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Electronic Personal Health Records Come of Age

Transcribed and adapted for publication by
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SPECIAL EDITORIAL

David B. Nash, MD, MBA

We are pleased to bring you this special supplement to the *American Journal of Medical Quality* (AJMQ) focused on the personal health record (PHR). This supplement is a timely follow-up to our previous report on e-health that documented progress on issues such as implementing electronic medical records (EMR) and forming regional health information organizations (RHIOs). Please see the November/December 2005 issue of AJMQ and the supplement titled "e-Health Initiative Update: Proceedings from the e-Health Technology Summit."

In September 2005, the National Committee on Vital and Health Statistics (NCVHS) determined that there is no uniform definition of a PHR in industry or government, and the concept continues to evolve. The committee noted that "experts often use the concept of the PHR to include the patient's interface to a healthcare provider's electronic health record. Others consider PHRs to be any consumer- or patient-managed health record. This lack of consensus makes collaboration, coordination, and policy making difficult."

As a result, the NCVHS concluded that it is not possible or even desirable to attempt a unitary definition of a PHR at this time but noted that it was possible to characterize PHRs by their attributes

(ie, scope or nature of the information contained, source of information, features and functions offered, owner of the record, type and location of data repository, technical approach to security, party authorizing access to the information).

We have taken the NCVHS recommendations and observations to heart and present in this special supplement a detailed picture of the PHR using a company called InterComponentWare, Inc (ICW) as a concrete example. Why ICW? Because this international corporation is at the forefront of a number of global companies focused on developing PHR technologies and the platforms that facilitate universal connectivity. Through a nonrestricted educational grant, ICW enabled the Department of Health Policy at Jefferson Medical College to host an international advisory board meeting on the future of the PHR and, specifically, the LifeSensor product line from ICW.

This special supplement, with contributions from faculty of the Department of Health Policy, as well as from industry leaders concerned about the future of the PHR, will form the foundation for an ongoing discussion about the strengths and limitations of our current technology. The supplement contains an overview of the PHR arena, detailed descriptions of ICW's current PHR technology and experience in deploying systems in Western and Eastern Europe and other countries, and a candid exchange of ideas regarding the barriers and possible solutions to implementing this technology in the United States. Surely we recognize that there are different models for PHRs, and it is not our intention to promote any single platform. Rather, we are highlighting ICW's technology as a fine example of a fully functional, globally implemented system.

Finally, a note to our readers. This supplement extends our coverage of new technologies devoted to improving the quality and safety of medical care. As always, we are interested in your views, and I

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US ADVISORY BOARD: InterComponentWare, Inc

Richard Baron, MD, a director of the **American Board of Internal Medicine**: *"Primary care is in trouble and the solution lies partly in HIT [health information technology]. However, much must change on the physician side of the equation for HIT to work."*

Peter Bittel, EdD, CEO, **The Futures HealthCore**, a multistate health care staffing/management company providing clinical services in settings such as organizations serving individuals with developmental disabilities: *"The (US) healthcare market is cynical about (new HIT) because of previous technological failures . . . it's a tough selling environment."*

E. Thomas Coleman, senior counselor, **The Livingston Group**, a business-oriented, government affairs consulting firm with policy and political expertise in the national and international marketplaces. *"HIT is on government and business radar screens in Washington, DC, and across the country."*

John R. Combes, MD, president and COO of **Center for Healthcare Governance**, an American Hospital Association affiliate organization: *"It is imperative that PHRs [personal health records] be able to interface with hospital and other central health records."*

Henry A. DePhillips, MD, executive vice president and CMO of **MEDecision, Inc.**, a provider of integrated collaborative care management systems to payers and emerging regional health information organizations (RHIOs): *"Our health records should be accessible at an ER in the United States or abroad in the same way our money can be accessed from an ATM in Rome."*

Raymond J. Fabius, MD, president and CMO of **I-trax**, an integrated health and productivity management company providing wellness and disease management services: *"(HIT) implementation and orientation issues are complex . . . addressing them in a collaborative, phased approach will yield the best results."*

William F. Jessee, MD, president and CEO of **Medical Group Management Association**, the nation's leading voice for group medical practice: *"In US healthcare systems, the payers accrue economic benefits of EHR [electronic health record] and PHR while physicians and hospitals bear the acquisition costs. It may take legislation requiring payer investment to break the current logjam."*

Vishu J. Jhaveri, MD, MSA, COO and corporate medical director, **FutureHealth Corporation**, a population risk management organization: *"PHR technology can be used as a tool to change the behavior of consumers."*

Janet Marchibroda, CEO of **eHealth Initiative** and its foundation: *"One impact of Hurricane Katrina is that health records were irretrievably lost. This makes a good argument for EHR and PHR."*

Roger F. Mecum, executive director, **Pennsylvania Medical Society**: *"Security—who can access the data—is a big issue."*

David Merritt, project director for the **Center for Health Transformation**, a collaboration of public- and private-sector leaders working to transform health and health care in America: *"Consumers must become more engaged in their healthcare, and a PHR is a perfect tool to help them."*

Blackford Middleton, MD, MPH, MSc, corporate director, **Clinical Informatics Research and Development** and chairman of the **Center for Information Technology Leadership** at Partners HealthCare System: *"The value of a PHR will be largely dependent on how well patients use the tool to engage actively in their care . . . updating medication lists, supplying relevant information, engaging in chronic care programs."*

Harold Robles, president and chairman of the **Medical Knowledge Institute**, an international organization committed to health care education and information: *"Broader dissemination of PHR technology could have a positive impact on global health (eg, AIDS disease management in South Africa)."*

David M. Spratt, DO, corporate medical director, **Crown Cork & Seal Corporation**: *"Successful HIT companies will focus less on managing costs and more on managing health."*

Donald Wilson, MD, medical director, **Quality Insights of Pennsylvania**, a medical quality improvement organization charged with fostering Pennsylvania-based HIT and RHIOs: *"The federal mandate to implement EHRs poses a huge challenge for every state."*

Figure 1. US advisory board.

welcome your comments. Please feel free to write to me directly at david.nash@jefferson.edu.

INTRODUCTION

In its October 2005 report, "American Health Information Community Potential Breakthroughs,"

the Office of the National Coordinator for Health Information Technology (ONCHIT) defined *breakthrough* as "the use of health information technology that produces a tangible and specific value to the health care consumer and that can be realized within a 2-3 year period." Three broad categories of potential breakthroughs were described:

Acronym	Definition
PHR	Personal health record: a person-centered system designed to track and support health activities across one's entire life experience; not limited to a single organization or provider.
EMR	Electronic medical record: a computerized platform for managing medical information collected by a hospital or physician practice.
EHR	Electronic health record: a computer-based collection of health information (from a patient population) that has been gathered by and is managed by an enterprise, typically a physician or hospital. There are those who view EHRs as a combination of EMRs and PHRs, but an EHR is used by clinicians, not patients.

Figure 2. Common e-health acronyms.

consumer empowerment (eg, PHR, medication history, health record locator, registration/demographic information), health improvement (eg, electronic health record [EHR], e-prescribing, quality monitoring/reporting, chronic disease monitoring, childhood immunization record), and public health protection (eg, emergency information network, bio-surveillance/pandemic surveillance, adverse drug event reporting/notification).

The new Web-based PHR technology has breakthrough potential in a number of dimensions. In addition to engaging consumers and enabling them to access and coordinate their lifelong health information and make it available to health care providers, it creates opportunities for improved communication between patient and provider, improved medical practice efficiency, and increased drug security (ie, via interaction and contraindication checks).

On December 8, 2005, the Department of Health Policy at Jefferson Medical College convened a group of opinion leaders in health information technology (HIT) to evaluate a Web-based PHR technology that has been deployed successfully throughout the European Union (EU) and other countries. This advisory board was charged with identifying barriers to the introduction of such technology in the United States and proposing solutions.

In addition to information on PHR technology and its role in the context of electronic health systems, the following pages contain the insights of

advisory board members (Figure 1) and salient points raised during their discussions.

BACKGROUND: EVOLUTION OF THE PHR

With the growing interest in e-health technology, it is important to clearly define the current terminology. The acronyms shown in Figure 2 often are used interchangeably in discussions and in the media, which can cause confusion.

Today, only a few PHR products are clearly linked to compatible EMR systems (ie, hospital-based and/or practice-based systems). However, such linkage is key to providing the level of portability and accessibility necessary to make the PHR equally useful for consumers and health care providers.

PHRs are not a new concept. For decades, many consumers have maintained paper PHRs to facilitate the transfer of information between health care providers and to ensure that comprehensive health information is available for future care. The burden of responsibility for the collection, maintenance, secure storage, and communication of this information rested primarily with the consumer and required tenacity and a significant investment of time.

The advent of the Health Information Portability and Accountability Act (HIPAA) privacy and security regulations officially enabled patients to "own" their medical information and to view, adjust, and comment in their records. HIPAA also granted patients the right to know who has accessed their records.

Electronic PHRs can facilitate the otherwise daunting task of ensuring that pertinent health information is shared among the patient and his or her team of providers. The ideal PHR will allow all medical information (eg, testing, radiology, discharge orders, medications) to be automatically updated, consumer controlled, and Internet accessible. Unlike the EMR, which often is tied to a specific hospital or provider office, the PHR will pull from multiple sources to create a comprehensive, lifelong medical history and will allow consumers to grant access rights to others based on type of provider or type of information.

Consumers' Perspectives on PHRs

The Markle Foundation's Connecting for Health program has conducted several surveys to determine health care consumers' interest in and readiness to use PHRs. Their findings indicate the following:

Nearly 70% of respondents say they would use an online PHR service to

- check for mistakes in their medical record and
- check and refill prescriptions.

Nearly 50% of respondents say they would use a PHR to

- conduct secure and private e-mail communication with their physicians and
- retrieve test results over the Internet.

Barriers to Adoption of PHRs

The number of PHR options is increasing (eg, iHealthRecords [Medem], MyChart [Epic], About MyHealth [Medscape]), and the potential benefits are many (eg, improved patient self-management, enhanced patient-provider communication, increased collaborative decision making, improved access to data in emergency situations, reduced costs). However, consumer and provider acceptance and adoption are not assured. Among the many complex issues that may prevent the widespread use of PHRs are

Consumer-related issues:

- Trust (eg, who will have access to the information?)
- Privacy and security concerns (eg, will private PHR companies be regulated?)
- Cost (eg, will consumers be willing to pay all or part of the cost if the PHR is not linked to any of their providers? Will consumers understand the nuances of different PHR products and be able to select the one with the best tools and functionality for their needs?)
- User interface
- Digital divide (eg, will PHRs increase health care disparities by further enlarging the gulf between the “haves” and “have-nots”?)
- Maintaining data (eg, who will be responsible for ensuring that data are updated accurately and in a timely fashion?)

Provider-related issues:

- Limited electronic data systems in small-scale practitioner offices
- Cost (eg, cost of producing the EMR, cost of lost productivity during the transition period)
- Reimbursement for online communication
- Integrating the information from the EMR and PHR into the practice workflow (eg, how much additional time will be required to make

the information intelligible and accessible to patients?)

- Maintenance of data and transfer of EMR data into PHRs

Technical issues:

- Interoperability
- Data repository
- Data standards (eg, variations in coding and documentation exist, handwritten and through data entry)
- Security

ICW'S APPROACH TO THE PHR: LifeSensor

PHR options are increasingly available on the market. In addition to those noted in the previous section, a product that has achieved success throughout the EU and other countries is poised for introduction in the United States.

LifeSensor is a Web-based PHR that is highly protected and secured via encryption, distributed data storage, authorization, and authentication. It is patient centered and patient controlled, with utility for physicians to encourage their acceptance. Only the patient has the right to grant a clinician access to his or her PHR.

The record contains all relevant medical data for its owner (eg, emergency data, health assessment and status, medical history, drug documentation and history, laboratory results, clinical data, and care action plans). It also contains specific tools for disease management programs, case management (episodic or chronic), care action plans, and prevention programs and integrates remote patient monitoring (eg, chronic heart failure) and a living will (ie, legal authorization capability with an additional component). Capabilities include various language options and measurement conversions that can be made available as needed. These features enable the PHR owner, and any clinicians so authorized by the owner, to access the health record and the reports contained therein in his or her primary language and terminology.

The technology supports integration with professional medical source systems via a Web application program interface that permits seamless transfer of data to and from the PHR. Other features for the transmission of data in the online record include a printer (ie, documents can be printed directly into the record in PDF format from any application), Explorer (ie, a functionality by which any file can be easily uploaded by “drag and

Module	Description/Features
Medical history	Lifelong medical record with all relevant information on conditions, diagnoses, and treatments organized around a case management structure. Included functions: reminder for vaccinations and checkups, emergency section accessible by emergency code, self-check and data entry capability, diary function.
Diabetes assistant	Data can be entered either online, with an electronic pencil, or by SmartPhone. Some glucometers are equipped to transmit data wirelessly to the health record.
Breast cancer assistant	Automated synchronization among all involved physicians and hospitals via LifeSensor. Dedicated patient information about disease and treatment options. Benchmarking.
Maternal/child	Support for mother throughout pregnancy. Monitoring of child-specific surveys.
Healthy lifestyle	Fitness assistant and nutrition assistant.

Figure 3. LifeSensor personal health record module examples.

drop”), fax, document upload and download, secure e-mail, laboratory interface, and the potential for direct integration with medical devices (eg, wireless remote patient monitoring capabilities.) Figure 3 describes various LifeSensor modules.

Of equal interest are the prevention programs supported by this technology. LifeSensor’s primary prevention program is oriented toward specific healthy populations and focuses on healthy behaviors including age-appropriate nutrition and sports activities. The secondary prevention program targets wellness and treatment in the early stages of conditions via therapy, activity, and nutrition. Preventing or delaying complications of chronic conditions and improving quality of life are the focus of tertiary prevention. Rehabilitation and telemedicine features for persons with conditions such as diabetes, hypertension, and chronic heart failure are included (Figure 4).

In the United States, the growing trend toward consumers’ involvement in their health care is spurring discussions about PHRs—their potential content and uses as well as the challenge of integrating PHRs with other e-systems and data sources. How receptive will the US public be to using a PHR? ICW reports that there has been good acceptance among insurers for patients with complex conditions. In these cases, use of a PHR improves the efficiency of care, thereby helping to manage costs. Acceptance has also been excellent in cases requiring home monitoring (eg, heart failure). Use of PHRs in conjunction with prevention programs is increasing. There is also a reported rise in PHR adoption by individuals as they experience shifts in health status (eg, from infrequent acute episodes to chronic, complex conditions.) ICW’s European experience suggests that healthier individuals have been slower to adopt the technology,

but they have observed a developing trend toward lifestyle uses (eg, fitness, nutrition, self-care services), which are of equal interest to payers.

The advisory board envisioned other potential uses and benefits. For instance, PHRs could support the health records managed by gatekeepers and physicians (eg, reminders to take medications, monitoring vital signs) for a growing community of elderly persons with chronic conditions. Board members perceived value in an online/offline, “Quicken-like” health record that is available at any time and any place and can be used as a personal decision support system. They agreed that for PHRs to reach their full potential, they must be designed to become part of the medical workflow environment, and they must integrate with the rest of the care management system. The entities that the board projected would benefit most from PHR technology are RHIOs, disease management companies, self-insured employers and other insurers, and individual consumers desiring a tool to manage a medical condition.

INTEGRATED PLATFORM DESIGN (THE ICW MODEL)

Throughout the world, “fragmentation” is cited as a problem that compromises the quality and efficiency of health care systems and impedes the successful implementation of HIT. Government and market forces are under considerable pressure to erase the lines of fragmentation, and, increasingly, they are looking to HIT for a solution.

In the relatively short history of HIT, we have learned that a stand-alone component or service is limited in its usefulness, but integration of the

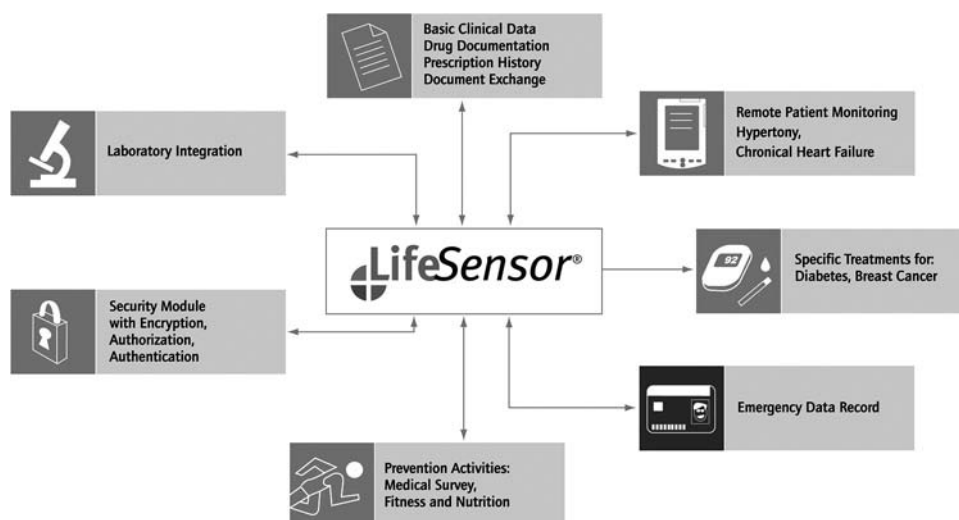


Figure 4. Modules of the personal health record.

component or service adds substantial value. For PHRs to realize their full potential, they should be fully integrated with regional hospital and physician practice EMRs.

In formulating its strategy, ICW began by focusing on solving the problem of integration with other systems. With the overarching goal of integrating products and services to improve health care service delivery for target groups, the company has developed a PHR with controlled access for care providers and patients that integrates with primary care systems, particularly EMRs, for seamless health data exchange (Figure 5).

ICW's platform strategy is designed to achieve HIT integration and connectivity by simple and affordable means. Rather than envisioning a single electronic record, it focuses on integrating multiple e-health records. Original data entered by the physician, the hospital, or the patient stay with the physician practice or hospital. Via the specialized adapters that are integral to ICW's platform, only digital copies of original data are transferred to the PHR.

The LifeSensor PHR contains a comprehensive health record that can be accessed by SmartPhone (a handheld device that integrates mobile phone capabilities with features of a handheld computer or personal digital assistant) or personal computer. The record includes emergency data, fitness, nutrition, and other specialized data fields. ICW's open architecture allows for uncomplicated integration of these data with virtually any health information

system. To date, the company has successfully implemented such integration efforts with numerous health information systems.

In its first 7 years, ICW has learned valuable lessons that are being carried forward.

1. **Focus on core competencies:** the ability to partner (eg, currently more than 100 partnerships with companies such as Cisco Systems, Inc and Hewlett-Packard), secure long-term financing, and scalability in all areas. Most important, outsource as soon as one component of the platform becomes a commodity.
2. **Architecture-driven product development:** service-oriented architecture based on openness and cost-sharing with partners, use of standards and standardization, scalability and international applicability from inception.
3. **Partnerships for a total solution concept:** a prerequisite for acceptance of a platform. Partners must be relied on to share in high financing needs, and the platform can be useful in a collaborative business model. Balance must be maintained between partnership and competition.

ICW's platform strategy and guiding principles differentiate it in the HIT marketplace in several respects. First is its strong involvement in interoperability initiatives (ie, seamless data exchange via connectors/adapters with existing health information systems: hospital information systems, practice

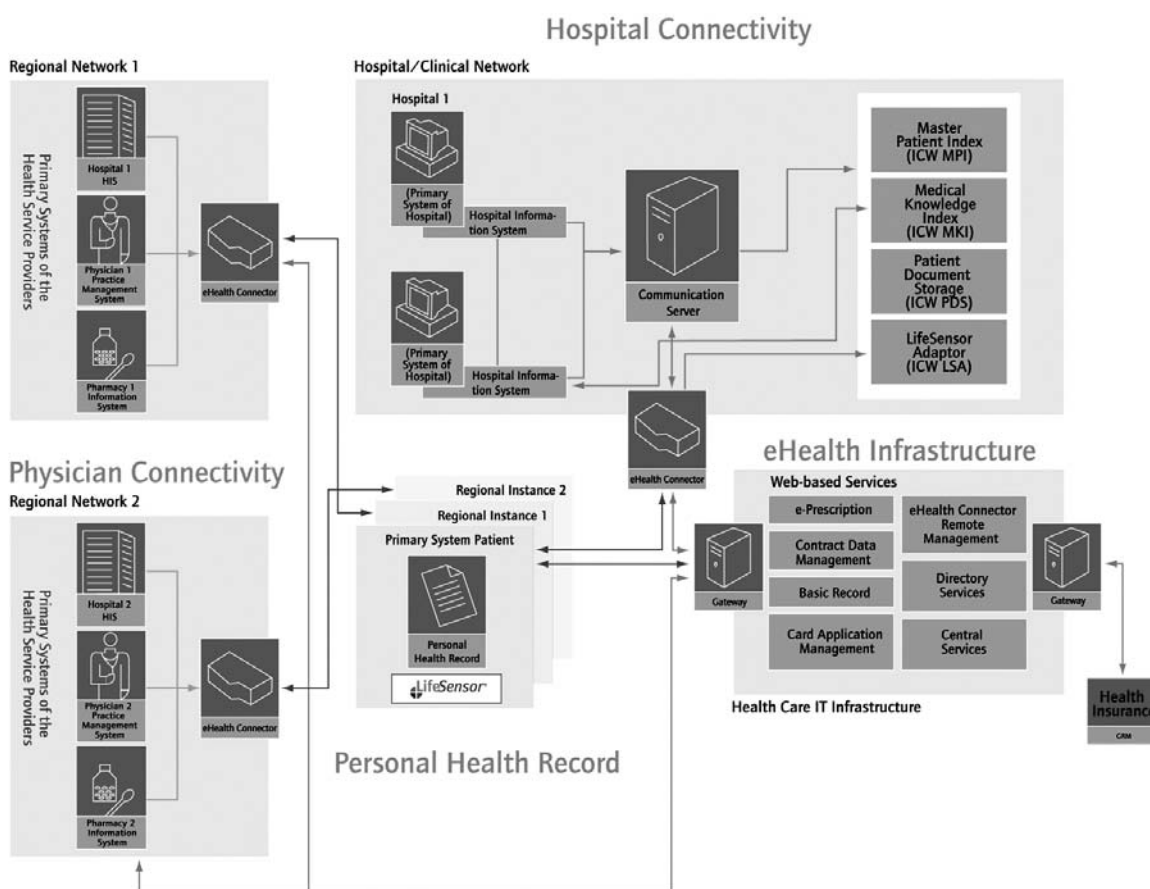


Figure 5. InterComponentWare, Inc's platform implementation.

management systems, EMR, EHR, and medical monitoring devices). Other differentiating features include emphasis on collaborative business models and sophisticated partner concepts; scalable and highly secure technology; service-oriented, component-based architecture; and a wide range of functionality (eg, specific chronic diseases [diabetes, types of cancer], fitness, nutrition).

These features dovetail with some of the major US e-health goals set by ONCHIT (ie, focus on PHR, remote patient monitoring, and regional information exchanges via strategic partnerships with primary EHR systems and data warehouses).

INTERNATIONAL EXPERIENCE: INSIGHTS FROM THE EU AND OTHER MARKETS

The challenge of fragmentation in developing and implementing an e-health initiative is not unique to the United States. The e-health infrastructure in Europe is fragmented also (Figure 6).

The EU has launched ambitious initiatives in an effort to create a Europe-wide health information network and has fostered a collaborative approach to e-health by its member states.

Most EU member states are introducing national e-health infrastructures that will eventually be interconnected. Most countries have chosen to use electronic health cards (EHCs) as the basis of their systems. The EHC is a secure microprocessor-equipped "smart card" with cryptographic capabilities. These cards store emergency information and serve to identify the bearer and allow access to medical services. They also store electronic prescriptions and are key to additional planned e-health services such as access to a PHR.

While all EU countries mandate universal health insurance, some health systems are nationalized and others permit choice. As a first EU-wide step for harmonization, all citizens of EU member states are currently receiving a European Health Insurance Card (EHIC) that entitles its owner to

Sample of Targeted Population Estimates:

Italy – 9 million
 Austria – 8 million
 Spain – 7 million
 Czech Republic – 4 million
 Germany – 3.5 million
 Sweden – 1.6 million

Legend:

■ eHealth Infrastructure in Place
 ■ eHealth Infrastructure Planned
 ■ No eHealth Infrastructure yet



Figure 6. E-health infrastructure in Europe: a fragmented picture.

receive health treatment in any EU member state. The data contained on the EHIC differs by country, but all must contain emergency information.

How difficult is it to forge the cards or gain access to the information they contain? Real-world use indicates that the cards are highly secure. The technology used for EHICs is more sophisticated than the technology used for cards issued by banks, and the cards contain a miniprocessor.

As of the summer of 2005, approximately 50 million EHICs had been issued in the EU. Of the 19 countries in which EHICs are deployed, the current top 3 users are the Czech Republic (all 4 million citizens), Germany (3.5 million citizens), and Sweden (1.6 million citizens). The following are brief descriptions of e-health infrastructure deployment throughout the EU and other countries.

Nordic countries. With a highly developed e-health infrastructure already in place, Denmark implemented a portal solution driven by a national e-health strategy. In Sweden, where e-prescribing grew from 9% in 2001 to 45% in 2005 (saving the average physician approximately 100 hours per year), there are plans for introducing a national medical record and EHC deployment.

Benelux. In Belgium, an e-health portal is planned as well as EHCs. There are multiple systems for

health care networks, and shared patient records are already operational. Regional e-health pilot programs in the Netherlands are driven by hospitals.

Baltics. The Baltic states are influenced by the Nordic countries. Some cross-border operability and pilot programs are in place, and there is a high degree of health care provider connectivity.

Southern Europe. More than 9 million EHCs have been issued in Lombardy, a dedicated test region for Italy. In this region, an EHC is used in combination with a PHR.

Central Europe. In Germany, ICW plays a key role in the development of a nationwide e-health infrastructure including EHCs and PHRs for 82 million citizens. Other ICW-led initiatives include regional health information networks in pilot regions (ie, Munich, Walldorf/Mannheim, Schleswig-Holstein), a PHR-diabetes assistant program at Heidelberg University Clinic, and a PHR program at a large breast cancer treatment network.

ICW is currently implementing an interconnectivity solution for a 35-clinic hospital system, one of the largest in Germany. Although the clinics were previously unable to exchange information among the facilities' multiple and disparate systems, the implementation permits full data exchange without replacing the existing systems.

In Austria, ICW participated in the development and rollout of the national EHC with its respective e-health infrastructure. Other value-added services such as PHRs and e-prescriptions are being planned.

United Kingdom. The National Health Service has proposed an e-health plan that includes e-prescriptions, an EHR, and an EHC. The planned investment is 3.3 billion Euros for the next 3 years.

Non-EU countries. Switzerland has government initiatives to comply with the EU recommendation for EHIC and plans to implement an EHC similar to the German model, with deployment planned by 2008. Two pilot regional initiatives, Ticino and Geneva, are sponsored by industry. Russia has deployed EHCs in the region of Moscow.

According to the EU plan, a European interoperability standard for EHRs is to be defined by the end of 2006. By the end of 2008, most European health organizations and health regions should be positioned to facilitate online services such as teleconsultation (second medical opinion), e-prescription, e-referral, telemonitoring, and telecare.

While very impressed with the reported HIT implementation successes in the European and other e-health environments, the advisory board concurred that considerable barriers exist to replicating such systems in the United States. "In the US there is resistance to standardized health cards—even 'dumb' cards." Some experts predict that there will never be a unique patient identifier, and the ultimate owner of the data will be the consumer. What delete/edit capability should consumers have? For instance, if a married woman had an abortion at the age of 18, does or should she have the ability to mask that information in her medical record? Suppose a prior health-related event becomes clinically relevant and the data are masked?

US PERSPECTIVES: ADVISORY BOARD INSIGHTS

Fragmentation poses a huge challenge in the United States. As one member noted, "There are multiple places to obtain data (1000 insurers, 5000 hospitals, 200 000 different medical practices plus pharmacy benefits management companies and free-standing laboratories)." There is no large, nationwide system or set of standards. All agreed that US HIT is in a state of flux, with relatively few operational RHIO-based companies and systems.

The introduction and establishment of a Web-based e-health platform in the United States would fill an urgent need for advanced PHRs and enable interoperability. Members noted that, with open interfaces, such a platform would provide business-partnering opportunities and would enable integration among solution providers and health care service providers in different health care settings. One board member observed, "It would help in our drive toward the availability of online PHR and EHR for all citizens."

Consumer Perspective

PHRs offer many potential advantages to consumers (eg, health data accessibility across state lines and abroad, faster transmission of relevant clinical data, improved quality of information to support decision making), all of which contribute to improved health outcomes. Consumers' engagement in managing their health via PHRs may lead to improved health status in terms of prevention, early detection, and overall wellness; moreover, it may empower them to manage chronic and complex conditions more effectively.

"The President calls for every American to have a personal electronic medical record, but even those consumers who currently have PHRs aren't using them." Board members expressed some pessimism with regard to US consumers taking total control of their health care, noting that US health culture requires a conversation between the physician and the patient. Patients are accustomed to relying on an authority figure for interpretation of medical information and assistance in forming opinions and making health care decisions. A related point: the data that are most useful for decision making are not encoded and require a physician to interpret their meaning to the patient.

Other barriers to the widespread dissemination and use of PHRs include privacy issues, lack of technical proficiency among the elderly/Medicare populations, and access issues for lower socioeconomic and Medicaid populations.

Proposed solutions. In today's mobile society, consumers require PHRs that allow access to their health records at any time and any place. In addition to making this possible, Web-based PHR technology allows the health record to be viewed by the consumer and his or her physician simultaneously,

fostering improved physician-patient communication. To meet consumer needs, a PHR must be easy to use, especially when its user is in distress. The PHR should also be as portable and easy to remember as one's wallet or house keys. One board member suggested the use of collateral PHR products with essential medical data.

Health literacy is another issue that must be addressed in connection with PHR products. For the US population, general written material must be understandable at the seventh-grade reading level. When medical terminology and concepts are introduced into the text, intelligibility is affected.

Finally, members questioned if, and to what extent, US consumers would be willing to pay all or a portion of the cost for a PHR out of pocket.

Health Care Provider Perspective

The board recognized many potential advantages of PHRs for providers (eg, making complete patient information readily available, reducing record search time, improving the quality of information, contributing to a reduction in adverse events). However, the consensus was that US providers will be slow to adopt a PHR. One member observed, "Even if physicians are persuaded to extract information from a PHR, it will be difficult to convince them to enter information without appropriate incentives."

Other barriers to physician acceptance included a general resistance to change and the fact that most practices still are not wired. Many of those physicians who invested early in EMR systems experienced financial losses (due to the failure of systems manufacturers) and have grown suspicious of new e-health technologies.

Proposed solutions. An open architecture that permits interoperability of patient PHRs and provider EHR systems would eliminate barriers related to multiple data entry. Some board members predicted greater interest among large provider groups, but most agreed that physicians will not adopt a technology unless they perceive that it is of some value to them. Several members advised building in an incentive for physicians (eg, authorized providers can receive free access to comprehensive patient health information); one member suggested partnering with a payer and reimbursing physicians for participation.

US Health Care System Perspective

Concerning the question, "What is the most important relationship in health care . . . the doctor and patient or the health care system and patient?" board members were in agreement. "The doctor and patient relationship may change for a variety of reasons, but not the health care system and patient relationship."

For the health care system, Web-based PHRs (with interoperability capacity) hold the greatest promise (eg, improved connectivity among providers, increased drug security, reduced complications and adverse events, improved public health outcomes data) and present the most formidable barriers (ie, data reside in multiple places on multiple systems in multiple formats).

The advisory board supported the premise that e-health technology and products, combined in an integrated platform, could be a vital component of the solution to our fragmented health care system because of their long-term integrating effect. PHRs that incorporate interoperability features were thought to have great utility and value in such a restructured system. Board members commented that most of the existing EHRs have an EMR backbone, and all agreed that a model integrating a PHR with EMR-based tools presents an uncomplicated, practical solution.

Board members pointed out 4 aspects in which the US health care system will differ from EU systems in implementing e-health technology:

- the US solution will come from the private sector,
- the national health information network will be built incrementally,
- the private sectors will eventually get together for the "end game," and
- the current administration's position on standards is that they are necessary but government will act only as an enabler, not as an enforcer.

Payer Perspective

In the United States and Europe, a number of payer-sponsored PHR programs with interoperability are providing value to health care organizations, their networks, and members. For payers (ie, insurers, large employers), the potential advantages of PHRs include reducing duplication of services,

improving preventive care, avoiding costly complications, and increasing drug security. There are cost concerns (eg, cost of implementation), but in general, health insurers will pay for PHRs through health care providers. Self-insured large employers may have to enlist the support of labor unions. In recent years, health care coverage issues have led to more strikes and work stoppages than any other issue in the United States. "Unions (eg, International Association of Machinists) will come to realize that PHRs are of value to *all* stakeholders."

In the US health care system, much is driven by Medicare. "As Medicare goes, so goes the private sector." Several board members suggested contacting state Medicaid programs or Medicare to discuss potential PHR demonstration projects.

ADVISORY BOARD OBSERVATIONS AND SUGGESTIONS REGARDING THE US MARKETPLACE

RHIOs

Initially, because of the scarcity of operational models and useful data, board members viewed the prospects of a company such as ICW partnering with RHIOs (to test the PHR-integrated platform concept) with some skepticism. However, as discussions progressed, members opined that such a partnership with RHIOs could be of great value as a demonstration project. "Fledgling RHIOs have all the pieces in place and (ICW) can provide the platform to integrate them—an attractive proposition for many communities."

Nontraditional and Alternate Health Care Settings

Board members commented on the value of PHR technology to caregivers. An increasing number of people—primarily middle-aged women—are caring for 4 to 5 family generations living in the home. As caregivers, they need tools to help them care for others with disabilities and chronic physical and

mental conditions. A PHR facilitates capture and transmission of different types of health data (eg, medications taken, vital signs).

The board also considered the potential value of PHRs in alternate health care settings. It was noted that the "concierge" approach to health care is growing and likely to become more popular in the future. One example of a nontraditional setting was that of nurse practitioners delivering care in pharmacies or retail store-based clinics.

Population and Disease Management

Based on successful programs in the European market, board members were optimistic about the potential of PHRs for US populations with diabetes, asthma, or certain types of cancer.

Outcome Measure Reporting

PHRs with integrated platform technology would be of value to private-sector payers as an improved means for collecting the data necessary to meet reporting requirements (eg, for the National Committee for Quality Assurance). Such technology might also improve a payer's ability to establish benchmarks.

CONCLUSION

PHRs and related e-health technology could be an essential part of the solution to an overwhelming issue in the US health care system: the lack of connectivity and interoperability. Patient involvement will be a critical factor in making the necessary connections, and a Web-based PHR that is interoperable with hospital and physician systems could provide the "gateway" for the patient. An excellent venue for pilot testing such a system would be in select areas, or RHIOs, where physician groups, payers, and hospitals have developed a model and are actively engaged in collaboration to build a connected health care community.