In a novel knowledge translation initiative, the Government of Ontario's Asthma, Management, and Patient Education (AMPE) project funded the development of a Asthma Care Map to enable adherence with the Canadian Asthma Consensus Guidelines. Following its successful evaluation within the Primary Care Asthma Pilot Project, respiratory clinicians from the Asthma Research Unit, Queen's University (Kingston, Ontario) are leading an initiative to incorporate a standardized Asthma Care Map data elements into electronic health records in a primary care setting. The focus is expected to include asthma, chronic obstructive pulmonary disease and policy development. Acknowledging that the issue of data standards affects all respiratory conditions, and all provinces and territories, the Government of Ontario approached the CTS Respiratory Guidelines Committee. At its meeting in September 2010, the CTS Respiratory Guidelines Committee agreed that developing and standardizing respiratory data elements for electronic health records are strategically important. In follow-up to that commitment, representatives from the CTS, the Lung Association, the Government of Ontario, the National Lung Health Framework and Canada Health Infoway came together to form a planning committee. The planning committee proposed a phased approach to inform stakeholders about the issue, and engage them in the development, implementation and evaluation of a standardized dataset. An environmental scan was completed in July 2011, which identified data definitions and standards currently available for clinical variables that are likely to be included in electronic medical records in primary care for diagnosis, management and patient education related to asthma and COPD.

The scan, sponsored by the Government of Ontario, includes compliance with clinical nomenclatures such as SNOMED-CT® and LOINC®. To help launch and create momentum for this initiative, a national forum was convened on October 2 and 3, 2011, in Toronto, Ontario. The forum was designed to bring together key stakeholders across the spectrum of respiratory care, including clinicians, researchers, health informaticists and administrators to explore and recommend a potential scope, approach and governance structure for this important project. The Pan-Canadian Respiratory Standards Initiative for Electronic Health Records (PRESTINE) goal is to recommend respiratory data elements and standards for use in electronic medical records across Canada that meet the needs of providers, administrators, researchers and policy makers to facilitate evidence-based clinical care, monitoring, surveillance, benchmarking and policy development. The focus initially is expected to include asthma, chronic obstructive pulmonary disease and pulmonary function standard elements that are applicable to many respiratory conditions. The present article summarizes the process and findings of the forum deliberations.

Key Words: Asthma; Clinical practice guidelines; Clinical variables; COPD; Data definitions; Electronic health records; Electronic medical records; Knowledge translation; Respiratory data sets; Surveillance

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Can Respir J Vol 19 No 2 March/April 2012

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L’Initiative PRESTINE sur les normes respiratoires pancanadiennes pour les dossiers de santé électroniques : les délibérations du forum national 2011

INTRODUCTION
Louis-Philippe Boulet, M Diane Lougheed

At least 20% of the Canadian population suffers from one or more respiratory diseases (1). Asthma and chronic obstructive pulmonary disease (COPD) are two of the most common chronic respiratory diseases. Despite improved understanding and better treatment strategies for these conditions, they are still responsible for a large human and socioeconomic burden (2,3). In this regard, the estimated aggregate cost of respiratory diseases to the Canadian health care system in 2000 was estimated by the Public Health Agency of Canada to be $5.6 billion (www.phac-aspc.gc.ca).

Rapid scientific advances and an exponentially increasing volume of literature make it difficult for health professionals to keep abreast of optimal care. To address this problem, clinical practice guidelines (CPGs) have been developed to make evidence-based recommendations regarding the diagnosis and management of various health conditions (4). The Canadian Thoracic Society (CTS) aims to reduce the burden of respiratory disease among Canadians by promoting the best respiratory care. To help achieve this goal, the CTS has produced and disseminated numerous respiratory guidelines since the 1980s (5).

In the past few years, the CTS created the Canadian Respiratory Guidelines Committee (CRGC) to standardize the guideline development process and ensure adherence with optimal methodologies for producing and disseminating these documents. The structure of the CRGC and the guideline development process have been previously published (6). An important mandate of the CRGC is to promote the implementation of CTS guidelines, and various strategies have been proposed in keeping with the best evidence in the knowledge translation field (7,8).

The electronic health record (EHR) may be viewed as an emerging knowledge translation tool, which offers an opportunity to promote the implementation of key recommendations from guidelines into current care. The EHR offers not only a means of integrating guidelines into day-to-day clinical practice, but also to evaluate the effects of interventions and treatments on the population. A list of benefits of EHRs is presented in Table 1.

The CTS and CRGC recognize the need to promote the standardization of data elements in the EHR, particularly to ensure interoperability. Standardized data collection can clearly benefit the full spectrum of stakeholders, but also places a clear demand on clinicians, researchers and guideline developers to establish guideline implementation initiatives to support uptake and reduce care gaps; enhance quality management, evaluation and surveillance through access to use of electronic medical records (EMRs)/EHRs; and collaborate to ensure that systems are designed to collect valid, relevant respiratory information for performance measurement (e.g., quality of life instruments).

The Pan-Canadian REspiratory STandards INitiative for Electronic Health Records (PRESTINE) is a project of the CTS, the medical section of the Canadian Lung Association working in collaboration with The Ontario Lung Association and the National Lung Health Framework. PRESTINE builds on work currently underway in Ontario to establish data standards for respiratory care and aims to extend this work on a pan-Canadian basis.

The main goal of the PRESTINE National Forum 2011 was to initiate discussions to develop a common language for guidelines-based indicators of chronic disease management of asthma and COPD applicable to EMRs used in primary care. Stakeholders were invited to provide input regarding the PRESTINE project scope, governance and operational structure including sponsor organizations, steering committee, working group(s) and project team. Six grounding didactic presentations provided participants with the following: an overview of the status of EHRs in Canada; an overview of the asthma and chronic obstructive pulmonary disease (COPD) national strategy; Canadian Lung Association working in collaboration with the Ontario Lung Association; the status of data standards for asthma and COPD in primary care; and development of an asthma and COPD data standard.

On the second day, large and small group discussions were facilitated to establish a project goal statement, agree on project scope and guiding principles, and identify resources as well as potential partners and collaborating agencies. The present document summarizes the workshop proceedings and presents a strategy for a national PRESTINE initiative.

REFERENCES

SECTION I. THE STATUS OF EHRs IN CANADA

Shari Dworkin

Canada Health Infoway (Infoway) is an independent, not-for-profit corporation created by Canada’s First Ministers in 2001. It is accountable to 14 federal, provincial and territorial governments. Infoway jointly invests with every province and territory to accelerate the development and adoption of information and communications technology projects for health. Fully respecting patient confidentiality, these secure systems will support safe care decisions and help patients manage their own health.

TABLE 1 Potential benefits of electronic health records and standardized data elements

<table>
<thead>
<tr>
<th>Benefit</th>
<th>Description</th>
</tr>
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<tbody>
<tr>
<td>Improved quality of care</td>
<td>• Adherence with best practice • Prompts and alerts • Inclusion of key recommended parameters to assess • Interpretation of diagnostic and test results • Patient safety • Diminished prescription errors, adverse drug events</td>
</tr>
<tr>
<td>Improved access and productivity</td>
<td>• Access to integrated patient information • Easy retrieval of information (patient data, test results) • Possible comparisons of various parameters over time • Reduced time loss to reproduce data on each visit • Reduced wait times (automated referrals)</td>
</tr>
<tr>
<td>Outcomes monitoring</td>
<td>• Patient/program evaluation or practice audit • Performance measurement • Benchmarking • Surveillance and registries</td>
</tr>
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</table>

for asthma and COPD in primary care; and development of an asthma and COPD data standard.
Infoway’s vision is for a highly sustainable and effective Canadian health care system supported by an infrastructure that provides residents of Canada and their health care providers with timely, appropriate and secure access to the right information when and where they enter the health care system. Infoway has 12 targeted investment programs with a total funding allocation of $2.1 billion. As of September 30, 2011, there were 340 active or completed projects.

The roles of Infoway are to:

- provide a technology framework to guide EHR development;
- support and sustain communications and technology standards that enable health information systems to share patient health information accurately and securely;
- invest jointly with provinces and territories to implement information and communications technology projects for health;
- provide tools and services to technology vendors to accelerate EHR development and implementation; and
- foster and support clinical adoption of EHRs (1).

Infoway’s Standards Collaborative was established in 2006 to support and sustain health information standards and foster collaboration to accelerate the implementation of pan-Canadian standards-based solutions to realize this vision. The collaborative provides the processes, resources and governance structure for building pan-Canadian consensus-based health information standards.

What is a health information standard?

A pan-Canadian health information standard is defined as a document, established by pan-Canadian consensus, which provides for common and repeated use, rules, guidelines or characteristics for activities or their results, aimed at the achievement of the optimum degree of order in a given Canadian health informatics context (2). Standards documents are designed and intended for broad use in Canada and are approved through the Infoway Standards Collaborative Governance process.

Standards support integrated, patient-centric health records enabling a longitudinal view of an individual’s key health history and care, including patient visits, hospitalizations, diagnostic images and reports, laboratory test results, prescribed drugs and immunizations. They also ensure that common terminologies are in place to describe, record and aggregate diagnoses, medications and other key clinical information, and that this critical information can be updated, managed, shared and interpreted in a meaningful and secure way, when and where required (2).

As a specification progresses through the standards ‘life cycle’, from development to maintenance, each stage is reviewed and approved at specific decision points defined in the decision-making process as follows:

- Canadian Strategy Selection
- Canadian Draft For Use
- Canadian Approved Standard
- Canadian Deprecated

What is the status of EHR standards in Canada?

To date, several pan-Canadian Standards have been established, including standards for client and provider registries, laboratory systems, diagnostic imaging, drugs, interoperability of EHRs, public health surveillance, national e-Claims, transport level interoperability and data security (2). Many of these standards include codified clinical terminology.

Systematized NOMenclature of MEDicine Clinical Terms® considerations

Systematized NOMenclature of MEDicine Clinical Terms (SNOMED-CT®) is a key terminology standard selected by Canadian stakeholders for use in information and communication technologies for health. It is already in use in more than 50 countries. SNOMED-CT® facilitates the interoperability of EHRs by enabling clinical data to be captured, retrieved, aggregated and shared across health care settings and providers in a reliable, safe way. SNOMED-CT® specifically features codes for more than 300,000 clinical concepts, ranging from diagnoses to medication orders. Each concept is linked to multiple descriptions, which allows clinicians to express a clinical concept in a way they would prefer without losing its intended meaning. The value of SNOMED-CT® can be illustrated through the example of heart attack. While there are many different ways to describe the condition (e.g., myocardial infarction, cardiac infarct) they all share the same unique code and meaning.

SNOMED-CT® was developed by clinicians for clinicians. As with all coding standards, clinicians will use solutions when effective change management strategies and user interfaces are designed. Implementers are leveraging what they need from SNOMED-CT® to meet their business and clinical needs (e.g., reference sets). There are more than 20 planned and/or SNOMED-CT®-enabled implementation initiatives in Canada. Examples range from large-scale pan-Canadian implementations to small primary care clinics.

Key points

- Infoway is an independent, not-for-profit corporation created to foster and accelerate the development and adoption of information and communications technology systems for health (www.infoway-inforoute.ca)
- Infoway’s Standards Collaborative supports and sustains health information standards and fosters collaboration to accelerate the implementation of pan-Canadian standards-based solutions
- SNOMED-CT® is a key terminology standard selected by Canadian stakeholders for use in information and communication technologies for health.

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SECTION II. MEASURE TODAY, CHANGE TOMORROW

Walley J Temple

Extensive literature identifies that outcomes of cancer patients are significantly linked to the quality of surgery, particularly as it relates to the adherence to guidelines. Incorporation of guidelines in cancer surgery has resulted in increases in survival by up to 10% and decreases in morbidity, costs and resource utilization by 20% to 30% (1, 2). Unfortunately, despite the scientific validity of guidelines, their incorporation into practice has been disappointing. Latosinsky et al (3) documented this phenomenon in Canadian breast cancer guidelines were introduced in 1998 in Manitoba. As measured by three quality measures in more than 7000 breast cancer patients, there was no effect on the change in practice three years after guideline publication. This challenge provided the impetus for the Alberta Cancer Board to fund the development of Cancer Surgery Alberta in 1999, to improve the surgical care of cancer patients across the province. The strategy to seamlessly introduce guidelines into a surgeon’s practice was to harness the EMR in an entirely new way. The traditional EMR is a view-only document. We embarked on a project to develop software that would exploit the EMR’s dynamic capability to record a web-based operative report with a structured synoptic format available to all practitioners across the province. The data entered not only produces the operative report, but real-time outcomes can also be generated. This format allows for the introduction of explicit and implicit guidelines to be integrated into the surgeon’s practice as they
complete the record. The prospect of surgeons assessing their outcomes and being able to compare these with their colleagues in aggregate form was the main driver for the adoption of an electronically generated synoptic operative report. However, it had to be equally as efficient and not require an additional narrative document.

To shift from the narrative record, which has been the gold standard for medical records for more than 3000 years, we also had to demonstrate that the synoptic format results in an equivalent record. A number of studies, including our own, have documented the erratic quality of narrative records, which provide on average fewer than 50% of the details required for subsequent care (4). There was no difference in the quality of information whether it was completed by trainees, specialists or subspecialists.

In addition to a significant improvement in quality, the synoptic record has many other attributes. It has created a standard for surgical care supported by the Alberta surgeon community. The record can be reviewed in real time and submitted with an electronic signature to be distributed instantaneously to all care providers including the hospital, pathology, the Alberta Cancer Registry, the Cancer Centre, as well as all referring physicians. This concept was tested with an Infostray investment in 2006, which showed that synoptic reporting was successfully introduced in five regions, using six templates, over two years. The evaluation showed that the recording of a breast cancer operation took less than 5 min, with 97% of records completed in one day. The templates were educational and provided instant links to current guidelines, which could be accessed while entering information into the record. The elimination of transcription saved at least $100 per record. Even more importantly, it saved health care personnel significant time by removing the need for reading a typical 1000- to 2000-word report, instead reducing it to 10 to 20 key phrases that enabled them to determine subsequent management. In Alberta, if this format were used for all cancer operations, it would eliminate more than 15,000,000 words of transcription per year. Alberta surgeons have made a unique contribution by demonstrating that a dynamic medical procedure, such as an operative procedure, can be represented by a synoptic record.

To date, more than 18,000 reports have been voluntarily submitted, completely encompassing six tumour sites: gynecology oncology, sarcoma, cutaneous, breast, endocrine and gastroenterological. In addition, a number of templates are being tested, including lung cancer, prostate cancer, hospital discharge summary, nurse navigation and some general surgical operations. This methodology has also been adopted by radiation oncology for cervical cancer and prostate cancer, and test templates have been created by medical oncology in neurosciences. This concept has also been tested in other areas of medicine using the Alberta webSMR technology, demonstrating its applicability to all types of medicine.

During the process of developing these templates, surgeons wanted to expand them to include all pertinent preoperative care pathways. This included such elements as clinical staging, functional issues, decision making, tumour banking records, tumour biology (ie, response to preoperative treatment) and follow-up triage. These are all data elements that a surgeon inherently knows, or should know, when they perform a cancer operation. This has significantly expanded the functionality of an operative report and is the beginning of synoptic incorporation of care pathways in our practices.

The change management principles that were necessary included the use of text-entered commentary, avoiding elements that might direct inappropriate practice, capturing all current or reasonable practice options, eliminating unimportant details (such as type of staples for bowel anastomosis, the incidentials of ligating vessels or suture types) so that only meaningful data are captured, and allowing for a dictated addendum (1,2,5,6).

Recently, the option of dictating an addendum was assessed in 3366 consecutive reports; only five addendums and 21 redactions were found, the latter missing at least two key surgical processes despite having the template to remind them of the required items. Once again, this emphasizes the variability of the narrative report.

We have generated critical outcome information, examples of which are provided. In more than 6000 breast cancer reports, we have identified that only 50% are found radiologically and all but 4% of the remainder are found by the patient. This is a measure of our breast screening system in our province, which, if fully utilized, could identify 80% of all breast cancers. What is extremely valuable is that any intervention to increase the adoption of breast screening will be reflected within two to three months in the surgeon’s outcomes. Our information also documents that Alberta surgeons adopted guidelines for using sentinel lymph node detection in breast cancer staging before the Canadian guidelines identified this practice as a standard, as a direct result of the template usage and a provincial workshop on sentinel lymph node surgery. It also identified how surgeons interpret guidelines regarding breast conservation, the current overall rate being 48%. However, the information generated for the decision-making question identified that only 65% were candidates for breast conservation, so that the true rate is 78%, an exceptional result. It also generated systems measures such as body mass index differences in patients among five regions, differences in regional stage IV presentation in breast cancer and a wide range of wait times. Noncancer issues, such as the use of prophylactic antibiotics and deep vein thrombosis prophylaxis, showed wide variation in practice with an enormous potential for cost savings if standard care was implemented.

The literature conclusively demonstrates that outcomes feedback is the most powerful educational tool to change practice (1). We have monitored surgical care of rectal cancer from 1996 to 2009, with implementation of feedback introduced in 2006. During this period, the use of abdominal perineal resections decreased from 43% to 29%, and the use of the standard for resection (total mesenteric excision) increased from 20% to 98%.

This work formed the impetus for Canadian Partners Against Cancer (CPAC) to implement a pan-Canadian initiative to adopt synoptic operative reporting. The Surgical Reporting Tools Project (SRTP) was funded from 2008 to 2012, and has successfully concluded with adoption in pilot sites in Nova Scotia, Quebec, Ontario and Manitoba in addition to Alberta. Four templates were used (ovarian, colorectal, breast and oral cancer). Both rural and urban sites participated and more than 5000 reports were completed.

Just as there were differences in Alberta among regions, the SRTP evaluation identified potentially significant differences across the provinces. These observations provide enormous potential for measuring real-time issues of care and identifying strategies to improve outcomes in Canada. This is a major success story for CPAC.

In summary, a digitized synoptic operative reporting system, which captures the surgeon’s knowledge of the pre- and intraoperative care pathway, creates a critical bank of information that is key to understanding the dynamics of patient care and the biology of disease in our own practices, provinces and country. This format elevates a surgeon’s own practices, provinces and country. This format elevates a surgeon’s standing the dynamics of patient care and the biology of disease in our own practices, provinces and country. This format elevates the surgeon’s standing the dynamics of patient care and the biology of disease in our own practices, provinces and country. This format elevates a surgeon’s standing in Canada. This is a major success story for CPAC.

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SECTION III. THE ONTARIO EXPERIENCE:
ELECTRONIC ASTHMA CARE MAP IN PRIMARY
CARE PILOT
M Diane Longheed, Janice Minard
In 2000, following recommendations from an inquest into the death of
a young man from asthma, the Government of Ontario established the
‘Asthma Plan of Action’, a collaborative integrated strategy consisting
of 13 initiatives with a focus on health promotion, prevention, surveil-
ance, evaluation and asthma management (1). One of these Asthma
Plan of Action-funded initiatives was the Primary Care Asthma Pilot
Project (PCAPP, 2002 to 2006), which enrolled patients from eight
primary care locations to evaluate an asthma care program. The pro-
gram, delivered by certified asthma educators, was comprised of the
Ontario Lung Association’s (OLA) Asthma Care Map (ACM) for Primary
Care and OLA’s asthma action plan, a management algorithm and
generic program standards (2). At 12 months follow-up, there were
significant reductions in self-reported exacerbations, emergency
room visits due to asthma, school absenteeism in children, and both
daytime and nighttime symptoms (2). In 2006, the Government of
Ontario funded the transition of this pilot project to the Primary Care
Asthma Program (PCAP). PCAP is currently coordinated by the
OLA, guided by an Advisory Committee, and is available in 12 pri-
mary care sites involving over 100 locations.

In PCAPP, although most of the sites had access to an EMR, pro-
viders were using a paper copy of the ACM and action plan.
Recognizing that EMRs are becoming the standard of practice for
documentation and communication in health care, a review of the
literature was undertaken to ascertain the status of an electronic
asthma data set in use in primary care (3). Only 76 of the 309 articles
identified met the inclusion criteria for the review, and were categor-
ized by the type of EMR and theme addressed. Most primary care arti-
cles reported on the status or utility of EMRs. Of the 76 asthma
articles, only 17 were related to asthma primary care EMRs; most of
these reported on decision support tools (n=3) and/or utility (n=14),
specifically the ability to predict mortality, assess severity and timeli-
ness of diagnosis. A standardized asthma data set was not found in this
literature review.

As a next step in the asthma strategy, two primary care sites in
Ontario participated in a five-month observational study. In this pilot,
we demonstrated that it was feasible to incorporate the majority of
data elements in the ACM into an electronic format (4). Asthma
educators, at both sites, documented on the care map in the electronic
record, which automatically produced individual patient summaries
for the patient chart. De-identified data were sent in real time (daily or
weekly) to a central secure server for analysis and generation of sum-
mary reports (by individual, site and aggregate reports) without any
loss of data or security breaches. There were many challenges encoun-
tered during the pilot, which are outlined in Table 2.

The primary lessons learned from the e-record pilot project were that
EMR data are reliable only if there are standardized data definitions; and
that data standards are needed to enable ‘interoperability’ (ie, the ability
for EMRs to communicate with one another). Data definitions were
developed for the majority of the care map data elements. Elements in
the care map were cross referenced with the SNOMED-CT® and
Logical Observation Identifier Names and Codes (LOINC®), two

<table>
<thead>
<tr>
<th>Process Issues</th>
<th>Collaborating with various health care models, each with their own approval processes</th>
</tr>
</thead>
<tbody>
<tr>
<td>Different composition of interdisciplinary teams at various sites</td>
<td>Understanding and applying privacy and security legislation</td>
</tr>
<tr>
<td>Need for site-specific ethics approval or lack of process for ethics approval</td>
<td>Differing opinions regarding the need for consent to collect patient data</td>
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<table>
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<tr>
<th>Technology issues</th>
<th>Intermittent or no internet access in remote locations</th>
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<td>Multiple site EMR vendors</td>
<td>Stand-alone clinical management systems not linked to site EMR</td>
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<tr>
<td>Electronic patient summaries being scanned into EMRs or attached to a paper record</td>
<td>Data analysis issues</td>
</tr>
<tr>
<td>Missing data due to inconsistent data capture</td>
<td>Inconsistent interpretation of data dictionary definitions</td>
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<tr>
<td>Inconsistent programming for drop-down menus (multiple versus mutually exclusive response options)</td>
<td>Need to recode variables before merging data</td>
</tr>
<tr>
<td>Analysis of frequency variables (eg, exacerbations since last visit)</td>
<td>Analysis of complex variables (eg, asthma control with multiple parameters; yes/no versus raw values)</td>
</tr>
</tbody>
</table>

EMR Electronic medical record

Acknowledgement: This work was supported by the Government of Ontario.

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SECTION IV. IS IT FEASIBLE TO USE INDICATORS TO COLLECT DATA ON ASTHMA PERFORMANCE IN THE PRIMARY CARE SETTING?

Teresa To

Rationale
Asthma is the sixth most prevalent chronic disease overall and the most prevalent chronic disease in children, yet there is no standard way to document, describe or evaluate the delivery of asthma care in primary care settings. Previously, 15 evidence-based primary care asthma performance indicators (PC-APIs) were developed to evaluate the quality of asthma care in the primary care setting (1). We conducted two studies: the first was designed to test the feasibility of collecting data for each PC-API in the primary care setting and the second study was to test the feasibility of measuring these indicators using population-based health administrative data (HA-API).

Methods
In the PC-API study, primary care practitioners at three family health teams and two community health centres across Ontario participated in testing the feasibility of using an indicator form. For ease of data collection, the APIs were grouped into nine categories: use of pulmonary function tests, asthma medication use, asthma control, exacerbations, health care use, asthma action plan, smoking cessation and quality of life (Figure 1). Each site collected and submitted data on APIs using either a paper form returned by regular mail or fax, an Adobe® form printed and faxed or submitted by e-mail, or a web-based form. Physicians provided data on 10 consecutive prospective asthma patient visits and, using chart abstractions, 10 randomly selected retrospective patient visits. Data from the Ontario Asthma Surveillance Information System (OASIS) were used in the HA-API study. The OASIS used Ontario health administrative data to identify individuals with incident and prevalent asthma from 2003 to 2009. Six of the 15 APIs were available from the OASIS health administrative data.

The OASIS cohort was categorized into those cared by fee-for-service solo practitioners, fee-for-service Family Health Groups and salaried Primary Care Teams defined by the Government of Ontario. In the PC-API study, asthma quality indicators were collected for 100 patients at the primary care setting. Health care providers found the API form easy to use. The feasibility study results suggested wide variations in asthma care across the participating sites in both prospective and retrospective patient visits (2). The HA-API study showed that there was an overall increase in the use of pulmonary function tests (PFTs) to diagnose and monitor asthma in Ontario from 2003 to 2009 (3). While there was an increase in the use of inhaled corticosteroids, the use of beta-agonists decreased slightly. Similar to the findings in the PC-API study, the HA-API study also showed variations in asthma care measured by the APIs among different physician practice types. For example, compared with others, solo practitioners had a lower rate of use of PFTs for asthma diagnosis and monitoring and their patients tended to have a lower rate of inhaled corticosteroid prescriptions filled.

Conclusion
Asthma performance indicators provide comparable and standardized information about the quality of asthma care among health care practitioners and across primary care settings. The use of these asthma performance indicators in both the community and at a population level is feasible and data collected could help improve asthma management and care. The population-based results can potentially be used as ‘benchmarks’ for the respective indicators. These benchmarks may enable practitioners to compare measured results with expected performance and help in establishing best asthma care practice.

ACKNOWLEDGEMENT: This work was supported by the Government of Ontario, Canadian Institutes of Health Research (PHE-85212) and the Public Health Agency of Canada. The opinions, results and conclusions reported are those of the author and are independent from the funding sources.
There are still additional data that can be gathered after the environmental scan, namely from the Quebec INESSS project, the British Columbia Fraser Health Region COPD exacerbation clinical pathway and from other international initiatives in the United Kingdom, Australia and the Netherlands.

Discussion with the authors of these other specifications should be included in the stakeholder engagement process and their data specifications mapped to the draft consolidated worksheet and draft data-information model. With sufficient requirements gathered to understand the issues, the next step is to work with the stakeholders to harmonize an initial draft standard.

The development of data standards is an ongoing iterative process supported by a maintenance process (eg, version release management). For example, additional lessons learned from ACM implementations in Ontario can be incorporated as part of the next steps. In the standards development and stakeholder engagement process, actual requirements are defined and refined.

Key observations include:

1) There are data elements and/or values that are not currently captured by the ACM for Primary Care (eg, comorbidities, education provided, self-management goal, height and weight, etc).
2) Some of the data elements in the source are captured in different sections in reference (eg, rhinitis is captured as allergy in source while it is captured as comorbidity in reference; sinusitis is captured as risk factor in source while it is captured as comorbidity in reference).
3) A number of the references do not differentiate between initial and follow-up visits (eg, Ontario EMR Specification v4: asthma diagnosis and management algorithm); as well, there is significant overlap in data captured for asthma and COPD, and there are data elements captured for COPD only (eg, tests, including blood work and sputum).

The results indicate that Ontario is leading the asthma/COPD data definition and standards development in Canada. Most provinces commented that they have not addressed data standards with respect to care maps but are very interested in what the PRESTINE project recommends.

REFERENCE


SECTION VI. DEVELOPING AN ASTHMA/COPD DATA STANDARD – DATA DISCONNECTS

Mary-Ann Juurlink

A more in-depth analysis of the environmental scan was completed to further understand and discuss data disconnects. Data disconnects are a summary of the differences across the various data sets. This may include differences in data elements, definitions, labels, categories and formatting. Harmonization of these differences is necessary in developing data standards. A harmonization process eliminates unnecessary, redundant data, and aligns regional data in preparation for a pan-Canadian standard. This process enables improved consistency in the use of data elements, in their meaning and format. These data disconnects are outlined with examples, and potential PRESTINE project strategies are identified.

It is not easy to see the similarities and understand differences between data when viewing it in a spreadsheet. To align and harmonize data between specifications, the HL7 Health Development Framework was used. This describes a model-driven development approach that includes specifying an information model, data types, vocabularies and value sets. The draft asthma/COPD information model below represents all data categories and example data elements and values as seen in the environmental scan mapping exercise (Figure 2).
Key data observations

There are a significant number of new data element sections or values identified in the references that are not currently captured by the OLAs ACM (eg, data elements for comorbidities, education, self-management goal, height and weight; and value sets for education regarding the chronic nature of disease).

In examining potentially new data elements or values sets, one must consider whether the data elements should be added, and if so, how the information should be classified or coded. Finally, it must be confirmed if the new data needs to be harmonized with other data. The harmonization/reconciliation activities would involve confirming requirements, and making changes to the information model. Furthermore, terminology maps for semantic interoperability across organizations would need to be created.

There are discrepancies in how similar elements are labelled, making it unclear as to what the element means and what is the intent of the data being captured. Examples are presented in Table 3.

To harmonize labelling of data, an understanding of how different stakeholders use similar data is required. This is achieved with stakeholders confirming the definition and the intent of information, eg, how is the data going to be used?

An additional observation is the variation in the level of detail being captured. The harmonization/reconciliation activities would involve confirming requirements, and making changes to the information model. Furthermore, terminology maps for semantic interoperability across organizations would need to be created.

A number of the references do not differentiate between initial and follow-up visit information. This is apparent in the list of the asthma data elements approved by the OntarioMD 4.0 Specification, the organization responsible for certifying EMR vendors for primary care in Ontario. It is important to understand how the specification is intended to be used. Does an initial and follow-up visit differ, and if so, what are the differences? What are the data requirements for each?

There is significant overlap in data captured for asthma and COPD; in addition, there are data elements captured for COPD only. Examples include:

- Tests for blood work and sputum are similar for asthma and COPD;
- COPD specifications saw the addition of a new category (comorbidities such as ischemic heart disease, the metabolic syndrome, etc); and
- A number of data elements/data values are categorized differently (eg, rhinitis captured as allergy [source], gastrointestinal reflux disease captured as risk factor [source], but both are captured in reasons for poorer COPD outcomes [reference], etc).

To understand the overlap and the need to harmonize the data elements, one needs to know what data is specific to COPD and asthma and how the differences will affect an information model.

Another observation is the variation in the level of detail being captured, lack of definitions and value sets. For example, the source document captures influenza vaccination, date and past reaction. The source document captures immunization (flu) yes/no; another reference captures just referrals. To choose the most appropriate data element from the various specifications, the data element requires a clinical definition, ideally evidence-based, a value set and coded to an approved terminology. More work is needed to complete terminology and value sets for areas that are not yet standardized.

An additional observation is that elements are categorized differently. Table 4 provides examples of differences in the capture of data elements in the source document and other references.

When developing a standardized data set for any chronic condition, it is important to keep in mind a broader view of chronic disease and begin to understand what data elements are the same, different and where there is overlap. The creation of an e-Health information chronic disease model for Ontario, and ideally for Canada, would help prevent duplication of work and maximize the benefits of an EHR for all Canadians. Current efforts should be leveraged with other Canadian chronic disease initiatives such as the Western Health Information Collaborative and the Ontario Diabetes project. These initiatives will help inform PRESTINE and recommendations for respiratory standards for a pan-Canadian EHR.

![Diagram of Medical Record Number Information Model](image)

Figure 2) Draft asthma/chronic obstructive pulmonary disease (COPD) information model. CBC Complete blood count; DOB Date of birth; MRN Medical record number.

<table>
<thead>
<tr>
<th>TABLE 3</th>
<th>Similarities in labelling asthma/chronic obstructive pulmonary disease data elements across specifications</th>
</tr>
</thead>
<tbody>
<tr>
<td>Source*</td>
<td>Reference category</td>
</tr>
<tr>
<td>Family history of allergy or asthma</td>
<td>Family history of asthma/atopic disorder</td>
</tr>
<tr>
<td>Other labels more vague, eg, family medical history or concern</td>
<td></td>
</tr>
<tr>
<td>Irritant triggers</td>
<td>Environmental triggers</td>
</tr>
<tr>
<td>Environmental triggers</td>
<td>Triggers</td>
</tr>
<tr>
<td>Tree/grass/weed pollen</td>
<td>Pollen/trees</td>
</tr>
<tr>
<td>Grasses/ragweed</td>
<td></td>
</tr>
</tbody>
</table>
*Asthma Care Map for Primary Care

<table>
<thead>
<tr>
<th>TABLE 4</th>
<th>Differences in data capture across specifications</th>
</tr>
</thead>
<tbody>
<tr>
<td>Hospitalized ever, prednisone use ever</td>
<td>Beta-blocker</td>
</tr>
<tr>
<td>Severity</td>
<td>Risk factor</td>
</tr>
<tr>
<td>History of exacerbations</td>
<td>Medication history</td>
</tr>
<tr>
<td>Second hand smoke exposure</td>
<td>Sinusitis</td>
</tr>
<tr>
<td>Risk factor</td>
<td>Risk factor</td>
</tr>
<tr>
<td>Comorbidity</td>
<td>Comorbidity</td>
</tr>
<tr>
<td>Rhinitis</td>
<td>Allergy history</td>
</tr>
<tr>
<td>Comorbidities</td>
<td></td>
</tr>
</tbody>
</table>

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To understand the overlap and the need to harmonize the data elements, one needs to know what data is specific to COPD and asthma and how the differences will affect an information model.

Another observation is the variation in the level of detail being captured, lack of definitions and value sets. For example, the source document captures influenza vaccination (flu) yes/no; another reference captures influenza vaccination, date and past reaction. The source document captures referrals and to whom (asthma education, specialist or other); another reference captures just referrals. To choose the most appropriate data element from the various specifications, the data element requires a clinical definition, ideally evidence-based, a value set and coded to an approved terminology. More work is needed to complete terminology and value sets for areas that are not yet standardized.

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SECTION VII. RESOURCES, RISKS/CHALLENGES AND GUIDING PRINCIPLES
Marc Koehn, Anne Van Dam, Janice Minard

The PRESTINE national forum was convened to gather core planning parameters from stakeholders across the full spectrum of respiratory care, including clinicians, researchers, health informaticists and administrators. In addition to deliberations intended to establish core project management parameters such as the potential project scope, the overall approach and governance structure, the forum incorporated several breakout groups to brainstorm a number of additional topics intended to help provide guidance to the PRESTINE Steering Committee as outlined below:

- Resource inventory: An inventory of organizations, people and other assets that can be leveraged by the project;
- Risks/challenges: Areas of risk or challenges that the project needs to mitigate or address to meet its objectives; and
- Guiding principles: A set of principles to be considered by the PRESTINE Steering Committee as the project is further developed and, ultimately, delivered.

The following sections summarize the outcomes of discussions in these three topic areas.

Resource inventory
A key challenge for the PRESTINE steering committee will be to secure funding to resource the PRESTINE project and to ensure that it can meet its objectives within relatively tight timelines. As a collaborative effort among various stakeholder organizations, all willing to operate within the broader pan-Canadian standards milieu, an opportunity exists to leverage expertise, resources and funding from the members of this broad community. Key members of this community include Infoway’s Standards Collaborative, CIHI and Statistics Canada, as well as the various jurisdictional players ranging from provincial or territorial e-Health programs through to the many implementers at the regional or Local Health Integration Network level across the country. These players offer access to a broad portfolio of e-Health standards to lay a foundation for respiratory-focused standards; a layered stakeholder engagement model and associated governance mechanisms to enable collaborative standards development and decision making; as well as a wide range of support services, including training and consulting to offer support to the PRESTINE project team. In addition, Infoway, as Canada’s national e-Health funding catalyst, may be in a position to provide a degree of project funding support.

Stakeholders also noted the rich expertise available through collaborative engagement of the full spectrum of stakeholders including clinicians, informaticists, standards experts, administrators, researchers and vendors — whether engaged individually or through groups such as Information Technology Association of Canada Health. Perhaps the most significant resource identified, not only in the brainstorming breakout but also through various broader discussion segments, was the CTS and its clinical guidelines — both in terms of the associated, well-established governance process as well as the guidelines themselves. The latter provide a sound clinical context while the governance process may provide a proven mechanism for stakeholder engagement and decision making.

Risks/challenges
A number of stakeholders looked well beyond the horizon at the many risks and challenges that need to be overcome in aggregating and analyzing data pertaining to respiratory conditions such as asthma and COPD. Who coordinates data collection? How and where are data aggregated and stored? What are the privacy and data ownership implications?

Ultimately, it was recognized that PRESTINE, at this time, is intended to provide content and associated technical standards that help align data collection practices and that provide a foundation not only for exchanging and storing respiratory condition focused clinical data, but for making better, evidence-based decisions. Even within the narrower scope of a standards development project a series of risks and challenges surfaced, ranging from the complexities of effective pan-Canadian stakeholder engagement, through intellectual property considerations, bilingual support and potential difficulties in finding and building consensus around coding scales and systems, to the set of technical and human resource challenges in staffing and executing an effective standards project at a national level.

Guiding principles
Another key dimension of the forum’s brainstorming activities included the identification of a set of guiding principles. This was intended to give those participants in the forum who might not be able to remain engaged throughout the duration of the PRESTINE project, to provide initial guidance for consideration by the project steering committee as the PRESTINE initiative is launched and brought into active operation.

Among the guiding principles that were identified by participants, the following stand out as the most significant:

- Build on what exists: The project must leverage existing standards and standards development processes and expand these in the area of respiratory care.
- Ensure that the common language being devised addresses the requirements of the full spectrum of stakeholders: The needs of a broad stakeholder community — including clinical, administrative and research interests — must be considered on a pan-Canadian, bilingual basis so that the common language can help address the needs of patients and patient communities, the ultimate stakeholder in the health care equation.
- Proceed in phases: Although the project should focus on a broad, long-term vision it should move towards this vision incrementally through feasible phases.

Through the establishment of these inventories and lists, the forum participants did their part in helping to shape and guide this important initiative.

RECOMMENDATIONS AND CONCLUSION
M Diane Lougheed, Louis-Philippe Boulet

Recommendations
A key challenge for PRESTINE is the establishment of a concrete project scope to, among other things, assess resourcing requirements and establish a viable project schedule. As part of the preparation for the forum, the PRESTINE planning committee identified several potential scope dimensions that were explored by the participants and provided the following recommendations:

- Disease/condition focus: Whether there should be an initial focus and, if so, what should constitute this focus? For example, are asthma and COPD reasonable starting points?

Recommendation: The group agreed that asthma and COPD would be reasonable initial focus areas, but cautioned against a disease-focused design approach because data capture before diagnosis is highly relevant. Moreover, they observed that broader issues, such as smoking behaviour and cessation, are prime candidates for this community to address and provide leadership direction, subject to other projects that are underway.

- Targeted clinical setting(s): Whether the specification should be focused on one or more particular clinical settings (eg, acute care, primary health, etc) and, if so, what setting or settings are included?

Recommendation: There was general consensus that primary care is a reasonable initial focus setting of care. However, it should not be addressed in isolation given the movement of patients across the continuum of care and the need for an incentive for primary care providers to be engaged in this process. Furthermore, if primary care is a focal area, stakeholder engagement should be broad and include other clinical groups (eg, pharmacists).
**CONCLUSION**

The PRESTINE National Forum succeeded in obtaining input from relevant stakeholders. Forum participants concurred that there is a need to develop respiratory-related data definitions and standards for inclusion in EHR. Participants endorsed the establishment of a Steering Committee and working groups. The Steering Committee will build on the recommendations of the national forum; receive and approve recommendations from the working groups; confirm data standards and definitions for entry into the EHR; identify test pilot venues; develop a process for integrating respiratory data elements and standards with existing chronic disease models; develop a communications and outreach plan; confirm project budget, project work plan and project change management plan; identify sustainable resources for the ongoing development of the standards; and establish criteria and process for evaluating outcomes.

This represents an opportunity for the CRGC, CTS Clinical Assemblies, health care providers, administrators, and health informatics experts to collaborate and to promote guidelines implementation by integrating key recommendations into current care via the EHR.

**ACKNOWLEDGEMENTS:** The authors are grateful to the members of the PRESTINE Planning Committee: Janice Minard, Anne Van Dam, Nancy Garvey, Ana McPherson, Shari Dworkin, Andrea MacLean, Connie Côté, the co-Chairs Diane Lougheed and Louis-Philippe Boulet, and the facilitator Marc Koehn for their help with the organization of the national forum, and Julie Carrier for recording the meeting notes. The forum was made possible with contributions from the following partners: the Canadian Thoracic Society, the Ontario Lung Association and the National Lung Health Framework.

The authors also thank the National Forum participants: Louis-Philippe Boulet, Institut universitaire de cardiologie et de pneumologie de Québec, Québec, Québec; Patricia Camp, University of British Columbia, Vancouver, British Columbia; Julie Carrier, National Lung Health Framework, Ottawa; Lisa Colizza, McMaster University, Hamilton; Connie Côté, National Lung Health Framework, Ottawa, Ontario; Francine Ducharme, Centre de Recherche du CHU Sainte-Justine, Montréal, Québec; Shari Dworkin, Canada Health Infoway, Toronto; Madonna Ferrone, Respiratory Therapist/Educator, Windsor; Nancy Garvey, Government of Ontario, Toronto; Andrea Gershon, Sunnybrook Health Sciences Centre, Toronto, Ontario; Brian Graham, Saskatchewan Lung Association, Saskatoon, Saskatchewan; Samir Gupta, University of Toronto/St Michael's Hospital, Toronto, Ontario; Mary Ann Juurlink, MAJ Associates, Chelsea, Québec, Québec; Pamela Kaduri, Centre for Addiction and Mental Health, Toronto; Alan Kaplan, Canadian Royal College of Family Physicians, Richmond Hill, Ontario; Marc Koehn, Gordon Point Informatics Ltd, Victoria, British Columbia; Chris Licklai, University of Western Ontario, London; Diane Lougheed, Kingston General Hospital, Queen's University, Kingston; Andrea MacLean, Canada Health Infoway, Toronto; Ana MacPherson, Ontario Lung Association, Toronto; Louise McRae, Public Health Agency of Canada, Ottawa; Janice Minard, Kingston General Hospital, Queen's University, Kingston; Todd Sands, Centre for Smart Community Innovation – University of Windsor, Windsor; Sue Schneider, eHealth Ontario, Toronto; Peter Selby, Centre for Addiction and Mental Health, Toronto, Ontario; Kathleen Spurr, Dalhouse University, Halifax, Nova Scotia; Andrea Stevens-Lavigne, Ontario Lung Association, Toronto; Janet Sutherland, Canadian Thoracic Society/Canadian Respiratory Health Professionals, Ottawa; Itamar Tamari, Stonegate Community Health Centre, Etobicoke, Ontario; Hamid Tavakoli, University of British Columbia, Vancouver, British Columbia; Walley Temple, University of Calgary, Calgary, Alberta; Teresa To, SickKids Hospital, Toronto; and Anne Van Dam, Canadian Lung Association, Ottawa, Ontario.