
Respiratory Health in Canada
Asset Map: *Preliminary Report*

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1. Background and Introduction

This Asset Map *Preliminary Report* is one of several key outputs resulting from the National Lung Health Framework initiative. The National Lung Health Framework is an initiative led by the Lung Association in collaboration with the Public Health Agency of Canada (PHAC), the Interim Steering Committee and other stakeholders. The National Lung Health Framework vision statement is “*to advance respiratory health and health care of Canadians through public engagement in collaborative policy development, leadership, research, innovation and education*”.

The idea of mapping respiratory health assets originated with the Respiratory Health Pre-Summit Workshop held in April of 2006. The Pre-Summit Workshop was organized to begin to better understand the existing respiratory health assets as well as possible gaps, and to come to an initial agreement on what needed to be done to move forward. The Workshop laid the foundation for further support and engagement. Subsequent to the Workshop, the Interim Steering Committee initiated several priority projects. The Asset Map project was one of these.

The Asset Map development process gave rise to several important observations. First, it should be noted that there are many possibilities in terms of what format an Asset Map can take or what it should contain. Asset Maps can vary from simple plots of physical locations to complex schematics of community resources, linkages and relationships; the scope of what Asset Maps can contain includes tangible physical assets such as facilities or people and intangible assets such as intellectual property, financial assets or social assets. Second, there are few really good examples of Asset Maps that can be used as models for development, although there are many examples of resources (catalogues, lists, databases, spreadsheets etc.) that can be said to contain assets. Third, the processes used to develop Asset Maps or their proxies vary widely from simple brainstorming exercises lasting an hour or two to lengthy data gathering processes requiring months or possibly even years to complete. The tools and resources used to support these processes also vary accordingly.

The process used to develop the Respiratory Health Asset Map is described in the next section of this report. However, it is important to note that during the consultations conducted as part of the development of the Asset Map, a number of recurring questions were raised by stakeholders and key informants. It soon became clear that a question and answer format could contribute significantly to the understanding of the Asset Map. What follows is a list of Asset Map questions and related answers generated, in part, by the stakeholder and key informant consultations undertaken during the development process.

Asset Map Frequently Asked Questions (FAQs)

The following “**frequently asked questions**” (FAQs) and their corresponding answers are intended to help foster a shared understanding of, and orientation to the Respiratory Health Asset Map.

What is the Lung Health Asset Map?

The Respiratory Health Asset Map is a knowledge management tool designed to answer the question of “*who is doing what and where*” on the respiratory health front in Canada and to a limited degree, internationally.

The Respiratory Health Asset Map consists of two (2) components:

- a) this Report which provides background, orientation and analysis; and,
- b) a populated, searchable database, with the possibility of being expanded into a widely-accessible, web-based portal.

The database is currently in development and is not yet available. However, this report provides an overview of the content, highlighting many of the unique assets on the Canadian respiratory health front.

Is the Asset Map just about organizations?

No. While organizations make up a significant portion of the Asset Map, many other key assets are included such as networks, seminal documents and reports, committees, web sites, significant programs and campaigns. An asset can be anything that is deemed to have lasting value including physical, intellectual, financial and socio-economic value.

Does the Asset Map only contain respiratory health assets?

No. Many assets are multi-faceted in nature just as health care issues are inter-related (for example circulatory and respiratory). However, all the assets included in the Asset Map have a connection to respiratory health.

How was the information in the Asset Map obtained?

Many key informants contributed to the Asset Map through their responses to surveys and interviews. Extensive web and document searches have also been conducted. The Asset Map is still in its early formative stages and, as such, it is very much a work in progress.

What criteria were used to select assets?

A key criterion for inclusion in the database was that the asset be deemed to have some lasting value. Another related criterion was that information assets be less than five years old; assets older than five years were not included unless they were deemed to have legacy value. Some categories of assets such as experts or leaders in the field of lung health, were not included as part of this iteration.

How will gaps in the Asset Map be addressed?

The Asset Map is still in its early phase of development and does not claim to be exhaustive. The inclusion of individuals, international sources and other categories of assets could potentially push the number of records into the thousands. The approach has been to start with a subset of primary assets before moving to secondary assets.

How will the asset map be extended and kept up to date?

As part of the overall Framework development and implementation, the Asset Map will be considered and recommendations for its future will come as part of that process.

2. Process/Methodology

This Asset Map Preliminary Report is the result of a multi-stage process involving extensive review, collaboration and input by stakeholders and key informants engaged in the field of respiratory health. The process is still in its early stages. As such, the Asset Map should be considered a work in progress. Building on the success of the Respiratory Health Pre-Summit (April, 2006) and subsequent Framework Working Group sessions (Dec., 2006), work on the Asset Map began in earnest in January, 2007, with an extensive review of documentation and web sites pertaining to respiratory health. To further inform the development of the Asset Map Preliminary Report and database, exploratory surveys and interviews were conducted with key informants throughout the months of February and March, 2007. These included NGO executives and respiratory health experts from across Canada. Key to the process were discussions and input from stakeholders and The Lung Association regarding what format the Asset Map should take and how it could best add value beyond the many resources that already exist.

An important outcome of these discussions was the notion that the Asset Map needed to be more than just a static catalogue or listing; rather, it would need to be a “dynamic” enabling tool to answer important questions about “who is doing what and where” in the field of respiratory health in Canada and in some cases beyond. This vision led to the decision that the first generation of the Asset Map would consist of two components: a high level Report summarizing analysis, gaps and other key findings; and, an on-line searchable database of Assets. This objective guided the development process of the Asset Map.

3. Purpose of the Asset Map

The Asset Map is an information and knowledge tool meant to be used by stakeholders to answer key questions about “who is doing what and where” in the field of respiratory health. While the primary focus is on Canada, high level international assets are also included, especially when these impact Canadian activities or policies in matters of respiratory health. The Asset Map addresses a key concern among respiratory health experts and stakeholders, namely, that not enough is known about what is happening in the different jurisdictions across Canada and abroad with respect to respiratory health activity. This knowledge “gap” is seen as a significant barrier to progress and optimal decision-making. Conversely, awareness and knowledge about what others are doing facilitates collaboration, information exchange and asset sharing ultimately resulting in more efficient and effective health outcomes. This is the core principle that underpins the Asset Map initiative.

4. Linkages

The various entities that make up the asset map are not independent; many are linked and indeed overlap. For example, many stakeholder organizations which are assets in and of themselves also lead, sponsor, host or participate in programs, campaigns, committees and other assets. Thus, an organizational asset such as PHAC is the source for other important assets. In this regard, the system of respiratory health assets can be viewed as quite intricate and dynamic, somewhat like a wheel with many spokes.

5. Context Issues and Priorities

Several key contextual issues and priorities relevant to the National Lung Health Framework were brought to light by the Phase I Working Groups and by the Asset Map consultation process. The first is that the comparatively low level of awareness of the term “respiratory health” and certain related disease conditions such as COPD and sleep apnea is a barrier to progress. Low levels of awareness can translate into under-diagnosis (low recognition and self-reporting) and sub-optimal prevention, treatment and disease management. Furthermore, there are a large and diverse number of stakeholder groups that operate in the field of respiratory disease. With no overall coordinating strategy or framework in place, efforts are easily fragmented; it is not unusual for stakeholders to compete among themselves for funding and resources. Yet, encouraged by the success of other plans and frameworks, stakeholders welcome the National Lung Health Framework initiative and see it as an important catalyst for change. Continued progress on the tobacco front, exploiting the potential of stronger links between lung health and the environment, maintaining the current level of support for pandemic preparedness and leveraging the growing force of international agreements such as the Framework Convention on Tobacco Control (FCTC), are seen as priorities.

SWOT Analysis

In the course of developing the Asset Map, stakeholders were surveyed regarding their perceptions of current strengths, weaknesses (gaps), opportunities and challenges (threats). The results of this “SWOT” analysis are summarized in the following table. Certain points require emphasis. With regard to strengths, there are important “pockets of excellence” across the country and numerous assets (networks, committees, web sites, conferences etc.) exist for collaboration and sharing of resources. Thus, the absence of an asset in one region does not necessarily signal a gap or deficiency. Continued, and in some cases increased, investment in coordinating assets should be seen as a priority to ensure that existing pockets of excellence do not become silos.

Among core strengths, tobacco programs are seen to be clearly having an impact; however, with success there is also concern that complacency is setting in. Much more work needs to be done on the tobacco front especially in regards to at-risk or vulnerable populations.

The many excellent partnerships and collaborations that exist among stakeholders should also be seen as core strengths. The Canadian Lung Association itself has numerous working groups and committees that draw participation from across Canada. Fostering these relationships should be seen as a priority, especially in light of the fact that the flip side of this coin – self-interest and competition for attention and funding - are also identified as major systemic weaknesses.

With respect to weaknesses, lack of awareness of respiratory health and disease conditions such as COPD and sleep apnea is seen as a key issue. Many stakeholders believe that the timing is right for a respiratory health framework especially in light of the growing focus on environmental issues. Linking respiratory health to the issue of the environment is seen as a major strategic opportunity.

A number of other weaknesses are notable. Greater access to spirometry as a routine standard of care is seen as a priority. Use of spirometry as a diagnostic tool is not at level deemed sufficient by experts in most jurisdictions. Similarly, lack of sufficient disease management resources is

identified as a weakness, especially as physicians do not always have the time to spend educating patients on how to keep their disease in check. Support for more certified respiratory educators (CAEs) and therapists could help alleviate the problem. Insufficient and uneven access to pulmonary rehabilitation is also a major weakness.

The comparative rarity of Tuberculosis in Canada is a significant accomplishment and a tribute to the excellence of our health system. That being said, some informants express concern that the continued prevalence of TB in the developing world and in some of our own communities is a sign of complacency. This, in turn, manifests itself in a perceived lack of appropriate funding, inadequate TB program support, incidences of misdiagnosis and poor access to proper treatment.

With the National Lung Health Framework cutting across many jurisdictions and disease categories, consistency of interpretation and application of the many standards and guidelines that exist is widely seen to be problematic.

The current shift towards prevention is generally acknowledged as a positive trend. However, stakeholders suggest that more needs to be done to bolster awareness, promotion and prevention.

Education about respiratory health is also thought to be insufficient. Respiratory health education is not routinely integrated within school curricula nor are educators necessarily equipped to teach about respiratory health. The lack of provincial support for in-school education assets is a significant gap.

The lack of overall strategic level planning for respiratory health in Canada is seen as an important gap, one which the National Lung Health Framework may help to close. This gap is evident at several levels including the research, medical education, monitoring and surveillance, and care delivery levels.

As previously noted, with the growing concern for the environment (greenhouse gases, air quality), many see an opportunity to build a stronger association between environmental health and respiratory health by building on the growing body of research in this area. Because everyone has a stake in the environment, this issue is seen as having the potential to engage all Canadians in respiratory health awareness. The timing is, therefore, thought to be good for developing a respiratory health approach. The environmental issue is seen to have implications on a number of fronts. For example, new awareness, promotion and prevention messages will need to be developed and targeted to the appropriate demographic segments.

Raising awareness for respiratory disease to a level that is in keeping with its risk is seen as a serious challenge. While risks of pandemics are well exploited by the media, there is concern by some that this may result in attention being taken away from more mundane, but far more deadly, respiratory risks. Other notable challenges include reaching vulnerable populations (e.g. children, Aboriginals Peoples, seniors, new immigrants and others), overcoming systemic complacency (e.g. TB, tobacco), achieving coordinated and sustainable funding for research and education initiatives, and fostering collaboration. Many assets exist to respond to these challenges but it is felt that many more are needed and that some of the current ones need to be strengthened.

How do the issues and priorities raised by stakeholders compare to those identified by major international respiratory organizations? A scan of major strategies and initiatives reveals

remarkable consistency. For example GARD¹, the IUATLD, and WHO all agree that the following are key issues:

- fragmented surveillance, prevention and control activities; little formal cooperation across jurisdictions and organizations
- scientific information and public awareness are not well coordinated, i.e. there is poor translation of scientific medical knowledge into collective consciousness, e.g. in the form of guidelines for GP's and/or their patients
- advocacy is weak as efforts are fragmented, and evidence-based information is inadequately presented to governing structures
- funds and resources are limited (WHO estimates the world wide shortage of doctors, nurses and other health care workers to be around 4.3 million)
- existing clinical guidelines and prevention programs are not adequately implemented or monitored (linked to above)
- many surveillance, prevention and control activities are not sustainable, and much activity is crisis driven

GARD's vision is "a world where people breathe freely" and its overall goal is to improve global lung health by better understanding (data) of Chronic Respiratory Disease (CRD) risk factors, encouraging health promotion and prevention and recommending affordable strategies for CRD management. Similar alignment can be found on tobacco control, infectious disease (esp. TB) and environment issues and priorities. For example, Canada's Tobacco Control policies and FCTC priorities appear to be closely aligned² and international protocols are forcing growing consensus on both the infectious disease and the environmental fronts.

¹ *Global Alliance Against Chronic Respiratory Disease*, World Health Organization, March 2006 and IUATLD Annual Report 2005,

² FCTC Monitoring Report, February 2006.

SWOT Analysis Summary

Strengths	Weakness (Gaps)
<ul style="list-style-type: none"> • collaboration and exchange among national and regional committees, working groups • tobacco programs are making a difference; many tobacco assets in place and working • willingness and ability to work together • pockets of excellence (e.g. youth tobacco, air quality, sleep apnea, Stop TB etc.) • many drivers of excellence – including local champions or experts, program needs, regional prevalence of disease • strong partnerships and relationships • existing and emerging networks for information sharing and practice • proven NGO capability and track record for delivery • some governance structures that facilitate cooperation and as opposed to competition • growing support for focus on environment and tobacco • growing emphasis on health promotion and prevention • improved pandemic preparedness • public willingness to take more active role in their own health care • increasing prevalence of interdisciplinary / integrated care model 	<ul style="list-style-type: none"> • inconsistencies in interpretation and application of guidelines • lack of RH awareness and health promotion • lack of pulmonary rehabilitation and respiratory therapy • shift to prevention not yet a reality • lack of respiratory health information services in communities • insufficient support of spirometry and sputum tests • lack of funding and resources • lack of national research policy for RH • medication gaps – lack of support for formulary • lack of coordination – need to work together to make an impact • problems with self interest and working against each other; competing for resources; fear of lessening the pie • changing (aging) donor demographics • lack of a (sustainable) strategy for respiratory health • missing an RH plan for the environment; current approach is piecemeal • insufficient RH public education • lack of understanding of the danger/risk of small airborne particulates • lack of disease self-management • uncertain surge capacity
Opportunities	Threats (Challenges)
<ul style="list-style-type: none"> • environmental awareness is timely opportunity • timing may be good to talk about a lung health approach • the lung framework can give us the big umbrella we've been needing • traditionally targeted people who already have disease; opportunity now to target prevention • engage 100% of the population through respiratory health messages and not just those with specific disease conditions • establish clear goals on the environment linked to health outcomes • focus on the cause not the effect of the disease • greater focus on corporate donors; engage the private sector • more and better promotional events (marathon runs etc. to reach new donors and demographics) 	<ul style="list-style-type: none"> • systemic complacency (perception that the war against Tobacco and TB have been won) • overall low level of awareness for respiratory health issues and disease conditions/risks (COPD, sleep apnea) • changing demographics; old approaches no longer work • how to reach at-risk or vulnerable populations (youth, Aboriginal Peoples, immigrants) • environment issue requires a different set of messages and approaches • preparedness for infectious outbreaks (pandemic etc.) • media distortion of risk factors and impact on health priorities • unstable or lack of long-term funding • fragmentation and self-interest; risk of mixed or confusing messages

6. Stakeholder Expectations

Stakeholder organizations figure prominently in the Asset Map database. Stakeholders themselves are important assets but so too are the many other assets that they manage or host. Stakeholders also interact with each other in many dynamic ways to generate additional assets. These assets include reports, research studies, campaigns, working groups, committees, networks and conferences, among others.

Stakeholders interviewed during the Asset Map consultation process convey important expectations for both the National Lung Health Framework and the Asset Map. Provincial NGO executives, for example, feel that national initiatives of this nature are important levers for change at the provincial and local level. They also note that knowledge about who is doing what in other provinces or territories is beneficial for comparative purposes. For example, several stakeholders stated that the National COPD Report Card was an asset that helped raise the profile of COPD and free up badly needed resources and new investment. Similar expectations exist for the Framework.

Both the Framework and the Asset Map are expected to be tools that can help decision-makers avoid “reinventing the wheel”, thus saving time and expense. By serving as models, they are also expected to lead to more consistent messaging. Speaking of the Framework, one stakeholder notes, “*it will help to know what a respiratory health framework should look like and what it could lead to in terms of roles and outcomes*”. Another informant states, “*it will be helpful to see how many issues are similar among the provinces*”.

Stakeholders suggest that the appropriate role for the federal government is to create an enabling environment for effective health care delivery. A national framework is seen to send two important signals: 1) that the federal government views respiratory health as a priority and 2) that it is interested in working collaboratively with its partners to achieve progress. As one stakeholder observed, many of the provinces work autonomously and the respiratory health framework initiative is an opportunity to work together.

Furthermore, it is thought that the Asset Map could serve as a clearinghouse for shared information leading to shared resources. The Asset Map is seen as a potential knowledge portal or pathway to answers to key questions about the management of respiratory health in Canada. These answers are then expected to support key decision-making processes; better decisions should ultimately translate into better health outcomes.

Finally, the activities taking place in the field of respiratory health are seen by many informants to be quite fragmented and at risk of becoming silos. This perception appears to be due, in part, to the diversity of stakeholders, disease conditions and specialty functions that make up the field but also to the comparatively low level of public awareness surrounding the term “respiratory health” and the absence of any overarching strategy to coordinate activities. The Framework and the Asset Map are expected to provide a broader “system perspective” for respiratory health – a perspective that is currently lacking.

7. Frameworks, Plans and Strategies

The Asset Map set out to determine through research and interviews what respiratory health frameworks were already in place or under development internationally, nationally and in the provinces and territories. Because the term “framework” is somewhat abstract and ambiguous, the search was broadened to include “related plans and strategies”. Even here, the terminology is by no means perfect as many program and organizational assets contain strategic planning dimensions. With this in mind, the discussion that follows is based on an analysis of key frameworks, strategies and plans discovered in each of the three jurisdictions. It should also be noted that the existence of a framework, strategy or plan does not necessarily mean that it has been adopted, funded or implemented. For example, some may be in their formative stages while others may be unsupported.

7.1 International

The main focus of the Asset Map was on Canadian assets. However, a cursory scan of international assets was undertaken as part of the Asset Map development process. Some examples of International Frameworks, Plans and Strategies are noted below:

Examples of International Frameworks, Plans and Strategies

- WHO Strategy for Prevention and Control of Chronic Respiratory Diseases (2001)
- WHO Global Initiative on Children’s Environmental Health Indicators (2006)
- WHO Global Strategy to Stop TB (2006)
- European White Book on Lung Disease (2003)
- Europe: A Global Initiative for Chronic Obstructive Lung Disease (GOLD) (2001)
- GINA – Global Initiative for Asthma’s Global Strategy for Asthma Management and Prevention (2006)
- International Union Against Tuberculosis and Lung Disease (IUATLD)
- Chronic Respiratory Diseases in Australia
- Western Australia: Chronic Respiratory Disease Clinical Service Improvement Frameworks
- Australia: National Asthma Action Plan (1999 - 2002)
- Northern Ireland: A Healthier Future: A Strategic Framework for Respiratory Health Conditions (2005)
- Framework Convention on Tobacco Control (FCTB)
- Global Alliance Against Chronic Respiratory Diseases (GARD) – see 2006 Report

Organizational Assets

At the international level, there are several organizations that deal with respiratory disease, with many of these organizations cooperating, and even partnering, with each other on the prevention of risk factors, identification and delivery of appropriate treatments and finally, on research aimed at increasing existing knowledge and understanding of these diseases.

The World Health Organization (WHO) is a key player involved in a number of international respiratory health programs, most notably the Global Alliance against Chronic Respiratory Diseases (GARD) launched in March 2006 in Beijing, China.³ GARD is a voluntary alliance of national and international organizations, institutions and agencies committed to improving global lung health. GARD brings together various governmental and not-for-profit organizations with the common objectives of standardizing the identification method for chronic respiratory disease risk factors; encouraging countries to adopt policies that promote health and disease prevention; and producing guidelines for the management of these diseases.⁴ The WHO also participates in various promotion, prevention and screening initiatives such as the Global Initiative for Asthma (GINA), the Global Initiative for Chronic Obstructive Lung Disease (GOLD) and the Global Strategy to Stop TB.

The International Union Against Tuberculosis and Lung Disease (IUATLD)⁵ promotes lung health in low and middle-income countries by disseminating information, offering technical assistance to its members and promoting research on lung disease. Some of its partners, including the World Lung Foundation⁶ and the Global Fund to Fight AIDS, Tuberculosis and Malaria⁷, are important international players in the field of respiratory health. The Union has created a global research fund, *fidelis*⁸ which received its initial funding from the Canadian International Development Agency (CIDA); the objective of this fund is to support innovative interventions in the fight against tuberculosis.

In Europe, the European Respiratory Society (ERS) is an international non-profit medical organization whose main activities are education and medical research.⁹ The ERS and the American Thoracic Society frequently issue joint publications. The ERS created the European Lung Foundation (ELF) as an international partnership whose primary mandate is to inform the public using scientific data provided by the ERS.

Finally, many countries, including most European countries, the UK, US, Australia, China, and others have a Lung Association and a Thoracic Society working to promote the prevention and treatment of chronic lung diseases.

³ World Health Organization (2006c). Global Alliance against Chronic Respiratory Diseases (GARD): General Meeting Report. Geneva: WHO.

⁴ Ibid

⁵ http://www.ihatld.org/index_en.phtml

⁶ <http://www.worldlungfoundation.org/>

⁷ <http://www.theglobalfund.org/en/>

⁸ <http://www.fidelistb.org>

⁹ European Respiratory Society & European Lung Foundation. (2003). European Lung White Book: The First Comprehensive Survey on Respiratory Health in Europe. UK : The Charlesworth Group.

Guidelines

On the international scene, respiratory diseases are classified as: asthma, chronic obstructive pulmonary disease (COPD), lung cancer, pneumonia, tuberculosis, cystic fibrosis or mucoviscidosis, sleep apnea and interstitial lung diseases including sarcoidosis, among others.¹⁰ Guidelines tend to focus mainly on asthma, COPD and Tuberculosis. Among these can be found the guidelines from GINA, GOLD and the Global Plan to Stop TB, whose ultimate goal is to eradicate tuberculosis by 2050.¹¹ Interestingly, all these guidelines suggest a multidisciplinary approach where, in addition to presenting recommended diagnostics and treatments, the guidelines refer to prevention, the management of risk factors, as well as pulmonary rehabilitation, as needed.

Tobacco and the environment are given prominence as the two most common risk factors associated with respiratory disease. Tobacco is one of the principal aspects targeted by a number of groups, as indicated by the landmark WHO- negotiated public health treaty *Framework Convention on Tobacco Control (FCTC)*.¹² The FCTC is the first occasion where the WHO has used a treaty process to address a globalized health problem. The treaty was unanimously adopted at the World Health Assembly in 2003 and has received significant global support; over 180 countries have signed, ratified or acceded to it.¹³ On the environment front agreements such as the Kyoto Accord are receiving much attention and demands for action are gaining momentum.

Frameworks – Some Examples

a) Australia

The Australian National Asthma Strategy 2006-2008 is articulated around six elements:

1. The increase of knowledge on asthma within the population;
2. The involvement of asthmatics in the self-management of their health as well as the development of new care programs;
3. The development of models of care in order to reach out to vulnerable sections of the population;
4. The improvement and integration of continuity of care through a multidisciplinary vision of care;
5. The recognition of local, regional and national organizations that work to fight asthma; and finally,
6. The improved understanding of asthma through research.¹⁴

In addition, the Australian Lung Foundation together with the Thoracic Society of Australia and New Zealand has developed the *COPD-X Plan: Australian and New Zealand Guidelines for the Management of Chronic Obstructive Pulmonary Disease*.¹⁵ In these guidelines, two organizations have included the treatment and management of asthma as well as of bronchitis. These guidelines form a global plan of action that takes into account treatment as well as diagnostic tools. The use

¹⁰ ERS & ELF, 2003

¹¹ WHO 2006b

¹² WHO 2005

¹³ FCTC Monitoring Report, A Review of Canada's Progress towards Implementing the Framework Convention on Tobacco Control, February, 2006

¹⁴ Australian Health Ministers' Conference, 2006

¹⁵ The Thoracic Society of Australia & New Zealand and The Australian Lung Foundation, 2006

of a complete multidisciplinary model is presented that requires the participation of nutritionists, psychologists and social workers. A section is dedicated to the “end of life” management of respiratory diseases.

b) United Kingdom

The UK has developed a strategic framework for respiratory diseases titled *A Healthier Future: A Strategic Framework for Respiratory Conditions*.¹⁶ Its six elements are:

1. The promotion of health and welfare;
2. The prevention of respiratory diseases;
3. The reduction of health inequalities;
4. The development of multidisciplinary care aimed at the individual;
5. The development of services appropriate for the patients’ needs and based on probing data and best practices guidelines; and,
6. The assurance of a better continuity of care between the different health services (front, second and third-line services).¹⁷

c) United States

In the United States, there are a large number of important respiratory health assets. Included in these are the American Lung Association, the American Thoracic Society, the Centres for Disease Control and Prevention and a multitude of disease specific assets. Many stakeholders in Canada work closely with their U.S. counterparts, taking advantage of common language and proximity. Each of these organizational assets has periodically produced frameworks, plans and strategies for various disease conditions.

Conclusion

Most countries recognize that respiratory diseases threaten the lives and well-being of a significant number of individuals both at home and abroad. In addition to acknowledging the high rates of morbidity and mortality associated with respiratory diseases, the international community recognizes that these diseases generate substantial costs to society through diminished productivity, absenteeism, poor quality of life for individuals living with these diseases and their families. The pressure on health care infrastructure, systems and services from respiratory disease is also recognized as being highly significant. International initiatives feature prevention, promotion of self-care and the allocation of appropriate treatments; and finally, they all stress the importance of research as it constitutes the intellectual foundation of all intervention frameworks.

¹⁶ Department of Health, Social Services & Public Safety, 2006

¹⁷ Department of Health, Social Services & Public Safety, 2006

7.2 National

The National Lung Health Framework initiative is the first of its kind in Canada. There has not been nor is there currently a national framework, plan or strategy for respiratory health. National approaches for other disease groups have existed for some time. Examples include:

- The Canadian Strategy for Cancer Control (1999)
- National Cancer Institute of Canada Strategy – NCIC 2015 (2005)
- Heart and Stroke Foundation, Canadian Stroke Strategy (2003)
- Health Canada, Centre for Chronic Disease Prevention and Control, Canadian Heart Health Initiative (1987-2000)
- Public Health Agency of Canada, Canadian Diabetes Strategy (1999)

While differing in detail, what these strategies have in common is the goal to deal comprehensively and collaboratively with the disease on a pan-Canadian basis.

Two national COPD reports have been released that contain data with strategic implications. These are:

- COPD: A National Report Card (2005)¹⁸
- Women and COPD: A National Report (2006)¹⁹

The Canadian Institute for Health Research (CIHR) has developed plans specifically to address research, innovation and knowledge transfer. However, there is as yet no separate national research policy framework specific to respiratory disease.

- Investing in Canada's Future: CIHR's Blueprint of Health Research and Innovation²⁰
- CIHR Knowledge Translation Strategy 2004-2009²¹

National policy and legislation has resulted in strategic initiatives and programs, especially in the tobacco and environment arenas. This includes:

- New Directions for Tobacco Control in Canada: A National Strategy (1999)
- Health Canada, Federal Tobacco Control Strategy: A Framework for Action (2001)
- The National Strategy: Moving Forward, Progress Report (2006)²²
- Environment Canada, Canada's Clean Air Act (2006)²³
- Canadian Environmental Protection Act (1999)
- Natural Resources Canada (NRCan), One-Tonne Challenge (2005)²⁴

¹⁸ COPD: A National Report Card (2005) http://www.lung.ca/resources/2005.copd_reportcard.pdf

¹⁹ Women and COPD: A National Report http://www.lung.ca/resources/Women_COPD_Report_2006.pdf

²⁰ Investing in Canada's Future: CIHR's Blueprint of Health Research and Innovation <http://www.irsc.gc.ca/e/20266.html>

²¹ CIHR Knowledge Translation Strategy <http://www.irsc.gc.ca/e/26574.html>

²² This report contains a summary of actions and initiatives taken by the federal government and the provinces/territories in support of the overall strategy. Visit: http://www.hc-sc.gc.ca/hl-vs/pubs/tobac-tabac/prtc-relct-2006/index_e.html (March 6, 2007)

²³ The federal government is in the process of developing a new environmental plan for reducing greenhouse gas emissions.

²⁴ This program has since been cancelled.

Gaps and Opportunities

The lack of a national respiratory health framework can be seen as a gap when viewed comparatively against other major disease categories where broad strategies have existed for a number of years. With respect to specific National Lung Health Framework Phase I Working Group topic areas²⁵, there is not currently a national approach to addressing environmental causes of respiratory disease nor is there a national infectious disease strategy although there is a Canadian Pandemic Influenza Plan for the Health Sector.²⁶ Work to address these issues nationally has been through NGOs (such as the Lung Association) that have dedicated resources and created national working groups targeting programming and research in respiratory health. Growing public concern over environmental issues including global warming/climate change points to a key opportunity. Described by some as “hot button” issue, the environment has the potential to engage the entire population. At the Federal Government level, Health Canada has created a healthy environment secretariat which has been dealing with a number of respiratory issues such as indoor air quality and radon; this work is in its infancy and has just begun. There has also been recent work to establish a national air quality health index. The timing would appear to be right for linking the issue of respiratory health to the environment and for building on the growing body of research in this area.

With respect to chronic disease, elements of national approaches exist for Asthma and COPD; however, no evidence could be found of nationally supported strategies or plans for sleep apnea or other chronic lung diseases.

As already noted, Canada’s National (Federal) Tobacco Control Strategy (FTCS) was established in 2001. The FTCS was announced as a federal contribution to the national tobacco control plan endorsed by the Ministers of Health in 1999. The Strategy is described as both a framework and a plan of action; it runs for a period of 10 years and is sustained by federal funding over that period. The Strategy focuses on four components: protection, prevention, cessation and harm reduction (denormalization). The Strategy was bolstered by an evolving legal framework that included the Tobacco Act (1999) and subsequent regulations (2000) governing the manufacture, sale, labeling and promotion of tobacco products.

The approach to tobacco control has been built around coordinated actions of federal, provincial, territorial, and municipal governments working together in collaboration with non-governmental organizations. While much more needs to be done, especially with regards to at-risk populations such as Aboriginal Peoples, youth and immigrants, the approach has yielded results (reduced smoking rates, lower mortality and morbidity). The tobacco control strategy highlights the broader opportunity for a successful nationally coordinated respiratory health strategy.

The lack of a nationally coordinated respiratory health framework, action plan or strategy signals an important gap that is being addressed by the process that is now underway. Many provinces, territories, municipalities, and NGOs have excellent programs in place to address needs, thus providing a foundation for progress. Evidence from past initiatives suggests strongly that nationally supported initiatives attract considerable attention among stakeholder groups and frequently serve as important levers to advocate for programs and resources at all levels of government and among NGOs, the private sector and the public at large.

²⁵ National Lung Health Framework Phase I Working Groups (Oct 2006-Mar 2007): Chronic Disease Working Group; Infectious Disease Working Group; Environment Working Group; and Tobacco Control Working Group

²⁶ Canadian Pandemic Influenza Plan for the Health Sector <http://www.phac-aspc.gc.ca/cpip-pclcpi/hl-ps/index.html>

7.3 Provincial/Territorial

Through the various health ministries, each province and territory has mapped out its own approach to health care delivery. As might be expected, provincial plans and strategies exist in many forms, and are constantly evolving to reflect new and emerging realities. For example, *Ontario's Plan for Health*²⁷ builds on the Local Health Care System Integration Act (March 2006) which requires the development of a long-term health plan. The plan will be strategic in nature; it will cover a 10 year period and result from an extensive process of public engagement. As part of its planning agenda, Alberta Health and Wellness has developed the *Framework for a Healthy Alberta* which sets objectives and targets to the year 2012 for guiding the government's actions in promoting health and preventing disease and injury.

Provincial/territorial health care plans notwithstanding, current strategies to address respiratory health are disease-specific, rather than broad, integrated strategies addressing a range of diseases and risk factors. One province (Alberta) is in the early stages of developing a respiratory strategy but it is too early to determine the outcome or impact this may have. Ontario's Chronic Disease Prevention and Management (CDPM) Framework encompasses respiratory disease, although not exclusively. The Framework, which reflects many of the elements of the Wagner Model invokes a system of health care organizations, individuals, families, and communities interacting together to achieve positive health outcomes. The framework is meant to be transformative – from an illness orientation to a wellness orientation.

Asthma and COPD strategies and/or programs and Tobacco Control strategies and/or programs exist or are in development in most provinces;²⁸ these often take their cue from national programs or initiatives. These provincial/territorial strategies and programs are typically the product of the various health ministries or of NGO's such as the Lung Association, working in collaboration with other stakeholders.

These can be categorized along the same lines as the National Lung Health Framework Phase I Working Groups themselves, namely: Chronic Disease, Infectious Disease, Environment and Tobacco Control. Based on the reference documents identified, Aboriginal tobacco strategy stands as an important sub-element of tobacco control. An important overarching dimension to these categories is provincial "healthy living" strategies, increasingly focusing on disease prevention and health promotion. Combined with a significant number of disease prevention and management strategies (Chronic/COPD/Asthma etc.), there is growing evidence that health care focus is indeed shifting towards the causal end of the continuum.

Gaps and opportunities

A scan of frameworks, plans and strategies identified at the provincial level points to considerable activity on the chronic and infectious (mainly flu programs) disease front. With respect to respiratory health in general, there are virtually no generic lung or respiratory health frameworks although Alberta is in the early stages of developing one. There are plans and strategies however, with the greatest number occurring in the chronic disease and tobacco control categories. With respect to chronic disease, the main focus is on Asthma and COPD. These include the Ontario

²⁷ Ontario's Plan for Health www.ourplanforhealth.ca

²⁸ As might be expected, there are a number of strategies and plans under development. The Ontario Lung Association's proposal for a comprehensive COPD Strategy targeted for May, 2007 submission to the Ministry of Health and Long Term Care (MOHLTC) is one example.

Asthma Plan of Action, the New Brunswick Asthma/COPD Strategy, the Winnipeg Regional Health Authority (WRHA) Asthma Strategy, the Newfoundland and Labrador Framework for COPD and the Alberta Strategy to Help Manage Asthma (A.S.T.H.M.A), among others. A small but important focus exists on sleep apnea primarily in the Prairie Provinces. The Winnipeg Regional Health Authority has developed a sleep apnea strategy and Saskatchewan has at least two sleep apnea labs. In Alberta, the Sleep Apnea Association is part of the Lung Association and operates as The Lung Association of Alberta Sleep Apnea (LASA).

As has already been noted, numerous tobacco control and related strategies exist at the provincial level and at the municipal or community levels. These strategies, which include the Smoke Free Ontario Tobacco Control Strategy, the Alberta Tobacco Reduction strategy (ATRS) and the Newfoundland and Labrador Tobacco Reduction Strategy, are empowered by legislation and regulations at all three levels of government. Tobacco control strategies also exist for Aboriginal Peoples and include the First Nations and Inuit Tobacco Control Framework, the B.C. Aboriginal Tobacco Strategy and the Government of Nunavut Tobacco Program. Tobacco strategies are also synergistic with cancer control strategies. For example, Cancer Care Ontario, an umbrella organization that steers and coordinates Ontario's cancer prevention efforts features a number of tobacco control information assets on its website²⁹, including web links, tobacco facts, the Smoke Free Ontario Strategy and Ontario's Aboriginal Tobacco Strategy.

Except for influenza strategies related to the potential pandemic and the flu shot, no examples were found of comprehensive strategies to deal with infectious disease as broadly defined. TB control is a centralized feature of the Manitoba and Saskatchewan health systems due to historically high rates among Aboriginal Peoples (17x the national average). TB is receiving more attention at the national and international level due to high rates among immigrants who represent around 70% of TB cases in Canada.

Despite the growing focus (and an increasing body of research) on the environment, no examples were found of comprehensive strategies linking respiratory health to the environment. Some elements of such strategies exist under certain Occupational Health and Safety guidelines. However, there are signs that environment is poised to become the new tobacco in terms of catching the attention of policy makers and the public. If this happens, stakeholders will likely be emboldened by increasingly stringent environmental legislation, regulation and protection. Internationally, the IPCC report on climate change and global warming and the Kyoto Protocol continue to occupy centre stage in the public debate. At the federal level, the government's Clean Air Act is receiving considerable attention.

The provinces are also becoming more active. Air quality has been a longstanding issue in New Brunswick which has its own Clean Air Act and is also home to the New Brunswick Climate Change Hub. The Province of Newfoundland and Labrador also has a climate change strategy. As with tobacco, the environment disease front is likely to be shaped and influenced heavily by legislation and regulation in response to public pressure combined with the accumulated weight of evidence-based research findings. The opportunity that is emerging is for respiratory health stakeholders to use these statutory tools (and the heightened awareness they bring) to strengthen the linkages between the environment and respiratory disease. As several Lung Health experts put it, the focus on the environment facilitates the branding of respiratory health into a "big tent" disease category along the lines of cancer or heart disease. This approach would help overcome what has been identified as one of the key barriers to fighting respiratory disease, namely low public awareness of risk and prevalence compared to other major disease categories.

²⁹ Cancer Care Ontario www.cancercare.on.ca

Conclusion

On the surface, the various frameworks, plans and strategies that exist across the Canadian respiratory health landscape reveal some fundamental gaps. However, it could also be said that the same landscape points to some significant “pockets” of excellence and many, perhaps timely, opportunities. Within the context of a national respiratory health framework, the challenge is to find ways to ensure that those “pockets” avoid becoming “silos” where exchange of information, knowledge and resources is stifled. This will require coordinating mechanisms and protocols that function at a pan-Canadian level.

Although the GARD initiative comes close, there is nothing that is as comprehensive as the emerging National Lung Health Framework anywhere in the world. In this respect, the National Lung Health Framework is a first-of-kind initiative. It is unique in the sense that it covers the whole of respiratory disease, cuts across jurisdictional and organizational boundaries, and involves a wide variety of stakeholders from practitioners, to researchers, patient groups, government and industry, medical policy writers, and others. Gaps are to be expected whenever something of this scale and complexity is being undertaken for the first time. These gaps include the lack of a proven road map to guide the process and a firm commitment of the resource requirements needed to achieve outcomes. However, the National Lung Health Framework development process is aided by a clear consensus-based vision of the destination and by enthusiastic participation from stakeholders, many of whom see the Framework as being long overdue.

The National Lung Health Framework is seen as an opportunity for Canada to show leadership both domestically and internationally. Building on past successes, adopting and adapting proven best practices, and leveraging the considerable good-will towards this endeavour can all help address many longstanding gaps between the current and desired state of respiratory health in Canada. A primary motivation among stakeholders is to ensure that resources available to address respiratory disease are at least proportionate to the level of population risk.

Examples of Provincial/Territorial Frameworks, Plans and Strategies³⁰

Category	Framework, Strategy, Plan
Provincial Health/ Healthy Living	<ul style="list-style-type: none"> • Ontario's Plan for Health Care • The Ontario Plan of Action for Healthy Living • BC Primary Health Care Charter (2006 – 2012) • Framework for a Healthy Alberta: Target 2012
Chronic Disease	<ul style="list-style-type: none"> • Newfoundland and Labrador Framework for COPD • New Brunswick Asthma/COPD Management Strategy • A Framework for Chronic Disease Prevention and Management in Ontario (2006) • The Ontario Asthma Plan of Action • The Winnipeg Regional Health Authority (WRHA) Asthma Strategy 2000 • The Winnipeg Regional Health Authority (WRHA) Sleep Apnea Strategy • Saskatchewan Sleep Apnea Labs • Lung Association of Alberta Sleep Apnea (LASA) • Alberta Strategy to Help Manage Asthma (A.S.T.H.M.A.)
Infectious Disease	<ul style="list-style-type: none"> • The Manitoba TB Control Program • Saskatchewan TB Control - Directly Observed Therapy Short-Course (DOTS) • Various provincial ministry flu shot programs
Environment	<ul style="list-style-type: none"> • Newfoundland and Labrador Climate Change Strategy • New Brunswick Clean Air Act • New Brunswick Climate Change Hub
Tobacco	<ul style="list-style-type: none"> • Newfoundland and Labrador Tobacco Reduction Strategy • Quebec Anti-Tobacco Legislation (Tobacco Act) • The Smoke Free Ontario Tobacco Control Strategy • Alberta Tobacco Reduction Strategy (ATRS) – Smoke Free Alberta • New Brunswick Smoke-Free Places Act (2004)
Aboriginal Peoples	<ul style="list-style-type: none"> • First Nations and Inuit Tobacco Control framework • BC Aboriginal Tobacco Strategy • Government of Nunavut Tobacco Program
Children	<ul style="list-style-type: none"> • Child Health Coalition

³⁰ This table includes only those that currently exist and not those under development

8. Policy and Governance

The policy and governance structures for respiratory health are rooted in legislation and regulation of the overall health system and the various jurisdictional roles played by key stakeholders. These, in turn, confer regulatory authority on the various governing bodies within the health professions. The Canada Health Act, Canada's federal legislation for publicly funded health care, establishes criteria that must be followed by the provinces to qualify for federal transfers. These include: administration (non-profit, public authority), comprehensiveness, universality, portability and accessibility. The Act sets out the primary objective of the Canadian health care policy, which is *"to protect, promote and restore the physical and mental well-being of residents of Canada and to facilitate reasonable access to health services without financial or other barriers"*.³¹

At the federal level, two relatively recent reports (assets) have contributed significantly to the policy environment. The Health of Canadians – The Federal Role, a Report by the Standing Senate Committee on Social Affairs, Science and Technology (Kirby, 2002) outlined a case for health care reform and restructuring based on fundamental realities and key principles.³² Chapter seven (7) of the Report is notable for its discussion of population health strategy. Building on Values, the Romanow Commission Report of the Future of Health Care in Canada (Romanow, 2002) is also a touchstone asset in terms of making the case, including recommendations, for sustainable Medicare in Canada.³³

The provinces and territories have a significant amount of scope to interpret and apply the broad principles contained in the Canada Health Act. Increasing demands on the health care system are resulting in new approaches. Health promotion, chronic disease prevention and management (healthy populations/population health) are being embraced as a means of reducing pressure on the system (e.g. wait times) and lowering health costs.

Beyond broad parameters, there is no single policy or governance structure that can be said to apply exclusively to respiratory health. In fact, as many key informants point out the term "respiratory health" is not universally defined or recognized and indeed suffers from low public awareness. Furthermore, informants are quick to point out that the respiratory system does not function in isolation from other bodily systems (e.g. cardiovascular and circulatory systems) and that there is often a compounding effect with patients suffering from multiple conditions. Thus, at a systemic level, the boundaries are at best artificial and at worst detrimental to proper care.

Due to competing interests and other factors, policy and governance structures are prone to gaps and "disconnects". For example, policy drivers for disease conditions tend to be medically focused (health system, research) while the drivers for tobacco control and the environment tend to be driven by advocacy and legislation. Whereas advocacy is the key driver for legislative change, it is only one of many factors with respect to health system change. Another disconnect occurs between science and public policy. Government priorities are often set in response to the public's perception of risk. Increasingly, this perception is shaped by mass media where business realities and sensationalism often take precedence over evidence-based science. As a consequence, many well informed stakeholders believe, for example, that the resources dedicated

³¹The Canada Health Act www.hc-sc.gc.ca

³² Kirby, M. and LeBreton, M. *The Health of Canadians – The Federal Role*, Senate of Canada, 2002.

³³ Romanow, R., *Building on Values: The Future of Health Care in Canada*. Commission of the Future of Health Care in Canada, November 2002.

to SARS, Avian Flu and pandemic preparedness are disproportionate to the actual risks posed by these infectious conditions and that public resources might be better used elsewhere.

A third disconnect regarding policy and governance and one that has already been mentioned results from the competing constituencies among stakeholders. With so many stakeholders competing for resources, self-interest can oftentimes trump cooperation with respect to policy formulation and execution. For example, with numerous stakeholder groups independently fundraising for disease conditions such as Asthma and COPD, confusion can result among donors with regard to who best speaks for the constituency.

These challenges notwithstanding, a number of important policy and governance assets are contained in the Asset Map. These include various strategy documents, models of care, guidelines and legislative Acts. The Canadian Cancer Society's Overview Summary of F/P/T Tobacco Legislation in Canada (Cunningham, 2006) is one such asset. Others include the FCTC Monitoring Report (2006) and Moving Forward - Health Canada's 2006 Progress Report on Tobacco Control.

Policy and governance assets exist in various formats for the environment as well. For example, Canadian Environmental.com³⁴ provides online access to summaries of F/P/T legislation and related documents such as *Environment Policy and Law*, a monthly subscription newsletter that provides an overview of environmental policy and governance as well as regular highlights and updates.

Given the many jurisdictions involved, compiling and maintaining up-to-date, objective and authoritative compendiums of policy and legislation will continue to be a significant challenge. Yet these reference oriented assets are important to answering the question of "who's doing what and where", both in Canada and abroad.

³⁴ Canadian Environmental .com www.canadianenvironmental.com

9. Models of Care, Guidelines and Best Practices

Like the term “framework”, the expression “model of care” was found to mean different things to different people. The goal was to uncover specialized, innovative or integrated approaches, programs or technologies being used for respiratory disease, especially those being offered in a community setting and possibly targeting specific populations.

When discussing models of care it is also useful to distinguish between chronic and acute disease. Chronic disease by nature requires continuous management and treatment because there is generally no cure. Acute illness is typically episodic and the focus tends to be on prevention and safety (e.g. vaccination, workplace health, exposure prevention). When injury or disease occurs, there is usually expeditious treatment, after which the patient recovers. Many infectious diseases are acute in nature but with their own dynamics. For example, like natural disasters, a key issue related to infectious outbreaks or even pandemics is surge capacity; however, unlike natural disasters, quarantine may be an issue. People living with lung disease are also exceptionally vulnerable to infectious respiratory disease. Meanwhile, chronic respiratory disease is being recognized as a growing problem and it is this trend that is one of the primary drivers of change towards models of care that are more client and community centred.

Another key driver of change influencing care models is the increasing focus on population health, which is generally defined as covering a broad range of activities centred on health promotion and disease prevention while taking into account socio-economic factors and other social determinants of health.

Due to the systemic nature of health care settings, it is often difficult to distinguish or define models that apply uniquely to respiratory health versus models that exist for other disease categories or the health system in general. For example, when asked about models of care in their province or territory, key informants often refer to the organizing framework for health care delivery itself. In most Canadian jurisdictions, this is now a regional model which would include for example: the regional health authorities in BC (5), the Local Health Integration Networks (LHINs) in Ontario (14) and the Health Care regions in Saskatchewan (10) and Alberta (9). The degree of regional autonomy differs in each case; coordination and communication across regions can also be a challenge.

The term “model” can also be used to refer to how the components of a system interact or fit together. One well known example of this is the Chronic Care Model developed by Dr. Ed Wagner and staff at the MacColl Institute for Healthcare Innovation. The model identifies what are seen as the essential elements of a health care system that encourage high-quality chronic disease care. These elements are: the community, the health system, self-management and support, delivery system and design, decision support and clinical information systems.³⁵ These elements work together with an informed and activated patient and a prepared, proactive practice team, to produce functional and clinical outcomes.³⁶ Closer to home, CANA – the COPD & Asthma Network of Alberta, offers an example of a care model for asthma. CANA’s model includes the following elements: specialty care, community, primary health care, healthlink, acute care and disease education. A “System Map” depicts the health provider linkages with primary care as a hub, disease education as essential, patient flow as circular and the ideal care being

³⁵ Ontario’s Chronic Disease Prevention and Management Framework contains many of these same elements and features.

³⁶ Information on the Wagner model can be accessed at www.improvingchroniccare.org

team- based and patient-centric. The role of each element in the model is defined and needs, barriers and sample solutions are mapped out for each element.³⁷

On an operational level, team based (interdisciplinary) models of care are emerging as a way to deal with respiratory disease. These models are enabled by technologies that facilitate the formation of primary care networks as is the case throughout Alberta, for example. This approach involves physicians (both GPs and specialists) working as a team with nurses, nurse practitioners, social workers, therapists, pharmacists and patients themselves, among others. Ontario is also investing heavily in this approach and it is expected that by 2007/2008, 150 Family Health Teams will be in place across the province. The model requires specialized resources for the management and treatment of certain disease conditions. This might include for example, asthma education centres staffed by trained respiratory therapists or certified asthma educators (CAEs) as is the case in PEI (asthma centres in Charlottetown and Summerside). It could also include streaming of emergency patients towards special care facilities or resources as is the case in B.C. Home oxygen programs are a feature of most provincial/territorial approaches although the criteria to qualify for coverage may differ from one jurisdiction to another.

Education and self-management are key features of respiratory care models in many Canadian jurisdictions. RESPTrec (including ASTHMATrec and COPDTrec) was developed jointly by the Lung Association of Manitoba and the Lung Association of Saskatchewan for training respiratory educators. RESPTrec is a central feature of Saskatchewan's Chronic Disease Management Plan. The province has over 130 trained asthma educators. A key message in the COPD Guidelines promotes patient self-management: "Education of the patient and family with supervision and support based on disease specific self-management principles is valuable. In addition to improving coping skills and quality of life, self-management plans also reduce hospitalization and health care costs".

Disease management is a notable feature of respiratory care models across Canada although access to pulmonary rehab remains a serious gap. For example, according to one recent study, only one in every 80 Canadians suffering from COPD has access to rehab programs and in much of the country access to rehabilitation is non-existent.³⁸ Disease management comes in many forms but usually begins with education and awareness through the primary care channel. Communications campaigns, web sites (e.g. Quebec's Info-asthme), help lines (telehealth, smokers) and other information tools and media are also key ingredients of patient care and self-management. The model is increasingly patient-centric i.e. designed to support and empower patients with the tools and resources to manage their disease conditions. For example, the Saskatchewan COPD model was launched initially as a disease program designed for a hospital setting. The program has since migrated to recreational settings and even shopping centres in a bid to reach out to the public and break down barriers to access. BreathWorks, a COPD patient program is another example of patient centred care, as is "Living Well with COPD" a patient centred disease management program.

Community settings are playing a significant part in these respiratory care models. In some jurisdictions, nurses, therapists and educators are working with and through local recreation and fitness facilities to provide care. Calgary's multidisciplinary community-based model includes a regular exercise component offered in gyms (15 locations). More about this approach will be discussed under the section on Supportive Environments.

³⁷ Information on the CANA System Map can be accessed at www.canahome.org

³⁸ Study by Dr. Roger Goldstein, Director of respiratory rehabilitation at West Park Healthcare Centre in Toronto. Reported by the Globe and Mail and posted to www.globeandmail.com March 14, 2007.

Guidelines and Best Practices

The health professions have been actively engaged in developing practice and treatment guidelines for their respective fields in Canada and Internationally. The Canadian Thoracic Society (CTS) guidelines³⁹ are used by all jurisdictions, albeit not exclusively. American Lung Association guidelines are also used, or recommended for use, in some cases. Canadian Asthma Consensus Guidelines have been developed and are distributed through the CTS Dissemination and Implementation Committee⁴⁰, as are the Canadian COPD Consensus Guidelines. The upcoming 6th edition of the Canadian Tuberculosis Standards⁴¹, will have a number of recommendations for TB prevention and control. The Sleep Disordered Breathing Guidelines have been developed by the CTS. A new set of Asthma/COPD guidelines have been released by Medical Use Management Services (MUMS) targeting family practice. In response to the range of available guidelines that are available, the CTS is currently working to develop a centralized infrastructure to produce high quality guidelines for the Canadian community.

The Public Health Agency of Canada (PHAC) maintains an extensive repository of guidelines⁴² for many disease conditions including biosafety, cancer, infection control, TB and vaccines. Many professional health organizations and advisory groups have contributed to the development of these guidelines. Many guidelines are developed and promoted within the provinces and territories. For example, the Guidelines Advisory Committee⁴³ (GAC), an independent partnership of the Ontario Medical Association and the Ontario Ministry of Health and Long Term care, develops and promotes the use of evidence-based clinical practice guidelines for a wide variety of disease categories throughout the province.

Education is an integral component of guidelines for respiratory disease conditions. For example, the Asthma Consensus Guidelines state that education should be provided at each contact and that a written Action Plan for guided self-management should be considered for all patients and reviewed on each visit.⁴⁴ The Canadian Respiratory Health Professionals (CRHP) promote programs and guidelines for respiratory health education.

A distinction also needs to be made between subscribing to the guidelines in principle and following the guidelines in practice. A case in point - drugs listed and approved for use under the CTS guidelines are not necessarily covered by provincial formularies. The COPD agent Spiriva⁴⁵ is one example. Furthermore, the level of awareness and use of the guidelines among physicians is said to vary considerably.

The World Health Organization (WHO) also maintains guidelines⁴⁶ for certain disease conditions including the management of infectious disease such as influenza, TB and SARS. WHO is coordinating the global response to human cases of H5N1 and monitoring the threat of a potential

³⁹ Canadian Thoracic Society Guidelines www.lung.ca/cts-sct/guidelines-lignes_eph

⁴⁰ Canadian Asthma Consensus Guidelines www.asthmaguidelines.com

⁴¹ Canadian Tuberculosis Standards - co-produced by the Canadian Lung Association/Canadian Thoracic Society and the Public Health Agency of Canada; to be published in 2007

⁴² www.phac-aspc.gc.ca/dpg_e.html, March 1, 2007

⁴³ www.gacguidelines.ca

⁴⁴ An example of an asthma management plan, *iCAN Control Asthma Now*, can be accessed at www.calgaryhealthregion.ca/ican

⁴⁵ Spiriva - a joint product from Pfizer and Boehringer Ingelheim

⁴⁶ <http://www.who.int/csr/disease/>

influenza pandemic. Statutory guidelines also exist at the national and provincial level as a result of regulations governing health practice and the professions (certification and licensing).

Standards and guidelines typically flow from the authorities conferred to the professions, by the regulatory bodies and legislative Acts. These exist at all levels of government - international, federal, provincial/territorial and municipal. With so many parties involved in the development and publication of guidelines, the potential for inconsistencies in their content and application is an ongoing concern. Thus, the issue of quality monitoring is an important one. It is also important to note that while some provinces consistently recommend following the CTS guidelines, others use other sources and the general pattern is not consistent.

The extent to which guidelines represent “best practices” is difficult to determine in the absence of systematic measurement and monitoring. With practices differing from one jurisdiction to another, the quality of outcomes is difficult to determine on a system wide basis. One notable effort to foster best practices is the Public Health Agency of Canada’s Canadian Best Practices Portal for Health Promotion and Chronic Disease Prevention⁴⁷. The Portal is an easy to use access point for best practice information, models and approaches on all aspects of the chronic disease continuum. As such it represents a substantial asset.

The distinction between guidelines and best practices can be somewhat semantic, so much so that the term “best practice guidelines” is commonly used. For example, Ontario’s Best Practice Manual for Preventing Febrile Respiratory Illnesses⁴⁸ sets out the infection and control practices required to prevent transmission of droplet-spread (febrile) respiratory illness. Best practices for the control and containment of infectious disease are an ongoing focus. For example, many new protocols from front-line health professionals were put in place in Ontario following the SARS crisis. Studies are ongoing, including a recent (September 2006) Ottawa study to determine the effectiveness of a short-term intervention to promote best practices for control of respiratory infections in primary care physicians’ offices.⁴⁹ Best practices for enhanced protection of first-responders have also been a priority in the United States since 9/11.⁵⁰

Gaps and Opportunities

Little information could be found on oversight or measurement of the effectiveness of respiratory health guidelines. This may be due to the self-governing nature of many of the professional bodies involved. It is unclear at this time whether the assessment of guidelines takes place systematically within the various jurisdictions and thus, this is an area that requires further exploration. For example, stakeholders have observed that a thorough *a posteriori* assessment of the effectiveness of quarantine measures during the SARS outbreak in Toronto was never conducted despite the massive costs and disruptions associated with them. Though quarantining continues to find itself imbedded in various pandemic preparedness documents, some informants believe that there is no clear evidence that these quarantine measures contributed to the eventual containment of the outbreak, i.e. that they were effective, justified or even well carried out. There

⁴⁷ http://cbpp-pcpe.phac-aspc.gc.ca/index_e.cfm

⁴⁸ *Preventing Febrile Respiratory Illnesses*, Ontario Ministry of Health and Long Term care, August 2006.

⁴⁹ Hogg, W. *Promoting Best Practices for the Control of Respiratory Infections*, Canadian Family Physicians. Published Online, September 10, 2006. See also the following link:

<http://www.pubmedcentral.nih.gov/articlerender.fcgi?artid=1783740> (March 4, 2007)

⁵⁰ *OSHA Best Practices for Hospital-Based First Receivers of Victims from Mass casualty Incidents Involving the Release of Hazardous Substances*, OSHA, January 2005.

appears to be at least some evidence to support these views. For example, a report by Justice Campbell suggests that over 50% of SARS quarantines were non-compliant.⁵¹ The issue is one of both quality and consistency in guideline formulation and application. For guidelines to be effective, a number of key steps must take place. First, guidelines must be developed in a coherent manner based on best available evidence. Second, guidelines must be endorsed by and communicated to key audiences. Third, training must take place to ensure guidelines can be properly applied by health professionals. Fourth, effectiveness monitoring must occur. Fifth, a feedback mechanism must ensure that guidelines are revised in accordance with best practice and in response to monitoring data. This is the basis of a systematic approach – one which would ideally be coordinated across jurisdictions.

Further to more effective application and monitoring of guidelines, there is clearly a strong case to be made for more extensive and standardized use of certain treatments. This includes for example, the use of pulmonary rehabilitation across Canada. Investment in rehab, which includes exercise therapy, education and psycho-social support, are also likely to pay off because when respiratory conditions are poorly controlled, patients spend more time in hospital or visiting their doctors. Pulmonary rehab is consistent with the rationale underpinning emerging wellness models, including a statement by Canada’s Auditor General noting that “preventive health activities are estimated to be 6 to 45 times more effective than dealing with health problems after the fact”.⁵² This view is also echoed in the Kirby Report, articulated as follows:

“The Committee believes that there are potentially enormous benefits to be derived from health and wellness promotion, illness prevention and population health, primarily in terms of improving health outcomes for Canadians, but also in terms of their financial impact on the publicly funded health care system.”⁵³

⁵¹ “The SARS Commission Interim Report, SARS and Public Health In Ontario”, The Honourable Mr. Justice Archie Campbell, Commissioner April 15, 2004

⁵² Auditor General of Canada, *2001 Report*, Chapter 9.

⁵³ Kirby, M., LeBreton, M. *The Health of Canadians – The Federal Role*, Senate of Canada, 2002

10. Public Awareness, Health Promotion and Prevention

There are a large number of respiratory health assets dedicated to public awareness, health promotion and prevention (awareness, promotion and prevention assets are featured prominently on the vast majority of NGO web sites). These assets include: campaigns, education and training, meetings and conferences, programs, publications and others. Since the number of assets in this category is constantly evolving, the focus for the purposes of the Asset Map has been on assets with significant and lasting value.

With increasing attention being paid to healthy living and healthy environments as a means of addressing chronic disease and reducing the burden on health care systems, it is not surprising that the disease prevention end of the care continuum is receiving greater interest. Awareness and health promotion efforts can be seen as important front line steps in informing and educating publics, health care providers and other stakeholders about ways to prevent or avoid illness and maintain wellness. This approach is consistent with a “wellness” paradigm (prevention) versus an “illness” paradigm (treatment) or a focus on cause versus effect. This approach necessitates efforts to influence behavioural change.

With respect to public awareness, there are several disease-specific assets that require special mention. World Asthma Day⁵⁴ an annual event organized by the Global Initiative for Asthma (GINA) to improve asthma awareness and care around the world is one such asset. World Asthma Day 2007 which will take place on May 1st, is organized around the self-management theme “You Can Control Your Asthma”. Another is World COPD Day⁵⁵ an annual awareness event organized by the Global Initiative for Chronic Obstructive Lung Disease (GOLD). World COPD 2007 will take place on November 14. Similarly, World TB Day, an annual event sponsored by the STOP TB Partnership⁵⁶ to draw attention to the global problem of TB, is scheduled to take on March 24, 2007 under the banner “TB Anywhere is TB Everywhere”. World No Tobacco Day is yet another “World Day”, scheduled for May 31. All of these events generate significant publicity worldwide and are important assets for the Lung Associations and related stakeholders in Canada, who build their own programs around them. National Non-smoking Week⁵⁷, an annual campaign sponsored by the Canadian Council for Tobacco Control has a similar effect in generating awareness and publicity for smoking cessation and protection. The theme of the 2006 campaign was *Work, live, play... even better smoke-free.*

National, regional and local media coverage is vital to the success of all campaigns. Print media, including mailings, posters, newsletters, brochures etc. distributed to health practitioners are often used to generate awareness. While important in their own right, few of these meet the “legacy” criteria to be considered as primary assets. Events such as runs, walks, meetings with public officials are also common modes of generating awareness. Meetings with F/P/T Ministers and Deputy Ministers of Health form a key plank in efforts by all NGOs and stakeholders to draw attention to and gain support for their respective causes.

Many NGO activities and events also serve as fundraisers. In this regard, the Christmas Seals campaign⁵⁸ which dates back to 1903 is an example of a key asset. Not all disease categories are equally amenable to fundraising. For example, as one informant noted, it is difficult to fundraise

⁵⁴ World Asthma Day www.ginasthma.com

⁵⁵ World COPD Day <http://gold.com>

⁵⁶ World TB Day www.stoptb.org

⁵⁷ National Non-Smoking Week www.nnsw.ca

⁵⁸ Christmas Seals Campaign www.lung.ca/christmas

on infectious disease. Low awareness of COPD and in the broader sense respiratory health itself is also thought to be a constraint to fundraising, although new COPD awareness efforts may be beginning to have an impact.

Major research initiatives, conferences and studies conducted globally, nationally or regionally can be important assets for awareness, promotion and prevention. The Lung Association's National COPD Report Card has been an important asset for drawing attention of health officials to the problem of COPD, as has the more recent report on Women and COPD. For some provinces and territories, these reports have been levers for obtaining new funds.

With both tobacco and environment, a great deal of awareness is generated by legislative, regulatory and policy making processes (Tobacco Control Act, Provincial Smoke Free Acts, Clean Air Act, Environmental Protection Act, etc.). In this regard, the various Acts and regulations governing both these spheres might be considered important awareness building assets and often lead to or fuel strategies of NGOs and other stakeholders.

Prevention

It is helpful to make a distinction between primary prevention and secondary prevention when discussing assets. Beyond vaccination and pandemic preparedness, primary prevention involves steps to prevent exposures or behaviours that can lead to disease. Smoking, exposure, diet/weight are examples of risk factors associated with primary prevention. The focus of secondary prevention is generally aimed at preventing a re-occurrence or flare-up - a problem with infectious conditions such as pneumonia and chronic conditions such as Asthma and COPD. Thus, disease management is vital in secondary prevention.

Many respiratory disease prevention assets can be linked to health promotion, disease management, community care models and healthy living policies and programs now emerging. Ontario is a case in point. In addition to a Ministry of Health and Long Term care, Ontario has a Ministry of Health Promotion⁵⁹ and as already noted, the province has also developed a comprehensive Chronic Disease Prevention and Management Framework.

Addressing the social determinants of health are also key components in effective prevention of respiratory disease. For example, Community Acquired Pneumonia, tuberculosis as a "*disease of poverty*", exposure to indoor mold, and the smoke from wood burning stoves are all examples of where the prevention aspects of a lung health strategy need to extend into social care as housing conditions and other economic factors become predictors of poor lung health. Across Canada, there is a patchwork of community-based prevention initiatives targeting seniors, First Nations/Métis/Inuit, children and other vulnerable groups with many of them featuring respiratory health.

Much of the primary prevention effort surrounding respiratory disease involves smoking prevention and cessation. The tobacco-related efforts are often targeted at specific populations. For example, several provinces are targeting youth at the secondary school and college/ university level. The youth oriented Quit 4 Life⁶⁰ program, BLAST – Building Leaders in Schools Today, and Leave the Pack Behind⁶¹ are three such examples. Some provinces are supporting an activist

⁵⁹ Ontario Ministry of Health Promotion www.mhp.gov.on.ca/english/

⁶⁰ Quit for Life www.quit4life.com

⁶¹ Leave the Pack Behind www.leavethepackbehind.org

youth agenda that includes advocacy. Ontario, for example, has a provincially funded youth institute that trains youth advocates for tobacco control as part of the health system. Ontario is organizing a Take Action Youth Summit in Ottawa in May, 2007. Manitoba also has a smoking prevention in schools program for K to 12 focused on the Winnipeg and Brandon regions; it is also currently running an Aboriginal pilot. Saskatchewan is also doing in-school primary prevention. What these program assets have in common is the desire to reach youth either before they become habituated to smoking or to get them to quit before the onset of disease.

Youth are not the only target demographic. The problem of second hand smoke is receiving more attention. The nationally televised Heather Crowe campaign⁶² put a human face to the problem.

Smoke free legislation is growing as are moves to ban smoking in environments where children, employees, multi-unit apartment dwellers and others may be at risk of exposure. Quit/Smokers help lines are other important assets on the smoking cessation front. The Canadian Network of Smokers Help Lines (CNSH) is an example of a Health Canada funded asset that aims to maximize the effectiveness of telephone counseling services.

Three other assets that have already been noted in this report are worth mentioning again due to their importance for infectious disease prevention. These are the Public Health Agency of Canada, the Canada Health Portal, and the Centres for Disease Control and Prevention. The lesser known of the three, the Canada Health Portal⁶³ is an internet portal situated on the Canada Site within Service Canada. The portal provides Canadians with an integrated view of health information and services from various government jurisdictions and organizations across Canada.

Finally, education assets are vital to effective prevention. RESPTrec and Clean Air Online⁶⁴ are two examples of educational assets that are making an important contribution to respiratory disease management and prevention. Another important information asset, Environment Canada's Air Quality Services,⁶⁵ helps many Canadians make day-to-day decisions about outdoor activities. Virtually all assets in the Asset Map have some information and educational value.

Gaps and Opportunities

Gauging the effectiveness of awareness, promotion and prevention assets can be a challenge without objective and precise performance measures and indicators. Attribution – linking of cause and effect, is a common problem with awareness campaigns. The assets that exist rely on a mix of channels to reach a variety of target audiences and segments including: the general public, health care providers, public officials and at-risk populations to name a few.

Evidence suggests that awareness of “respiratory health/disease” as a broad term and many disease specific conditions such as COPD is low. These are important gaps and potential barriers to progress. The association between the environment and respiratory health represents a largely untapped opportunity. Concern over the environment is growing but with the exception of Pollution Probe, Environmental Defense and Lung Association provincial environment programs there are few legacy assets that make a strong connection between the two. This situation is beginning to change but more awareness, promotion and prevention assets are needed. This is an important opportunity. According to some NGOs, concern over the environment is an issue that

⁶² Heather Crowe Campaign <http://www.smoke-free.ca/heathercrowe/FAQ.htm>

⁶³ Canadian Health Portal <http://chp-pcs.gc.ca>

⁶⁴ <http://www.ec.gc.ca/cleanair-airpur/>

⁶⁵ http://www.msc-smc.ec.gc.ca/air_smog/index_e.cfm

help can give respiratory disease the attention it deserves because like breathing, the environment affects everyone.

Comparatively and in keeping with the seriousness of the risk, there are many tobacco control assets dedicated to awareness, promotion and prevention. These assets also appear to be working. However, much more still needs to be done to reach vulnerable populations and to counteract tobacco industry promotional efforts. Youth oriented assets, aboriginal assets, cessation assets, child protection assets, second-hand smoke assets, industry denormalization assets and statutory assets are important.

It is apparent to many key informants and stakeholders that the demographics of respiratory health audiences are changing. They point out that messages and approaches developed 30 years ago do not work as well today or that campaigns crafted for seniors do not work as well for youth. Similarly, messages crafted for the general population may not work as well for vulnerable segments such as Aboriginal Peoples or immigrants. With a focus on prevention, there is a perceived need for greater emphasis on campaigns that appeal to today's youth since the behaviours that affect youth now can potentially last a lifetime.

Finally, the majority of the assets used for awareness, promotion and prevention are disease specific. While this is important for precise messaging, these assets do little to establish respiratory health as a broad disease category. This is an important gap and one which the National Lung Health Framework may help address.

11. Detection and Disease Management

The evidence is clear that early detection and management improves outcomes, saves lives, costs less and reduces the overall burden on the health system. This is because left undetected or untreated, disease conditions can get worse and have a cascading effect leading to other illnesses. The problem is magnified in the cases of particularly deadly respiratory diseases (pandemic) where surge capacity is tested. For most diseases, poorly managed conditions mean greater frequency of visits to the doctor or more hospital re-admittances.

The Chronic Care Model (Wagner), Ontario's Chronic Disease Prevention and Management Framework and CANA's System Map are examples of assets that contain important detection and disease management elements. This is because the basic premise for each of these models is integrative and systemic in nature; the focus is as much or more on wellness than on illness, with the individual, families and communities playing important roles.

As has been noted elsewhere in this report, the chronic care model is a very different paradigm than the acute care model where, for simple infectious respiratory diseases, a single intervention may be all that's required to treat the patient. With respect to respiratory health, the focus often tends to be on chronic disease. However, serious infectious disease generally requires acute care and thus the detection and management protocols and paradigms necessarily differ.

Within the Asset Map database, a considerable number of assets exist for chronic disease prevention and disease management. Consistent with the emerging wellness models and programs, it is safe to say that these assets are growing. Whether the same can be said of assets related to infectious disease is unclear. Important assets do exist, however. These include, for example PHAC's Fluwatch and the Respiratory Virus Detection and Surveillance System which reports on respiratory viruses in Canada based on weekly test data selected from lab reports. Influenza (the flu shot) is receiving plenty of attention as is the possibility of an influenza pandemic, but there is little evidence that detection and disease management hold any significant place in public consciousness.⁶⁶ The WHO, federal/provincial/territorial, and public health agencies (e.g. PHAC, CDC) are playing an important role as system assets to detect, respond to and manage infectious disease among individuals and populations. However, effectiveness is difficult to assess. Should a flu pandemic break out, neither Canada nor the U.S. will have enough vaccine stockpiled to treat the entire population, a situation that will require difficult decisions. The situation is made more complicated by the fact that effectiveness and desirability of the vaccination will take some time to establish.⁶⁷ With the constantly evolving nature of infections, some informants believe that the best that a pandemic preparedness program can do is to develop surge capacity and the ability to quickly develop the necessary vaccines. At this time and beyond vaccination, there is little evidence of full spectrum planning. Public awareness messages from health agencies are currently based mainly on ways to halt the spread of influenza (e.g. frequent hand washing, avoiding handshakes, staying at home etc.).

Although both can cause acute conditions, tobacco and the environment are major contributors to chronic respiratory disease. The effects of smoking can be easily detected but are often ignored. Many assets exist to manage and treat the chronic disease conditions brought on by smoking. However, the goal is not to manage the smoking habit but prevent the take up of the habit to

⁶⁶ Influenza and the Flu Pandemic feature prominently on both PHAC and the CDC web sites and both have information regarding surveillance, immunization, preparedness, prevention and control.

⁶⁷ For information on U.S. influenza preparedness visit www.pandemicflu.gov. The spectrum of planning on this site includes: federal, state and local, individual, business, schools, health care and community.

begin with, to help people quit and to counter or denormalize tobacco industry promotional efforts. Some combination of smoking cessation programming, help/quit lines, nicotine replacement therapy (NRT), anti-smoking campaigns and other assets exist in virtually all Canadian jurisdictions.

Respiratory problems due to environmental hazards are positively correlated with levels of smog, air pollution and chemical contamination. Various indices are now used to detect levels of atmospheric particulates that could be problematic. More difficult to detect are environmental contaminants and toxins that accumulate in the body over time as a result of both indoor and outdoor exposures. Bio-monitoring – the measurement of a chemical substance, the products it makes after it breaks down, or the products that might result from interactions in the body, is a growing science but still in its infancy.⁶⁸ Bio-monitoring assets can be found along with other environmental and workplace health assets within Health Canada⁶⁹. Health Canada's Environmental and Workplace Health section includes assets on air quality, climate change, environmental contaminants, occupational health and safety, radiation and water quality.

Like Health Canada, the US CDC is also asset rich in this regard. The CDC features bioterrorism agents as topic on its web site⁷⁰ along with a significant number of environmental health assets (chemical agents, hazardous substances, hydrocarbons, pesticides etc.). Environmental health at CDC “strives to promote health and quality of life by preventing or controlling those diseases or deaths that result from interactions between people and their environment”.⁷¹

At the level of primary health care, five detection and disease management protocols deserve mention for different reasons. These are: home oxygen programs, COPD BreathWorks and Living well with COPD, asthma action plans, access to spirometry and healthy lifestyle. Home oxygen program assets exist in most jurisdictions. These programs are meant to provide access to oxygen for those with breathing difficulties. These programs generally have qualifying criteria which may limit access for certain individuals in need. COPD BreathWorks and Living Well with COPD are two examples of COPD disease management tools of the Lung Association⁷². Asthma action plans for patients and physicians are useful disease management tools. Several such assets exist including one published by the Asthma Society of Canada⁷³, another by the Family Physicians Airways Group of Canada (FPAGC) and a third (iCan) produced by the Calgary Health Region⁷⁴.

Spirometry is a potentially effective diagnostic tool and method for testing breathing capacity. However, use of spirometry in Canada is at best sporadic and not generally supported by the health care system. Sputum testing, a microscopic test of material coughed up from the lung used in the detection of TB, is also sporadic. The fourth management element is healthy lifestyle, including diet, exercise and stress management. Community care models are increasingly incorporating lifestyle modalities into disease management approaches.

⁶⁸ Information on bio-monitoring can be found at http://www.hc-sc.gc.ca/ewh-semt/contaminants/biomonitoring-biosurveillance_e.html (March 1, 2007)

⁶⁹ Health Canada www.hc-sc.gc.ca

⁷⁰ www.cdc.gov, March 1, 2007

⁷¹ www.cdc.gov environmental health link (March 1, 2007)

⁷² The Lung Association www.lung.ca

⁷³ The Asthma Society of Canada www.asthma.ca

⁷⁴ The Calgary Health Region www.calgaryhealthregion.ca/ican

Gaps and Opportunities

Detection and disease management strategies are critical to ensuring appropriate care and treatment and to relieving the overall pressure on the health care system. Many respiratory diseases are thought to be under-reported. One reason for this is low public awareness of disease conditions such as COPD and sleep apnea. However, there are other factors as well, including the stigma associated with these diseases. There continues to be stigma among the general public as well as among some health care providers, towards individuals that are experiencing respiratory disease caused by tobacco because it is “self-induced” illness. Furthermore, informants point out for example, that prevalence of Asthma is much higher than reported because many people with Asthma simply modify their lifestyle to accommodate the disease. Similarly, people suffering from respiratory impairment due to environmental factors may not associate the environmental triggers with their condition and, therefore, adverse events go unreported or undocumented. These are important gaps and more research is needed to understand the impact of under-reporting and ways in which more accurate data can be obtained.

As a strictly preventative measure, there is currently no standard test conducted as part of a general medical exam to determine lung function despite the critical nature of the respiratory system to overall health. Informants have suggested that spirometry, should be routinely administered as part of general medical practice. Spirometry is a quick and simple breathing test that measures how much air can be blown out of the lungs. Wider use of spirometry is one of numerous possible detection approaches that could result in earlier treatment and better disease management.

Detection of the environmental associations to respiratory disease is an evolving science. There are signs that research is proving fruitful. For example, there is a growing body of research pointing to the harmful effects of environmental tobacco smoke, and much is being learned about the broader effects of indoor and outdoor air quality on human health. New techniques are also emerging. For example, bio-monitoring - testing for chemical contaminants in the body, is receiving greater attention. Despite these signs of progress however, more research is needed to understand the interplay of the multitude of environmental factors that lead to respiratory disease.

Strategies for infectious respiratory disease detection and management have been in place for many years. The effectiveness of these approaches has been called into question by the SARS crisis and the still enduring concern for H5N1. As a result, detection and management assets are constantly evolving. For example, in recent years, attention has been focused on detection strategies and preparations surrounding a potential flu pandemic. Due to media speculation, some stakeholders believe that there is a growing gap between science and policy and between perceived risk and actual risk. As a result, the question of whether resources are being channeled to the right areas is one that requires serious informed debate.

12. Research, Surveillance and Knowledge Translation

In order to understand the current landscape for respiratory research, it is important to grasp the three key structural components: distributed research programs, intricate and interdependent granting procedures and increased government involvement.

In 1960 a conscious and deliberate decision was made to channel research resources to universities and teaching hospitals across the country. At the time, this was in contrast to the US and UK models of centralized non-affiliated laboratories. It was argued that medical research in Canada should be closely tied to medical education in order to develop fully. It was further argued that this association would be necessary for the recruitment and training of new investigators as well as for stimulating teaching. As it stands today, this distributed model, with the university medical school as the locus of research, is augmented with centralized and specialized labs. Health research is currently conducted in a variety of settings including hospitals, research institutes and private industry.⁷⁵

Added to this multiplicity of researchers is the intricacy of the funding sources. Funds for medical [health] research in Canada now originate within a network of federal and provincial government divisions, from disease and hospital based foundations, and from the private sector, including pharmaceutical and biotechnology companies. Foreign sources and the universities themselves may also be providing funding. Dollars distributed by these sources are awarded through a whole host of mechanisms including but not limited to personnel awards, fellowships, operating grants and infrastructure awards. The competitive granting process is a complex multi-stage process.

It is worth noting the distribution of federal funds between the provinces and the key institutions within each province. Owing to the interdependencies between the grants it would appear that one source follows another - the rationale for this being the need to "protect" the operating grant or fellowships with an infrastructure support funding. This outcome of more concentrated funding in certain institutions and provinces is apparent throughout the various funding agencies. From a 2006 report which compared the current levels of federal funding between the provinces, the relative positions were tabulated. Regarding overall funding from CIHR, Ontario leads the pack with 39.5% or \$1.47 billion, Quebec at 29.8%, Alberta at 11.8%, British Columbia at 11.3% and Manitoba and Nova Scotia at 3%. Essentially, the same pattern with a few anomalies holds true for funding received from the other national agencies: Alberta, Quebec, British Columbia and Ontario are out front.⁷⁶ At present, a ball park analysis of CIHR research funding indicates that just 2% of funding is dedicated towards respiratory issues.

Securing funding from national funding bodies depends to a great extent on the level of matching and other provincial funding. An array of provincial departments and ministries are involved in funding health research including those responsible for advanced education, science, technology and innovation, and health. The nine Provincial Health Research Organizations (New Brunswick does not have a dedicated provincial health research funding body) administer the funding on behalf of the provincial governments. According to a background paper prepared for the Manitoba Health Research Council in May 2006, all provinces use varying mechanisms to support health research. Training of new investigators and provision of funds for matching or

⁷⁵ Celebrating the Medical Research Council of Canada, Medical Research Council of Canada, PWGSC 2000 pg 12 <http://dsp-psd.pwgsc.gc.ca/Collection/MR21-19-2000E.pdf>

⁷⁶ Envisioning the Future Manitoba Health Research Strategy: Provincial Consensus 2006-2011, Health Research Strategy Steering Committee, November 2006

partnership activities are important to all provinces and supported at a relatively high level.⁷⁷ Provincial performance measurement and the level and depth of assessment vary across the country. This report also included the total provincial dollars (\$) expended towards the support of health research per province.

ON	at least \$145 M
BC	at least \$127 M
AB	at least \$96 M
QC	at least \$93 M
SK	at least \$17 M
MB	at least \$14 M
NS	at least \$13 M
NFLD	at least \$3 M
NB	at least \$264 K
PEI	at least \$100 K

Once again, the manner in which research funding is accounted for and reported does not allow for the amount of research funding devoted to respiratory to be broken out. However, an analysis of provincial respiratory initiatives and the number of times key word searches produced results may indicate which provinces invest more heavily in respiratory research. Moreover, research priorities for certain institutions are dictated to an extent by the health concerns of the local or regional population while not precluding the areas where the province has an opportunity to become a world leader.

It should be reiterated that funding also flows from local organizations including local hospital based foundations, disease based foundations and medical services foundations. The Canadian Lung Association has research funds both provincially and federally and in some provinces like Quebec, funds research chairs.

Recently, an additional precedent has been set. The federal government has assumed increased responsibility for support of the three key elements of the public-sector research: people, ideas, and infrastructure. Canada's top national specialized research granting agencies, Canadian Institutes of Health Research (CIHR), the Natural Sciences and Engineering Research Council (NSERC) and Social Sciences and Humanities Research Council (SSHRC), deliver that mandate by supporting researchers (salaries, direct costs of research) and institutions (indirect costs of research, infrastructure).⁷⁸ Through the newly established Federal Indirect Costs Program, the federal government protects this research investment by helping universities ensure federally-funded projects have the required facilities, equipment and administrative support. Infrastructure costs are also funded through the Canada Foundation for Innovation (CFI) granting process. It should be noted that the Indirect Costs Program is only accessible by those who have research projects funded through one of its three granting agencies. The rationale is that by providing support for infrastructure costs, the prior funds granted for pure research will be "protected". A special fund, the Leaders Opportunity Fund, has also been set up to support the infrastructure costs component of the Research Chairs Program. There is concern on the part of the Health Charities that by being excluded from this pool of funding, their research funding programs will be viewed as second tier.

According to the leaders of the top granting agencies, Governments have a critical role to play in supporting long-term, 'up-stream' fundamental research, and research for the public good (e.g. research on wait times, palliative care, the environment, and health). And there is growing recognition that "Government will have to play a larger role in transforming science into a profitable company" a role once hoped would be taken on by the private sector.⁷⁹ The

⁷⁷ A background paper, Manitoba Health Research Council, May 2006
http://mhrc.mb.ca/pdfs/MHRC_report_May06.pdf

⁷⁸ From a presentation Building the Infrastructure for a Nation of Innovation By Dr. Eliot A. Phillipson, President & CEO, Canada Foundation for Innovation <http://www.innovationcanada.ca/26/en/articles/cfi.html>

⁷⁹ <http://www.innovationcanada.ca/26/en/articles/cihr.html> By Dr. Alan Bernstein, President, Canadian Institutes of Health Research

recognition of the need to attract and retain top young talented researchers also appears to be stronger than ever.

How has respiratory research fared in this funding arena? Although the funding available is comparably small, according to a recent 2006 report produced by the Council of Canadian Academies, the findings are generally positive for the current state of respiratory research. The concern lies with maintaining this positive position relative to the other disciplines and within the international research community.

The State of Science & Technology in Canada identified the Circulatory & Respiratory sub-sector within one of the four macro clusters as an area of Canadian strength. Within this cluster, Health & Related Life Sciences and Technologies, Canada demonstrates strength in a number of areas related to respiratory disease, cancer research and control, circulatory and respiratory health and infectious diseases and immunity. Canada also demonstrates strength in emerging multidisciplinary fields such as Aboriginal health, aging, gender and health. The current strength of Circulatory & Respiratory research ranked 37th of 197 sub-areas. However, Circulatory & Respiratory had the smallest difference between the percentage of respondents who believe the area is gaining ground and those who see it losing ground. The sub areas which had the largest positive gap were: Infection & Immunity, Neuroscience and Genetics, Genomic & Proteomics. Circulatory & Respiratory research is holding it's own; however, it is not identified as an area for emerging opportunities nor is it identified as having strong growth prospects.⁸⁰

Contributing to Canada's overall respiratory research are the following programs: Canada Research Chairs (CRC) program, the Networks of Centres of Excellence (CNE), Genome Canada and National Research Canada (NRC) Institutes.

Canada Research Chairs (CRC) program

Of the two thousand (2000) research professorships budgeted for, more than 1,600 Chairs have been established in multiple fields including health sciences, engineering, natural sciences, humanities and social sciences. Respiratory research currently is represented by twelve (12) chairs and \$1.6 million funding annually. More specifically, there are four (4) Tier 1 chairs and eight (8) Tier 2 chairs. Analysis of the Respiratory Chairs indicates that all four of the Tier 1 chairs are up for renewal within the next two years.

The Chairs are located at the following universities: University of Toronto (2), McMaster University (2), University of British Columbia (2), University of Calgary (1), University of Alberta (1), University of Manitoba (1), University of Laval (1), McGill University (1), and University du Quebec (1). The placement of Chairs correlates directly with the federal funding pattern. The research is concentrated in the area of asthma. Chair holders are also eligible for infrastructure support from the Canada Foundation for Innovation (CFI) Leaders Opportunity Fund which as alluded to earlier, may exacerbate biases towards certain institutions.

It should be noted that the following three organizations are mandated with promoting translation of research versus the production of knowledge/research. However, there is little evidence to suggest that research is being rapidly translated into commercially viable products.

The Networks of Centres of Excellence (NCE)

Of the twenty three (23) networks established, one contributes directly to applied respiratory research. Allergen (2004-2009) has been established to investigate causes of – and therapies for –

⁸⁰ Ibid pgs 5,7, and 21-23

allergic/immune diseases that affect up to 40% of Canadians, including asthma. Research projects are grouped in five broad-based themes that reflect the "from cell to society" approach the network is taking to better understand and deal with allergies and asthma. The funding associated with respiratory research, in particular asthma, could be determined with additional analysis.

Genome Canada

Currently three research projects in the area of lung cancer and cystic fibrosis have been established through GenomeBC and the Ontario Genomics Institute respectively, keeping in mind that "genetically 'customized' health care" was identified as the second ranked emerging area where Canada is best positioned to develop prominent strength in the future.⁸¹ Additionally, the area of genetic, genomics, and proteomics research was rated near the top by the survey respondents as gaining ground and having the highest growth prospects.⁸² There may be opportunities for more cross discipline research projects.

NRC – IRAP and the NRC Institutes

The NRC's Industrial Research Assistance Program (IRAP) provides seed funding grants and contributions for innovative technology projects in regions across Canada. IRAP maintains a network of industrial technology advisors (ITAs) whose role it is to assess applications for eligibility. Most companies applying for funding are small and medium sized enterprises and many are in the pre-commercialization or start-up stage. IRAP does not publish the names of companies that receive assistance and so it is not possible to determine how many, if any, respiratory related projects are being funded at this time. NRC is, however, currently supporting respiratory research within the Institute for Biological Sciences.

Pharmaceutical and BioPharmaceutical Contribution to Respiratory Research

Sustained investments in research by the federal and provincial governments, the voluntary organizations and the private sector have gone a long way to creating an internationally-recognized health research community. In turn, Canadian academic institutions have increasingly recognized the opportunity and responsibility to translate research discovery into practice and, where possible, produce economic value. This is required now more than ever. An aging population with a longer life expectancy will result in an increase in cancer, age related chronic diseases and viral respiratory infections. These will be the most important factors in the growing demand for drug therapies. Unfortunately, the development of antiviral drugs against viral infections, particularly respiratory, has proved to be much more difficult than anticipated. Serious infections for which no vaccines are available include respiratory syncytial virus among others.⁸³

Translating research discovery into practice and producing economic value, commonly referred to as knowledge translation, requires infrastructure, talent and funding. CIHR's vision for knowledge translation, "the development of a systematic, integrated approach to accelerate optimal use of the best available research evidence in the interest of the health of Canadians", includes information dissemination and product commercialization⁸⁴. CIHR's strategy for the commercialization of health research also includes strengthening the linkages and engagement with research-based pharmaceutical companies, the relatively new biopharmaceuticals, and the biotechnology sector at large.

⁸¹ Ibid pg 20

⁸² Ibid pg 23

⁸³ The Canadian Biopharmaceutical Industry Technology Roadmap 2006 Industry Canada

⁸⁴ CIHR Knowledge Translation Strategy 2004-2009 <http://www.irsc.gc.ca/e/26574.html#defining>

From 2002 to 2004, Canadian gross domestic expenditures on R&D in the health field averaged about 22.8% of all R&D, up from less than 18% prior to 2001. The largest performers were the higher education sector (universities and teaching hospitals) and business enterprises, which in 2004 accounted for 60% and 35% respectively of all health R&D⁸⁵. With respect to respiratory therapeutic research, significant investment has been made in Canada by the traditional multinational pharmaceuticals that dominate in the global respiratory market. The most recent and significant investments to discover new medicines and treatments have been highlighted in the table below.

Pharmaceutical	HQ	Respiratory Investment
GlaxoSmithKline	ON	<ul style="list-style-type: none"> • \$5 million Ontario • \$2.5 million Alberta • Asthma Care Centres • \$9 million Quebec
Pfizer Canada Inc.	QC	\$50 k NB
Boehringer Ingelheim Canada Inc	ON	tbd
AstraZeneca Canada Inc.	ON	\$2 million BC
Merck Frosst Canada Inc.	QC	\$8 million Ontario \$1 million Manitoba
Schering Canada Inc,	QC	tbd
Sanofi-Aventis Canada	QC	tbd
Novartis Pharmaceuticals Canada	QC	tbd
ALTANAPharma Canada	ON	\$225k Quebec

The field broadly defined as biopharmaceuticals was spawned from the discovery of recombinant DNA technology over 25 years ago. Since then Canada has made impressive progress in the application of biotechnology to the discovery, development, and manufacture of medicines and vaccines. Canada's biotechnology firms continue to diversify their products and processes for detection, diagnosis and treatment. As well, Canadian universities and research hospitals are conducting research with significant commercial potential.

Relating to respiratory disease, it is being determined whether genes may directly cause, or make someone more likely to develop a respiratory disorder. For example, according to the data collected by Industry Canada on biotechnology, scientists are investigating several different genes as possible contributors to asthma. A specific defective pair of genes is identified as responsible for cystic fibrosis. Current genetic respiratory disorders research includes uses of gene therapy, monoclonal antibodies and interferons. In addition, protein-based drugs and vaccines to treat and prevent respiratory disorders are currently being investigated.⁸⁶ The only biotechnology-derived drug available in Canada to treat respiratory disorders directly is used to treat cystic fibrosis. Introduced onto the market in the mid-1990s, it was the first new drug to treat CF in more than 30 years.

⁸⁵ The Canadian Biopharmaceutical Industry Technology Roadmap 2006 Industry Canada

⁸⁶ <http://www.biobasics.gc.ca/english/view.asp?x=772#what>

By 2004 there were over 500 prospective products, including a number of respiratory products, in the biopharmaceutical product pipeline from research through to market.⁸⁷

THERAPEUTIC PRODUCTS IN DEVELOPMENT (PI-PIII)

Cancer	57
Infectious diseases	19
Neurologic	18
Heart diseases	14
Growth and Digestive disorders	9
AIDS/HIV and Autoimmune disorders	8
Eye conditions, Transplantation, Diabetes	7
Blood, skin and respiratory disorders	7

Another Canadian estimate made in 2003 puts the inventory at 600 to 1000 new biopharmaceutical compounds, generated through public research, that are not being adequately developed and therefore, will provide no clinical benefits to the waiting public. The probability of a compound's success increases as it advances through the drug development process. However the majority of biopharmaceutical compounds in Canada have not moved beyond the preclinical phases of development.⁸⁸

Unfortunately, most biopharmaceutical companies have limited or no sales, and need additional financial resources and clinical research expertise to commercialize their innovations. However, there is concern among some stakeholders that the capacity of Canada's innovative pharmaceutical companies to compete for global R&D investment dollars for drug discovery, clinical development and biomanufacturing may be steadily eroding. Challenges such as non-competitive intellectual property protection (IPP), formidable delays and barriers to patients' access to innovative therapies and restrictive pricing and taxation policies all stand out as impediments to R&D investment growth.⁸⁹ The impact is reduced R&D productivity, higher costs and slower rate of new product launches. Under these conditions, the risk is that discoveries of Canadian bioscience will be sold at undervalued prices with their full potential benefiting international competitors. One such respiratory research company is TmBioscience Corporation which invests heavily in Genetic testing for Cystic Fibrosis mutations. It was just recently acquired by Luminex Corporation, an American company. The deal was completed March 1, 2007.⁹⁰

In closing, Rx&D, the researched based pharmaceutical community, believes that Canadian researchers, despite impediments, have combined to create one of the fastest-growing biopharmaceutical sectors in the world. Fueling this growth is the 'omics revolution'⁹¹ - a science that is less than 10 years old. Canada's growing R&D capacity in biopharmaceuticals is a natural evolution from a research base that has won an international reputation in fields such as genomics, proteomics, bio-informatics, stem cells, immuno-therapies, protein engineering and

⁸⁷ Industry Canada Life Sciences Branch Source: Peter Winter, August 2004 http://strategis.ic.gc.ca/epic/site/lsg-pdsv.nsf/print-en/h_hn00079e.html

⁸⁸ Biotechnology Drug Development Accelerator (BDDA) Model November 2003

⁸⁹ Rx&D Submission to Innovation Canada Sept 2002

<http://www.innovation.gc.ca/gol/innovation/site.nsf/en/in02379.html>

⁹⁰ <http://phx.corporate-ir.net/phoenix.zhtml?c=79403&p=irol-newsArticle&ID=969215&highlight=>

⁹¹ One impact of genomics — the study of the human genome — on life sciences is to make every element of the cell into an 'omics specialty, such as proteomics for proteins and metabolomics for cellular fluids

new drug delivery systems. Sixteen Canadian universities are affiliated with a network of more than 100 teaching hospitals and research institutes. In order to keep this momentum going, informants see a need for improvements in policy and regulations and in commercialization strategies.

To create a business and regulatory environment that is more conducive, Rx&D crafted a pharmaceutical strategy (Oct. 2004) which identifies multiple policy and regulatory changes. The highest priority was placed on the need for better protection of intellectual property for Canadian companies. This means enforcement of patent protection rules, effective data protection, and a commitment to the concept of patent term restoration. A second pressing issue was the need for a model at the Patented Medicine Prices Review Board (PMPRB) that reflects innovation. It was felt that the PMPRB structure should balance fair and reasonable prices with a reflection of the research and the development undertaken to produce an innovative medicine. Thirdly, improvement was still thought to be required in drug review and approval times.

Rx&D companies believe approval times in line with Health Canada's own targets can be better achieved through a new independent drug approval agency. Other measures to accelerate drug reviews and approvals require better international harmonization of standards with other countries and appropriate implementation of the User Fee Act. Better access to medicines across provinces and territories is also seen as a requirement. Rx&D also believe that federal transfers for catastrophic drug coverage from the 2003 Health Accord and the 2004 Health Agreement should be directed towards listing new medicines on provincial and territorial formularies. Lastly, improvements to taxation legislation are seen to be needed. It is thought that Canada's taxation legislation could be broadened and become more competitive through actions such as expanding the definition of research and development to encourage study in the field of social sciences which would bring it into conformity with the Organization for Economic Co-operation and Development (OECD) definition.⁹²

Industry Canada identifies the key barriers that limit the commercialization success rate of Canadian companies. They are:

- insufficient experienced senior management with the skills in product development and commercialization needed to guide the development plans and obtain funding;
- a lack of the timely and sustained capital required at the early seed phase to strengthen IP and complete proof-of-principle; and
- the consequent premature spin-off of start-up companies by universities, establishing
- companies with weaker patent and product portfolios.⁹³

Other Research

Aside from the formal granting agencies and research foundations, it should be recognized that a great deal of research is performed by governments or commissioned directly by governments. This includes a large amount of social and socio-economic research. An example of such assets include: the Canadian Health Measures Survey and the PHAC Enhanced Chronic Disease Surveillance Grant. Furthermore, the research conducted in association with this Framework initiative and funded by PHAC could itself be considered a significant asset.

⁹² Rx&D Towards Increasing Research and Development in Canada: A New Innovative Pharmaceutical Strategy October 2004

⁹³ The Canadian Biopharmaceutical Technology Roadmap 2006 Industry Canada

While the quality of respiratory research is clearly high, the amount of funding available for this type of research is considerably below the commensurate cost of respiratory disease to the economy. In fact, it seems evident that researchers in the field have been doing more with less for quite some time. There is also concern about the impact of specific demographics and at-risk population segments on a number of fronts. For example, TB researchers note that while the disease has been largely controlled in Canada, it continues to grow elsewhere in the world; as a result, Canada is importing TB through immigration. In addition to concerns about whether enough specialized research is being conducted, a key concern is that knowledge transfer and succession planning are so far not being systematically addressed. There is a limited pool of funds both within Canada and internationally and respiratory health will have to compete with the emerging health sciences such as Genetics, Genomic and Proteomics. Moreover, the growing pipeline supported by balanced private and public investments, requires specific issues to be resolved in order to move the industry towards CIHR's vision for knowledge transfer, and to capitalizing on the new federal research programs, including infrastructure support. As Canada's population ages, effective management today will yield results tomorrow.

13. Supportive Environments

There are at least two aspects to supportive environments to be considered within the respiratory health context. The first aspect relates to supportive communities where policies, regulations, resources and infrastructure exist to support an engaged population at every stage of the care continuum but especially attuned to self-management. The second aspect relates to supportive environments within the health system itself and includes system design, information technology and decision support systems. This notion is consistent with the Community (1) and Health System (2) elements of the Chronic Care model (Wagner Model) and also analogous with the Community and Self Care elements of the CANA System Map.

As has already been noted, many jurisdictions in Canada have been moving towards integrated community care models that are accessible and interdisciplinary in scale and scope. These care models are supported by technologies that facilitate community care networks that serve to link people, information and resources. Community care models are not new although they are evolving. According to the Association of Ontario Health Centres (AOHC), as of early 2006 there were over 300 Community Health Centres (CHCs) across Canada, including 54 in Ontario. Between 2006 and 2008, Ontario will be expanding its provincial CHC network through the creation of 22 new CHCs and 17 smaller satellite CHCs.⁹⁴ AOHC describes its vision as being “rooted in a care model that provides primary care service delivered by interdisciplinary teams of professionals practicing within a health promotion framework”. Member centres specialize in delivering primary care that is integrated with other social and health service partners.

This same approach can be found in other provinces. In Quebec, for example, a province-wide network of local community service centres - Centres locaux des services communautaires (CLSCs) – dates back to the ‘70s. Since that time services have evolved and have further integrated with the health and social services network (Centre de santé et des services sociaux).⁹⁵

While the community care model has been in place for some time, the notion of supportive community environments for health promotion, disease prevention and management is finding new meaning in health and healthy living programs. One example of this is the recent revival (Feb. 2007) of Health Canada’s *ParticipACTION* program. The fact that Ontario now has a Minister responsible for Health Promotion is another example of this new emphasis. In British Columbia, the BC Healthy Living Alliance⁹⁶ has received \$25 million in funding for the *Act Now Initiative*. Act Now has four key pillars: 1) Healthy Eating, 2) Physical Activity, 3) Tobacco and Alcohol and 4) Pregnancy. Pillars two and three directly relate to lung health. In PEI, the Pediatric Tobacco Control Alliance, Healthy Eating and Active Living programs are attempting to merge into the Healthy Living Alliance, and in Newfoundland and Labrador, a government wellness plan is in the works for 2008. In Manitoba, the Chronic Disease Prevention Alliance is described as a clearinghouse of resources for community initiatives designed to address chronic disease prevention and management. Also in Manitoba, Partners in Healthy Living, a project spearheaded by Cancer Care Manitoba with the Canadian Cancer Society and the Heart and Stroke Foundation, is now in place. The Cancer Society of Manitoba’s Knowledge Exchange Network (KEN) is actively supporting research and promoting healthy living, chronic disease management and community capacity as key initiatives. Smoking prevention in schools is also a key focus there.

⁹⁴ For information on the Association of Ontario Health Centres (AOHC) and the CHCs visit www.aohc.org.

⁹⁵ For information on the Association of Quebec Health and Social Services Establishments visit www.aqess.qc.ca

⁹⁶ BC Healthy Living Alliance www.bchealthyliving.ca

The provinces, as well as cities and other communities in general, have been taking a more activist approach to health prevention, promotion and management. In addition to the programs already noted, anti-tobacco legislation at the provincial/territorial level and smoking bylaws (bans in public places, bars, restaurants etc.) at both the provincial and municipal levels have been put in place in many jurisdictions across the country.

On the environment front, legislation at the federal and provincial levels (e.g. Clean Air Act, federal and NB) are having a cascading effect similar to what has been experienced with tobacco legislation. Many provinces and communities are looking at regulations or bylaws to improve air quality such as idle free zones for motor vehicles, especially school buses, and pesticide free zones.

Gaps and Opportunities

While these community initiatives are substantive, less can be said about changes to the health system itself. Many jurisdictions have complained about lack of funding and resources to upgrade information systems or to purchase the latest diagnostic equipment. Wait times for certain procedures continue to be a major preoccupation across Canada and are proving to be stubbornly resistant to change even when new investment is made. Physician shortages and access to specialist care are also significant systemic problems in many communities and are particularly acute in some remote regions. While there are signs of improvement, poor integration of health system technologies and inadequate and outdated health records systems continue to pose a barrier to research, monitoring, surveillance and treatment.

14. Conclusion

This Asset Map Preliminary Report combined with the Asset Map database attempts to answer the question of “who is doing what and where” with respect to respiratory health in Canada and, to a lesser extent, internationally. The Asset Map as it currently exists is only a first step. Given the appropriate support, the Asset Map has the potential to become a significant “knowledge portal” that will help stakeholders answer key questions about respiratory health in Canada and beyond.

The Asset Map development process has itself been highly informative, leading to a number of important observations and conclusions.

- The term “respiratory health” and some of the disease categories contained within that banner such as COPD and sleep apnea suffer from comparatively low public awareness. This low awareness has many implications including the risk that resources needed to address respiratory disease will not be commensurate with the actual scale of the problem.
- There is concern among some stakeholders that the public may have become desensitized or complacent regarding respiratory diseases such as tuberculosis and tobacco related illness, feeling that those battles may have been fought and won. The reality is that many population segments are increasingly vulnerable to developing respiratory disease.
- While pockets of respiratory health excellence exist across Canada, these pockets are at risk of becoming silos without effective pan-Canadian coordinating mechanisms. Ongoing investments, cooperation and communication will be needed to ensure that new mechanisms are effective.
- Assets focusing on disease prevention, detection and disease management highlight a trend towards dealing with the cause as well as the effects of illness. This trend has been referred to as a “wellness” orientation as opposed to a “sickness” orientation. The result is a more highly integrated health system focused on prevention.
- Team-based multidisciplinary models of care are emerging as the preferred approach for dealing with many respiratory disease conditions.
- The focus on vulnerable or at-risk populations is evident from the assets recorded in the database. This includes, youth, immigrant populations, Aboriginal Peoples, the elderly, women and the homeless, among others. These specialized, targeted assets contain tailored approaches and targeted messages that are more effective than mass campaigns at addressing needs. This speaks to the need for an approach that is sensitive to multicultural realities.

The environment is seen as the most important opportunity on the respiratory health horizon because of growing public concern about pollution and climate change. The environment is seen as an issue that affects everyone; the links to respiratory disease can also be made clear with appropriate research and communications.

- Tobacco is by far the biggest known risk factor associated with respiratory disease. Tobacco assets are achieving results which can serve as encouragement for efforts on

other fronts. But with success comes concern about complacency. Continued investment in tobacco assets will be needed to reach vulnerable populations.

- Beyond the numerous flu programs, the assets surrounding infectious disease relate mainly to TB and Influenza with many assets dealing with pandemic preparedness. Prevention, detection, surveillance/monitoring, and management protocols are key themes.
- A key issue surrounding infectious disease and one that is the subject of much debate is the extent to which there may be gaps or “disconnects” between science and policy, between research and the health care community, and between Public Health and health care delivery. Given the media potential to distort perceptions of risk, there are concerns that public agenda is sometimes driven more by emotion than by evidence.
- A key issue for stakeholders is whether resources are being used optimally or whether efforts are being duplicated. Knowing what others are doing or what is being done elsewhere is seen as essential for effective and efficient management. In this regard, the National Lung Health Framework and Asset Map initiatives are seen to be important drivers for shared information, knowledge and collaboration.

There is currently no comparable comprehensive respiratory or lung health framework in place in any jurisdiction in Canada or, for that matter, in the rest of the world. As such, the proposed National Lung Health Framework is the first of its kind. As such, it is widely anticipated as a potential catalyst for leveraging new assets to promote respiratory health across many fronts and in other jurisdictions. As a process, it also promises to break new ground in terms of bridging traditional organizational boundaries, improving the flow of information and best practices, and making possible many improvements in the level of respiratory health across Canada and possibly at the international level. In keeping the Framework’s vision, improving respiratory health outcomes for Canadians is seen overwhelmingly by stakeholders as the prime motivator for change; doing so more efficiently and effectively is an important attendant consideration.

Appendix A: Asset Map Survey and Questionnaire

Asset Map Survey and Questionnaire

As part of the National Lung Health Framework, an Asset Map of health resources, initiatives and networks is being developed. The Asset Map will be an evolving tool designed to answer important questions regarding “who’s doing what” in terms of respiratory health in Canada. The Consulting firm of Gelder, Gingras & Associates has been engaged to help gather information related to the Map. This questionnaire is part of that process. Thank you for your participation. For information or assistance regarding this questionnaire, please contact John Gelder at: jgelder@sympatico.ca or 613-749-2963.

A. Provincial/Territorial Frameworks

Some provinces and territories may have already developed respiratory health frameworks or may be in the process of doing so.

Q.1 Have you/your province developed a framework (or related plan, initiative, strategy or model) for respiratory health?

- a. Yes
- b. Under development
- c. No

Q.2 If yes, who led/is leading this initiative?

Q.3 If you answered a) or b) above, could you please describe the initiative(s).

Name and Focus of Framework Initiative	Description	Completion date	Key Features

Q.4 May we receive or access a copy of the framework(s) or related document(s)?

- a. Yes, will send to jgelder@sympatico.ca
- b. Yes, at the following link
- c. No, confidential or not yet complete

B. Practice: Community Models of Care and Guidelines

Patients with respiratory health problems require specialized care and treatment. Identifying models of care (i.e. specialized or integrated approaches, programs or technologies), especially those being offered in a community setting and possibly targeted to specific populations, is an important goal of the Asset Map.

Q.5 Are there specific or defined approaches or models, programs and technologies used to manage respiratory disease in your province/territory? If so, please identify and describe those

that specifically address the management of respiratory health in your province. Please indicate the population group targeted.

#	Name	Description	Target Population
1.			
2.			
3.			
4.			
5.			

Other – Please describe

Q.6 Are there specific standards or guidelines governing the policy and practice of respiratory health that are unique to your province/territory? If so, who sets them and how are they implemented and measured?

#	Unique Respiratory Health Practice Standard /Guideline	Who Sets/How Implemented and Measured?	Target Population
1.			
2.			
3.			
4.			
5.			

C. Public Awareness, Prevention and Advocacy

Many jurisdictions have implemented campaigns to heighten awareness of respiratory disease among the public and key stakeholders; many have also undertaken key advocacy and prevention initiatives.

Q.7 Please list and describe any major **public awareness** campaigns in your province or territory that have been introduced to heighten awareness of respiratory disease.

Public Awareness

#	Name/What is it?	Who is the lead and what other stakeholders are involved?	Target Audience
1.			
2.			
3.			
4.			
5.			

Q.8 Please list and describe any major **prevention** initiatives in your province or territory that have been introduced to address respiratory disease.

Prevention

#	What is it?	Who is the lead and what other stakeholders are involved?	Target Population
1.			
2.			

3.			
4.			
5.			

Q.9 Please describe any major **advocacy** initiatives in your province or territory that have been introduced to address respiratory disease.

Advocacy:

Q.10 Finally, in the space below please provide us with any suggestions that would make the Asset Map useful to you?

Suggestions:

Thank you for your participation. Please send any supporting documents that you feel would be helpful to our goal to jgelder@sympatico.ca

Appendix B: External Interview Guide

External Interview Guide

Frameworks

Q.1 Are you aware of or involved in any respiratory health (RH) frameworks, plans, strategies or initiatives that address RH issues? (If yes, what are they and who's involved?)

Q.2 Can we get a copy?

Practice: Models of Care, Guidelines and Best Practices

Q.3 Are there specific RH models of care that you are aware of or part of in your role? (If yes, please describe for each target population) (Probe policy and governance)

Q.4 Are there standards, guidelines and best practices that are relevant to your role and the work that you do in respiratory health? (Who sets them and how measured?)

Q.5 Is/are they successful? Why?

Q.6 What lessons were learned/ what would you do differently?

Public Awareness, Prevention and Advocacy

Q.7 What major campaigns do you feel have an impact on the work that you do? (Describe lead stakeholders and target)

Q.8 What prevention and advocacy initiatives?

Research, surveillance and knowledge translation

Q.9 What research, surveillance or knowledge translation initiatives?

Detection and Chronic Disease Management

Q.10 What detection and chronic disease management initiatives are you aware of or involved in?

Supportive environments

Q.11 What health care systems or community programs are you aware of or involved in?

Gaps and SWOT

Q.12 What gaps exist from your perspective regarding RH?

Q.13 What strengths (successes), weaknesses, opportunities/challenges/barriers exist?

Other

Q.14 Any suggestions to inform the Asset Map / What would help you?