centers (CHCs). Our forecasts will focus on the health information systems that are plausible over the next decade. We will provide what we think are likely forecasts and consider those as we connect the biomonitoring forecasts to the forecasts for cancer and diabetes prevention and treatment. Other forecasts are also plausible – developments could be faster or slower than those assumed here.

The Institute for Alternative Futures (IAF) believes it is important to focus on both individual and collective health information systems since there is likely to be growth in both and the line between them is likely to blur. For the purposes of this report, health information systems will refer to a variety of information technologies that can improve patient care including:

- Health Coaching and Monitoring Software
- Electronic Personal Health Records (PHRs) for Patients
- Electronic Medical Records (EMRs) for Providers
- Communication Technologies
- Web based clinical care activities
- Access to healthcare information sources

Diffusion of Technology

Since the 1990s, advances in computer power and connectivity have created new ways to manage health data and disease. The price of computing power both in relative and absolute terms has also dropped, making computing power, once only available to government agencies, research laboratories and large companies, available to small healthcare clinics and average citizens. This same computing power is also available in smaller, mobile platforms such as the cell phone. Improved user interfaces have made interacting with and using information systems easier and more intuitive.

The use of information technology in healthcare has lagged behind other information intensive industries. Electronic medical records (EMRs) have the potential of reducing medical errors, improving collaboration between healthcare providers and reducing the cost of healthcare. The fragmented nature of the healthcare industry, privacy concerns, and institutional inertia are all slowing the adoption of information technology, especially EMRs.

The individual use of information technology, on the other hand, has been diffusing rapidly into the mainstream. The majority of households now have a computer and internet access. Newer, third generation cell phones will allow more sophisticated access to the internet, enabling the cell phone to be used as a portal for health information, coaching, and monitoring. However, the rates of diffusion of information technology have been uneven among different income and ethnic groups, which has often been labeled the digital divide.

The diffusion of new technology usually follows a clear pattern where more affluent populations become early adopters of the technology. Early adopters often subsidize the development of the technology. As the technology becomes more robust and cheaper, rates of adoption increase. The rate of adoption continues to grow as more people who want or need the technology have access to it. However, as the technology is available to a larger percentage of the population, the rate of adoption decreases until the market is saturated. There will also be those who do not adopt the technology due to high cost or other constraints.

Access and use of information technologies have followed this same pattern of early adoption and diffusion. As new information technologies and applications come to the market, they will likely follow

a similar pattern. In looking at health disparities, it is important to recognize the process of diffusion and to identify ways to speed up the process. It is also important to realize that there may be laggards in the adoption process for a variety of reasons including the cost of the technology, access issues or cultural considerations. The diffusion of technologies can be encouraged by a variety of mechanisms ranging from the use of subsidies to the use of networks to encourage innovation and “bottom of the pyramid” business strategies.¹

Access to the Internet and Cell Phones

Forecast: By 2015, 95% of households have home access to a computer and the internet. Seventy-five percent of people have a cell phone with broadband capabilities. Typically, the poor are slower in getting advances, but access to the basic technologies needed for health coaching and management are widespread. Health coaching software is more advanced, and works with the patient and a healthcare provider to set personal health goals for weight loss, diabetes prevention and stress reduction. The system provides real-time feedback and alarms to help the patient achieve her health goals. Advances in computer software make these programs intuitive, easy to use, culturally appropriate and available in a wide variety of languages.

Access to information technology is growing rapidly regardless of family income, age or ethnicity. From 1997 to 2003, the percentage of households with a computer has risen from only 36.6% of households to 61.8% of households. Over the same period, the percentage of households with internet access has grown rapidly from 18.6 percent to 54.6 percent.² From 2000 to 2003, the percentage of households with broadband internet access has grown from 4.4% of households to 19.9 percent.³

Worldwide Interoperability for Microwave Access (WiMAX) is often mentioned as the next stage in both broadband and wireless. WiMAX broadcast towers will have a radius of three to ten kilometers that proponents claim is capable of supporting hundreds of businesses and thousands of residences at broadband speeds.⁴ Standards for mobile WiMAX have just been completed and mobile products based on WiMAX should probably hit the market in 2008.⁵ WiMAX also has the potential for transforming broadband, wireless internet access into a public utility since it can cover wider areas than current wireless technologies and is able to penetrate buildings. Cities such as Philadelphia are already developing citywide wireless access using the current Wireless Fidelity (WiFi) technologies to help narrow the digital divide.⁶

However, the benefits of the information age have not been shared equitably. There is a considerable gap in access and use of information technology. This divide is largely a function of income and education level with those earning less than \$30,000 a year and those with no college education having significantly lower rates of computer use at home to access health information.⁷ Only 31.2% of families with income less than \$15,000 are internet users.⁸ Access to information technologies, especially broadband internet access, is also lower in rural areas where private companies are less likely to invest in infrastructure.⁹

Internet use seems to be following a standard pattern for technology diffusion. Internet is growing rapidly for all income groups, but the rate of growth is fastest in groups with the lowest percentage of utilization. The highest rates of growth from 2001 to 2003 were among African-Americans and families earning less than \$15,000. The rate of growth among Hispanics was slightly higher than the national average.¹⁰

On the other hand, the digital divide for cell phones has been much less pronounced. The penetration rate for cell phones is 66% in the United States. Cell phone penetration rates for Hispanics are roughly similar at 64%.¹¹ A 2002 study by knowledge networks showed that a higher proportion of African-Americans owned a cell phone (65%) than whites (62%).¹²

New third generation cell phones that are currently being deployed in major cities will blur the line between cell phones and personal computers. Third generation cell phones are able to download information from the internet at speeds in between dial-up and broadband. Costs for third generation service will initially be high as the service is rolled out, but is likely to be lowered in price or included as part of a basic wireless package as the technology becomes widespread. Wireless phone companies have already set standards for faster 3.5 generation cell phones and WiMax has been mentioned as a possible fourth generation cell phone technology, but no standards have been set yet.¹³

The functionality of cell phones will grow and enable them to take on many of the functions currently offered by computers. It will be commonplace for the cell phones of 2015 to link to medical or personal biomonitoring devices and relay the information to the individual's personal health record or to their doctor's system. It is likely that the cell phone and biomonitors will relay data over the network during

low use periods to allow more cost effective applications. It is also possible that cell phones themselves will become a biomonitoring tool able to record and analyze heart rate, motion, and other data.

Electronic Medical Records & Personal Health Records

Forecast: By 2015, all Community Health Centers will have Electronic Medical Records tied into advanced clinical management systems. Patients will have access to a personal health record that is linked to the electronic medical records of their healthcare providers and to biomonitoring devices. The personal health record is automatically updated with information from the electronic medical record and biomonitoring devices. Patients can adjust the security settings on their personal health record and control which providers have access to the health information in their personal health record. Both patients and providers have access to powerful knowledge management software to help turn this healthcare data into useful information to improve health outcomes. This software presents the biomonitoring data in easy to read format. This software reduces the disparities in health literacy among different patient groups by making it easier for them to access health information in their own language and in culturally appropriate ways.

The data relevant to doctors and healthcare providers is growing rapidly. Advances in biotechnology are expanding the number and range of treatments for disease. At the same time, evidence-based medicine is expanding the amount of data through post-market studies on efficacy and safety. As medicine becomes more personalized to the genetic proclivities and specific health conditions of individual patients, and as our definitions of disease broaden to subdisease and to predisease states, the amount of data relevant to the clinician will rise.

The Electronic Medical Recordⁱ (EMR) is a platform on which a more efficient healthcare system with better outcomes for patients can be built, but the EMR alone is not sufficient. Rather a collection of advances need to be combined with the EMR to improve the healthcare system with:

- Interoperable Data
- Knowledge Management Software
- Patient Access
- Digitally Linked Biomonitoring Platforms
- Regional and National Information Infrastructure
- Protections to Ensure Privacy and Security and Prevent Discrimination

ⁱ The Electronic Medical Record (EMR) is a phrase with often varied meanings. For this paper, it will be used synonymously with the term Electronic Health Record (EHR). At their most basic level EMRs are an electronic platform for health information storage, retrieval and sharing.

Currently, the information in EMRs is a combination of older paper records scanned into an electronic format and data stored in an interoperable format. The second type of data is more useful in improving clinical care because it improves the interoperability of the health information systemⁱⁱ and can be interpreted by knowledge management software.ⁱⁱⁱ

Community Health Centers have successfully implemented electronic medical records systems. A network of community health centers in New Hampshire, the Community Health Access Network (CHAN), has successfully used Electronic Medical Records to improve care delivery.¹⁴

Policies will be needed to develop common standards to reduce the risk of vendor lock-in and ensure a robust collection of vendors able to serve the needs of smaller providers. Open source standards and software, which are discussed in greater detail below, might reduce the risk of vendor lock-in and create a wider variety of provider choices for community health centers.

Today, patients have little access to the information and knowledge they need to manage their own care. The Personal Health Record (PHR) is designed to address the needs of the patient by bridging the gap between providers and patients.^{iv} A number of different electronic PHRs are available online. Currently, these PHRs are stand-alone systems with limited interoperability with the EMRs of most providers. Recent trends in healthcare, such as consumer directed health care, will increase the need for patients to have access to and use of their health data. They will be more responsible for choosing plans based on their risk profiles, for choosing treatments, and for navigating the healthcare system.

Patients may have a number of options on how their personal health record is stored. The data might be saved at a central location and accessed online through a username or password. It might also be stored in a physical device like a flash memory drive designed to look like a necklace or bracelet. Another

ⁱⁱ Interoperability between electronic systems can be broken down into three levels. Basic interoperability allows messages from one system to be received by another but does not require the computers to interpret the data. Functional interoperability allows the receiving computer to interpret the data fields, but does not allow the computer to interpret the data inside. Semantic interoperability allows information within the data fields to be used intelligently. The interoperability of an EMR system depends not only on the technology the system uses, but how the data in the system is entered.

ⁱⁱⁱ Knowledge Management Software is a specialized kind of software that supports tasks and decision making.

^{iv} Unlike the EMR, the PHR is designed to address the needs of patients rather than providers. If the goal of an interoperable National Health Information Infrastructure (NHII) is realized, it is likely the two records will be combined with different knowledge management programs layered over the top to organize the information in ways that fit the different needs of patients and providers.

possibility is a combination of both with important information stored in a physical device accessible by emergency personnel and larger, harder to store items, such as medical images stored in a database accessible to those with access to the physical device. It is also possible that implantable microchips with this information will become widespread, especially for highly mobile populations like military personnel and the homeless.

Like EMRs, the addition of knowledge management software can help patients use their own health data to improve their health care. This can take the form of tracking software that can integrate the readings of digitally linked biomonitoring devices or the results of lab tests into easy to read charts showing trends in the patient's health. Other applications of knowledge management software to PHRs are actively linking new healthcare research so patients know the latest developments in their disease areas, health coaching software that helps patients set healthcare goals and helps them monitor their progress, and software that uses the patient's medical and family history to develop risk profiles for disease.

In forecasting health information systems, from a consumer perspective, it is relevant to consider the strategies of Revolution Health. Founded by Steve Case, founder of AOL, Revolution Health seeks to put patients at the center of health care by providing enhanced content, context and care. In 2006, Revolution Health will launch a consumer-friendly health portal that will enable consumers to manage their health needs and the health needs of their families. The portal will show health news and information, find and schedule medical appointments, manage health care spending, and support community-based searches for information about health needs and issues. Just as many individuals use Quicken to manage, link and download their financial information, Revolution's tools will allow integrated health management. The company also intends to have a number of walk-in clinics to provide fast, affordable treatment for routine medical conditions, as well as screenings, medical tests, and immunizations and other preventive services.¹⁵

Revolution Health and others will support consumers with knowledge management software, enabling the patient to use their own health data to improve their health care. The health data can take the form of tracking software that can integrate the readings of digitally linked biomonitoring devices. The results of lab tests can be presented in easy to read charts showing trends in the patient's health. Knowledge management software can link PHRs to healthcare research, so patients know the latest developments in

their disease areas. Health coaching software can also help patients set healthcare goals and help them monitor their progress.

These advances in knowledge management software will be enabled by new IT tools that change the way people access data and turn it into usable knowledge and wisdom. Natural language processing, for example, helps computers “understand” human languages. Computers that are better able to “understand” human queries are better able to manage and present information in a context that leads to knowledge. Artificial intelligence (AI), in the form of expert systems, combined with ontologies,^v are becoming a powerful tool in mining data for patterns of significance within large bodies of data. As more knowledge from research is placed directly into machine readable formats, opportunities will expand for “automated learning” in which AI systems generate hypotheses and, where possible, test them against appropriate data.¹⁶ These systems will be useable by consumers/patients in their own language and by 2015 these systems will be culturally and ethnically sensitive in how they operate, present information and support health behavior and decision making.

The ability of IT tools to manipulate data to create knowledge for doctors and patients is vital as new biomonitoring devices create loads of data for analysis. As these tools develop, less and less time will be needed by doctors and patients to analyze the data from biomonitoring devices and more time can be spent on using the knowledge gained from biomonitoring to improve health. AI systems will be able to sift through vast amounts of biomedical data to highlight and analyze the data that is important to specific patients. Better biomonitors, biomarkers and genomic information will enable these systems to apply the data to the patient’s unique circumstances. This kind of tailored healthcare is likely to be much more efficacious and cost-effective than current treatments.

Moving to a National Health Information Infrastructure

Forecast: By 2015, there is a national health information network in the United States for the electronic transfer of health information. The system will largely be comprised of regional networks linked by open standards. Interoperability problems will remain, as will gaps in coverage. If current trends continue, many regions will not have a regional health information infrastructure or will have a system that is not interoperable with the national system. However, most patients at CHCs will be able to have their health information travel with them. CHCs that are more electronically isolated will

^v Ontologies are exhaustive and rigorous conceptual maps of concepts and their relationships within a domain of knowledge.

have effective internal systems that provide advanced services but are not effectively linked to the national system.

A number of important trends are driving the healthcare industry to embrace health information systems. These include:

- The growth of market-driven healthcare
- The increasing digitization of information
- The restructuring of the healthcare industry to be more efficient
- The demands of evidence-based medicine
- The need to improve quality and reduce preventable errors
- And the continuing advances in information technology.

Better health information systems could dramatically improve the delivery of healthcare and lower the cost of services. It has been estimated that better information technology could prevent two million adverse drug interactions and 190,000 hospitalizations a year.¹⁷ Better health information systems have been shown in one study on computerized order entry to reduce medication errors by 86%.¹⁸ Over 3000 hospitals have committed to save 100,000 lives between June 2005 and June 2006 by performing six common procedures successfully, without defects. One of these procedures is medication reconciliation – which would be aided by a computerized physician order entry (CPOE) system.¹⁹

While the healthcare industry in the United States invests roughly 2% of its revenues into information technology, other information intensive industries invest closer to 10%.²⁰ The United States lags behind other developed nations, such as Britain, in the use of health information systems. Britain's \$12 billion plan to revolutionize the National Health Service's through information technology is the world's biggest civilian information technology project.²¹

There are a variety of reasons for the slow adoption of health information systems. The healthcare industry in the United States is fragmented, unlike the single payer system in Britain. The medical practices and hospitals that pay for upgrades for information technology do not see most of the benefit of the systems they would install. The majority of the cost savings from information technology goes to the insurers and employers who pay for the insurance. There is little incentive for providers to invest in information technology unless they are subsidized by insurers or the government.²²

Over half of all doctors in the U.S. also work in small practices that cannot afford the investment in information technology. The Markle Foundation estimates that these practices would need incentives worth \$3 to \$6 per patient-visit to install an IT system. Another key problem is a lack of interoperability, although an “interoperability consortium” comprised of eight of the world’s largest software companies^{vi} came together in January of 2005.²³

Despite these obstacles, health information systems are being rolled out in healthcare provider networks and regions across the United States. PeaceHealth, a multistate provider network based in the Northwest, is a good example of a successful integration of health information systems into care delivery. Keys to success at PeaceHealth were a “process-centered” approach, a continuous cycle of improvement and extending their system to include affiliated providers and patient-consumers. A “process-centered” approach realizes that the people, processes (including workflow), governance and structure of the organization are just as important as the technology. A continuous cycle of improvement is needed to effectively integrate the collection of data into systems of analyses to produce better informed decisions, improved processes, and better outcomes. Since the start of their project, PeaceHealth has expanded their information technology systems to the community through their Community Health Record. The Community Health Record provides a single, communitywide, longitudinal medical record (with security safeguards) to providers and patients associated with PeaceHealth.²⁴ Since the Community Health Record program began, the adherence to care guidelines has tripled among diabetic patients in two of PeaceHealth’s facilities.²⁵

Community Health Centers have taken similar steps to develop regional systems. An example is the Community Health Access Network which has linked a number of community health centers in southern New Hampshire into a regional network. The network members established mutual standards for software selection and operations. All but one of the members used the same practice management system and adopted the same electronic medical record system.²⁶

The next step in healthcare information systems is to link multiple providers into regional or national systems. Regional Health Information Organizations (RHIOs) are being developed to share EMRs and

^{vi} The companies are Microsoft, Oracle, IBM, HP, Intel, Cisco, Accenture and Computer Sciences.

other information among providers in a region.^{vii} The Indiana Network for Patient Care (INPC) is an early example of a successful RHIO. The INPC links five major hospital systems, county and state health departments, Indiana Medicaid and RxHub^{viii} to provide laboratory results, radiology images, dictation and other documents to the majority of Indiana's office practices. For RHIOs to succeed, they must reach a critical mass of users by focusing on high-volume data producers first such as large hospital systems and moving to smaller offices second.²⁷ A possible outshoot of RHIOs is that areas that are primarily rural or lack a large hospital system may lag behind the nation in developing regional systems because they cannot reach the needed critical mass.

RHIOs are a key part of President Bush's push to have EMRs accessible to every American within 10 years. RHIOs would then be linked together to form a National Health Information Network (NHIN).²⁸ However, interoperability between different RHIOs remains a major challenge for a NHIN. Currently, each individual RHIO is being developed using different systems and therefore many different standards.

The Department of Health and Human Services (HHS) understands the need for common standards for RHIOs.²⁹ Without a common set of standards, it is likely that the nation's health infrastructure will remain fragmented along regions. Poor and rural regions might be worse off since they would be less able to afford upgrades to their system. This would leave them with antiquated systems based on standards that are not supported by the NHIN. A better solution might well be open standards and open source software for electronic medical records and health information systems.

Open source standards and software is one potential advance that could encourage a broader rollout of health information systems and reduce disparities between different providers in the United States. Open standards^{ix} makes interoperability requirements much lower. Open standards would also facilitate easier sharing of health information between providers and between providers and patients on a peer-to-

^{vii} A Regional Health Information Organization (RHIO) is a multi-stakeholder organization that enables the exchange and use of health information, in a secure manner, for the purpose of promoting the improvement of health quality, safety and efficiency.

^{viii} RxHub is a company that electronically routes up-to-date patient medication history and pharmacy benefit information to physicians in their offices and at hospitals.

^{ix} Open Standards, as defined here, are the set of specifications developed to define interoperability between diverse systems and are owned and maintained by a vendor-neutral organization and are provided royalty-free (certification may require a fee). Common Standards, by contrast, are standards that are commonly applied across a system, but may be owned by a particular vendor and therefore constitute considerable lock-in by the organizations that use them.

peer basis. Open source software^x can provide a lower cost alternative to proprietary systems. It is also more likely to have continuing maintenance and support options since the source code is in the public domain. To a certain extent, the use of open standards make the need for open source software less acute by making it easier for proprietary and custom designed health information systems to communicate with each other. However, both open source standards and software will make it easier for smaller, less affluent providers to find vendors that can meet their needs and to change vendors if needed.³⁰

Open source software for healthcare is likely to be of higher quality and more available in the near future. One of the world's largest, most respected and most widely deployed health information system, VistA, is developing into an open source alternative. VistA is the complete health information system developed by the Department of Veteran's Affairs and released free of charge to the public under the Freedom of Information Act.^{xi} A number of supporting institutions and private companies are coming together through organizations such as the VistA Software Alliance and World VistA to promote the adoption of VistA.³¹ VistA is also gaining interest as a health information system for networks of Community Health Centers. The Community Health Centers of West Virginia, for example, recently signed with Medsphere Systems Corporation to use their comprehensive electronic health information system which is designed for ambulatory care clinics and based on VistA.³²

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^x Open Source Software is a software program where the source code is available to anyone for use and/or can be modified by anyone from its original design free of up-front license fee charges.

^{xi} VistA is used not only by the VA, but also by the Indian Health Service and the Health Resources and Services Administration. A version of VistA, the Composite Healthcare System, is used in Department of Defense Facilities. A number of international, state and private institutions are also using VistA or looking at implementing VistA.

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