

NATIONAL LUNG HEALTH FRAMEWORK

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PHASE I TECHNICAL REPORT

APRIL, 2007

Chronic Disease Working Group

National Lung Health Framework Vision

“to **advance respiratory health** and health care of Canadians through public engagement in collaborative policy development, leadership, research, innovation and education”.

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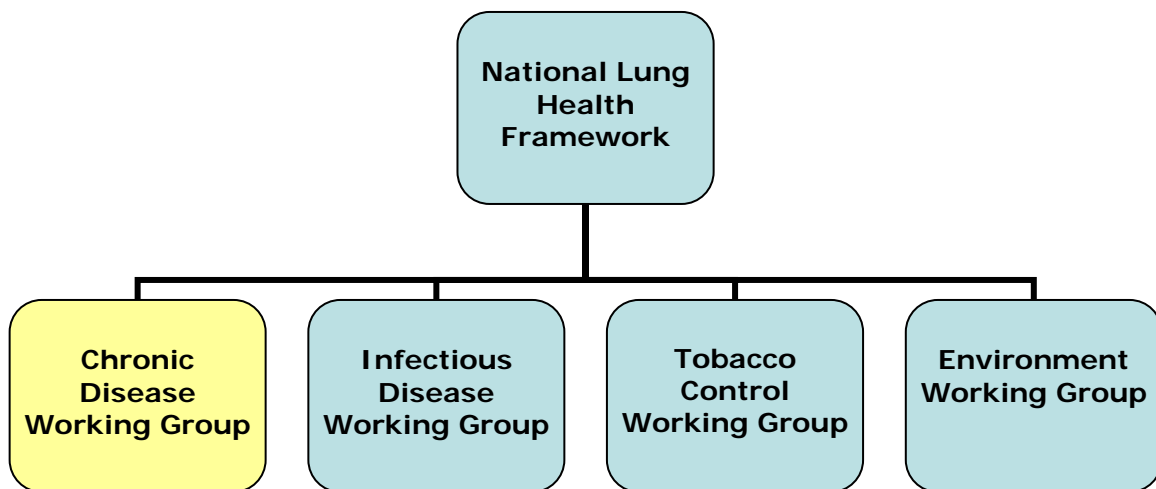
Background

The National Lung Health Framework is a “made in Canada” initiative spearheaded by The Lung Association in collaboration with the Public Health Agency of Canada (PHAC), which will provide a coordinated action plan for the prevention and management of respiratory diseases. The development of this plan is an inclusive process seeking to maximize opportunities for stakeholder collaboration, and is guided by the following vision statement:

“to advance respiratory health and health care of Canadians through public engagement in collaborative policy development, leadership, research, innovation and education”.

The Chronic Disease Working Group is one of four working groups charged with providing input, recommendations and guidance towards the creation of this Framework. This Report is a summary of the initial discussions held by members of this working group.

This report provides direction for achieving important and measurable outcomes in the field of respiratory health in Canada. It reflects a range of emerging issues raised by working group members, and includes possible strategies and actions that should be considered when developing a National Lung Health Framework. This report is a launch pad for discussion, and will continue to be informed by additional research and stakeholder engagement in the months ahead.



Process/Methodology

The development of the National Lung Health Framework began in April, 2006, when The Lung Association, with support from Health Canada, the Public Health Agency of Canada, and industry partners, initiated the planning of a multi-stakeholder workshop to bring together parties interested in collaborating on the development of a National Lung Health Framework. During this two-day workshop, participants outlined a number of activities and research priorities that needed to be taken on in order to move forward, among which included:

- an asset map and gap analysis, to help create a clear picture of what is happening in respiratory health in Canada;
- a cost-benefit/risk analysis, to outline where financial investment will result in the most gains;
- the creation of a multi-stakeholder Steering Committee, chaired by the Lung Association; and
- the creation of four working groups to drive the content of the Framework, in the areas of Chronic Disease, Infectious Disease, Tobacco Control and Environment.

Since that workshop, steps have been taken to follow through on these action items, and Working Groups were formed. Each of the Working Groups began preparations for holding their own workshops, beginning with the design and distribution of a pre-workshop questionnaire to survey Working Group.

The Chronic Disease Working Group workshop was held in Ottawa on December 11, 2006, with the following objectives:

- to develop a shared understanding of the strategic issues, challenges and opportunities related to the chronic disease theme of the National Lung Health Framework;
- to articulate the desired outcomes to achieve related to the Chronic Disease theme; and, in light of the desired outcomes,
- to identify the key results that must be achieved and the activities to be pursued to deliver the outcomes.

The workshop followed a classic “strategic planning” approach beginning with an environmental scan to take stock of the issues, trends and factors influencing the chronic respiratory disease environment and proceeding to identifying key priorities and ways to achieve them.

Subsequent to the workshop, key documents were consulted to support the environmental scanning process conducted during the workshop. Working Group members and key informant interviews by the consultant team were undertaken to further inform various aspects of the Report and to sharpen its focus. The Report is the result of an iterative,

multi-stage process of engagement involving a wide range of stakeholders. The following table summarizes the key stages in the process to date and the timeline at each stage.

Step	Process Activity	Timeline
1.	“Breathing Matters” Workshop	April, 2006
2.	Working Group Formation	November, 2006
3.	Pre-Workshop Survey	December, 2006
4.	Working Group Workshop	December, 2006
5.	Scan of key documents	Dec. 2006 – ongoing
6.	Review of Draft Report by Members	Jan. / Feb., 2007
7.	Key Informant Interviews (in conjunction with Asset Map and Gap Analysis research)	Jan. / Feb., 2007
8.	Discussion Draft, Draft and Final Report	Feb. / Mar., 2007

These steps are just the beginning. Highlights of this report and other key pieces of research will be compiled into a Framework Discussion Document, to be used to facilitate further discussion and stakeholder engagement over the coming months.

Objectives of the Working Group

The Working Group members were tasked to work together to provide recommendations and guidance for the content of the National Lung Health Framework. More specifically, the Working Group members were asked to:

- expand on the work completed by Working Groups at the “Breathing Matters” workshop, held in April, 2006;
- identify additional stakeholders to be involved in the development of the National Lung Health Framework;
- identify additional respiratory health issues to be included in the National Lung Health Framework;
- identify additional goals, objectives, and outcomes to be included in the National Lung Health Framework; and,
- identify potential activities that can achieve these goals, objectives and outcomes.

Members of the Chronic Disease Working Group share the common overarching goal of lowering chronic respiratory disease mortality and morbidity rates through better prevention, early detection and treatment, and effective management. Given the increasing toll of chronic respiratory disease in Canada, this goal has taken on a greater urgency in recent years.

Other expectations, of which there are many, provide motivation and momentum towards this overarching goal. Working Group members see an opportunity to make strides in the area of respiratory health and to learn lessons from other health related framework initiatives undertaken in Canada and internationally. An effective approach for combating chronic respiratory disease demands an understanding of the scope of the problem including knowledge gaps. In keeping with the National Lung Health Framework objectives, it also requires a true partnership, coordinated with, and supported by, provincial and territorial governments and other key stakeholders.

Multiple Perspectives

A multitude of perspectives are needed to fully inform the strategies employed to achieve anticipated outcomes. The Working Group acknowledges the importance of the patient voice/perspective in addressing respiratory disease. The Working Group also recognizes the need for extensive coordination and linkage across many organizations to adequately respond to the wide range of chronic respiratory conditions. No single organization has either the means or knowledge to succeed alone.

Nor can chronic respiratory disease be considered in isolation from other respiratory disease categories or disease in general. The acute care sector perspective, in particular, needs to be factored into the discussion as well as the broader public health perspective, with an increasing focus on prevention and advocacy. The Working Group understands that the delivery of health care is constantly evolving. The perspectives of the primary care community, multi-disciplinary teams, community care practitioners and those involved in environmental health areas are all required to fully inform strategies to promote respiratory health.

Logic Model

The following table illustrates the logic model that serves as the organizing framework for the Chronic Disease Working Group Report. The model contains five (5) broad elements. Associated with each element are specific expectations, inputs, strategies, activities and outputs all of which lead to ten (10) key overarching outcomes. The model is shown to be informed and supported by the various steps in the development process. The logic model content will be further developed as the consultation process unfolds.

Vision	To advance respiratory health and health care of Canadians through public engagement in collaborative policy development, leadership, research, innovation and education.						
Elements	Public Awareness, Health Promotion & Prevention	Detection and Chronic Disease Management	Supportive Environment (Systems, Human and Community)	Surveillance	Research and Knowledge Translation		
Expectations	See page 8	See page 8	See page 8	See page 8	See page 8		
Inputs	Next steps	Next steps	Next steps	Next steps	Next steps		
Strategies	See page 19	See page 20	See page 21	See page 22	See page 22		
Activities	See page 19	See page 20	See page 21	See page 22	See page 22		
Outputs	Next steps	Next steps	Next steps	Next steps	Next steps		
Overall Outcomes	<ol style="list-style-type: none"> 1. Health care practitioners have access to best evidence, training and information, and the resources/support to implement this into all areas of practice (and actually implement) 2. Quality data (focused, relevant) is used to guide policy, program and service delivery and research on an ongoing basis 3. There will be timely access to integrated, coordinated and interdisciplinary respiratory health services focused on best practices standards for chronic respiratory care 4. Canadians and their communities are aware of and participate in actions to promote optimal respiratory health 5. We will have better management of respiratory disease leading to improved health outcomes 6. There will be reduced burden of chronic respiratory disease, reduced morbidity and mortality, with early prevention, diagnosis and detection, and effective chronic disease management 7. Improved awareness and early detection of risk factors associated with chronic respiratory disease will lead to improved quality of life 8. A more sustainable health care system with adequate funding will be directed at programs to address prevention and management of chronic respiratory disease 9. There will be a well funded, successful research program aligned with the National Lung Health Framework 10. Work, school, home and social environments (indoor and outdoor) will support optimal respiratory health 						
Breathing Matters Workshop	Working Group Collaboration	Working Group Member Survey	Working Group Workshop	Key Document Consultation	Key Informant Interviews	Working Group Review of Draft	Iterative Reports

Framework Elements

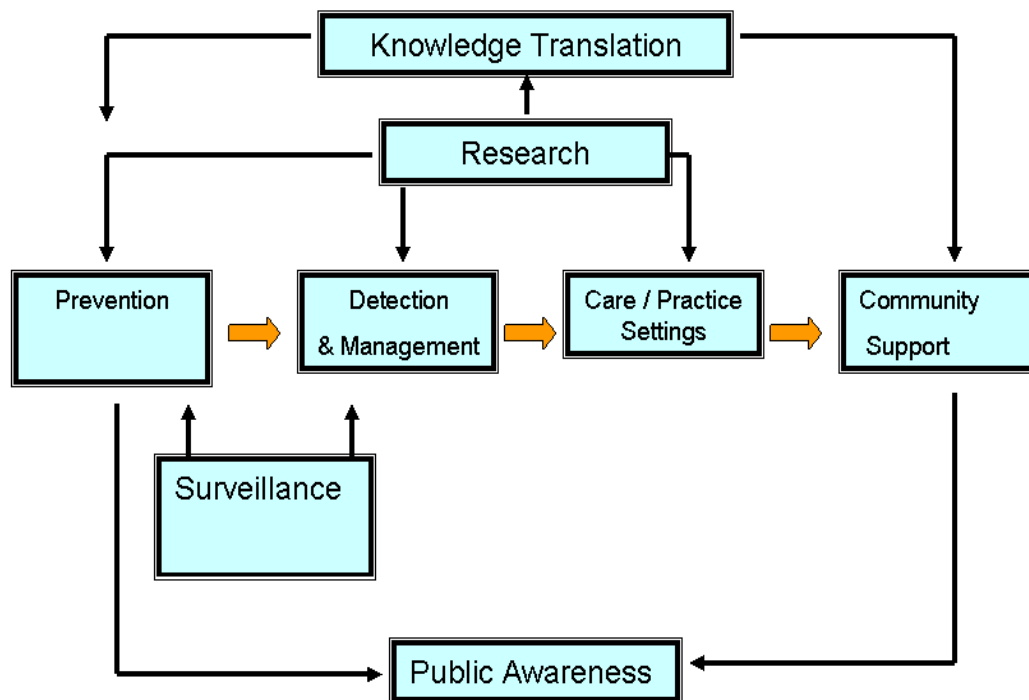
Five (5) key elements constitute the organizing framework for the Chronic Disease Working Group strategy and logic model, and represent broad areas within which resources (inputs), key strategies, activities and outputs are to be aligned. The five key elements are:

Logic Model Elements	Public Awareness, Health Promotion & Prevention	Detection and Chronic Disease Management	Supportive Environment (Systems, Human and Community)	Surveillance	Research and Knowledge Translation
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- 1. Public Awareness, Health Promotion and Prevention** – Chronic respiratory disease suffers from comparatively low public awareness which results in adverse consequences such as unnecessary exposure to risk, under-diagnosis and treatment.
- 2. Detection and Chronic Disease Management** – Early detection and appropriate management can lead to significant improvement in quality of life for patients.
- 3. Supportive Environment (Systems, Human and Community)** – Supportive environments are essential to an effective chronic respiratory disease strategy. This includes information systems infrastructure within the health care system, health education as well as supportive human and infrastructure environments in the community.
- 4. Surveillance** – Tracking lung disease, its risk factors, impacts and outcomes in the population over time provides valuable information to decision-makers to guide strategies and resources for an optimal response.
- 5. Research and Knowledge Translation** – Research is needed to address critical information gaps and support intelligent, evidence-based responses to chronic respiratory disease challenges and it is vital that this research be translated into meaningful action and results.

Linkages

The Logic Model is a useful tool as an organizing framework. However, it is important to recognize that the elements of the model are not static but interdependent; each element influences the other and together they form a complex system. This systemic aspect of the model is illustrated below.



Important linkages also exist among the various Working Group components that will comprise the National Lung Health Framework. For example, many issues raised in the Chronic Disease Working Group were also raised or implied in other Working Groups such as Environment and Tobacco. These linkages, which will become evident as the process evolves, will highlight the dynamic and interdependent nature of the Framework components.

Stakeholder Interests, Expectations and Roles

All Canadians have a stake in addressing chronic respiratory disease. To be effective, however, it is important for strategies to focus on addressing the unique needs and interests of specific stakeholder groups. With respect to chronic respiratory health, key stakeholders identified by the Working Group include:

- The federal government
- Provincial / territorial governments
- Regional health authorities
- Municipal governments
- First Nations, Inuit and Métis
- Health care providers
- Patients and families
- Private Industry
- General public
- Educators (health system and academic)
- Employers
- Research community
- Non Governmental Organizations (NGOs)
- Private health care including pharmaceutical industry and insurers

Core Overarching Expectations

A number of core overarching expectations among these stakeholders were identified. These include:

1. Better respiratory health and quality of life - a community environment that is supportive of the prevention and management of chronic respiratory disorders;
2. Coordinated, focused data collection – better information systems to promote understand of what is happening;
3. Targeted research to add to new knowledge, to address gaps – translate research into knowledge and into practice;
4. Improved integration, cost effectiveness, coordination and access to respiratory health services;
5. Empowering information and communication about how to promote, maintain, protect and optimize lung health;
6. Increased use of good quality, existing knowledge in practice;
7. Resources to carry out the strategy and support for resource reallocation;
8. Ongoing coordination whereby each player understands the role they need to play;
9. Recommendations for public/private policy and guidelines; and,
10. Buy-in from stakeholders to the framework and its implementation.

Map of Core Expectations to Key Elements

Logic Model Elements	Public Awareness, Health Promotion & Prevention	Detection and Chronic Disease Management	Supportive Environment (Systems, Human and Community)	Surveillance	Research and Knowledge Translation
Core Expectations	1, 3, 4, 5, 6, 7, 8, 9, 10	1, 2, 3, 4, 5, 6, 7, 8, 9, 10	1, 2, 3, 4, 5, 6, 7, 8, 9, 10	1, 2, 6, 7, 9, 10	1, 2, 3, 6, 7, 9, 10

Analysis of Stakeholder Perspectives, Interests and Potential Roles

Individual stakeholders have differing perspectives, interests and roles with respect to chronic respiratory disease. An analysis of these differences is summarized in the following table; the analysis serves to inform the Working Group strategies and activities which are integral to this Framework component.

Stakeholder	Key Perspective	Primary Interest/Expectation	Potential Role
Federal Government	National, pan-Canadian in scope	<p>Access and Universality</p> <p>Canada Health Act and standard of care</p> <p>Affordable and sustainable health care</p>	<ul style="list-style-type: none"> Better respiratory health indicators – position Canada as a world leader Specific recommendations within federal role (surveillance, knowledge exchange and development, policy, leadership and coordination) Stakeholder agreement to work together and agree on common outcomes Foster effective partnerships in the field of respiratory health Leadership in support for research in providing respiratory health care/prevention Better surveillance and data collection Support for framework implementation across Canada (materials, programs, surveillance)
Prov. / Ter. Government	Provincial, regional and local in scope	<p>System access and capacity planning and management</p> <p>Efficient/ affordable health care delivery</p> <p>Quality care and metrics; e.g. reduction in wait times; health system infrastructure and human resources</p>	<ul style="list-style-type: none"> Information to support and direct program creation and delivery Help identify respiratory priorities/issues in strategic planning re. programs, resources, funding required Guidance in organizing various community programs and allocating healthcare resources Examples of good and best-practices Provincial/territorial commitment to

Stakeholder	Key Perspective	Primary Interest/Expectation	Potential Role
			<p>framework</p> <ul style="list-style-type: none"> • Cost/benefit analysis of recommendations
Regional Health Authorities	Regional in scope	<p>Coordination of regional resources</p> <p>Emergency preparedness</p> <p>Service delivery and capacity</p>	<ul style="list-style-type: none"> • Coordinated initiatives (with shared understanding) • Partnerships (e.g. patient, health care professional, community) • Improved quality of life for patients in the community • Specific recommendations within their purview e.g. transportation, recreation, social services, public health • Appropriate local investment by province, NGOs, etc. • Integration of health services into community (supportive role)
Municipal Government	Community-based care; local in scope; efficient and effective delivery	Capacity, quality service and access - responding to needs and demands of the community	<ul style="list-style-type: none"> • Aboriginal health initiatives • Participation of Aboriginal Peoples in health care delivery • Implement commitments of the Canada-Aboriginal Peoples Roundtable on Health • Research regarding prevalence of CRD in Aboriginal communities • Restore funding to combat tobacco use
First Nations, Inuit and Métis	National, provincial/territorial and regional and community based On-reserve and off-reserve	<p>Improved Aboriginal health</p> <p>More and better resources targeted to needs</p>	<ul style="list-style-type: none"> • Information on best practices • Fewer sick and more healthy patients • Integration of quality health care delivery • Help with coping with heavy demands now • Tools to help guidelines implementation • Evidence-based education based on guidelines • Appropriate referrals to specialists / specialized services • Government funding and availability of health care providers (non physician) to provide interdisciplinary care • Participation in surveillance and research • Translation of evidence-based knowledge into practice
Health Care Providers	Community-based	<p>Tools and resources along the continuum of care</p> <p>Patient care</p> <p>Inter-disciplinary care</p>	<ul style="list-style-type: none"> • Greater focus on self-management (optimal) • Support for disease management • Patients identify what standards of care they should expect for management of their chronic disease

Stakeholder	Key Perspective	Primary Interest/Expectation	Potential Role
			<ul style="list-style-type: none"> • Improved integration of care • Access to information (accessible, high quality, personal) • Broader variety of services • Active member of interdisciplinary team
Patients and Families	Perceptions of quality and responsiveness of health care system and providers; Was the treatment effective?	Improved access Improved and better health care outcomes Better quality of life	<ul style="list-style-type: none"> • Support/funding for HR infrastructure for implementation • Recommendations to implement healthy workplace policy and actions • Prompt access to expert evaluation • Work absenteeism initiatives • Continuing professional education/requirements for occupational health and safety staff
Employers	Worker productivity; ability to attract and retain workers; competitiveness	Healthy workplace and workers; productivity and reduced absenteeism Education and awareness	<ul style="list-style-type: none"> • Information to direct investment • Potential to collaborate on respiratory programs/services • Understanding patient needs, perceptions and expectations • Cost/benefit analysis • Accurate statistics/metrics • Clearer standards for access to drugs in order to eliminate provincial variations in funding • Quality products reasonably priced to meet the needs of health care providers, patients and families
Private Industry (Private healthcare, pharma, insurers etc.)	Partners in the health care system; efficiency and effectiveness; innovation, research	Investment opportunity Avoid/minimize losses Shareholder value	<ul style="list-style-type: none"> • Information on prevention and self-management • Better understanding of respiratory health issues and burden • Good value for dollars invested by government and NGOs • Better knowledge (importance/impact) about respiratory health • Higher level of lung health awareness and when to seek help i.e. spirometry • Health promotion across continuum of care • Coordinated messaging re. CRD Canadian and World “days”
General Public	Affordability, fairness sustainability, quality, access Awareness and	Access, quality health care and service, value for taxpayer dollars Self-management and	<ul style="list-style-type: none"> • Evidence-based care / education • Primary care education • Multidisciplinary provider of education (e.g. training, college, university, CME)

Stakeholder	Key Perspective	Primary Interest/Expectation	Potential Role
	prevention of chronic respiratory disease and promotion of lung health	prevention information Health care as opposed to sick care	etc.) <ul style="list-style-type: none"> • Universities, nursing colleges etc. • Vision of what the workforce needs to look like and how they will practice • Input into curriculum for variety of health care providers • Curriculum content
Educators (Health System and Academia)	Systemic enablers and constraints; knowledge transfer and management Evidence-based research and knowledge translation	Education and research standards; best practice guidelines World-class education and certification/licensing of providers Oversight mechanisms	<ul style="list-style-type: none"> • Advocate for more money (e.g. from F/P/T and granting/funding agencies) • Develop, respond to RFP opportunities • Help identify research opportunities needed • Identify the gaps in knowledge • National pulmonary rehab strategy esp. mild, moderate, severe COPD • Pediatric strategy – asthma • More funding; vetting of research priorities • Build partnerships (e.g. CIHR, Heart and Stroke) • Integrate research i.e. from cell to person • Collaborate with F/P/T on research priorities
Research Community	Advancement of knowledge	Advancement of knowledge to obtain results along the continuum of care	<ul style="list-style-type: none"> • Give direction for activities – advocacy, education • Funding potential • Improved / effective coordination with similar/related NGOs • Better health outcomes for its targeted groups • Mechanism for valued input into ongoing • Development and implementation of National Lung Health Framework (include their issues) • Opportunities for collaboration within and without the respiratory community • Better patient outcomes • Develop and distribute evidence-based education materials • Support F/P/T initiatives for general public, patients, families and providers • Support/provide research funding opportunities • Collaborate to define issues, needs and priorities

Stakeholder	Key Perspective	Primary Interest/Expectation	Potential Role
NGOs	Stakeholder specific; Issue specific	Advance agendas through research, advocacy etc. Respond to member needs and priorities	

Environmental Scan

There are a variety of key issues, trends and factors that are shaping the chronic disease environment which point to both challenges and opportunities for progress on the chronic respiratory disease front. This environmental scan summarizes relevant considerations of Working Group members, key informants and stakeholders.

Chronic Respiratory Disease – An Increasing Problem

Over 3 million Canadians are coping with serious respiratory disease.¹ The vast majority of these Canadians suffer from chronic conditions such as asthma, chronic obstructive pulmonary disease (COPD) and sleep apnea. These diseases affect all ages – children, teens, adults and seniors.

Canada is facing a wave of chronic respiratory disease. This is due, in part, because many such diseases tend to worsen with age and Canada's population is getting older.

For example, societal influences that encouraged women to smoke 30 to 40 years ago have contributed to the emergence of COPD as a crucial women's health issue. According to one recent report, more than 425,000 women in Canada have been diagnosed with COPD.² Since the year 2000, female mortality due to COPD has risen at double the rate of breast cancer.³ Of the leading causes of death, COPD is the only one experiencing increasing mortality. Hospitalization rates are also high and climbing.⁴

Like COPD, asthma is a serious and growing problem. Asthma is the most common respiratory disease among Canadian children, accounting for a quarter of school absenteeism. Among adults, the prevalence of asthma increased from 2.3% in 1979 to 8.4% in 2004.⁵ Sleep apnea is also a growing concern among many health care professionals. Thousands of Canadians are thought to be suffering from sleep apnea without knowing it. Obstructive sleep apnea (OSA) affects 1% – 3% of children. In addition, one in five adults have at least mild sleep apnea and at least one in 15 has moderate sleep apnea.⁶

Environmental factors are also playing a part in the problem. As the quality of the air we breathe deteriorates the prevalence of chronic respiratory illness increases. The adverse effects are made worse due to the trend towards increased urbanization. Health Canada estimates that in 11 major Canadian cities, air pollution alone is responsible for 5,000 premature deaths.⁷ Nor is the problem limited to outdoor air pollution. Studies have shown that adult Canadians spend about 90% of their time indoors. Indoor air quality is

¹ *Respiratory Disease in Canada*, 2004 The Lung Association/Health Canada

² *Women and COPD: A National Report*, 2006 The Lung Association

³ Ibid

⁴ *Chronic Obstructive Pulmonary Disease: A National Report Card*, The Lung Association, 2005

⁵ *Asthma: A Resource for Canadian Journalists*, The Lung Association

⁶ <http://www.lung.ca> Dec. 30, 2006

⁷ Burnett R, Cakmak S, Brook JR. *The effect of ambient air pollution mix on daily mortality rates in 11 Canadian cities*. Canadian Journal of Public Health 1998; 89:3152-56

influenced by a variety of factors including: outdoor air, environmental tobacco smoke, biological material, consumer and building products and radioactive materials.⁸

Rising rates of obesity and adverse work conditions are also contributing factors as are persistent levels of tobacco use. According to recent data, 18% of the population 15 and older are current smokers, of which 14% reported smoking daily. Among current smokers 15 years and over, approximately 20% are males and 15% females.⁹ High rates among groups such as Canada's First Nations, Inuit and Métis Peoples, young women and immigrant populations are of particular concern. Furthermore, respiratory illnesses are being increasingly linked to the indirect and environmental exposure to tobacco smoke (ETS).

There is also evidence to suggest that chronic respiratory conditions such as COPD are considerably under-diagnosed, due in part to low awareness. Although it is the fourth leading cause of death in Canada, fewer than half (46%) of Canadians have heard of chronic obstructive pulmonary disease and fewer yet of the acronym COPD (13%), according to recent survey data.^{10, 11}

As was noted by a recent study conducted by The Lung Association, the projected increase in the number of individuals with COPD will have major implications for families and for the delivery of comprehensive hospital and community services.¹² The same study noted that the prevalence of self-reported asthma is increasing for both men and women. The data on activity restriction, emergency room visits and hospitalization suggest that many individuals with asthma require help in keeping their disease under control.

Evidence indicates that Canada's First Nations, Inuit and Métis Peoples are disproportionately affected by chronic respiratory diseases such as asthma and COPD. One study noted that Aboriginal Peoples in Alberta were 2.1 times and 1.6 times more likely to have an emergency and office visit for asthma or COPD, respectively, compared to non-aboriginals.¹³ While more data are needed, chronic respiratory diseases are thought to be exacerbated in Aboriginal communities due to housing conditions such as overcrowding and the presence of toxic mould; poverty and substance abuse may also be contributing factors.

Like COPD and, to a lesser extent asthma, it is widely believed that the prevalence of sleep apnea is significantly under-reported. This is because thousands of Canadians have sleep apnea and don't know it.¹⁴ Furthermore, experts and key informants believe that there continues to be large variances in access to diagnosis and treatment of sleep apnea from province-to-province.

⁸ *Respiratory Disease in Canada*, 2004 The Lung Association/Health Canada

⁹ Canadian Tobacco Use Monitoring Survey, February-December 2006

¹⁰ Statistics Canada, Selected Leading Causes of Death (last modified 2005-02-17)

¹¹ 2006 Leger Marketing Research - consumer

¹² *Respiratory Disease in Canada*, 2004 The Lung Association/Health Canada

¹³ Sin D, Wells H, et al. *Asthma and COPD Among Aboriginals in Alberta, Canada*. *Chest* 2002;121:1841-1846. 2002 American College of Chest Physicians

¹⁴ National Sleep Awareness Week March 27 – April 3

Lack of Awareness

Respiratory health, in general, has very little “currency” in the collective mind of the public. Even though chronic respiratory disease is much broader than cancer for example, people don’t see themselves as part of this group. One reason for this is that there is no one “lung disease”. Rather, lung disease consists of more than 30 different conditions, the causes of which are widespread and varied.¹⁵ Another reason may be that there has never been a sustained, coordinated campaign to inform and educate the public about the importance of respiratory health.¹⁶ As a result, media coverage is comparatively low. For example, in the first nine months of 2005, there were 252 print references to COPD in Canadian media, compared to 2,848 for Alzheimer’s, 7,157 for breast cancer and 13,023 for HIV/AIDS.¹⁷

Low levels of awareness are not confined to the public; they also impact care and treatment. For example, only one quarter of doctors in Canada (26%) consider themselves to be very familiar with Canadian Thoracic Society’s COPD guidelines and only 7% say they follow the treatment processes outlined in those guidelines.¹⁸ The CTS guidelines emphasize the importance of spirometry as the most efficient means for accurately diagnosing COPD. Even though access to spirometry is high, spirometry testing is low and comfort interpreting the results even lower.¹⁹

Low levels of awareness are seen to translate into under-diagnosis, under-funding and complacency. Some experts and key informants believe that there is a significant stigma associated with lung disease, which may pose a barrier to detection and treatment. Notably, certain chronic respiratory conditions such as childhood sleep apnea are virtually neglected. The overall result according to stakeholders is that chronic respiratory illness is not receiving the attention it deserves. This, in turn, means that the health care system response is far from optimal.²⁰

Stakeholders in the field of chronic respiratory disease feel that the time for sustained action is long overdue and that there is a need for a nationally coordinated campaign aimed at improving awareness and quality of life for those suffering from the disease.²¹

Fragmented Efforts/Lack of Coordination

According to many experts, the respiratory health community can only be described as fragmented compared to other major disease categories (e.g. Diabetes, Heart and Stroke, Cancer). Despite the efforts of many bodies and individuals, the coordination needed for

¹⁵ *Towards a National Framework for Respiratory Disease in Canada: Environmental Scan*. The Lung Association 2006

¹⁶ There have, of course, been many campaigns to educate the public on the risks of smoking. The broader issue relates to respiratory health in general and the multitude of other risk factors.

¹⁷ *Chronic Obstructive Pulmonary Disease: A National Report Card*. The Lung Association, 2005

¹⁸ Ibid

¹⁹ Ibid

²⁰ Chronic Respiratory Disease Working Group workshop and consultations 2006

²¹ Ibid

sustained improvement and integration of strategies is seen to be lacking. Indeed, it has been suggested that institutional rivalry often leads to a level of competition for support for various activities to the detriment of the field as a whole.

Furthermore, there are wide variations in funding for diagnosis and treatment across Canada. For example, a recent “report card” study noted that provincial capacity to deal with COPD varied significantly. Several provinces received a grade of D or lower with respect to their capacity to deal with COPD; three provinces actually failed.²² The study noted that differences exist among provinces with respect to funding for COPD medications as well as adherence to the CTS guidelines for management of COPD, including access to pulmonary rehabilitation.

Federal/provincial/territorial politics are viewed as presenting a challenge to adopting a coordinated approach while the public / private health care debate is seen as hindering the ability to take concerted action. According to many informants, there is a significant opportunity for implementation of national guidelines (e.g. COPD) as a means of mitigating some of these challenges.

Limited Resources, Research and Data

While much is known about the broad issues, trends and impacts related to respiratory disease in Canada, there are also significant information gaps. The prevailing view is that the use of decision support and information management systems is too often sporadic and uneven across Canada. It has been noted that some locales are using computers and system support tools routinely but that these are generally in the minority. Thus, there is a need to make such systems more widely and consistently available so that respiratory health professionals involved in all facets of respiratory health care have the information tools they need to be optimally effective. Such resources are seen to be important as a precondition to ensuring greater and faster knowledge transfer and adoption.

While improving, data on chronic respiratory health in Canada still contain significant gaps. For example, it is widely believed that more research is needed to determine the impact of chronic respiratory diseases such as asthma and COPD on at-risk or vulnerable population groups such as children, the elderly and women, as well as immigrant, aboriginal, low income and rural segments.

In addition to system requirements and better research data to address gaps, past evidence suggests that health care system results are slow to emerge without investments in the health human resources to translate information and knowledge into practice. The lack of appropriate health human resources to address chronic respiratory disease is seen as a considerable impediment to progress. Even when programs are implemented and actions taken, many feel that there are often insufficient resources available to ensure effective monitoring and measurement of results. These views point to a need for greater emphasis on chronic respiratory diseases such as COPD; they are supported by recent survey data

²² *Chronic Obstructive Pulmonary Disease (COPD): A National Report Card, 2005*. The Lung Association

indicating that 56% of physicians feel that their provincial government is not making COPD a healthcare priority.²³

Demands on HC System

Respiratory diseases represent a very significant economic burden on the Canadian health care system. Together, they account for nearly \$12.18 billion of direct and indirect expenditures per year (1993 dollars).²⁴

Demands on the health care system are increasing across Canada. These demands are placing the system under considerable stress. Provinces and territories as well as the federal government and other stakeholders are looking to primary health care reform to address these challenges including new ways to diagnose, prevent and manage chronic disease. Health care reform will affect how health care is delivered – with a renewed focus on infrastructure – as well as how people are organized and funded for delivery. While the challenges of health care reform are significant, many stakeholders feel that there is also an opportunity for innovative, practical and effective ways to address chronic respiratory health issues.

Changing Focus and Attitudes

Stakeholders note that shifting societal attitudes are changing the face of health care and the way it is delivered. The focus is clearly shifting away from acute care in favour of prevention, early detection and diagnosis. Consumer advocacy is seen to be playing an increasing role in driving allocation of resources. Informants suggest that the best models for this approach include HIV and breast cancer. Consumers, frustrated by systemic health care constraints, are said to be increasingly seeking new and innovative ways to take charge of their own health. This trend has been described as a shift from a “sickness” culture to a “wellness” culture.

Stakeholder informants suggest that there has also been a tendency to put respiratory disease in a clinical setting. In keeping with a respiratory health approach, they say that there is a need to focus more on what is available in a community setting, including infrastructure, activities, dietary counseling, exercise programs, awareness and more. Informants note that there is increasing acceptance that patient-centric interdisciplinary health care is the emerging model best suited to address new societal norms and expectations.²⁵

²³ Ibid

²⁴ *Respiratory Disease in Canada*, 2004 The Lung Association

²⁵ Chronic Respiratory Disease Working Group consultation 2006

Overall Outcomes

Key outcomes represent the desired “future state” for chronic respiratory health in Canada as articulated by Working Group members and other stakeholders (including leading experts, practitioners and key informants). The outcome statements reflect the world as stakeholders would like it to be with the strategy fully implemented - that is, over the longer term. The key longer-term outcomes defined by Working Group members are as follows:

1. Health care practitioners have access to best evidence, training and information, and the resources/support to implement this into all areas of practice (and actually implement)
2. Quality data (focused, relevant) is used to guide policy, program and service delivery and research on an ongoing basis
3. There will be timely access to integrated, coordinated and interdisciplinary respiratory health services focused on best practices standards for chronic respiratory care
4. Canadians and their communities are aware of and participate in actions to promote optimal respiratory health
5. We will have better management of respiratory disease leading to improved health outcomes
6. There will be reduced burden of chronic respiratory disease, reduced morbidity and mortality, with early prevention, diagnosis and detection, and effective chronic disease management
7. Improved awareness and early detection of risk factors associated with chronic respiratory disease will lead to improved quality of life
8. A more sustainable health care system with adequate funding will be directed at programs to address prevention and management of chronic respiratory disease
9. There will be a well funded, successful research program aligned with the National Lung Health Framework
10. Work, school, home and social environments (outdoor and indoor) will support optimal respiratory health.

Map of Outcomes to Key Elements

Logic Model Elements	Public Awareness, Health Promotion & Prevention	Detection and Chronic Disease Management	Supportive Environment (Systems, Human and Community)	Surveillance	Research and Knowledge Translation
Overarching Outcomes	1, 2, 3, 4, 6, 7, 8, 10	1, 2, 3, 5, 6, 7, 8	1, 2, 3, 6, 7, 8, 10	1, 2, 6, 7	2, 6, 7, 9

Key Strategies/Activities

Following are preliminary strategies and activities associated with each key element that can potentially lead to the achievement of the overall outcomes specified.

A. Public Awareness, Health Promotion and Prevention

S.1 Increase awareness by the public and other stakeholders

- Increase awareness through specific initiatives and communication strategies
- Increase Public and Government awareness to encourage additional funding for research relevant to respiratory health
- Build awareness across the full spectrum of chronic lung disease in Canada reflective of its burden (e.g. asthma, COPD, OSA, cystic fibrosis, pulmonary fibrosis, etc.)
- Get respiratory health onto government agendas and into public consciousness
- Create a national, public awareness campaign on respiratory health
- Increase awareness of each of COPD, asthma and OSA to >90%
- Public knowledge and support for respiratory risk factors
- Engage all stakeholder groups in discussions
- Put a public face to chronic lung disease

S.2 Strengthen health promotion and advocacy

- Promote smoking cessation, prevention and protection
- Advocate for respiratory health (health promotion) where people “live, work and play”
- Achieve buy-in to the Framework by high risk groups
- Engage vulnerable populations in the design and implementation of initiatives to improve respiratory health
- Engage health care professionals in the development, implementation and evaluation of initiatives that promote respiratory health

S.3 Step up chronic respiratory disease prevention efforts

- Integrate tobacco cessation, prevention and protection counseling into respiratory healthcare professionals' practice
- Facilitate health care reform to focus on disease prevention
- Encourage the public to seek medical attention when appropriate for COPD, asthma and OSA (i.e. 30 second asthma test, Lung Health test, Sleepiness test)
- Work to decrease smoking rates; maintain tobacco prevention, protection and cessation efforts
- Link lung health to emerging issues such as air quality / climate change; regional disparity in access; wait times, and the push for wider smoking bans across the country

B. Detection and Chronic Disease Management

S.1 Better education and training

- Have more educators trained in asthma and COPD management
- Develop training program for OSA management
- Educate healthcare practitioners particularly in primary care setting of the value of chronic disease management approach to conditions such as COPD, asthma, sleep apnea
- Focus on chronic disease management to ensure adequate numbers of trained respiratory educators
- Educate GPs on current chronic lung disease management practises
- Increase access to respiratory educators; train adequate numbers of respiratory educators for all regions of the country and promote role of a certified respiratory educator
- Establish national certification for respiratory educators
- Integrate more asthma and COPD education into relevant practice settings

S.2 Better treatment and rehabilitation

- Establish multi-disciplinary COPD and respiratory clinics in large tertiary care hospitals to manage complex patients with these disorders
- Coordinate care with patient's family physician
- Coordinate current resources for optimal efficiency, e.g. collaborate with cardiac rehab facilities to provide exercise and self-management to pulmonary/other patients while adding a pulmonary component for disease specific management
- Increase access to rehabilitation programs
- Ensure homogenous access to spirometry, medications and special programs (pulmonary rehab, home ventilation, smoking cessation, home O2 etc.)

S.3 Earlier detection

- Diagnose CRDs earlier
- Understand the impact of early diagnosis of respiratory disease conditions on the health of patients
- Increase access to screening, pulmonary rehab programs, medications for those with COPD
- Promote increase use of spirometry especially for at risk groups; explore barriers to the use of spirometry (e.g. by family physicians and others)
- Increase access to sleep apnea diagnosis and treatment
- Ensure trained medical professionals are regularly available to First Nations, Inuit and Métis Peoples and communities

S.4 Patient empowerment and self-management

- Promote patient self-management/responsibility for lifestyle choices and their impact on respiratory health status
- Begin decreasing acute care use for respiratory disease (hospitalizations and emergency department visits) increase rehab programs for patients
- Make health educator consultations mandatory for newly diagnosed patients and upon discharge from hospital or ER
- Increase access to asthma and COPD education (eg. Certified Asthma Educators (CAEs) in clinics and asthma education centres to enable better self management)

C. Supportive Environment (Systems, Human, Community)

S.1 Integrated processes and systems

- Increase the integration of hospital based services (e.g. emergency) with outpatient based services (e.g. family practice)
- Align respiratory diseases with all settings along the continuum of care addressing “systems integration” so that care of the patient is seamless, efficient and effective

S.2 Supportive care

- Lower waiting times for sleep apnea diagnosis and treatment
- Support interventions in primary care
- Establish multi-disciplinary COPD and asthma clinics in smaller community-based hospitals to manage complex patients with these disorders
- Ensure that certified Respiratory Educators are in primary care, clinics, hospitals and communities
- Provide treatment and rehabilitation for all who need it

S.3 Supportive community environments and programs

- Focus on respiratory health of communities, urban and rural, and identify respiratory healthcare providers as champions, conducting research and promoting healthy environments
- Decrease indoor and outdoor pollution
- Reduce the prevalence of Asthma among Aboriginal Peoples and other high risk groups
- Understand the role of community programs (e.g. smoking cessation programs) in improving the health and reducing health service utilization of patients with airways disease
- Understand whether community-based rehabilitation/exercise programs can improve the health and health outcomes of patients with airway disease
- Make all public places and workplaces smoke-free and scent-free
- Ban smoking in all vehicles carrying children
- Improve end of life care for people with CRDs
- Increase access to pulmonary rehab and smoking cessation programs
- Engage employers and community agencies more fully in the prevention of occupational related respiratory disease

D. Surveillance (Including Guidelines and Best Practices)

S.1 Analyze trends for better information and results

- Identify the presence of common and important risk factors for CRDs
- Determine the prevalence and incidence of CRDs in various communities
- Understand the impact of lung problems and health service utilization of individuals with lung problems
- Determine access rates to established CTS diagnostic techniques (especially spirometry) and therapies (COPD rehab, patient education, recommended medications, etc)
- Understand the impact of current pharmacologic and non-pharmacologic therapies on the health and health service utilization of patients with CRD

S.2 Increase monitoring and use of guidelines

- Expand the use of and adherence to relevant clinical practice guidelines for CRDs
- Update emergency room guidelines for asthma and COPD
- Implement relevant guidelines in all practice settings including a regular method for implementing changes or new knowledge, especially in primary care

S.3 Implement best practices

- Identify, assess and implement initiatives that show evidence of best practice and evaluation on an ongoing basis
- Set realistic, measurable and achievable benchmarks
- Develop and implement “best-practices” from existing or emerging CRD prevention and management frameworks
- Identify and develop strategies based on existing models i.e. Wagner’s Chronic Illness Care Model.

S.4 Increase support for surveillance mechanisms

- Continue the respiratory disease surveillance committee with PHAC
- Develop tools (such as Canadian Lung Health test) to increase use of targeted screening for COPD and other CRDs in general population. Have spirometry become part of the “periodic health exam”
- Continue planning with the First Nations and Inuit Health Branch with Aboriginal organizations playing a greater role

E. Research and Knowledge Translation

S.1 Increase funding for chronic respiratory disease research

- Ensure stable funding for research
- Ensure that funding for respiratory research is to equal burden rates

S.2 Find a cure for respiratory diseases

- Investigate more effective pharmacological treatment for CRDs
- Identify the causes of respiratory disease both genetic and environmental
- Explore the role of pharmacogenetics in predicting responsiveness to novel or current medications

S.3 Develop/implement respiratory health norms, standards and guidelines

- Determine normal pulmonary function values (e.g. for Aboriginal Peoples)
- Develop evidence-based standards for home testing for OSA
- Determine evidence-based standards for patient education (patient-centred, self-management)
- Support guidelines development or endorsement when good international guidelines exist
- Disseminate/implement relevant guidelines in all practice settings including a regular method for implementing changes or new knowledge, especially in primary care and at the local level

S.4 Better measure the impact of services and policies on lung problems and health care utilization

- Understand the impact of chronic disease management problems in affecting rates of hospitalization and emergency visits for patients with CRD and asthma; understand the biology of asthma and CRDs
- Understand the impact of multi-disciplinary specialty clinics as well as the implementation of treatment and management strategies in a variety of practice settings in affecting rates of hospitalization and emergency visits for patients with COPD and asthma
- Measure the effectiveness of interventions that promote respiratory health
- Evaluate the effect of the implementation of an integrated strategy
- Demonstrate that basic research and chronic disease management models such as “home based pulmonary rehab” or “self-management education in primary care setting” are effective

S.5 Knowledge translation of research findings

- Evaluate barriers of knowledge transfer from clinical trials to community-based practices
- Determine novel (and improved) ways to communicate “best evidence” to health care practitioners, patients and other stakeholders.
- Communicate best practices to physicians and health care professionals (utilize established respiratory educator programs)
- Continue to and improve upon knowledge transfer to respiratory educators (sharing of experiences, mentoring, training, good ideas, research results)

Conclusions and Next Steps

The Chronic Disease Working Group Report is the result of an intensive research and engagement process involving many stakeholders, however, it also marks the beginning the launch of a collective process to develop the National Lung Health Framework. This Report, along with those from the other Working Groups and other pieces of researcher, will inform the Framework outline being prepared for the “Lung Health Framework: Plan for Action” Working Meeting scheduled for April, 2007. The Meeting represents a key milestone in the collaborative effort to address the challenge posed by respiratory disease in Canada. There will be many more opportunities to build on the efforts of the Working Group, and further stakeholder engagement lay ahead. Members of the Working Group look forward to continued engagement in that process.

Appendices

- A. Working Group Members
- B. Working Group Roles
- C. Workshop Agenda
- D. Pre-Workshop Questionnaire

Appendix A: Working Group Members

CHRONIC DISEASE WORKING GROUP – P PHASE I

Name	Organization
Dr. Gerard Cox – CO-CHAIR	Canadian Thoracic Society
Nancy Garvey – CO-CHAIR	Ontario Ministry of Health and Long-Term Care
Donna Bleakney	Saskatoon Health Region
Dr. Dina Brooks	Canadian COPD Alliance
Vicki Bryanton	The Lung Association – PEI
Dr. Anna Day	University of Toronto
Dr. Ilana Kogan Gombos	Canadian Institute for Health Research
Jan Haffner	The Lung Association - Saskatchewan
Dr. Paul Hernandez	Dalhousie University
Dr. Rick Hodder	University of Ottawa
Dr. Oxana Latycheva	Asthma Society
Douglas Maynard	Canadian Society of Respiratory Therapists
Dilshad Moosa	The Lung Association - Ontario
Robert Ryan	National Aboriginal Health Organization
Mary-Pat Shaw	The Lung Association
Dr. Don Sin	Canadian Research Chair in Chronic Obstructive Lung Disease
Dr. Paula Stewart	Public Health Agency of Canada

Appendix B: Working Group Roles

Working Group Objectives

Each Working Group is to work together to provide recommendations and guidance for the content of the Respiratory Health Framework. The Working Group members will:

- expand on the work completed by working groups at the Pre-Summit, held in April, 2006;
- identify additional stakeholders to be involved in the development of the Respiratory Health Framework;
- identify additional respiratory health issues to be included in the Respiratory Health Framework;
- identify additional goals, objectives, and outcomes to be included in the Respiratory Health Framework; and
- identify potential activities that can achieve these goals, objectives and outcomes.

The primary deliverable of each Working Group is a report reflecting this discussion, to be researched and completed by a researcher assigned to this task. This report will be submitted to the Respiratory Health Framework Steering Committee for consideration.

Chair

The role of the Chair is to work with the Senior Researcher and the Facilitator to ensure that the vision of the Respiratory Health Framework is reflected in the activities and outcomes of the Working Group.

Specific responsibilities include:

- review the members list;
- participate in a teleconference with the Senior Researcher and Facilitator to review the process and meeting agenda;
- review and comment on the goals and objectives of the meeting;
- review (and comment if necessary) on the background materials that will be provided to the members prior to the meeting;
- provide a welcome and introduction at the meeting;
- provide concluding comments at the end of the meeting; and
- if requested by the Steering Committee, to speak briefly at the outset of the Summit about the Working Group activities.

Senior Researcher

The role of the Senior Researcher is to work closely with the Chair and the Facilitator to ensure that the structure and resources are in place for the Working Group to achieve its goals.

Specific responsibilities include:

- identify potential participants for each working group;

- identify the background documents that are required for members;
- develop the goals and objectives of each working group; and
- work with the Facilitator and Chair to identify the strategy that will be used to meet the goals and objectives.

Meeting Facilitator

The role of the Facilitator is to provide the meeting coordination and to ensure that the meeting progresses towards its goal and objectives.

Specific responsibilities include:

- coordinate the Working Group meeting,
- ensure full and meaningful participation of all working group members;
- ensure that the discussion adheres to the identified schedule and meeting structure; and
- identify and review key messages, themes, recommendations, activities, goals, objectives and activities communicated throughout the meeting.

Working Group Researcher

The role of the Researcher is to participate in the meeting as an observer and to ensure that the discussions are reflected in a Working Group report.

Specific responsibilities include:

- participate as an observer in the Working Group meetings and
- produce a report that accurately reflects all discussion points.

Working Group Members

The role of Working Group Members is to identify and discuss issues in respiratory health in Canada, and to make recommendations for issues to be included in the Respiratory Health Framework. Specific responsibilities include:

- become familiar with the past work of the “Breathing Matters” Pre-Summit and other relevant documents;
- Provide feedback through the Pre-Meeting Questionnaire
- participate in a face to face meeting to discuss respiratory health issues in Canada (if scheduling permits);
- review and provide comments on the draft research report; and
- participate in a teleconference call to discuss the draft research report.

Steering Committee

The role of the Steering Committee is to use the Working Group report as a recommendation to identify the issues to be included in the Respiratory Health Framework.

Appendix C: Workshop Agenda

CHRONIC DISEASE WORKING GROUP MEETING - AGENDA

December 11th, 2006

Meeting Location: Novotel Hotel, Whitton Meeting Room, Ottawa, Ontario

Objectives of the meeting:

- *To develop a shared understanding of the strategic issues, challenges and opportunities related to the Tobacco Control theme of the Respiratory Health Framework;*
 - *To articulate the outcomes that we wish to achieve related to the Tobacco Control theme; and*
 - *In light of the desired outcomes, to identify the key results that must be achieved and the activities to be pursued to deliver the outcomes*
-

- 08h30 Coffee
- 09h00 Welcome, objectives of the meeting
- Overview of the agenda and approach for the day
 - Participant expectations
- 09h15 Setting the Stage
- Update on the Respiratory Health Framework
 - Mandate & objectives of the Working Group
 - Identification of additional stakeholders who's perspectives are necessary
 - Individuals
 - Organizations
 - Sectors
 - Researcher's role
 - Proposed logic model and framework elements
- 10h30 Health Break
- 10h45 Identification of Strategic Issues/Challenges/Opportunities
- Important issues/trends/factors
 - Stakeholder expectations
 - Strategic implications and assumptions
- 12h00 Lunch
- 13h00 Development of the Short, Medium and Long Term Desired Outcomes
- In light of the strategic issues/challenges and opportunities, what outcomes do we wish to achieve short, medium and long term
- 14h30 Health Break
- 14h45 Framework Element Key Results
- Working with the proposed framework elements, what key results must we achieve over the next 3 years in order to move the yardstick forward?
- 15h30 Next Steps
- Evaluation
- 16h00 Adjourn
-

Appendix D: Pre-Workshop Questionnaire

CHRONIC DISEASE WORKING GROUP PRE-MEETING QUESTIONNAIRE

Please complete and return by **Thursday December 7th** to:

E-mail address: achapman@lung.ca
Fax: 613 569 8860
Attention: Ainsley Chapman, Senior Researcher

Your Strategic Outlook for the Next 3 Years -

- 1. In order to begin to shape the desired outcomes for the future of Chronic Disease related respiratory health in Canada is important to understand our current and future contexts.**
 - a) With regard to our current environment, what are your key working assumptions (information/knowledge, important issues/ trends, Canadian population expectations, etc.)?
 - b) With regard to the future, what is going on in your world that is either shifting or changing that will have a real impact on respiratory health?

- 2. Strategies work best when people at all levels share a basic common vision in relation to the directions that we are pursuing and outcomes that we are trying to achieve.**

In your mind, what Chronic Disease related outcomes should we be trying to achieve short, medium and long term?

- 3. In light of all of your answers above, what key results must be achieved in the following areas?**
 - a) Applied research
 - b) Surveillance and Monitoring
 - c) Detection, clinical practice and treatment
 - d) Community care and support
 - e) Knowledge transfer
 - f) Public awareness and prevention

From:.....

Phone / fax:

e-mail:.....