Learning from Abroad:
Lessons and Questions on Personal Health
Records for National Policy

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The AARP Public Policy Institute, formed in 1985, is part of the Policy and Strategy Group at AARP. One of the missions of the Institute is to foster research and analysis on public policy issues of importance to mid-life and older Americans. This publication represents part of that effort.

The views expressed herein are for information, debate, and discussion, and do not necessarily represent official policies of AARP.

Acknowledgements

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Acronyms

AHIC	American Health Information Community
AHRQ	Agency for Healthcare Research and Quality
CDS	clinical decision support
CHF	Consumers Health Foundation of Australia
CMS	Centers for Medicare and Medicaid Services
DHB	district health board
ECDL-F	European Computer Driving Licence Foundation
EDI	electronic data interchange
EHR	electronic health record
eiPHR	electronic integrated personal health record
ePHR	electronic personal health record
ERDIP	Electronic Record Development and Implementation Programme
EU	European Union
GDP	gross domestic product
GMS	General Medical Services
GP	general practitioner
HIPC	Healthcare Information Privacy Code
HIS-NZ	Health Information Strategy for New Zealand
HIPAA	Health Insurance Portability and Accountability Act
HIT	health information technology
IBD	inflammatory bowel disease
ICD	International Classification of Diseases
ICT	information and connectivity technologies
IOM	Institute of Medicine
IPA	independent practitioner association
IT	information technology
NCVHS	National Committee on Vital and Health Statistics
NEHTA	National E-Health Transition Authority
NHII	national health information infrastructure
NHS	National Health Service
NLM	National Library of Medicine
NPfIT	National Programme for Information Technology
NRC	National Research Council
NZHIS	New Zealand Health Information System
OECD	Organisation for Economic Co-operation and Development
ONC	Office of the National Coordinator
PACS	picture archiving and communications systems
PAERS	patient access to their electronic record system
PALS	Patient Advice and Liaison Services
PHI	Personal Healthcare Identifier
PHR	personal health record
PING	Personal Internetworked Notary and Guardian
PIP	Practice Incentive Program

PIPEDA   Personal Information and Electronic Documents Act
POSP   Physician Office System Program
QMAS   Quality Management and Analysis System
RIXG   Renal Information Exchange Group
SNOMED-CT® SNOMED Clinical Terms®
SWPE   standardized whole patient equivalent
SUSTAIN   Support Users to Access Information and Services
USB   universal serial bus
VCUR   vendor conference and usability requirements
WHO   World Health Organization

Foreword

Although the potential of health information technology (HIT) to improve health care quality is widely acknowledged, the United States (U.S.) lags considerably behind many of the developed countries in HIT adoption. On the assumption that there are valuable lessons to be learned from other countries that have outpaced the U. S. in HIT adoption, and with a particular interest in personal health records (PHRs) as a means of helping consumers become better informed, AARP commissioned Dr. Detmer and Ms. Steen, both experts in international HIT, to determine the extent to which PHRs are in use in several English-speaking countries (Australia, Canada, England, and New Zealand).

 The key objective of the research was to identify experiences in the international arena that might inform policies in the U.S. The authors found that the underlying cultural differences among the U.S. and the countries studied (that are attributable to their different delivery systems, financing approaches, and national health information infrastructures) account for a disparity in interest in PHRs and divergent approaches to HIT. Nevertheless, they also identify areas of common focus, including recognition of the need to improve the quality and safety of the health care system, the need for robust information infrastructures, and the importance of designing systems that are patient-centric and that focus explicitly on the patient. While AARP does not necessarily endorse all of the authors' recommendations, we are eager to stimulate discussion about personal health technology and hope that this study will contribute to that discussion.

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Tables

Executive Summary

<u>Background</u>

Electronic personal health records (ePHRs) are a relatively young technology with limited but growing use.[1] At their most basic level, personal health records (PHRs) are tools that allow individual patients or citizens to manage their health information. There are several models of ePHRs, all of which have a common goal (i.e., to provide patient access to personal health data to support personal health management and enable sound decision making). But they do vary in terms of the technologies or applications used, the kinds of functions offered (e.g., basic information management [ePHR], how they are integrated for full interaction with health care professionals [eiPHR]), and the source and types of data in the record. Considerable progress has been made in advancing the concept of ePHRs but there is still ambiguity surrounding their form and function.

<u>Purpose</u>

AARP commissioned this study to examine the use of and approaches to personal health records in selected English-speaking countries (Australia, Canada, England, and New Zealand) with the goal of identifying best practices and lessons that may be applicable to development of PHRs in the United States.

<u>Methodology</u>

The study methodology included interviews with health information technology experts in each country; a review of the published literature; and a review of websites related to health technology and PHRs to gather information on the structure of the health system, the health information technology environment, concept and status of a national health information infrastructure, and experience with PHRs in each country. In addition, the study gathered highlights of PHR activity in Scotland and Sweden as well as the European Union. After compiling information on each country, we compared and contrasted the experiences in these countries to identify common themes and lessons that might prove instructive for PHR development in the United States. Our analysis focused on what private and public organizations could do in the United States to create an environment that would foster ePHR development and implementation, with particular attention to federal national health information infrastructure (NHII) policy.

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[1] We distinguish several types of personal health records due to their differing scope and value. The commonly used term, personal health record (PHR), encompasses both paper- and computer-based PHRs. Electronic personal health records (ePHRs) are computer-based records that are not integrated with the information technology systems of caregivers. Electronic integrated personal health records (eiPHRs) do have such integration.

<u>Findings</u>

Despite differences in the structure of the health system of the four nations (see Table 2), there is a consistent focus across countries with respect to goals for the health sector. Specifically,

- Patient safety must be assured, and quality of services must be improved across the health care system.
- Population health, primary care, and chronic disease management capabilities are pivotal to achieving these goals.
- A robust information infrastructure that enables connectivity among providers is essential to addressing current shortcomings in the health care delivery system.
- The health system and electronic patient records must be patient-centered and support patient empowerment while maintaining patient privacy.

ePHRs are an emerging technology. Evaluations of ePHRs have yielded generally positive results. While acknowledging the limitations of survey data, most surveyed citizens support the concept of ePHRs. It is not clear, however, how many citizens would actually use ePHRs if they were broadly available.

The four countries studied, particularly England and Canada, have made considerable progress in planning and implementing NHIIs and are ahead of the United States with respect to developing the infrastructure needed to support widespread ePHR use (e.g., unique patient identifiers, connectivity and EHR use by physicians). In general, however, PHR and ePHR activity in these countries is limited. At present, England's National Health Service (NHS) offers all patients a mechanism for developing a patient-initiated health organizer through HealthSpace. England and Australia plan to provide patients with access to at least part of their clinical care records in the future (by 2008 in England), but the records will have limited functionality. Otherwise, ePHR activity has been largely limited to small-scale evaluations, and there is less private sector focus in those countries on ePHR development than there is in the United States.

<u>Conclusions and Recommendations</u>

We conclude that the disparity in interest in ePHRs is due primarily to differences in the cultures that underlie the health care systems of the United States and the countries studied. The United States emphasizes individualism, while the nations studied focus on the collective, or what they refer to as social solidarity. These cultural differences lead to divergent approaches to health care delivery, financing, and NHII planning, which, in turn, create different levels of demand for a tool that enables patients to manage and better influence their own health care services. The cultural split also accounts for differences in attitudes toward personal health identifiers and the political will of elected representatives to set policy relating to them.

We identify five areas where U.S. policy makers can learn from other countries. First, the NHS approach to developing ePHRs within a national framework for EHRs points to an organizational issue the United States needs to address. The U.S. approach to NHII development does not provide the same level of focus, funding, or infrastructure that is present in England. Regardless of the approach taken, regular communication and ongoing coordination is needed among the public and private organizations that have a role to play in ePHR development and diffusion.

As a starting point for this communication and coordination, federal agencies currently involved in NHII activities (e.g., the Office of the National Coordinator [ONC] and its American Health Information Community [AHIC] Consumer Empowerment Workgroup, the Agency for Healthcare Research and Quality [AHRQ], National Library of Medicine (NLM), Center for Medicare and Medicaid Services [CMS], U.S. Department of Defense [DOD], and Veterans Administration [VA]),along with interested private organizations (e.g., Markle Foundation, AARP, voluntary and professional groups, and representatives of third-party payers) should jointly develop a focused research agenda that identifies appropriate sponsors for addressing key research questions (including relevant research issues). Of equal if not greater importance is the need then for these nongovernmental bodies to agree on a few central, crisply defined policy initiatives to generate the political will in the legislative and executive branches to assure federal legislation essential to a functional interoperative NHII for the nation.

Second, and as part of this effort, public advocacy and policy groups need to consider whether the current U.S. privacy framework will support widespread implementation of ePHRs. In particular, they should evaluate whether ePHRs can be implemented on a broad scale without unique patient identifiers. Organizations interested in advancing ePHRs should examine privacy approaches such as England's Care Record Guarantee and national privacy commissioners as ways to strengthen the privacy infrastructure in the United States. These organizations should also support a comprehensive study of privacy attitudes of American citizens to guide policy on unique identifiers beyond the common and very flawed method of "opinion surveys from the street." Finally, these organizations can support both ePHR and electronic health record (EHR) development by educating the public on the benefits of the technology, available privacy protections, the unavoidable tensions and trade-offs between health and privacy in accessing person-specific information at some levels, and the role of unique health identifiers in supporting efficient and effective health care delivery.

Third, several good examples of consumer engagement and education may provide useful guidance to ePHR developers on how to obtain consumer opinions about and support for ePHRs. In particular, AARP or another public advocacy organization may be able to play a role similar to that of Australia's Consumer's Health Forum. In addition, ONC should ensure that it includes consumer representation in its various planning groups and obtains feedback from consumers on its pilot projects, as did England's NHS Connecting for Health program.

Fourth, public advocacy groups like AARP can help to advance ePHR implementation by focusing on citizen readiness. To advance ePHR development, AARP and other public advocacy groups should strengthen efforts to improve health literacy and numeracy in the U.S. population and develop a more comprehensive approach to improving the computer literacy of key ePHR user groups (e.g., senior citizens, individuals with chronic disease, and individuals who may need to monitor the health of a family member from a distance) (Institute of Medicine, 2004). The European Union's e-Citizen program provides one model for such an effort.

Fifth, the growing interest in health information among citizens of all nations highlights the urgency for international standards of terminology and classifications of health, illness, and health care. In particular, SNOMED Clinical Terms[®] (SNOMED-CT[®]) and International Classification of Diseases (ICD) need to be harmonized and maintained on a global basis. As part of its efforts to advance interoperability, ONC should assure sufficient collaboration with other nations and the World Health Organization (WHO) to develop and maintain international standards that will facilitate global sharing of medical knowledge and enable integration of systems incorporating ePHRs. ONC needs to work with the White House, health agencies, and standard-setting entities to ensure sufficient federal appropriations for ongoing support of these standards.

Background

Electronic personal health records (ePHRs) are a relatively young technology with limited but growing use. An estimated 250,000 Americans had access to such systems in 2003 (Connecting for Health, 2003). An ePHR released in 2005, iHealthRecord, reported that 10,000 Americans built a PHR during the first few weeks of availability (Protti, 2005). As the largest purchaser of health care services in the United States, the Centers for Medicare and Medicaid Services (CMS) issued a request for information on PHRs in summer 2005 to obtain guidance on "how to proceed on participating with existing PHRs or fostering development of PHRs which focus on the needs of the Medicare population" (CMS, 2005). Other organizations, including insurance groups, are considering moving into this emerging space, especially to manage chronic conditions.

At their most basic level, personal health records (PHRs) are tools that allow individual patients or citizens to access and manage their health information. Until recently, personal health records tended to be paper and (with the exception of patients with chronic conditions) were an afterthought for most patients who might or might not save immunization records, lab results, or lists of medications taken for future reference. But just as the health community's understanding of the form and function of patient records evolved from paper charts to electronic health records and from static repositories of raw data to interactive tools that integrate information and provide support for decision making, the concept of personal health records is being developed and refined in response to technological capabilities, consumer needs, and changes in the health sector.

ePHRs have emerged from the confluence of two forces that have been growing in strength over the past 15 years. First, the role of information management in the health sector has been expanding. This trend has been fueled by growing recognition of the need to manage information as a means of improving quality, managing costs, and capturing data that can provide new insights into and knowledge of effective health care delivery and health management. The 1991 Institute of Medicine (IOM) report on computer-based patient records presented a vision of improved information management in health care and accurately described the challenges to be overcome (IOM, 1997). Diffusion of and national attention to electronic health records (EHRs) remained quite low until the relationship between information management capabilities and quality of care was made startling clear for policymakers and the public alike in the IOM's 1999 report on patient safety and 2001 report on health care quality (IOM, 1999, 2001a). These reports drew attention to deficiencies in the U.S. health care system and made clear that a national health information infrastructure (including a workforce skilled in information management) is critical for improving health care quality. These reports proved to be influential abroad as well.

Equally important, improved information management has been made possible through ever increasing capabilities of information and connectivity technologies (ICT). The banking, retail, and travel industries were early adopters of ICT and have used it to transform their businesses. The benefits of effectively deployed ICT have begun to be documented in health care organizations as well (Hillestad et al., 2005).

One of the most visible results of this trend is that many developed countries have begun to develop national health information infrastructures (NHIIs) with plans to implement EHRs throughout their health care system. NHII implementation has lagged in the United States, but debate has shifted from whether electronic health records supported by an NHII should be available in every health care setting in the nation, to how to expedite the diffusion of this technological capability that is essential to effective health care delivery (Detmer, forthcoming; Shortliffe, 2005; U.S. GAO, 2005).

Second, in the United States, health care is increasingly patient-centric, and many health care providers seek to empower patients. The increase in consumerism as a general trend in society, combined with the specific developments in the health sector, has contributed to the evolution of the role of patients as participants in health care decisions and awareness by all citizens of the need and potential to manage their health through behavior. (This trend appears to be most prevalent in the United States, the Netherlands, and the Scandinavian countries, with physicians in other nations continuing to use more traditional or "paternalistic" approaches to their interactions with patients.) Health care organizations recognize that patient satisfaction is one component of quality and that empowered patients can improve their health outcomes. As growing numbers of patients experience chronic disease there is increased incentive to manage their care experiences; improved information management for patients is one mechanism for doing so.

Healthy individuals also have incentive to develop accurate personal and family health histories to help identify potential risks and to stay abreast of current knowledge about contributors to health as a means of reducing that risk through their behaviors. As the costs of health care are continually shifted to consumers in the United States, there are growing incentives for consumers to stay informed and make sound decisions for their personal health and the health of their checkbooks. Finally, although the impact of genomic medicine is not yet widespread, it will most likely lead to personalized care becoming a routine part of the practice of health care and, hence, will create even greater amounts of data about an individual's and a family's health to be tracked over time (Underwood & Springen, 2005).

ePHRs: An Evolving Concept

This paper focuses specifically on electronic personal health records (ePHRs) and uses the definition developed by ASTM for personal health records as a starting point:

> an electronic application through which individuals can maintain and manage their health information, and that of others for whom they are authorized, in a private, secure, and confidential environment that allows the individual or other authorized persons to access and share such information.[2]

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[2] Extracted, with permission, from *E2211-02 Standard Specification for Relationship Between a Person (Consumer) and a Supplier of an Electronic Personal (Consumer) Health Record*, copyright ©ASTM International, 100 Barr

This definition captures three fundamental dimensions of ePHRs: information management as the core function, emphasis on consumer control, and the importance of privacy and security.

In 2000, the National Committee on Vital and Health Statistics (NCVHS) articulated a vision for a NHII in the United States that includes a personal health dimension and broadens the ASTM concept of ePHRs in several ways (NCVHS, 2001). First, NCVHS identifies the purpose of the NHII's personal health dimension as supporting management of individual wellness and health care decision making. Second, these two goals are achieved through access to data about health status and health care in the format of a personal health record and other information and resources relevant to personal health. Third, the ePHR provides "convenient, reliable, secure, and portable access to high quality individual health and wellness information supplied by both the individual and by his or her health care providers." Thus, the ePHR must be able to accommodate information from a variety of sources. These two dimensions of the ePHR envisioned by NCVHS imply that connectivity to other parts of the NHII is a necessary function.

Fourth, NCVHS provides greater detail on the kind of information management functions to be expected from ePHRs. Thus, individuals will be able to capture information related to their health from a variety of sources; store information through a variety of mechanisms (e.g., home information programs, third-party information guardian services, or smart cards); share information; process information (e.g., with computer-based decision support); and present information in a variety of formats, depending on the individual's needs. Finally, NCVHS delineates the ways ePHRs are likely to contribute to improved personal health management: health and wellness management, personal health risk assessment, health decision making, patient-doctor communication, adherence to medication regimens and care plans, reduction of problems with lost or illegible information, improvement of health quality through a complete continuum of patient care received across settings, better patient understanding of and participation in the care process, and chronic disease management. This is particularly a feature of eiPHRs, in which the patients and clinicians work together in a fully integrated manner due to information technology (IT) systems designs that assure secure and seamless connectivity.

Sittig (2002) offers a fairly narrow definition of ePHRs, but also provides guidance on specific attributes that contribute to the functionality and ultimate value to users:

> Internet-based personal health records include any Internet-accessible application that enables a patient (or guardian) to create, review, annotate or maintain a record of any aspect(s) of their health condition, medication, medical problems, allergies, vaccination history, visit history, or communications with their health care provider.

According to Sittig, ePHRs must be able to gather data from a user or import it from a clinician's system, code these data according to a standard clinical vocabulary, store these coded data values in a database, and provide interfaces to the coded data that allow other applications to access and use the data. Sittig's definition highlights two-way connectivity as a feature of ePHRs.

Connecting for Health (2003), a private-public collaborative of more than 100 organizations funded by the Markle and Robert Wood Johnson foundations, has conducted the most comprehensive review and analysis of PHRs in the United States As part of this work, the Personal Health Working Group identified seven attributes of PHRs**:**

1. Each person controls his or her own PHR.
2. PHRs contain information from one's entire lifetime.
3. PHRs contain information from all health care providers.
4. PHRs are accessible from any place at any time.
5. PHRs are private and secure.
6. PHRs are "transparent"; individuals can see who entered each piece of information, where it was transferred from, and who has viewed it.
7. PHRs permit easy exchange of information with other health systems and professionals.

The Working Group acknowledged the difficulty associated with meeting all of these attributes in the current health information technology (HIT) environment, but expects that attributes 1, 4, and 5 can be achieved today. Further, the Working Group emphasized that there are noteworthy examples of PHRs in both the public and private sector that "currently enable meaningful electronic information sharing between patients and clinicians and allow patients to manage their own health." The Working Group also developed a useful framework for comparing PHR models in terms of where and how patients access their PHRs, how information gets into the PHR, and the range of functions the PHR offers. Table 1 provides an overview of this framework.

Table 1: A Framework for Comparing PHR Models (Connecting for Health, 2004)

Medium (Where and how do patients access their PHR?)	Desktop-based Web-based Portable device

Data
(How does information get into the PHR?)
	Patient sourced
	Professionally sourced
	   • Institutional gateways
	      ○ Integrated service gateways
	      ○ Single-service gateways
	   • Aggregator models
	      ○ Third-party repositories
	      ○ Record locator service

Functions
(What can people do with their PHR?)
	Core repository of personal heath data
	• Name and demographic information
	• Emergency contacts, next of kin
	• Family history
	• Insurance information
	• Problem list (diseases and conditions)
	• Medications (Rx, over-the-counter [OTC], vitamins, herbals and other alternative therapies)
	• Allergies and reactions
	• Immunizations
	• Labs and tests
	• Hospitalizations/surgeries
	• Other therapeutic modalities (counseling, occupational therapy, alternative, etc.)
	• Visit summaries
	• Advance directive form
	• Spiritual affiliations/considerations
	• Other concerns—free text field to share other information with physicians
	• Goals, next step, or disease management plan
	Optional content or transactional services
	   • Links to patient education, self-care content, and consensus guidelines
	   • Secure messaging
	   • Doctor's notes and other narrative information
	   • Appointment scheduling and reminders
	   • Preventive service reminders
	   • Adherence messaging
	   • Patient diaries (pain, symptoms, side effects)
	   • Longitudinal health tracking tools (charts, graphs)
	   • Drug interactions checking
	   • Prescription refills
	   • Financial information such as Explanation of Benefits
	   • Scanned images such as CT scans

Another dimension of ePHRs is whether they support access to information or enable interaction with health care professionals along with access to information. The degree to which health care professionals and their information systems can and will interact with

PHRs depends in part on the source of ePHR data (e.g., patient-, provider-, or insurer-sourced). There are, however, also questions concerning whether and how health care professionals will respond to electronic messages that might be generated when a patient uses an ePHR; whether in a given system a health care provider's information system is capable of generating reminders for appointments or preventive service recommendations to be sent to the patient's PHR; or whether the health care provider's information system can accept data from a given ePHR.

While it is clear that ePHRs offer the potential to empower patients through better access to their health information, it remains to be seen whether the full potential of ePHRs as a means of extending the relationship between the patient and the health professional beyond the health care setting will be achieved. Early evidence suggests that eiPHRs that support "clicks and mortar" care—an ongoing monitoring link between caregivers and patients that enables continuity of care, particularly for chronic disease management—could be enabled significantly through ePHRs if health professional behaviors and information systems possess this capability. Further, in time, selected data from eiPHRs could be made available to public health professionals, in addition to clinicians, for biosurveillance and other public health objectives.

Widespread implementation of robust ePHRs depends on conditions in the HIT environment (e.g., interoperability standards, physician access to and use of ePHR-compatible systems, and adequate privacy protections). The types of PHRs actually implemented within a country will be influenced by the NHII's structure. In turn, the form of a country's NHII is shaped by the structure of its health system. Moreover, adoption of ePHRs will depend in part on the readiness of citizens to invest in and use these systems.

Study Purpose

Although the general concept of ePHRs is readily embraced, it does require further clarification, and experience with ePHR implementation is fairly limited (CMS, 2005). Wide-scale implementation of ePHRs raises a host of questions for policy makers, health care provider organizations, third-party payers, and citizens. AARP commissioned this study to examine the use of and approaches to PHRs in selected English-speaking countries to identify best practices and lessons that may be applicable to ePHRs in the United States

Study Methodology

This analysis of the status of ePHR development outside the United States examined the structure of the health system, the health information technology environment (including citizen use of computers and the Internet), and the national health information infrastructure concept and status, in addition to experience with PHRs and ePHRs in each country.

The study methodology included interviews with health information technology experts in each country, a review of the published literature, and a review of websites related to health technology and PHRs. Individuals to be interviewed were selected on the basis of their knowledge of health information developments in their nation. We used a standard set of questions as a starting point of the interviews (see Appendix 1). In two instances, telephone interviews could not be scheduled, so participants responded to the survey in writing. In all instances, interviewees were guaranteed confidentiality with respect to their comments to enable them to provide frank responses to our queries. The names of the individuals surveyed were shared with AARP, the study sponsor.

In addition, the study gathered highlights of PHR activity in Scotland and Sweden as well as related activities organized by the European Union. After compiling information on each country, we compared and contrasted the experiences in these countries to identify common themes and lessons that might prove instructive for ePHR development in the United States. Our analysis focused on what private and public organizations could do in the United States to create an environment that would foster ePHR development and implementation, with particular attention to federal NHII policy.

Findings

The Health Systems

Table 2 provides an overview of the keys features of the health systems in Australia, Canada, New Zealand, England, and the United States. Specifically, we collected data on how much the country spends on health care (percent of gross domestic product [GDP] spent on health); the amount of leverage held by the government as a purchaser of health services (public expenditure as a percentage of total expenditure on health); the percentage of the population that can be expected to access the system routinely (percentage of population covered by health insurance); the structure of the health system as shaped by the health insurance model and delivery models used; and the kinds of incentives present in the system (i.e., reimbursement).

In general, England has the most centralized system. Australia, Canada, and New Zealand have a similar structure in which the federal government sets health policy and standards for the country and health services are provided at the jurisdictional level (i.e., states, territories, provinces, or District Health Boards). The public sector dominates health care delivery in each of these countries, with the size of private sector health care delivery varying. The United States has a very complex and often fragmented approach to delivering and financing health care, with the private sector and market forces playing a larger role than they do in the other countries. In contrast, New Zealand recently deliberately moved away from the market-based reforms it implemented in the 1990s to a more planned and community-oriented approach (Ashton, 2005).

Despite the differences in the structures of their health systems, these countries face common challenges and are striving to achieve common objectives (Blendon, Schoen, DesRoches, Osborn, & Zapert, 2003). Challenges include aging populations, increased availability of new technologies and treatments, rising public expectations and awareness of health system deficiencies, and patient demand for greater choice and involvement in decision making (Coulter & Magee, 2003). Health system objectives include ensuring equal access to health services, raising quality, improving health outcomes, achieving sustainable financing, improving efficiency, fostering greater responsiveness and citizen involvement in decision making (European Observatory on Health Care Systems, 2002; Commission of the European Communities, 2004; Schoen et al., 2004; Commonwealth of Australia, 2005a). Further, each of these nations has recognized that information and communications technology play a pivotal role in improving health care.

<u>Overview of the Health Information Technology Environment and Electronic Personal Health Records</u>

The countries are at different stages of building their national health information infrastructures (NHIIs) (see Table 3). They present two different models of NHII development—centralized implementation of a single system and national development of a framework that guides regional and local implementation.

Specifically,

- Australia's Health*Connect* is envisioned as a network of EHRs to be implemented nationally on a state-by-state basis. This national network will have some centralized features but will also allow local applications that meet interoperability standards. Australia has completed some field testing of this system and recently released an implementation strategy that will guide the system rollout.
- <u>Canada's Health Infoway</u> is responsible for the development of a pan-Canadian EHR framework built on provincial systems. Each province has its own timetable and road map for EHR implementation, with an overall goal of 50 percent of the population having EHRs by 2009. The most recent annual report describes Infoway as moving from strategy to implementation, with a three-year joint investment and technology plan in place and 105 projects underway. Health Infoway is using national coordinated investment to develop the building blocks for EHR systems, and provinces are promoting local initiatives. There will be some common elements across the system, but there will not be mandated applications.
- <u>England</u> is using a very centralized approach. A single system is envisioned to connect over 300,000 general practitioners (GPs) to almost 300 hospitals. Plans call for providing EHRs for more than 50 million NHS patients with expected completion by 2010. Over 90 percent of primary care offices are already computer-based.

- New Zealand recently issued a revised information technology strategy for the health sector. This strategy will be the focal point for coordination of IT development since the country cannot afford a top-down grand plan. Some progress has already been made on key tasks (e.g., national health index, national minimal dataset, privacy laws), and there is a high level of computer use among physician offices.

There are also similarities in the HIT environment across the four countries. Specifically,

- There is a strong emphasis on standards to enable connectivity and interoperability.
- Privacy is a priority and is recognized as a greater challenge in those countries where both federal (national) and state or provincial laws must be aligned. In each of the four countries, a privacy commissioner provides a visible focal point for the development of privacy policy and the enforcement of privacy laws.
- Unique personal health identifiers are planned or are in use at the national level in three of the countries and at the province level in Canada.
- The public is increasingly using the Internet and does so for health purposes much of the time.

ePHR implementation is still in its early stages. Of the four English-speaking countries we studied,
- England is the furthest along in planning and implementation, with the expectation of offering an ePHR as part of its national health IT program. It has placed a strong emphasis on public engagement. HealthSpace is now available and provides consumers with a personal online health organizer that links to "choose & book" for making appointments (www.healthspace.nhs.uk). Future plans include providing patients with access to parts of their own EHR via a secure link to the NHS. A fully integrated clicks and mortar approach is not part of the national plan, but efforts outside the centralized IT program are beginning to result in patients with chronic conditions able to access their information online (https://www.renalpatientview.org, E-Health Media, 2005).
- Australia plans to offer summary consumer health information in Health*Connect* records and to allow consumers to access these records and add to them.
- Canada has limited work on ePHRs underway at the local level, and the concept of ePHRs is acknowledged as a long-term goal for its national information infrastructure.
- ePHRs are not part of New Zealand's current national HIT strategy. New Zealand's existing National Health Index (unique patient identifier) and privacy framework, as well as its focus on chronic care and disease management as an explicit priority in its current strategic plan, will likely provide a strong foundation for implementation of ePHRs in the future.

Thus, two of the countries plan to offer ePHRs to their citizens as part of their national EHR/NHII system rollout, and two of the countries are currently focused on NHII development more generally. Both countries that will offer ePHRs as part of their national systems have control over the data that will be offered to consumers and seem to be focused on the ePHR model of offering access to information with little attention to potential for changing care delivery approaches in the near term. These findings suggest that early ePHR implementers have a basic level of NHII capacity in place and are adopting a simple ePHR model. It is not clear at this point whether the ePHR systems will evolve into more comprehensive models that enable electronic interaction between patients and health care professionals.

Paper-based PHRs are still being updated and introduced in some locations. Limited commercial offerings allow patients to create their own ePHRs, but data on the number of subscribers to these services are not available, so their scope cannot be assessed.

In all four countries and Scotland, health care provider organizations, groups that support patients with specific diseases, and the private sector are considering or pursuing more comprehensive ePHR models to support chronic disease management. These activities may be more comparable to ePHR activity in the United States, but information to date is limited.

Citizens and citizen health advocacy groups in each of the countries appear to be ready for ePHRs. Where surveyed, most (but not all) citizens respond positively to the ePHR concept. There are generally similar rates of Internet penetration in each country (roughly 65 percent, with the exception of New Zealand, at 50 percent [OECD 2004, 2005b]). Evaluations of patient use of ePHRs (or access to paper PHRs) have yielded generally positive results; however, tt is not clear how frequently patients would access their ePHRs. Further, initial physician reactions are not always as positive as those of patients, and in at least one instance (Australia's evaluation of Health*Connect*), patients had higher expectations of how physicians would interact with the system than what actually occurred. England has had mixed responses from GPs while implementing its new NHS Care Record system.

Experience with the SUSTAIN system in Sweden (see Appendix 2) points to specific issues that ePHR developers must confront. The availability and complexity of the technology used to support the ePHR is a significant factor in the success of ePHR systems. Some citizens may need education on the benefits of ePHRs to prompt their participation (Eklund & Joustra-Enquist, 2004). Citizen proficiency with the ePHR specifically and the technology used in general may be a barrier to effective use. Regular users (i.e., those with chronic illness) may be more likely to achieve and maintain proficiency than will infrequent users (i.e., generally healthy individuals). A national patient identifier was pivotal to the system, and lack of one may hinder development in other countries. Finally, if the ePHR is not part of a national health system, then the issue of how to pay for it is critical.

The European Union is fostering general e-health capabilities that will ultimately support ePHR use by citizens and enable such systems to cross country lines and is paying particular attention to the computer and health literacy skills of its population. The e-Citizen program may provide a model for meeting computer training needs of U.S. citizens.

Australia's Health Information Technology Environment

<u>NHII Approach</u>

Australia has recently shifted the focus of Health*Connect*, its national health information initiative, from an emphasis on technology to one on the providers and consumers of health information and from development of a stand-alone system to development of a communication network (Commonwealth of Australia, 2005a; Health*Connect*, 2005a). Health*Connect* is described as "an overarching change management strategy to improve safety and quality in health care by establishing a range of standardized electronic health information products and services for health care providers and consumers" (Commonwealth of Australia, 2005a, p. 6).

Health*Connect* will establish a national system of sharable electronic health records to "receive, store, retrieve and deliver consumers' health information via secure e-health communications with strict privacy safeguards for use in the delivery of health care" (Canada Health Infoway, 2005a). EHRs within Health*Connect* will include basic identifying and health information and event summaries that are generated each time a health service is provided (Schloeffel, 2004). Access to this information will be available to health care providers on local computer systems through a web-based portal on consent by the patient. Providers will continue to maintain their own clinical health records. In the longer term, software vendors are expected to integrate information retrieved from the Health*Connect* repository into their clinical information systems so it is available electronically for decision support purposes (Commonwealth of Australia, 2005a).

Health*Connect* will have three layers:

- Records systems layer—regional storage repositories that will store summary consumer health information to form consumers' Health*Connect* records
- User or source system layer—software that will interface with Health*Connect* to allow providers or consumers to view Health*Connect* records or add new event summaries to the record
- National coordination layer—linking all regional storage repositories and linking these repositories and user systems to allow consumers to access their records throughout the nation

The initiative is the result of a joint effort by Australia's national government, states, and territories. The Australian government has committed $128 million over four years for Health*Connect*. The implementation strategy acknowledges that additional funding "is

likely to be required for a full national implementation" (Commonwealth of Australia, 2005a, p. 18). The primary role for the Australian government is to facilitate creation of an environment in which governments can work with the private sector to deliver improved health services and outcomes.

The Australian government's contributions includes developing standards through the National E-Health Transition Authority (NEHTA), coordinating development of interconnecting components (e.g., systems, policies, legislation, processes) that will underpin the flow of health information, and stimulating a market environment conducive to the operation of Health*Connect*. NEHTA was created to facilitate the cooperation needed to develop the foundations of e-health (National E-Health Transition Authority, 2005). NEHTA is charged with advancing 12 priority initiatives, including clinical terminology, clinical information, personal health identifier, health care provider identifier, medicines directories, supply chain efficiency, interoperability framework, secure messaging, user authentication, consent frameworks, EHR design, and standards implementation.

Initial state and territory government Health*Connect* projects focus on local health service needs. Early implementations will occur in those regions in which state and territory governments have already "invested in building the capacity of public hospitals and/or State or Territory funded community services to send and receive standardized clinical messages to other health care providers such as general practitioners and pharmacies" (Commonwealth of Australia, 2005a). Implementation began in Tasmania and the Northern Territory and will roll out progressively to other regions on a staged basis. As implementation progresses, other health care providers, such as specialists, allied health professionals, and private hospitals, will be able to participate in Health*Connect* as their software systems are accredited. Tasmania is implementing the first Health*Connect* project—standardized electronic messaging between general practitioners and hospitals in the form of automatic hospital admission and discharge notifications, improved emergency department notifications, and, eventually, a full discharge summary (Dearne, 2005). All states and territories are making progress toward Health*Connect* implementations in the form of memoranda of understanding or development of actual projects (Richards, 2005).

Privacy and Confidentiality

A report on legal issues associated with Health*Connect* described the law applicable to privacy of consumer health information in Australia as being highly complex across Australia's jurisdictions (Utz, 2005). The Privacy Act contains 10 national privacy principles that apply to all health care service providers (Office of the Privacy Commissioner, n.d.). These principles address collection, use and disclosure, data quality, data security, openness, access and correction, identifiers, anonymity, trans-border data flows, and sensitive information.

Some but not all jurisdictions have separate health records legislation. To achieve consistent privacy rules across the country, privacy and health record laws at the federal and state level need to be amended (Utz, 2005). A proposed National Health Privacy Code provides national uniform rules for the collection, use, and disclosure of health information. This code was proposed in 2003 but has not been adopted yet. A working group is being formed to develop privacy and security rules specific to Health*Connect*.

The majority of consumers who participated in trials of Health*Connect* and a related system (i.e., Medi*Connect*) had no privacy concerns in deciding whether to participate in the trials; those consumers who did express concerns tended to be between the ages of 25 and 40 and without chronic health conditions (Commonwealth of Australia, 2005b).

National Health Identification Number

A national health identification number is planned for all Australians who register for participation as consumers in Health*Connect* (National E-Health Transition Authority, 2005). The NEHTA Personal Healthcare Identifier (PHI) Initiative is working to "establish an identifier assigned to a person to enable accurate identification of that individual for health care purposes." Assigned to all Australians, the PHI will be recognized throughout the health sector. The PHI initiative is currently developing a detailed business case that builds on the existing national information infrastructure. Initial implementation is expected to begin in 2006–2007 and will be phased in over two years.

Incentives/Policies to Encourage HIT Use

E-health is a high priority for the current Australian government (Abbott, 2005). There are two notable incentive programs to encourage HIT adoption. The Practice Incentive Program (PIP) was established to compensate GPs "for the limitations of fee-for-service arrangements." It focuses on aspects of general practice that contribute to quality care, including information management technology, provision of after-hours care, student teaching, and better prescribing. The payment formula pays $2 per standardized whole patient equivalent (SWPE) for use of bona fide electronic prescribing software to generate the majority of prescriptions in the practice and $2 for use of an onsite computer connected to a modem to send and receive clinical information (Government of Australia, 2005a). (The average GP sees 1,000 SWPEs annually.)

Broadband for Health is a $60 million Australian government program to provide broadband Internet access to GPs and consortia of health organizations (Government of Australia, 2005b; Health*Connect* Tasmania, 2005a). Incentives are available to help meet costs of professional installation and 12 months' use of approved services. Practices that use approved local area network security receive an additional one-time $1,000 payment. An earlier phase of the program funded broadband access for pharmacies.

EHR Use

Data from 2000 show that 25 percent of primary care physicians and 13 percent of specialists were using EHRs in their practice at least some of the time (Harris Interactive, 2001). These results compare to a high of 59 percent and 22 percent, respectively, in the United Kingdom and a low of 14 percent and 16 percent, respectively, in Canada.

Household Use of Computer and the Internet

Sixty-six percent of households have access to a computer (OECD, 2005b), and 46 percent of households have access to the Internet (OECD, 2004).

Engagement of Stakeholders

Australia has sought a high level of participation among stakeholders in the early stages of Health*Connect* and has focused on identifying and communicating anticipated benefits and outlining principles (e.g., provider privacy and consent responsibilities) to guide the organizations and individuals that will be involved with the system. For example, the Australian Health Information Council hosted a forum in November 2005 for invited attendees to provide feedback on Health*Connect* and its implementation (Health*Connect*, 2005a).

Health*Connect* leadership has paid particular attention to educating the public about the benefits of Health*Connect* and seeking consumer input on those parts of Health*Connect* that will affect consumers directly (e.g., consumer registration and consumer access portal) (Canada Health Infoway, 2005a). The Consumers Health Forum (CHF) of Australia participated in the evaluations of Health*Connect* field tests. It has an ongoing project to improve communications and engagement with health consumer organizations about EHR developments and to participate in consultative processes related to consent, electronic security, and privacy (Consumers Health Forum of Australia, 2003, 2005). For example, CHF has offered a series of presentations and workshops on EHRs to a wide range of audiences, captured the discussion from those sessions, and posted a summary on its website (http://www.chf.org.au).

At the state level, the Health*Connect* Tasmania Implementation Office launched a website in September 2005 as part of its communications and stakeholder strategy (http://www.healthconnecttasmania.net.au). This website is intended to provide up-to-date information about Health*Connect* implementation in Tasmania as well as to invite and collect feedback from visitors to the site through online forums and surveys (Health*Connect*, 2005b). Also in September, the Tasmania Implementation Office formalized consumer representation on its Implementation Advisory Group (Health*Connect* Tasmania, 2005b). These consumer representatives were chosen for their experience in consumer health affairs and geographic representation. In addition,

Health*Connect* Implementation Teams have been participating in presentations about the development and implementation of the system. For example, members of the Health*Connect* Tasmania Participation team presented an information and feedback gathering session to the Association of Independent Retirees in November 2005 (Health*Connect* Tasmania, 2005c).

Consumer Attitudes about HIT and PHRs

According to the written response to our questions, citizens who are informed are positive about HIT, but many of them are unaware of plans for and benefits of HIT. A 2004 survey on community attitudes toward privacy found that 64 percent of surveyed individuals thought that inclusion in a national health database should be voluntary, and 32 percent thought that all medical records should be entered into that database as a matter of course (Roy Morgan Research, 2004).

Consumers who participated in Health*Connect* trials that provided access to their health records had high expectations regarding the benefits of the system (Commonwealth of Australia, 2005b). Specifically, they anticipated benefits in empowerment, access to records in an emergency and when traveling, reduced requirements to recall past health care events, and reduced requirements to maintain medication lists. Consumers who had access to their records gained better understanding of their condition.

ePHR Status

Health*Connect* implementation plans call for consumers to be able to access important health information (e.g., current medications, major diagnoses, recent pathology results, health plan for patients with chronic illness) via the Internet or on a smart card (Commonwealth of Australia, 2003). There is no specific timeline for when such access will be available to citizens.

There has been some limited attention to PHRs and ePHRs outside Health*Connect*.

The New South Wales Department of Health offers two types of paper-based PHRs to citizens. The NSW Personal Health Record (also known as the Blue Book) is issued to each child at birth and provides a place for parents and health care professionals to record information that will aid parents in managing their child's health care. The Blue Book, in use for 18 years, is currently undergoing evaluation (NSW Health, 2000, 2005a).

New South Wales has also developed a paper-based PHR, called My Health Record, as part of a chronic care program with plans to extend it to all health service consumers in the state (NSW Health, 2005b)

The Down Syndrome Association of New South Wales offers a downloadable PHR for adults with Down syndrome that is intended to support the independence of individuals with Down syndrome so that they do not need to rely on memory or the presence of a family member at each physician visit (Down Syndrome NSW, 2000).

The Royal Children's Hospital in Melbourne is conducting an 18-month pilot test of an ePHR designed to support collective care for patients in its diabetes clinic. This record enables patients to create a lifelong health record, access summaries of clinic visits, load glucose readings into the record, track and graph all test results, send secure messages to diabetes educators, authorize educators to view parts of the record as an aid in providing advice, and establish an emergency record on the Internet (Royal Children's Hospital, 2004). This system was described by one observer as "the only active online PHR in Australia" (H. Leslie, personal communication, 2005).

Ocean Informatics is evaluating the potential of universal serial bus (USB) keys to serve as a medium for patient-held ePHR and will develop a pilot focused on chronic care users (H. Leslie, personal communication, 2005). In a recent commentary in the *Australian Health Review*, the project leader suggested that USB keys offer a "bottom-up, consumer-driven, faster approach with the benefit of a simplified privacy and consent model, compared with the current slower and somewhat ponderous top-down implementation" (Leslie, 2005).

Other ePHR activity in Australia includes:

- myHealthfile, available to members of myDr (a website designed for Australian residents), consists of a registration profile, individual folders to store links to articles from myDr, links to useful support groups, and a list of individual health care providers(www.mydr.com.au).

- Healthe, which offers an online health management system to its members for an annual fee of $99, allows members to create and manage personal health and emergency records that include a history of personal illness or injury, medications taken, health regimes or fitness programs, vaccinations, and body weight (www.healthe.com/au/healtheRecord.do).

- HotHealth, designed by clinicians to include a clinical summary, some assessments, customizable plans, and links to authoritative websites and to be supportive of self-management and best practice guidelines, offers an online subscription product that enables members to store and maintain personal health records (https://www.hothealth.com/tour/overview.htm).

- YourHealthRecord.com is offering its ePHR free for one year for a limited time. Patients build records that include current health issues, past health, medications, immunizations, allergies, family history, a health diary, and images. It also provides a link to a sister site, YourDiagnosis.com, which uses a questionnaire to generate a proposed diagnosis. There is a fee for each diagnosis.

- Fitness2Live.com targets fitness and weight loss by providing individualized diet and exercise programs for subscribers as well as online health assessments. It also maintains limited personal health data.

- Intrahealth offers software to GP and specialist physician practices in Australia, Canada, and New Zealand (www.intrahealth.co.nz). Its Accession product allows health professionals to interact with their patients and provides online patient access to make appointments, retrieve personal medical information, check results, send observations, and search for medical information.

Canada's Health Information Technology Environment

NHII Approach

Canada Health Infoway, an independent, not-for-profit organization, is leading Canada's efforts to improve its health care system through information systems. Its members include the 14 federal, provincial, and territorial Deputy Ministers of Health. Launched in 2001, Canada Health Infoway is responsible for development of a pan-Canadian EHR framework built on provincial systems. Meanwhile, provinces are focusing on developing health information infrastructures and funding local and regional health consortia of health providers to promote local initiatives (Canada Health Infoway, 2005b; Sheridan, 2005). Canada seeks to have 50 percent of Canadians benefit from EHRs by 2009.

A network of EHR infrastructures is planned. Infoway provides a national framework, with implementation at the provincial level and replication of projects as appropriate (e.g., diagnostic imaging and client registry). Central EHR repositories and potential domain-specific repositories are envisioned at the jurisdictional level (i.e., provinces and territories). The EHRS (Electronic Health Record Solution) Blueprint provides a framework for interoperability and promotes reusable replicable solutions that can be aligned with jurisdictional priorities. Work is currently underway to define requirements and solutions for privacy and IT security; next steps include definition of data requirements and messaging and vocabulary standards.

Since 2001, Infoway has received $1.2 billion investment capital from the Government of Canada to work with the provinces and territories to accelerate implementation of electronic health information systems in Canada (Canada Health Infoway, 2005c). Infoway is using strategic investment to accelerate development and funds 75 percent of costs for approved projects, with the remainder coming from local jurisdictions. This funding ratio was increased in 2005 (from 50 percent) to reduce financial barriers to projects aligned with strategic objectives. As of March 31, 2005, Health Infoway had approved $320 million for 105 projects in every Canadian province and territory; by March 31, 2006, Infoway is planning to approve an additional $325 million in projects. Investments are organized into nine key areas: registries, diagnostic imaging systems, drug information systems, laboratory information systems, interoperable electronic health record systems, telehealth, public health surveillance, innovation and adoption, and "infostructure" (i.e., common solution architecture and standards to ensure interoperability of EHR solutions).

For example, the Ontario government is collaborating with Canada Health Infoway on a $10 million system that provides hospital emergency departments with real-time access to prescription drug claims history for patients receiving benefits through two provincial drug programs—one that covers seniors and one that covers people who have high drug costs in relation to their income (Canada Health Infoway, 2005d). The Saskatchewan Pharmaceutical Information Program provides confidential access to medication records of patients for authorized health care professionals and helps them select the best medication to avoid drug interactions and duplication of therapy. Canada Health Infoway will contribute $5 million of the $7 million invested in the project (Canada Health Infoway, 2005e). In Edmonton, Canada Health Infoway will contribute $46 million of $189 million to digitize x-rays and CT and MRI scans across the province (Canada Health Infoway, 2005f).

Privacy and Confidentiality

Currently, responsibility for protecting personal health information in Canada is shared among federal, provincial, and territorial governments with a patchwork of legislation, policies, regulations, and voluntary codes of practice. Two federal privacy laws are in place. The Privacy Act covers federal departments and agencies, and the Personal Information Protection and Electronic Documents Act (PIPEDA) applies to all private sector organizations, including private health care organizations, except those in provinces with substantially similar legislation (Government of Canada, 2004a, 2004b). The Privacy Commissioner of Canada oversees both acts. In addition, provinces and territories have privacy laws. Alberta, Saskatchewan, Manitoba, and Ontario have passed legislation to deal specifically with collection, use, and disclosure of personal health information by health care providers and other health care organizations. Provincial legislation must be approved by the federal Privacy Commissioner as being the equivalent of or superior to the federal law to take effect.

The Privacy Act, in effect since 1983, imposes obligations on federal government departments and agencies to respect privacy by limiting the collection, use, and disclosure of personal information. PIPEDA includes 10 core principles for information practice.

PIPEDA Key Principles:

1. Organizations are accountable for protecting personal health information under their control.
2. The purposes for which the personal information is being collected must be identified before or during collection.
3. Information must be collected with the knowledge and consent of the individual and for a reasonable purpose.
4. The collection of personal information is to be limited to what is necessary for the identified purposes and will be collected by fair and lawful means.
5. Information can only be used and disclosed for the purpose for which it was collected and is retained only as long as necessary to fulfill its purpose.

6. Information must be as accurate, complete, and up to date as possible.
7. Information must be protected by adequate safeguards.
8. Information about an organization's privacy policies and practices must be readily available.
9. Information must be accessible for review and correction by the individual whose personal information it is.
10. Organizations are to provide the means to an individual to challenge an organization's compliance with the above principles.

In January 2005, the Federal/Provincial/Territorial Conference of Deputy Ministers of Health released a *Pan-Canadian Health Information Privacy and Confidentiality Framework* to "respond to Canadians' privacy and confidentiality expectations and to suggest a harmonized set of core provisions for the collection, use and disclosure of personal health information in both the publicly and privately funded sectors" (Health Canada, 2005). The framework consists of a set of core provisions "aimed at protecting the privacy and confidentiality of individuals with respect to their health information, while enabling the flow of information where appropriate to support effective health care, the management of the health system, and an interoperable health record." Underlying the provisions is the principle that "the collection, use, and disclosure of health information is to be carried out in the most limited manner, on a need-to-know basis and with the highest degree of anonymity possible in the circumstances." The Framework acknowledges privacy as a consent-based right and unless otherwise specified in legislation, an individual's consent must be obtained for any collection, use, and disclosure of personal health information. It also proposes an implied knowledgeable consent model for the use of personal health information within the circle of care.

On the technical side, Infoway has a multiyear project to design a Privacy and Security Conceptual Architecture well underway and "has defined business-level privacy and security requirements for an interoperable EHR" (Canada Health Infoway, 2005g).

National Health Identification Number

Patients have a unique health identifier at the provincial level. One interviewee reported that patients may still have multiple identifiers within a single institution, but this practice is being eliminated. A single Canada-wide number is not likely according to interviewees. Provincial patient registries have been developed in Newfoundland/Labrador and Edmonton with financial support from Infoway. In March 2005, Infoway launched a Client Registry Toolkit to "help Canadian jurisdictions and health authorities reduce the risks, time frame, and costs of implementing client registries (Canada Health Infoway, 2005h). There are no official plans for a nationwide patient registry.

Incentives/Policies to Encourage HIT Use

Incentives for HIT adoption for physicians are most evident in the Province of Alberta; there is little activity in other provinces. The Alberta Medical Association, Alberta Health and Wellness, and Alberta's Regional Health Authorities jointly fund the Physician Office System Program (POSP) (POSP, n.d.). POSP is intended to "establish a physician office information infrastructure that is integrated with the health information system and support the development of an electronically-enabled culture within the physician community." Financial assistance is provided on a per physician basis; each physician is eligible for 48 months of funding. In addition to financial support, POSP provides change management support to assist participating physicians as they select a system and vendor, implement the system, and train and adjust to the system over time. POSP provides vendor conformance and usability requirements (VCUR).

POSP offers three levels of automation. Level 1 consists of a computer with Internet connection and the browser version of the province's electronic health record; this level is intended for physicians who use little or no information technology in their practices. Level 1.5 consists of computer access at the point of care with the browser version of the provincial electronic health record. Level 2 consists of a physician office system integrated with the provincial electronic health record as per VCUR, with system-to-system messaging for receipt of regional data (e.g., labs, diagnostic imaging text reports) where available. Funding varies by level (Level 1: $1,050 per year; Level 1.5: $2,800 per year; Level 2: $7,700 per year). The funding is structured so that the physician and POSP share the costs of implementation, since some of the benefits accrue to the physician and some accrue to the provincial health care system. POSP is not intended to cover indirect physician office costs such as lost productivity due to system implementation or training time for staff.

Currently, 2,814 physicians are enrolled in POSP (52 percent of Alberta's practicing physicians). The majority of participants (2,322) are enrolled in Level 2. POSP is in its second phase, which began in January 2004 and will run until March 2006.

EHR Use

EHR use varies by province. Hospitals tend to be automated but are not necessarily using computer-assisted physician order entry. In 2001, Harris Interactive found that 14 percent of primary care physicians and 16 percent of specialists were using EHRs. Interviewees estimate that 30 to 35 percent of general practitioners were using EHRs in 2005 (Harris Interactive, 2001).

Household Use of Computer and the Internet

A total of 66.8 percent of households have access to a computer at home (OECD, 2005b), and 54.5 percent of households have access to the Internet at home (OECD, 2004).

Engagement of Stakeholders

Infoway works actively with co-investors and project implementers (e.g., health ministries, public sector sponsors, regional health authorities, hospitals, etc.) as well as vendors and suppliers. Active involvement of health care providers and their associations, regulatory colleges, information technology trade associations, and academia is due to Infoway's partners and its investments (Canada Health Infoway, 2003). For example, in 2005, a series of information meetings was held across the country for health care information technology solution providers on the EHR Blueprint Architecture, Privacy and Security Architecture and Standards.

Infoway's focus to date has been primarily on bringing health care providers on board with EHRs and related systems. In May 2005, Infoway released *End User Acceptance Strategy: Current State Assessment* which defines end users as individual health care providers who will ultimately use EHR technologies in the delivery of patient care (Canada Health Infoway, 2005a). This document is intended to contribute to the development of a set of strategies to increase end user acceptance of EHRs and other systems.

The Infoway website includes case studies that help to describe the vision of EHRs in Canada and discusses the benefits of EHRs. In general, however, there is not yet evidence of a strong national approach to engaging and educating consumers about EHRs and related systems. One interviewee noted that a public education strategy would likely be done at the province and territory level.

The Centre for Global eHealth Innovation has funded a project to "create the physical and technological infrastructure for public engagement" (Centre for eHealth Innovation, n.d.). This infrastructure is intended to engage stakeholder groups and the general public in health policy, services, and governance issues.

Consumer Attitudes about HIT and PHRs

Several studies suggest that Canadian citizens are supportive of HIT. A 2001 study conducted by PricewaterhouseCoopers found that Canadian citizens are willing to embrace both EHRs and PHRs (Martin, 2001). Specifically,

- 82 percent of respondents supported the notion of centrally storing medical information to give physicians quicker and easier access to information;
- 85 percent were willing to permit central storage so they could have access and control over their records;
- 92 percent were somewhat willing to carry smart cards containing personal health information for use in an emergency; and
- 79 percent were willing to carry smart cards that include entire medical history. Canadians age 65 and over were the least likely to be willing to carry smart cards for any purpose.

A 2003 report on information technology in Canadian Hospitals found that a majority of Canadians believe that EHRs will speed and improve patient care (Canadian Healthcare Technology, 2003). Specifically,

- 85 percent believe EHRs will improve physicians' effectiveness;
- 83 percent believe EHRs will improve pharmacists' effectiveness; and
- 81 percent believe EHRs will improve the effectiveness of nurses, patients, and the health care system in general.

These findings are supported by the Health Quality Council of Alberta (2005) study in which respondents identified "lack of computerized medical records" as a cause of preventable medical errors.

The public may be ahead of physicians, however, on patient empowerment. A Canadian Medical Association (2002) study found that physicians were not yet regularly encouraging patients to be proactive with health information on the Internet.

ePHR Status

One interviewee noted that PHRs are not on the radar screen for most of the nation. Rather, the focus is on implementing EHRs and related systems in acute and community care settings. A move from professional-centric to patient-centric systems is being discussed, but actual systems are in the distant future. Thus, it is not surprising that interviewees believe that consumers are generally unaware of the possibility of ePHRs and what they could do.

A 2002 report on the future of health care in Canada specifically identified personal health records, that is, secure online access to personal EHRs by citizens as a means of strengthening the health system in Canada. This report also emphasized the need to improve citizens' health literacy (Commission on the Future of Health Care in Canada, 2002).

A March 2005 analysis by Booz, Allen & Hamilton for Canada Health Infoway concluded that EHRs create the potential for PHRs and defined PHRs as "a personal version or view of the EHR, giving the patient control over his or her own information and the capacity to personally present it to a clinician" (Booz, Allen & Hamilton, 2005). This report recognized the PHR as a tool to help patients manage disease, particularly chronic conditions, and suggested that personalized information, combined with guidance, prompts, and reminders, "may improve health outcomes by more effectively engaging [the] patient in self-care." Further, EHRs and PHRs have the potential to promote patient-centric health care that includes information following the patient as he or she moves through the system; customization of prevention and care; greater engagement of patients, which may lead to more accurate collection of information; and more informed patients who adhere more strictly to treatment regimens. The report notes that PHRs are identified as part of the Infoway vision for the second 10-year time frame (i.e., beginning in 2015).

Infoway's 2005–2006 Corporate Business Plan specifically mentions PHRs as critical in the management of chronic disease but does not provide a timeline for their development by Infoway.

Private sector activity related to ePHR development appears to be limited but increasing at this time. A web and literature search identified some PHR development activities outside Infoway:

- The National Research Council (NRC) Institute for Information Technology is working on a project funded by the U.S. Centers for Disease Control and Prevention to implement a PHR that was developed in the United States (i.e., PING (the Personal Internetworked Notary and Guardian) in Canada. The NRC is also developing a PHR to support web-based diabetes management in the health region (see www.chip.org/research/ping.htm).

- INFORMED, Personal Health Records, Inc., is a Canadian-owned company offering a range of personal health record products (www.informedrecords.com).

- HealthRecordsOnline.com, also a Canadian-based company, offers an Internet-based approach for subscribers to store and access health data.

- Capital Health Authority of Edmonton is working on a patient self-service portal as part of its netCare, a regional electronic health record that will provide patients with access to certain personal health information and appointment schedules as well as tools to manage chronic conditions. Plans call for the portal to offer three sections: an area for individuals to maintain their own personal health records online, a results section where lab tests can be viewed or lab appointments scheduled, and self-management components (see http://www.capitalhealth.ca/default.htm).

- The University Health Network established the "iChart" project to develop and evaluate patient access to online EHRs with a focus on patients with chronic illness (i.e., inflammatory bowel disease [IBD]) (Winkelman, Leonard, & Rossos, 2005). This relatively small qualitative evaluation of the system found that "simply providing access to electronic medical record**[s?]** has little usefulness on its own. Useful technology for patients with IBD is multi-faceted, self-care promoting, and integrated into the patient's already existing health and psychosocial support infrastructure."

England's Health Information Technology Environment

<u>NHII Approach</u>

England's Department of Health has been working on lifelong EHRs for all citizens since 1998. The NHS is in the midst of implementing a new IT infrastructure that eventually will connect over 30,000 general practitioners and 300 hospitals for a total of 18,000 sites (Connecting for Health, 2005a). An agency of the Department of Health, known as Connecting for Health, is implementing the National Programme for Information Technology (NPfIT). This infrastructure will link computer systems across the NHS and provide EHRs (called NHS Care Records), electronic booking, a personal health organizer for patients, electronic transmission of prescriptions, a national broadband network for the NHS, picture archiving and communications systems (PACS), IT supporting GP payments, the Quality Management and Analysis System, and a central e-mail and directory service for NHS. The system will offer patients ePHR functionality in the future.

The NHS is funding this initiative and projects that the system will cost $12 billion ("The no-computer-virus," 2005). Implementation of systems and services has begun and is expected to be completed in 2010. Five regional clusters, that is, five to seven Strategic Health Authorities working together, will oversee procurement and implementation of the National Programme at the local level.

A summary of care and clinical history will be held on a national database, known as the Spine. These data (e.g., name and address; NHS number; allergies; adverse reactions; and major treatment that has been provided, is continuing, or has been completed) will be available to all NHS locations. More detailed information will be maintained at the site where most care is delivered (e.g., records of conditions, medication, operations, tests, X-rays, scans, and other results). Links to local information will be available from the summary record.

This will largely be a centralized system, although some variations at the local level may be allowed. An NHS document describes the approach:

> The core of our strategy is to take greater central control over the specification, procurement, resource management, performance management and delivery of the information and IT agenda. We will improve the leadership and direction given to IT, and combine it with national and local implementation that are based on ruthless standardization. (Department of Health, 2002)

The Central Design Authority and Technology Office develops and controls standards for the NHS IT systems (Connecting for Health, 2004). The NHS is designing IT systems that support care across NHS organizations and support National Service Frameworks (i.e., national standards and services models for a specific service or care group such as diabetes management.) The Central Design Authority and Technology Office develops

business and technical architectures, sets and monitors technical standards, evaluates supplier proposals, and ensures that migration and implementation strategies are robust and achievable.

In addition, NHS has adopted an e-health strategy of "harnessing information technologies to meet patient information needs" (Gann, 2004). NHS Direct is the largest provider in the world of direct access health care using modern communication technologies. Using online capabilities, digital TV, call centers, touch screen kiosks, and self-help books, NHS Direct provides access to clinical information and advice, self-care guidance, or referral to appropriate health care service, 24 hours a day, 7 days a week.

Privacy and Confidentiality

Citizens' right to confidentiality derives from the Data Protection Act of 1998, the Human Rights Act of 1998, and the common law duty of confidence (Information Commissioner, n.d.). In addition, the NHS has developed the Care Record Guarantee, which comprises 12 commitments to patients about their records. For example, patients have the right to choose not to have information in electronic care records shared; the NHS tracks everyone who accesses a patient's information in the NHS Care Records Service; and NHS takes action against individuals who access patient records without permission or good reason (National Health Service, 2005). (See Appendix 3 for exact text of the guarantee.)

National Health Identification Number

The NHS number is used to track patients across NHS organizations. This number has been standardized, and a process is underway to match every existing patient record to the correct NHS number. The U.K. government recently announced its commitment to a national health identification card (UK ID Card) in addition to its NHS number.

Incentives/Policies to Encourage HIT Use

Since the NHS is a single organization providing health care to the citizens of England, whether to implement EHRs and a national health information infrastructure is a management decision by the Department of Health. There has been some GP resistance to this new system. NHS is working on educating health care professionals on the need for and benefits of the new system.

Two initiatives support GPs' adoption of IT. First, the General Medical Services (GMS) contract (i.e., the fee schedule for reimbursement to GPs from the NHS) issued in 2003 provides 100 percent funding for "the purchase, maintenance, future upgrades, running costs of integrated systems as well as telecommunication links to branch surgeries and

other NHS infrastructure and services" (British Medical Association, 2003a). As hardware and software systems are replaced, ownership will transfer from the practices to primary care trusts (i.e., local organizations that oversee primary care services). The GMS contract guaranteed funding of $490 million over three years for this program (British Medical Association, 2003b).

Second, in 2004, the Department of Health implemented the Quality Management and Analysis System (QMAS) to support its Quality and Outcomes Framework (British Medical Association, 2004; Connecting for Health 2005b). QMAS is a single national IT system that provides objective evidence to GP practices and Primary Care Trusts on the quality of care delivered to patients. The system shows how well each practice is doing, compared to national achievement targets. GP practices are rewarded financially based on the quality of care they provide; QMAS paid out over $1.75 billion in achievement payments for fiscal year 2004–2005.

EHR Use

A 2001 survey by Harris Interactive found that 52 percent of GPs and 22 percent of specialists used EHRs. A 2004 report on GP computer systems in England reported that "more than 95% of GP practices in England are automated" (Protti, 2004).

Household Use of Computer and the Internet

A total of 65.26 percent of households have access to a computer at home (OECD, 2005b), and 55.11 percent of households have access to the Internet at home (OECD, 2004).

Engagement of Stakeholders

NHS Connecting for Health uses a variety of approaches at both the national and local levels to build awareness among and consult with its stakeholders (Canada Health Infoway, 2005a). Several standing groups, such as the National Clinical Advisory Board, Public Advisory Board, Chief Executive Information Forum, Chief Information Officer Forum, and Information Standards Board, provide two-way communication between Connecting for Health and key stakeholders. In November 2005, the Care Record Development Board held its second annual conference for patients and carers**[caregivers?]**, representatives from patient organizations, and individuals involved in health and social services delivery. The conference provided an opportunity for participants to learn about the work of Connecting for Health and contribute their views on the NHS Care Record (Connecting for Health, 2005c).

Regional implementation directors manage stakeholder engagement strategies in each geographic cluster. A national communication and stakeholder engagement group works to create a consistent engagement approach across the clusters as well as to ensure that intelligence gathered from stakeholders is used to inform development and implementation of Connecting for Health Systems. Targeted engagement plans are under

development for specific features of the national program (e.g., electronic prescribing, electronic booking, the NHS Care Record). In addition, clinical leads have been appointed to the Service Implementation Team to encourage communication about and input into the design of new systems and working practices (Connecting for Health, n.d.). Connecting for Health has also identified NHS Patient Advice and Liaison Services (PALS) as an important target for education about the national program in light of its role as a source of information and advice to citizens about NHS services (Department of Health, n.d.).

For example, clinicians, patients, and professional bodies have been consulted during development of the NHS Care Records. In particular, patients have been engaged through research and consultation, on project boards and advisory groups, testing the new system, reading draft materials, and attending meetings and briefings. Their participation contributed to additions to the NHS Care Record, a new approach to confidentiality, the NHS Care Record Guarantee, change to design of HealthSpace and Choose and Book, changes to public information materials, and phasing decisions. Ongoing National Programme for Information Technology engagement activities are currently focused on raising awareness, meeting the public's needs, and maximizing benefits of the new system.

As the NHS prepared to launch its system, it developed a public information campaign that focuses first on NHS staff, then later on patients. In September 2005, NHS Connecting for Health began distributing information booklets that describe the NHS Care Record Service to 1.3 million NHS employees (Connecting for Health, 2005d). This will be followed by more detailed information in early 2006 on how the NHS Care Record can benefit members of NHS staff. Posters and a film will accompany these written materials. When the system goes live, patients will get a summary brochure that explains how the information will be stored and used and what patients can do to protect their data (including constraining data exchange). The information campaign will also include 20 regional road shows, material for local media, kiosks in NHS hospitals, a video for waiting rooms and post office lobbies, and a website that is currently under construction.

Consumer Attitudes about HIT and PHRs

One interviewee noted that the public has mixed views about Connecting for Health, with reports of targets for implementation of the new system being missed. The public appears to see the benefits of Connecting for Health, but GPs have some concerns about how the new system is going to work and what the impact will be of allowing patients to see their records in a system that relies on GPs to serve as gatekeepers and under which care is rationed.

England's NHS has conducted the most extensive research on patient attitudes about and preferences for access to their own health records. Much of this research was conducted through the Electronic Record Development and Implementation Programme (ERDIP), which ended in 2003 (NHS Information Authority, 2003). Key findings from ERDIP and other studies that analyzed patient experiences with accessing their records include Jones

et al., 1999; Pyper, Armery, Watson, Crook, & Thomas, 2002; NHS Information Authority, 2003; Pyper et al., 2003; Pyper, Armery, Watson, & Crook, 2004a; Pyper, Armery, Watson, & Crook, 2004b.

- Patients expect sharing of information.
    - One study noted, "Patients on the whole think the information sharing happens already; some patients are quite interested and there is a general acceptance that the electronic record is a good thing."

- Public awareness and interest appear to be low.

- Patients want to decide who has access to records.
    - Yet, a survey of patients who had seen their records found that over 90 percent would share their whole record with their GPs, hospital doctors, and consultants.

- Patients expressed concern over commercial exploitation, external access, security, and confidentiality.

- Patients who had access to their records felt better informed and more able to ask questions of their doctors; they also felt that their relationship with doctors improved.

- Patients preferred systems that provided information from their medical records over systems that just provided general health information.

- Patients felt empowered to take charge of their own health.

- Patients understood the information in their records.

- Patients were able to correct or challenge information in their record. Some patients wanted to add personal information to their record.

Subsequently, NHS MyHealthSpace used focus groups and in-depth, semistructured interviews to ascertain what patients want with respect to the patient-oriented components of the new NHS information system (Pyper et al., 2003). Patients expressed preferences for:

- Simple language and layout
- Access to their own electronic GP records
- Simple-to-use calendar and reminder section
- Minimal use of mouse and keyboard
- Help section

<u>ePHR Status</u>

Connecting for Health has developed a two-phase plan for offering individuals access to their personal health data. The first phase involves HealthSpace, a secure place on the Internet where people living in England can store personal health information:

> Patients will have their own personal online health organiser, HealthSpace. This will act as a calendar, allowing them to record appointment details and set up reminders. It will also enable them to keep a record of their blood pressure, weight and height. It will store self-care programmes on, for example, stopping smoking or managing diabetes. HealthSpace will incorporate a search feature, allowing patients to look for up-to-date, reliable health-related information, and offer guidance and information on healthy lifestyles. (Connecting for Health, 2005e, 2005f)

HealthSpace is currently available for NHS patients. In the second phase,

> (P)atients will eventually be able to access their own electronic health records via a secure Internet link to the NHS. They will be able to check their record for accuracy and, in time, will be able to add their treatment preferences and information about their needs, such as wheelchair access requirements. (Connecting for Health, 2005g)

Patients will be able to access their national summary record beginning in 2008..

There are limited examples of ePHR development outside of HealthSpace:

- The Renal Information Exchange Group (RIXG) has developed Renal PatientView to provide patients with online information about diagnosis, treatment, and latest test results (see http://www.renalpatientview.org).

- The PAERS (patient access to their electronic record) System, being tested at four GP offices, allows a patient to access his or her EHR via kiosks at the office. Its notable feature is the use of thumbprints in lieu of passwords (NHS London, 2003; "Thumbprints used to access patient records," 2004).

EMMS International (a UK-based firm) offers Global Health ID, a service that enables individuals to maintain personal health records via the Internet and provides a membership card that alerts potential health care providers of the availability of the information in an emergency (see http://www.pemms.com/solution?c29sSUQ9MjU).

New Zealand's Health Information Technology Environment

NHII Approach

In August 2005, the Minister of Health released an updated Health Information Strategy for New Zealand (HIS-NZ) (Health Information Strategy Steering Committee, 2005), which builds on previous national health information technology strategies (i.e., the Health Information Strategy for the Year 2000 and the WAVE Project) (Ministry of Health, 1996; WAVE Advisory Board, 2001). It recognizes that as a small nation, New Zealand does not have the resources to "approach information system challenges with a grand plan from the top down" while still needing some consistency across approaches to IT implementation (Health Information Strategy Steering Committee, 2005, p. 10). The health sector is highly independent, and decision making is decentralized; thus decisions must be made in a collaborative manner, and a national strategy is needed to enable coordination of local decisions.

As described in the strategy document, New Zealand's vision of a distributed EHR includes three levels:

- Local systems will support the delivery of personalized care and manage most of the detailed data; these systems will be owned and operated by individual service providers.

- Regional systems will consolidate specific clinical data at a regional level for the coordination of care and decision making around service delivery. These systems typically will rely on key event summaries that abstract relevant information from consumer encounters. These systems will be owned and driven by regional agencies such as district health boards.

- National systems such as the national patient index and the health practitioner index are core systems that will provide shared data and consistent business practices to the health and disability sector of New Zealand. They support the management of "nationally significant information and events and support clinical safeguards such as the Medical Warnings System." (Health Information Strategy Steering Committee, 2005, p. 13).These systems, already in place or under development, are owned and operated by the Ministry of Health, District Health Boards, or Accident Compensation Commission.

New Zealand's implementation of its health information strategy will build on its existing Health Intranet (or electronic data interchange [EDI] network), which supports electronic claims submission, exchange of clinical messages such as laboratory results and referrals, and access to administrative systems such as the National Health Index (New Zealand Health Information Service, 2003; Protti & Graham, 2003).

Privacy and Confidentiality

New Zealand has been working on privacy, security and confidentiality issues for more than a decade and has a Privacy Commissioner who oversees enforcement of privacy legislation. The Privacy Act of 1993 outlines 12 privacy principles that are mandatory for all government entities. In general, the Privacy Act is based on the concept that "the collection, storage, use and disclosure of personal information should be carefully considered and that all activities in this area should be as transparent as possible" (Kerr, 2004). The Healthcare Information Privacy Code 1994/6 (HIPC) is based on the Privacy Act, but modified to address health care privacy issues. It applies to all health entities in New Zealand.

The Ministry of Health sponsored the development of the Code of Practice, an agreed-upon set of rules outlining how information can be exchanged electronically in the health sector. The Code is complemented by a set of security requirements for organizations seeking to connect to the Health Intranet (Office of the Privacy Commissioner, n.d.). In combination, the Code and security standards assist health care providers who need to communicate securely by electronic means (Galpottage & Norris, 2004; Health Information Strategy Steering Committee, 2005).

One interviewee noted that the guidance and legislation for privacy have created a degree of confidence among the public with respect to privacy issues and health information. Another observer noted that privacy and confidentiality are big issues, but New Zealand has very good privacy legislation, both generic and health care-specific, that is very pragmatic and avoids the wasteful bickering that afflicts other countries. HIS-NZ did identify two ways in which New Zealand's approach to privacy could be strengthened, however. First, HIS-NZ recommends development of a single consolidated guide for the health sector. The Ministry of Health and Accident Compensation Commission is leading development of a Privacy, Authentication and Security (PAS) guide for the health sector. Second, gaps still need to be addressed in educating both the sector and the public on privacy issues. In addition, a recent study found a lack of policy for the release of patient-identifiable information for medical follow-up studies (as might be needed in an epidemic situation) and genetic research in New Zealand (Galpottage & Norris, 2004).

National Health Identifier

New Zealand assigns a National Health Index number (NHI number) to each person, using health and disability services. The NHI stores the following information: name, NHI number, address, date of birth, sex, New Zealand resident status, ethnicity, date of death, and flags indicating medical warnings or donor information. The NHI number is encrypted when health information is released to third parties not involved in the care of the patient. The NHI is managed by the New Zealand Health Information Service (NZHIS; www.nzhis.govt.nz), a group within the Ministry of Health responsible for collecting and disseminating health-related data.

The HIS-NZ calls for expanding use of the NHI, resolution of duplicate NHI numbers, improved access to the NHI for those parts of the health sector that do not yet have access, and remedial work that will allow the NHI number to be used as an identifier for population-based activities. One interviewee noted that some citizens are not yet aware that a unique identifier has been assigned to them. Leaflets have been distributed to physician offices to begin the process of educating the public on the NHI.

Incentives/Policies to Encourage HIT Use

In 1997, the government mandated electronic claims submission for physician offices (Protti & Graham, 2003), which required practices to acquire practice management systems and connect to the Health Intranet (also known as the HealthLink network). The formation of independent practitioner associations (IPAs) encouraged adoption of information technology as many IPAs paid the costs for their member GPs to access the HealthLink network. The introduction of capitation-based funding and emphasis on population health provided an incentive for IPAs to collect data. The emergence of Practice Managers who are capable of overseeing the installation, management, and training for physician office systems supported the diffusion of HIT.

The Accident Compensation Corporation has provided incentives to encourage greater adoption and use of information systems (e.g., payment of $1 per claim billed electronically) (Health Information Strategy Steering Committee, 2005). The HIS-NZ will guide future annual IT investment by District Health Boards.

EHR Use

A 2001 Harris Interactive survey found that 52 percent of primary care physicians and 14 percent of specialists in New Zealand used electronic medical records (Harris Interactive, 2001). A 2003 study reported that 95 percent of GP offices were computerized and using electronic medical records or practice management systems (Protti & Graham, 2003). This study also reported that the proportion of specialists based in hospital computer use ranges from 30 percent to 90 percent, depending on the region, while 15 percent to 20 percent of specialists who work in the private sector use electronic medical records.

Household Use of Computer and the Internet

Forty-seven percent of households have access to a computer at home (OECD, 2005b), and 37.4 percent of households have access to the Internet at home (OECD, 2004).

Engagement of Stakeholders

During development of HIS-NZ, stakeholder engagement was sought in a variety of ways (Health Information Strategy Steering Committee, 2005):

- Steering committee members included representatives from across the health sector.

- Representatives of key sector organizations were interviewed.

- Planning sessions were held with district health board (DHB) chief information officers (CIOs) and the DHB chief executive officer (CEO) Information Group.

- Stakeholder meetings included representatives from laboratory, pharmacy, aged care, nongovernmental organizations, primary care, district health boards, and public health.

- Regional workshops were held to identify issues, priorities, and opportunities and to validate draft material.

- Online web-based and simultaneous teleconferences were held to test regional workshop input.

- The draft plan was sent to representatives of key sector organizations for final validation.

The governance group to be established to oversee implementation of HIS-NZ is charged to "ensure wide buy-in to HIS-NZ through whole of government and all parts of the sector, including community providers," "represent both public and private interests in the sector," and "report to key stakeholders on implementation progress (Health Information Strategy Steering Committee, 2005, p. xiii). There is no specific mention of patient involvement in this process, however.

Public education on HIT for the most part has been based on the benefits of the health care program rather than on the benefits of the technology. For example, the public has been educated on the minimum vaccination program and accompanying database.

Consumer Attitudes about HIT and PHRs

Interviewees concurred that the New Zealand population is generally IT-literate and that there has been excellent uptake of technology at physician practices and pharmacies. They concluded that the public has grown to accept the role of IT in the provision and administration of care to the point where citizens are more likely to comment if the technology is not installed.

The government has not sponsored any trials or evaluations of PHRs in New Zealand, and the literature review did not yield results on consumer attitudes on PHRs.

<u>ePHR Status</u>

New Zealand's health information strategy does mention "consumers electronically interacting with providers, where appropriate" (Health Information Strategy Steering Committee, 2005, p. xii), but at present the primary emphasis is on building the infrastructure to support information management by health care professionals and organizations. There are no plans for government initiatives for ePHRs.

Experience with PHRs in New Zealand appears to be limited, based on a web search:

- There is mention of keeping personal records and health goals on a web page discussing how to manage risk of cardiovascular disease (www.everybody.co.nz). This is consistent with the very strong emphasis on chronic disease management in New Zealand. As described by one interviewee, current activities focus mainly on clinical decision support for general practitioners, but these could certainly be extended to enable patient participation.

- An attempt to market ePHRs to providers and patients by a NZ company (i.e., Doctor Global) in 2001 was not successful, and the company subsequently refocused itself as a medical software developer for chronic disease management (Yellowlees, 2005). The Doctor Global website does continue to offer an ePHR— MyLife Health Record—on its website, which allows consumers to record information about allergies, medications, physical examinations, medical illnesses, surgical procedures, childhood history, vaccinations, smoking and alcohol, exercise and activity, family history, and tests. It also offers Health e-Monitor, which enables remote tracking and evaluation of various health conditions (e.g., asthma, diabetes, prostrate cancer) over time (www.doctorglobal.com, accessed July 19, 2005).

- *Your Personal Health Record* is a booklet that provides the means for individuals to document and carry key medical information. (see www.yourpersonalhealthrecord.com/index.html).

Conclusions and Recommendations

Interest in PHRs and ePHRs has been growing in the United States (Connecting for Health, 2003, 2004; Tang & Lansky, 2005; Tang, Ash, Bates, Overhage, & Sands, 2005; Office of the National Coordinator for Health Information Technology, 2006). This study sought to identify lessons for the United States from four other English-speaking countries on the development and implementation of personal health records. These countries, particularly England and Canada, have made considerable progress in planning and implementing NHIIs and are ahead of the United States with respect to developing

the infrastructure that would be needed to support widespread ePHR use. With the exception of England (i.e., the National Health Service's MyHealthSpace), however, there is not much ePHR activity in these countries' public or private sectors.

We conclude that the disparity in interest in PHRs (and, in the case of England, the somewhat limited vision of PHRs) is due primarily to differences in the cultures that underlie the health care systems of the United States and the countries studied. In the United States, individualism is a predominant value; in the other countries, however, solidarity (i.e., promoting the dignity and well-being of all persons and the welfare of society as a whole) is a predominant value (Priester, 1992). Individualism in the United States is accompanied by distrust of government and a preference for private solutions to social issues. Hence, the private sector plays a major role in delivering and financing U.S. health care. The strong presence of the market in the U.S. health sector has created the need for individuals to act as consumers of health care services (rather than as recipients of health services, as in other countries). Moreover, as the United States (particularly employers and third-party payers) moves toward consumer-driven health care as a strategy for managing health care costs, American patients have to shoulder even more responsibility for managing their use of health care services. (There is a very legitimate debate on the likely success of this approach, particularly if it is pursued in isolation from adequate education and safety net strategies. Indeed, one could make few better arguments favoring universal implementation of eiPHRs than pursuing a policy of health savings accounts.)

Meanwhile, a culture with solidarity as a primary value is more open to public sector approaches to and leadership for social challenges. The resulting predominantly public health care systems do not currently encourage an active role for citizens as consumers of health care. Europe has been moving toward "informed patients" with the potential for becoming involved patients (Detmer et al., 2003; Detmer & Singleton, 2004), but there are no plans to put patients in charge of their health care. This approach is consistent with predominantly publicly-funded health care systems, which rely heavily on clinicians as gatekeepers as a means of rationing available resources. Outside the United States, health care systems define "patient involvement" not in terms of "integrated" care between patient and caregivers so much as the patient's understanding of what his or her health problems are and what the doctor is seeking to achieve through treatment. As a result, there is little demand for ePHRs as tools for patients to manage their own health care.

The individualism/solidarity split also accounts for differences in how the countries approach their NHII planning and implementation. The countries studied are planning and funding their national health information technology strategies centrally, with implementation at regional levels. The United States is focusing on creating conditions for private markets to respond to national health information technology needs despite the reality that the federal government foots about half of the total bill. (To date, it is safe to say that countries with more centralized planning and significant national investment in NHII development have achieved the greatest gains in building their respective infrastructures.)

Further, individualism complicates the management of personal health data by creating the sense that individuals want to maintain total control over their data and would be unwilling to support mechanisms that would support its use by others (Detmer & Steen, 1996). Solidarity does not eliminate concerns about protecting personal health data, but it does enable policymakers to implement mechanisms that support data management (e.g., personal health identifiers) and may lead to greater acceptance among citizens with respect to privacy issues and sharing health data.

Given the health care environment in other countries, widespread ePHR adoption would likely emerge through government policy and funding. Thus, the primary challenge these countries face with respect to ePHRs is the decision of what to build—what level of ePHR functionality would best support their citizens. This study itself may have stimulated thinking among interviewees as they considered a future where the health system's IT infrastructure would go beyond patient/citizen education on matters of health to integrating the patient and his or her loved ones directly into patient care through common health records shared between patients and their caregivers over time. The nature of a predominantly public health care system, however, will create a constant tension between activating patients as consumers of health services and the reality of limited choices that arise from the system's constrained resources. In contrast, in the United States, fairly robust eiPHRs have already been envisioned that are consistent with how the health system is evolving. The question facing the United States is how to stimulate and fund ePHR development and adoption, and eiPHRs in particular.

<u>Guidance for USA Policy Makers</u>

Several approaches used in other countries may be instructive for the United States. First, the NHS approach to ePHRs points to an organizational issue U.S. policymakers must confront as they consider ePHRs as a potential tool for individuals to manage their health and as a means of supporting consumer-driven health care. England is pursuing ePHRs within the context of its national framework for EHRs. In so doing, England has clearly addressed the issue of who should develop, implement, and fund ePHRs. The NHS conducted extensive research on what consumers want from PHRs and ePHRs as part of its national IT program. In addition, by developing a single ePHR for all citizens, it will ensure that all citizens can access their ePHR if they so choose, and that health care providers will not face different ePHRs for different groups of patients (as could happen in the United States if insurers or different hospitals offer ePHRs). Further, the NHS is well positioned to implement incentives, if needed, for health care providers and patients to use ePHRs. In short, England has the focus, funding, and infrastructure to implement ePHRs.

Currently, a variety of U.S. organizations, including the Markle Foundation's Connecting for Health, the American Health Information Community's Consumer Empowerment Workgroup, the VA, DOD, and CMS), are exploring important issues surrounding ePHRs. In addition, health care providers, researchers, and insurers are developing, evaluating, or implementing ePHRs. While such an approach provides opportunity for input from a wide range of perspectives and likely facilitates innovation, it does not

provide a large pool of resources to support needed activities, nor does it offer a mechanism for prioritizing tasks or advocating for specific supportive legislation. Thus, there is a need for regular communication and ongoing coordination among the public and private organizations that have a role to play in ePHR development and diffusion.

As a starting point for this communication and coordination, federal agencies currently involved in NHII activities (e.g., ONC and its AHIC Consumer Empowerment Workgroup, AHRQ, NLM, CMS, DOD, and VA), along with interested private organizations (e.g., Markle Foundation, AARP, voluntary and professional groups, and representatives of third-party payers), should jointly develop a focused research agenda that identifies appropriate sponsors for addressing key research questions, including relevant policy issues. In particular, early implementations of ePHRs (e.g., England's HealthSpace, iHealthRecord, and the VA) provide opportunities for studying a range of questions, including, but not limited to:

- Is there an optimal approach to introducing ePHRs to large populations?
- What levels and kinds of resources are needed to support large ePHR implementations, particularly user support?
- How do various patient populations (e.g., different ages, healthy versus chronic versus terminal patients) use ePHRs?
- Can we quantify the costs and benefits of ePHR systems for individual citizens, health organizations, and the health system? These evaluations should include costs to consumers (computers, Internet service), costs to the ePHR manager (data management and transfer), and providers' costs of interacting with PHRs. The evaluations should seek to measure the benefits to consumers, health providers, and third-party payers.
- Can ePHR modules designed abroad to support chronic disease management be adapted for use in the United States? Can ePHR modules developed in the United States be shared among organizations?

Of equal if not greater importance is the need for these nongovernmental bodies to agree on a few central, crisply defined policy initiatives to generate the political will in the legislative and executive branches to assure federal legislation essential to a functional interoperative NHII for the nation.

Second, international experience shows that personal health identifiers greatly aid authentication and are a key first step to moving forward with Health IT infrastructures, including ePHRs. The entire European Union, along with many other developed economies, is adopting health insurance cards with unique health identity numbers and cards. Yet despite the Health Insurance Portability and Accountability Act (HIPAA) mandate for unique patient identifiers, the United States cannot even bring itself to allow citizens to opt into or out of a national personal health identifier let alone be assigned one without the option to opt out. The United States is alone in this regard.

What complicates the creation of "IT-friendly" ePHR policy in the United States today is an apparent major disconnect between public perceptions "on the street" and policy conclusions "inside the Beltway" about privacy fears and the actual experience in care settings where patients explicitly trade off health and privacy concerns. Anecdotal experience from practice settings that offer thousands of patients "clicks and mortar" care reveals how few patients even express any concern about so-called threats to their data privacy, even in sites like California and Massachusetts, which have been characterized as very concerned about such matters. The number of patients who express a concern and/or do not engage the opportunity for such care is thought to be less than 5 percent (AcademyHealth 2005; AMIA/HIMSS 2005). This urgently needs to be studied formally.

Also needed is a comprehensive study on privacy attitudes of American citizens to guide policy on unique identifiers beyond the common method of "opinion surveys from the street." Formal research of experiences from those environments where eiPHRs that enable "clicks and mortar" care are available to patients would add a great deal of reality to what have been, to date, largely hypothetical questionnaires. Finally, both ePHR and EHR development would be supported by educating the public on the benefits of the technology, available privacy protections, and the role of unique health identifiers in supporting efficient and effective health care delivery.

Public advocacy and policy groups need to consider whether the current U.S. privacy framework will support widespread implementation of ePHRs. In particular, they should evaluate whether ePHRs can be implemented on a broad scale without unique patient identifiers. Organizations interested in advancing ePHRs should examine privacy approaches such as England's Care Record Guarantee and national privacy commissioners as ways to strengthen—in actuality or perception—the privacy infrastructure in the United States.

Third, several good examples of consumer engagement and education may provide guidance to ePHR developers on how to effectively obtain consumer input into and support for ePHRs. In particular, AARP or another public advocacy organization may be able to play a role similar to that of Australia's Consumer's Health Forum. In addition, ONC would do well to include consumer representation in its various planning groups and obtain feedback from consumers on its pilot projects, as did England's NHS Connecting for Health program.

Fourth, public advocacy groups like AARP can help to advance ePHR implementation by focusing on citizen readiness. To advance ePHR development, AARP and other public advocacy groups should strengthen efforts to improve health literacy and numeracy in the U.S. population and develop a more comprehensive approach to improving the computer literacy of key ePHR user groups (e.g., senior citizens, individuals with chronic disease, individuals who may need to monitor the health of a family member from a distance) (Institute of Medicine, 2004). The European Union's e-Citizen program provides one model for such an effort.

Fifth, the growing interest in health information among citizens in all nations highlights the urgency for international standards for terminology and classifications of health, illness, and health care. In particular, SNOMED-CT$^®$ and ICD need to be harmonized and maintained on a global basis. As part of its efforts to advance interoperability, ONC should assure sufficient collaboration with other nations and the WHO to develop and maintain international standards that will facilitate global sharing of medical knowledge and enable integration of systems incorporating ePHRs. ONC needs to work with the White House, health agencies, and standard-setting entities to assure that federal appropriations will allow for ongoing support of these standards.

Unresolved Issues

Three issues essential to development and implementation of ePHRs cannot be addressed by looking abroad.

First, because we do not anticipate federal financing to support a rollout of ePHRs for all American citizens, the critical question of funding must be addressed. ePHRs require patients to have computers with Internet access and relatively current browsers. Will individuals who do not already own computers be willing or able to purchase them to access ePHRs? Clearly, the unit costs for accessing the Internet are dropping, and efforts are underway to create very cheap Internet access machines. A recent survey suggests that citizens would be willing to pay a few dollars a month to have access to electronic health records. Palo Alto Medical Foundation is charging for one version of its "clicks and mortar" PHR, and people are paying for it willingly. That environment, however, is noted for its highly educated, affluent population, so the wisdom of generalizing from this experience may be limited.

Whether ePHRs are operated by health care provider institutions or others, all require that someone oversee the flow and quality of data exchanged. Today, health care professionals are expected to pick up the investment and operational costs of information systems that support the larger delivery system. While this may work for larger hospital or care systems, it clearly does not work for very small practices, and these providers deliver most of the care. As *Connecting for Health* (2003) concluded,

> There is no short-term incentive or immediate return on investment to justify the significant cost of developing a PHR that can exchange data with disparate, non-standardized and often reluctant institutional sources. There is no evidence, yet, that a significant market of paying customers exists for such a service (p.26).

So who should pay for PHR systems and their ongoing costs? The principle laid down in the 1991 IOM computer-based patient record study is that costs should be borne by all who benefit. Once robust "clicks and mortar" systems are in place, it becomes easier to see who benefits and who should pay fairly to sustain the system and its benefits. The anecdotal evidence to date suggests that these systems improve patient-centeredness, efficiency, and effectiveness and, thus, provide benefits to patients, health care providers,

and third-party payers. These systems could eventually support important public health monitoring needs. Moreover, society should experience gains in productivity from improvements in health status that play out in economic benefits that do not accrue to the health care system but to society at large. In that context government would be wise to make the investment. Clearly, England's plan for EHRs and ePHRs is based on the calculation that the benefits will outweigh the costs. More research is needed in the United States to guide policy makers.

Realistic funding models for ePHRs will need to consider several factors:

- Are third-party payers likely to invest in ePHRs for their enrollees? (Early evidence in states like Massachusetts suggests that this is possible but not at nearly the rate at which efficiencies might be realized if such a model were the norm for care.)
- What kind of cost sharing might be feasible for some patient groups?
- Might innovative approaches be useful? For example, the Netherlands provides a discretionary "client-linked budget" to individuals with chronic illness; such funds could be used to pay for Internet services and virtual health services, thereby enabling ePHR use as opposed to paying for transportation costs to get to care settings (Peelen, van der Kraan, & Helderman, 2004; The Royal Netherlands Embassy, 2003).

Second, it is essential that the U.S. NHII be capable of supporting eiPHRs, and that NHII developers attend to the issue of integrating eiPHRs fully within the NHII on both technical and organizational levels. The ONC AHIC Consumer Empowerment Workgroup appears to be taking a first step in this direction. However, the capability and willingness of health care organizations and professionals to embrace the changes associated with adopting eiPHRs must be addressed.

Third, the unique nature of the U.S. health care system creates an environment in which eiPHRs could emerge as a pivotal tool. In theory, they have the potential to empower patients and to transform health care delivery. U.S. policymakers in both the private and public sectors have already demonstrated interest in and are applying their considerable expertise to ePHRs. The reality of ePHRs ultimately depends on sustained political will to invest in an issue that will not yield immediate results, but that over time could bring considerable benefits in the form of the improved health and well-being of U.S. citizens within the context of a society that values individualism over solidarity.

Table 2: An Overview of the Health Sectors

Country	Percent of GDP spent on health	Public expenditure, % total expenditure on health	Health Insurance	Delivery	Reimbursement	Other
	2003	2003				
Australia	9.3	67.5	100% (Medicare) public insurance 45% have private supplementary insurance	Health care services are provided by states (i.e., public hospitals, mental health services, and community health services), private practitioners, and private hospitals.	Mixed. GPs fee for service. Pharmaceuticals negotiated prices. Hospitals prospective block grants and DRG payments.	Predominantly publicly financed. Commonwealth collects most taxes, but States administer or deliver most public services. Relies heavily on GPs and family doctors, less than half of MDs are specialists. Most GPs are self-employed. Uses a global budget.
Canada	9.9	69.9	100% covered (Medicare) Covers primary and hospital care, Premiums charged in some provinces. Some citizens obtain supplemental insurance for non-covered services.	Provincial & territorial governments are responsible for the management & delivery of health care services. 95% of hospitals are public. Some for-profit hospitals and clinics exist.	MDs- fee for service. Public hospitals – negotiated budgets	Publicly financed national health system that provides hospitals and other medical services to the entire population. Primary care MDs as gatekeeper. Wait times for secondary care services is a major issue. National principals in place,

Country	Percent of GDP spent on health	Public expenditure, % total expenditure on health	Health Insurance	Delivery	Reimbursement	Other
	2003	2003				
			Recent court decision has opened up possibility of private health insurance for procedures covered by Medicare.			**but implementation varies at jurisdictional level.**
England	**7.7**	**83.4**	**100 % of population covered by public insurance. Most comprehensive coverage with few or no patient costs. 11.5% have complementary or supplementary private insurance**	**Centrally administered. NHS provides health care largely free with copayments for certain pharmaceuticals.**	**Capitation with performance incentives.**	**Requires patients to register with a GP clinic. GPs have arrangements for after hours care. Uses a global budget.** **Very centralized.**

Country	Percent of GDP spent on health	Public expenditure, % total expenditure on health	Health Insurance	Delivery	Reimbursement	Other
	2003	2003				
New Zealand	**8.1**	**78.7**	**The Accident Compensation Corporation, a Crown entity, provides universal accident insurance coverage.** **For health care needs not arising out of an accident, public hospital outpatient and inpatient services are free. Primary care services are free or subsidized for certain groups. (40% covered for primary care).**	**Public & private. District Health Boards fund primary care services and provide hospital services for their communities.**	**Moving towards capitation**	**Relies heavily on GPs and family doctors, less than half of MDs are specialists. Uses a global budget.** **Moving away from market like incentives introduced in the 1990's towards planned & community oriented approach.**

Country	Percent of GDP spent on health 2003	Public expenditure, % total expenditure on health 2003	Health Insurance	Delivery	Reimbursement	Other
			Private insurance is voluntary and funds insure against gap or supplementary costs but do not offer comprehensive coverage. *33-37 % of population has private health insurance.*			
United States	**15** **(Highest of 30 OECD countries)**	**44.4** **(lowest of 30 OECD countries)**	**Over 65, 100% covered through Medicare; under 65, 17.5% no coverage, 14.2% public coverage, 65.8% employer-based; 6.6 % individually purchased.**	**Public & Private**	**Predominantly fee for service**	**High percentage of specialists, mix of primary care physicians.** **Financing system is complex, administrative costs are high.** **Decentralized.**

(Ashton, 2005; Australian Government, Undated; Canadian Health Care, 2004; Coulter and Magee, 2003; European Observatory of Health Care Systems, 2002; Institute of Medicine, 2001b; Kundig Associates, Undated; OECD, 2005a)

Table 3: Overview of Findings with Respect to National Action[3]

Comparison of Health Systems

England	*Centrally administered health system. 100% of population covered for at least some services.*
Australia *Canada* *New Zealand*	*Federal government sets policy & standards; services provided by jurisdiction. Public sector dominates health care delivery. 100% of population covered by health insurance for at least some services.*
United States	*Large private sector role (lowest percentage of public spending on health care). 17.5% of population under 65 is uninsured.*

Comparison of Approaches to NHII Development

England	*Centralized development of a single system with implementation coordinated by regional health authorities.*
Australia *Canada*	*National framework with system implementation at state (or province) level.*
New Zealand	*A mixture of national, regional (e.g., district health boards), and local (i.e., provider-based) systems developed in the context of a national strategy*
United States	*National framework under development with system implementation at provider level and heavy reliance on private sector.*

NHII Maturity

Canada *England*	*Strategy clearly articulated. Development & implementation well underway.*
Australia *New Zealand*	*Strategy clearly articulated. Development & implementation in early stages.*
United States	*Strategy under development.*

Privacy Framework

England *New Zealand*	*Fairly robust. Privacy Commissioner in place. Care Record Guarantee developed by NHS in UK. Code of Practice for electronic*

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[3] Since most ePHR activity in the countries studies is the result of governmental policy and action, this overview focuses on USA national policy. AARP has commissioned a separate study on private sector ePHR activity in the USA.

	exchange of health information developed by Ministry of Health in New Zealand.
Australia	*Somewhat robust. Privacy Commissioner in place. Efforts underway to harmonize inconsistencies among various jurisdictional rules that govern privacy of health information. Specific privacy and security rules being developed as part of national health information framework.*
Canada	
United States	*Mixture of state laws and federal legislation (i.e., HIPAA).*

Approach to Unique Personal Health Identifier at National Level

New Zealand   *In place and being refined.*

England

- *National Health Index number assigned to each patient in NZ*

- *NHS number is used to track patients across NHS organizations.*

Australia   *Personal health identifier is planned for all citizens. Implementation expected to begin in 2006-2007.*

Canada   *Unique patient identifiers at the provincial level. Not anticipated at national level.*

United States   *Still under debate with strong resistance from some privacy groups.*

EHR Use by Physicians

England   *52% primary care*

            22% specialists

New Zealand   *53% primary care*

            14% specialists

Australia   *25% primary care*

            13% specialists

Canada   *According to 2001 survey data: 14% primary care and 16% specialists.*

            Interviewees estimated 30 to 35% of general practitioners in 2005.

United States   *17.6% of all physicians with rates varying by size of practice and by speciality (e.g., orthopedic surgery 24%, family practice 17%, and psychiatry 8%) (Burt and Sisk, 2005).*

Approach to Consumer Engagement and Education

England   *Very strong.*

Australia

New Zealand   *Strong.*

Canada   *Not evident.*

United States   *Limited to date.*

PHR & ePHR Activity

England   *Currently offers a personal online health organizer for patients. Plans call for patients to be able to access their national summary record beginning in 2008. Some activity focused on disease management outside of NHS information technology program. Very limited private sector activity is evident.*

Australia   *Plans to offer summary consumer health information to consumers via its national network, No timeline has been specified. Several groups offer paper-based PHRs for their patients Pilot of ePHR for patients in diabetes clinic underway. Some private sector activity is evident.*

Canada   *No mention of PHRs as part of current national strategy.*

New Zealand

- *Some provider-based development underway and limited private sector offerings in Canada.*

- *Limited disease management or private sector offerings in NZ at this time.*

United States   *Wide variety of PHR projects in private sector. Veterans Administration has implemented ePHR for its patients.*

Citizen/Consumer Attitudes Towards HIT & ePHRs

Australia   *Participants in Health***Connect** *trials had high expectations about and positive experiences with access to their health records.*

Canada   *Surveys of citizens found*

- *A majority of respondents support EHRs and believe that EHRs will improve effectiveness of health care professionals.*

- *A majority of respondents would be willing to carry smart cards with medical history.*

England   *Research for the Electronic Record Development and Implementation Programme found*

- *Patients expect sharing of information*

- *Public awareness and interest is low*

- *Patients have concerns about security & confidentiality*

- *Patients who had access to their records felt better informed, more able to ask questions of their doctors, and that the relationshiop with their doctors had improved*

- *Patients understood the information in their records*

- *Patients felt empowered*

New Zealand   *NZ has not conducted any evaluations or surveys of PHRs. Interviewees concurred that the public is IT-literate and has grown to expect IT to be used by health care professionals and organizations.*

United States   *Markle Foundation Connecting for Health survey found strong support for and interest in ePHRs.*

Appendix 1

Survey Instrument
Questions on Personal Health Records

1) <u>Public Attitudes about Health Information Technology (HIT)</u>

   a) Are stakeholders (including patients/consumers) involved in HIT adoption?

   b) What are public perceptions about HIT?

   c) Is the public aware of benefits of HIT?

   d) If public education is/was being conducted, what approach is/was being taken, what messages were used?

2) <u>Personal Health Records (PHRs)</u>

   a) In your nation, what constitutes a personal health record (e.g., electronic information on health issues, electronic communication with a clinician, online repository of patient data that can be accessed by the patient)?

   b) What is the current state of PHRs in your country?

   c) If data are available, what are consumer attitudes about PHRs?

   d) Which features of PHRs do consumers use most frequently?

   e) Have there been any evaluations of PHRs?

   f) Is there any evidence of impact of PHRs on outcomes?

3) <u>Privacy and confidentiality</u>

   a) How big an issue is this and how does it reflect itself?

4) <u>NHII</u>

   a) Are there recent documents describing current activities and status and plans for the future, including budget and governance issues?

   b) Are clinicians in your country explicitly part of the strategic plan for planning and implementation?

5) <u>Resources</u>

Are there reports, websites, research activities or demonstrations, or other relevant citations on PHR use in your country?

Appendix 2

Highlights of Other PHR-related Activities

<u>European Union</u>

A survey on Internet use in the European Union (EU) found that one third of respondents reported using the Internet to search for health-related information. "This translates into about one in five of the European population aged 15 years and over when non-Internet users are taken into account." Online searching for health information is growing in importance in Europe and is even more prevalent in the United States (more than half of Internet users, translating into two in five of the U.S. population) (SIBIS Work Research Centre, 2003). It is not clear whether this is due to a lack of quality information for Europeans (especially non-English speakers) or to Americans' motivation to be better informed about their health system, a willingness of American physicians to discuss searches, or a stronger sense of consumerism in American society in general. It is also not clear whether this trend suggests that U.S. citizens will be more active users of ePHRs than are Europeans.

Europe is fostering general e-health capabilities that will ultimately support ePHR use by citizens and enable such systems to cross country lines. The Commission of the European Communities has an action plan for improving e-health capabilities across Europe. The eEurope 2005 Action Plan calls for a European health insurance card to replace paper forms currently used (when citizens need health treatment in other member states) by 2008. This will require common approaches to patient identifiers and electronic health record architecture. There are also strategies aimed at system interoperability, integrated health information networks, and improving health information available online for European citizens (Commission of the European Communities, 2004).

e-Citizen is "a basic computer skills certification developed by the European Computer Driving Licence Foundation (ECDL-F) in response to the urgent and growing need for an increase in e-skills within the community as a whole" (ECDL Foundation, n.d.). The program, designed for citizens with limited knowledge of computers and the Internet, is intended to give them the necessary skills to participate online in a range of activities. e-Citizen involves approximately 30 hours of training, including both tutor-led sessions and independent study. It covers foundations skills such as files and folders, simple applications, and Internet and e-mail basics; information search; and e-participation. Participants take a test at the end of their training to assess their competence.

In addition, the Informed Patient study concluded that "the future of health care in Europe demands far greater health-related information for patients and citizens" and developed a framework for action to improve the provision of health information (Detmer et al., 2003; Detmer & Singleton, 2004).

Scotland

Although Scotland shares some aspects of its National Health Service with England, its health information strategy is quite distinct. Scotland's national health information technology strategy seeks "to deliver an Integrated Care Record jointly managed by patients and professional NHS staff with built-in security of access governed by patient consent" (NHS Scotland, 2004). Further, the strategy is intended to enable service redesign and a shift in the balance of care provided in different settings. Considerable progress has been made in assigning Community Health Index numbers (unique patient identifiers) to citizens. In addition, isolated projects provide patients access to their records (e.g., www.babylink.info/Edinburgh/BabyLink/project.aspx; www.renalpatientview.org), and others are under development (e.g., diabetes). In December 2005, the National Resource Centre for Ethnic Minority Health launched a hand-held paper patient record for Gypsies/Travellers to allow them to have complete medical information with them at all times ("Personal health records for Gypsies/Travellers," 2005).

Sweden

The SUSTAINS (Support Users to Access Information and Services) project in Sweden provides useful lessons on ePHRs (Eklund & Joustra-Enquist, 2004). The central concept of this project was to create "a copy of Internet banking but for health care." Users have health care accounts and log in using a one-time password (that is sent to their mobile phone three seconds after the PIN code is entered) to ensure privacy while personal information is being transferred both ways. Users can explore their medical record in detail and view a list of prescriptions and lab results. They can also exchange information with their physicians.

Results from two pilot projects (SUSTAINS I and II) have been combined into specification for a system (SUSTAINS III) that has been launched in limited production, with plans to serve all patients within the region within three years. The SUSTAINS I pilot involved 100 patients who were given access to personal information at the hospital information system of Uppsala University Hospital. The evaluation gave "a very clear indication that the users wanted 'all information available' including the medical record." (Elkund and Joustra-Enquist, 2004, p. 184). SUSTAINS II implemented users' requests and increased security level up to an "Internet banking level." Patients had access to GP's Medical Record Database. This phase involved establishing two private companies and two public organizations to manage the flow of information. In addition, considerable effort was devoted to disseminating information to the media and participating in conferences to overcome "some obstructive cultural barriers in the professional organization" and inform the public about new ways to interact with the health care system.

SUSTAINS III (in place since November 2002) allows patients with Health Care Accounts to access data from three different sources (Hospital Information System, laboratory database, and GP medical records) and communicate with the GP office to ask for medical advice, an appointment, or a prescription. This system does require users to have reasonably up-to-date web browsers.

Evaluations of the SUSTAIN project found that:

- After testing three different technical solutions, the less complex the technical environment, the more stable the solution for users.

- The functions most preferred by patients included seeing medical records, booking visits, communicating with health care providers, availability of prescription lists, access to a medical dictionary, and ability to read fees.

- Most participants were not were not concerned about security risks during the trials.

- No extra calls came from patients who did not understand information in their medical records

- The best security solution is the one-time password issued to mobile phones. This approach, however, limits participation to patients with mobile phones and raises question of fairness.

- Current uptake is about 15 percent of population, but general awareness of such services in Sweden is low.

- The system requires a national patient identifier.

- It is not clear who should pay for the system on an ongoing basis—the patient or the health care organization or system.

- Some physicians expressed concern that patients would be "hostile and suspicious" when they could read notes. In actuality, however, patients appeared to have more confidence and trust in their physicians.

- Physicians anticipated that the project would lead to more efficient care as users became more accustomed to the system and more functions become available. They also expect that as patients better understand the complex and time-consuming processed involved in their care, they will be more satisfied with it.

- Compared with Internet banking, there is a challenge in maintaining users' skills since many people are only sick once a year. A natural focus group may be the elderly and people suffering from chronic diseases.

Appendix 3

National Health Service
The Care Record Guarantee
Our Guarantee for NHS Care Records in England

Our commitments to you:

1. When we receive a request from you in writing, we must normally give you access to everything we have recorded about you. However, we may not give you confidential information about other people, or information that a health professional considers likely to cause serious harm to the physical or mental health of you or someone else. This applies to paper and electronic records. If you ask us to, we will also let other people see health records about you. Wherever possible, we will make your health records available to you free of charge or at a minimum charge, as allowed by law. We will provide other ways for you to apply to see your records if you cannot do so in writing. We will provide information in a format that is accessible to you (for example, in large type if you are partially sighted).

2. When we provide health care, we will share health records about you with the people providing care or checking its quality. They must keep the information confidential, whether shared using the computer system or in any other way (such as on paper). We will aim to share only as much information as people need to know to play their part in your health care.

3. We will not share information outside the NHS (particularly with other government agencies) that identifies you for any other reason, unless:

   - you give us specific permission;
   - we have to do this by law; or
   - we have good reason to believe that failing to share the information would
   - put someone else at risk.

   If we share information without your permission, we will make sure that we follow the NHS confidentiality code of practice and other national guidelines on best practice. There is more information about existing guidelines at www.dh.gov.uk/PolicyAndGuidance/InformationPolicy/PatientConfidentialityAndCaldicottGuardians.

4. Under current law, no-one can make decisions about sharing health information about you on your behalf. At the moment, the only exceptions to this are parents or legal guardians, or people with powers under mental health law. However, if you are not able to make decisions about sharing information, a senior health care

professional involved in your care may consider it to be in your best interests to share information.

This judgment should take account of the views of relatives and carers, and any views you have already recorded.

5. Sometimes your health care will be provided by members of a care team, which might include people from other services, such as social services or education. We will tell you if this is the case. When it could be in your best interests for us to share health information with organisations outside the NHS, we will agree this with you beforehand. If you don't agree, we will discuss with you the possible effect this may have on your care and alternatives.

6. You can choose not to have information in your electronic care records shared. In helping you decide, we will discuss with you how this may affect our ability to provide you with care or treatment, and any alternatives available to you.

7. We will deal fairly and efficiently with your questions, concerns and complaints about how we use information about you. All trusts have a Patient Advice and Liaison Service which can answer questions, point people toward sources of advice and support, and advise on how to make a complaint. We will have a clear complaints procedure. We will use what we learn from your concerns and complaints to improve services.

8. We will take appropriate steps to make sure information about you is accurate. You will be given opportunities to check records about you and point out any mistakes. We would normally correct factual mistakes. If you are not happy with an opinion or comment that has been recorded, we will add your comments to the record. If you are suffering distress or harm as a result of information being held in your record, you can apply to have the information amended or deleted.

9. We will make sure, through contract terms and staff training, that everyone who works in or on behalf of the NHS understands their duty of confidentiality, what it means in practice and how it applies to all parts of their work. Organisations under contract to the NHS must follow the same policies and controls as we do. We will enforce this duty at all times.

10. We will take appropriate steps to make sure we hold records about you – both paper and electronic – securely and only make them available to people who have a right to see them.

11. We will keep a record of everyone who looks at the information the NHS Care Records Service holds about you. You will be able to ask for a list of everyone who has looked at records about you and when they did so.

There may be times when someone will need to look at information about you without having been given permission to do so beforehand. This may be justifiable, for example, if you need emergency care. We will tell you if the action cannot be justified.

12. We will take action when someone deliberately looks at records about you without permission or good reason. This can include disciplinary action, ending a contract, firing an employee or bringing criminal charges.

What you can do in return:

1. Tell us if any information in your records is wrong.

2. Allow us to share as much information about you as we need to provide you with health care.

3. If you have decided not to allow us to share records of your care with others in the NHS, tell us if you change your mind. Preventing us from sharing information may make diagnosis very difficult and treatment dangerous. And, in extreme circumstances, we might not be able to offer you the most appropriate treatment.

4. Only let others – insurers, mortgage lenders, employers, solicitors and so on – look at your records if you are sure it is necessary. Think carefully about who you give permission to and why. Try to restrict their access to what they need to know and no more.

5. At some time, we might ask your permission to use records from which you could be identified for important research. Please give us permission unless you feel strongly that you do not want us to use your information in this way.

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