

# The Value of the International Patient Summary in Canada

A CHIEF Executive Forum White Paper

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# Terminology & Acronyms

**CEN**: European Committee for Standardization

CEN/TC251: European Committee for Standardization, Technical Committee 251

eHN: eHealth Network (Europe)

EMR: Electronic Medical Record

epSOS: European Patient Smart Open Services

**GDHP**: Global Digital Health Partnership

HL7: Health Level Seven

**IPS**: International Patient Summary

RCU2: Resumo Clinico Único do Utente (Portugal)

**SDOs**: Standards Developing Organizations

SPMS: Portugal Serviços Partilhados do Ministério da Saúde (Shared Services of the Ministry of

Health)

WHO: World Health Organization

# Executive Summary

Implementing the International Patient Summary (IPS) will benefit the Canadian healthcare system and its patients, clinicians, and other healthcare providers.

An International Patient Summary (a type of electronic health record extract) can follow a patient across borders, meaning that data can be shared with other health authorities, provinces, territories, and countries. It enables better care abroad, where healthcare providers have no medical history of a patient.

IPS may also result in better healthcare outcomes at home and across Canada. The IPS provides a baseline of medical data to a healthcare provider, including information on medications, health conditions, past surgeries, and more. Patient Summaries can be shared across primary, acute, specialty, community, and long-term care. IPS data collection has been implemented in a wide range of healthcare services, such as emergency departments, hospital units, and private clinics, and in pharmacy, dental, eye care, and palliative care.

With an IPS, patients would not need to give their complete patient story to each healthcare provider they encounter. The IPS puts the power in the hands of the patients, allowing them to advocate for their own care and have access to their personal health data. With better integrated data, there are reductions in care gaps and needless tests and procedures could be eliminated.

Clinicians would have better decision-making abilities with this baseline of data, including preventing adverse drug reactions and reducing malpractice. The IPS can make healthcare systems run more efficiently, with resources better allocated and costs decreased due to fewer readmissions.

This white paper provides an overview of IPS implementation globally, including lessons learned from other countries. Benefits and value to patients, clinicians, and the healthcare system are explored. These lessons are translated into key themes for IPS in Canada, as well as a roadmap to successful implementation.



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# Background

The movement of people around the globe continues to increase, with international travel and remote work opportunities becoming more accessible to a larger number of people. As seen during the COVID-19 pandemic, this interconnection of people means that sharing essential health information, such as data around personal medical records, infectious disease, outbreaks, and immunization status, is essential.

The International Patient Summary (IPS) is an electronic health record extract containing essential healthcare information intended for use in both scheduled and unscheduled, cross-border care scenarios. Patients' private health data would be able to follow them when in other countries, while healthcare professionals can retrieve the data when and where it matters the most.

Patient summaries would allow Canadians to be more at ease about their health while abroad, but also be able to move across healthcare settings and jurisdictions and provinces while allowing for a continuity of care while at home in Canada. Clinicians and healthcare providers would be able to provide more informed diagnosis and treatment and better manage patients.

The COVID-19 pandemic has exemplified the need for data sharing in Canada. IPS could be implemented for virtual care, cross border, provincial and territorial care, support of vaccine data and certificate and other use cases. Implementing a standardized patient summary could aid in better public health in Canada, as well as better disease control and pandemic responsiveness.

# Purpose

This CHIEF Executive Forum white paper explores and articulates the value of the International Patient Summary (IPS) to Canada's healthcare system. It aims to inform the industry of the clinical and health-system value of the IPS as a key component of interoperability. Topics explored include:

- International adoption of IPS
- Lessons learned from those countries and regions where IPS has been implemented
- Clinical value for practitioners
- Benefits and anticipated value to patients
- The opportunity and value of implementing IPS in Canada

As part of the background research, stakeholder interviews were conducted to identify key themes, quantifiable benefits, and emerging opportunities and value of implementing IPS in Canada. A literature review was done, as well as a content analysis and case study selection. The CHIEF Executive Forum held a meeting to workshop the scenarios related to implementing IPS in Canada. This workshop discussion resulted in insights about priority opportunities and value to stakeholders, as well as clarity on the gaps, obstacles, and risks involved in implementing IPS in a Canadian context.

## What is the International Patient Summary (IPS)?

When medical emergencies happen outside of a person's home country, access to clinical data is essential for providing timely care. The International Patient Summary (IPS) is an electronic health record extract originally intended for use in emergency international care situations but that has many uses domestically. For example, the information contained in the IPS could be used to support transitions of care.

Patient summaries are not new. Since record-keeping began, healthcare records have been created and maintained by all care providers. Patient summaries are holders of important medical information and are now an essential part of the fabric of healthcare.

A patient summary provides a snapshot in time of a person's medical information and healthcare situation. It's a health record consisting of a standardized collection of clinical information obtained from healthcare professionals, such as known allergies, current medications, and medical diagnoses.

The International Patient Summary (IPS) allows the important information in patient summaries to be shared across regions and countries. The IPS is not exhaustive and doesn't contain the patient's full medical record. Rather, it's a concise summary, a starter set of data to inform a person's treatment at the point of care.

There are many initiatives to standardize patient records that take considerable time and resources to define, design, and agree upon the minimum data set to be collected. An internationally recognized patient summary is a set standard that will reduce rework, decrease investment, and increase the value of many digital health initiatives for clinicians, patients, and healthcare systems.



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While the focus of the IPS is on unscheduled, cross-border care, the data also provides a baseline of medical information for other scheduled and planned healthcare situations across various care settings.

### The required information in an IPS record includes1:

- General patient information, such as name, birth date, and gender
- Medication summary
- Allergies and intolerances
- Problem list

### Recommended data includes:

- Immunizations acquired
- History of procedures
- Medical devices used
- Diagnostic results

### Optional IPS record data can include:

- History of illness
- Pregnancy status and history
- Social history, such as history of alcohol and tobacco use
- Functional status, such as disabilities, level of autonomy or invalidity
- Plan of care
- Advance directives

## Why is the IPS important internationally?

Since the advent of the COVID-19 pandemic, infectious disease outbreak and patient medical data have become even more valuable. Global healthcare systems must be prepared for future pandemics and the IPS would accommodate that.

The IPS allows global health data to be shared in a standardized way. The IPS must strive for global accessibility of standards and broadly usable terminologies, meaning that local healthcare solutions not available globally shouldn't be included. Conversely, if a local solution exists that utilizes the same standard, it could and should be included. IPS data could also help countries more effectively operate their own care delivery networks.

<sup>&</sup>lt;sup>1</sup> International Patient Summary Implementation Guide Version: 0.1.0 ®© FHIR Version: 3.0.1(IG Publisher v3.0.1-11917) generated on Wed, Apr 4, 2018 19:21+1000

When a person needs emergency medical care in a foreign country, a request can be made for a patient summary from their home country's healthcare system. When the patient summary is received at the point of care, it can be integrated into the local healthcare system.

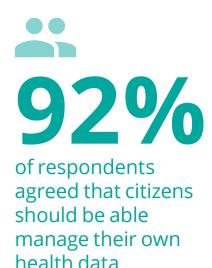
Poor quality of healthcare is a major concern in many countries around the world. Between 5.7 and 8.4 million deaths each year in low and middle-income countries are attributed to poor-quality care—around 15 percent of overall deaths in these countries<sup>2</sup>.

It should be noted that there have been almost no formal evaluations of the usage and benefits of the International Patient Summary, but many parallels can be drawn between IPS in particular and Health Information Exchange (HIE) in general and whose use has more documentation. HIE has the potential to "improve the healthcare quality, promote patient safety, resulting in cost savings by avoiding readmissions and emergency appointments, reducing unnecessary laboratory and imaging tests and preventing adverse drug reactions."<sup>3</sup>

The study "A review of successful initiatives and models on Patient Summary standards in mHealth apps" found that 92% of respondents agreed or strongly agreed with the statement that: "citizens should be able manage their own health data".4

Like HIE, IPS could reduce strain on healthcare systems worldwide by using enhanced information to provide care. There is the potential for reductions in testing and prescription duplication. Using machine learning, analyses of IPS data could reveal new care innovations and ways to make healthcare systems more efficient.<sup>5</sup>

The IPS data set aims to be minimal and concise. It is comprised of a standardized collection of core, clinically relevant data (required and recommended elements) but it is built to be extensible and accommodate future healthcare and patient needs. In the future, the IPS dataset should mature and increase in detail as required by stakeholder communities and in response to patient concerns about data usage and collection.



<sup>&</sup>lt;sup>2</sup> National Academies of Sciences, Engineering, and Medicine; Health and Medicine Division; Board on Health Care Services; Board on Global Health; Committee on Improving the Quality of Health Care Globally. Crossing the Global Quality Chasm: Improving Health Care Worldwide. Washington (DC): National Academies Press (US); 2018 Aug 28. PMID: 30605296.

 $<sup>^3</sup>$  Sadoughi, Farahnaz & Nasiri, Somayeh & Ahmadi, Hossein. (2018). The Impact of Health Information Exchange on Healthcare Quality and Costeffectiveness: A Systematic Literature Review. Computer Methods and Programs in Biomedicine. 161. 209-232. 10.1016/j.cmpb.2018.04.023.

 $<sup>^4</sup>$  Dantas C.; Tageo V.; Chronaki C.; Lowe C.; Berler A.(2019) A review of successful initiatives and models on Patient Summary standards in mHealth apps, Journal of Aging & Innovation, 8 (2): 65-76.

<sup>&</sup>lt;sup>5</sup>Abby Swanson Kazley, PhD, Annie N. Simpson, PhD, Kit N. Simpson, DPH, Ron Teufel, MD, Association of Electronic Health Records With Cost Savings in a National Sample, The American Journal of Managed Care, June 2014, Volume 20, Issue 6

## Why is the IPS important in Canada?

Patient care is enabled by information, yet there is no standardized sharing of critical patient information in Canada. Healthcare providers are often missing the complete patient story which is needed to properly inform diagnosis and treatment. Digital health leaders in Canada recognize that the data set required in IPS is a key piece of information currently missing on patient charts.

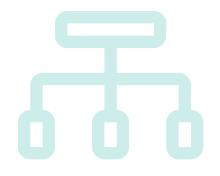
When a patient moves through the healthcare system, they likely encounter different healthcare professionals in multiple environments. IPS can support these transitions in care by providing critical patient information across sectors and settings. These could include:

- Doctors and nurses in emergency rooms
- Physiotherapists in ambulatory care outpatient clinics
- Family doctors in primary care patient clinics
- Specialists in speciality care clinics
- Doctors and nurses in acute care discharge settings
- Nurse practitioners in community care and home care settings

Since the beginning of the COVID-19 pandemic, virtual healthcare appointments have also flourished. Now each medical encounter could occur in person, online, or over the phone, which can further complicate data collection.

IPS is designed for both international and domestic use. Standardized medical information can be shared among health authorities, provinces or territories, or countries abroad. Without a patient's full medical history, there is the potential for tests and medications to be re-ordered or mis-ordered.

Currently in Canada, there is no standardized patient summary or record sharing between provinces or even individual health authorities within a province or territory. This paper will explore the benefits of implementing IPS to Canadian patients, clinicians and healthcare workers, and for the healthcare system as a whole.



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There are few large-scale studies detailing quantifiable benefits of implementing IPS from an international perspective. This white paper brings together benefits found from the literature and case studies as well as interviews with stakeholders into a framework for implementation. Key questions we set out to answer with this paper include:

- Why is IPS implementation important in Canada?
- What are the key benefits of IPS implementation, for patients, clinical stakeholders, and the healthcare system?
- What are the challenges to implementation in Canada?
- What are the immediate and longer-term opportunities to implement IPS in Canada?

# Overview of Adoption and Use of IPS Internationally

While the International Patient Summary (IPS) has not been implemented globally, patient summary records have been put in place as well as the use of IPS data sets. Use studies of patient summaries have been conducted below and the benefits to patients, healthcare providers, and healthcare systems extracted for lessons learned.



## International Adoption and Use of IPS

The IPS is a global solution to contemporary healthcare data-sharing issues. After the European Union (EU) was formed, a movement to share essential medical data across country borders began.

The European Patient Smart Open Services (epSOS) project, started in 2008, first proposed infrastructure to share patient summary records across the EU. This dataset was refined by the eHealth Network (eHN). IPS specifications were originally developed as a joint initiative between the European Committee for Standardization (CEN) and Health Level 7 (HL7) International.

In June 2021, following the G7 Health Ministerial meeting, the ministers reaffirmed the importance of international collaboration on health including a commitment to working towards adopting a standardised minimum dataset through the International Patient Summary standard.<sup>6</sup>

There are now five standards development organizations (SDOs) collaborating on IPS, which will be outline below. Standards provide a common language and set of expectations that enable interoperability between systems. These SDOs include:

- HI 7
- IHE
- CEN
- ISO
- SNOMED

In June 2021, following the G7 Health
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Summary standard.6

<sup>&</sup>lt;sup>6</sup> G7 Health Ministers' Communique – G7 UK Presidency 2021; g7uk.org

**Health Level Seven International (HL7)** is a standards developing organization supported by more than 50 countries. HL7 is developing implementation guides and a global framework for the exchange, integration, sharing, and retrieval of electronic health information.

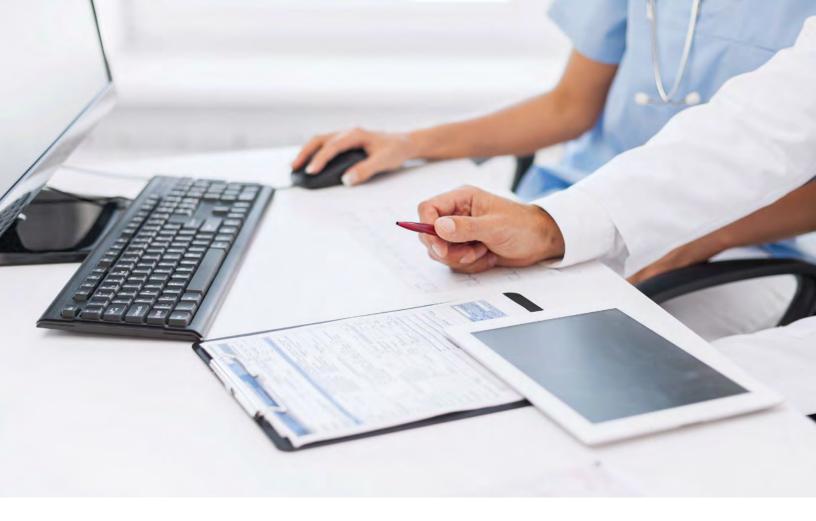
**Integrating the Healthcare Enterprise (IHE)** International is sponsored by associations of healthcare professionals around the world and promotes integration within and across all realms of healthcare, including radiology, pharmacy, dental, eye care, laboratory, IT infrastructure, and more.

**CEN/TC251** is the decision-making body within the European Committee for Standardization (CEN), named the Technical Committee 251 (TC251). This committee works in co-operation with other SDOs at a global level and adapts the standards for the European Member States.

**The International Organization for Standardization (ISO)** is an independent, non-governmental international organization with a membership of 166 national standards bodies. ISO standards are internationally agreed on by experts.

**SNOMED** is a systematic collection of medical codes, terms, synonyms, and definitions used in clinical documental and reporting. It allows for meaning-based retrieval of clinical information in electronic health records. Data is recorded consistently while removing language barriers through multilingual uses.

The Global Digital Health Partnership (GDHP) Interoperability Work Stream's IPS Work Group kicked off in December 2020 to advance efforts to have patients' health data flow across country borders for unscheduled patient care. The workgroup comprises 17 countries, territories, and organizations, including Canada and the World Health Organization (WHO).



## Rationale and Context for use Internationally

When a disaster or serious emergency occurs, the patient summary can be accessed from a mobile phone and provides relevant information in a recognizable, standard format anywhere in the world. Emergency response teams can use patient medical data to aggregate individual and community needs.

The International Patient Summary (IPS) would make unscheduled care when abroad safer, and it can also make unscheduled care in the patient's home country and local jurisdiction better, safer, and more efficient. IPS can support transitions in care by providing critical patient information across sectors and settings. Healthcare providers have access to more knowledge of the patient's medical history and can make better informed decisions, while reducing unnecessary prescriptions, tests, and procedures. Healthcare systems benefit from more efficient use of services, fewer readmissions, increased speed of assessment, and better record keeping.

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One of the most comprehensive studies of the benefits of a national patient summary was conducted by England's National Health Service (NHS) between 2008 and 2011.<sup>7</sup> This study evaluates how the early implementation of the summary care record benefitted physicians, staff, and patients in different care settings. Analysis found that benefits included:

- Improved incidence, speed and appropriateness of patient assessment and treatment in urgent care settings outside hospitals, resulting in fewer home visits
- Fewer ambulance call outs from urgent care settings
- Fewer hospital emergency admissions, increasing capacity of elective care and leading to quicker treatment for patients
- Improved patient outcomes by reducing adverse drug reactions, repeat tests, and procedures
- Reduced number and cost of unnecessary prescriptions, tests, and procedures
- Reduced administration and paperwork when establishing and recording key patient information during urgent care
- Improved patient outcomes as primary care teams can quickly follow up on a patient's discharge from the hospital
- Improved protection of children and vulnerable adults as healthcare professionals can identify unusual patterns of healthcare events
- Reduced incidence of healthcare-associated infections
- Improved protection of hospital staff and healthcare professionals through alerts to risk of violent patients

# Healthcare Areas IPS is being Utilized

In some countries, patient summaries are being used in all aspects of the healthcare system. Each department of a hospital can benefit from the use of IPS data, from emergency to intensive care to cardiac care. The standardized IPS would allow for the core data set to be shared across multiple systems and settings. For example, paramedics in ambulances and other healthcare workers in community care and home care settings could access important medical records when and where they are needed.

These data sets are used in specialty and ambulatory clinics, private clinics, and walk in clinics. In some countries, patient medical records are integrated with dental clinics. IPS data can be especially useful in long-term care and eventually palliative care, as well as community support and home health.

 $<sup>^7</sup>$  D5.1 v2019-08-02 Recommendations for the EU/US eHealth interoperability roadmap: Open Innovation in digital Health: the case of the international patient summary-WP5-HL7

# Benefits and Outcomes of IPS Implementation Internationally

There is currently no standardized IPS accepted in all countries, though national and regional defined data sets have been implemented across the globe. Some of these data sets have been evaluated below to determine lessons on how to implement IPS and the benefits and outcomes

### Europe

### **Denmark**

The Danish Health Data Authority established a Shared Medication Record which contains up-to-date medical information on every citizen in Denmark.

### Value for patients

 Safer for Danish and international citizens to cross borders as they will receive correct medical care when needed

#### **Clinical value**

- Reduces time spent clarifying a patient's medical history, enabling healthcare practitioners to provide better care with full online access to a patient's medical files.
- Reduces readmissions rates and risk of malpractice.

### **Systems benefits**

- Vendor TRIFORK used an infrastructure-driven project to facilitate safe care.
- Patient's medical records are shared across all local systems in the healthcare sector, including pharmacy and dentist systems.
- In the North Denmark region, IPS is integrated with the prehospital and electronic patient records to be used by paramedics in ambulances on tablets.<sup>9</sup>

<sup>&</sup>lt;sup>8</sup> Dipak Kalra, Mie Hjorth Matthiesen, Veli Stroetmann, Rainer Thiel, Lucas Deimel, Marcello Melgara, Catherine Chronaki, plus SPMS and CEN to promote the Member State survey, Robert Stegwee, Willem-Jan Jacobs and Hans Gille; 2018; Trillium Bridge II – Reinforcing the Bridges and Scaling up; EU/US Cooperation on Patient Summary

<sup>&</sup>lt;sup>9</sup> Hausam, Robert MD 2019; International Patient Summary – Opening New Horizons for Global Clinical Data Exchange, June, 2019; HL7 FHIR DevDays 2019

#### **France**

France has three patient summaries available in the national e-health interoperability framework called ASIP Santé:

- the periodic medical synthesis from the patient's primary care physician to other clinicians and healthcare providers
- an emergency liaison document, to be used in emergency care and elderly facilities
- a liaison letter for primary care physicians and hospitals

### Value for patients

• Patients have access to three records in national Electronic Health Record which can be shared with their healthcare providers.

### **Clinical value**

- Summaries produced by healthcare providers from their applications in daily practice.
- Data collected on: active problems, history of illness, list of surgeries, allergies
  and other adverse reactions, social history, hazardous working conditions,
  family medical history, results, medications, reason for referral, care plan,
  and event outcomes. Also includes long-term medications and a comments
  section.

### **Systems benefits**

- Privacy ensured by national Public Key Infrastructure (PKI). Only healthcare providers can access patient summaries using a smartcard.
- Records exchangeable through the national health secured emailing services.

#### **Norway**

The CAPABLE tool enables citizens to actively utilize their personal health information to manage medications, improve nutrition, and facilitate health services.

### Value for patients

- Using the "CAPABLE tool", each citizen is the carrier of their own health information in all interactions with the healthcare system, as well as abroad. Connected with GPs, primary care, private clinics, specialty clinics, and nursing homes and other care facilities.
- Supports citizens in better managing their medications, understanding how to maintain a nutritious diet, and coordinating data from all their interactions with the healthcare system.

#### Clinical value

- Clinicians and healthcare providers more informed of patient's medical history and past encounters with the full healthcare system.
- Improves digital health literacy.

### **Systems benefits**

- May contribute to 800 million Norwegian Krone in reduced hospital costs, and additional reductions in primary care.<sup>10</sup>
- A large-scale study of a proof-of-concept version of the CAPABLE tool to be conducted.<sup>11</sup>

### **Portugal**

Portugal's Shared Services of the Ministry of Health (SPMS) allows for presentation of IPS-related information in different cards, including medical information on vaccinations and allergies<sup>12</sup>. The patient record called the Resumo Clinico Único do Utente (RCU2) is part of a more comprehensive electronic health record.

### Value for patients

 Available to all Portuguese citizens. Patients can access their RCU2 record via the national health data platform and modify data and information which they have added themselves.

#### **Clinical value**

 The RCU2 record contains summary data of the last treatment provided by each physician or specialist who considers the information relevant for other physicians.

### **Systems benefits**

• All patient data is retrieved and displayed in the local storage locations of hospitals and medical practices via a national platform.

 $<sup>^{10}</sup> Health Informatics - The International Patient Summary: Guideline for European Implementation https://ec.europa.eu/health/sites/default/files/ehealth/docs/ev_20190611_co122_en.pdf$ 

<sup>&</sup>lt;sup>11</sup> Janson AL, Moen A, Fuglerud KS. Design of the CAPABLE Health Empowerment Tool: Citizens' Needs and Expectations. Stud Health Technol Inform. 2020 Jun 16;270:926-930. doi: 10.3233/SHTI200297. PMID: 32570517

<sup>&</sup>lt;sup>13</sup> Tageo et. al. (2020), Business Model Canvas Insights for the Adoption of International Patient Summary Standards in the Mhealth Industry, Vol. 8, No. 3, pp. 91-106

#### **Amsterdam, Netherlands**

IPS was implemented in Amsterdam, Netherlands, to better the care of citizens in cross-border, unscheduled healthcare situations across the globe that is readily usable

### Value for patients

 Specialized data can be added to the patient summary when required for particular health conditions.

### **Clinical value**

- Baseline data of the IPS can be also used within scheduled and planned care cases.
- Promotes the evolution and convergence of existing standards.

### **Systems benefits**

• Emphasizes the need to provide generic solutions for global application beyond a particular region or country.

### South America

### **Argentina**

HL7 Argentina will deploy the IPS as the minimum data set for an Electronic Health Record shared among providers.<sup>13</sup>

### Value for patients

- Better healthcare for citizens through the integration of healthcare information systems.
- Healthcare providers are aware of patient's health history and current state.

### **Clinical value**

- The IPS is being used for document and information sharing, including query information, and federated patient identification.
- Data prioritizes diagnostics, allergies, current medications, and immunizations.

### **Systems benefits**

- The shared clinical health record has prescription and clinical workflow information and can be used for health statistics, programs, and registries.
- Improved information flow, updated online, for public healthcare from diverse jurisdictions.
- Improves patient management.

<sup>&</sup>lt;sup>13</sup> H Hausam, Robert MD 2019; International Patient Summary – Opening New Horizons for Global Clinical Data Exchange, June, 2019; HL7 FHIR DevDays 2019

## Obstacles, Risks, and Gaps

Countries implementing patient summaries and IPS systems have been met with obstacles, risks, and gaps, including:



# Lacking a national standard approach to the evaluation of digital health records

In some countries, such as Argentina, there is no national approach to evaluating how digital health technologies are working and benefiting citizens.

It should be noted that there are published IPS implementation guides and experience in using the IPS is increasing in certain countries. Work being done by the Global Digital Health Partnership, the Whole Health Organization, and the European Health Union will help mitigate these concerns and in leading the way toward a standard approach.



### Lengthy, difficult processes

The process of creating the HL7 CDA Implementation Guides in Austria took three years of harmonization effort in working groups.



### Clinician and physician adoption

In the past, other areas of digital health implementation have met with some resistance from clinicians and other allied health care providers. Although there is growing proof that, in the wake of the COVID-19 pandemic, clinician opinion on the adoption of digital health technologies has been changing <sup>14</sup> there is still the issue of the time required to document the IPS and the associated compensation for that time.

Clinicians may lack education in creating and efficiently updating patient summaries. They likely have not incorporated the time necessary to complete and consult the summary.



### Funding for digital health initiatives and patient record keeping

In Amsterdam, lack of funding for patient summary initiatives meant that it was left behind in IPS advancements. Funding is needed for any digital health initiative and must be prioritized.

<sup>14</sup> https://insights.infoway-inforoute.ca/





### **Ease of accessing patient summaries**

Electronic health records can be slow or cumbersome to access, especially if they require a different login and password. The patient summary may not exist for a patient if their normal healthcare provider is not participating in the collection of the data.



### **Inconsistent patient identification numbers**

In implementing epSOS, difficulties in accessing the service arose due to inconsistent requirements, such as health identification cards and numbers which varied considerably in format between countries.<sup>15</sup>



#### **Extensive consultation**

When Norway implemented a patient summary system, they saw the benefit in involving multiple stakeholder groups to meet the needs and expectations articulated by citizens.



#### **Socio-technical factors**

Different languages and clinical and cultural norms have challenged the implementation of a standardized IPS data set. What has been traditionally recorded by care providers may differ from current data needs. Communication can be difficult when crossing language and culture barriers.

<sup>&</sup>lt;sup>15</sup> Montse Moharra, Cari Almazán, Marie Decool, Anna-Lena Nilsson, Natalia Allegretti, Merik Seven, Implementation of a cross-border health service: physician and pharmacists' opinions from the epSOS project, Family Practice, Volume 32, Issue 5, October 2015, Pages 564–567.

# Quantifiable Benefits of IPS

Health information exchange may improve care while reducing healthcare costs. A systematic literature review on health information exchange found that benefits included fewer duplicated procedures, reduced imaging, lower costs, and improved patient safety<sup>16</sup>. The majority of the studies were of widespread health information exchange in the United States.

Patients treated in hospitals with advanced electronic health records cost 9.66% less, found a study in *The American Journal of Managed Care*.<sup>17</sup> The researchers looked at patients treated at 550 acute care hospitals in the United States. The cost of treating patients in hospitals with advanced EHRs was on average US\$731 less than the cost of treatment in hospitals without EHRs.

Samsung Medical Center, a general hospital in Korea, developed an electronic medical record (EMR) for outpatients from 2006 to 2008 and a cost-benefit analysis was conducted. Researchers found that, while there were costs incurred in building and adopting the EMR, these were offset by reductions in costs after its adoption and additional revenues found from remodeling paper chart storage areas and reducing medical transcriptionists' contributions.

There are now more than 300,000 health apps available worldwide. Using digital health apps can result in reductions in acute care utilization for diabetes treatment and prevention, asthma, cardiac rehabilitation, and pulmonary rehabilitation, potentially saving the U.S. healthcare system US\$7 billion per year. Significant clinical evidence points to the positive effects of using digital health apps for patients with cancer, post-traumatic stress disorder, arthritis, stoke, genitourinary conditions, pulmonary rehabilitation, and dental care. If these findings could be achieved across all disease areas, estimated cost savings of as much as US\$46 billion could be realized.

Unfortunately, there have been few large-scale formal evaluations of patient summaries and how the International Patient Summary (IPS) has been implemented around the globe.

Activity to move forward with IPS goals was occurring prior to the COVID-19 pandemic, yet much of this work has been put on hold.

9.66%

cost savings with

cost savings with advanced electronic health records



potential cost savings with digital health apps for treatment and prevention

<sup>&</sup>lt;sup>16</sup> Nir Menachemi, Saurabh Rahurkar, Christopher A Harle, Joshua R Vest, The benefits of health information exchange: an updated systematic review, Journal of the American Medical Informatics Association, Volume 25, Issue 9, September 2018, Pages 1259–1265.

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 Cost Benefit Analysis of EHR Records.pdf

<sup>&</sup>lt;sup>19</sup> The Growing Value of Digital Health. Evidence and Impact on Human Health and the Healthcare System Copyright © 2017 IQVIA.

# Lessons Learned

Standardizing digital health records through the IPS for cross-border use would improve healthcare outcomes and patient care for people around the world.

Implementing digital health technologies, like patient summaries, is costly and labour and time intensive. This can be challenging for many governments and non-government organizations (NGOs) around the world.

Quality supporting evidence for implementing IPS in another countries is essential for informing future decisions. Lessons learned about what did and didn't work can better healthcare services for greater amounts of people and at a lower cost.

## Lessons learned by theme

Key themes have arisen from compiling lessons learned on implementing the International Patient Summary (IPS). These themes must inform healthcare data collection going forward in order to continue building effective IPS systems.

### For patients:



### Access to personal health information

Patients value access to their medical records. A survey of 1000 adults in the United States found that the top three capabilities expected in a digital health app are access to medical records, appointment management, and prescription refills.<sup>20</sup>



### Patients must be made aware of the benefits

Patients must be informed of how IPS can improve quality care and allow for safer travel abroad. In Denmark, it was found that using patient summaries made it safer for citizens to cross borders. International data is especially useful for people engaging in higher-risk activities like skiing or diving and for senior "snowbirds" spending long periods of time away from home. People concerned about their health would not be required to transport large amounts of paper-based medical information abroad.

Data can be collected and access at all points of care, from hospital wards to pharmacies to the dentist. There is peace of mind and improved care outcomes as healthcare providers are more aware of the patient's health history and current state.

Patients are better able to advocate for their own healthcare with the ability to access personal medical records. Digital health apps also have the potential to manage health, nutrition, and appointments.

 $<sup>^{20}\,</sup> The\, Growing\, Value\, of\, Digital\, Health.\, Evidence\, and\, Impact\, on\, Human\, Health\, and\, the\, Healthcare\, System\, (2017)$ 

### For clinicians and healthcare providers:



### Ensure physicians and healthcare providers see value

Physicians and other healthcare providers may have concerns about smooth adoption of digital health records. A study by the American Medical Association of 1300 physicians found that they were most attracted to digital health tools that would improve work efficiency, increase patient safety, and improve diagnostic ability.<sup>21</sup>

Healthcare providers should be aware that the IPS could cut down on time spent clarifying medical information and reduce the risk of re-admissions and malpractice. The IPS contributes to improved decision making for clinicians in disaster situations and patient travel.



# Educate providers on how to use patient summaries and compensate for their time

Clinicians and other healthcare providers must be educated on how patient summaries are created, how to appraise the validity and trustworthiness of the data, and how to handle clinical accountability for decisions made or changed based on the information. Clinicians must receive information on removing data from patient summaries, such as outdated allergy lists.

New clinician workflows must be established and understood to enable the clinician to work with and consult the patient summary and reduce the risk of error or information being omitted during busy work times. Finally, a successful IPS implementation will include adequate compensation for extra time required to properly update the patient information in the new system.



### Establishing trust in using and recording IPS data

Clinician buy-in is essential for IPS implementation to be successful. In addition to being properly educated in how to use IPS, trust must be established in using and recording data. Physicians need to understand the benefits of using IPS data and realize how it will provide a more fully informed picture of a patient. A complete buy-in and understanding can reduce adverse drug reactions and unnecessarily repeated tests and procedures.

 $<sup>^{21}</sup> The Growing Value of Digital Health. Evidence and Impact on Human Health and the Health care System (2017)\\$ 

### For the healthcare system:



### **Healthcare systems must see benefits**

Standardizing patient summaries and data collected allows for improved information flow for public healthcare from diverse jurisdictions. The baseline data of the IPS can also be used within scheduled and planned care cases, which means more efficient care abroad and at home. The importance of technology and interoperability will be made clear when cost savings for healthcare systems and delivery organizations are seen.



### Political support is required for system-wide digital initiatives

Implementing any widespread digital system is difficult, if not impossible, without political support. Political decision and policy makers should be informed of the benefits to Canada's healthcare system, such as better care for patients and the potential for reduced costs. Gaining approval for digital health solutions and support for IPS implementation funding—federally, provincially, or through private and public partnerships—is essential.



### Prioritize what data needs to be measured and collected

Successful IPS implementation requires widespread agreement on what data will be collected and measured, and which format and languages will be supported.

Use medical data to better inform future healthcare services

Patient summaries can be used to extract health statistics to better inform future service, improve patient management, and better allocate resources.



### Consult with a complex and broad group of global stakeholders

Build in extensive consultation with patient groups, clinicians, font-line healthcare workers, access-seeking individuals, and others before taking steps to implement an IPS that works for all. Synthesize jurisdictional, national, and international standards for IPS healthcare information to flow smoothly across borders and jurisdictions.

## Roadmap to implementation

In Canada, HL7, IHE, ISO/TC215 and SNOMED International are working together through Canadian executive leaders of standards development and delegations to enable the evolution of IPS.

In June 2021, the G7 Health Ministers Communique was released that committed to working together to implement a standardised minimum health dataset for patients, including the IPS standards. The communique states that: "we recognise the importance of digital health solutions in transforming healthcare including but not limited to in response to pandemics."

"In order to derive maximum benefit from advances in digital health, we need to have data governance, system security, privacy, regulatory and data protection standards in place according to national and regional contexts. This includes ensuring that digital health solutions are inclusive, comprehensive and equitable."<sup>22</sup>

Recent IPS standards work has resulted in the creation of the 27269:2021 ISO data standard, the HL7 Implementation Guide, the IHE profiles and the SNOMED CT IPS Reference Set (Refset) package. There is also a Canadian expert contribution to the international cross-SO IPS Governance Group, led by HL7.

The Canadian Collaboration on IPS, a team of experts on implementing patient summaries, have completed standards artefacts which are ready to be adapted and nationally adopted and deployed. The collaboration is communicating with national and jurisdictional leaders about IPS and the value of implementation. Major Canadian authorship contributed to the Joint Initiative Council's (JIC) Patient Summary Standards Set (PSSS), which provides early guidance on IPS standards, profiles, criteria, and use cases.

Ontario Health's Digital Health Information Exchange (DHIEX) project is meant to enable clinicians to access and securely share patient summaries across different solutions to support transitions of care and cross-jurisdictional patient flows. Potentially, citizens of Ontario will be able to access the same medical information in the future.



"We recognise the importance of digital health solutions in transforming healthcare including but not limited to in response to pandemics."

 G7 HEALTH MINISTERS COMMUNIQUE, JUNE 2021

<sup>&</sup>lt;sup>22</sup> https://www.gov.uk/government/publications/g7-health-ministers-meeting-june-2021-communique/g7-health-ministers-meeting-communique-oxford-4-june-2021#digital-health



IPS adoption models can be market driven, voluntarily made by developing companies where the industrial and commercial advantage facilitates the exchange and sharing of medical information. Alternatively, it can be government driven, where local and national leaders enforce the adoption of IPS standards. Certification entities, either governmental or appointed by accreditation bodies, could enable adoption with labelling embedded in conformity assessment schemes and related criteria.

While Canada is working towards a fully aligned IPS, it is important to acknowledge that systemic transformation is required before the full benefits of its implementation can be achieved. This transformation and the implementation of IPS will be a journey requiring cooperation and alignment from all areas of healthcare – public and private as well as government.

An open consultation about the European Roadmap for Electronic Health record standard exchange format was conducted.<sup>23</sup> To overcome barriers to access and sharing of healthcare data in the EU, study respondents proposed the best options to be: develop harmonized standards for data quality and reliability (59.6%), standardize Electronic Health Records (56.8%), propose health-related cybersecurity standards (54.4%), and support interoperability with open exchange formats (53.5%).

<sup>&</sup>lt;sup>23</sup> Dantas C.; Tageo V.; Chronaki C.; Lowe C.; Berler A.(2019) A review of successful initiatives and models on Patient Summary standards in mHealth apps, Journal of Aging & Innovation, 8 (2): 65-76.



# Application of lessons in a Canadian Context

### **Develop standard benefit and outcome measures**

Standardizing what will be measured in terms of benefits and outcomes will allow for the comparison of results between healthcare systems and participating countries.

### Develop evaluation frameworks and an evidence base

Canadian healthcare systems should continue to work with academia, international groups, and organizations to study the impacts of digital health implementations. New methodologies and key findings on IPS benefits are essential for proper implementation and service evaluation.

### Ensure physician and healthcare provider buy-in

Physicians, healthcare providers, and other key stakeholders must see the value of implementing IPS and understand how to incorporate data collection and update within their workflows. The IPS must use clinical data to enable decision making on care and treatment.

### Properly train healthcare providers in how to use IPS

There can be technological barriers to implementing any new digital health system but using an IPS system requires precise recording of proper health data.

### Develop awareness and communications campaigns

Widespread awareness campaigns are required to ensure that patients, clinical stakeholders, and policy makers see the value to our healthcare systems on implementing IPS.

### **Ensure ease of access of patient summaries**

A standardized patient summary should be easy to access from any clinical location as well as in the community. It should contain relevant and up-to-date information that is easily extracted for clinical decision making.

# The Opportunity and Value of Implementing IPS in Canada

The implementation of cross-border exchange of IPS is among the highest priorities of the European commission, the World Health Organization, and the G7 Health Ministers. The opportunity and value of implementing IPS in Canada can be examined through the lens of patients, clinicians, and healthcare systems.

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# Value for patients

With the International Patient Summary (IPS), a patient could visit a hospital or clinic for the first time, even in a new country they are travelling or working in, and the healthcare provider would know their relevant medical history. Most importantly, IPS can support transitions in care by providing critical patient information across sectors and settings.

Patients would have a medical record that can be used locally, regionally, provincially, nationally, and internationally. This allows for peace of mind, a greater sense of security while travelling, and better health outcomes. The IPS has the potential to establish unbroken continuity of care from healthcare professionals with clear information about the patient's medical and medication history.

With a better baseline of data, clinicians have improved decision-making abilities in diagnosing and treating patients. An IPS could potentially improve the health of a population.

Implementing the IPS could more efficiently make use of physician's time, making patient interactions with the healthcare system more seamless. With IPS, patients would not need to spend extra time to inform every new caregiver of their complete health and medication history.

The implementation of cross-border exchange of IPS is among the highest priorities of the European commission, the World Health Organization, and the G7 Health Ministers

Patients could better advocate for themselves and their healthcare with their medical information captured in a way that they can access and use. The IPS would facilitate equitable access to a person's own health information and ensure that across the country, healthcare providers have access to similar levels of information. Currently, patients can access medication records or diagnostics through different platforms, but it's not easy and the data isn't connected in any way.

### Clinical Value

Imagine the value of accessing an up-to-date clinical summary at any point of care, in any care setting locally, nationally, and in countries around the world.

A patient summary is the starting point for healthcare providers to use in diagnosis and treatment. Having access to that data at the start of an appointment would save time and reduce potential mistakes. The IPS could be regarded as a high level "place of truth", a snapshot of key information that a physician would need to know to treat appropriately and efficiently.

Physicians and patients often struggle to exchange information between health care settings. The IPS would include important information such as hospital discharge summaries and would be able to flow between primary and acute care settings.

# Systems benefits

Currently, medical data collection and availability is segregated across Canada's regional and provincial healthcare systems. Streamlining medical information would allow for better care and enhanced care coordination locally in jurisdictions across Canada and abroad.

While IPS is an international specification, IPS use cases cover scheduled and unscheduled cross-border interoperability regionally and locally. The same specification can be used to move information from Canada to other countries, between provinces and territories, and between local health authorities. The same data can also flow between hospitals and physicians, as well as other care settings such as virtual, long term care, and palliative care.



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The value of healthcare data interoperability is exemplified during pandemic events. The pandemic response in Canada was more difficult in part because the lack of federal and provincial data sharing.

When healthcare is being delivered more efficiently, there are cost savings. One of these cost savings would be the reduction of redundant testing.

IPS data could be used to plan healthcare resource allocations and analyze data for better public health outcomes.

# Gaps, Obstacles, and Risks to Implementing IPS in Canada

Through knowledge gained from clinical stakeholders and lessons learned from other countries, the following gaps, obstacles, and risks exist in implementing IPS in Canada.

### Standardizing data collection

There are challenges to standardizing the data required in the IPS. Healthcare system implementation is in the early stages in Canada and limited standardization of data elements exists in many healthcare areas such as community-based practices.

In Canada, there is no standardized information collected about many key areas of healthcare, such as emergency department visits. Client and patient data might not be complete depending on how clinicians document the information. Data about previous appointments at other healthcare facilities and clinics could greatly benefit primary care.

In Canada, we run the risk that jurisdictions could individually define standards, resulting in miscommunication and inefficient use of resources in pursuit of solutions that may already exist. Centralized, coherent communication of the benefits and uses of IPS may help to reduce time and energy invested and allow jurisdictions to realize value through implementation of IPS.

### Lack of centralized governance and funding

Canada's lack of centralization (healthcare is not federally managed) is a challenge to national IPS implementation. While some regions may be more prepared than others to implement and fund an IPS, a patchwork approach to standardization and adoption will negatively impact its value. A consistent national approach is required in order to fully realize the benefits of the new system.



Centralized, coherent communication of the benefits and uses of IPS may help to reduce time and energy invested and allow jurisdictions to realize value through implementation of IPS

### **Hesitancy about implementing IPS**

Work on standards has already taken place. Instead of further redefining, the focus should be on implementation. Delaying implementation until there is a "perfect" IPS system is counterproductive—the system can be refined over time.

### Lack of understanding and education on the IPS

Senior-level education on past initiatives, current implementations, and use cases is required for decision-makers to understand the building blocks, the gaps, and available solutions. The value of the IPS must be articulated to leaders and policy makers, including how IPS data helps plan, finance, and make resource allocation decisions.

### Healthcare providers' time

A key obstacle to implementing the IPS in Canada is the tight restraints on time for physicians and other healthcare providers. Healthcare providers have to be allocated or compensated for the time required to document information for the IPS in order for the system to be successful. One idea would be to explore dictation for easier IPS data collection by physicians.

Additional resources dedicated to the implementation of IPS must be identified. The challenge of human resource capability and capacity cannot be addressed solely by incentives and additional capital investment. A plan for skilled and experienced people to support implementation is imperative.

### **Vendor adoption**

Implementation support for vendors and system stakeholders does not currently exist. Vendors need to be included in the journey and should be encouraged to leverage existing global standards.

### **Privacy and security concerns**

The public needs to be included on the journey toward a national patient summary infrastructure and fully informed about what information will be included and in which scenarios their data may be accessed. End users will need to be informed of their options (Can I opt out? Is there information I can hide?) and educated on how to use the system.

# Summary and Call to Action

With robust interoperability, important pieces of a patient's health record can be electronically accessed during planned and unplanned care transitions, potentially reducing duplicative care and costs as well as supporting improved outcomes.

Implementing the International Patient Summary must be part of the bigger vision for healthcare in Canada. Provinces, territories, and jurisdictions must align and move towards this vision together. The benefits of more efficiently run healthcare systems, better clinical decision making, reduced medical risks, and better care for all patients will be realized with patients, clinicians, and government on the side of medical data interoperability in general and the implementation of the International Patient Summary specifically.



### Harmonize data capture and sharing

Currently, every jurisdiction uses a different data set, with different end goals. Harmonized data capturing and sharing and introducing IPS counterparts from other provinces will help move this forward.

### Move forward with IPS as a standard

The industry must rally behind the G7 consensus on the need to move forward with IPS as a standard in order to gain momentum in the movement towards implementation. Expanding on the utility of the international standard is eminently preferable to creating a unique Canadian version or localized extensions of the IPS. To enhance the standards and ensure the IPS is truly international, input should be gathered and passed back to the SDOs.

### Mandate and accountable governance

Create a national mandate equivalent to the USA's Office of the National Coordinator for Health Information Technology.



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### **Strong policies**

Private and public organizations need to partner together to implement IPS. Strong policies will be required to move the IPS forward and these policies must happen at the federal, provincial, and regional levels, as well as horizontally.

#### **Incentives**

Incentives must be created and aligned for better interoperability across Canada.

### **Federal funding**

Sufficient federal funding is an absolute necessity for successful implementation.

## **Change management**

Change management is key. Integrating IPS into clinical workflows will go a long way towards defining architectural considerations that are essential for ensuring the creation of useful data.

Implementation will need clinical and vendor support; clinicians should be consulted on what information they want in terms of interoperability. The clinician journey map can be used to identify starting points.

### **Engage vendors**

Create an open invitation for vendors to implement IPS into their products and to test them for interoperability compliance at testing events. Once vendors can deliver, implementations are made possible. While the IPS is broad, focus should be narrowed to specific parts of it. Once standardization is in place, the data set can be augmented.

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