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Assessing the Potential of National Strategies for Electronic Health Records for Population Health Monitoring and Research

U.S. DEPARTMENT OF HEALTH AND HUMAN SERVICES
Centers for Disease Control and Prevention
National Center for Health Statistics

Disclaimer

The findings and conclusions in this report are those of the author and do not necessarily represent the views of the Centers for Disease Control and Prevention.

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Assessing the Potential of National Strategies for Electronic Health Records for Population Health Monitoring and Research

Data Evaluation and Methods Research

U.S. DEPARTMENT OF HEALTH AND HUMAN SERVICES
Centers for Disease Control and Prevention
National Center for Health Statistics

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Summary

Assessing the Potential of National Strategies for Electronic Health Records for Population Health Monitoring and Research

January 2006

Rationale (see Chapter 1)

Healthcare costs continue to increase. The media, the public, and health professionals now recognize that unnecessary morbidity, mortality, and healthcare costs resulting from adverse events and medical errors are serious problems. The U.S. and other developed nations are adopting health information technology as a tool for rationalizing complicated healthcare systems, improving the quality of patient care, moderating healthcare costs, and reducing the incidence of adverse events. Electronic health records constitute the core of health information technology. The U.S., Australia, Canada, England, and New Zealand are all developing national strategies for electronic health records, accompanied by substantial investments of public and private sector funds in implementing those strategies.

Purpose (see Chapter 1)

The Centers for Disease Control and Prevention's National Center for Health Statistics commissioned this report to assess the potential contribution of national strategies for electronic health records to population health monitoring and research. The report focuses on those types of population health monitoring that generate health statistics for measuring the population's health, rather than those types of population health monitoring used to detect health events and diseases for the purposes of immediate public health interventions.

Methods (see Chapter 2)

This study:

1. Reviewed national strategies for electronic health records in Australia, Canada, England, and New Zealand, and especially the implications of those strategies for population health monitoring by producing health statistics and by encouraging research employing health statistics. The review relied on reports, presentations, Web pages, and articles, which were publicly available before January 2006. Structured and directed Web and literature searches were conducted. See Chapters 2, 3, and 4.
2. Identified the potential contribution of national strategies for electronic health records to population health monitoring and research and barriers to achieving that potential. The identification of the potential contribution and barriers relied on interviews with 96 experts with national and sub-national responsibilities for strategies for electronic health records, for population health monitoring and research, and for related research in U.S., Australia, Canada, England, and New Zealand. The interviews were qualitative and were conducted via telephone using structured interview guides. See Chapters 2, 5, and 6.
3. Delineated fundamental issues that must be confronted to maximize the contribution of national strategies in the development of electronic health records for population health monitoring and research. See Chapter 7.

This study did not explore issues relating to the potential of national strategies for electronic health records for health event and disease detection for the purposes of immediate public health interventions, such as case-based surveillance, syndromic surveillance, and bioterrorism surveillance.

Key concepts (see Chapter 1)

This report defines the electronic health record as an electronic repository of patient-centric data that are identifiable, longitudinal and preferably life-long, cross-provider, cross-provider site, and cross the spectrum of healthcare, including primary care, acute hospital care, long-term care, and home care. In contrast, this report defines the electronic patient record as the electronic record of the periodic care provided mainly by one institution. Widely accepted definitions of electronic health records and electronic patient records do not exist internationally, and comparisons of different usages of the terms should focus on specified functions rather than assuming comparability based on the terms themselves.

Population health encompasses the level and distribution of disease, functional status, and well-being within a group. Population health monitoring is the collection and analysis of data to detect and describe changes in the population's health or factors that affect the population's health.

Health statistics are "numerical data that characterize the health of a population and the influences that affect its health."[1] The types of population

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[1] Parrish RG, Friedman DJ, Hunter EL (2005). Defining health statistics and their scope. In: Friedman DJ, Hunter EL, Parrish RG (editors), Health Statistics: Shaping Policy and Practice to Improve the Population's Health. New York City (NY): Oxford University Press;3.

health monitoring that typically generate health statistics are reportable diseases and registries, administrative health data, and population-based surveys; nonhealth data sources also provide health statistics, especially relating to the influences on the population's health.

A numerator is "the upper portion of a fraction, used to calculate a rate or a ratio."[2] Numerators represent the aspect of the population's health being measured, such as a health event, disease, condition, functional status, or well-being. A denominator is "the lower portion of a fraction used to calculate a rate or ratio. The population. . . at risk in the calculation of a rate or ratio."[3] Denominators represent the population in which the particular aspect of population health is being measured. Population-based health statistics require both a known numerator and a known denominator.

National strategies in Australia, Canada, England, and New Zealand (see Chapters 3, 4, and 5)

Chapter 4 provides overviews of national strategies for electronic health records in Australia, Canada, England, and New Zealand, including the locus of responsibilities, current status and plans, electronic health record definition, national health information infrastructure elements related to electronic health records, electronic health records storage, patient confidentiality and participation, patient identification, and uses for population health monitoring and research. See Table S.1 for an abbreviated summary of the four national strategies.

National strategies for electronic health records reflect the political, healthcare and systems, and market systems of individual countries (see Chapters 3 and 4). National strategies for electronic health records also reflect both technical decisions and political judgments, which may change over time. National strategies in Australia, Canada, England, and New Zealand are developing and evolving, and passing through stages of conceptualization, design, pilot testing, and implementation. Only England has moved to implementation of a national strategy for electronic health records. Australia has conducted local pilot testing and is now designing its national strategy. Canada is conducting local pilot testing through strategic investments and is now designing its national strategy. New Zealand is conceptualizing its national strategy.

Review of publicly available reports, presentations, Web sites, and articles, and interviews with experts, reveal that population health monitoring and research is explicitly secondary to the primary uses of clinical care and management in the investigated national strategies for electronic health records (see Chapters 4 and 5). Only England has conceptualized, designed, and is now implementing the use of electronic health records for population health monitoring and research: the National Health Service Secondary Uses Service has been established to "provide the NHS with higher quality data to enable investigation of trends and emerging health needs which can inform public health policy and planning."[4] Canada's strategy includes communicable disease surveillance.

Consensus within nations does not exist on key issues underlying the use of electronic health records for population health monitoring and research. These issues include but are not limited to whether and how national strategies for electronic health records should support population health monitoring and research, the parameters of patient confidentiality and participation, the harmonization of clinical data standards with population health monitoring data standards, and the extent to which electronic health records contain structured data. In Australia and Canada, consensus has not yet been achieved on unique patient identification, or whether unique identification will apply to residents who encounter the healthcare system or to all residents.

Potential contributions of electronic health records to population health monitoring and research (see Chapters 5 and 6)

Experts interviewed in Australia, Canada, England, New Zealand, and the U.S. identified potential contributions of electronic health records to population health monitoring to produce health statistics and research employing health statistics. Examples of these potential contributions include the following.

Integrating healthcare performance measurement with population health monitoring, such as the development of integrated systems for measuring healthcare system performance at individual and provider group levels, with provider and provider group measurements systematically aggregated to the population level.

Developing entirely new data for population health monitoring and research and entirely new options for population health monitoring and research, including:

- Establishing new disease and health condition registries yielding previously unavailable population-based morbidity and disease prevalence data;
- Tracking how people move through and beyond the healthcare system;
- Ongoing linking of clinically rich data with population health monitoring data from registries and reportable disease systems, administrative health data, population-based surveys, and complementary data sources; and
- Using electronic health records as sampling frames for population health monitoring and research.

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[2] Last JM, Spasoff RM, Harris SS, Thuriaux MC, eds. (2001). A dictionary of epidemiology. NewYork City (NY): Oxford University Press;126.

[3] Ibid;49.

[4] NHS Connecting for Health (2005 Oct). The National Programme for IT implementation guide: Designed for the NHS by the NHS. Guidance to support trusts when implementing National Programme products and services. Version 3. London (UK): NHS Connecting for Health:27.

Shifting predominant paradigms for population health and clinical research, through erasing current distinctions between clinical data and population health data.

Fundamental issues in the relationship between national strategies for electronic health records and population health monitoring and research

(see Chapter 7)

Numerators and denominators as necessary conditions

Data derived from electronic health records may prove useful for multiple purposes in addition to the clinical care of individual patients, including detecting health events and diseases for the purposes of immediate public health interventions, identifying adverse events, monitoring the quality of clinical care, and managing the provision of health care and health care resources. But in order for data derived from electronic health records to be used to characterize the health of population, three conditions must be met. These three conditions relate to the known numerators and denominators needed to produce population-based health statistics.

1. First, electronic health records must produce numerator data about health events, conditions, diseases, functional health status, well-being, or influences on population health.
2. Second, denominator data must exist that describes the population in terms of size, geographic location, and basic demographic characteristics for the numerator data produced by electronic health records. Denominators are typically defined at some geographic level in health statistics.
3. Third and finally, a match must exist between the numerator and the denominator; in other words, the numerator must be drawn from the population denominator.

Data derived from electronic health records can only be useful for population health monitoring and research if they are associated with a geographically based denominator with known characteristics, and especially demographic characteristics.

Numerator and denominator issues

In order to be most useful for generating valid population-based health statistics, national strategies for electronic health records should confront the following numerator and denominator issues:

Penetration of electronic health records: Electronic health records must either penetrate an entire geographically based population, or a truly random subset of that population with known characteristics, or a non-random subset of that population with known characteristics that can be linked to a population denominator with known characteristics.

Data quality and completeness: Numerator and denominator data produced by electronic health records must meet the same professional standards of validity, reliability, and completeness as currently met by population health monitoring data sets such as births, cancer incidence, and population-based surveys.

Consent: Patient control of what data are entered into electronic health records and used for population health monitoring and research may adversely affect the quality and completeness of numerator and denominator data.

Unique patient identification: Some form of unique identification of individual patients is necessary if electronic health records are to provide data for population health monitoring and research. Unique patient identification could occur through numbering systems, or through algorithmic probabilistic or deterministic linkage of a specified set of identifier variables, or through a master patient index. To the extent that health statistics extend beyond health events, diseases, and conditions treated through the healthcare system, unique identification of patients rather than unique identification of each person in the population may limit the development of population-based health statistics.

Overarching issues

Even if national strategies for electronic health records successfully address issues relating to generating numerators and denominators, the penetration of electronic health records, data quality and completeness, consent, and unique patient identification, other overarching issues remain that may limit the utility of electronic health records for population health monitoring and research.

Population health and healthcare: Healthcare is only one of many influences on population health. Given the multitude and variety of influences on population health, data collected through electronic health records in healthcare settings may not adequately represent the full range of population health and the influences on it. In addition to electronic health records, population health monitoring and research may continue to require collection of data from other sources and through other mechanisms.

Structured data in electronic health records: Electronic health records will only be useful for population health monitoring and research if they contain or can yield structured data that can be coded, classified, and statistically analyzed.

Analysis: In order to cull needed data in the needed formats from the huge amount of data in electronic health records, public health practitioners will need new technologies and methodologies.

Cultural changes: Cultural changes will need to occur among public health practitioners, clinicians, and the public if electronic health records are to be used for population health monitoring and research.

Incentives for the adoption and use of electronic health records: Issues of providing and aligning incentives to clinicians for adopting and using electronic health records for the secondary uses of population health monitoring and research will be even more daunting than for the primary uses of clinical care.

Transformative limits of electronic health records

No single answer can be provided to questions about the potential contribution of national strategies for electronic health records for population health monitoring and research. Answers will depend upon at least four questions:

1. Does the particular data collection stream include reportable diseases and registries, administrative health data, or population-based surveys?
2. Are electronic health records envisioned as supplementing current data collection streams, or replacing current data collection streams, or as a data source for linkage with current data collection streams?
3. Do electronic health records meet current population health monitoring criteria for data quality and completeness?
4. Will population-based implementation of electronic health records lead to new population health monitoring criteria for data quality and completeness, different from those currently employed?

Success factors

A definitive analysis identifying the factors leading to the successful use of electronic health records for population health monitoring and research is not possible given the current status of national strategies for electronic health records. However, this report provides cautious speculation—intended to provoke discussion and debate—about factors maximizing the potential use of electronic health records for population health monitoring and research.

Enabling factors increase the likelihood of the successful use of electronic health records for population health monitoring and research.

Health system enabling factors include:

- greater funding of the healthcare system by the government;
- a low percentage of individuals without health insurance; a higher ratio of general practitioners to specialists; and
- greater central coordination of the health system.

Health information system enabling factors include:

- a closer relationship between the provision of health care information for clinical and administrative purposes from data sources and the conduct of population health monitoring;
- reduced fragmentation among population health monitoring data collections;
- clinician incentives for adopting and using electronic health records; and
- cultural changes among clinicians supporting the use of electronic health records for population health monitoring.

Threshold factors are factors without which the successful use of electronic health records for population health monitoring and research may fail.

A business threshold factor is the explicit inclusion of population health monitoring and research as integral components of the national strategy for electronic health records.

System threshold factors include mandates within the national strategy for electronic health records for:

- integrated electronic provision of data and integrated data flows from diverse healthcare sources for clinical, reimbursement, administrative, and population health monitoring purposes;
- use of structured data for electronic health records;
- the development of data standards jointly useful for clinical, reimbursement, administrative, and population health monitoring purposes;
- clear definitions of the data required to be collected for population health monitoring and clear rules for the derivation of those data from electronic health records; and
- some form of unique patient identification and the use of unique patient identification, encrypted or unencrypted, for all electronic provision of data.

Tipping factors maximize the potential for the successful use of electronic health records for population health monitoring and research. Tipping factors include:

- a form of reimbursement for physicians that could mandate the nature, contents, and use of electronic health records, such as salary-based reimbursement or other systems where physicians are required to follow established uniform recording protocols;
- mandated implementation of implementation of electronic health records with mandated standards; and
- confluence of strong governmental leadership of the healthcare sector and greater governmental coordination or control of the healthcare sector, which may be promoted through the existence of a predominant payer for healthcare or a predominantly single payer system.

Conclusions (see Chapter 7)

In 2006, it is still too early to ascertain the actual potential of national strategies for electronic health records for population health monitoring and research. With the exception of England, the development of national strategies remains in germinal stages. Even in England, implementation is in an early stage. An evidence base does not exist from which to judge how successfully national strategies for electronic health records can support population health monitoring and research. As indicated by the National Health Service Information Authority, ‘‘data needed to support secondary information purposes. . . should be derivable from data that is collected as part of the operational care process. . . However, critical aspects of this hypothesis remain operationally untested.’’[5]

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[5] NHS Information Authority, National Dataset Development Programme (2002 Sep). Emerging dataset issues: enabling the derivation of ‘‘business’’ information from electronic records. Draft 0.5 London (UK): NHS Information Authority: 3–4.

Table S.1. National strategies for electronic health records, by country: 2005

	Australia	Canada	England	New Zealand
Locus of national responsibilities	Health*Connect* (Department of Health and Ageing); National E-Health Transition Authority	Canada Health Infoway	National Health Service (NHS) Connecting for Health	New Zealand Health Information Service (Ministry of Health)
Stages*	Design	Design, with broad national target dates for implementation	Implementation, with specific national target dates	Conceptualization
Current status	– Initial national strategy published in 2004 – Local pilots implemented and evaluated – Locus of responsibility for national strategy evolving – Key elements of supporting national health information infrastructure being specified, including: interoperability framework, health record design, clinical terminologies, clinical information, healthcare identifier, and E-health consent	– Initial national strategy published in 2003, with updated strategy to be published in 2006 – Strategic investments in key elements of supporting national health information infrastructure, including: registries (client, provider, and location), interoperable electronic health record systems, infostructure, innovation and adoption, and public health surveillance	– National strategy iteratively developed since 1998 – Local pilots implemented and evaluated – Implementation of electronic patient records occurring regionally – Implementation of electronic health record occurring nationally	National strategy published in 2005
Patient identification	Under discussion and development, with possibility of adaptation of elements of national health insurance number	Under discussion and development, with emphasis on development of jurisdictional unique identifiers and inter-jurisdictional identifier	National Health Service number	National Health Index number
Patient confidentiality and consent	– Initial conceptualization of opt-in consent for participation in electronic health records – Consent options currently under reconsideration and in development	Support for "lockbox," enabling patients to "mask" information at their request	– "Sealed envelope," enabling patients to designate information not to be shared beyond their immediate clinician – Pseudo-anonymized and anonymized data can be shared for population health monitoring	Not ascertained from publicly available materials
Population health monitoring	– Initial conceptualization of National Data Store of electronic health records, enabling uses of largely de-identified data for population health monitoring – Does not appear as current priority secondary use	Investment in communicable disease surveillance as part of national strategy	Secondary Uses Service implemented, with emphasis on uses of electronic health records and other data streams for population health monitoring	Emphasis on national data collections

* Stages not intended to represent a continuum.

Highlights

Assessing the potential of National Strategies for Electronic Health Records for Population Health Monitoring and Research

January 2006

Why NCHS commissioned this study

Healthcare costs continue to increase. The media, the public, and health professionals now recognize that unnecessary morbidity, mortality, and healthcare costs resulting from adverse events and medical errors are serious problems. The U.S. and other developed nations are adopting health information technology as a tool for rationalizing complicated healthcare systems, improving the quality of patient care, moderating healthcare costs, and reducing the incidence of adverse events. Electronic health records constitute the core of health information technology. The U.S., Australia, Canada, England, and New Zealand are all developing national strategies for electronic health records, accompanied by substantial investments of public and private sector funds in implementing those strategies.

The Centers for Disease Control and Prevention's National Center Health Statistics commissioned this report to assess the potential contribution of national strategies for electronic health records for population health monitoring and research. The report focuses on those types of population health monitoring that generate health statistics for measuring the population's health, rather than those types of population health monitoring used to detect health events and diseases for the purposes of immediate public health interventions.

What this study did

This study:

1. Reviewed national strategies for electronic health records in Australia, Canada, England, and New Zealand, and especially the implications of those strategies for population health monitoring by producing health statistics and by encouraging research employing health statistics. The review relied on reports, presentations, Web pages, and articles, which were publicly available before January 2006. See Chapters 2 and 4.
2. Identified the potential contribution of national strategies for electronic health records for population health monitoring and research and barriers to achieving that potential. The identification of the potential contribution and barriers relied on interviews with 96 experts in U.S., Australia, Canada, England, and New Zealand. See Chapters 2, 5, and 6.
3. Delineated fundamental issues that must be confronted to maximize the contribution of national strategies for electronic health records to population health monitoring and research, and especially to health statistics. See Chapter 7.

This study did not explore issues relating to the potential of national strategies for electronic health records for health event and disease detection for the purposes of immediate public health interventions, such as case-based surveillance, syndromic surveillance, and bioterrorism surveillance.

What this study found

National strategies for electronic health records reflect the political, healthcare, and market systems of individual countries. National strategies for electronic health records also reflect both technical decisions and political judgments, which may change over time. National strategies are developing and evolving, and passing through stages of conceptualization, design, pilot testing, and implementation. Only England has moved to implementation.

Population health monitoring and research, and especially health statistics, are explicitly secondary to the primary uses of clinical care and management in all national strategies for electronic health records. Only England has conceptualized, designed, and is now implementing the use of electronic health records for population health monitoring and research. Canada's strategy does include communicable disease surveillance, but not broader population health monitoring for developing health statistics.

This study identifies definitional issues, numerator and denominator issues, and overarching issues that must be evaluated in assessing the potential of national strategies for electronic health records for population health monitoring and research. It also delineates success factors that increase the potential for those national strategies to contribute to population health monitoring and research, including threshold, enabling, and tipping factors. Finally, this study offers a sobering assessment of the barriers that must be overcome if national strategies for electronic health records can contribute to population health monitoring and research, and especially to health statistics.

Assessing the Potential of National Strategies for Electronic Health Records for Population Health Monitoring and Research

by Daniel J. Friedman, Ph.D., Population and Public Health Information Services

Abstract

Objectives

This report assesses the potential of national strategies for electronic health records for population health monitoring and research.

Methods

This study: 1. Reviewed national strategies for electronic health records in Australia, Canada, England, and New Zealand, through written materials available before January 2006. 2. Identified the potential of national strategies for electronic health records for population health monitoring and research through interviews with 96 experts in the U.S., Australia, Canada, England, and New Zealand. 3. Delineated fundamental issues that must be confronted to maximize the contribution of national strategies for electronic health records to population health monitoring and research.

Results

National strategies for electronic health records reflect the political, healthcare, and market systems of individual countries. National strategies also reflect technical decisions and political judgments. National strategies are evolving, and passing through stages of conceptualization, design, pilot testing, and implementation. Only England has moved to implementation.

Population health monitoring and research are secondary to the primary uses of clinical care and management in all national strategies for electronic health records. Only England has conceptualized, designed, and is implementing the use of electronic health records for population health monitoring and research. Canada's strategy includes communicable disease surveillance, but not broader population health monitoring for developing health statistics.

This study identifies definitional, numerator, denominator, and overarching issues that must be evaluated in assessing the potential of national strategies for electronic health records for population health monitoring and research. It delineates success factors that increase the potential for those national strategies to contribute to population health monitoring and research. Finally, this study assesses barriers that must be overcome if national strategies for electronic health records can contribute to population health monitoring and research, and especially to health statistics.

Keywords: *Electronic health records • population health • health statistics*

Chapter 1. Introduction

Initiated in October 2004, this project builds upon two previous reports that portray a new landscape for health statistics: *Shaping a Health Statistics Vision for the 21st Century: The Final Report,* a joint report developed by the National Committee on Vital and Health Statistics, the Centers for Disease Control and Prevention's National Center for Health Statistics, and the U.S. Department of Health and Human Services' Data Council (Friedman, Hunter, Parrish 2002); and *Information for Health: A Strategy for Building the National Health Information Infrastructure,* a report released by the National Committee on Vital and Health Statistics (2001). The two reports describe a more rational future for population-based health data collection and analysis in the U.S., distinguished by:

- increased integration of presently distinct data collections, especially those in which healthcare providers now respond to different but overlapping data collection mandates from a single state health agency;
- decreased burden on healthcare providers responding to data collections mandates from state and federal health agencies;
- multiple uses for collected data and ‘‘repurposing’’ of data integrated at the point of data collection; and
- greater utility and utilization of collected data for healthcare providers, health agencies, and other analysts and users.

Both reports describe general strategies for achieving that more rational future, revolving around conceptual and practical integration of health statistics into the developing U.S. national health information infrastructure (NHII). In related articles, Detmer (2003), Lumpkin and Deering (2005), and Lumpkin and Richards (2002) also conceptualized the potential relationship between health statistics and the national health information infrastructure.

Purpose

The purpose of this report is to assess the potential of national strategies for electronic health records for population health monitoring and research. The emphasis in this report is upon those types of population health monitoring typically used to develop health statistics, such as population-based registries, population-based surveys, and administrative health data, rather than those types of population

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health monitoring used to detect health events and diseases for the purposes of immediate public health interventions.

More specifically, this report has a fourfold purpose: first, to describe the current status of national strategies for electronic health records and their supporting national health information infrastructures in Australia, Canada, England, and New Zealand, especially as those national strategies relate to population health monitoring to produce health statistics and research employing health statistics; second, to summarize themes about the potential contributions, and barriers to those contributions, of national strategies for electronic health records for population health monitoring and research and barriers that emerged from key informant interviews with experts in the same four countries; third to summarize themes emerging from key informant interviews with U.S. experts; and fourth, to delineate major fundamental issues in the relationship between national strategies for electronic health records and population health and monitoring. This study did not explore issues relating to the potential of national strategies for electronic health records for health event and disease detection for the purposes of immediate public health interventions, such as case-based surveillance, syndromic surveillance, and bioterrorism surveillance.

Central Concepts

Central concepts utilized throughout this report are defined and discussed here. These include population health, population health monitoring, population health research, health statistics, electronic patient records, shared electronic health records, and national health information infrastructure. Especially important for understanding this report's discussions of developments in Australia, Canada, England, and New Zealand are the distinctions between electronic patient records and shared electronic health records described below. Additional definitions of terms and acronyms are provided in the Glossary.

Population health

Kindig and Stoddart define population health as ''the health outcomes of a group of individuals, including the distribution of such outcomes within the group'' (Kindig and Stoddart 2003, p. 381). Population health encompasses the level and distribution of disease, functional status, and well-being within a group (Parrish, Friedman, and Hunter 2005, 18). See Figure 1.1.

Population health monitoring

Population health monitoring can be defined as the collection and analysis of data to detect and describe changes in the population's health and influences on the population's health. See Figure 1.1. Population health monitoring can occur through either (a) intermittent but regularly scheduled primary collection of data (that is, data specifically collected for the purpose of population health monitoring) and the analysis of those data, or (b) ongoing primary collection data and their analysis, or (c) intermittent or ongoing secondary collection of data (that is, data not specifically collected for the purpose of population health monitoring) and their analysis. Primary collection of data for population health monitoring typically occurs through registries and mandated reports of diseases and population-based surveys (Koo, Wingo, and Rothwell 2005; Madans and Cohen 2005). Secondary collection of data for population health monitoring typically occurs from administrative health data and nonhealth data sources (Bailey et al. 2005; Iezzoni, Schwartz, and Ash 2005).

Population health research

Population health research is research on population health or those factors that affect population health.

Numerator

A numerator is ''the upper portion of a fraction, used to calculate a rate or a ratio'' (Last et al., 126). Numerators represent the aspect of the population's health being measured, such as a health event, disease, condition, functional status, or well-being.

Denominator

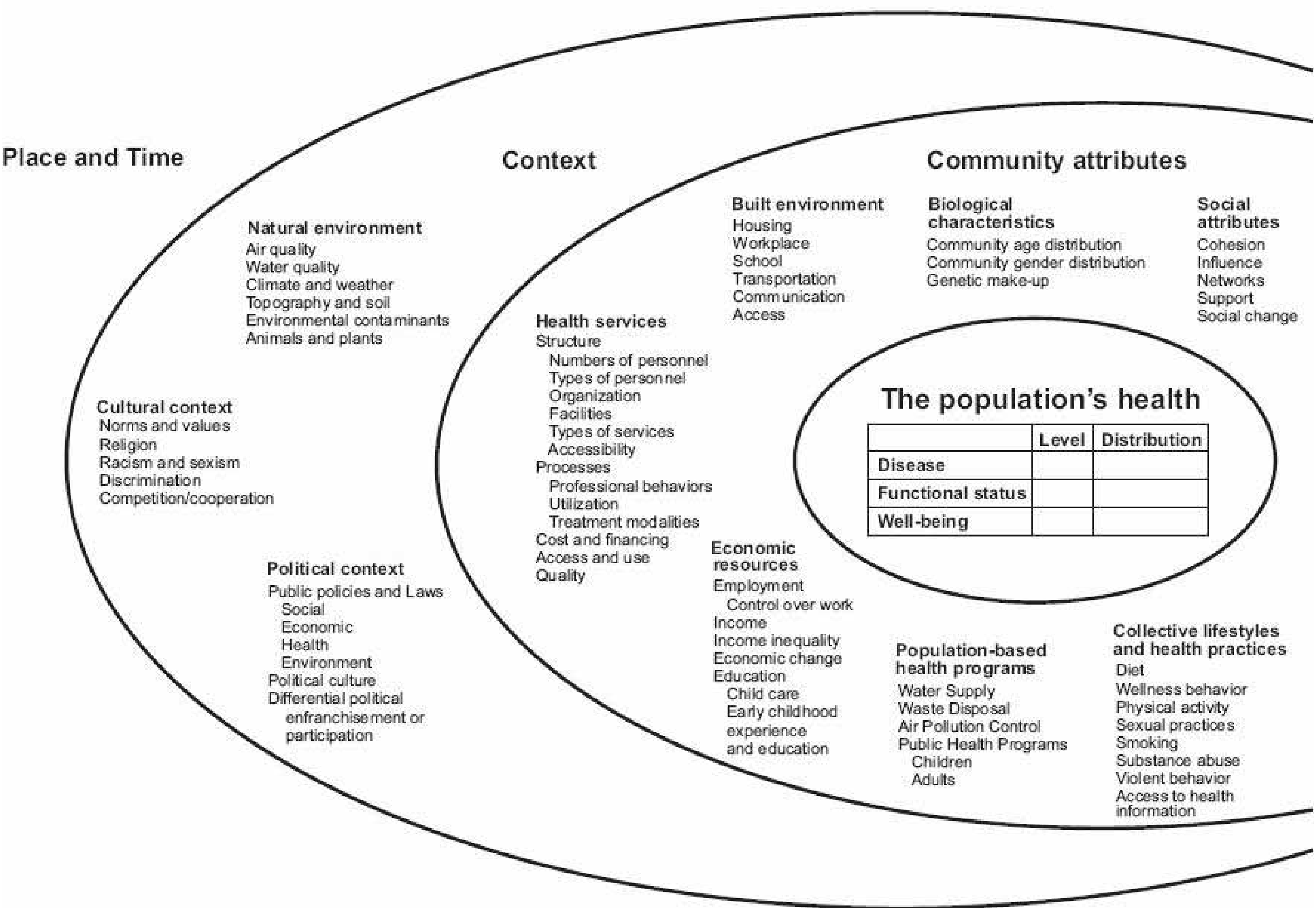
A denominator is ''the lower portion of a fraction used to calculate a rate or ratio. The population. . . at risk in the calculation of a rate or ratio'' (Last et al., 49). Denominators represent the population in which the particular aspect of population health is being measured.

Health statistics

Health statistics are defined as ''numerical data that characterize the health of a population and the influences that affect its health'' (Parrish, Friedman, and Hunter 2005, 3). Health statistics are generated through population health monitoring, and are employed for conducting population health research. The types of population health monitoring that typically generate health statistics are reportable diseases and registries, administrative health data, and population-based surveys, as well as nonhealth data sources (Bailey et al. 2005; Iezzoni, Shwartz, and Ash 2005, 139–160; Koo, Wingo, and Rothwell 2005, 81–118; Madans and Cohen 2005, 119–138). This report focuses largely on those types of population health monitoring that generate health statistics.

Population-based health statistics require both a known numerator and a known denominator. In order to characterize the health of a population through health statistics, three necessary conditions relating to numerators and denominators must be met. First, numerator data must exist about a health event, condition, disease, functional health status, well-being, or an influence on population health. Second, denominator data must exist that describe the population in terms of its size, its geographic location, and its basic demographic characteristics. Third and finally, a match must exist between the numerator and the denominator; in other words, the numerator must be drawn from the population denominator.

Figure 1.1. Influences on the population's health



SOURCE: Parrish RG, Friedman DJ, Hunter EL (2005). Defining health statistics and their scope. In: Friedman DJ, Hunter EL, Parrish RG (editors), Health Statistics: Shaping Policy and Practice to Improve the Population's Health. New York: Oxford University Press; 18.

Electronic patient records (EPRs)

This report adopts the definition of electronic patient records used by the United Kingdom's National Health Service in its *Information for Health:* the "'Electronic Patient Record' describes the record of the periodic care provided mainly by one institution" (NHS Executive 1998 Sep, 25). In other words, as used here in contrast to the shared electronic health record described immediately below, the electronic patient record is the desktop record utilized by the clinician in providing, managing, and recording care for individual patients. Also in contrast to the shared electronic health record (defined below), the electronic patient records can be specific to an individual healthcare provider or an individual healthcare provider site, or it can be shared or interoperable across providers and provider sites. As described by the Institute of Medicine, by the National Health Service, and by numerous other sources, the electronic patient record can include a wide range of functionalities in support of the direct provision of care (Brennan 2005, 67–70; Institute of Medicine 2003, 7–12).

Electronic health records (EHRs)

For the purposes of this report, electronic health records are defined as an electronic repository of patient-centric data that are identifiable, longitudinal and preferably life-long, cross-provider, cross-provider site, and cross the spectrum of healthcare, including primary care, acute hospital care, long-term care, and home care. The definition of electronic health record used in this report assumes that they are interoperable and capable of being shared across healthcare providers and provider sites.[1] This report deals principally with national strategies for electronic health records and supporting national health infrastructures (defined below).

This report seeks to synthesize the perspectives of almost one hundred experts in five countries. As the report describes, the definition of electronic health records differs across these countries. In extracting common themes

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[1] "In healthcare, interoperability is the ability of different information technology systems and software applications to communicate, to exchange data accurately, effectively, and consistently, and to use the information that has been exchanged" (National Alliance for Health Information Technology [hp]).

across countries from interviews with those informants and in identifying fundamental factors across countries enabling the use of electronic health records for population health monitoring and research, this report will use a definition of electronic health records used throughout this report is similar to the definition posited by the International Standards Organization Technical Committee 215 in its ''Health Informatics—Electronic health record—definition, scope, and context'', in which it the electronic health record for integrated care (ICEHR) is described as ''a repository of information regarding the health status of a subject of care in computer processable form, stored and transmitted securely, and accessible by multiple authorised users. It has a standardized or commonly agreed logical information model which is independent of EHR systems. Its primary purpose is the support of continuing, efficient and quality integrated healthcare and it contains information which is retrospective, concurrent, and prospective'' (ISO TC 215/WG 1 2004 Jul 29; Schloeffel 2004). The definition is also similar to that posited by the United Kingdom's National Health Service in *Information for Health:* the EHR ''is used to describe the concept of a longitudinal record of patient's health and healthcare—from cradle to grave. It combines both the information about patient contacts with primary healthcare as well as subsets of information associated with the outcomes of periodic care held in the EPRs'' (NHS Executive 1998 Sep, 25; see also Brennan 2005, 81–3).

The definition of electronic health records employed in this report does not necessarily include the actual desktop electronic record used by clinicians for direct care functions such as care management, clinical decision support, and operations management and communication (DeVault, Fischetti, Spears 2005 Nov, 8). As such, the definition of electronic health records used in this report differs from some other definitions of electronic health records, such as those of the Institute of Medicine in its ''Key capabilities of an electronic health record system'', by the Office of the National Coordinator for Health Information Technology in its ''The Decade of Health Information Technology: Delivering Consumer-centric and Information-rich Healthcare'', and by Amatayakul in her *Electronic Health Records: A Practical Guide for Professionals and Organizations* (Amatayakul 2004, 1–4; Institute of Medicine 2003, 7–12; Thompson and Brailer 2004 Jul 21, 37).

It is essential to realize that ''there is as yet no one internationally accepted definition of the electronic health record'' or the electronic patient record (Standards Australia 2005, v, 4). Many different terms describing systematic electronic record keeping for patient information have been used at different times and in different countries by different authors and different organizations (Brailer 2003 Oct, 7; DeVault, Fischetti, Spears 2005, 4; Schloeffel 2004 Sep 1). Some definitions are broad and general (for example, see: Canadian Institute for Health Information [hp] Partnership for Health Information Standards, Glossary of Terms; CEN/TC 251; Wyatt and Liu 2002). Other definitions include detailed functionalities (for example, see: DeVault, Fischetti, Spears 2005). When comparing definitions of electronic patient records and electronic health records, it is essential to focus on the attributes described in the particular definitions rather than assuming that commonalities exist between definitions of electronic patient records or electronic health records from different sources (National Committee on Vital and Health Statistics 2005 Sep 9).

National health information infrastructure (NHII)

In Information for Health: A Strategy for Building the National Health Information Infrastructure, the National Committee on Vital and Health Statistics (NCVHS) described ''the heart of the vision for the NHII . . . [as] sharing information and knowledge appropriately so it is available to people when they need it to make the best possible health decisions'' (National Committee on Vital and Health Statistics 2001, 1). According to the NCVHS, ''the NHII includes not just technologies but, more importantly, values, practices, relationships, laws, standards, systems, and applications that support all facets of individual health, healthcare, and public health. It encompasses tools such as clinical practice guidelines, educational resources for the public and health professionals, geographic information systems, health statistics at all levels of government, and many forms of communication among users'' (National Committee on Vital and Health Statistics 2001, 1). As initially conceptualized by the NCVHS, the national health information infrastructure includes three main dimensions: the healthcare provider, population health, and personal health dimensions (National Committee on Vital and Health Statistics 2001, 14–16). These dimensions can also be seen as different ''views.'' The three dimensions can be extended and re-conceptualized to include others dimensions or views, such as research, public health, healthcare delivery, and personal health management (Detmer 2003).

This report uses a narrower, component-based definition of national health information infrastructures, focusing on electronic health records, often built upon electronic patient records, and shared through interoperability, electronic connectivity, common standards for coding and classification, nomenclature, and messaging. Paraphrasing the NCVHS, a national health information infrastructure, as defined for the purposes of this report, refers to the technologies, relationships, laws, standards, systems, and applications that support the development, implementation, and dissemination of electronic health records.

Chapter 2. Methods

The potential of national strategies for electronic health records for population health monitoring and research has been explored through two mechanisms: environmental scans of related developments in Australia, Canada, England, New Zealand, and the U.S.; and interviews with experts in each of these countries. Australia, Canada, England, and New Zealand were chosen as a convenience sample for several reasons: the four countries represent a range of national strategies for electronic health records; their national strategies are at different stages of implementation; the healthcare systems of the four countries differ from that of the U. S., yet some comparable aspects exist; and the environmental scans and interviews for this study could be conducted in English.

Environmental Scan of Related Developments

The environmental scan encompassed review of documents and other materials relevant to national strategies for electronic health records that were publicly available before January 2006, including World Wide Web sites, presentations, reports, and articles in peer-reviewed and trade journals. The review used four strategies:

1. *Structured search of the World Wide Web to identify relevant materials.* Fixed search criteria were employed to search for Web sites, government reports, presentations, and articles relevant to each country. The same fixed search criteria and algorithms were used for each country of the four countries. The structured search criteria and algorithms are described in Appendix 1.
2. *Directed search of the World Wide Web.* Additional follow-up Web searches were conducted for each country. Key Web sites were identified for each country, including national government, provincial and state government, and quasi-governmental organization sites, and then thoroughly searched.
3. *Structured literature reviews.* The same search algorithms as used in the Web structured search were also used to identify published scientific literature through PubMed.
4. *Directed literature reviews.* Tables of contents for selected peer-reviewed and trade journals were reviewed since 2000 (or since the first year of journal publication, if the first year of publication was later than 2000). See Appendix 2 for a list of these journals. Additional follow-up searches were also conducted to obtain individual articles in other journals.

Review of publicly available reports, presentations, and articles pertinent to national strategies for electronic health records may provide incomplete or only partially accurate information, especially relating to secondary uses of electronic health records such as population health monitoring and research. National strategies for electronic health records vary widely in their development and their articulation. Information about some issues—and especially issues relating to population health monitoring and research—may be sparse or absent. National strategies for electronic health records are relatively recent. Some national strategies for electronic health records are germinal, and all national strategies are still evolving. The author has attempted to explore thoroughly publicly available materials.

Expert Interviews

Key informant interviews were conducted with experts knowledgeable about national strategies for electronic health records or population health monitoring and research in each country. The basic purpose of the interviews was twofold: first, to identify the current status of the relationship between each nation's strategies for electronic health records and population health monitoring and research; and second, to identify the potential future contribution of each nation's national strategies for electronic health records to population health monitoring and research.

All interviews were conducted through scheduled telephone conversations, which ranged from 30–90 minutes. Each interview was preceded by at least one introductory e-mail letter introducing the purpose of the project and the nature of the interview, and sometimes also preceded by an introductory telephone call. Following each interview, follow-up e-mail exchanges typically occurred in order to clarify points made during the interview and to obtain additional information.

Interviews were informal and not for attribution to an identified expert. The contents of each interview were tailored to the specific professional roles of each respondent. Interview guides were employed for all interviews. Appendix 3 provides an example of a typical interview guide.

Telephone interviews were conducted with sixteen experts in Australia, eighteen in Canada, twenty in England, eleven in New Zealand, and thirty-one in the United States, for a total of ninety-six interviews in the five countries. Table 2.1 summarizes the number of completed interviews and the number of interview requests for each country. Interviews were conducted with experts responsible for population health monitoring at national and sub-national levels; experts responsible for national strategies for electronic health records and implementation of those strategies at national and sub-national levels; university-based population health researchers; and other experts, including primary care physicians with management responsibilities and particular interests in electronic health records. Table 2.2 summarizes the numbers and types of respondents by country. Appendices 4A–4E list, by country, all experts interviewed, their positions, and their affiliations.

Table 2.1. Requested and completed key informant interviews, by country

Key informant interviews	Australia	Canada	England	New Zealand	United States	Total
Interview requests	19	18	28	18	35	118
Interview completions	16	18	20	11	31	96

Table 2.2. Types of key informants, by country

Type of respondent	Australia	Canada	England	New Zealand	United States	Total
National						
Population health monitoring	8	6	2	3	4	23
Shared electronic health records	2	2	2	2	8	16
Subnational						
Population health monitoring	4	3	4		2	13
Shared electronic health records		3	3	1	12	19
Clinical				2		2
University	1	4	9	3	2	19
Other	1				3	4
Total	**16**	**18**	**20**	**11**	**31**	**96**

Chapter 3. Factors Impacting on National Strategies for Electronic Health Records

The development of national strategies for electronic health records and their relationships to population health monitoring and research must be viewed within the larger context of national health systems, including national population health status; health expenditures; and health system context, structure, processes, and performance. This chapter provides context for later chapters of this report discussing the potential contribution of national strategies for electronic health records to population health monitoring and research, through a quick overview of population health status, health expenditures, health systems, and public opinion relating to the health system and the use of personal health information in Australia, Canada, New Zealand, the United Kingdom (U.K.), and the U.S.

Population Health Status

The development of national strategies for electronic health records is affected by available resources and health system priorities, which are, in turn, affected by both population health status and health expenditures. Among the five countries investigated, population size varies greatly, from less than 4 million in New Zealand to almost 300 million in the U.S. See Table 3.1. Population health status, as measured by life expectancy at birth and infant mortality, is relatively similar in the five countries. Australia and Canada have the highest life expectancy at birth and Australia has the lowest infant mortality rates. The U.S. ranks last among the five nations in life expectancy at birth and infant mortality rate.

Health Expenditures[2]

Substantial differences exist between the U.S. and the investigated nations in health expenditures. See Table 3.2. U.S. expenditures on health as a percentage of gross domestic product in 2002 (14.6%) ranked highest, almost twice as high as the U.K. (7.7%), and substantially higher than Australia (9.5%), Canada (9.6%), and New Zealand (8.5%). Similarly, general government expenditures on health as a percentage of total government expenditures were almost fifty percent higher in the U.S. (23.1%) than in any of the four countries (range from 15.5% to 171%). However, general government expenditures as a percentage of total expenditures on health in the U.S. (44.9%) were substantially lower than in the U.K. (83.4%), New Zealand (77.9%), Canada (69.9%), and Australia (67.9%). Conversely, private expenditures account for a much higher share of total expenditures on health in the U.S. (55.1%) than in the U.K. (16.6%), New Zealand (22.1%), Australia (32.1%), and Canada (30.1%).

Health Systems

Australia, Canada, New Zealand, the U.K., and the U.S. have contrasting health system contexts, structures, and process and performance. Selected examples of these contrasts especially relevant to NHIIs and their relationships to population health monitoring and research are presented here, with additional details provided in Tables 3.3, 3.4, and 3.5.

Universal health insurance is firmly established in four of the nations, with the U.S. constituting the sole exception. Similarly, healthcare is perceived as a public good and as a right in the same four countries. See Table 3.3. Healthcare in Australia, Canada, New Zealand and the U.K. is financed primarily through taxes, as opposed to the U.S.'s mixed private/public financing with employer-based insurance playing a major role. Greater centralized control of healthcare also exists in these four countries, with some control devolving to Australian states, Canadian provinces, and New Zealand District Health Boards. Hospitals in these four countries are primarily public, unlike in the U.S. In each of these four countries, the ratio of general practitioners to specialists is approximately even (ranging from 51:49 in Canada to 60:40 in the U.K.), with the U.S. again standing as an exception with a general practitioner to specialist ratio of 30:70. See Table 3.4. Consistent with the greater centralized control of healthcare in Australia, Canada, New Zealand, and the U.K., these nations also allocate healthcare resources at macro-levels in the public sector. See Table 3.5. In Australia, state-level allocation of hospital resources occurs; in Canada, global budgets and price controls are imposed at the provincial level, with authority delegated down to Regional Health Authorities within provinces; in New Zealand, population-based global budgets are established for District Health Boards; and in the U.K., and in the U.K., population-based global budgets are set centrally by the NHS, and allocated through regional and district health authorities to local Primary Care Trusts and NHS Hospital Trusts.

Public Opinion

The Commonwealth Fund's International Health Policy Survey provides informative data relating to public opinion about health systems in Australia, Canada, New Zealand, the U.K. and the U.S. (Kaiser Family Foundation 2004; Schoen and Osborn 2004; Schoen, Osborn, and Huyna et al., 2004). Of the surveyed countries, U.S. respondents were most likely to say that their national healthcare system needs to be rebuilt completely (33%), more than twice the percentage in Canada and the U.K. (See Table 3.6.) U.S. respondents were least likely to report having a regular doctor or place of care, also

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[2] For definitions, original data sources, and methodology for gross domestic product, general government expenditures on health, total government expenditures, private expenditures on health, and total expenditures on health, see: World Health Organization (2005). World Health Report 2005. Geneva: World Health Organization. Statistical Annex Explanatory Notes, pp. 159–164. Available from: http://www.who.int/whr/2005/10_annexes_notes_en.pdf [cited 2006 Jan3].

least likely having a regular doctor or place of care for more than five years. Reflecting the health expenditures data reported earlier, 26% of U.S. respondents indicated out-of-pocket medical expenses of more than U.S. $1,000 in the past year, compared to a range from 4% (U.K.) to 14% (Australia) for the other investigated countries.

The Commonwealth Fund survey also provides data relating to medical records and health information. When asked if they wanted information on physician quality of care when seeing a new doctor, 56% of U.S. respondents said "yes," a much higher percentage than in the other four countries (range from 40% in Canada to 18% in the U.K.). A higher percentage of U.S. respondents indicated that they currently have access to their own medical records (51%), compared to the other four countries (range from 45% in New Zealand to 28% in the U.K.). A higher percentage of U.S. respondents also said that test results or records were not available at the time of a medical appointment and that a doctor ordered tests that had already been done. Finally, New Zealand and U.S. respondents were more likely than respondents in the other three countries to say that they currently can e-mail their doctor.

Table 3.1. Population health status, by country[1]

Country	Total population (000)[2]	Life expectancy at birth[2] (years)	Infant mortality[2,3] (per 1,000 live births)
Australia	19,731	81	4.8
Canada	31,510	80	[4]5.4
New Zealand	3,875	79	[5]5.6
United Kingdom	59,251	79	5.3
United States	294,043	78	[4]7.0

[1] Data source: World Health Organization (2005). World Health Report 2005. Geneva: World Health Organization, Statistical Annex Table 1, pages 175–180. Available from: http://www.who.int/whr/2005/annexes-en.pdf [cited 2005 Sep 12].

[2] Data year 2003.

[3] Organisation for Economic Cooperation and Development (2005) [hp]. OECD Health Data 2005. Frequently Requested Data. Geneva: Organisation for Economic Cooperation and Development. Available from: http://www.oecd.org/document/16/0,2340,en_2825_495642_2085200_1_1_1_1,00.html [cited 2005 Sep 12].

[4] Data year 2002.

[5] Data year 2001.

Table 3.2. Health expenditures, by country

Country	Total expenditures on health as percentage of GDP[1,2]	General government expenditures on health as percentage of total government expenditures[1,2]	Private expenditures as percentage of total expenditures on health[1,2]	General government expenditures on health as percentage of total expenditures on health[1,2]
Australia	9.5	17.1	32.1	67.9
Canada	9.6	15.9	30.1	69.9
New Zealand	8.5	15.5	22.1	77.9
United Kingdom	7.7	15.8	16.6	83.4
United States	14.6	23.1	55.1	44.9

[1] Data source: World Health Organization (2005). World Health Report 2005 Geneva: World Health Organization. Statistical Annex Table 5, pages 193–199. Available from: http://www.who.int/whr/2005/annexes-en.pdf [cited 2005 Sep 12].

[2] Data year 2002.

Table 3.3. Health system context, by country[1]

Dimension	Australia	Canada	New Zealand	United Kingdom	United States
Historical	– Universal insurance dating to 1946, PBS to 1948 – Medicare introduced in 1984 with public/private mix	– Universal insurance dating to provincial plans in 1940s – Hospital insurance (1957), medical insurance (1968), leading to Medicare (1971), strengthened in 1984	– Universal insurance, with roots dating to the 1930s	– Social insurance dating from 1911, with universal coverage since 1948	– Private insurance since 1930s – Limited social insurance, Medicare and Medicaid since 1965
Economic	– Capitalist system – Health care perceived as a public good	– Capitalist system with social responsibility – Health care perceived as a social/public good	– Capitalist system, heavily deregulated – Health care perceived as a public good	– Capitalist system – Health care perceived as a public good	– Capitalist system – Health care perceived as a private good
Political	– Health care highly visible as a political issue	– Health care highly visible as a political issue	– Health care visible as a political issue, but with some bipartisan agreement	– Health care viewed as a political issue – NHS viewed as public institution	– Usually a secondary issue in national elections, although it occasionally emerges as one of several leading issues
Sociocultural	– Paternalistic attitude of federal government towards health – Trustful of government serving the public interest	– Long-standing emphasis on collectivism and social responsibility – Trustful of government serving the public interest	– Long-standing emphasis on collectivism and social solidarity, but with growing individualism and acceptance of inequality – Trustful of government and public institutions	– Long-standing emphasis on state paternalism – Trustful of government serving the public interest	– Long-standing emphasis on individualism and self-reliance – Trustful of democratic institutions, but distrustful of governmental bureaucracy managing social programs
Ethical	– Health care viewed as a right – Utilitarian view prevails	– Health care viewed as a right – Utilitarian view prevails	– Health care viewed as a right – Utilitarian view prevails	– Health care viewed as a right – Utilitarian view prevails	– Health care viewed as an entitlement right for elderly; as an eligibility-based right for disabled and medically indigent; and as a financially-based privilege for remaining population – Libertarian view generally prevails

[1] Data source: Cohen AB (2005). Comparative health care systems: frameworks for analysis. Boston (MA): Boston University Health Policy Institute.

Table 3.4. Health system structure, by country[1]

Dimension	Australia	Canada	New Zealand	United Kingdom	United States
Financing and payment	– Mixed public (67%) and private (33%) financing – Public—tax-financed through Medicare levy on income – Private—15% insurance, 18% self pay – Uniform payment methods: public hospitals-budgets from federal and state governments; PBS-federal government; MDs—FFS – Centralized control, experimenting with case mix	– Tax-financed system – Private insurance is supplemental only – Uniform payment methods: MDs-negotiated FFS, some capitation; hospitals-global budgets – Centralized provincial control with federal oversight, together with decentralization and regionalization in most provinces	– Mixed public (78%) and private (22%) financing – Public-tax financed, with revenue collected through general taxation – Fairly uniform payment methods, with providers receiving capitated payment (population-based formula) from District Health Boards – Centralized control	– Tax-financed system (85% general tax revenues, 13% insurance payroll tax, 2% user fees) – Uniform payment methods: hospital-based MDs-salary, FFS; GPs-capitation, FFS, salary; NHS self-governing trusts-budgets based on contracted fees and DRG payments – Centralized control, but shifting as an internal market expands to include Primary Care Trusts	– Dominant model is employer-financed health insurance – Selected defined population groups covered by public programs (such as medically indigent and elderly) – Mixed private and public financing – Multiple payment methods – Decentralized control
Hospitals	– 70% public, 30% private	– 95% non-profit, 5% private	– 52% public, 48% private		– Diverse public and private, non-profit and for-profit
Practitioners	– Generalists > specialists (55/45) – Generalists are gatekeepers	– Generalists > specialist (51/49)	– Generalists > specialists (60/40)	– Generalists > specialists (60/40) – Generalists are gatekeepers	– Specialists > generalists (70/30) – Group practices increasing, solo practices decreasing

[1] Data source: Cohen AB (2005). Comparative health care systems: frameworks for analysis. Boston (MA): Boston University Health Policy Institute.

Table 3.5. Health system process and performance, by country[1,2]

Dimension	Australia	Canada	New Zealand	United Kingdom	United States
Governmental regulation	– Macro-level controls on state and territorial budgets, system capacity	– Macro-level controls on provincial budgets, hospital budgets, technology	– Macro-level controls on capitated District Health Board budgets and payments to providers	– Macro-level controls on capitated RHA budgets, DHA budgets, PCT budgets, system capacity	– Micro-level controls on financing and payment, utilization, technology, professional licensure
Resource allocation and monitoring	– Macro-level resource allocation in public sector – Micro-level resource allocation in private sector – 5-year service agreements emphasize measurement of service outputs and outcomes	– Macro-level provincial resource allocation, with global budgets and price controls, now sub-provincial regionalized decision-making – Less intensive monitoring of clinical practices and service utilization than in U.S.	– Macro-level resource allocation in public sector, with adjustments to address imbalances in population-based budgets – Less intensive monitoring of clinical practices and service use than in U.S.	– Macro-level resource allocation, with population-based global budgets for RHAs, DHAs, PCTs, NHS trusts – Clinical standards and performance measures on rise	– Micro-level resource allocation – Monitoring of practices, service use, costs
Health insurance	– Universal insurance	– Universal insurance, with benefits varying by province	– Universal insurance	– Universal coverage	– 15% uninsured
Cost containment	– Good experience since 1984	– Good experience	– Good experience	– Good experience with global budgets – Market reforms intended to improve efficiency	– Poor overall experience with various strategies
Efficiency	– Strong emphasis on technical efficiency – Administrative efficiency better than U.S.	– Technical efficiency as good as U.S. – Administrative efficiency better than U.S.	– Technical efficiency relatively high – Administrative efficiency better than U.S.	– Strong emphasis on technical efficiency – Administrative efficiency better than US.	– Technical efficiency hampered by financial incentives, service

[1] Data source: Cohen AB (2005). Comparative health care systems: frameworks for analysis. Boston (MA): Boston University Health Policy Institute.

[2] Macro-level refers to national or high level controls. Micro-level refers to institutional controls.

Table 3.6. Public opinion about health system, by country: 2004[1]

Dimension	Australia	Canada	New Zealand	United Kingdom	United States
Views of the health care system—percentage responded “rebuild completely”	23%	14%	19%	13%	33%
Length of time with regular doctor or place of care—percentage with regular doctor/place of care	94%	95%	97%	99%	91%
Length of time with regular doctor or place of care for more than 5 years—percentage	50%	53%	56%	63%	37%
Out-of-pocket medical expenses in last year—percentage with more than $1,000 U.S.	14%	12%	5%	4%	26%
Wanted information on quality of care doctor provides when had to see a new doctor—percentage responding “yes”	28%	40%	24%	18%	56%
Access to own medical records—percentage currently having access	40%	34%	45%	28%	51%
Currently can e-mail doctor—percentage responded “yes” of those having regular doctor or place of care	16%	10%	22%	13%	20%
Test results or records not available at time of doctor appointment—percent responded “yes” of those who have seen a doctor within past 2 years	12%	14%	13%	13%	17%
Doctor ordered tests that had already been done—percentage responded “yes” of those who have seen doctor within past 2 years	7%	6%	7%	4%	14%

[1] Data source: Schoen C, Osborn R (2004). The Commonwealth Fund 2004 international health policy survey of primary care in five countries. New York: Commonwealth Fund. Available from: http://www.cmwf.org/usr_doc/ihp_2004_survey_charts.pdf [cited 2005 Sep 12].

Chapter 4. Nation Snapshots: Australia, Canada, England, and New Zealand

This chapter provides nation-specific overviews of national strategies for electronic health records (EHR) and their supporting national health information infrastructures (NHII), and how those national strategies relate to population health monitoring and research, for Australia, Canada, England, and New Zealand. The chapter is based upon review of publicly available materials published in 2005 or earlier. For each nation, the discussion includes the national strategy for electronic health records, the locus of national responsibilities, current status and plans, the electronic health records definition, national health information infrastructure elements related to electronic health records, electronic health records storage, patient confidentiality and participation, patient identification, and uses for population health monitoring and research. The chapter includes a comparative table describing the current status of national health information infrastructures as they relate to population health monitoring and research for the four countries (see Table 4.1).

England

Summary

Of the four countries investigated here, England has the most thoroughly articulated and fully developed national strategy for electronic health records, the supporting national health information infrastructure, and plans for utilizing electronic health records for population health monitoring and research. Consequently, the overview of England is presented first in this chapter, and can serve as a comparison point for the later overviews of Australia, Canada, and New Zealand.

England's articulation of a national strategy for electronic health records started with the publication of *Information for Health: An Information Strategy for the Modern NHS 1998–2005, A National Strategy for Local Implementation* in 1998, and has continued since then through a series of reports, pilots and accompanying evaluations, and implementations (NHS Executive 1998 Sep). NHS Connecting for Health is the national information technology agency responsible for delivering the National Programme for Information Technology within NHS England (NHS Connecting for Health 2005, 9). NHS Connecting for Health is now deploying the NHS Care Record Service, with electronic patient records (Patient Clinical Records) implemented through local clusters and a common national electronic health record (National Summary Record). The Secondary Uses Service, managed by NHS Connecting for Health and the NHS Health and Social Care Information Centre, will transform electronic health records and other data for population health monitoring and research and additional secondary purposes.

Locus of national responsibilities

Connecting for Health is the executive agency within the National Health Service (NHS) responsible for developing and implementing the English national health information infrastructure and electronic health record agenda (E-Health Insider 2005 Mar 22). Connecting for Health was established as a new NHS executive agency following the closure of the NHS Information Authority (NHSIA) in March 2005. The National Health Service Information Authority was created in 1998, with responsibility for the National Programme for Information Technology (NPf IT) (NHS Executive 1998 Sep, 89; NHS National Programme for Information Technology 2004 August, 1).

Current status and plans

The current status of and plans for electronic health records and the supporting national health information infrastructure in England should be viewed within the context of three related developments: first, governmental modernization within the United Kingdom; second, reform of the National Health Service; and third, public pressures on the NHS.

Modernising Government, a report presented to Parliament by Prime Minister Tony Blair in 1999, stressed the need for ‘‘information age government’’, leading to more responsive public services (Prime Minister 1999 Mar, 7, 13). Information age government would ‘‘move from counting what goes in, to assessing what is being delivered’’ and would ‘‘use the right information at the right level (Prime Minister 1999 Mar, 37).

The movement to reform the National Health Service was articulated in *The new NHS,* a 1997 report which pointed to ‘‘a third way of running the NHS—a system based on partnership and driven by performance’’ (Department of Health 1997 Dec, Chapter 2). The new NHS would set measurable targets for annual improvement in local services, and would hold newly constituted Primary Care Groups accountable for meeting those targets (Department of Health 1997 Dec, Chapter 4). These themes were expanded upon in *A First Class Service: Quality in the new NHS,* a 1998 report which emphasized the need to reduce unacceptable local variations in clinical practice in the NHS through national standards enforced through consistent monitoring (Department of Health 1998 Jul). National Service Frameworks would ‘‘set national standards and define service models for a specific service or care group’’ and ‘‘establish performance measures against which progress within an agreed upon timescale will be measured’’ (Department of Health 1998 Jul, 2.34). A National Framework for Assessing Performance was instituted, which would measure overall NHS performance in health improvement, fair access, effective delivery of healthcare, efficiency, patient experience, and health outcomes of NHS care (Department of Health 1998 Jul, 2.27, 2.28).

A third development setting the context for electronic health records in England was public pressures on the National Health Service. Three highly visible critical reports were released between 2001 and 2003, which highlighted NHS shortcomings and pointed the way to information technology-related reforms. *Learning from Bristol: The Report of the Public Inquiry into Children's Heart Surgery at the Bristol Royal Infirmary, 1984–1995* (''Kennedy report'') was published in 2001, with two important conclusions for electronic health records and the associated national health information infrastructure (Department of Health 2001 Jul). First, the Kennedy report found that ''the clinicians in Bristol had no one to satisfy but themselves that the service which they provided was of appropriate quality. There was no systematic mechanism for monitoring the clinical performance of healthcare professionals or of hospitals'' (Department of Health 2001 Jul, 3). Second, the Kennedy report also stressed that ''the current 'dual' system of collecting data in the NHS in separate administrative and multiple clinical systems is wasteful and anachronistic. A single approach to collecting data should be adopted, which clinicians can trust and from which information about both clinical and administrative performance can be derived'' (Department of Health 2001 Jul, 455). *Securing our Future Health: Taking a Long-Term View* (''Wanless report'') was issued in 2002, pointing to the ''particularly poor ICT [information and communications technology] investment record of the UK health service'' (Wanless 2002 Apr, 55). The Wanless report emphasized that ''stringent [information and communications technology] standards should be set from the [NHS] centre to ensure that systems across the UK are fully compatible with each other'' (Wanless 2002 Apr, 121). Wanless described three alternative scenarios for the NHS in 2022, with ''the difference between the *solid* [mid-level] *progress* and *fully* [highest level] *engaged* scenarios. . . [being] a dramatic improvement in public engagement, driven by widespread access to information'' (Wanless 2002 Apr, 39). The fully engaged scenario was characterized as follows:

> ''Modern and integrated information and communication technology is being used to full effect, joining up all levels of health and social care and in doing so delivering significant gains in efficiency. Repetitive requests for information are a thing of the past as healthcare professional can readily access a patient's details through their Electronic Health Record'' (Wanless 2002, 15).

Finally, in his widely-publicized inquiry into the death of a young girl from child abuse, Lord Laming concluded that ''information systems that depend on the random passing of slips of paper have no place in modern services. Each agency must accept responsibility for making sure that information passed to another agency is clear'' (Lord Laming 2003 Jan, 10).

Simultaneously with the above developments, the National Health Service expanded and further specified its strategy for electronic health records and the supporting national health information infrastructure as an integral part of governmental modernization and NHS reform. Reducing unacceptable variations in local NHS practice, becoming more patient-centric, setting and monitoring performance targets across the NHS, and providing more integrated (''joined-up'') NHS services were seen as largely depending upon the development and implementation of electronic health records.

Information for Health: An Information Strategy for the Modern NHS 1998–2005, A National Strategy for Local Implementation, released in 1998, laid out a strategy for meeting distinct information needs for patients, healthcare professionals, managers and planners, and the public (NHS Executive 1998 Sep, 16). Principles for the new strategy included person-based information, integrated systems, ''management information derived from operational systems'', and information-sharing across the NHS (NHS Executive 1998 Sep, 15). The creation of ''lifelong electronic health records for every person in the country'', which would ultimately include primary care, hospital, and social care information, was at the center of the new strategy (NHS Executive 1998 Sep, 9). The public would be provided with ''fast and convenient public access to information'' and ''the effective use of NHS resources by [would be achieved through] providing health planners and managers with the information they need'' (NHS Executive 1998 Sep, 9).

Building the Information Core—Implementing the NHS Plan, published in 2001, reiterated the patient-centric care information theme: ''the key lies in integrating information across the various parts of health and social care to achieve a single or 'whole' system centered around the individual that also meets the requirements of all parts of the care system'' (NHS 2001 Jan, 11). Patient access to information was again stressed, especially within the context of electronic records: ''electronic records are full development of a patient centred service. They are a major step forward in delivering the type of service people expect from a modern NHS and ensure that. . . patients have access to reliable information to improve their knowledge and involvement in their own treatment and care'' (NHS 2001 Jan, 25). Electronic records would be implemented through a combination of ''Local Implementation Strategies'' and development and application of national clinical and management information standards and technical standards, with full implementation of ''integrated primary and community EPR'' (NHS 2001 Jan, 38, 28, 43).

Delivering 21st Century IT Support for the NHS: National Strategic Programme and Delivering 21st Century IT Support for the NHS: National Specification for Integrated Care Records Service, Consultation Draft, both published in 2002, represented an evolution of the strategy for moving towards electronic health records (Department of Health 2002 Jun; Department of Health 2002 Jul). The maturation of the ‘‘strategic programme for IT in the NHS is the shift to more corporate, national approaches’’, ‘‘tak[ing] greater central control over the specification, procurement, resource management and delivery of the information and the IT agenda’’ (Department of Health 2002 Jul, 5; Department of Health 2002 Jun, i). Increased central control would be accompanied by ‘‘national and local implementation that are based on ruthless standarisation’’ (Department of Health 2002 Jun, i).

Making IT Happen: Information about the National Programme for IT and *Creating a Patient-led NHS: Delivering the NHS Improvement Plan* constitute the most recent comprehensive statements relating to the NHS England’s electronic health record strategy (NHS National Programme for Information Technology 2004; Department of Health 2005 Mar). The achievement of a ‘‘joined-up system’’ of more integrated care, supported by patient-centric electronic health records and ‘‘a far higher level of information and technology than exists currently’’ continue as core themes, as does improved measurement of Primary Care Trust and NHS [hospital] Trust performance through Payment by Results and National Service Frameworks (Department of Health 2005 Mar, 31). The timetable for electronic health records would now include full implementation, with integration of health and social care systems, by 2010 (NHS National Programme for Information Technology 2004 Aug, 14; Department of Health 2003 Dec 8).

Electronic health record definition

The National Health Service distinguishes between an electronic patient record and an electronic health record (Brennan 2005, 81–83; Protti 2001, 19). Electronic patient records (EPR) can be thought of as the transformation of current paper ‘‘organizational records’’, with entries whenever a patient is treated, into electronic form (NHS 2001 Jan, 25). As stated in *Information for Health* in 1998, the *‘‘Electronic Patient Record’’* describes the record of the periodic care provided mainly by one institution. Typically this will relate to the healthcare provided to a patient by an acute care hospital. Electronic patient records may also be held by other healthcare providers, for example, specialist units or mental health NHS Trusts’’ (NHS Executive 1998 Sep, 25). Implementation of electronic patient records, now designated as ‘‘patient clinical records’’, is occurring regionally in five geographical clusters in England (NHS Connecting for Health 2005 Apr, 14; NHS Connecting for Health 2005 Jul 5, 1–2). Private firms serve as Local Service Providers for each cluster. Local Service Providers are responsible for developing electronic patients records in each cluster, for delivering information technology services, and for integrating local systems (de Glanville 2004 Sep; NHS Connecting for Health 2005, 13). While general practices were initially mandated to use only electronic patient records developed by the Local Service Providers responsible for their geographical cluster, general practices will now be provided with choice of any practice systems accredited by any of the Local Service Providers (Department of Health 2005 Mar 23; E-Health Insider Primary Care 2005 Mar 23; E-Health Primary Care Insider 2005 Oct 11).

The electronic health record, as differentiated from the electronic patient record, ‘‘is used to describe the concept of a longitudinal record of patient’s health and healthcare—from cradle to grave. It combines both the information about patient contacts with primary healthcare as well as subsets of information associated with the outcomes of periodic care held in the EPRs’’ (NHS Executive 1998 Sep, 25). In other words, a ‘‘subset of [EPRs] . . . will contribute to a lifelong record of a patient’s health and healthcare—the Electronic Health Record’’ (NHS 2001 Jan, 25). The electronic health record will consist of ‘‘essential information [that] will be automatically uploaded’’ and will include ‘‘. . . a summary of care encounters and clinical events [which] will be held on a national data repository. Now known as the National Summary Record, the electronic health record will be designed to ensure that important information is available wherever and whenever it is needed’’ (NHS Connecting for Health 2005 Apr, 8; NHS Connecting for Health 2005 Jul 5, 2–4; NHS National Programme for Information Technology 2004, 4). The electronic health record will include:

- ‘‘personal health information—e.g., drug allergies; details of operations and/or conditions; medication history; pathology, radiology and other results and a summary of contacts with care providers
- ‘‘demographic data—e.g., address details, held nationally and accessible through local systems
- ‘‘Each patient’s NHS Care Record will have a unique identifying NHS number, which will also form the common link between personal health information and demographic data’’ (NHS National Programme for Information Technology 2004, 4).

The electronic health record, together with the locally-maintained electronic patient records, constitute the overarching NHS Care Record (formerly Integrated Care Record): ‘‘. . . a cradle-to-grave NHS Care Record for each patient, which will transcend traditional care organisations’ boundaries’’ (NHS National Programme for Information Technology 2004, 4). The NHS Care Record will be phased in by function, starting with patient demographic information and recording of allergies in 2004–2005; proceeding to orders, results for diagnostic images and pathways, and support for care pathways in 2005–2006; and ultimately leading to full functionality with full integration between health and social care in 2010 (NHS National Programme for Information Technology 2004 Aug, 14). A private firm serves as the National Application Service Provider responsible for the development and implementation of the NHS Care Record (Shifrin 2003 Dec 8).

National health information infrastructure elements related to electronic health records

The National Programme for Information Technology (NPfIT) within Connecting for Health includes core infrastructure components (NHS Connecting for Health [hp] Programmes and System Delivery), such as:

- the NHS Care Records Service, responsible for the NHS Care Record (NHS Connecting for Health [hp] NHS Care Records Service);
- Choose and Book, through which general practitioners schedule patient appointments at dates, times, and locations of the patient's choosing (NHS Connecting for Health [hp] Choose and Book);
- Electronic Transmission of Prescriptions, enabling electronic transfer of prescriptions to the pharmacy of the patient's choosing and providing points-of-prescribing and -dispensing information support (NHS Connecting for Health [hp] Electronic Transmission of Prescriptions);
- N3—the National Network, providing broadband networking capabilities in support of NPfIT components (NHS Connecting for Health [hp] N3-the National Network);
- Picture Archiving and Communications Systems (NHS Connecting for Health [hp] Picture Archiving and Communications Systems); and
- Information technology supporting general practitioners, including QMAS (Quality Management and Analysis System), which measures patient quality of care and provides feedback to Primary Care Trusts, in support of monitoring the General Medical Services contract (NHS Connecting for Health [hp] What is QMAS?).

Electronic health record storage

The NHS Care Record Service will store patient data both locally and centrally. ‘‘The Spine is a huge central database which will be used to store summary patient records of every NHS patient in England’’ (NHS Connecting for Health 2005 Jul 4, 12). The Spine includes the Personal Demographics Service, the Personal Spine Information Service, and the Secondary Uses Service (Cooke 2004; NHS Connecting for Health [hp fact sheet] The Spine; NHS Connecting for Health 2005, 13). The Personal Demographics Service ‘‘will be the definitive authoritative source of patient information and their administrative preferences’’ (Cooke 2004; NHS Connecting for Health [hp fact sheet] NHS Personal Demographics Service (PDS)). The Personal Spine Information Service ‘‘will contain enduring clinical information about individuals’’, including medication history and contra-indications, allergies, and encounter or episode of care reports (Cooke 2004; NHS Connecting for Health 2005 Apr, 8). The Secondary Uses Service ‘‘will provide timely, pseudoymised patient-based data and information for purposes other than direct clinical care’’ (NHS Connecting for Health [hp] Secondary Uses Service). The Secondary Uses Service will be discussed more thoroughly below in Uses for population health monitoring and research.

In addition to central storage of identifiable data on the Spine and pseudo-anonymized data in the Secondary Uses Service, ‘‘full [Electronic Patient] records will remain locally where care is delivered. As indicated above, summary information will be automatically ‘uploaded’ from local electronic patient records to a summary record [on the Spine]’’, which ‘‘will show where more detailed information is stored locally and also record an individual's consent for care professionals to view their health information’’ (NHS Connecting for Health 2005 Apr, 8). In February 2005, the first general practice was connected to the Spine (E-Health Insider 2005 Feb 4; E-Health Insider Primary Care Feb 7; NHS Connecting for Health no date, 7). The location of local storage has been under discussion. A recommendation for a ‘‘three level architecture’’ emerged from the Electronic Record Development and Implementation Programme (ERDIP), which apparently would have included storage of electronic patient records at both the local healthcare provider level and at the Strategic Health Authority level (NHS Information Authority 2003 Apr 11, 14). However, it is not now clear whether such a three level architecture will be uniformly implemented.

Patient confidentiality and participation

In 1997, Dame Fiona Caldicott and her colleagues pointed out that ‘‘the introduction of new technologies. . . brings with it new risks, and concerns over the confidentiality of patient information have been raised in the last few years as a result of the increasing use of information technology within the health service, and the possibility that unauthorized or inappropriate access to personal information may become more likely as a result’’ (Caldicott Committee 1997 Dec, 5). Substantial legal, policy, and research attention has been focused on patient consent requirements for Electronic Patient Records and Electronic Health Records. The legal framework for consent has been set by the Data Protection Act of 1998, the Human Rights Act of 1998, common law, and the Health and Social Care Act of 2001 (Newton and Garner 2002, 33–36, 40). In sum, the legal framework mandates that ‘‘patient information may be collected and stored in computerised records, provided the purpose of the record is clearly defined, data is held securely and confidentially, and the patient is able to check the content and accuracy of the record. Patient identifiable data may not be used without the patient's consent, unless exemption has been obtained’’ (Adams et al. 2004, 872). As the former NHS Information Authority indicated, ‘‘depending on the circumstances, consent can either be assumed or actively asked for’’ (NHS Information Authority 2002 Oct, 6). The National Health Service distinguishes between express consent, in which ‘‘consent is expressed orally or in writing’’, and implied consent, in which ‘‘consent is inferred from a person's conduct in the light of facts and matters which they are aware of, or ought reasonably to be aware of, including the option of saying no'' (Newton and Garner 2002, 26; Tranberg and Rashbass 2004, 33). Implied consent has been operationally defined as meaning that ''information concerning a patient should normally be available to any clinician giving clinical care to that patient within a defined local health network, unless that patient has requested that such sharing should not occur'' (General Practitioners Committee 2003 Sep, 22). The type of consent required has been interpreted to vary with the sensitivity of the data.

Public opinion regarding patient consent for use of data contained in electronic health records has been explored in National Health Service-sponsored population-based surveys, focus groups, and in several Electronic Record Development and Implementation Program sites. A 2002 population-based survey found that 35% of respondents wanted express consent each time their electronic data were shared for any purpose, and 30% wanted express consent each time their electronic data were shared for other than treatment purposes (NHS Information Authority 2003b 27). ERDIP site evaluations found that ''there was no evidence that people were seriously concerned about their information being shared within an electronic health record'' and ''implied consent is acceptable to most classes of patient, with certain exceptions'' (Adams et al. 2004, 874; Foord et al. 2003 Jan 31, 78). On the other hand, a United Kingdom-wide survey commissioned by the British Medical Association revealed that ''81% [of respondents] were worried that non-clinicians and those not involved with their care would be able to see their information'' (Carvel 2005 Jun 30; E-Health Insider 2005 Jun 30). Research results also indicated that concerns about patient consent for provider access not surprisingly varied with both the perceived sensitivity of the information and the site of care, with patients assuming a greater need for sharing of information in secondary care (Health Which? 2003 Oct, 11; NHS Information Authority 2002 Oct 24, 15).

The ''sealed envelope'' is the National Programme for Information Technology's method for providing patients with the capacity for using express consent to limit sharing of information contained in the NHS Care Record. Richard Grainger, the Director General for NHS IT, indicated in February 2005 that ''the idea of a sealed envelope arose from research with patients and the public and through wider consultation with the public and the NHS. It had strong support as a way of allowing people to restrict particularly sensitive information, such as gynaecological and metal health information, from being routinely shared (with those who have the right access privileges) without having to block sharing of the whole record'' (NHS Connecting for Health [hp] Questions and answers from a recent King's Fund Seminar). In the NHS Care Record Guarantee, announced by Health Minister Lord Warner in May 2005, the NHS pledged that ''you can choose not have information in your electronic care records shared'' (Department of Health 2005 May 23; NHS 2005 Jun 2, 5). Practitioners can either ''break the seal'' with the patient's express consent, or ''if a care professional considers it necessary to see this information and is unable to get the patient's consent'' (NHS Connecting for Health 2005 Apr, 21).

In addition to patient consent for the sharing of specific parts of the electronic record beyond the immediate healthcare provider, the National Health Service also has confronted issues relating to opting out entirely from electronic record keeping in local electronic patient records and the national electronic health record. Confusion and subsequent controversy about patient consent and opting out arose from two sources. First, at least one Electronic Record Development and Implementation Program site apparently permitted patients to opt out of electronic record-keeping, while another site apparently adopted a ''sealed envelope'' approach (South Staffordshire Health Community 2002 Mar; Hampshire and Isle of Wight Strategic Health Authority [hp] How to withhold your record; Hampshire and Isle of Wight Strategic Health Authority 2004 Nov 30, 3). Second, the national health minister, indicated that patients could opt out of inclusion of data in the National Care Records Service (Carvel 2005 Jan 14), followed by a well-publicized instance in which a practice manager failed in her attempts to have all instances of her personal information removed from the NHS-Wide Clearing Service and other downstream data repositories (E-Health Insider 2005 Mar 30).

The National Health Service position seems to be that patients cannot opt out of electronic record keeping; however, patient rights to opt out of electronic patient records and electronic health records has engendered both controversy and confusion within the NHS, between the NHS and Parliament, and between the NHS and the British Medical Association (Cross 2005 Feb 5; E-Health Insider 2005 Jun 14; E-Health Insider 2005 Aug 1; E-Health Insider 2005 Oct 18; E-Health Insider Dec 6; Lettice 2005 Mar 30). In keeping with the recommendations of the NHS' Ethics Advisory Group of the Care Records Development Board, Dr. Phil Walker, the head of digital information policy for the Department of Health, wrote in a widely publicized e-mail note that ''patients do not have any right to determine what is recorded, nor to veto the media on which it is recorded etc. The Government is convinced that patients will benefit from a shared record system. . . Whilst clinicians might choose not to record information with NCRS systems[,] it is not because of any right of veto given to patients'' (NHS National Prgramme for Information Technology, Ethics Advisory Group 2004 Dec 3, 4–5, 12; Walker 2005 Mar 3; E-Health Insider Primary Care 2005 Apr 5; BBC News 2005 Mar 30). The only instance in which patients can opt out of electronic record-keeping is if inclusion of their records would entail ''significant damage or distress'' (Walker 2005 Mar 3; NHS National Programme for Information Technology Ethics Advisory Group 2004 Dec 3, 4; E-Health Insider 2005 Mar 8). The complexities of actually implementing the sealed envelope and highly limited patient opt-out has engendered concerns over the appropriate balance between patient consent, on the one hand, and costs and efficiency, on the other hand: ''We can have a high-quality and well-regulated health service or a highly confidential service where data is not shared when needed, but trying to have both may be impossible, and certainly expensive'' (Singleton 2005 Apr 5).

Patient identification

Patient identification for the NHS Care Record is through the NHS number, initially instituted in 1948 and revised in 1996 (National Health Service Information Authority [hp] NHS Number; National Health Service Information Authority [hp] NHS Numbers for Babies). The NHS number is used on the NHS medical card and can be traced through the NHS Strategic Tracing Service (National Health Service Information Agency [hp] NHS Strategic Tracing Service; Rivett No Date). The NHS number has been issued upon officially joining the NHS. Since 2002, the NHS number has also been issued at birth through the NHS Numbers for Babies (NN4B) service, instead of upon completion of civil birth registration as previously done (National Health Service Information Authority [hp] NHS Number for Babies). NN4B is viewed as a means of improving neonatal surveillance. Questions around the universal use of the NHS number have been raised, and in 2004 the NHS Information Standards Board announced that NHS Trusts would be required to use the NHS number as their unique identifier (Department of Health 2001 Sep 25, 38; E-Health Insider 2004 Mar 10).

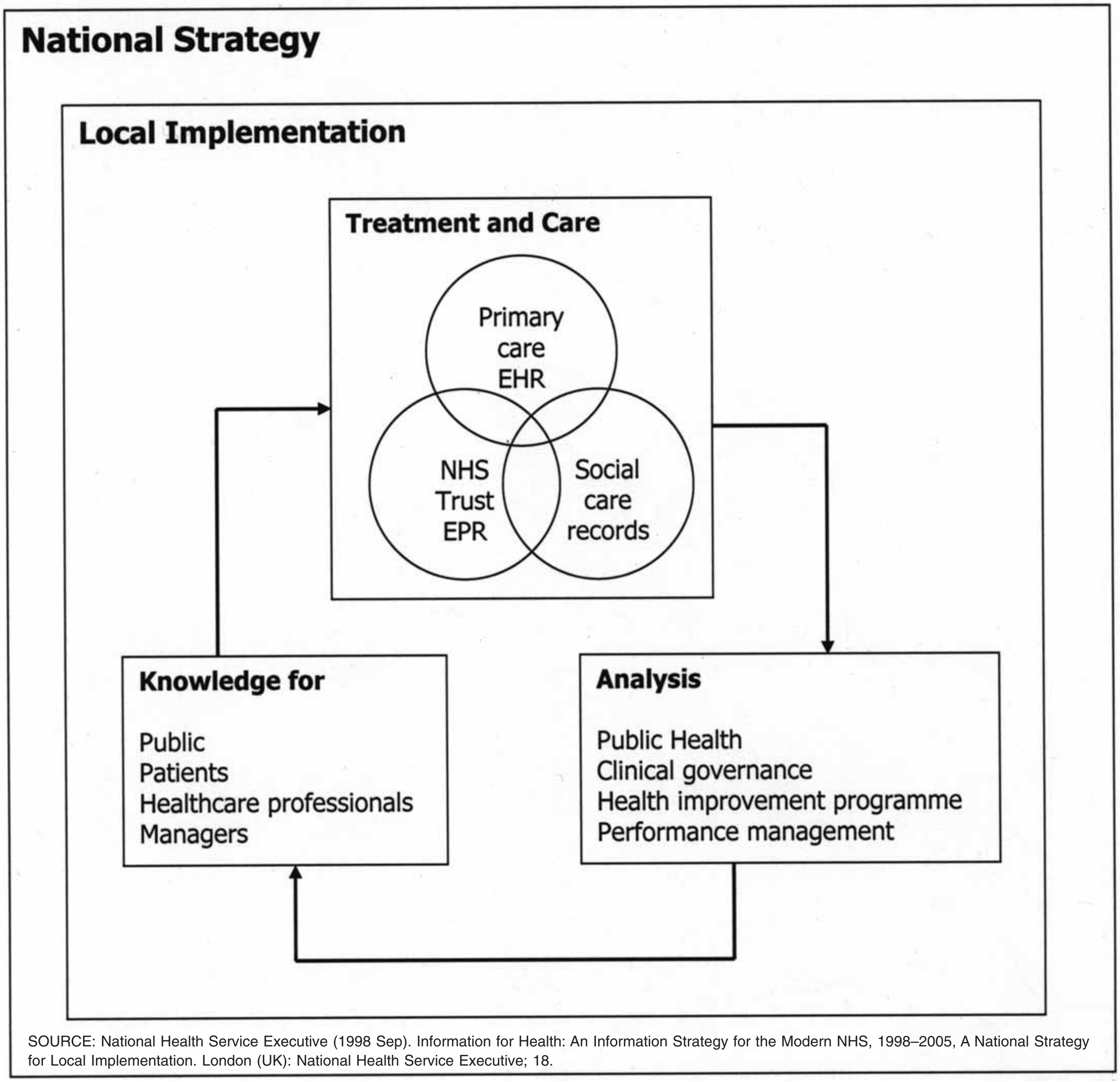
Issues related to the use of the NHS number for patient identification are integrally related to the ''sealed envelope'' and other approaches for maintaining patient confidentiality. In its discussion of protecting the confidentiality of patient records, the Caldicott Committee report distinguished between identified patient data and identifiable patient data: ''Whilst it may be necessary for a patient to be *identifiable,* . . . outside of the provision of care it should rarely be necessary for individuals to be *identified*. For an individual to be *identifiable,* but not *identified,* there must be a mechanism for using the information available to establish identity'' (Caldicott Committee 1997 Dec, 21). The NHS has built upon the Calidicott Committee report through recognizing a hierarchy of identifiability, including three general levels. First, identifiable electronic data are necessary for direct healthcare, and the ''sealed envelope'' discussed earlier pertains to these identifiable data. Second, pseudo-anonymized data are used in indirect healthcare, for which linkable data are necessary via the mechanism of an encrypted individual identifier. Third, anonymized data are used for statistical analyses outside of healthcare (Singleton et al. 2001 Jan, 25; General Practitioners Committee 2003 Sep, 24–26). The ''pseudonomisation'' required for indirect healthcare uses has further levels, such as use of the NHS number or other coded information to identify individuals, ''information in which identifiers have pseudonymised, in a reversible manner'', and ''information in which identifiers have been pseudonymised, but with an irreversible one-way encryption facility; this will enable subsequent linkage of data relating to the same individual'' (Walker No Date). Since pseudo-anonymized (''pseudonymised'' in NHS parlance) and anonymized data protect the identity of individual patients and since the pseudo-anonymized and anonymized data are used only for aggregate statistical purposes, the sealed envelope apparently does not apply. National Health Service-sponsored population-based survey and focus group research has revealed public support for use of anonymized data outside of direct healthcare, without express consent and apparently without a sealed envelope (NHS Information Authority 2003b, 10, 15–17).

Uses for population health monitoring and research

The National Health Service commitment to development and deployment of electronic health records and electronic patient records has been accompanied by recognition of their potential for population-based monitoring and research. In 1998, *Information for Health* posited ''an integrated model for information'', in which EPRs and EHRs would feed analyses for public health, clinical governance, health improvement programs, and performance management (NHS Executive 1998 Sep, 18). See Figure 4.1. *Information for Health* envisioned ''. . . a fundamental change in emphasis of Health Authority information responsibilities (from contracting to public health and service effectiveness) and a need to establish a two-way flow of information between the NHS and the communities it serves'' (NHS Executive 1998 Sep, 66). EPRs and EHRs would ''. . . provide the source of the base anonymised and aggregated data to support the clinical audit process and over time they will contribute to the growing knowledge base informing the development of national and local guidelines'' (NHS Executive 1998 Sep, 68). The development of National Service Frameworks in 2000 and 2001 for cancer, older people's services, mental health, coronary disease, and diabetes, covering roughly half of NHS spending, further contributed to the potential importance of EPRs and EHRs as analytic data sources (NHS 2001 Jan, 19). EHRs were also recognized as essential in the further development of population-based disease registries (Newton and Garner 2002, Feb, 24). The extent to which EPRs and EHRs were gaining importance as potentially supporting statistical analyses was indicated by Professor Denis Protti's 2002 comment in his NHS-commissioned review of progress towards achievement of *Information for Health*, that ''one of the many observations I made this year was the apparent shift from the primary target of *Information for Health* in supporting day-to-day clinical practice to one of collecting data for retrospective analysis such as clinical governance'' (Protti 2002 Jun 11, 7).

Electronic Record Development and Implementation Program site evaluations revealed the possible utility for secondary analysis of anonymized and linked data sets joined in an electronic health record (Sanderson et al. 2004). ERDIP site evaluations also exposed problems requiring national attention if

Figure 4.1. England's National Health Service integrated model for information



SOURCE: National Health Service Executive (1998 Sep). Information for Health: An Information Strategy for the Modern NHS, 1998–2005, A National Strategy for Local Implementation. London (UK): National Health Service Executive; 18.

electronic health records were to become useful as an ongoing data source for population monitoring and research, such as multiple coding schemes, lack of consistency and completeness in data recording, and additional quality issues (NHS Information Authority 2003a; Sanderson et al., 2004). Evaluations pointed to the need for the NHS Information Authority to "offer an 'anonymisation service' to other NHS organizations, providing secure facilities for 'pseudonymisation' . . . then it should be far easier for confidentiality to be supported by not using personal data for other than direct medical care" (Singleton 2002, 9).

Early conceptualizations of operationalizing the NHS vision of using electronic health records and electronic patient records for population health monitoring and research included the development of "a population based record that is a comprehensive list of people within a defined population containing sufficient, accurate and timely information to enable the planning and provision of health services" (Department of Health 2001 Sep 25, 3). The population record could bring together, in a single virtual location, the multiplicity of current population data sets, streamlining data collection and analysis, joining up population based data through patient-centric record linkage, and anonymizing the data for analysis (Department of Health 2001 Sep 25, 18–20). The 2001 *Strategic Outline*

Case for Population Records pointed to five content options for supporting Population Records, with the most elaborate option including extended demographics, index pointers to other data systems with additional information about each patient, a range of patient clinical information, and anonymized information for authorized users, with these options further expanded upon in the 2003 *Strategic Outline Case for a National Patient Record Analysis Service* (Department of Health 2001 Sep 25, 25–26; Department of Health 2003 Jan-Feb). Population records would support ''. . . managers, researchers and other professional not involved in direct patient care—for example epidemiologists—to: 1. have ready access to aggregated and anonymised information to support research, planning and management of care services; [and] 2. be able to use high quality information in support of the implementation of clinical governance and improvement of public health'' (Department of Health 2002 Jul 26, 18).

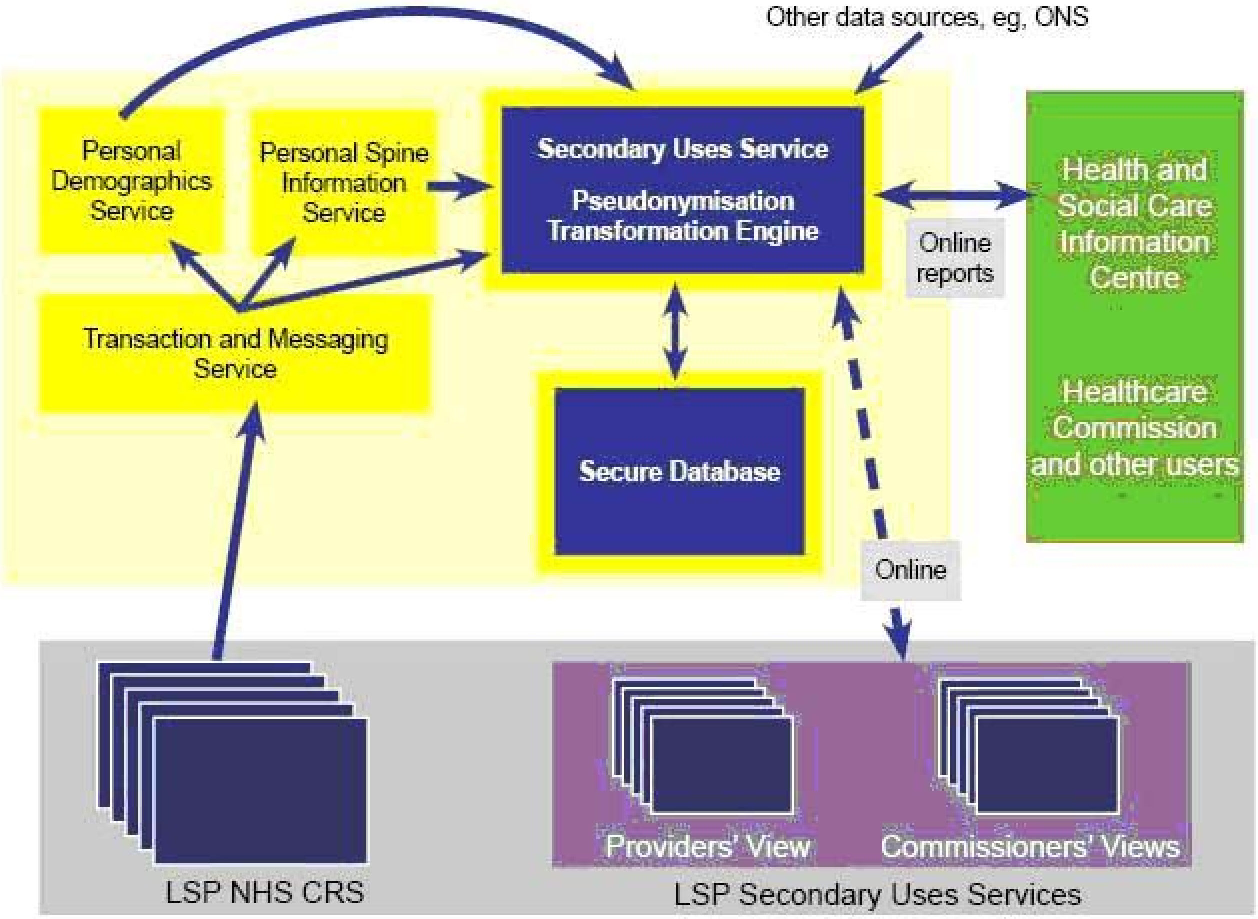
The current National Health Service solution to building a population record and making data culled from the NHS Care Record available for population health monitoring and research and other statistical analyses is the NHS Care Record Secondary Uses Service (SUS). The Secondary Uses Service forms part of the overall NHS Care Record infrastructure being deployed by the National Application Service Provider and is being jointly delivered by the Health and Social Information Centre and NHS Connecting for Health (NHS Health and Social Care Information Centre 2005 Apr 1; NHS [hp] Welcome to the Health and Social Care Information Centre). The mission of the Secondary Uses Service is to ''provide the NHS with higher quality data to enable investigation of trends and emerging health needs which can inform public health policy and planning'' (NHS Connecting for Health 2005 Oct, 27). The SUS is envisioned ''to be the central repository of health data for secondary uses'', with ''most data to be collected or derived from clinical systems as a by-product of direct care'' and also to ''have non-patient record based data, as well as all NHS related activity'' (NHS Health and Social Care Information Centre 2005 Apr 1). The SUS will provide ''. . . patient-based data and information for purposes other than direct clinical care'', including planning, public health, clinical audit, benchmarking, performance improvement, research, and clinical governance (NHS Connecting for Health [hp] Secondary Uses Service).

As described by Jeremy Thorp, the chair of the Secondary Uses Service project board, the SUS will adopt a multi-layered approach to protecting the confidentiality of data subjects, including controlled access to data, pseudonomisation, and various ''presentation layers'' enabling filtered ''views'' of data (E-Health Insider 2005 Jul 8). The SUS will transform and pseudonymise data from the Personal Demographics Service, the Personal Spine Information Service, and other data sources such as the Office of National Statistics (NHS National Programme for Information Technology 2004 Jun 24, 5–6; Cooke 2004 Jun 9). See Figure 4.2. Data will be held in a secure data base, and made available through an ''extract service for standard routine and ad-hoc queries'', ''on-line analyses via web query'', ''distributed queries involving SUS and local data'', and ''scheduled analysis—blocks of data'' (NHS National Programme for Information Technology 2004 Jun 24, 12). SUS users will include NHS Trusts of all types, Strategic Health Authorities, Public Health Observatories, the Department of Health, NHS agencies, registries, researchers, professional bodies, and local governments (NHS National Programme for Information Technology 2004 Jun 24, 13–14).

Data will be phased into the Secondary Uses Service in at least five stages. The initial stage, in 2005, will include data from the Personal Demographics Service (with birth and death status), the Mental Health Minimum Data Set, and admitted patient care, elective admission, accident and emergency, mortality, and other data sets (NHS National Programme for Information Technology 2004 Dec, 14). The fourth stage of SUS will enable ''. . . data linkage across the whole patient journey. SUS content [will] expand to reflect the full range of NHS services (primary, community and secondary care) and enables SUS to explore the potential for generating central returns and other national dataset requirements directly from the SUS'' (NHS National Programme for Information Technology 2004 Dec, 20). In the fifth and final stage, the SUS will become ''the primary source of health data for non-care purposes, supporting the full range of information requirements at local, community and national levels'' (NHS National Programme for Information Technology 2004 Dec, 21).

The Secondary Uses Service intends to support the complex of standards, quality requirements, criteria, targets, and benchmarks developed by the Department of Health and the NHS (Department of Health 2004 Jul, 5). These include the four National Health Service priority condition areas of cancer, coronary heart disease, diabetes, and mental health and their accompanying targets, the Department of Health's National Healthcare Standards in seven domains, and the ''Star Ratings'' (Department of Health 2001 Mar, 66; NHS Executive 1999 Jun; NHS Health Development Agency 2004, 2, 3; NHS in England [hp] Star Ratings; Stevens 2004). The new General Medical Services contract, which ''. . . rewards GP practices for providing specified services, delivering quality and involving patients'', will also require support, as will the Quality and Outcomes Framework (QoF), which will ''measure achievement against a scorecard of 146 evidence-based indicators'' in the clinical, organizational, patient experience and additional services domains'' and will produce results for general practioner practices and Primary Care Trusts in England (NHS National Programme for Information Technology No Date, 1). The Quality and Outcomes Framework Management and Analysis System (QMAS) has been designed to automatically produce the Quality and Outcomes Framework clinical point scores from clinical disease registers defined in the General Medical Services (General Practitioners Committee 2004

Figure 4.2. Data flows for England's Secondary Uses Service



SOURCE: NHS Connecting for Health [hp]. Secondary Uses Service (SUS). Available from: http://www.connectingforhealth.nhs.uk/publications/ [cited 2006 Jan 10].

Oct; Roscoe 2004 Aug 5). Finally, the SUS will also support the new Payment by Results ". . . system, planned to be fully operational by April 2008, [which] is designed to underpin patient choice by enabling money to 'follow the patient', thus rewarding providers for the activity they undertake" (Hunter and Marks 2005 Feb, 4). SUS outputs will be phased in over several years (NHS National Programme for Information Technology 2004 Dec, 7–13).

Australia

Summary

A national strategy for electronic health records and the supporting national health information infrastructure was formulated in the *HealthConnect Business Architecture version 1.9,* published by the Australian Department of Health and Ageing's Health*Connect* Program Office in November 2004 (Health*Connect* Program Office 2004a). The proposed architecture included the building of a national health information network, with voluntary patient provision of data into electronic health records. A series of event summaries would form the core of the electronic health records. Electronic health records would be stored in a federated Health*Connect* record system for clinical uses and in the National Data Store for secondary uses. These secondary uses would include the provision of primarily deidentified data for population health monitoring and research. With the formation of the National E-Health Transition Authority Ltd in July 2005 by the Commonwealth, state, and territorial governments, the Health*Connect* architecture is now being re-examined and implementation will depend upon the outcomes of the National E-Health Transition Authority's current initiatives.

Locus of national responsibilities

The locus of responsibilities for the development of a national Australian strategy for electronic health records and the supporting national health information infrastructure changed substantially during 2005 (Health*Connect* Program Office 2004b). National strategy is now shared between one governmental organization and one quasi-governmental organization with complementary roles: the Health*Connect* Program Office and the National E-Health Transition Authority (NEHTA). The Health*Connect* Program Office, located within the Australian Department of Health and Ageing, has been responsible for the management of the Health*Connect* trials for electronic health records, evaluation of those trials, and design of key documents relating to the future architecture and national implementation (Health*Connect* Program Office [hp] 2004). During 2005, the role of the Health*Connect* Program Office changed from managing the Health*Connect* electronic trials and designing a national EHR architecture with Health*Connect* ''as a technical solution to address healthcare reform in Australia'', to ''ensur[ing] coordinated activity between all areas of the health care sector, underpinned by the mandatory application of specifications, standards, and infrastructure developed by the NeHTA'' (Health*Connect* 2005 Oct, 2; *HealthConnect [hp] HealthConnect* and the information management and information communications technology industry).

The National E-Health Transition Authority, Limited was established as a not-for-profit company in July 2005 by the Australian Health Ministers' Advisory Council, including Australian federal, state, and territorial governments and is governed by a board of directors made up of CEOs from health departments across Australia. NEHTA's role is ''. . . to develop better ways of electronically collecting and securely exchanging health information'' with ''a key task. . . to establish the fundamental standards necessary to progress e-health. These standards will need to be adopted by software developers so that the promise of e-health can be delivered on a national scale'' (National E-Health Transition Authority [hp] Fact sheet—standards implementation). NEHTA will ''oversee and progress national IM&ICT priorities that underpin Health*Connect*'' (Health*Connect* Program Office 2004b), including developing timelines, business cases, standards, and provides advice and resources (Department of Health and Ageing 2005).

Current status and plans

The current status of and plans for the development of a national strategy for electronic health records and the supporting national health information infrastructure must be viewed within a developmental context. In 2000, Australia's National Electronic Health Records Taskforce presented its report on *A Health Information Network for Australia*, which called for the establishment of a national approach to sharing EHRs in Australia, including:

- the ''building of a national health information network . . . which provides for the systematic collection of clinical and demographic information at the point of care'';
- ''this information would take the form of event summaries . . . rather than the full set of information that providers may collect for each episode of care''; and
- ''Information would be collected only for those consumers and providers who agreed to participate'' (National Electronic Health Records Taskforce 2000b, xxii-xxiii).

This basic framework formed the basis for the development of Health*Connect* in 2001. In 2002, Health*Connect* trials were instituted in North Queensland, focusing on pre-operative hospital assessment; the Northern Territory, focusing on services in remote areas; New South Wales, focusing on chronic disease management and a hospital-based children's health information network; and Tasmania, focusing on adults with diabetes and their healthcare providers (South Australian Department of Human Services 2004). These trials have been extensively evaluated (Health*Connect* Program Office 2003).

While the national approach set forth in 2000 by the National Electronic Records Taskforce remains operative, three important changes seem to have occurred during 2005. The first change is the before-mentioned shift from Health*Connect* as an overarching national technical solution to Health*Connect* collaborative process to ''leverage existing projects and infrastructure [in Australian states and territories] to achieve short-term results and drive longer term outcomes. This approach will avoid long delivery timeframes by building 'from scratch' in isolation from existing initiatives'' (Health*Connect* 2005 Jul 6, 7). The second change is Health*Connect*'s moving states, territories, and local services towards compliance with standards set by the National E-Health Transition Authority, through regionally-based process of planning for, assessing, and developing compliance with NEHTA standards for interoperability of EHRs and supporting national health information infrastructure elements. The third change is a greater emphasis on ''a market place that adopts standards to enable organisations, people and systems to interoperate. This approach depends for its success on a highly competitive market place that competes on functionality, service quality and price'' (Reinecke 2005 Aug 1, 3; Brewin 2005 Aug 22). NEHTA's role, complementary to Health*Connect*'s role, ''. . . is to identify, and prepare national standards for, the most important types of clinical information to be captured by e-health systems'' (National E-Health Transition Authority [hp] Fact sheet—clinical information specification).

Electronic health record definition

The recent evolution of the Australian national strategy for electronic health records and the supporting national health information infrastructure seems to include an evolution in the working definition of an electronic health record. Health*Connect* defined the electronic health record as:

- ''a longitudinal collection of health information relating to a single consumer that is stored within the Health*Connect* system itself'' (Health*Connect* Program Office 2004a, 129); and
- ''a series of event summaries, each containing key information about a specific healthcare event such as a general practitioner consultation, hospital admission or discharge, community health centre visit, pathology test of a pharmacy dispensing a prescription'' (Health*Connect* Program Office 2004a, 1).

The Health*Connect* EHR ''will not replace providers' own clinical records or clinical information systems. Providers will continue to maintain their own consumer health records but may choose to incorporate selected

Health*Connect* EHR information in their records or clinical information systems (Health*Connect* 2004a, 2).

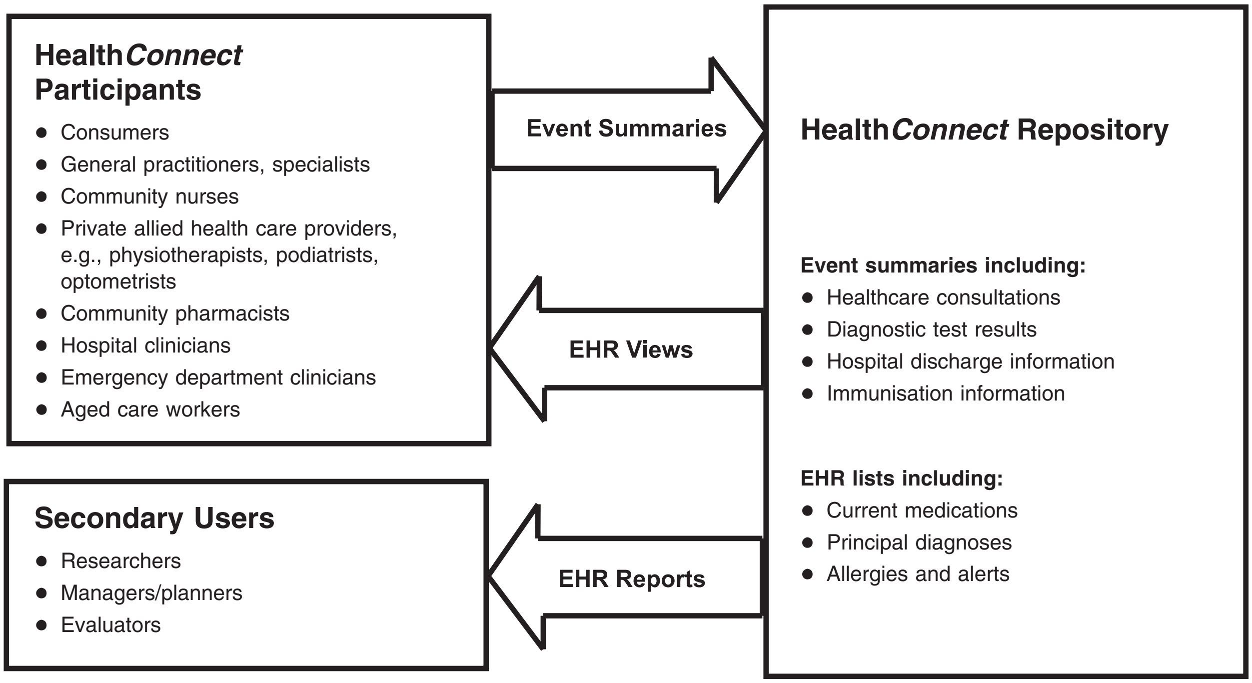
The National E-Health Transition Authority provides definitions of electronic health records in its glossary (National E-Health Transition Authority [hp] Glossary). These definitions, based on standard sources such as Standards Australia, share Health*Connect*'s earlier definitional emphasis on longitudinal data and conceptual separation of clinical care functions from the EHR itself (Standards Australia 2005). As will be discussed immediately below in *National health information elements related to electronic health records*, NEHTA also has continued Health*Connect*'s emphasis on health event summaries. However, the storage of electronic health records within the Health*Connect* system itself, referred to in Health*Connect*'s earlier electronic health records definition, is omitted from the NEHTA definition; this is a potentially important change that may relate to the uses of EHRs for population health monitoring (see section below on *Uses for population health monitoring and research*).

National health information infrastructure elements related to electronic health records

The *HealthConnect Business Architecture version 1.9*, published in November 2004, identified key national health information elements relating to electronic health records (Health*Connect* Program Office 2004a). Central to the Health*Connect* conception of the electronic health record and its supporting national health information infrastructure were event summaries and electronic health record lists (see Figure 4.3). Event summaries would include information such as observations; allergies; test orders and results; diagnoses; care plans; services and treatments provided, including immunizations; medications prescribed and dispensed; and referrals (Health*Connect* Program Office [hp] Event summaries). EHR lists will be both derived automatically from the event summaries, and also maintained by providers when clinical judgment is required (Health*Connect* Program Office 2004a, 136–7). Data from event summaries and EHR lists will be made available to providers and patients themselves through pre-defined views.

The National E-Health Transition Authority's twelve major 2005–2006 initiatives continue Health*Connect*'s emphasis on event summaries, through the planned development of twelve national event summary templates in its clinical information initiative (National E-Health Transition Authority [hp] Initiatives—major NEHTA initiatives 2005–06). The development of a national minimum hospital discharge summary template has been identified as especially important; other priority events identified by NEHTA include the initial health profile, medical consultation—general practitioner, medical consultation—specialist, hospital discharge—emergency, pharmacy provision, community based health consultation, allied health consultation, and referral (National E-Health Transition Authority 2005 Jun 16, 17; National E-Health Transition Authority 2005 Jun 17, 4). In addition to NEHTA's clinical information initiative with its event summary templates, other NEHTA initiatives for 2005–2006 include a managed approach to clinical terminologies, an individual healthcare identifier (see *Patient*

Figure 4.3. Key elements of Australia's Health*Connect*



SOURCE: Health*Connect* Program Office (2004 Nov). *HealthConnect* Business Architecture version 1.9. Canberra ACT (AU): Commonwealth of Australia; 2.

identification below), an e-health consent framework (see *Patient confidentiality and participation* below), and specifications for developing a national architecture for EHRs (National E-Health Transition Authority [hp] Initiatives—major NEHTA initiatives 2005–06).

Electronic health records storage

The Health*Connect* Business Architecture version 1.9 specified that each Health*Connect* electronic health record would be stored in two locations: a Health*Connect* Record System and the National Data Store. Taken together, the national network of interoperable Health Record Systems would constitute an electronic health record repository, supported by national-level common services. The ''federated model'' of Health Record Systems would enable healthcare provider and consumer access to the views of event summaries and lists described above. The National Data Store would maintain archival copies of EHRs (Health*Connect* Program Office 2004a, 7, 35, 110–13). NEHTA's electronic health record design initiative for 2005–06 includes ''defin[ing] requirements for a national network of shared electronic health records''; this work remains in progress and EHR storage under the NEHTA business architecture has not yet been specified (National E-Health Transition Authority [hp] Initiatives—major NEHTA initiatives 2005–06).

Patient confidentiality and participation

The specifics of patient participation and control over their electronic health records have been a topic of much consideration in Australia (Australian Health Information Council 2005). At least three population-based surveys have been conducted since 2001 dealing with issues directly relevant to patient participation in Health*Connect* (Campbell Research and Consulting 2004; Roy Morgan Research 2001; Roy Morgan Research 2004). Sixty percent of respondents in a 2004 survey agreed that ''your doctor should be able to discuss your personal medical details with other health professionals—in a way that identified you—WITHOUT YOUR CONSENT if they thought this would assist your treatment.'' On the other hand, the same survey also revealed that 64 percent of respondents felt that inclusion in a national health database, such as the Health*Connect* National Data Store, should be voluntary (Roy Morgan Research 2004, 46, 49). In addition to survey research, focus group research has been conducted on patient participation and electronic health record privacy (Campbell Research and Consulting 2004; Consumers' Health Forum 1998; TQA Research 2004), and several issues commentaries have been developed (Office of the Privacy Commissioner 2004a; Office of the Privacy Commissioner 2004b; Consumers' Health Forum 2001; Health*Connect* Program Office 2002; NSW Ministerial Advisory Committee on Privacy and Health Information 2000; Paterson and Iacovino 2004).

The Health*Connect* trials were designed to test several different consent models for patient participation, such as the Northern Territory model ''in which consumer consent is obtainined before the inclusion of an event summary on thte Health*Connect* record and prior to a provider accessing an individual's Health*Connect* record'', the Tasmania model in which consumers provide ''standing consent at registration'' in Health*Connect*, and the New South Wales model in which consumer consent at registration includes the ''capacity to exclude particular individuals from accessing records'' (Aitken and Gilhotra 2004, 19; Health*Connect* Program Office No Date a; Health*Connect* Program Office No Date b). Patient participation in Health*Connect* would be voluntary, and electronic health records would only be maintained for those who specifically register for Health*Connect* (Health*Connect* Program Office 2004a, 25, 52; Health*Connect* Program Office [hp] Q & As). The *HealthConnect Business Architecture version 1.9* indicates that patients must provide informed consent ''before their EHR and other personal information can be collected, accessed, used or disclosed by Health*Connect*'' (Health*Connect* Program Office 2004a, 52). This is essentially ''push'' access for consent, with consumers deciding when their data should be ''pushed'' into EHRs at the Health Records Systems and the National Data Store, and when it should not (Gunter and Terry 2005). Some formulations of Health*Connect* patient participation and consent indicated that patients could control what events would be included in their electronic health records, what providers and provider organizations could have access to their EHRs, and for what purposes that access would be provided, resulting in ''layered-consent'' (Crompton 2004; Health*Connect* Program Office [hp] Q& As).

The National E-Health Transition Authority's major initiatives for 2005–06 include ''developing e-health consent frameworks to support other key NEHTA initiatives—-the shared electronic health record. . . [and] the Individual Healthcare Identifier'' (National E-Health Transition Authority [hp] Initiatives—major NEHTA initiatives 2005–06). NEHTA has indicated that its ''recommended approach involves taking a holistic view of privacy requirements, providing strong privacy protection while enabling the implementation of an operationally and financially feasible SEHR [electronic health record] system. It does not support an emphasis on 'consent' to the exclusion of other important privacy requirements and argues that consent and privacy requirements must be assessed against specific initiatives or proposals'' (National E-Health Transition Authority [hp] Initiatives—major NEHTA initiatives 2005–06). NEHTA's approach to patient consent reflects a key lesson learned from the Health*Connect* trials: ''keep consent simple'' (Richards 2005 Nov 25). The NEHTA approach would presumably require ''trade-off [on] issues such as a patient's desire to protect confidentiality, the impact of the consent systems on clinical work, and the cost of designing and maintaining a potentially highly complex system'' (Coiera and Clarke 2004, 137).

Patient identification

Australia does not now have a national system for unique identification of its citizens or residents. A Medicare number system exists to enable reimbursement for healthcare provider fees, and Standards Australia issued a Healthcare Client Identification standard in 2002 (Australian Institute of Health and Welfare 2004, 46). National identifiers in Australia have a controversial history, based in the Australia Card proposal of 1986, which would have mandated a national population register, a national identifier, and an associated identification card (Clarke 1987; Greenleaf 1987). Although the Australia Card was never implemented, the Australia Card debate has been cited as a reason for especially careful public and governmental review of patient identification strategies for Health*Connect*. However, a 2004 population-based survey found that 57% of respondents agreed that ''to enable the government to better track the use of HEALTH SERVICES, all individuals should be allocated a NUMBER and that numbers should be used when accessing ANY health service or facility'' (Roy Morgan Research 2004, 48).

As with patient participation in Health*Connect* and patient controls of their electronic health records, the specifics of patient identification in Health*Connect* have not been finalized. The Health*Connect* trials used locally-generated schemes for identifying patients. The *HealthConnect Business Architecture version 1.9* indicates that ''each consumer and their EHR information will be uniquely identified within Health*Connect* by use of a single unique identifier able to be linked to any future National Health Identifier'' (Health*Connect* Program Office 2004a, 30). The National E-Health Transition Authority's major initiatives for 2005–06 include ''the NEHTA Individual Healthcare Identifier (IHI) Initiative [that] will establish an identifier assigned to a person to enable accurate identification of that individual for healthcare purposes'' (National E-Health Transition Authority [hp] Initiatives—major NEHTA initiatives 2005–06). According to NEHTA, ''the IHI will be assigned to all Australians and will have cross recognition within the entire healthcare sector'' (National E-Health Transition Authority [hp] Initiatives—major NEHTA initiatives 2005–06). NEHTA also assumes that ''an IHI system requires the retention and maintenance of an accurate core set of personal data for every individual accessing Australian health services'' (National E-Health Transition Authority [hp] Initiatives—major NEHTA initiatives 2005–06). The NEHTA approach may include leveraging existing elements of the Medicare Australia (formerly Health Insurance Commission)number for developing the IHI and the necessary associated personal information (Australian National Audit Office 2004).

Uses for population health monitoring and research

Several Australian government and Australian government-commissioned reports have emphasized the potential contribution of shared EHRs to population health monitoring and research. In 2000, the National Electronic Health Records Taskforce pointed to evidence of the consumer benefits of shared EHRs for population and medical research (National Electronic Health Records Taskforce 2000a). In 2001, the National Health Information Advisory Council called for ''a national system of electronically stored health records, appropriately constructed, [which] would permit administrative, planning and research information to be gathered in much better ways to aid research and planning purposes'' (National Health Information Advisory Council 2001, 111). In 2002, the National Health Information Management Group indicated that ''further opportunities for enhancing population health data, for instance in disease surveillance, can be expected from successful implementation of Health*Connect*'' (National Health Information Management Group 2003, 21). A comprehensive evaluation of ''National Health Information Management and Information and Communications Technology Strategy'', prepared by the Boston Consulting Group for the National Health Information Group in 2004, emphasized that ''it is critical that new systems being built to support clinical care. . . take into account the needs of population health research. For example, longitudinal health records would be of enormous benefit to researchers if they were widespread, standardized and complete. . . A complete electronic health record could provide population level data with detail sufficient to support the most ambitious research'' (Boston Consulting Group 2004, 74–5). Finally, in *Australia's Health 2004*, the Australian Institute for Health and Welfare emphasized the potential benefits of Health*Connect* for statistical information, as well as the potential limits on those benefits imposed by voluntary participation in Health*Connect*, the nature of health event summaries, and lack of harmonizing of clinical and population health data standards (Australian Institute of Health and Welfare 2004, 350–1).

In the *HealthConnect Business Architecture version 1.9*, primary users of Health*Connect* are defined as healthcare consumers and providers. Secondary users are defined as ''researchers seeking information to conduct research needed for improving healthcare and its delivery''; ''planners and managers . . . seeking information to assist management decision making''; and ''evaluators seeking information directly related to monitoring the effectiveness of Health*Connect*'' (Health*Connect* Program Office 2004a, 38). Appropriate secondary uses of Health*Connect* electronic health records include authorized national data collections; clinical research; quality improvement activities, including clinical audits, health outcomes analysis, adverse events monitoring, and product recalls; and health policy development (Health*Connect* Program Office 2004a, 93–4). As described in the *HealthConnect Business Architecture version 1.9*, the National Data Store would be the source for all secondary uses, rather than the Health*Connect* Record Systems accessed by consumers and healthcare providers. Use of the National Data Store for secondary uses would "... generally be for de-identified record analysis" or for the production of aggregated reports (Health*Connect* Program Office 2004a, 41). Secondary uses by researchers would follow approval protocols already established by national legislation (Health*Connect* Program Office 2004a, 46).

The relationship between Health*Connect* and registries has not been thoroughly specified. According to the *HealthConnect Business Architecture version 1.9*, "Health*Connect* will potentially support registers through the provision of information such as diagnosis and treatment information on which specialist registries may be built" (Health*Connect* Program Office 2004a, 30). Such practice-based registries may or not be population-based, depending upon the particular circumstances. Health*Connect* would "... provide a mechanism for facilitating the notification of notifiable events to national health registers", but "it will not seek to replace any registers or become a registry service" (Health*Connect* Program Office 2004a, 46). Finally, it is important to note that utilization of Health*Connect* for population-based registries would be predicated upon voluntary consumer participation (Health*Connect* Program Office 2004a, 46).

The nexus between secondary uses of Health*Connect* electronic health records and the National Data Store for population health monitoring and research, on the one hand, and patient control over their EHRs, on the other hand, is not entirely clear. What is clear is that—according to the current conceptualization of Health*Connect*—"individuals will be able to control the details that are included in their Health*Connect* records... [and] will have the ability to determine what information gets added to their record and control who has access to it" (Health*Connect*] Q&As). What is not entirely clear is whether Health*Connect* enrollees will have control over what data are included in the National Data Store, whether enrollees will be able limit the data included in the National Data Store and differentiate those data from those included in their local or regional Health Records Service, and whether enrollees will provide permission for de-identified and identified secondary uses of their data in the National Data Store.

Key issues relating to the use of electronic health records for population health monitoring and research have been acknowledged by the National E-Health Transition Authority. Dr. Ian Reinecke, NEHTA's chief executive officer, has indicated that "researchers will benefit from access to standardized, longitudinal, de-identified patient information" and that aggregated information from EHRs will be made available (Reinecke 2005 Mar; Australian Health Information Council 2005, 85). NEHTA has identified researchers, as well as administrators and funders, as secondary users of electronic health records. See Figure 4.4.

Canada

Summary

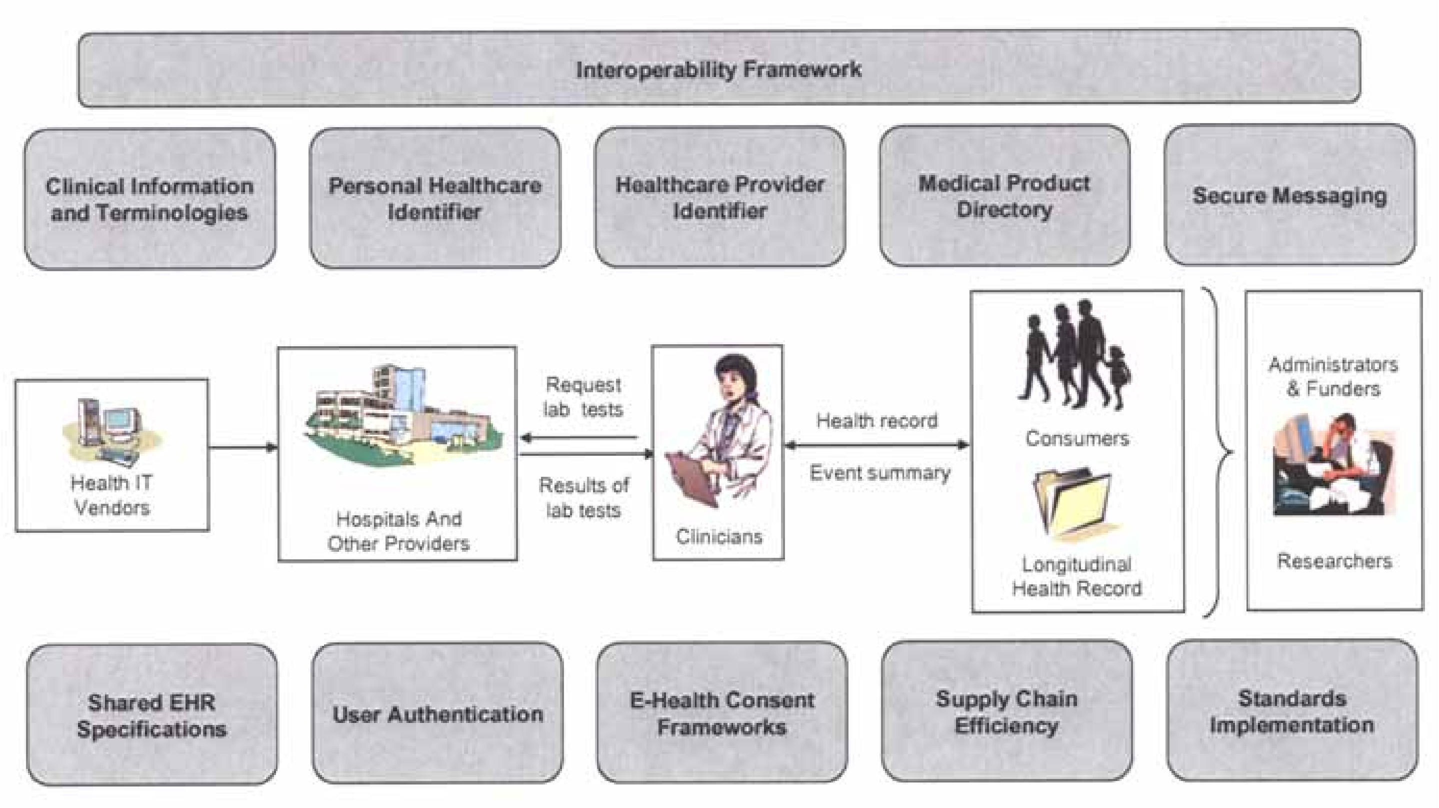
Canada Health Infoway (Infoway) was funded by the government of Canada in 2002 to develop the national strategy for electronic health records and the supporting national health information infrastructure. Infoway is an independent not-for-profit corporation, and is accountable to the fourteen federal, provincial, and territorial governments. Canada's national strategy is evolving, with the initial strategy published by Infoway in July 2003 as the *EHRS Blueprint: An Interoperable EHR Framework, Version 1.0*, and a *Version 2.0* slated for publication in February 2006. Canada's goal is to have electronic health records covering 50% of Canada by 2009 and all of Canada by 2020. The national strategy includes "a network of connected EHR solutions (EHRS), each covering a defined geography, [with the patient...] seen as being in one cross-jurisdictional EHR" (Canada Health Infoway 2005 Dec, 59). The Canadian electronic health record will contain "patient-centric data, womb to tomb, [with] encounter based information" (Canada Health Infoway 2005 Dec, 59). Although the original Infoway business plan did not include population health monitoring as one of its investment programs, in 2004 Infoway was funded to design a pan-Canadian public health surveillance system for communicable diseases as part of the national strategy for electronic health records.

Locus of national responsibilities

The locus of responsibility for the development of a national agenda and strategies for electronic health records is Canada Health Infoway Inc. (Infoway). Infoway was established in 2002 as an independent not-for-profit corporation and is accountable to the fourteen federal, provincial, and territorial governments (Health Canada [hp] eHealth Resource Centre, Canada's Health Infostructure, Chronology; MacLean 2004). Infoway has been provided with funding of approximately U.S. $1.044 billion from the federal government (Giokas 2005 Jun 28, 5). Infoway's mission is "to foster and accelerate the development and adoption of electronic health information systems with compatible standards and communications technologies on a pan-Canadian basis... [and] to build on existing initiatives and pursue collaborative relationships in pursuit of its mission" (Hodge 2004). Infoway "provides leadership in setting the strategic direction and standards for EHR deployment across Canada" and Infoway acts as a "strategic investor" in furthering its mission (Hodge 2004).

The creation of Canada Health Infoway reflected the recommendations of several pan-Canadian advisory bodies dating to the mid-1990s. The Advisory Council on Health Infostructure was established by the national Minister of Health in 1997, in order to develop a "Canadian vision of a health information system on the information highway[,] identify... the essential needs it should meet[, and] generat[e]... a federal action agenda to implement the most vital components of the system" (Health

Figure 4.4. Initiatives of Australia's National E-Health Transition Authority



SOURCE: Reinecke I (2005 Jun 21). National E-Health Agenda. Presented at DSTC electronic health breakfast, Canberra (AU).

Canada [hp], eHealth Resource Centre, History). In its 1999 final report, the Advisory Council recommended that ''the federal Minister of Health should work with his provincial and territorial counterparts to improve patient care through the creation of provincial and territorial person-based, electronic health record systems. . . [which] would make accessible—on a need-to-know basis and under the control of patients—all relevant information about their past medical histories'' (Advisory Council on Health Infostructure 1999, 9). Between 2000 and 2002, Health Canada, the Federal/Provincial/Territorial Committee on Health Infostructure, and the national Kirby and Romanow Commissions all argued for the development of a pan-Canadian electronic health record system (Commission on the Future of Healthcare in Canada 2002, 76; Advisory Committee on Health Infostructure 2001b; Siman 2000, 33; Standing Senate Committee on Social Affairs, Science and Technology 2002, 177, 180). In its January 2005 report, the Health Council of Canada, founded by the government of Canada as an independent non-profit agency in response to the Kirby and Romanow Commissions' reports, re-emphasized ''the value of electronic health records. . . as tools to improve access, quality and comprehensiveness of care [and that they] should be reinforced so that the public clearly understands the benefits and demands their introduction'' (Health Council of Canada 2005 Jan, 41).

Current status and plans

Canada Health Infoway's overarching ''plan is to have interoperable electronic health records in place across 50 percent of Canada (by population) by the end of 2009'', and across 100% of Canada's population by 2020 (Alvarez 2004; Hodge 2004). In its role as strategic investor, Infoway funds nine strategic investment programs, including interoperable electronic health records (U.S. $152 million); client, provider, and location registries (U.S. $117 million); and public health surveillance systems (U.S. $87 million) (Giokas 2005 Jun 28, 9).[3]

Canada Health Infoway defined its initial national strategy for electronic health records and what Infoway calls the electronic health record infostructure in its *EHRS Blueprint: An Interoperable EHR Framework, Version 1.0*, published in July 2003 (Canada Health Infoway 2003). Infoway maintains that ''the real value of the EHRS Blueprint is having all Jurisdictions [throughout Canada] actively reusing its components for their strategy, design and implementation of an interoperable EHR'' (Canada Health Infoway 2005 Jan, 13). Infoway has been undertaking an EHRS Blueprint Evolution Project that will culminate in the publication of the *Blueprint, Version 2.0* in February 2006 (Canada Health Infoway 2005 Fall, 9). As discussed below, preliminary materials available

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[3] As indicated in Chapter One, the definition of electronic health record employed in this report includes interoperability. Hence, Canada Health Infoway's ''interoperable electronic health records'' will be referred to here solely as ''electronic health records.''

from Infoway indicate that substantial changes will occur from *Blueprint, Version 1.0* to *Version 2.0* in the national strategy for electronic health records, especially relating to uses of electronic health records for population health monitoring.

Development of electronic health records is progressing at the provincial level, although the stage of development varies from province to province (Sweete 2004). Alberta is developing a province-wide electronic health record that would initially provide access to patient demographics, pharmacy, and laboratory data (Alberta Health and Wellness 2004; Alberta Health and Wellness [hp] Alberta Wellnet; Binns 2004; Morgan 2004, 9–21; Zeidenberg 2004). Capital Health, a Regional Health Authority in Alberta, has rolled out netCARE, a region-wide electronic health record that will link to the provincial Wellnet and will include hospital discharge summaries and radiology and operating room reports (Freeman 2004). British Columbia is evaluating the development of province-wide electronic medical summaries (Protti 2004; Vancouver Island Health Authority 2004). Newfoundland/Labrador is developing a province-wide patient registry with linkages to diagnostic images as necessary (Canada Health Infoway No Date a, 13).

Electronic health record definition

As defined in Infoway's *EHRS Blueprint, Version 1.0*, the electronic health record is ''a life-long longitudinal record of clinical data. . . it will accumulate and keep clinical information about an individual health record from womb to tomb.'' The electronic health record ''provides each individual in Canada with a secure and private lifetime record of his or her key health history and care within the health system. The record is available electronically to healthcare providers and the individual anywhere, anytime in support of high quality care''. It will contain ''summary level information about healthcare encounters for each patient/person and often also the detailed clinical data replicated from the point of service applications.'' However, the ''EHR is not an operational data store and is never the source for newly created clinical data.'' The electronic health record ''is not one system but rather an interoperable network of peer-to-peer related infostructures which enables sharing of clinical data across organizations and providers involved in the circle for any patient/person'' (Canada Health Infoway 2003, 13, 29, 35, 40, 164).

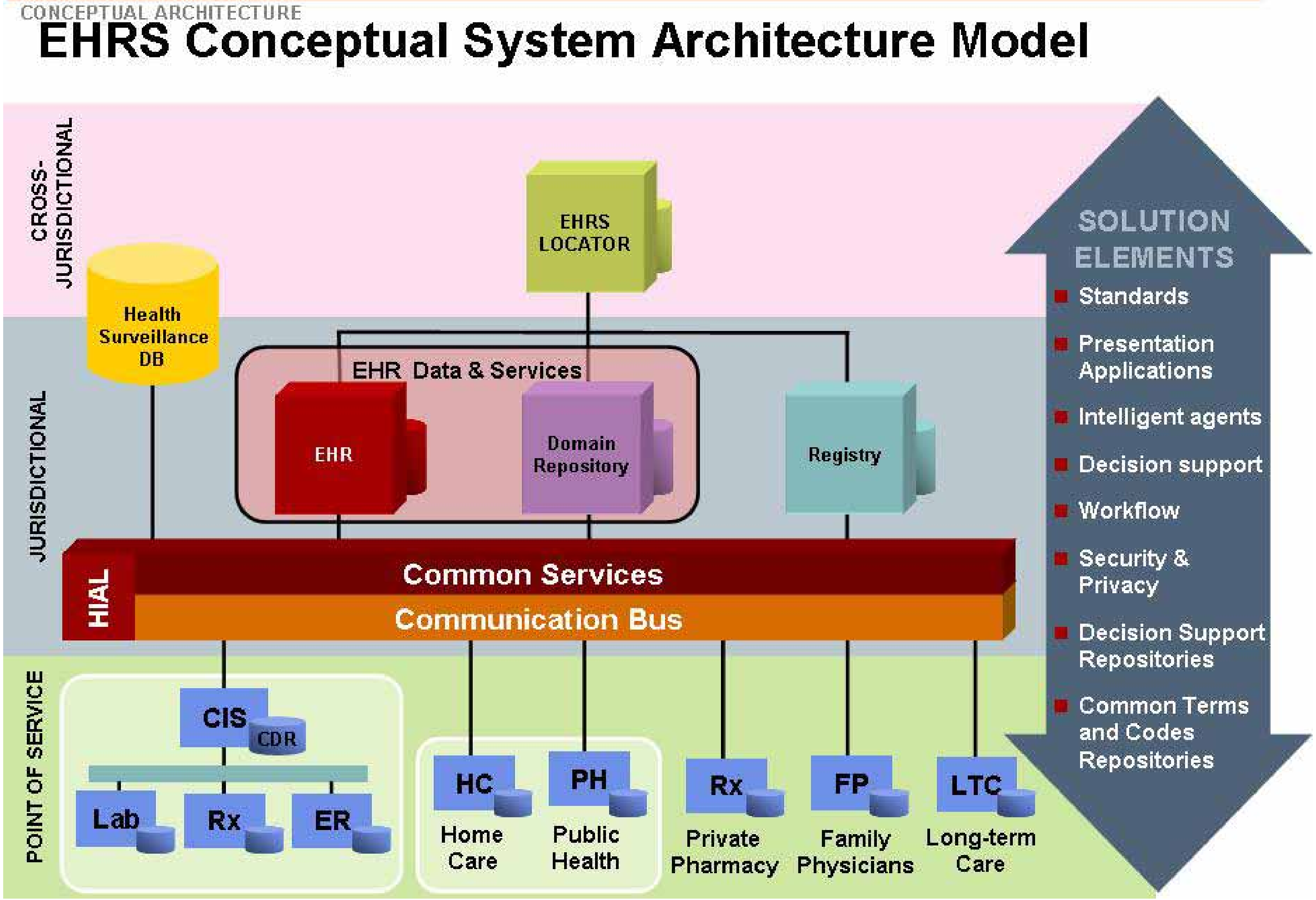
National health information infrastructure elements related to electronic health records

Infoway's national strategy for electronic health records is evolving from the 2003 publication of the *EHRS Blueprint, Version 1.0* to the February 2006 publication of *Version 2.0*. As described in the *EHRS Blueprint, Version 1.0*, Infoway's electronic health record solution includes cross-jurisdictional, jurisdictional (provinces, territories, and sub-provincial and sub—territorial Regional Health Authorities), and point of service elements (see Figure 4.5). Cross-jurisdictional services would be supported by a health information access layer (HIAL), enabling a pan-Canadian electronic health record ''service'' (Canada Health Infoway 2005 Dec, 8). Implementation of the electronic health record infostructure may vary at the jurisdictional level, depending upon provincial and jurisdictional size and other considerations (Canada Health Infoway 2005 Dec). ''Full featured'' implementation of an electronic health record infostructure will include: registries data and services (client, provider, location, and terminology registries); ancillary data and services (infectious disease outbreak management and public health surveillance reporting); electronic health record data and services (shared health record, and drug information, diagnostic imaging, and laboratory domain repositories that are operational data stores); a data warehouse; longitudinal record services (business rules and message structures); and the health information access layer, which provides access to the registries, ancillary data and services, and electronic health data and services for applications at points of service, such as laboratories, home care, and family physicians. Point of service elements will include systems for public health services, systems used by individual providers (pharmacy, radiology, laboratory, hospital, physician office, and so forth), and an electronic health record viewer through which the provider can access the electronic health record data (Canada Health Infoway No Date b, 116). See Figure 4.6. Reflecting the emphasis on public health surveillance added through the funding of Infoway to develop public health surveillance systems in March 2004, *Blueprint, Version 2.0* will apparently more thoroughly explore and define the public health surveillance delivery systems within the national strategy for electronic health records (Canada Health Infoway No Date b; Canada Health Infoway 2005 May; Canada Health Infoway 2005 Dec). These issues are discussed below in Uses for population health monitoring and research.

Electronic health record storage

As currently conceived in Canada's evolving national strategy for electronic health records, data storage may vary somewhat among jurisdictions of different sizes. In the ''full featured'' electronic health record infostructure, data storage at the jurisdictional level would include a shared health record, which was described in Infoway's *EHRS Blueprint, Version 1.0* as the electronic health record data base ''contain[ing] client-centric longitudinal data. . . belonging to multiple clinical domains'' (Canada Health Infoway 2003, 48, 13; Canada Health Infoway No Date b, 116). Additionally, domain repositories will ''store and provide access to specific clinical data, typically at a jurisdictional level that is not replicated in the EHR'' and ''will typically be the operational data stores for jurisdictional-level domain functions, such as drug prescribing and dispensing'' (Canada Health Infoway 2003, 40). Client identifying information will be stored in the client registry. Finally, a data warehouse with health information may

Figure 4.5. Key elements of Canada's Electronic Health Record Solution Conceptual System Architecture model



SOURCE: Canada Health Infoway, Inc. (2003 Jul). *EHRS Blueprint: An Interoperable Framework* version 1.0, Montreal QC (CA): Canada Health Infoway, Inc; 39.

also exist at the jurisdictional level (Canada Health Infoway No Date b, 116). Additional operational data would also be stored in point of service systems maintained by individual healthcare providers.

Patient confidentiality and participation

A basic tenet of the Romanow Commission was that ''individual Canadians should have ownership over their personal health information, ready access to their personal health records, [and] clear protection of the privacy of their health records'' (Commission on the Future of Healthcare in Canada 2002, 76). In keeping with the Romanow Commission's finding, a key feature of Infoway's national strategy for electronic health records is that ''patients have the right to determine the purpose, when and who can access their PHI [personal health information]'' (Ratajczak 2005 Nov, 11). However, given the nature of the Canadian governmental system, the legal specifics of patient consent and participation in electronic health records will vary among the provinces and territories (Canada Health Infoway 2005 Jun, 61–62). Canada Health Infoway's electronic health record infostructure will enable electronic health records to reflect jurisdictional variation in the ''statutory right of an individual to restrict the use or disclosure of his or her PHI'' [personal health information], known in Canadian parlance as a ''lockbox'' (Canada Health Infoway 2005 Jun, 63). According to the *EHRS Blueprint, Version 1.0* ''at the very least, consent will be specific to a particular encounter with a specific healthcare provider'' (Canada Health Infoway 2003, 31).[4]

Since the publication of the *EHRS Blueprint, Version 1.0* in July 2003, Infoway has specified in detail consent and participation issues relating to electronic health records (Canada Health Infoway 2005 Jun; Ratajczak 2005 Nov). The electronic health record infostructure will contain ten privacy and security services, including a ''Consent Directives Management

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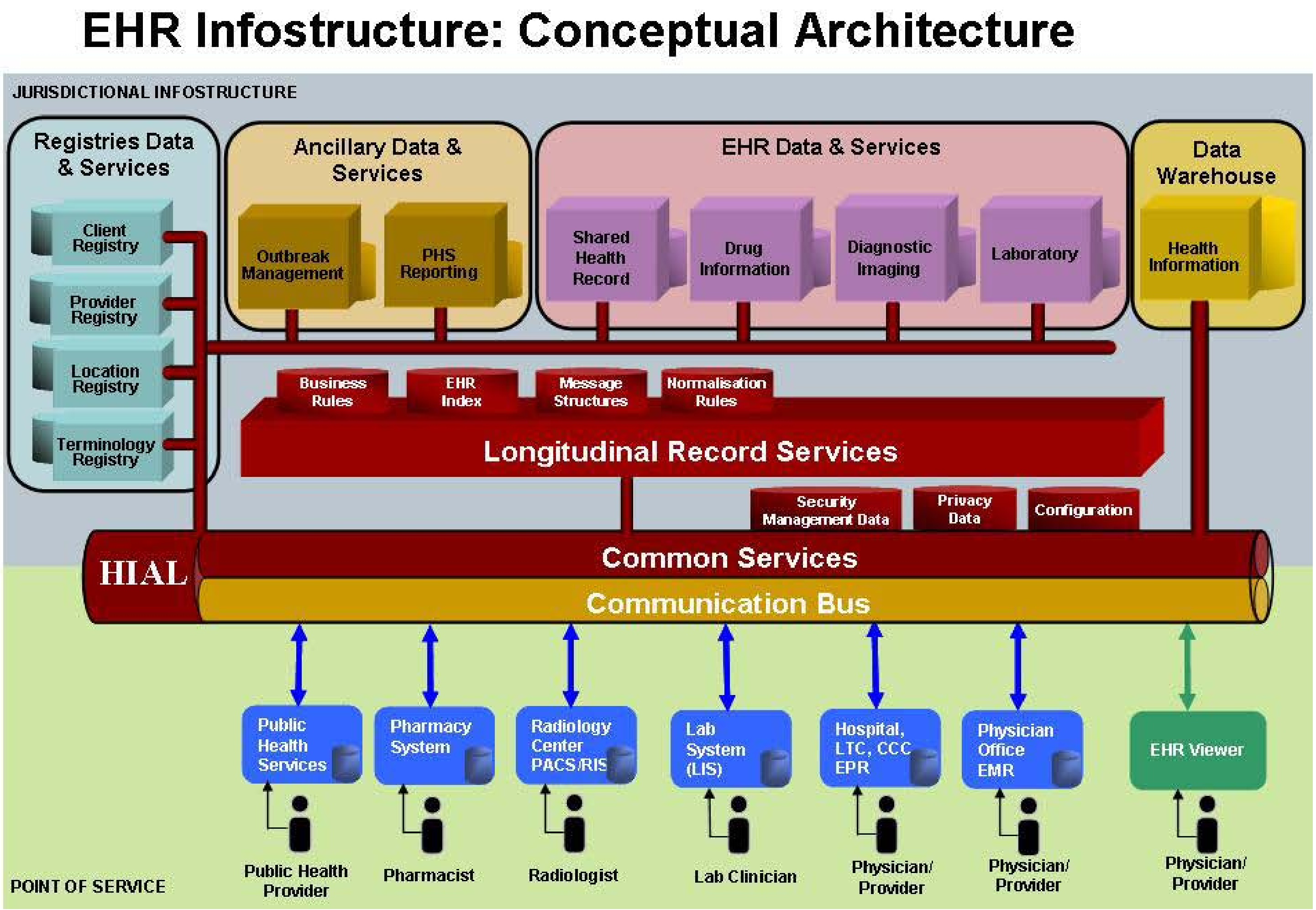
[4] The ''Pan-Canadian health information privacy and confidentiality framework'', developed by the Federal/Provincial/Territorial Conference of Deputy Ministers of Health, recommends that ''personal health information may be disclosed for the purpose of public health surveillance without the individual's consent subject to overriding constraints'', which would affect jurisdictional implication of any lockbox (Health Canada 2005 Jan 27).

Figure 4.6. Canada’s full featured Electronic Health Record Jurisdictional Infostructure



SOURCE: Canada Health Inforway (No Date b). Infoway architecture update. Montreal, QC (CA): Canada Health Infoway Inc. Available from: http://forums.infoway-inforoute.ca/webx?50@424.y3SsaHXmarA.3@.eec6995/2 [cited 2006 Jan 18]: 116.

Service that translates privacy requirements arising from sources such as legislation, policies, and individuals’ specific consent directives, and applies these requirements” (Canada Health Infoway 2005 Jun, 26). An additional privacy and security service will be an “Anonymisation Service.” The Anonymisation Service will anonymize data by removing all personal identifiers for secondary uses such as healthcare research and administration (Canada Health Infoway 2005 Jun, 27). It will also pseudonymize data, enabling person-specific linkage of person-specific data through “a meaningless but unique identifier” for approved researchers and some public health surveillance purposes (Canada Health Infoway 2005 Jun, 78).

Canada Health Infoway’s *EHRS Blueprint, Version 1.0* does not address healthcare provider consent issues relating to the electronic health record. Resolution of these issues will probably be jurisdiction and perhaps sub-jurisdiction (Regional Health Authority)-specific, and will also depend upon the particular role and organizational locus of the individual healthcare provider.

Patient identification

Canada has neither a unique national identifier nor a unique national health identifier (Advisory Council on Health Infostructure 1999, 3–6; Canadian Institute for Health Information 2000, 9). The Advisory Council on Health Infostructure “is strongly opposed to multipurpose identifiers and believes that they can lead to serious invasions of privacy”, and a national workshop on recipient identifiers and registries held by the Canadian Institute for Health Information (CIHI) concluded that “a single unique lifetime healthcare recipient identifier **is not** required at a national level” (Advisory Council on Health Infostructure 1999, 3–6; Canadian Institute for Health Information 2001a, 7). A CIHI study found that “a wide variety of unique identifiers were found to be in use in the Canadian healthcare system with varying levels of sophistication”, and the CIHI workshop concluded that jurisdictionally unique health identifiers are necessary (Canadian Institute for Health Information 2000, 9; Canadian Institute for Health Information 2001b, 1). In some provinces, provincial health numbers could be employed or adapted as unique health identifiers for electronic health records (Ontario Hospital eHealth Council 2003, 3).

Canada Health Infoway has focused on client registries as its solution to unique identification of patients for electronic health record purposes. Infoway defines a client registry as ''like a 'white pages' phone book, a directory of people being treated'' Canada Health Infoway 2004a, 11). The client registry ''uniquely identifies individuals across a large segment of a regional healthcare continuum, typically an entire jurisdiction'' and will serve as a ''single 'source of truth' in each jurisdiction'' (Canada Health Infoway 2003, 41; Hodge 2004). As defined by Infoway in 2005, the client registries will include a range of identifying data about all people who have received healthcare in a given jurisdiction: static ''natural person'' identifying information (such as birthdate), dynamic natural person identifying information (such as address and telephone number), and static and dynamic ''artificial person'' identifying information (such as various health identifiers used by individual providers) (Canada Health Infoway 2005 Jun, 22; Canada Health Infoway 2005 Dec, 23). Jurisdictional client registries will recognize that individual clients may have multiple health identifier numbers even within a single jurisdiction, and will provide identification services to enable unique identification of individuals for electronic health record purposes despite the existence of those multiple identification numbers (Canada Health Infoway 2003, 37). As currently conceptualized by Infoway, each jurisdictional client registry will generate unique electronic health record infostructure client identifiers (ECID), which will be ''a meaningless but unique number that is only known or used within the jurisdictional implementation of the EHRi'' [electronic health record infostructure] (Canada Health Infoway 2005 Jun, 26). In addition to the ECID, another meaningless but unique number known as a federated identifier (FID) will be developed for those individuals who receive care within more than one jurisdiction, enabling the sharing of data without disclosure of the ECID (Canada Health Infoway 2005 Jun, 26–27).

Infoway and individual provinces are investing in developing client registries. In March 2005, Infoway announced new investments of U.S. $1,566,000 in four new projects, including a client registry project and a ''client registry toolkit'' to facilitate implementation of jurisdictional client registries (Canada Health Infoway, 2005b; 2005c). Infoway also collaborated with Newfoundland and Labrador's Centre for Health Information in the development of its provincial client registry, and with the Capital Health Regional Health Authority in Edmonton in the development of its netCARE client registry (Canada Health Infoway 2005c). Other jurisdictional client registry efforts underway include a common client registry for Prince Edward Island and Alberta's Wellnet (Miller No Date; Ryan 2002; 2003).

Uses for population health monitoring and research

In 1999, Health Canada instituted a National Health Surveillance Infostructure program, with federal, provincial and territorial partners (Health Canada 1999). In its 2001 recommendations regarding the National Health Surveillance Infostructure, the Advisory Committee on Health Infostructure emphasized ''national standards needed to create the core data set for the electronic health record include the needs of preventive public health'' (Advisory Committee on Health Infostructure 2001a, 8). In 2002, both the Romanow Commission and an invitational workshop convened by Health Canada pointed to the potential uses of aggregated, de-identified EHRs for research and policy-making purposes (Commission on the Future of Healthcare in Canada 2002, 79; Deerfield Group 2002, 8). Health Canada has acknowledged EHRs as ''contribut[ing] significantly to public outcomes'' and as ''perhaps the ultimate solution to enhancing chronic disease surveillance'' (Goddard et al. 2004, 114; Health Canada 2003). In its high level model for public health and healthcare, published as part of the *EHRS Blueprint, Version 1.0*, Health Canada identified the electronic health record as ''the integrating vehicle that allows data and information to flow from health sub-system to health sub-system'', including the public health system (Canada Health Infoway 2003, 139). The public health community has also recognized the ''use of the fully implemented EHR infrastructure as the primary feed for person-level clinical data to the data analysis environment'' as a ''could do'' requirement for the conceptual architecture for communicable disease surveillance (Canada Health Infoway 2004b, 6).

Although the *EHRS Blueprint, Version 1.0* identified research and disease surveillance as among six secondary uses of the electronic health record, the original Infoway business plan did not include any form of population health monitoring as a strategic investment program (Canada Health Infoway 2003, 7; Goveia 2004, 48). However, in the wake of the SARS epidemic, Infoway was funded in 2004 to add public health surveillance systems as one of its nine strategic investment programs (Canada Health Infoway [hp], What we do, public health surveillance).

Canada Health Infoway's public health surveillance ''investment will focus on a pan-Canadian approach to health surveillance and where appropriate integrate it into the electronic health record architecture and infostructure'' (Beasley, Danderfer, and Bornstein 2005 May). The public health surveillance program will focus on infectious diseases, and will include surveillance, outbreak notification (''health alert management''), outbreak management, case management, reporting, and immunization management (Beasley, Danderfer, and Bornstein 2005 May). As currently conceptualized, each electronic health record jurisdictional infostructure will include the ancillary data services of outbreak management and public health surveillance reporting; electronic health record data services with a shared health record supporting case management and an immunization registry; the health information access layer (HIAL) providing outbreak notification services;

a data warehouse providing public health surveillance data warehouse services; and a public health surveillance portal enabling point-of-service access to operational data (Canada Health Infoway 2005 Dec).[5]

New Zealand

Summary

The New Zealand Ministry of Health has set the national strategy for electronic health records and the supporting national health information infrastructure within the overall framework of national population health and health system strategies. New Zealand health information and health information technology strategies have been integrated into the larger population health and health system strategies since the publication in 2000 of *The New Zealand Health Strategy* and in 2001 of *From Strategy to Reality* (Ministry of Health 2000 Dec; Ministry of Health 2001 Oct). *Health Information Strategy for New Zealand*, published in August 2005, constitutes the most recent national strategic statement regarding electronic health records (Ministry of Health 2005 Aug). New Zealand has rejected ‘‘a single integrated record [. . . as] neither workable nor practicable’’ (Ministry of Health 2005 Aug, 10). Instead, New Zealand has adopted what it describes as a distributed electronic health record that consists of: local systems for direct clinical care, which are owned and operated by healthcare service providers and may vary among providers; regional systems for coordination of care and decision-making about service delivery; and national systems, which include individual health event- and health topic-specific data collections. Data held in local, regional, and national systems rely on the National Health Index number, which enables linkage at the individual patient level when allowable.

Locus of national responsibilities

The locus of national responsibilities for development of national health information infrastructure strategies lies within the Ministry of Health and its New Zealand Health Information Service.

Current status and plans

International data indicate that Internet usage in New Zealand is higher than in other surveyed countries, with 70% of respondents having used the Internet in the last month and 40% having dealt with New Zealand government through the Internet (Health e-News 2003 Mar 4). Almost 100% of general practices employ practice management software, with most using it for maintaining cervical screening, diabetes, breast screening, asthma, and blood pressure registries (Didham, Dovey, and Barker 2005, 8, 11). Over 90% of general practices utilize electronic messaging (Didham, Dovey, and Barker 2005, 8, 11). The Deputy Director-General of the Ministry of Health has estimated that ‘‘every hospital—‘100%’—uses EHRs’’ (O’Connor 2004, 16).

The New Zealand Ministry of Health has repeatedly emphasized the development of ‘‘a nationally coherent and consistent approach to a health information infrastructure, based on improving access to information and the consolidation of appropriate standards’’ (Ministry of Health 2000 Dec, 29). New Zealand’s national approach starts with an overall health strategy, addressing health systems issues within the context of population health and setting goals for both simultaneously. The 2001 Ministry of health information management and technology plan, reporting on the results of the Working to Add Value through E-information (WAVE) project, pointed out that ‘‘information systems do not exist in isolation from policy, programmes, or political imperatives’’ (Ministry of Health 2001 Oct, 9). The top ten priorities emerging from the WAVE project included a mix of population health information content priorities (collection of reliable ethnicity data and primary care information), information technology priorities (cleaning up messaging standards), and population health and health system priorities tied to information technology (making integrated care work by developing standards for data exchange, security, and network infrastructure) (Ministry of Health 2001 Oct). The Ministry of Health’s 2005 report, *Health Information Strategy for New Zealand*, similarly stresses the link between national health strategies, national health information strategies, and regional and local information systems strategic plans (Ministry of Health 2005 Aug). See Figure 4.7. The *Health Information Strategy for New Zealand* specifies twelve ‘‘action zones’’ that provide a focus for implementation planning for the next three to five years; these action zones also include a mix of population health information content priorities (national outpatient and primary care data collections), information technology priorities (national network implementation, ePharmacy, eLabs), and population health priorities (Ministry of Health 2005 Aug, x).

The *Health Information Strategy for New Zealand* points out that ‘‘as a small nation, New Zealand does not have the financial resources nor the time to approach information system challenges with a grand plan from the top down. Conversely, when it comes to making investments in complex information systems, we cannot afford to re-invent the wheel and have everybody decide to solve problems in their own unique way’’ (Ministry of Health 2005 Aug, 10). As a result, the Ministry of Health has chosen a limited set of national health information infrastructure targets for national investment, while adopting an entrepreneurial approach for others (O’Connor 2004). For example, the Ministry of Health ‘‘deliberately focuses on enabling better use of information

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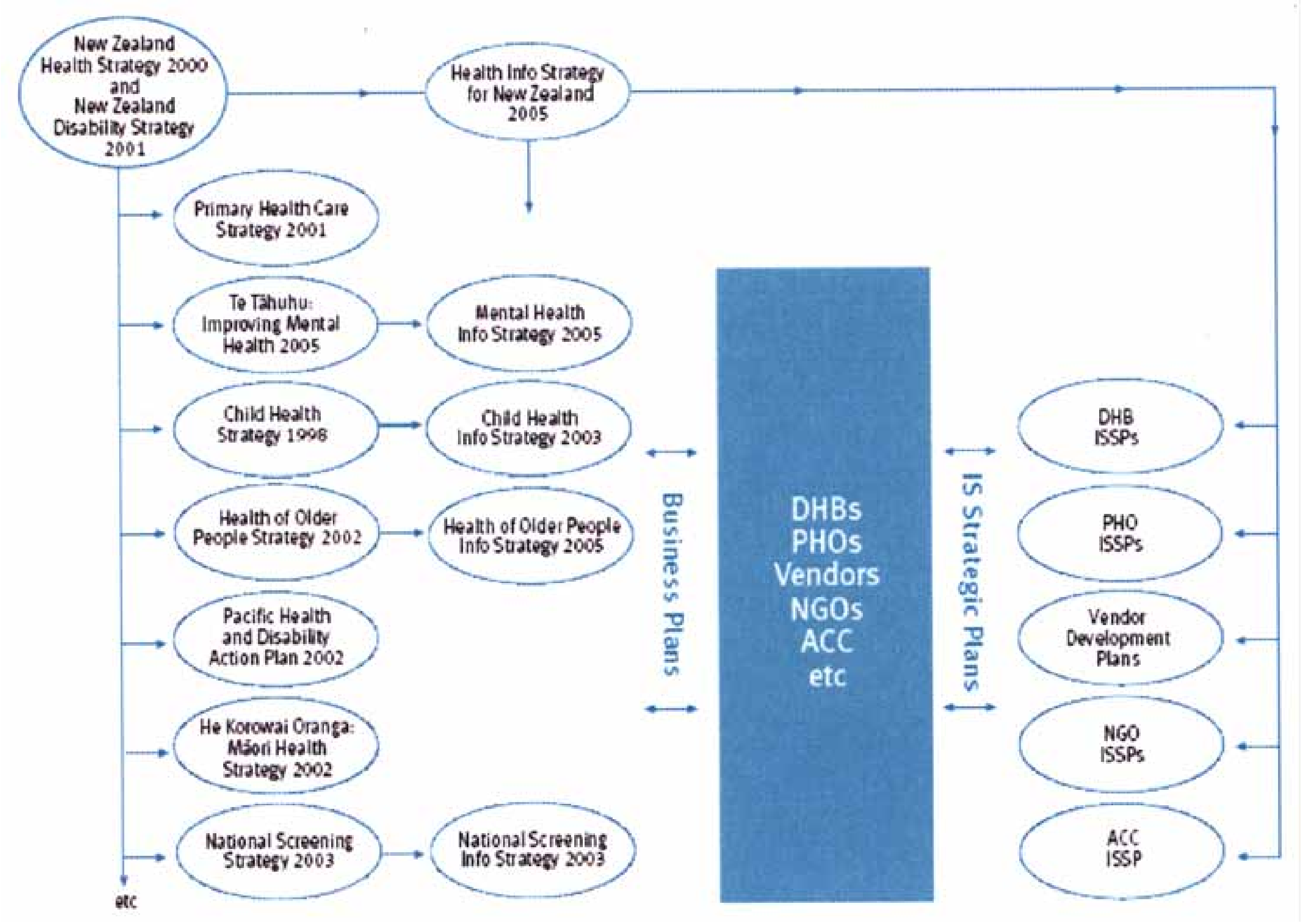
[5] Infoway officials have ‘‘acknowledged that synchronization between the proposed public health surveillance system and EHRs is a long-term prospect’’: ‘‘What will happen is that this communicable disease surveillance effort will unfortunately have to be fed mostly by the long-suffering staff at public health agencies that have to key enter a lot of data. . . In the near term, our job is to design and build surveillance systems so that they’ll have the hooks built into them to be able to accept input from EHR, but realizing that EHR systems are not going to be universal’’ (Schick 2005).

Figure 4.7. New Zealand's linkage between health strategies and information strategies



SOURCE: Ministry of Health (2005 Aug). Health Information Strategy for New Zealand. Wellington (NZ): Ministry of Health; 6.

between service providers across the New Zealand health and disability sector. Better information usage *within* any one organisation is supported by HIS-NZ [Health Information Strategy for New Zealand] setting priorities and providing guidelines. . . Each organisation, however, needs to take responsibility for their own strategic systems plans to guide the development of solutions to their unique business challenges'' (Ministry of Health 2005 Aug, 17).

''Historically, there has been no sector-wide approach to developing health information systems in New Zealand'' (Kerr 2004). However, New Zealand's twenty-one population-based District Health Boards, which have ''overall responsibility to assessing the health and disability needs of communities in their regions, and managing resources and service delivery to best meet those needs'', have been required to follow a common methodology in identifying strategic health information technology needs and to utilize a common format for Information Systems Strategic Plans (Jackson 2004 Sep 8; Ministry of Health 2001 Feb, 4; Ministry of Health 2003 Dec-b, 128). Shared information technology service agreements also exist among the District Health Boards (Kerr 2004; Ministry of Health 2005).

The Ministry of Health adopts an incremental approach to building the national health information infrastructure, as expressed by the then General Manager of Information Management and Technology of Statistics New Zealand: ''we cannot afford to make large mistakes. . . so let's make lots of small ones:-)'' (Osborne 2002 Aug, slide 19). The Ministry of Health and the New Zealand Health Information Service emphasizes their commitment to ''having a business plan that can be swallowed in small bits'' and ''accept[ing] that some of the anomalies in the [health] system—such as fragmentation—won't go away easily. . . it's better to work within this framework rather than try and change it in the short term'' (Health e-News 2002 Jun, 8). The incremental approach to developing New Zealand's national health information infrastructure is reflected in its information management building blocks approach, with an emphasis on ''getting the basics right'' (Osborne 2002, slide 7). The individual building blocks will be described in Electronic health records elements below (Ministry of Health 2005 Mar).

Electronic health record definition

New Zealand's approach to defining the electronic health record reflects the Ministry of Health's ''small bits'' approach. The 2001 WAVE report observed that ''feedback shows the preferred option [for implementing electronic health records] is an incremental approach, as it would minimise disruption, help stakeholder acceptance in the change management process, improve accountability for future proofing, and cost less. Furthermore, an incremental approach does appear to be happening, although it lacks a national approach'' (Ministry of Health 2001 Oct, 28). New Zealand has rejected what some New Zealand information system managers describe as the ''holy grail'' of an electronic health record that ''holds all medical information about a patient, is contributed to by every clinician involved in the patient's care, and is deployed for every patient. For a clinician to access the record, they must go onto the internet, enter a patient's ID and voila—everything about that patient is instantly available'' (Leech 2004 Mar). The Ministry of Health's emphasis is on the collection, use, and retention of patient information close to the actual site (the ''coal face'') of patient care (Cressey 2002 Aug, slide 20). The *Health Information Strategy for New Zealand* thus ''has discounted a single national repository EHR for all of an individual's identifiable health information'' (Ministry of Health 2005 Aug, 12). Instead, the Ministry of Health ''envisions an electronic health record distributed at local, regional and national levels, with the richest and most detailed information about a consumer kept locally'' (Ministry of Health 2005 Aug, 12).

National health information infrastructure elements related to electronic health records

The development of a distributed electronic health record will be facilitated by the following elements, some already implemented and some currently planned:

- National Health Index (NHI), which includes patient-specific demographic and other information associated with the National Health Index number (New Zealand Health Information Service [hp] National Health Index, NHI and MWS Fact Sheet). The National Health Index and the National Health Index number will be discussed further below in Patient identification.
- Medical Warning System, which is linked to the National Health Index and ''designed to warn health and disability support services of any known risk factors that may be important when making clinical decisions about individual patient care'', and contains medical warnings (allergies, adverse reactions, drug sensitivities), medical alerts (significant medical conditions), and hospital event summaries (New Zealand Health Information Service [hp] National Health Index, NHI and MWS fact sheet).
- National Minimum Data Set for hospital events, which is linked to the Medical Warning System via the National Health Index. The National Minimum Data Set for hospital events eventually will be supplemented by additional new National Minimum Data Sets (Ministry of Health 2005 Aug, 21, 25–26, 65; New Zealand Health Information Service [hp] Data & Services, Guide to NZHIS national collections: National Minimum Dataset (hospital events)).
- Electronic connectivity within the health sector through a ''national network strategy'', relying on secure broadband (Ministry of Health 2005 Aug, 22–23, 32–35). Connectivity is now primarily facilitated by HealthLink's virtual private network, which provides electronic data interchange for 75% of health sector organizations and 95% of GPs (health eLink 2004 Aug; Protti and Graham 2003, 29).
- Health Information Standards Organisation, an independent body established in 2003 to coordinate the development and implementation of standards (Health e-News 2004 Jul; Ministry of Health 2005 Aug, 43–44).
- ePharmacy, eLabs, and the Health Provider Index, all of which are included in the New Zealand Health Information Strategy as essential ''action zones'' for implementation within a five year time frame (Ministry of Health 2005 Aug, 24–25).

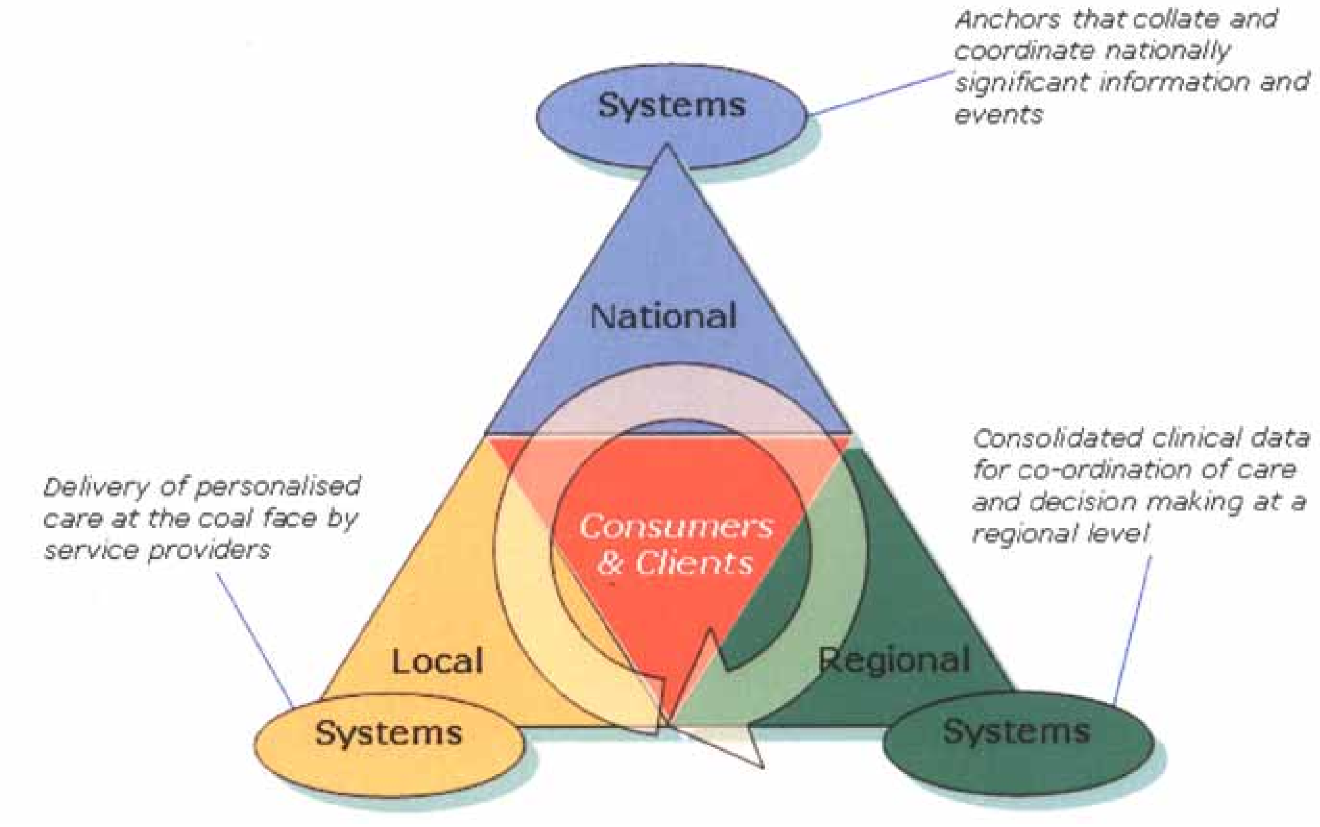
Electronic health records storage

As described in the *Health Information Strategy for New Zealand*, the distributed electronic health record approach includes three levels of systems and apparently three levels of data retention as well. See Figure 4.8.

The first level of data storage is ''local systems [that] support the delivery of personalised care 'at the coal face' by service providers. These systems have the most amount of detail and carry rich data about a consumer and any given interaction'' (Ministry of Health 2005 Aug, 12). Under the distributed electronic health record model, ''these systems are owned and driven by the individual service providers'' (Ministry of Health 2005 Aug, 12). These local systems are 'diverse' applications [that] are typically built for a specific purpose and often require local development of highly innovative applications'' (Ministry of Health 2005 Aug, 37).

The second level of data storage is ''regional systems [that] consolidate specific clinical data at a regional level for the co-ordination of care and decision making around service delivery. Typically they provide key event summaries that abstract relevant information from consumer encounters'' (Ministry of Health 2005 Aug, 12). In contrast to the local systems featuring diverse applications, the regional ''systems are owned and driven by regional agencies such as DHBs [district health boards], shared support agencies and PHOs [primary health organisations]'' (Ministry of Health 2005 Aug, 12). Regional systems feature 'common' applications, supporting clusters of organisations operating with standard business processes [which. . .]

Figure 4.8. New Zealand's distributed Electronic Health Records model



SOURCE: Ministry of Health (2005 Aug). Health Information Strategy for New Zealand. Wellington (NZ): Ministry of Health; 12.

should be consistent with national directions'' (Ministry of Health 2005 Aug, 37).

The third level of data storage is national systems (''anchors'') that ''provide shared data and consistent business processes to the health and disability sector of New Zealand. They provide reference points and 'anchors' for nationally significant information and events and support a number of clinical safeguards such as the Medical Warnings System (MWS)'' (Ministry of Health 2005 Aug, 13). Systems operating at the national level are 'core' applications [that] can only function well if they are singular and are best managed nationally'' (Ministry of Health 2005 Aug, 37). These national ''systems are owned and operated by national agencies such as the Ministry of Health'' (Ministry of Health 2005 Aug, 13). Examples of national data retention include the current National Health Index and Medical Warnings System, the current National Minimum Data Set (inpatient discharges) together with its planned enhancements, and planned national collections for outpatient or community care and primary care (Ministry of Health 2005 Aug, 25–28, 82–85).

Patient confidentiality and participation

Issues relating to patient consent to collection and use of data included in electronic health records would be governed by the New Zealand Privacy Act of 1993 and the Health Information Privacy Code of 1994, as amended most recently in July 2000 (O'Connor 2004; Stewart 2004). Neither the Privacy Act, nor the Health Information Privacy Code, nor the *Health Information Strategy for New Zealand* directly address or resolve issues relating to e-consent. The Health Information Privacy Code stipulates that health agencies must take reasonable steps to ensure that individuals are informed of data collection about them and the intended recipients of the data, provided access to the data, entitled to request correction of the data, and that use of the collected data for any other than the original purpose is subject to the individual's authorization (Office of the Privacy Commissioner 2000 Jun, 8, 10–11, 13; Office of the Privacy Commissioner 2002). The Health Information Privacy Code permits disclosure of health data, without the individual's consent, if the data are not identified and are used for approved research or statistical purposes, or are identified and are needed to avert a public health or safety threat (Office of the Privacy Commissioner 2000 Jun, 14–15). The Office of the Privacy Commissioner has addressed some issues related to e-consent, such as concerns emerging from patient request for destruction of medical records, concerns about privacy and centralized health data bases, event summaries, and integrated care (Office of the Privacy Commissioner 1998 Apr, 1998 May, 1998 Aug, 1998 Nov–Dec, July–August 2001 Jul–Aug,

The *Health Information Strategy for New Zealand* does not directly address provider participation in electronic health records. Policies regarding provider participation would probably occur at the District Health Board or Primary Health Organization levels.

Patient identification

The National Health Index number is an alphanumeric seven digit code intended to serve as a unique identifier ''assigned to each person using health and disability support services'' (New Zealand Health Information Service [hp] National Health Index, NHI Frequently Asked Questions). The New Zealand Health Information Service estimates that ''about 95% of New Zealanders have their own unique NHI number'' (New Zealand Health Information Service [hp] National Health Index, NHI Frequently Asked Questions). The National Health Index ''is an index of information associated with that unique number'', and includes name, maiden name, date of birth, sex, residency status, ethnicity, and any medical warnings.

The National Health Index number can be used only by authorized users, such as health services providers, screening programs, and public health programs. Authorized users can only employ the National Health Index number for stipulated purposes, including obtaining information from clinical information systems, and accessing the Medical Warnings System and the National Immunization Register. Additionally, the Ministry of Health uses an encrypted National Health Index number for unique identification of individuals on central data bases for statistical purposes (New Zealand Health Information Service [hp] National Health Index, NHI Frequently Asked Questions).

In its 2001 WAVE report, the Ministry of Health identified the need to ''fix up the National Health Index (NHI)—allow primary provider access, improve ethnicity data'' (Ministry of Health 2001 Oct). The WAVE report recommendation has been implemented through a 2003–2004 effort to de-duplicate the National Health Index through ensuring that each National Health Index number pertains to only one New Zealander and that each New Zealander has only one National Health Index number (New Zealand Health Information Service [hp] National Health Index, NHI Frequently Asked Questions). Implementation also occurred through the development of the NHI On-line Access for Health (NOAH), a Web-based application that provides access to the NHI and the Medical Warnings System for health services providers, regardless of their particular electronic Patient Management System (Delany 2002, slides 14–15; Health e-News 2004 Jul). Despite these efforts, the 2005 *Health Information Strategy for New Zealand*, which identified the National Health Index as one of the national anchor applications, pointed out that ''while it has been available for a number of years, it has been implemented comprehensively only within secondary care, and in more recent years by organised general practice for pharmacy and laboratory referrals and in enrolment; it will need to be more widely available across the entire sector to effectively support other applications such as EHRs'' (Ministry of Health 2005 Aug, 36).

Uses for population health monitoring and research

Any current and potential uses of New Zealand's distributed electronic health record for population health monitoring and research should be viewed within the larger New Zealand context of its attempts to integrate population health content development with national health information infrastructure development. As indicated earlier, the Working to Add Value through E-Information Advisory Board set forth 10 top priorities in 2001, with four priorities relating to population health monitoring: ''collect reliable ethnicity data'', ''fix up the National Health Index'', ''gather primary care information'', and ''sort out health event summaries—with data dictionaries, electronic discharges and referrals'' (Ministry of Health 2001 Oct). These priorities reflected the Advisory Board's assessment of then current shortcomings with population health information: ''Health providers are collecting large amounts of data, yet important information on ethnicity or health status is not being captured. The collected data is stored in a variety of databases but not fed back and is, therefore, of only limited use. No organisation currently has a mandate (or resources) to mine existing healthcare data sets systematically. Lack of links (such as NHI) makes research at the population health level difficult'' (Ministry of Health 2001 Oct, 23). Later Ministry of Health reports identified the need to improve data in order to match and support changing service delivery priorities, including greater integration between primary and secondary care, reducing inequalities, and reorganizing primary care (Ministry of Health 2002 Aug, viii). As the Ministry of Health increases its emphasis on chronic disease management for diabetes and cardio-vascular disease, it also recognizes needs for new information (Ministry of Health [hp] Leading for Outcomes, What is leading for outcomes?; Protti and Graham 2003, 30).

The Ministry of Health addresses information needs now through several national collections, which are a range of data sets that ''support policy, research and prioritisation by enabling the analysis of national trends and outcomes'' or ''support the delivery of healthcare'' (Ministry of Health 2005 Aug, 39). Depending upon the specific purpose of the national collection, either the NHI number or encrypted NHI number and personal information is included. National collections include the Breast Cancer Screening Programme, Maternity and Newborn Information National Collection, Medical Warnings System, Mortality Collection, National Health Index, National Minimum Data Set (inpatient and day patient publicly funded hospital discharges), New Zealand Cancer Registry, and the Private Hospital Reporting System, (Ministry of Health 2005 Aug, 40–42; New Zealand Health Information Service [hp] Data & Services). The national collections are now derived from a variety of healthcare provider sources in a variety of ways, including paper forms and electronic files.

Independent efforts are underway to extract population health data automatically from physician-held electronic records on an ongoing basis as part of the care process. PREDICTTM-CVD is a Web-based clinical decision support program that uses electronic patient records for profiling cardiovascular risk in individual patients, and as a byproduct electronically extracts from electronic patient records standardized data that can be aggregated to the practice and population level. The National Health Index number is used to link mortality and National Minimum Data Set hospital discharge data to data generated from PREDICT^{TM}-CVD (Entwistle and Shiffman 2005 Mar; Wells and Jackson 2005 Mar). The Royal New Zealand College of General Practitioners Computer Research Network has extracted clinical and demographic data from Patient Management Systems used in a sentinel sample of general practices, using encrypted NHI numbers as patient identifiers and as a linkage mechanism (Dovey and Tilyard 2001; Hall et al. 2002; Tilyard and Dovey 1999).

The Ministry of Health envisions using physician-held electronic data as the source for ongoing national collections. The National Immunisation Register is conceived as ultimately leading to a ‘‘hierarachy of registers of children’’ that would ultimately lead to ‘‘further implementation of electronic collection of well child information over time’’ (Ministry of Health 2003 Apr, v; Ministry of Health 2003 Dec-a, vi, 6–7; Paediatric Society of New Zealand 2004 Aug). The *Health Information Strategy for New Zealand* describes the distributed electronic health record model, using as an example the potential transformation of health event summaries from the current system with substantial with local variation, into a national anchor system. The national anchor system would include data shared at the regional level for healthcare purposes and data aggregated to the national level for population health monitoring purposes (Ministry of Health 2005 Aug, 13). Similar approaches are contemplated for new national collections, such as diabetes, in which data would be generated at the practice level for care purposes, shared at the regional level also for care and practice monitoring purposes, and aggregated at the national level for population health information purposes (Ministry of Health 2005 Aug, 14, 78–79). Other planned national collections, such as national primary care and community care collection and national [hospital] outpatient collection, would be generated for purposes of regional and national population health monitoring (Ministry of Health 2005 Mar, 84–87).

Table 4.1. National strategies for electronic health records, by country: 2005

	Australia	Canada	England	New Zealand
Locus of national responsibilities	– Health*Connect* (Department of Health and Ageing); National E-Health Transition Authority	– Canada Health Infoway	– National Health Service (NHS) Connecting for Health	– New Zealand Health Information Service (Ministry of Health)
Major documents	– *HealthConnect* Business Architecture, version 1.9 (2004 Nov)	– *EHRS Blueprint: An Interoperable EHR Framework,* version 1.0 (2003 Jul)	– Information for health: an information strategy for the modern NHS 1998–2005, a national strategy for local implementation (1998 Sep) – Building the information core—implementing the NHS plan (2001 Jan) – Delivering 21st century IT support for the NHS: national strategic programme (2002 Jun) – Making IT happen: Information about the National Programme for IT (2004) – Creating a patient-led NHS: delivering the NHS improvement plan (2005 Mar)	– The New Zealand Health Strategy (2000 Dec) – From Strategy to Reality: the WAVE Project Health information management and technology plan: Working to Add Value through E-information (2001 Oct) – Health information strategy for New Zealand (2005 Aug)
Stages*	– Design	– Design, with broad national target dates for implementation	– Implementation, with specific national target dates	– Conceptualization
Current status	– Initial national strategy published in 2004 – Local pilots implemented and evaluated – Locus of responsibility for national strategy evolving – Key elements of supporting national health information infrastructure being specified, including: interoperability framework, health record design, clinical terminologies, clinical information, healthcare identifier, and E-health consent	– Initial national strategy published in 2003, with updated strategy to be published in 2006 – Strategic investments in key elements of supporting national health information infrastructure, including: registries (client, provider, and location), interoperable electronic health record systems, infostructure, innovation and adoption, and public health surveillance	– National strategy iteratively since 1998 – Local pilots implemented and evaluated – Implementation of electronic patient records occurring regionally – Implementation of electronic health record occurring nationally	– National strategy published in 2005
Patient identification	– Under discussion and development, with possibility of adaptation of elements of national health insurance number	– Under discussion and development, with emphasis on development of jurisdictional unique identifiers (electronic health record infostructure client identifier) and inter-jurisdictional identifier (federated identifier)	– National Health Service number	– National Health Index number
Patient confidentiality and consent	– Initial conceptualization of opt-in consent for participation in electronic health records – Consent options currently under reconsideration and in development	– Support for "lockbox," enabling patients to "mask" information at their request	– "Sealed envelope," enabling patients to designate information not to be shared beyond their immediate clinician – Limits of "sealed envelope" and implications for national electronic health record under discussion – Pseudo-anonymized and anonymized data can be shared for population health monitoring	– Not ascertained from publicly available materials

Table 4.1. National strategies for electronic health records, by country: 2005—Con.

	Australia	Canada	England	New Zealand
Population health monitoring	– Initial conceptualization of National Data Store of electronic health records, enabling uses of largely de-identified data for population health monitoring – Does not appear as current priority secondary use	– Investment in communicable disease surveillance as part of national strategy	– Secondary Uses Service implemented, with emphasis on uses of electronic health records and other data streams for population health monitoring	– Emphasis on national data collections

*Stages not intended to represent a continuum.

Chapter 5. Common Themes in Interviews with Expert Informants in Australia, Canada, England, and New Zealand

This section provides an overview of common themes relating to the potential contribution of national strategies for electronic health records to population health monitoring and research that emerged from interviews with expert informants in Australia, Canada, England, and New Zealand. Two broad categories of themes are emphasized here: first, the potential contributions of electronic health records to population health monitoring and research; and second, constraints on the realization of those potential contributions.

The reported themes represent the distilled responses of interviewed experts. The themes presented in this chapter should *not* be interpreted as objective renditions of the relationships between national strategies for electronic health records and population health monitoring and research: the themes are presented as reported in the interviews and do *not* constitute the conclusions of this report's author. Finally, given the qualitative and minimally structured interview format, no attempt has been made to quantify interview results or the number of informants making a particular point.

Potential Contribution

Integrating healthcare performance measurement with population health monitoring

Informants in all four nations stressed the potential for shared electronic health records to lead to real-time decision support systems and real-time feedback loop systems for clinicians and public health practitioners. What is now regarded as clinical data could be transformed into statistical data at population levels: ideally, this transformation would occur seamlessly. As articulated by New Zealand experts, Primary Health Organisations in New Zealand are already active in population health management in such areas as cardiovascular disease, diabetes, immunization, well child care, and hepatitis B and C. Widespread screening of adults ages 45 and over for cardiovascular disease now occurs among general practitioners using an automated Web-based risk assessment tool. Employing such Web-based risk assessment tools for patient management requires the collection of basic risk factor data, which are electronically recorded using standard data elements in standard formats. Although these data are being collected for solely clinical patient management purposes, they also have a high yield for population health monitoring and healthcare performance measurement. Collection of the data for patient management improves data quality and completeness, in contrast to data requested or required only for secondary purposes seemingly unrelated or only indirectly related to patient management. Bridges from clinical patient management to population health management to population health monitoring and healthcare performance measurement are thus built, transparently to the general practitioners entering the data. The recently implemented Leading for Outcomes chronic disease strategy in New Zealand was cited as encouraging the inclusion of standard data elements for selected diseases and conditions into ‘‘slim and focused’’ electronic patient records, potentially resulting in measurements that can ‘‘cascade’’ from general practitioners to Primary Health Organisations to District Health Boards to the Ministry of Health. Similarly, an English informant described the development of ‘‘care pathways’’ for specific conditions, which will require general practitioners and other healthcare providers to enter structured data pertinent to screening and treatment into electronic patient records; the electronic patient records will convert those structured data into SNOMED-CT codes, with data aggregatable to practice, Primary Care Trust, Strategic Health Authority, and national levels.

A Canadian informant stressed that population health monitoring does not require different strategies or information structures than those needed for healthcare performance measurement. According to another Canadian informant, public health reporting is now integrated into day-to-day clinical care and medical records, and could be similarly integrated with EHRs. Yet another Canadian respondent stressed that tight integration of population health monitoring into electronic health records can occur.

A related observation was the potential of electronic health records to lead to the development of integrated systems for measuring healthcare system performance at individual provider and provider group levels, with provider and provider group level performance measures then capable of being systematically aggregated to population level health system performance measurements.

Development of new data sets for population health monitoring and research

Informants pointed out that within ten to twenty years entirely new options for population health monitoring will exist as electronic health records become prevalent. New options for population health monitoring may be most evident for the earlier identification of emerging epidemics and other public health threats through electronic health records. In the nearer term than ten to twenty years, potential exists for the development of new data sets, such as post-marketing pharmaceutical surveillance, surveillance of adverse drug reactions, and expanded longitudinal follow-up registries for chronic diseases and conditions. In realizing this potential, new data sets could be iteratively implemented as EHRs are phased in on geographic or healthcare provider site bases, leading to the possibility of ‘‘early wins.’’ If electronic health record penetration is higher in acute care hospitals than in primary care settings, the potential for early wins was identified as highest for hospital-based data sets. Respondents also indicated additional potentials for transforming currently highly-targeted surveillance systems to broader based population health monitoring, and for incorporating some current survey questions into EHRs on a routine basis, such as questions relating to functional status, disability, smoking, and obesity. Based on the comments of the interviewed experts, it seems that these new data sets for population health monitoring derived from EHRs are envisioned as developing through information captured by the healthcare provider or extracted from electronic patient records and other clinical and administrative information systems and then transmitted to electronic health records.

Patient identification

When national, or state and provincial uniform patient identification systems include core demographic data, EHRs provide potential for stratifying by various demographic characteristics healthcare and population health outcomes measurements that are routinely available for analysis. The unique NHS number was mentioned as ''giving an edge on other countries through improving data quality and allowing linkage'' of EHRs with other data bases, such as cancer incidence data in cancer registries, for population health purposes.

Implications for population health research

Electronic health records could transform both clinical research and population health research. Once electronic health records penetrate acute care hospitals and primary care practices to a sufficient extent, a major paradigm shift could occur in population health and clinical research, enabling ''one stop shopping'' for healthcare, clinical research, and population health research. The ''hybridization of data'' could occur, erasing current distinctions between clinical data and population health data. The conduct of research could change. EHRs could eliminate the need for medical record abstraction, as the formerly manually abstracted data could be automatically extracted from EHRs. Research resources currently devoted to abstraction from medical records for clinical, population health, and health services research could be redirected. Australian, Canadian, and English informants predicted that any replacement of current data collections by EHRs is most likely to occur initially for administrative health data, such as hospital discharge data. Several English experts also predicted that EHRs will feed data to or ultimately replace some current disease registries. Most likely for replacement are those disease registries, such as cancer registries, which already rely on semi-automated data collections.

New types of data: In addition to replacing current semi-automated disease registries, electronic health records could also enable creation of new population- and practice-based disease registries; current registries might persist but with data automatically extracted from electronic health records. New disease registries and the EHRs that support them will yield population-based morbidity and disease prevalence data, now largely unavailable. Electronic health records will make available on an ongoing basis data that are currently available only through resource-intensive data linkage, especially in those nations without national or sub-national unique patient identifiers or regional patient registers. EHRs utilized throughout healthcare systems will enable tracking of how people move through and beyond the healthcare system. Trajectories of healthcare for patients with different profiles and for different subpopulations will be more readily investigated, including key transitions between different health states and different parts of healthcare systems. EHRs will enable ''understanding the nature of the fire and not just seeing the smoke.''

Linkage: Electronic health records linked with or providing administrative data would constitute the ''best of all worlds'' for health services research explained one Canadian informant; and English informants discussed the potential for supplementing administrative health data with laboratory and prescription data. English informants stressed the opportunities for improved population health research with implementation of EHRs, but did so within the context of the Secondary Uses Service managed by the new Health and Social Care Information Centre, which will maintain both electronic health record extracts as well as other National Health Service clinical and administrative data sets. One English informant discussed the potential offered by supplementing existing population health data collections with data included in the Secondary Uses Service, especially when the SUS contains more clinically rich data. Another English informant pointed out as an example that such clinically rich data, derived from the NHS Care Record, would allow researchers to measure the prevalence of clinically recognized cardiovascular disease; match cardiovascular disease to risk factors such as smoking, body mass index, cholesterol and high blood pressure; link to the mortality file; and identify populations with the greatest potential for successful interventions. The EHR, linked to population health monitoring data collections, could provide better support for both clinical medicine and public health and for both patients and populations. Linkage of existing data collections to extracts from EHRs in the NHS' Secondary Uses Service was viewed ultimately as relatively easy to do with relatively small investments and large pay-offs.

Sampling: Given population-based implementation, electronic health records may introduce new sampling options on a widespread basis. EHRs, together with associated population-based uniformed patient identification numbers or patient registries, will serve as sampling frames. Enhanced case identification will occur through EHRs, such as defining and identifying cases based upon combinations of test results, symptoms, and diagnoses. Improved sampling stratification will occur, based upon the wider range of more readily accessible variables in EHRs; this could include stratification based upon clinical data available in EHRs, functional status measurements, as well as demographic characteristics. Similarly, EHRs will introduce new options for randomized designs of clinical trials through integrating randomized designs with population-based research. EHRs were also viewed as introducing new options for drawing samples in studies to follow-up on clinical and public health interventions. Distinctions between sampling frames and data sources could be minimized or eliminated: when EHRs achieve full penetration into a geographically-based population, EHRs could serve the dual purposes of sampling frames and data sources.

Glimpses into the future of electronic health records and population health monitoring and research

Several informants emphasized that ''little pockets'' of current projects and activities can provide glimpses of what may ultimately be feasible through widespread or population-based adoption of electronic health records. For example, various syndromic surveillance projects were mentioned as the ''thin edge of the wedge in terms of raising awareness of utility and quality of electronic health records for population health monitoring.'' Similarly, the New South Wales emergency department automated surveillance project in Australia and the Medical Office of the 21st Century project in Montreal, Canada (''MOXXI'') were also mentioned as potential case examples that could reveal hints of the eventual contribution of shared EHRs to population health monitoring and research (Muscatello et al. 2005; Tamblyn et al. 2003).

The tenor and content of the glimpses provided by English informants into the future of electronic health records and population health monitoring and research had some fundamentally different elements than the glimpses provided by Australian, Canadian, and New Zealand informants. Especially notable among many English informants was their speaking of population-wide implementation of EHRs as inevitable within five to at most ten years, in contrast to some informants in Australia, England, and New Zealand, who expressed greater skepticism about population-wide implementation informants, when speaking of the future, often referred to the specific implementation plans and activities underway in the NHS since the publication in 1997 of *The new NHS*, in 1998 of *A First Class Service and Information for Health*, and in numerous other publications since. English key informants typically pointed out that the investment in National Programme for Information Technology has been ''huge on a per capita basis'' and its ''sheer scale is colossal.'' NPfIT, including its electronic health records, ''will be magnificent if it works, and a huge failure if not'' with ''immense'' and ''massive'' potential. Despite shared concerns about meeting promised timeframes and professed insufficient clinical and public health input, to be discussed in Constraints below, several English informants maintained that they were ''confident that the right thing will happen in the implementation of the NHS Care Record'', which will function as an electronic health record. One informant described himself as ''excited by the opportunities [presented by NPfIT, the NHS Care Record, and SUS] for better analysis of care and better feedback to clinical staff about processes and outcomes''. He added that ''most clinicians now don't know how good they are'' and the ''need for reflective clinical practice'' will be met through NPfIT. Other English informants pointed to the shared EHR as a ''huge treasure trove'' of data for population health'' and as the ''largest epidemiological data base in the world.'' SUS was described as holding ''enormous potential to look at whole populations'' through its ''lifelong record of encounters and pathways through the health system,'' and as an ''huge opportunity to bring clinical information into population health and to add value to the Personal Spine Information Service.'' Another English key informant described ''NPfIT and SUS as the right model for creating a system to allow analysis of population health.''

Constraints

National strategies for electronic health records

Experts in Australia, Canada, England, and New Zealand emphasized that national strategies for electronic health records and electronic patient records focus on clinical care: the emphasis is also reflected in preceding sections of this chapter. National strategies have been developed in response to perceived needs for improving healthcare systems, with improvement defined in terms of increased efficiency, controlled costs, improved quality, and enhanced patient safety. Improving clinical care is viewed as the priority, not improving population health. Even when included in national strategies for electronic health records, population health monitoring and research are regarded as a secondary uses of electronic health records. In Australia, concern was expressed that the public may view the potential uses of EHRs for any purposes other than clinical care as a negative; if such concerns became prevalent or pronounced, they could derail the national agenda for EHRs. In Canada, the public health was described as ''separate and independent'' from Canada Health Infoway's agenda for electronic health records; to the extent that public health has entered into the national strategy for EHRs, it was viewed as a response to the SARS outbreak of 2003 and the 9/11 terrorist attacks in the U.S. In England, an informant with national public health responsibilities described the NHS Care Record a having ''no public health agenda'' and asserting that ''public health was thought about late in the day.''

Informants in all four nations who are involved in the development and implementation of national and sub-national strategies for electronic health records stressed that carefully delimiting those current agendas is necessary in order to avoid endangering the operational goals of building and disseminating EHRs, including primarily clinical care but also healthcare management. For example, an English informant with sub-national EHR responsibilities described the National Programme for Information Technology agenda as experiencing ‘‘scope creep’’ and ‘‘trying to do too much and trying to do it all at the same time.’’ Australian, Canadian, and New Zealand informants emphasized the need for manageable, achievable short-term agendas for EHRs, defined in terms of achievements within five years. One New Zealand expert, for example, described New Zealand’s strategy as ‘‘you eat an elephant one bite at a time.’’ In Australia and Canada, concerns were expressed that the inclusion of population health monitoring and research within the short-term agendas might interfere with the primary goals. At the same time, these informants did not reject population health monitoring and research as a longer-term application of electronic health records. They emphasized that a fuller, long-term electronic health records strategy could not be achieved rapidly or all at once: different elements of the strategy will need to be phased in and rolled out at different times, with population health monitoring and research clearly falling within a longer-term agenda.

Within both Australia and Canada, informants involved in population health monitoring and research emphasized that gaps exist between national strategies for electronic health records, on the one hand, and the reality of the implementation of those strategies, on the other hand. A ‘‘huge gap’’ was described between the current reality, practicality, and achievability of implementation of EHRs, on the one hand, and larger visions for EHRs. One informant described this as ‘‘big talk, small achievement,’’ emphasizing that the infrastructure necessary for supporting EHRs has not yet been developed: at least in Australia, this informant said, currently no examples exist illustrating the uses of EHRs for population health research.

Also in Australia and Canada, issues relating to jurisdictional and inter-governmental authority were viewed as impeding the successful implementation of national strategies for electronic health records. A Canadian informant described a ‘‘stand-off’’ between different layers of government as likely to threaten any national agendas for the development of EHRs with clinical records or data sharable beyond provincial borders; an Australian informant emphasized the power of the states and the need to ‘‘convince every state’’ in advancing the national agenda for shared EHRs. Any linkage of data derived from EHRs with population health data sets was viewed as at least five to ten years away, and is viewed as most likely to occur at Canadian provincial or Australian state levels, rather than nationally. Similarly, the ‘‘complexity of stakeholders’’ and the ‘‘need to get every stakeholder on board’’ was viewed as impeding the implementation of national strategies for electronic health records in Canada and England by informants, and especially advancing public health interests within those agendas.

Interviewed experts also emphasized that governmental policies and jurisdictional structures play central roles in facilitating or hindering the development and implementation of electronic health records. New Zealand informants pointed to their country as a nation-state with no federal-state tension and a ‘‘simple’’ healthcare system as helpful factors in advancing its national strategy. The existence of a ‘‘comprehensive, single, publicly-funded’’ healthcare system in England was described as making the implementation of the National Programme for Information Technology as ‘‘not easy, but more straight-forward.’’

Regardless of governmental structures, several informants in the four nations indicated that national leadership is a critical factor in implementation of national strategies for electronic health records, including ‘‘political will,’’ ‘‘clear signals about direction,’’ and what a New Zealand key informant described as ‘‘crystal clear articulation of strategic direction.’’ Leadership and clear guidance about what EHRs should deliver were articulated as being especially important for secondary uses of EHRs for population health monitoring and research, regardless of whether the national strategy for electronic health records was England’s ‘‘big bang’’ approach with National Health Service-wide implementation of electronic patient records and electronic health records, or the more incremental approaches of Australia (described as ‘‘lower risk’’) and New Zealand (described as ‘‘non-intervention’’).

In Australia, informants with population health monitoring responsibilities described themselves and their colleagues as adopting a ‘‘sit back and wait’’ attitude towards the national strategy for electronic health records and nationally-funded EHR pilot projects, partially because the ‘‘nut of what goes in health event summaries’’ has not been decided. An Australian informant described a twofold strategy. As the first part of this strategy, officials with population health monitoring responsibilities should work to ensure that national emphases and funding of the national strategy for EHRs does not threaten the successes already achieved and being achieved in Australian population health monitoring, including the development of minimum data sets that can be aggregated nationally, state and territorial agreements for national data aggregation, and data standards. The second part of this strategy is specific to standards: those responsible for population health monitoring and research should involve themselves in the development of standards for EHRs and related national health information infrastructure components. The rationale for this involvement is not based upon any prediction that the national strategy for electronic health records will eventually prove successful, but rather that if such success does occur, the resulting EHRs should at a minimum be compatible with standards used in current population health monitoring data sets. Some English informants described themselves as awaiting key operational decisions about the Secondary Uses Service, including the derivation of SUS data from health events and event messages contained in the Personal Spine Information Service or abstracted directly from Local Service Providers.

General practitioners

In all four nations, the organization of primary care was cited by informants as essential to the success of national agendas for the development of electronic health records generally, and for optimizing the potential contribution of EHRs to population health monitoring and research specifically. Concerns were expressed by informants in Australia and Canada that the current organization of primary care would constrain the adoption of electronic patient records and EHRs. In Australia, an informant described primary care as ''operating on a small business model, even though it's funded by the Commonwealth'' and the ''small business model'' was viewed as potentially impeding the implementation of EHRs.

Information technology, it was pointed out, will not solve current ''social and cultural'' issues affecting how data are used within the National Health Service, including ''how medicine in England moves from autonomous practices to a marriage of individual [practitioners] and supportive systems'' based partially upon the use of data derived from EPRs and EHRs. Similarly, the implementation of agendas for EHRs was described as ''hang[ing] critically on human factors'' and on ''human problems'' with general practitioners' use of computers. General practitioner-specific issues mentioned by informants included what an English informant described as the ''huge practice change'' made necessary by information technology and the need for general practitioner trust and clinical ownership of the National Programme for Information Technology agenda; other informants mentioned the apparent willingness of general practitioners to use computers for prescribing but not for entering diagnoses. The need for business model and cultural changes in general practice was described, as well as generational changes among general practitioners. An Australian informant indicated that the benefits of EHRs for general practitioners will occur at small local levels, rather than at regional or national levels. Similarly, an English informant maintained that the Personal Spine Information Service ''might be useful for one patient out of a thousand'', indicating that few of his patients required out-of-area treatment and especially out-of-area emergency treatment. The local nature of the benefits of EHRs for general practitioners was seen as constraining general practitioner support for use of EHRs for population health monitoring.

Experts in Australia, Canada, and New Zealand emphasized the need to provide incentives and alignment of incentives for general practitioners to adopt electronic patient records and to provide data for and utilize electronic health records and to use common terminology meeting national standards. Strategies for providing incentives to general practitioners for implementation of EPRs and to provide data for EHRs need to be based upon the recognition that at the local level, EHRs can be useful even without extensive utilization of coding, classification, and terminology standards.

Several informants directly linked their perception of issues around the uptake of electronic patient records and electronic health records by general practitioners to their perception of the potential contribution of EHRs to population health monitoring and research. An English informant described an ''imbalance'' between ''those who do the work on entering secondary data [into EHRs] and those who benefit from it.'' If general practices are asked to collect additional data for population health monitoring and research purposes, then the additional data collection must fit into the primary care work flow and general practice business needs. In Australia, an informant articulated concerns about collecting any population health data not of direct value to clinicians. The collection of population health data by clinicians for entry into electronic patient records and entry into or transmittal to EHRs was viewed as dependent upon four factors: first, strong clinical buy-in; second, specificity as to purpose; third, fitting into the routine process of care with minimal data input; or fourth, automated extraction of data for secondary uses. Any expectation that clinicians would enter data not needed for clinical purposes but needed for population health monitoring or other national purposes was described as problematic. The time pressures on general practitioners need to be recognized and successfully dealt with if population health monitoring and research add additional burdens to clinical data entry into EPRs and EHRs. In Canada, one informant responsible for population health monitoring expressed concern that adoption of EHRs will be accompanied by transition periods during which general practitioners will be asked to ''shadow bill'' in order to continue generating data currently collected for population health monitoring purposes.

Standards

Informants discussed several issues relating to standards as a constraint on the potential contributions of national strategies for electronic health records to population health monitoring and research. One issue is current limitations on the adoption of standards. While agreed upon standards exist for coding and classification, informants in Australia indicated that similar agreement has yet to be reached for reference terminologies and common abbreviations used in medical records. A concern was expressed that the development and adoption of relevant standards are not keeping pace with the rapid development and deployment of EHRs.

Informants also pointed to areas in which additional standards development needs to occur. Again in Australia, the need for standards for electronic patient records and electronic health records was stressed. For example, one informant emphasized that standards are needed for EPR and EHR functionality and interfaces: if front ends differ among EPRs or among EHRs, and if pick lists are presented differently with individual items in different orders in different EPRs or EHRs, variation will be introduced into recorded data resulting from the EPR and EHR data entry screens rather than from actual differences among patients and practices. If EHRs are to be used for population health monitoring and research, common standards will also need to be adopted for clinical, administrative, and population health data sets.

Several English experts honed in on issues about the granularity of standards and data to be contained in electronic health records as embodied in the NHS Care Record, especially relating to clinical practice, medical research, and population health monitoring and research. Referring to the NHS Care Record, a key informant asked rhetorically ''What questions could it legitimately answer?''; he then proceeded to say that the Secondary Uses Service' service management agenda is ''coarse grained'', while research needs are more fine-grained. Another English informant pointed out that granular terms and data can yield coding and classifications useful for population health monitoring and research, but the more coarse-grained coding and classifications often have no clinical utility and cannot yield the more granular terms and data needed for patient care and medical research. The same English informant, with national responsibilities for EHRs, emphasized the data sets are ''defined in a particular way for a particular purpose'' and that the purposes differ for reimbursement, service review, population health monitoring, and clinical medicine. Similarly, an Australian informant indicated the importance of ''purpose-driven tasks'' and stressed that population-based registries and EHRs and their supporting standards, have different purposes. To be successful for both population health and medical research purposes, an English informant said, EHRs will need breadth in terms of patients and depth in terms of data, with a mapping layer permitting movement from granular data for medical care and research to coarse grained data for population health monitoring and research. For English informants, of particular importance was whether and how data would move from clinical systems and electronic patient records into the Personal Spine Information Service and then into the Secondary Uses Service.

English informants pointed to the comparability of clinical standards with population health coding and classification standards as a crucial issue. An English key informant discussed his vision for solving this problem through the use of an ''extract, transform, and load'' function within the NHS Care Record. Operational data such SNOMED-CT coded facts would be extracted from the electronic patient record and used as input to the electronic health record, then transformed into forms useful for analysis, service management, billing, and so forth, and stored in the Secondary Uses Service.

A final standards-related theme that emerged is the need for the provision of incentives to general practitioners for actually using standards once electronic health records are deployed, especially for using common terminology, depending upon the nature of the EHRs themselves. An English informant mentioned the ''need to sell to clinicians the use of systematic, structured and automatically encoded data.'' Various types of incentives and ''paybacks'' were suggested by key informants in all four nations, ranging from financial incentives, to improved practice and practice site-level benchmark data, to clinical decision support systems, to individual patient-level warnings. A New Zealand informant pointed to the ''fundamental problem in any move from paper to paperless records that don't also include a move to structured text.''

Patient identification

Key informants in Australia and New Zealand stressed that current uniform patient identification number systems have their origins in both clinical care and in healthcare reimbursement. In Australia and New Zealand, uniform patient identification numbers have not been designed for the purposes of population health monitoring or research. In New Zealand, recognition exists of the need to de-duplicate uniform patient identification numbers at the national level in order to ensure that each person has single unique patient identification number; in other words, each person must hold a single patient identification number, and each patient identification number must be assigned to only a single person. But even with de-duplication of national unique personal identification numbers in New Zealand, concern was expressed that the National Health Index would not be used to the full extent possible for population health monitoring, illustrated by the continued creation of stand-alone population-based registries. In addition, concern was expressed that current patient identification numbers in New Zealand may not extend to the entire population, leading to limitations if the National Health Index is to be used for population health monitoring purposes.

Data quality

Informants with responsibilities for population health monitoring and research stressed that if electronic health records are to be used for monitoring and research, EHRs will need to provide the same high quality, robust data that are currently required from existing ongoing data systems. According to an English informant, the EHR will not solve the problems of inconsistent capture, inaccuracy, and incompleteness that currently occur with medical records. Another English expert emphasized that, in order for EPRs and EHRs to be useful for population health monitoring and research, implementation of a local data quality cycle will be essential. Several key informants pointed out that full population coverage will be necessary if EHRs are to replace existing population health data collections that are population-based. The same key informants expressed skepticism that EHRs could produce data of sufficient validity and reliability to replace existing population health monitoring data collections. The quality of data entry by general practitioners was particularly questioned, and described by one informant as generally ''partially to totally disastrous.'' The same informant expressed doubt that EPRs and EHRs will improve upon the accuracy of general practitioners' paper-based clinical records. Both population health monitoring and population health research require high quality, robust data. An Australian expert stressed that "an imperative exists not to move backwards in terms of data quality." He went on to say that Australia "now has an excellent [population] health information system in the absence of a national health information infrastructure and wide use of EHRs" and his overwhelming concern is not to have the current health information systems adversely affected by the move towards EHRs.

Confidentiality and patient consent

Informants in all four nations cited privacy issues as constraints on the potential contribution of national strategies for electronic health records to population health monitoring and research. In Australia, concerns were cited about the consistency and coverage of Commonwealth and state statutes, especially in terms of the applicability of statutes to both private and public healthcare sectors, to both paper and electronic clinical records, and to both clinical and population health research data. One informant pointed out that even if issues relating to other constraints on using EHRs for population health research were removed, issues would still remain around the development of legislation and protocols enabling researcher access to EHRs.

Closely tied to key informant discussions of confidentiality legislation as a constraint were discussions of patient consent. In both Australia and Canada, informants mentioned that the nature of national strategies for electronic health records and the speed of their implementation need to be balanced against the possibility of raising public fears about privacy and consequent opposition to EHRs.

Australian informants mentioned the Commonwealth government's desire to avoid public debates about data privacy as driving Health*Connect*'s decisions about patient consent for electronic health records. The desire to avoid public debates about the privacy of data held in EHRs was viewed by informants as resulting from government worries about repeating the Australia card debate of the 1980s, which revolved around proposals to institute a national identity card. In Australia, public demands were cited for freedom of choice about the uses of EHR data, including demand for patient permissions if de-identified data were to be released for research or monitoring. The Commonwealth government, through Health*Connect*, initially supported flexible and extensive patient "opt-ins" for EHRs. The opt-ins included patient choice of whether any or all information would be included in EHRs: patients could choose to include or exclude information from EHRs, such as information about particular healthcare encounters, health events, and diagnoses, as well as whether particular information would be made available to specific other providers or to the National Data Store for particular purposes, such as population health monitoring or research. The nature of the EHR opt-in was viewed by Australian experts as a major constraint on any uses of EHRs for population health monitoring and research. One key informant pointed out that fewer incentives would exist for infrequent users of healthcare services to consent to EHRs than for more frequent users. Flexible EHR opt-in was repeatedly mentioned by Australian informants as preventing the development of population-based data, because of its impact on obtaining complete data representative of populations. Finally, an Australian informant expressed skepticism about whether the national EHR structure envisioned in Health*Connect* could "handle the complexities" of a flexible consent model.

Also mentioned were fears about patient access to electronic health records, and how such access might interfere with uses of EHR data for population health monitoring and research. For example, it was envisioned that private firms would develop services based upon obtaining access to information held in EPRs and EHRs. Access to information included in EPRs and EHRs might be legally obtained by providing to patients financial or other incentives for release of their data. Concerns were expressed that such services might both make patient consents for EHR release for research and monitoring less likely without incentives, as well as create potential confusion among patients about privacy guidelines for different types of EHR releases.

Population health monitoring

In addition to discussions of more general constraints on the potential contribution of national strategies for electronic health records to population health monitoring and research, informants also provided some more specific insights. To be usable for population health monitoring, EHRs will need to achieve full population coverage so that they can mirror current population-based data collections. Failing full population coverage, EHRs might be useful for population health monitoring if two criteria were met: first, if EHRs cover a known subpopulation and the demographic characteristics of the covered and uncovered subpopulations are known; and second, if data extracted from EHRs for the known subpopulation covered by EHRs were comparable to data derived through other data collections from the remaining subpopulation not covered by EHRs. A Canadian informant pointed out that population health monitoring could not depend upon EHRs alone: subpopulations exist that do not access healthcare; much of population health monitoring, such as population-based surveys, is not health event-based and depends for validity on data collection that is off-cycle with healthcare encounters; and, as indicated above, patient consent issues may interfere with extracting data from EHRs for population health monitoring purposes, especially for some health events, diagnoses, and procedures that may be regarded as particularly sensitive.

Informants in Australia and Canada pointed to lack of awareness of the potential of electronic health records for population health monitoring and research as an important constraint. This lack of awareness was cited on the part of both population health monitoring and research professionals, on the one hand, and experts responsible for developing national strategies for electronic health records, on the other hand. Concern was expressed that the public health sector is not as focused or as strategic as the healthcare sector: public health officials are viewed as not represented as stakeholders in discussions and negotiations around the development of national and sub-national agendas for EHRs. Canadian experts indicated that the inclusion of public health in the development of national strategies for electronic health records seems to be limited to communicable diseases, laboratory data, bioterrorism, and sentinel events, rather than consideration of the full breadth of population health monitoring.

Australian informants expressed methodological concerns about the potential utility of electronic health records for population health monitoring. EHRs were viewed as generating huge volumes of data. New methods will need to be developed for dealing with the volume and complexity of EHR data. In particular, new methodologies would need to be developed for transforming free text entries in EHRs into usable data, even if national clinical terminology standards are adopted. An English informant questioned whether the masses of data generated by EPRs and potentially included in EHRs could be analyzed in ways that generate intelligence. One Australian informant stressed that Australian population health monitoring is ‘‘not now industrialized, and currently relies more on a craft guild model.’’ As a consequence, skepticism was expressed that the large-scale methodological changes needed for utilizing EHR data could be identified and incorporated into population health monitoring.

Experts in Australia, Canada, and England questioned whether any parts of present population-based surveys could be replaced in the short- to medium-term by EHRs. Informants said that survey items are not now used during routine patient care and thus survey items would not be collected for the EPR and EHR during the patient care process. Informants also mentioned that general practitioners and other clinicians would not take the time to collect and enter the ‘‘contextual’’ information needed for surveys, such as socio-economic status and ethnicity.

Chapter 6. Common Themes in Interviews with Expert Informants in the U.S.

This chapter provides a qualitative review of themes that emerged in 31 interviews with U.S. experts, with emphasis on the potential of electronic health records for population health monitoring and research in the U.S. and the constraints on achieving that potential. Some themes reported on in this chapter are similar to those derived from interviews with experts in Australia, Canada, England, and New Zealand, and reported in Chapter 5. However, the U.S. context, including its health system and national strategies related to electronic health records, differ from those of the other four countries. Consequently, the themes emerging from the U.S. interviews are reported here separately.

Potential Contribution

Electronic patient records and electronic health records as transformational for American healthcare and public health

Increased interoperability of electronic patient records was viewed by one U.S. informant as ultimately leading to improved healthcare, reduced errors, and increased opportunities for performance monitoring. Another informant indicated that a ''tipping point'' may have already been reached in the dissemination of electronic patient records although not in electronic health records. This informant predicted that within three to five years, forty to fifty percent of healthcare organizations would have some form of EPRs but not EHRs. EPRs were viewed as likely to result in a ''huge explosion'' of clinical and public health research, especially relating to genetic data. Another informant described his vision of all mandatory public health reporting being replaced with data derived from EPRs (see more on this topic in **Scenarios** below). A third informant discussed EPRs as leading to a ''transformational stage for public health, similar to what laboratory data did for early infectious disease surveillance.''

The transformation of public health through electronic patient records was viewed by several informants as resulting from a changed vision of the value of data, with EPRs leading to an emphasis on managing population health through clinical care informed by public health data. An informant argued that the inclusion of ''improve population health'' as the fourth goal in *The Decade of Health Information Technology: Delivering Consumer-centric and Information-rich Healthcare—Framework for Strategic Action* resulted from the potential high impact of population health, with its likely impact on other aspects of the U.S. healthcare system (Thompson and Brailer 2004 July 21). Other experts maintained that the ''real return'' from EPRs and EHRs would come from public health ''views'' of derived data and their uses for pay for performance and other performance measurements. Similarly, another informant maintained that the vision of population health tracking, assessment of health status, and assessment of quality of life remained essential to the development of EHRs.

Some informants envisioned a joint transformation of public health and clinical medicine resulting from electronic patient records and electronic health records through removing current barriers between clinical care and public health. One informant described informatics and EPRs as the ''Trojan horse'' through which increased connections between clinical medicine and public health would be facilitated and both transformed. The enhanced incorporation of population health data and public health interventions into EPR-based clinical decision support systems was cited by several key informants. Clinical decision support systems were viewed as a means of providing population health data to physicians for supporting the care of individual patients without ''getting in the way'' of how physicians conduct their practices.

''Shining hopes''

Key informants emphasized the existence of various efforts in the U.S. that could demonstrate the utility of electronic patient records and electronic health records for population health research and monitoring. Some of these efforts have been invested in and developed over several years, even if their connections to population health monitoring and research are germinal. Examples cited by U.S. key informants include:

- Centers for Disease Control and Prevention (CDC): One key informant described CDC as already pursuing the replacement of separate data collection streams with integrated data reporting from electronic clinical information systems maintained by large, multi-jurisdictional laboratories to states and then to CDC; 26 states were described as utilizing some form of electronic laboratory reporting utilizing pre-existing clinical data created as part of the clinical record. Facilitated by specifications developed through the National Electronic Disease Surveillance System (NEDSS) and Public Health Information Network (PHIN) efforts, this work was viewed as directly extensible into cancer registration and syndromic surveillance via the BioSense initiative to ''to support enhanced early detection, quantification, and localization of possible biologic terrorism attacks and other events of public health concern on a national level'' (Bradley CA, Rolka H, Walker D, Loonsk J 2005 Aug 26, 11). improve early event detection. These efforts were viewed as initial attempts only, presently constrained by needs for interested public health users willing to cope with dual reporting systems as a long-term interim step. (For additional information, see: Centers for Disease Control and Prevention [hp] National Electronic Disease Surveillance System; Centers for Disease Control and Prevention [hp] Public Health Information Network;

Centers for Disease Control and Prevention [hp] PHIN: BioSense.)

- Indian Health Service: Several key informants pointed to ongoing activities of the Indian Health Service (IHS) as examples of the potential of EPRs and EHRs for population health monitoring and research. Indian Health Service efforts include the Clinical Reporting System (CRS), described as currently used for national level clinical performance monitoring and reporting to Congress and local level analyses, with a national level data warehouse currently being developed to include data extracted from local level healthcare facility warehouses. Although a key informant described a current system in which data are primarily entered into the Clinical Reporting System from health summaries generated from paper records, the ultimate goal is to have Clinical Reporting System data generated from the IHS Electronic Health Record. CRS and the IHS Electronic Health Record were portrayed as tools for population health monitoring, including assessing population health status and quality of life. Especially important has been the development of local IHS codes for various health factors, initially limited to factors related to diabetes mellitus, alcohol use or abuse, tuberculosis status, and tobacco use, and now expanded to factors related to intimate partner violence/domestic violence screening, suicide surveillance, and other issues. (For additional information, see: Cullen T 2005 May 18; Grenier D 2004 Apr 13; Hays H 2003 Nov; Hays H 2004 Apr 22; Sequist TD, Cullen T, Ayanian JZ 2005 Dec; U.S. Department of Health and Human Services, Indian Health Service [hp] CRS (Clinical Reporting System, formerly known as GPRA+); U.S. Department of Health and Human Services, Indian Health Service 2003 Feb 10; U.S. Department of Health and Human Services, Indian Health Service [hp] Welcome to the IHS Electronic Health Record Website.)
- Indiana Health Information Exchange (IHIE): Several key informants described the Indiana Health Information Exchange as an especially well-established example of electronic interchange of health data based upon EPRs, already demonstrating utility for population health monitoring. According to a key informant, an essential part of IHIE's vision is the ultimate replacement of all mandatory public health reporting through electronic extraction and reporting of data, ''creating a person-centric data system for public health through driving all data into one location.'' This was described as already having been implemented for several data collections that are health event-specific, such as laboratory data and screening of hospital discharges for congenital anomalies, and as especially appropriate for hospital-based births, deaths, syndromic surveillance, and mandated sentinel reports not derived from laboratory data. Telephone follow-ups were regarded as still necessary for some data collections. As described by key informants, an important part of the IHIE vision is the provision of population-based information (such as immunization rates, fulfillment rates for prescriptions by type, and patterns of antibiotic use) to clinicians to aid them in the care of individual patients, without interfering with the clinical work flow. IHIE received AHRQ funding to implement a statewide public health surveillance network linking hospitals to share emergency department data. IHIE's success is viewed as partially resulting from its direct mediation of state and county health department work flow through enabling data to directly enter the public health work flow. (For additional information, see: Biondich and Grannis 2004; Overhage, Suico, and McDonald 2001; Overhage 2002 Apr 29; Overhage 2004 Oct 6.)
- Inland Northwest Health Services (INHS): According to several informants, Inland Northwest Health Services is an example of well-established electronic sharing of health information among hospitals and primary care practices, with potential for extension to population health monitoring and research. The INHS integrated health information system was described as reducing the reporting burden on hospitals for submission of the Community Hospital Abstract Reporting System (CHARS) to the Washington State Department of Health. Syndromic surveillance is occurring using hospital data, and discussions have started regarding integration of birth, newborn screening, and infectious disease reporting into the INHS integrated information system. (For additional information, see: Davies J 2004 May 25; INHS [hp] Information Resources Management.)
- Kaiser-Permanente: Informants also described Kaiser Permanente's plans to implement geographically phased-in electronic patient records for its membership as having promise for population health monitoring and research. Several elements were described as especially favorable, including Kaiser-Permanente's large membership; its history of using its electronic data for population-based research, monitoring, and reporting; its substantial previous experience in development of electronic patient records, together with its experience in structured data entry for progress notes; its use of clinical data repositories; and its attention to clinical workflow issues in introduction of EPRs. (For additional information, see: Backer, Bissell, and Vigia 2001; Broder 2004 Sep 10; Carroll 2004 Nov; Chin 2003 Sep 20; Wiesenthal 2003).
- Utah Health Information Network (UHIN): Although established as a ''postal service'' to reduce the transaction processing costs for administrative health data, the Utah Health Information Network recently received AHRQ funding to develop UHINClinical to expand the range of exchanged data beyond administrative health, to explore the

development of a centralized record locator service, and to utilize data exchanged within UHIN and UHINClinical for public health reporting. According to one expert, UHIN has already reduced the healthcare provider burden for administrative health data, such as using claims data to populate immunization registries and to generate submissions for the Utah Hospital Discharge Database; and automated reporting of laboratory data through a single portal. Ultimately, automated reporting of incidence and prevalence data from EPRs was mentioned as another possibility. (For additional information, see: Utah Health Information Network [hp].)

- Veterans Health Administration (VHA): The VHA's current veterans health information systems technology architecture (VistA) and computerized patient record system (CPRS) implemented in both VHA inpatient and outpatient sites, and its developing HealtheVet, were mentioned by key informants as excellent examples of the potential of EPRs and ultimately EHRs to support population health monitoring and research. As described by an informant, the VHA will maintain a national data mart, updated on an ongoing basis, including patient-centric summaries of care provided in VHA inpatient and outpatient sites; the expectation is that this data mart will then serve as the data source for population- and facility-based performance and health monitoring. It should be noted that the VHA's VistA-Office EPR will be made available through the Centers for Medicare and Medicaid Services to physicians within the Doctor's Office Quality-Information Technology program, and VistA has been adapted by the IHS. (For additional information, see: Centers for Medicare and Medicaid Services 2004 Sep 16; Chisholm 204 Aug 1; Christopherson 2003 Nov 19; Lomas 2003; Perlin, Kolodner, and Roswell 2004; Wark 2004 Nov 9.)
- Other efforts: Other efforts were also cited by informants as having potential for population health monitoring and research but had received investments only recently. One example cited by informants was Rhode Island's AHRQ-funded project to develop a statewide master patient index, which was described by an informant as potentially including the ultimate development of a de-identified population health data base. Another cited example was Tennessee's AHRQ-funded Volunteer eHealth Initiative to develop regional data sharing within three counties, including a regional databank storing core clinical data elements; provision of population-based data to public health agencies was described as an important part of the Volunteer eHealth Initiative vision.

Scenarios

U.S. informants were asked to react to four high level scenarios of the future relationships between electronic patient records and electronic health records, on the one hand, and population health monitoring and research, on the other hand.

- The first scenario was the use of EPRs and EHRs as an additional data source for current public health data collections; the use of data derived from EPRs and EHRs as a source for cancer registration data, in addition to manual record abstraction and electronic extraction from clinical information systems, was provided as an example.
- The second scenario was the use of EPRs and EHRs to supplement current public health data collections on an episodic, project-specific basis; the use of data derived from EPRs and EHRs for local fetal and infant mortality reviews, in addition to birth data, fetal death data, medical record abstractions, and possibly interview data was provided as an example.
- The third scenario was ongoing linkage of data from EPRs and EHRs with current public health data collections; linkage of data derived from EPRs and EHRs to cancer registry and death data was employed as an example.
- The fourth and final scenario was the total replacement of current public health data collections with data extracted from EPRs and EHRs.

Some informants reformulated these four scenarios. One informant described the four scenarios as a continuum, from linkage to supplementation to replacement; another described the scenarios as an evolutionary process, with supplementation leading to ongoing or batch linkage, and linkage leading to replacement. Other informants offered additional scenarios, such as retrospective use for population health monitoring and research of EPR and EHR data held in electronic vaults; use of EPRs and EHRs to generate entirely new data collections; and production of data and analyses from current data collections more rapidly than presently or with much improved case ascertainment.

Most interviewed experts combined the two scenarios of use of EPRs and EHRs as an additional data source for current data collections and as a source of supplementing current data collections. These scenarios were typically described as realistic, especially for reportable diseases and registries, and administrative health data. One informant described supplementation of current laboratory, communicable disease, and immunization registration data by EPRs and EHRs as ''trivial'' examples, and emphasized that supplementation for asthma, diabetes, and cancer registries would prove more challenging, as well as for varied performance monitoring such as the Health Plan and Employer Data Information Set (HEDIS). Another informant envisioned drilling down into EPRs and EHRs to answer specific research questions, especially after initial issues around patient consent were successfully addressed. Another informant doubted that EPRs would prove especially useful for retrospective research, but would be helpful in developing prospective protocols in which clinicians might be prompted to gather specific data for individual research studies.

A scenario of ongoing linkage of current population health monitoring data collections with data derived from electronic patient records and electronic health records was viewed with more skepticism. ''Real time'' linkage was rejected by an informant as not likely to occur. Periodic linkages were regarded as more likely. One informant pointed out that large scale ongoing linkage would be feasible only if facilitated by a national patient identifier, stressing that de-duplication of clinical data would prove a major impediment.

A scenario of total replacement of current population health monitoring data collections with data derived from EPRs and EHRs met with mixed reactions from informants. Informants differentiated the likelihood of a total replacement scenario based on the type of data collection. On the one hand, replacement was described by some informants as already widely occurring in states for reportable laboratory data, and on a more limited basis for laboratory-based syndromic surveillance and physician reportable disease data. On the other hand, replacement of population-based surveys by data derived from EPRs and EHRs was generally dismissed as impossible. Total replacement of current population health monitoring data collections was viewed by most informants as unrealistic or, in the words of one informant, as ''science fiction.'' One informant envisioned replacement as ultimately occurring for those population health data currently derived from clinical settings on a ''bottom up'' basis starting with individual communities, but as much less likely to occur on a national basis. Additionally, replacement was viewed by key informants as dependent upon the universality of EPRs and EHRs, resolution of privacy and clinical data quality issues, use of structured information entry into EPRs and EHRs and the existence of improved natural language processors, and widespread implementation of EPR and EHR standards with dual utility for clinical and population health data.

Constraints

U.S. healthcare system

Fragmentation and competition within the U.S. healthcare system were cited by several informants as a major constraint on the eventual development and use of electronic patient records and electronic health records for population monitoring and research. As one informant indicated, we ''need to recognize the reality of the U.S. healthcare industry.'' Another informant indicated that drivers for the development of EPRs and EHRs and are so different than drivers for population health in the market-driven U.S. healthcare system that ''there is no intersection right now.'' Among the drivers for EPRs and EHRs listed by informants were healthcare efficiency, quality, costs, and safety, rather than population health. Fragmentation and competition within the U.S. healthcare system were viewed by informants as leading to two additional constraints on the eventual use of EPRs and EHRs for population health monitoring and research: first, the lack of unique national or regional patient identifiers; and second, lack of a full set of standards for EPRs and EHRs that could simultaneously serve both clinical and population health purposes.

U.S. public health

One informant indicated that ''the real issue isn't technical, but public health's priorities.'' In almost identical language, several informants emphasized that it was essential for ''public health to sit at the table'' in cooperation with the private healthcare sector in planning activities fostering EHRs, such as Regional Health Information Organizations (RHIOs). Public health representatives need to ''stand firm,'' ''raise their voice,'' and ensure that ''public health isn't an afterthought.'' At the same time, the same informants stressed that the mind set of public health professionals also act as a constraint in using EHRs for population health monitoring and research. For example, one informant pointed out that public health ''takes the healthcare system for granted,'' ''needs to start working within the context of healthcare,'' and needs to ''accept health system priorities.'' Another informant argued that ''public health needs to stop whining and develop a 'sell' of its utility'' for RHIOs [Regional Health Information Organizations], EPRs, and EHRs. Public health, a third informant maintained, ''hasn't crossed boundaries well'' and ''doesn't know what it doesn't know.''

Some informants pointed out that public health needs to become more flexible in dealing with the healthcare system. According to an informant, one aspect of such flexibility is a willingness on the part of public health to modify its data collection for population health through ''tapping into existing hospital operations''; the example provided was the current existence of two separate data collection streams from hospitals for births and deaths. Other experts pointed to another aspect of needed flexibility: ''if data are not perfect for its needs, public health won't use it.'' Of particular importance here, another informant indicated, would be a willingness for public health to adjust to the ongoing use of dual data collection streams for population health monitoring, with one data collection stream based upon EPRs or EHRs and another data collection stream for the same data collection based upon current data collection streams.

Limitations of electronic patient records and electronic health records

As with informants in Australia, Canada, England, and New Zealand, some U.S. key informants discussed the limitations of electronic patient records and electronic health records in terms of the constraints on their potential use for population health monitoring and research. One U.S. informant maintained that EPRs and EHRs have generated ''far more enthusiasm than justified'' in discussions of their potential for population health monitoring and research. Another informant indicated that if standards are not developed for EPRs or EHRs, then their uses for population health monitoring and research would be solely through abstracts rather than ongoing automated extracts. A related standards issue, as with informants in other countries, related to perceived limitations of current clinical standards for population health information. For example, an informant cautioned that the ''technology might not be ready for prime time,'' and emphasized that any decreases in the timeliness of population health monitoring due to use of EPRs and EHRs would be unacceptable.

Also as with informants in other countries, some U.S. informants questioned whether the data quality of electronic patient records and electronic health records could support population health monitoring and research. An informant referred to the ''dirty little secret of EPRs that nobody talks about out loud or in the literature, that they are now not complete and are haphazard, with data entered by clinicians on a convenience basis.'' Both missing data in EPRs and EHRs as well as free text entry were earmarked as constraints on their use for population health monitoring and research. Finally, and again echoing comments made by some experts in other countries, U.S. informants questioned whether current public health methodologies were capable of analyzing the huge volume of data that would be generated by EPRs and EHRs.

Technology, political will, and financing

Any limitations of electronic patient records and electronic health records were viewed by an informant as less important than constraints resulting from the perceived lack of political will to take the steps necessary to maximize the potential of EPRs and EHRs for population health monitoring and control. Several key informants indicated that the financing needed so that EPRs and EHRs could contribute to population health monitoring and research is insufficiently discussed. Any such financing in the U.S., it was pointed out, is now dependent upon grants. A third informant unfavorably compared current U.S. governmental expenditures for EPRs and EHRs to governmental financing in other countries.

Chapter 7. Fundamental Issues in the Relationship of National Strategies for Electronic Health Records to Population Health Monitoring and Research

Previous chapters of this report provided overviews of national strategies for electronic health records and their potential for population health monitoring and research in Australia, Canada, England, and New Zealand, based on publicly available reports, World Wide Web sites, presentations, and literature (Chapter 4); reported themes about the potential contribution of electronic health records to population health monitoring and research, based on interviews with 65 experts in the same four countries (Chapter 5); and also reported on themes about the potential contribution of electronic patient records and electronic health records to population health monitoring and research in the U.S., based on interviews with 31 U.S. experts (Chapter 6). In contrast, this chapter represents the author's analysis of issues affecting the potential contribution of national health information infrastructures, and especially electronic health records, to population health monitoring and research. In this chapter, the author discusses definitional issues, numerator and denominator issues, overarching issues, and success factors for maximizing the potential contribution of national health information infrastructures to population health monitoring and research.

Definitional Issues

As indicated in Chapter 1: Introduction, health statistics are defined as ''numerical data that characterize the health of a population and the influences that affect its health'' (Parrish, Friedman, and Hunter 2005, 3). Population health monitoring, defined earlier ''as the collection and analysis of data to detect changes in the population's health and influences on the population's health,'' produces the data that typically constitute the basis for health statistics. These data include reports of notifiable diseases and registries, population-based surveys, and administrative health data. Health statistics, in turn, provide the basis for much of population health research.

As pointed out in Chapter 1, three necessary conditions must be met in order to characterize the health of a population through health statistics. First, numerator data must exist about a health event, condition, disease, functional health status, well-being, or an influence on population health. Second, denominator data must exist that describe the population in terms of its size, its geographic location, and its basic demographic characteristics. Third and finally, a match must exist between the numerator and the denominator; in other words, the numerator must be drawn from the population denominator.

A known numerator and a known denominator are both necessary to yield population-based health statistics. The known denominator should typically be defined at some geographic level, and include either (a) the total population in the geographic area, or (b) a sample of the total population that can be generalized to the total population in known and quantifiable ways, or (c) a specified sub-sample of the total population, with numerator data relating to the same specified sub-sample of the total population. The need for a population-based denominator distinguishes health statistics from some clinical research, from some health services research, and from some population health monitoring for the purposes of immediate public health interventions, such as case-based surveillance.

Numerator and Denominator Issues

In order to generate population-based health statistics, electronic patient records and electronic health records must yield accurate numerator data. Matching geographically-based population denominator data must also be available.

Penetration of electronic health records

In order to generate useable numerator data, electronic health records must either penetrate an entire geographically-based population, or a truly random subset of that population with known characteristics, or a non-random subset of that population with known characteristics. If electronic health records have not penetrated the entire geographically-based population, then the subset of the population with electronic health records and known characteristics must be linked with a population denominator with known characteristics. In order to generate health statistics reflecting at least some elements of population health and the influences on population health (see Figure 1.1), electronic health records also must either yield numerator data across the entire spectrum of population health (such as disease, functional status, and well-being) and healthcare (such as primary care, acute hospital care, home care, and long-term care), or must yield numerator data for a specific and definable subset of population health or the spectrum of healthcare. Wide penetration of electronic patient records and electronic health records may introduce new methodological quandaries for linkages of numerator data derived from electronic health records with numerator data derived from other data collection streams, and for linkages of numerator data derived from electronic health records with denominator data derived from other data collection streams.

Data quality

As Roberts and Hanson indicate, ''while electronic health records will impose more discipline on how information is recorded, they will not be a panacea for poor recording practices'' (Roberts and Hanson 2003 Sep 15, 278). Data recorded in electronic patient records and electronic health records may or may not meet standards for data quality in population health monitoring. The quality of data in electronic patient records and electronic health records may vary among healthcare providers, among healthcare provider sites, among healthcare institutions, among healthcare sectors, and among different electronic patient records and electronic health records. If electronic patient records and electronic health records are to yield numerator and denominator data appropriate for health statistics, then those numerator and denominator data must meet the same professional standards of validity and reliability as currently met by population health monitoring data sets such as births, deaths, cancer incidence, hospital discharges, and population-based surveys. Data quality checks for these data sets typically include data entry field checks, field out of range checks, consistency checks to identify discordant data in two or more fields, and healthcare provider- or healthcare provider institution-level checks to identify artifactual errors (such as inappropriate use of certain codes in individual healthcare institutions). Also typically, follow-ups occur on questionable data items by the county or state health department receiving the data; these follow-ups can be automated as well as conducted through person-to-person contact.

Data completeness

Numerator and denominator data derived from electronic patient records and electronic health records must meet the same measurable standards for completeness as currently met by standard population health monitoring data sets. These standards now vary from data set to data set, even for conceptually similar data elements (such as education or other demographic variables) that exist in several data sets. Standards for completeness are of two types. One type of standards for completeness pertains to denominator completeness. Data derived from electronic patient records and electronic health records must include all members of the specified geographically-based subpopulation or statistically represent the subpopulation. Incomplete penetration of electronic patient records and electronic health records can adversely affect denominator completeness, as can the presence of uninsured individuals and individuals who fail to use healthcare services in the specified subpopulation. A second type of standards for completeness pertains to numerator completeness, such as the completeness of individual items in the data set.

Maximizing data quality and completeness in electronic health records

Various authors have emphasized that recognizing and respecting clinical work flow requirements are essential if electronic patient records and electronic health records are to be successfully implemented (for example, see Baron et al. 2005 Aug; Brookstone and Braziller 2003; James 2005 Jan 19; Leonard 2004; Sprague 2004; Scott et al. 2005). Experts interviewed in the five countries included in this project stressed that meeting clinical work flow requirements are even more important if electronic patient records and electronic health records are to contribute to population health monitoring and research. Most basically, it is important to recognize that the collection of data for population monitoring and research purposes—''indirect patient care''—is explicitly secondary to the primary clinical ''direct patient care'' purposes of electronic patient records and electronic health records in national strategies for electronic patient records and electronic health records.[6]

In order to maximize the quality and completeness of data collected for secondary ''indirect patient care'' purposes through electronic patient records and electronic health records, one or more of three conditions must be met. The first condition is that the collection of data for secondary purposes would provide a demonstrable clinical return to the physician for the treatment of individual patients (for example, see: Hillestad et al. 2005 Sep/Oct, 1110–1112). For example, this condition could be met if data collected on a patient for population health monitoring purposes were then clearly included in a clinical decision support system used for the care of the individual patient. Meeting this condition may be especially difficult for all data elements in an ongoing population health monitoring data collection, because many data elements are collected both to continue time trends and to enable future analyses, the purposes of which may not have been explicitly defined to the clinician or healthcare institution providing the data. The second condition is that the collection of data for secondary purposes would be totally transparent to the clinician. For example, a cardiovascular risk assessment system now in use in New Zealand requires the clinician to enter patient-specific data needed for assessing patient risk, which should be collected during regularly scheduled examinations or other visits. These data could then be aggregated at the Primary Health Organisation, District Health Board, or national level for population health monitoring, still retaining the patient as the unit of analysis. The third condition is that the collection of specific data for secondary purposes is a contractual responsibility for physician reimbursement or for reimbursement-related physician performance review. Among the informants interviewed for this project, a consensus exists that collection of data for population health monitoring and research through electronic patient records and EHRs that does not meet any of these three conditions will result in poor data quality and incomplete data.

Consent

Patient consent for the entry of their data into electronic patient records and electronic health records is an important ingredient in data completeness. The most basic issue is whether patients should control (a) what data are entered

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[6] David Pencheon has stressed the importance of differentiating direct patient care from indirect patient care when discussing the uses of electronic patient records and electronic health records for population health monitoring and research (Pencheon D 2005 Nov 20).

into electronic patient records and electronic health records, (b) the uses of those data, and (c) access to those data for clinical care, healthcare management, and other purposes, including population health monitoring and research. As implied in Australia's Health*Connect* Business Architecture version 1.9, patients would have the right to opt in or out of electronic patient records and electronic health records overall, and also have the right to refuse entry of data for any individual health event, healthcare encounter, health condition, or disease, as well as to refuse transfer of data to any provider, to a Health*Connect* Record System, or to the National Data Store (Health*Connect* Program Office 2004a Nov). The Health*Connect* Business Architecture version 1.9 also indicates that physicians would have the right to refuse entry of data for their patients into electronic patient records and electronic health records (Health*Connect* Program Office 2004a Nov). In contrast, current English NHS policies indicate that physicians must enter appropriate patient data into electronic patient records and electronic health records, but that patients could opt for the utilization of a ''sealed envelope'' for any identifiable data that they do not want shared with other clinicians; similarly, Canada Health Infoway is considering the use of ''masking'' of identifiable data held in electronic patient records and electronic health records at the patient's request. Patient control of what data are to be entered into electronic patient records and electronic health records and later used for population health monitoring and research purposes will adversely affect the quality and completeness of both numerator and denominator data. Patient control over data entry into electronic patient records and electronic health records may be a surmountable problem if the control is only over identifiable data, and if techniques exist for tracking unique patients in de-identified data, such as through the encrypted health identifiers employed in England's Secondary Uses Service.

Unique patient identification

Some form of unique identification of individual patients is necessary if electronic patient records and electronic health records are to provide data for population health monitoring and research. Unique identification enables a patient-centric view of population health, in which individual patients as members of the population are counted rather than just counting individual health events or the incidence or prevalence of individual diseases. Unique identification also enables patient-centric linkage of data from different data collection streams and patient-centric linkage of data over-time within the same data set. If electronic patient records and electronic health records do not include unique identification but do include geographic identifiers for patient residence, then any linkage would occur at a geographic level (such as city, town, postal code, or neighborhood, depending on the geographic identifier). Unique identification of individual patients is necessary for the specified geographic level of interest for the specified population. For example, unique identification could occur at the county level, if population health monitoring and health statistics were to be generated at the county level and sub-county level. Unique identification of individual patients could occur through any of several different mechanisms. The NHS number in England and the National Health Index in New Zealand represent unique patient identification numbering systems that are continuously de-duplicated. Alternatively, unique identification of individual patients could also occur through algorithmic probabilistic or deterministic linkage of a specified set of identifier variables, used across different data collection streams, all using the same identifier variables for patient authentication, with the same standard definitions and meeting the same data standards. With a larger the number of patients, de-duplication of the results of ongoing linkage of patient identifier variables will obviously prove more challenging. Finally, unique identification of individual patients could also occur through a master patient index, which would essentially consist of a ''white pages'' listing all patients with all of their associated healthcare unique identifiers, enabling each local healthcare provider or provider site to maintain its own patient identification system. As with algorithmic linkage of a series of patient identifier variables, an accurate master patient index will prove more challenging to maintain with greater numbers of patients.

It is also important to recognize that schemes for uniquely identifying patients differ from schemes for uniquely identifying members of a population. To the extent that health statistics extend beyond health events treated through the healthcare system, unique identification of patients rather than unique identification of each person in the population may limit the development of population-based health statistics.

Known denominator characteristics

As discussed earlier in this chapter, data derived from electronic patient records and electronic health records can only be useful for population health monitoring and research if they are associated with a geographically-based population denominator with known characteristics. Known characteristics include any demographic variables that would be used for the purposes of stratifying or analyzing the population, such as age, sex, race, ethnicity, and education. Denominator data could be derived from the electronic patient records or electronic health records themselves, if they pertain to an entire population. Alternatively, matching population denominator data could be derived from a population census, again assuming that the numerator data derived from the electronic patient records or electronic health records is a random representation of that population or of a known sub-sample of that population. Finally, a matching population denominator and basic demographic descriptors could also be derived from some form of a population-based registry of patients, such as England's Personal Spine Demographics Service maintained by the NHS or New Zealand's National Health Index.

Overarching Issues

Even if electronic patient records and electronic health records were to successfully address issues relating to data quality, data completeness, consent, unique personal identification, and known denominator characteristics, several overarching issues remain that may limit their utility for population health monitoring and research.

Population health and healthcare

As has been repeatedly indicated in the literature, healthcare is only one of many influences on population health (Evans and Stoddart 1990; Evans and Stoddart 2003; Friedman and Starfield 2003 Mar; Parrish, Friedman, and Hunter 2005). Consequently, data collected through electronic patient records and electronic health records in healthcare settings, even if those healthcare settings cover the full spectrum of the healthcare sector, will not adequately represent the full range of population health and the influences on population health. Even if all numerator and denominator issues related to electronic patient records and electronic health records were successfully addressed, electronic patient records and electronic health records will still have at least two limitations in their utility for population health monitoring and research. First, all types of information pertinent to population health will not be included in medical records, including electronic patient records and electronic health records. For example, as experts interviewed in the five countries frequently pointed out, population-based surveys typically include many data items unlikely to be captured in electronic patient records and electronic health records, thus obviating the possibility of the replacement of population-based surveys by electronic patient records and electronic health records. For example, such typical survey items that may not be included in electronic patient records and electronic health records could include standardized batteries of questions relating to the patient's subjective perception health status, mental health sick days, gun ownership, and income. Second, all aspects of the influences on population health will not be captured in electronic patient records and electronic health records; this is especially true of influences that are community attributes such as the built environment and population-based health programs, and influences that are contextual such as the natural environment, the cultural context, and the political context (Parrish, Friedman, and Hunter 2005, 18).

Structured data in electronic patient records and electronic health records

For the purposes of population health monitoring and research and generating health statistics, electronic patient records and electronic health records will only be useful if they contain structured data. Those structured data should include either (a) the most preferable alternative of clinical code sets with the codes necessary for population health monitoring, or (b) the less preferable alternative of clinical code sets with direct mapping to the required population health monitoring variables and code sets (NHS Information Authority 2002 Sep, 8).

Analysis

Another overarching issue is the capacity of public health agencies and population health researchers to cull data from electronic patient records and electronic health records. At a national level, even in a nation such as England with a population substantially smaller than the U.S. population, electronic patient records and electronic health records will annually generate billions of health events, prescriptions, test orders, laboratory and test results, and so forth. New technologies will be needed for data storage, handling, and use. In order to utilize electronic patient records and electronic health records for population health monitoring and research, public health will need new technologies and methodologies that will enable it to cull those data to derive what it needs in the format in which it needs it.

Cultural changes

Informants pointed to cultural changes that need to occur if electronic patient records and electronic health records are to be used for population health monitoring and research, including culture changes among public health practitioners, among clinicians, and among the public. Public health professionals will need to adapt their current techniques for data analysis and will also need to adapt to new types of data. Unless and until complete population coverage of electronic health records occurs within a geographic area, public health professionals will need to explore means of utilizing data from electronic patient records and electronic health records as an additional data source to those currently in use. Similarly, unless and until a fully automated relationship exists between electronic patient records and EHRs, allowing automatic extraction of data from electronic patient records and electronic health records for population health monitoring and statistical processing of those data, public health professionals will also need to adapt their culture to an even more complex set of data collection streams than currently exists (Hunter, Friedman, and Parrish 2005). As indicated earlier, collection of data through electronic patient records and electronic health records for population monitoring and research may also require culture change on the part of clinicians, currently accustomed to collection of more limited data for clinical purposes (for example, see: Hendy et al. 2005; Sprague 2004, 7–8). Based on the interviews conducted with experts in the five countries, it should also be noted that minimal experience and minimal professional literature currently exists from which to assess the willingness of clinicians to collect the needed data. Finally, cultural change on the part of the public will also be necessary, if the public is to accept the secondary use of clinical data collected through electronic patient records and electronic health records for the purposes of population health monitoring and research (for example, see Lewin Group 2005, 5, 16–17).

Incentives for adoption and use of electronic patient records and electronic health records

A growing literature has pointed to the need to provide incentives to stimulate clinician adoption and use of electronic patient records and electronic health records (Benson 2002; Bower 2005; Commission on System Interoperability 2005; Connecting for Health 2004 Oct; Healthcare Information and Management Systems Society 2005 Feb; Miller and Sim 2004 Mar/Apr). In addition, a growing literature has also emphasized the need for better alignment of financial and other incentives for adoption and use of electronic patient records and electronic health records, such as incentives for maximizing healthcare quality, reducing adverse events and medical errors, enhancing healthcare provider revenue, maximizing healthcare efficiencies, and controlling costs (Economist 2005 Apr 30; Goodman 2005 Sep/Oct; Middleton 2005 Sep/Oct; Miller et al. 2005 Sep/Oct). It is important to realize that issues of providing and aligning incentives for the adoption and use of electronic patient records and electronic health records for the secondary purposes of population health monitoring and research, and especially for generating health statistics, may be even more daunting than providing and aligning incentives for the primary uses of clinical care.

Transformative limits of electronic patient records and electronic health records

No single answer can be provided to questions about the potential contribution of electronic patient records and electronic health records for population health monitoring and research. Answers will depend upon many factors. One factor is the particular data collection stream, and whether the data collection stream includes reportable diseases and registries, administrative health data, or population-based surveys. A second factor that is whether the potential contribution of electronic patient records and electronic health records to population health monitoring and research is envisioned as supplementing current data collections with electronic patient records and electronic health records as an additional data source, or as an ongoing linkage of electronic patient records and electronic health records with current data collections, or as a replacement of current data collections with data derived from electronic patient records and electronic health records. While supplementation of current population health data collections with data derived from electronic patient records and electronic health records may be realistic goals, total replacement of all current population health data collections and automated extraction of data from electronic patient records and electronic health records may not. In considering the potential contribution of electronic patient records and electronic health records to population health monitoring and research, a third factor is whether electronic patient records and electronic health records meet current data quality and completeness standards for population health data collections. In the U.S., with its fragmented healthcare system, its relatively high rate of individuals without health insurance coverage, and its likely fragmented implementation of electronic patient records and electronic health records dependent upon individual health providers and individual geographies, questions of the potential utility of electronic patient records and electronic health records for population health monitoring and research will probably be answered through a series of disease- and condition-specific data collections in individual geographies. A fourth factor, integrally related to the third factor, is whether population-based implementation of electronic health records lead to new criteria for data quality and completeness of population health monitoring, different from those currently employed.

As indicated by several interviewed experts, it is also important to recognize that electronic patient records and electronic health records may yield entirely new data for population health monitoring and research, on topics not now adequately covered by current data collections. For example, this could include population-based measurement of chronic disease morbidity, disease prevalence, functional status, and wellness, as well as expanded population-based registries for chronic disease and health conditions (for example, see: Booz, Allen, Hamilton 2005 Mar).

Success Factors

This report centers on an analysis of five countries, based on a combination of reviewing written materials and interviewing expert informants. An analysis of only five countries cannot yield a definitive or quantitative exploration of factors that lead to or are associated with the successful use of electronic health records for population health monitoring and research. Given how germinal and varied is the development, implementation, and penetration of electronic health records in these five countries, identifying success factors becomes even more problematic. For example, the current penetration of electronic patient records into general practice in New Zealand is estimated at almost 100%, compared to 17% in the U.S. (Didham, Dovey, and Barker 2005; Burt and Hing 2005). Finally, of the five investigated countries, only England has extensively planned at the national level for the derivation of population health monitoring from electronic health records, making the identification of success factors from this analysis even more perilous.

While a definitive analysis identifying the factors leading to the successful use of electronic health records for population health monitoring and research is not now possible given the parameters of this project and the current status of electronic health records in the investigated countries, it is nonetheless possible to speculate cautiously on those success factors. The following brief section provides this preliminary speculation; by its nature, this speculation is neither right nor wrong, but is intended to stimulate further discussion and debate. Success factors are divided into three categories: enabling factors, which increase the likelihood of the successful use of electronic health records for population health monitoring and research; threshold factors, without which the successful use of electronic health records for population health monitoring and research may fail; and, with apologies to Malcolm Gladwell, tipping factors, which ultimately will maximize the potential for the successful use of shared EHRs for population health monitoring and research (Gladwell 2000).

Enabling factors

Enabling factors that increase the likelihood of the successful use of electronic health records for population health monitoring and research include health system enablers and health information system enablers. Health system enabling factors are at least fourfold: first, greater funding of the healthcare system by government; second, a low percentage of uninsured individuals in the population; third, a higher ratio of general practitioners to specialists; and fourth, greater central coordination of the health system. Health information system enabling factors are at least fourfold: first, a closer relationship between the provision of healthcare information from data sources for clinical and administrative purposes and the conduct of population health monitoring; second, reduced fragmentation among population health monitoring data collections (Public Health Data Standards Consortium 2004); third, the existence of clinician incentives for adopting and using electronic patient records and electronic health records; and fourth, cultural changes on the part of clinicians supporting their collection of data of data for population health monitoring through electronic patient records and electronic health records (for example, see Bower 2005, xix, 86–88).

Threshold factors

Threshold factors, without which the successful use of electronic health records for population health monitoring and research may fail, include business threshold factors and systems threshold factors. A business threshold factor is the explicit inclusion of population health monitoring and research as integral components of the national strategy for electronic health records, and in particular the national mission for electronic health records, goals, plans and pilot or test implementations. System threshold factors are at least threefold. First, the national strategy for electronic health records must include the integrated electronic provision of data and integrated data flows from diverse healthcare sources for clinical, reimbursement, administrative, and population health monitoring purposes. Second, the national strategy for electronic health records must include the use of structured data entry for electronic patient records and electronic health records and the development of data standards useful for clinical, administrative, and population health monitoring purposes. Third, as indicated in *Emerging Dataset Issues: Enabling the Derivation of 'Business' Information from Electronic Records;* ''to generate consistent information beyond that needed for direct patient care requires consensus regarding. . . clear definitions of the data required to be collected or derived, the rules for the derivation of secondary information from primary [EPR and electronic health record] data. . ., and knowledge of electronic record design so that standards for derivation can be consistently applied by system developers and particularly those writing extraction routines'' (NHS Information Authority 2002 Sep, 6). Fourth, the national strategy for electronic health records must include the development of some form of unique patient identification and the use of that unique patient identification, encrypted or unencrypted, for all electronic provision of data. Unique patient identification could occur through a variety of mechanisms, including unique patient identification numbering systems for the specified geographic level of interest, or through algorithmic probabilistic or deterministic linkage of a set of identifier variables, or through a master patient index.

Tipping factors

Three tipping factors can be identified, which may ultimately maximize the potential for the successful use of electronic health records for population health monitoring and research. The first tipping factor is a form of reimbursement for physicians that could mandate the nature, contents, and use of electronic health records, such as salary-based reimbursement or other systems where physicians are required to follow established uniform recording protocols. The second tipping factor is the mandated implementation of electronic health records with mandated standards. Of course, these tipping factors should be viewed within the context of the political and health systems of individual nations. While a predominantly single payer system, as in England, may arguably increase the likelihood of successful use of electronic health records for population health monitoring, it does not follow that the lack of a single payer system makes use of electronic health records for population health monitoring impossible. Similarly, while mandated implementation of electronic health records may arguably increase the likelihood of successful use of electronic health records for population health monitoring, it does not follow that other approaches to implementation of electronic health records—such as business models providing incentives for implementation—will make use of electronic health records for population health monitoring impossible. The third tipping factor is the confluence of strong governmental leadership in the healthcare sector and greater governmental coordination or control of the healthcare sector, which may be promoted through the existence of a predominant payer for healthcare or a predominantly single payer system.

Conclusions

National strategies for electronic health records and their supporting national health information infrastructures should be viewed as nested within a series of overlapping contexts. One context is the nation's health and healthcare system. A second context is the nation's governmental and political system, structures, and policies. A third context is the nation's market system, especially as it relates to the population's health and the healthcare system. National strategies for electronic health records simultaneously reflect the nation's health and healthcare system, the nation's governmental and political system, and the nation's market system.

National strategies for electronic health records constitute both (a) technical decisions about architecture, information and communications technology, and standards, as well as (b) political decisions. The political decisions affecting national strategies for electronic health records can change, and those political decisions will affect the technical decisions. Political decisions affecting national strategies for electronic health records may be most likely to change during relatively early stages of national conceptualization, planning, and investments.

Australian, Canadian, English, and New Zealand national strategies for electronic health records and the supporting national health information infrastructures were reviewed for this report. In the four countries investigated, population health monitoring and research—especially population health monitoring to generate population-based health statistics—were clearly and explicitly secondary uses for electronic health records. England's National Health Service has most thoroughly explored and planned for the inclusion of population health monitoring, including for generating health statistics and supporting population health research, as part of its national strategy for electronic health records. Canada Health Infoway is devoting substantial resources to incorporating communicable disease surveillance within the Canadian national strategy for electronic health records. Nonetheless, little consensus seems to exist within or across these nations about the concepts, contents, or methods of how national strategies for electronic health records can or should fully support population health monitoring for producing health statistics.

In 2006, it is still too early to ascertain the actual potential of national strategies for electronic health records for population health monitoring and research. With the exception of England, the development of those national strategies are in germinal stages; even in England, the implementation of the national strategy is in an early stage. An evidence base does not exist from which to judge how successful national strategies for electronic health records can be in supporting population health monitoring and research (see similar but more general points in: Atherley 2005; Bend 2004). As indicated in 2002 by the National Health Service Information Authority, ''data needed to support secondary information purposes. . . should be derivable from data that is collected as part of the operational care process. . . However, critical aspects of this hypothesis remain operationally untested'' (NHS Information Authority 2002 Sep, 3–4).

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Acronyms and Glossary

Acronyms

Acronym	Term or organization
AHRQ	Agency for Healthcare Quality and Research (U.S.)
CIHI	Canadian Institute for Health Information
CRS	Clinical Reporting System (Indian Health Service, U.S.)
ECID	Electronic health record infostructure client identifier (Canada)
EHR	Electronic health record
EHRs	Electronic health records
EPR	Electronic patient record
EPRs	Electronic patient records
ERDIP	Electronic Record Development and Implementation Programme (England)
FID	Federated identifier (Canada)
GP	General Practitioner
HEDIS	Health Plan and Employer Data Informatin Set (U.S.)
IHS	Indian Health Service (U.S.)
IHIE	Indiana Health Information Exchange (U.S.)
Infoway	Canada Health Infoway
INHS	Inland Northwest Health Services (U.S.)
MWS	Medical Warning System (New Zealand)
NCVHS	National Committee on Vital and Health Statistics (U.S.)
NEHTA	National E-Health Transition Authority (Australia)
NHI	National Health Index (New Zealand)
NHII	National health information infrastructure
NHS	National Health Service (England)
NN4B	NHS Numbers for Babies (England)
NPfIT	National Programme for Information Technology (England)
PHO	Primary Health Organisation (New Zealand)
RHIO	Regional Health Information Organization (U.S.)
SUS	Secondary Uses Service (England)
UHIN	Utah Health Information Network (U.S.)
VHA	Veterans Health Administration (U.S.)
VistA	Veterans health information systems technology architecture (U.S.)
WAVE	Working to Add Value through E-information (New Zealand)

Glossary

Term	Definition
Denominator	“The lower portion of a fraction used to calculate a rate or ratio. The population. . . at risk in the calculation of a rate or ratio” (Last et al. 2001, 49). Denominators represent the population in which the particular aspect of population health is being measured. Population-based health statistics require both a known numerator and a known denominator.
Electronic health record	Electronic repository of patient-centric data that are identifiable, longitudinal and preferably life-long, cross-provider, cross-provider site, and cross the spectrum of healthcare, including primary care, acute hospital care, long-term care, and home care
Electronic patient record	Electronic record of the periodic care provided mainly by one institution
Health statistics	“Numerical data that characterize the health of a population and the influences that affect its health” (Parrish, Friedman, and Hunter 2005, 3)
Numerator	“The lower portion of a fraction used to calculate a rate or ratio. The population. . . at risk in the calculation of a rate or ratio” (Last et al. 2001, 126). Denominators represent the population in which the particular aspect of population health is being measured. Population-based health statistics require both a known numerator and a known denominator.
Population health	“The health outcomes of a group of individuals, including the distribution of such outcomes within the group” (Kindig and Stoddart 2003, p. 381). Population health encompasses the level and distribution of disease, functional status, and well-being within a group (Parrish, Friedman, and Hunter 2005, 18).
Population health monitoring	The collection and analysis of data to detect and describe changes in the population’s health and influences on the population’s health
Population health research	Research on population health or those factors that affect population health

Appendix 1. Structured Search Criteria

1. General Considerations for Structured Searches

a. All searches documented, with inclusion and exclusion criteria

b. Specified below are initial search algorithms. Due to the volume of material and the return rate of valuable material, the search algorithms changed somewhat during searches for individual countries.

c. When search algorithms yield an unwieldy amount of material from the Web, additional exclusion criteria will be applied
   i. PDF files only
   ii. Web sites updated during the last year only
   iii. English language only

2. Preliminary Search Algorithms

a. Search on ‘‘health information strategy’’ AND individual country
   i. search within individual country results by ‘‘health statistics’’
   ii. search within individual country results by ‘‘population health information’’
   iii. search within results by ‘‘surveillance’’

b. Search on ‘‘health information infrastructure’’ AND individual country
   i. search within individual country results by ‘‘health statistics’’
   ii. search within individual country results by ‘‘population health information’’
   iii. search within results by ‘‘surveillance’’

c. Search on ‘‘electronic health record’’ AND individual country
   i. search within individual country results by ‘‘health statistics’’
   ii. search within individual country results by ‘‘population health information’’
   iii. search within results by ‘‘surveillance’’

d. Search on ‘‘electronic medical record’’ AND individual country
   i. search within individual country results by ‘‘health statistics’’
   ii. search within individual country results by ‘‘population health information’’
   iii. search within results by ‘‘surveillance’’

e. Search on ‘‘health information network’’ AND individual country
   i. search within individual country results by ‘‘health statistics’’
   ii. search within individual country results by ‘‘population health information’’
   III. search within results by ‘‘surveillance’’

3. Documentation

a. Record all websites

b. Record all search algorithms

Appendix 2. Journals and Newsletters Reviewed

Australian and New Zealand Journal of Public Health
BMC Medical Informatics and Decision Making
British Medical Journal
E-Health Insider
E-Health Insider Primary Care
eHealth International
Electronic Healthcare
Guardian
Health Affairs
Health Care and Informatics Online
Health e-News
Health Informatics and Communications Canada
Health Informatics Journal
Health Information Management
HealthCare and Informatics Review Online
iHealth Beat
Journal of American Medical Informatics Association
Journal of Healthcare Information Management
Journal of Medical Internet Research
Selected articles in other journals and newsletters

Appendix 3. Typical Interview Guide (English Expert)

Introduction and Background

1. Conducting project for U.S. Centers for Disease Control and Prevention/National Center for Health Statistics on potential contribution of electronic health records and the developing U.S. national health information infrastructure to population health monitoring and population-based health research. The emphasis within the project is on data and information used to develop health statistics, such as registries, surveys, and administrative health data, rather than on data employed for rapid case identification and outbreak investigations.
2. Including within the concept of a national health information infrastructure
   - a. Electronic health records and electronic patient records, comparable to National Care Records Service
   - b. Electronic connectivity, comparable to N3 and NHSNet
   - c. Electronic prescribing, comparable to Electronic Transmission of Prescriptions
   - d. Standards development
   - e. Other associated technologies and infrastructure components
3. Three phases of this project
   - a. Investigation of related developments in Australia, Canada, New Zealand, and the U.K. (England) through environmental scans including
     - i. Web and peer-reviewed and trade literature
       - 1) Reviewed National Programme for IT web pages relating to Secondary Uses Web pages
       - 2) Reviewed NHS Information Authority web pages relating to the Dataset Development Programme and the NHS-Wide Clearing Service
       - 3) Read variety of NHS and DH reports relating to Information for Health, Building the Information Core, Delivering 21st Century IT Support for the NHS, Secondary Uses Service Phasing and Migration Description
     - ii. Key informant interviews in each country with representatives of national and sub-national governments responsible for development of national strategies for electronic health records and population health monitoring, researchers, and clinicians
       - 1) Just starting on England
       - 2) Suggestions and contacts will be much appreciated
   - b. Investigation of related developments in the U.S., which also includes
     - i. Web and peer-reviewed and trade literature
     - ii. Key informant interviews
4. Purpose of key informant interviews
   - a. To obtain snapshots of current projects and activities that do or have potential of electronic health records and NHII development to population health monitoring and research
   - b. To obtain feedback on key informant's realistic assessment of the potential relationships between national strategies for electronic health records and the NHII and population health monitoring and research, and what factors may facilitate or impede the development of those relationships

Questions:

1. Would like to start by obtaining a better understanding of
   - a. Secondary Uses Service
     - i. Uses for population health monitoring?
     - ii. Uses for research?
   - b. Dataset Development Programme
   - c. Bases for minimum data sets, such as
     - i. Acute Myocardial Infarction Data Set
     - ii. Summary Core Data Set fore Diabetes
     - iii. National Cancer Data Set
     - iv. Central Returns, such as sexually transmitted diseases

2. At most general level, what do you see as the potential of the national strategy for electronic health records and core elements of national health information infrastructures to contribute, directly or indirectly, to population health monitoring and research? In what timeframe?
    a. Personal Demographics Service
    b. Personal Spine Information Service
    c. Secondary Uses Service
3. At more specific levels:
    a. Especially potential for linkage of existing administrative (Hospital Episode Statistics), population-based survey (Health Survey for England, National Survey of NHS Patients), and registry (cases of infectious diseases, births, deaths), data with EHR data for population health monitoring and research purposes
        i. Should note that U.S. models for population-based registers may be different than the NHS practice-based registers for cancers, CHD, diabetes and stroke
    b. Replacement of current population-based data collections by EHRs, such as
        i. Disease and health event registers
        ii. Surveys, including institution-based surveys, provider surveys, and population-based surveys
        iii. Administrative health data
    c. If not actual replacement of current population-based data collections, does the potential exist for supplementation of current data collections by EHRs?
        i. Collection of new data items that would be added to population-based data collections
        ii. Entirely new data collections or new data collection streams?
    d. What conditions would facilitate the development of such uses?
        i. Linkages
        ii. Replacements
        iii. Supplementations?
    e. What conditions would impede the development of such uses
        i. Linkages
        ii. Replacements
        iii. Supplementations
4. Follow-up
    a. Other issues to discuss
    b. Other key informants who should be contacted

Appendix 4. Key Informants

4-A. Key Informants Australia

Name	*Position*
Helena Britt	Director Family Practice Medical Research Centre and Director, General Practice Statistics and Classification Unit, AIHW
Tim Churches	Manager Population Health Information Branch New South Wales Department of Health
Enrico Coiera	Professor and Foundation Chair in Medical Informatics Faculty of Medicine and Co-Director, Centre for Medical Informatics University of New South Wales
Amanda Cornwall	Director Environmental Policy Department of Sustainability and Environment Victoria
Margaret Fisher	Director Executive Unit, AIHW
John Glover	Director Public Health Information Development Unit University of Adelaide
Diana Hetzel	Senior Researcher Public Health Information Development Unit University of Adelaide
Louisa Jorm	Director Centre for Epidemiology and Research New South Wales Department of Health
Christopher Kelman	Medical Director Department of Health and Ageing
Richard Madden	Director AIHW
Ric Marshall	Manager Health Information and Performance Evaluation, Metropolitan Health and Aged Care Division, Department of Human Services, Victoria
Graeme Miller	Medical Director General Practice Statistics and Classification Unit, AIHW
David Muscatello	Senior Epidemiologist and Manager Emergency Department Surveillance Centre for Epidemiology and Research New South Wales Department of Health
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* Review of selected sections.

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For answers to questions about this report or for a list of reports published in these series, contact:

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