

Accurate Patient Identification— A Global Challenge

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Abstract

Patient identification and patient matching have long been a challenge in countries around the globe. The patient/consumer identity at the point of registration or access must be accurate and linked to the entire health history in order to support the immediate care or wellness event. From this point, the patient/consumer documentation must be linked to other points in order to truly create patient-centered care and wellness. This issue has gained attention recently as technology adoption increases, interoperability becomes a reality, and analytics uses the data to improve care and outcomes. In today's global healthcare environment, the patient matching capabilities range from basic exact matching on key variables to highly sophisticated algorithms. This article provides an overview of some specific patient identification strategies, along with their challenges and considerations, focusing on approaches in the United States, Singapore, Canada, Australia, and Wales. The authors present examples of better practices in which countries address governance early in the healthcare transformation process, technology is used to augment established identifiers, and clinicians and consumers are engaged early to ensure their adoption.

Keywords: patient identification, patient matching, data linkage, patient-centered care

Patient identification and patient matching have long been a challenge in countries around the globe. Global healthcare transformation efforts have moved the needle considerably on the topic of national patient identification and patient matching.

Improving the quality of care, providing easier access to care, and addressing the increasing healthcare costs are global challenges. A unified view of patient data across care settings must be created despite the variability in data capture, systems, and standards (or lack thereof) in order to meet the goals of improved quality and lower costs. Accurate, complete information is vital to delivering appropriate, high-quality, cost-effective care. Without a unified view of data, clinicians and caregivers will continue to struggle with inaccurate or incomplete information. This mantra is not unique to any specific country but is a universal truth as the rise of chronic disease and aging population stress healthcare budgets around the globe.

The patient/consumer identity at the point of registration/access must be accurate and linked to the entire health history in order to support the immediate care or wellness event. From this singular point, the patient/consumer documentation must be linked to other points in order to truly create patient-centered care and wellness. Without this foundation, care cannot be optimally coordinated, payments appropriately applied, consumers appropriately engaged, or outcomes accurately measured.

Market Drivers and Activities

The complexity of the patient identification and matching challenge has increased even more as the United States shifts to a patient-centered wellness approach, which translates to the need to understand the individual as a patient/citizen/consumer/subscriber/beneficiary. This shift is driving basic, advanced, and predictive analytics, for which linked records need to be created or used. Having access to numerous data stores related to health, society, cost, providers, and so forth and being able to transform this data into meaningful, trusted information is a major challenge. In addition to accessing data stores, having the ability to capture, collect, and analyze data streams from mobile devices, fall monitors, pacemakers, and other devices will be essential to enabling successful transformation. To add to the complexity, the timeliness of processing this vast amount of data will be a significant driver of change. Clearly, the initiatives are intended to delicately balance improving the care delivered and containing the costs associated with delivering care.

Often overlooked but foundational to coordinated care is the ability to accurately identify patients and link them with their records. This issue has gained attention recently as technology adoption increases and interoperability becomes a reality. The challenges associated with accurate patient identification have been the topic of many federal committees and professional association work groups over the past five years. The Office of the National Coordinator for Health Information Technology (ONC) contracted a study to identify “incremental steps to help ensure the accuracy of every patient’s identity, and the availability of their information wherever and whenever care is needed.”¹ The findings of the study focus on the need for standards in data capture, standards for matching algorithms, and certification of electronic health records (EHRs).

The problem is real, and the variables affecting accurate matching are both broad and deep. At a high level, consider how information is received from all the sources of health information—hospitals, physicians’ offices, clinics, rehabilitation services, long-term care, acute care, and others—and couple these sources with the variety of data formats and level of completeness or lack thereof, and the problem of inaccuracy. The level of completeness might be a missing Social Security number (SSN) or middle initial, for example. But sometimes the data are just wrong (mismatched city and state, such as “Chicago, TX,” or a SSN of 123-45-6789). Wrong data and incomplete data are types of inaccurate data. The current state of data quality is evidence of the variation that exists during the intake process.

The 2014 American Health Information Management Association (AHIMA) Practice Brief “Managing the Integrity of Patient Identity in Health Information Exchange (Updated)”² explores these challenges in the context of health information exchange (HIE), one of the healthcare transformation approaches. Healthcare providers and health information technology vendors recognize the challenges, yet the industry continues to leverage basic methods of linking existing records. This complex problem affects all aspects of care and requires solutions that can overcome many of the variables that exist at the time of patient registration, access, or intake.

Patient Matching Tools

The tools used to facilitate accurate matching vary as well. In today’s global healthcare environment, the matching capabilities range from basic exact matching on key variables to highly sophisticated, frequency-based probabilistic learning algorithms.

Additionally, many countries outside the United States have established national or more specific healthcare identifiers for their citizens. The premise is that all patients will be citizens and will always present or know their health identifier. Officials in most countries believe their identifier is sufficient to ensure that patients are linked to their records. However, the identifier is insufficient for broader information-sharing requirements. For example, the European Union has supported cross-border sharing initiatives for member countries. Quickly a country-specific identifier falls short in this regard. Compound that with the need to capture and share data from nontraditional sources such as social care settings, and the complexity starts to become obvious.

To make matters worse, many of these identifiers are wrapped in legislation that is quite specific as to how the identifier can be used and what can and cannot be done with the associated information. The most restrictive legislation actually prohibits “linking” any patient information for privacy and security reasons, thus creating site-specific documentation that is not available for continuity of care. Another example is a clause in the language of the legislation that affords an individual citizen “the right to be forgotten.” Individuals can control their information to the degree that no one can see their data.

The following is an overview of some specific patient identification approaches that certain countries have taken, along with their challenges and considerations.

Singapore

The Singapore Ministry of Health embarked upon the creation of a National Electronic Health Record (NEHR) in pursuit of a goal of “One Patient, One Record.” The NEHR supports healthcare delivery (acute and primary care), wellness, and data integration/data sharing, with longer-term goals also addressing research and analytics. The Ministry of Health Holdings (MOHH) is the sole holding company for the public healthcare assets, and private corporations also deliver a significant volume of healthcare. While Singapore is a small country in landmass, it is a complex environment with more than 5 million inhabitants, four official languages, a rapidly aging population, and only 4 percent of the gross domestic product (GDP) being allocated to healthcare. Thus the funding and governance of the NEHR is challenging.

The NEHR initial planning in the 2008–2009 time frame included the formation of the National Health Informatics Strategy (NHIS). Two key dimensions of the NEHR planning were data reuse and data interoperability and sharing, with both dimensions obviously needing strong patient/citizen identification principles and practices. Singapore has a National Registration Identity Card (NRIC) required for all permanent resident age 15 years and older; however, residents are not required to carry it at all times, nor are temporary residents required to have it. Approximately 28 percent of the Singaporean population consists of nonresidents. In the context of the NEHR, the use of the NRIC as a data element has no limitations.

As MOHH designed the NHIS and consulted with vendors, consultants, and governmental officials, it became clear that the NRIC would not be sufficient as a ubiquitous identifier. Therefore, the NEHR adaptive enterprise architecture uses registry services to support patient, clinician and facility, and document services. Specifically, since 2010 patient identification is delivered as a core service (within the service-oriented architecture) that is executed using master data management software and a probabilistic matching algorithm that is tuned for the Singaporean data. This core service is vital to the first dimension of the MOHH NEHR plan that focuses on a patient-centric view of data supporting integrated health. The second and third dimensions of the MOHH NEHR plan, consumer segmentation and care continuum, will also benefit from the core patient identification service approach while supporting the guiding principles of data reuse and data interoperability.

Canada

With the 2001 formation of Canada Health Infoway (Infoway), and the \$1.2 billion Canadian in initial funding from the Ministry of Health, Canada embarked on a massive realignment of EHR requirements, standards, and architecture, with an emphasis on standards-based connectivity for quality, accessibility, and efficiency of health information. Early in the discovery process Infoway and the jurisdictional representatives evaluated the political, legal, and governance implications of potentially establishing a federal health identifier to support the long-term goals of a pan-Canadian EHR. Provincial-level identifiers already existed to support the funding and payment of healthcare services, with functioning client (patient) registries for each province. Data quality problems related to the provincial identifiers were known to exist but were not impeding the purpose and use of the existing provincial identifiers.

Since healthcare is funded and governed at a provincial level, and each province has different privacy regulations, it would have been extremely difficult to design and execute a pan-Canadian identifier. Realistically, securing passage of federal legislation supporting such an identifier would have been very

difficult. Therefore the decision was made to develop registry services to support client (patient), provider, location, and terminology domains. These complex registries were a key component of the Health Information Architecture Layer (HIAL) and the common services and service bus.³ These components are used to support the priority EHR services including drug information, laboratory, diagnostic imaging (e.g., radiology, picture archiving and communication system [PACS], radiology information system [RIS]), and public health. Approximately 15 percent of the initial budget was allocated to support the design and deployment of the registry services.

The provincial-level execution of new client registries compliant with the Infoway HIAL was one of the first priorities for most provinces. From 2004 to 2008 the provinces procured master data management/EMPI (enterprise master person/patient index) software to augment or replace the existing client registries. In the course of providing this leading-edge service for the new jurisdictional information structure, data quality and governance challenges were encountered and addressed. For many provinces, this undertaking was the first for which provincial-level governance had to be established. This challenge was addressed with openness and transparency, and provincial-level data standards, data quality remediation, and governance policies were established. The Saskatchewan client registry initiative, SCI, won the Infoway 2007 Project of the Year award. As Eithne Reichert, president of RWI Informatics and the lead project manager, shared,

The successful long term management of the data quality in SCI required an understanding of business processes of the hospitals, insurance and other organization sources as well as long term uses. Both the governance and data quality was greatly enhanced through a shared accountability approach between the sources and provincial level management to ensure the quality. The data quality needed to be optimal for client identification to compile and assemble the patient results in electronic health record services and repositories. The processes to manage the upstream and downstream effect of identification errors were understood in terms of “patient safety.”

Today the provincial registry leaders, both technical and operational, continue to meet on a regular basis to refine governance, establish common policies, and communicate best practices among the provinces. Additionally, Infoway has recognized the need for interdependent registries (not stand-alone services) to promote connectivity, data reuse, and a true patient-centric approach to care delivery.

Australia

Australia, like many other countries around the world, addressed patient identification in conjunction with healthcare transformation and the increasing demand for data sharing initiatives. After years of planning and spending exceeding \$1 billion Australian dollars, Australia launched its Personally Controlled Electronic Health Record (PCEHR) in mid-2012. As shared by Peter Fleming, CEO of the National E-Health Transition Authority (NEHTA), in the NEHTA 2013 annual report, “The eHealth record system lets consumers control their own individual eHealth record. One of the key principles of the design is that the eHealth record is personally controlled and it is up to the consumer if they wish to have one or not, and importantly, they decide which healthcare providers can view their record.”⁴

As part of the infrastructure and policy needed for the PCEHR, in 2010 the Australian government passed several legislative acts, including the Health Identifiers Act of 2010, which legislated the governmental assignment of an individual health identifier (IHI) and the need for a patient to consent (opt in) for inclusion in the PCEHR. Moreover, the IHI is not made available to the citizens or the providers until a patient is enrolled in the PCEHR, although a 16-digit health identifier (HI), including check digits, has been issued to all enrollees in the Australia Medicare program, thus addressing almost all of the Australia population. State-level reports that assessed the data quality of the IHI and other relevant patient demographic data were conducted. The IHI query process and logic was also explored. However, the evaluations were not made public.

In late 2013 the federal government commissioned a study of the PCEHR, as considerable monies had been spent and after 1.5 years only 6 percent of the Australian population was using the PCEHR.⁴

This finding led to considerable clinician frustration, and the Australian Medical Association stated that clinician adoption would not improve until rich, relevant clinical data are present in the new system, which must have high usability. The study recommended changes to governance, a switch to an opt-out model by 2015, and the revamping of the board to include representation from clinicians, other healthcare providers, and software vendors.⁴

Wales

Wales is a country of 3 million people bordering the west of England and surrounded on the other three sides by the Bristol Channel and the Irish Sea. People speak English, Welsh, or both. It is part of the United Kingdom, which includes England, Scotland, Wales, and Northern Ireland, but many powers, including health, are delegated to the Welsh Assembly. In 2003, the assembly established the Informing Wales Health Care Program (IWHCP) to improve Welsh healthcare.

IWHCP identified accurate patient identification as a key need and noted that the lack thereof resulted in information being fractured and scattered not only through the seven health boards but also across hospitals and individual departments within the healthcare delivery system. Patients had multiple identifiers, and numerous duplicate patient records existed. Further, some Welsh names are widespread, and the frequency of names such as of Margaret Jones or Thomas Davies placed patients with common names at high risk of having their records confused with those of others.

Strategies for enhancing the ability to accurately identify patients using frequency-based probabilistic algorithms to overcome the problem of common names as well as leveraging multiple attributes with which to identify a patient within and across facilities were incorporated into the Wales IWHCP infrastructure. Ensuring a solid foundation with which to build the improved healthcare platform, these identification strategies became a key component of the e-health architecture.

In addition to accurate patient identification, the ability to understand where a patient had health information brought additional benefits to the National Health Service (NHS) Trusts merger program and helped the development of the Welsh Clinical Portal. Previously, searching several administrative systems to locate patient information was difficult and time consuming. Clinical staffs now see unified patient views, can identify instantly where supporting records are held, and can order tests online. “Much quicker,” enthused one doctor. “It’s just like Internet shopping!”

Other initiatives based on analytics are also coming into play as the Welsh government pursues plans to improve the Welsh healthcare system.

Summary

Patient matching is a global challenge, as evidenced by the countries’ stories included above. The authors believe the following observations can be applied to all countries as they embark on healthcare transformation activities and either address existing patient identification practices and principles or develop new models.

- *Governance comes first.* Defining and applying information and data governance frameworks first, not as an afterthought, is a key to success. The Canadian provincial approach, which continues to evolve, and particularly the principles applied in Saskatchewan serve as evidence to support this observation.
- *Existing identifiers likely have inherent limitations or data quality issues.* Officials from many countries noted in this article, as well as others not willing to publish their data, will privately disclose challenges of existing identifiers, particularly because the identifiers are tied to healthcare access or payment. Even the best of identifiers will fall apart if rigid queries are created for accessing the identifier or if the identifier was not designed to support data exchange

and coordination of services. Countries should not assume that an identifier created 10 to 20 years ago would be sufficient to underpin data exchange and healthcare transformation activities.

- *Do not forget about the clinicians and the consumers.* Governments may follow defined processes, hire consultants to explore issues, and create the “perfect” legislation, but these efforts will all be for naught if clinicians are not actively engaged in designing a system to support data exchange. Consumers should be engaged early to explore what an identifier might imply and the potential restrictions. Privacy advocates do not always represent the average consumer.

This article presents examples of better practices in which countries address governance early in the healthcare transformation process, technology is used to augment established identifiers, and clinicians and consumers are engaged early to ensure their adoption. The world will continue to become smaller, flatter, and interconnected. We are moving into the age of the globally integrated and intelligent economy, society, and planet. There is no better time to construct a solid data foundation for greater individual healthcare value and sustainability.

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Notes

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