

National Child and Youth Health Coalition



Council of Canadian
Child Health Research
(CCCHR)



Paediatric
Chairs of
Canada



Directeurs
de pédiatrie
du Canada



*National Child and Youth Health Coalition (NCYHC)**

And

*The Canadian Institutes of Health Research (CIHR) –
Institute of Human Development, Child and Youth Health (IHDCYH)*

Child and Youth Health Indicators RFA Workshop

May 31 – June 1, 2006
Delta Ottawa Hotel and Suites

Workshop Proceedings

October 4, 2006

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SickKids Foundation - National Grants Program.**



CIHR IRSC
Canadian Institutes of Health Research
Institute of Human Development,
Child and Youth Health

Instituts de recherche
en santé du Canada
Institut du développement et de la santé
des enfants et des adolescents

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CIHR IRSC

Canadian Institutes of Health Research
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Child and Youth Health
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des enfants et des adolescents

EXECUTIVE SUMMARY

BACKGROUND

On May 31-June 1, 2006, the National Child and Youth Health Coalition (NCYHC) and the Canadian Institutes of Health Research (CIHR) - Institute of Human Development, Child and Youth Health (IHDCYH) co-sponsored a workshop to help create the “blueprint” for a Request for Applications (RFA) to develop and nationally validate child and youth health indicators. Clinicians, researchers, and health and policy administrators representing over 25 organisations with an interest in child and youth health indicators attended the workshop.

The RFA is the next important step in an evolving process that began in May 2004. Since that time, over 150 members of the child and youth health and health research community from across Canada have attended two national workshops and have been engaged in six expert panels to develop a national child and youth health indicators strategy.

THE WORKSHOP

Representatives from 16 national and provincial organisations presented brief overviews of their respective organisation’s mandate, their interest in child and youth health indicators, and an assessment of where indicators need to be developed and validated. Following each presentation, research leaders identified common themes across organisations, priorities and gaps, and how best to address these priorities and gaps from a research perspective through an RFA.

All the organisations reported using indicators to make decisions, identified significant limitations with existing data, and supported the need to use robust indicators to make evidence-based policy and service decisions.

OUTCOME OF THE WORKSHOP

Workshop participants identified six RFA clusters and potential themes.

Participants agreed that the RFA should focus on health systems decision-making and that the format of support should be planned around an “operating grant”.

RFA Blueprint Clusters

1. Chronic Disease
2. Disabilities
3. Injury
4. Mental Health
5. Patient Safety
6. Primary Care

Cross Cutting Themes

- Access to care/wait times
- Adverse events
- Burden of illness/care
- Effectiveness of care/outcomes
- Efficiency of resource use
- Health care utilisation
- Quality of care/safety
- Uptake of guidelines and treatments
- Uptake of indicators and impact
- Well-being and resilience

BLUEPRINT

Workshop participants developed a blueprint in each of the six clusters that included key cross cutting themes, the form of support, the level of required funding and timing, and potential funding and health system decision-making partners.

Participants also provided advice on the development of indicators and the RFA to guide the final process. This advice included the following:

The RFA will need to:

- ❑ Be broad enough to get the interest and endorsement of providers and organisations (at local, provincial and national levels);
- ❑ Be focused enough to receive funding and support;
- ❑ Be relevant enough to be useful to policy and decision makers;
- ❑ Encourage research collaborations;
- ❑ Include a requirement to develop research and build training capacity; and
- ❑ Actively engage provincial health system decision-making partners.

The RFA should encourage investigators to:

- ❑ Have clear objectives with clearly understood indicators, clear research questions, and results that will be useful to policy and service decision makers;
- ❑ Maximise the use of existing data and indicators, and include an assessment of what can be done with available data;
- ❑ Address methodological issues to minimise error (such as clarifying definitions and denominators) to ensure that the indicators are useful to planners;
- ❑ Address methodological issues to allow for measuring and tracking compliance;
- ❑ Demonstrate readiness for stakeholder uptake, with the results to be used to make policy, service and/or clinical decisions;
- ❑ Include a knowledge transfer plan that takes into account many audiences, and uses a variety of communication methods;
- ❑ Demonstrate early and long-term wins;
- ❑ Address critical privacy, ownership and data access issues;
- ❑ Assess the impact of new technologies on the development of indicators;
- ❑ Support collaboration and encourage participation between researchers; and
- ❑ Actively engage provincial health system decision-making partners.

PARTNERSHIP DEVELOPMENT

CIHR–IHDCYH and the NCYHC will continue to work with our current partners to determine both in-kind and financial contributions. In addition, new partnership opportunities will be explored.

COMMUNICATION STRATEGY

CIHR–IHDCYH and the NCYHC will also develop a “communications strategy” to inform the broad child and youth health research community of the upcoming RFA and its anticipated outcomes. Workshop participants will also communicate information about the workshop and the impending RFA with their respective colleagues and research communities.

NEXT STEPS

Under the leadership of the CIHR–IHDCYH, a small RFA writing group will be convened to develop the first RFA using the draft blueprint as a guide.

FINAL REMARKS

It is becoming increasingly evident that effective knowledge translation requires continuous long-term interaction between researchers and information consumers. This national program must be understood as a long-term collaboration between partner organisations, researchers, service providers, and policy decision makers, to ensure “uptake” of the anticipated results.

In his closing remarks, Dr Michael Kramer, Scientific Director, CIHR Institute of Human Development Child and Youth Health identified this national research initiative as “the Institute’s Knowledge Translation Flagship.”

ACKNOWLEDGEMENTS

The National Child and Youth Health Coalition would like to acknowledge the leadership and contribution of its colleagues and partners from across the country that have participated in the various stages of development and consultation leading up to this RFA. We would like to extend our appreciation to:

- ❑ All participants and sponsors of the first indicator workshops who set the stage by identifying the key areas for child and youth health indicator development.
- ❑ The six expert panels whom extensively researched and consolidated available information on the identified prime areas for development.
- ❑ The many practitioners, administrators and researchers who provided ongoing input throughout the implementation of the NCYHC indicator strategy.
- ❑ All the workshop speakers, indicator expert panel chairs and organization delegates who participated in the RFA workshop.
- ❑ The members of the National Child and Youth Health Coalition Steering Committee.
- ❑ The CIHR-NCYHC Indicator Working Group - Michael Kramer, Shoo Lee, Bob Armstrong, Louise Poulin, Elaine Orrbine and Susan Pisterman for their steadfast leadership and commitment.
- ❑ Lisa Gordon, Craig Potvin and Joann Trypuc for their expertise and support.

RFA WORKSHOP PROCEEDINGS¹

INTRODUCTION

On May 31-June 1, 2006, the National Child and Youth Health Coalition (NCYHC) and the Canadian Institutes of Health Research (CIHR) - Institute of Human Development, Child and Youth Health (IHDCYH) co-sponsored a workshop to help create the “blueprint” for a Request for Applications (RFA) to develop and nationally validate child and youth health indicators. Clinicians, researchers, and health and policy administrators representing over 25 organisations with an interest in child and youth health indicators attended the workshop. See Attachment 1 for the workshop agenda, and Attachment 2 for the list of participants.

DAY ONE: SETTING THE STAGE

PROCESS

Day One of the workshop set the stage for developing the RFA blueprint. Representatives from 16 national and provincial organisations presented brief overviews of their respective organisation’s mandate, their organisation’s interest in child and youth health indicators, and an assessment of where indicators need to be developed and validated. The organisations were grouped into three panels according to similar or complementary mandates and/or interests.

After each panel’s presentations, two research leaders identified common themes across the organisations, priorities and gaps, and how best to address these from a research perspective through the RFA. The researchers’ observations were followed by a plenary session where all participants provided additional input. The organisations and researchers in each of the three panels are noted in Table 1.

OUTCOMES

Day One resulted in the dissemination of comprehensive information and recommendations for the RFA from the workshop organisers, partner organisations, researchers and service providers. These outcomes are summarized under the following headings:

- ❑ Workshop organisers’ advice on the development of the RFA;
- ❑ Summary assessment of indicator activity and interest of the 16 national and provincial organisations; and
- ❑ Advice and comments specific to each of the workshop panels.

During both days of the workshop, participants provided general comments and advice. This information is consolidated in the section on Day Two Outcomes (Conclusions and Recommendations).

¹ See Appendix A for the Agenda of the Workshop.

Table 1: RFA Workshop Panels

Panel 1: Mental Health and Development	Panel 2: National & Federal/ Provincial/Territorial (FPT) Perspectives	Panel 3: Chronic Health Conditions, Injury & Health Services
ORGANISATIONS		
Human Resources & Social Development Canada (Raynald Létourneau)	Statistics Canada (Mark Hamel)	Public Health Agency – Epidemiology & Surveillance Division (Reg Sauvé)
Canadian Council on Learning (Mark Lachance)	Canadian Institute for Health Information (Indra Pulcins)	Canadian Council on Health Services Accreditation (Christopher Dean)
Child Welfare League of Canada (Gordon Phaneuf)	Public Health Agency – Childhood & Adolescence Division (Mary Johnston)	Health Canada – Healthy Environments & Consumer Safety Branch (Susan Ecclestone)
Provincial (ON) Centre of Excellence for Child & Youth Mental Health (Ian Manion)	FPT Early Childhood Development (Rob Santos)	Transport Canada (Paul Boase)
Alberta Centre for Child, Family & Community Research (Nancy Reynolds – Via Teleconference)	Ontario Ministry of Children & Youth Services (Jill Rettinger)	Canadian Diabetes Association (Donna Lillie)
		Canadian Lung Association (Anne Van Dam)
RESEARCHERS		
Peter Rosenbaum	Boris Sobolev	Ian Pike
Melanie Barwick	Astrid Guttman	Teresa To

WORKSHOP ORGANISERS’ ADVICE ON THE DEVELOPMENT OF THE RFA

The workshop organisers emphasized that developing child and youth health indicators is complex and needs to be understood as an evolving long-term process. It is critical that the initiative be understood as a long-term collaboration between partner organisations, researchers, service providers, and policy decision makers.

There is a need to develop “blueprints” for a number of clearly focused RFAs. These RFAs should:

- ❑ Be broad enough to get the interest and endorsement of providers and organisations (both local, provincial and national);
- ❑ Be focused enough to receive funding and support;

- ❑ Be relevant enough to be useful to policy and decision makers;
- ❑ Encourage research collaborations;
- ❑ Include a requirement to develop research and build training capacity; and
- ❑ Actively engage national and provincial health system decision-making partners.

Recognizing that research funds will be limited in the first phase of the RFA, the release of the RFAs will need to be staggered over time, as additional research funds become available

SUMMARY ASSESSMENT OF INDICATOR ACTIVITY AND INTEREST OF THE 16 NATIONAL AND PROVINCIAL ORGANISATIONS

The 16 national and provincial organisations provided written overviews of their presentation material (Attachment 3). The activity and interest of these organisations in child and youth health indicators are summarised as follows:

- ❑ All the organisations use indicators to make decisions but identified limitations with the validity, reliability, availability, standardisation and fragmentation of the data.
- ❑ All the organisations support using valid, reliable and relevant indicators to make evidence-based decisions that support the implementation of policy and practice.
- ❑ The need for specific indicators varies by the mandate of the organisation.

ADVICE AND COMMENTS SPECIFIC TO EACH OF THE WORKSHOP PANELS

Mental Health and Development

The organisations that participated on the Mental Health and Development Panel, the expert researchers and the workshop plenary discussions identified the need for mental health and development indicators that include but are not limited to the following areas.

- ❑ Health indicators as a predictor of school readiness and learning ability;
- ❑ Indicators for children and youth in the child welfare system;
- ❑ Fatal child abuse indicators;
- ❑ Perinatal development indicators;
- ❑ Indicators for children with developmental disabilities (e.g., autism, and other pervasive developmental disorders);
- ❑ Mental health and early child development indicators in First Nations children and youth; and
- ❑ Indicators that broaden the spotlight and go beyond children and youth to include:
 - Family well-being and functioning which include measures of the functionality of children and youth (e.g., social inclusion, life participation), their caregivers (e.g., effective parenting), and the interaction between them;
 - The community's capacity to support children and youth that includes measures of social and economic support, and measures of participation that reflect quality of life and healthy social development; and

- The sustainability of social institutions, and their responsiveness to individual mental health and development needs. This includes measures of the “health” and integration of the system (e.g., how integrated are the education, social assistance, justice, housing and health systems).

National and Federal / Provincial / Territorial Perspectives

The organisations that participated on the National and Federal/Provincial/Territorial Perspectives Panel, the expert researchers and the workshop plenary discussions identified the need for indicators that includes but is not limited to the following areas.

- Pre-conception health indicators;
- Population- and community-health indicators including risk factors;
- Social and environmental determinants of health;
- Equitable collection of data by geographic region (especially in northern and remote areas), ethno-cultural groups and socio-economic status;
- Standard outcome indicators, as well as the capacity to link indicators to track cause and effect (e.g., do resource investments lead to change and sustained outcomes and improvements?);
- Health system performance indicators such as access to and wait times for services (including primary healthcare), and the effectiveness and efficiency of how services are delivered;
- Indicators to support accreditation, and set performance improvement targets;
- Performance indicators that link data across a number of “systems” such as education, social assistance, housing, healthcare, justice, etc.; and
- Indicators to measure the innovative capacity of the system to implement new technology, manage change, etc.

Chronic Conditions, Injury and Health Services

The organisations that participated on the Chronic Conditions, Injury and Health Services Panel, the expert researchers and the workshop plenary discussions identified the need for indicators that includes but is not limited to the following areas.

- Indicators to measure the exposure and impact of the environment and environmental hazards on the health and development of children and youth;
- Longitudinal indicators to track the impact of chronic conditions on development over the life course of the child;
- Outcome indicators for chronic disease that is appropriate to the development of the child;
- Indicators to identify and track the needs of disabled children;
- Injury indicators that include individual and family behaviours and compliance (e.g., smoking, drinking, using restraints properly);
- Indicators to determine access to emergency services for injuries, and the efficiency, effectiveness, safety and impact of these services on outcomes;
- Injury indicators that include the involvement of police, the judicial system, school and other community organisations; and
- Indicators to support a national surveillance system for injury including intentional injury.

DAY TWO: DEVELOPING THE BLUEPRINT FOR THE REQUEST FOR APPLICATIONS

PROCESS

Day Two of the workshop focused on developing a “*blueprint*” for the RFA. Workshop participants received a summary of the November 2004 recommendations of the six expert panels on indicator development.² Background information was also provided on a variety of CIHR funding programs that might be considered to support the RFA.

Workshop participants reached consensus on the six RFA clusters and themes that were relevant to all clusters (as listed below). Participants also recognized the advantages and appropriateness of researchers and decision-making partners collaborating to develop applications for the RFA competition.

Before breaking off into small groups, an “*RFA blueprint straw dog*” was presented to assist in the development process. Each cluster was asked to address the following questions:

- What are the key content/dimensional themes?
- What level of funding and timing are required to meet these needs?
- Who are potential funding partners?
- Who are potential health system decision-making partners?

After the small group presentations, workshop participants were given the opportunity to offer their “final advice and words of wisdom” on the development of the RFA.

OUTCOMES

IDENTIFYING CLUSTERS AND CROSS-CUTTING THEMES

Workshop participants agreed to develop RFA blueprints for the following six clusters:

1. Chronic Disease;
2. Disabilities;
3. Injury;
4. Mental Health;
5. Patient Safety; and
6. Primary Care.

² The six expert panels were: i) chronic conditions; ii) efficiency; iii) injury prevention; iv) mental health; v) patient safety; and vi) primary care.

In addition, workshop participants agreed upon a list of relevant crosscutting themes that included:

1. Access to care/wait times
2. Adverse events
3. Burden of illness/care
4. Effectiveness of care/outcomes
5. Efficiency of resource use
6. Health care utilisation
7. Quality of care/safety
8. Uptake of guidelines and treatments
9. Uptake of indicators and impact
10. Well-being and resilience

DEVELOPING BLUEPRINTS FOR THE REQUEST FOR APPLICATIONS

Underlying Assumptions

Workshop participants agreed that the RFAs focus should be on health systems decision making with an emphasis on:

- Synthesizing national and international research on indicators;
- Assessing the validity, reliability and usability of the indicators;
- Addressing ethical and operational issues of using indicators; and
- Identifying linkages to decision making.

CONCLUSIONS AND RECOMMENDATIONS

1. The objective of the RFA and the indicators needs to be clearly understood.

The RFA needs to be grounded by clear research questions, and a common and clear understanding of what we need to achieve. Indicators can be both process and outcome based. New knowledge generated by this RFA must be relevant to both policy/decision makers and service providers. The RFA should focus on answering the questions: “what do we need to know to make good decisions?” and “how do we ensure uptake based on these decisions?”

2. The RFA needs to maximise the use of existing data and indicators, and address methodological issues to minimise error.

The RFA should include an assessment of what can be done with available data. This can include but is not limited to:

- Developing an inventory of existing indicators (international, national, provincial, local);
- Determining the validity, reliability and usefulness of these indicators to measure outcomes;

- Uptake of the indicators; and
- Developing indicators in those areas where none or few exist.

3. *The RFA needs to demonstrate readiness for stakeholder uptake.*

The RFA needs to demonstrate that indicators will be adopted and have an impact on policy, service and/or clinical decisions. Potential approaches include getting early and ongoing political, organisational and provider buy-in and support for indicator development, and identifying incentives to use the indicators (e.g., improved organisation performance, accreditation standards).

Barriers to the uptake of indicators should be evaluated along with the impact of these barriers on outcomes (practice and policy).

4. *The RFA needs to include a knowledge transfer plan.*

Indicators can have many audiences including the patient, public, provider, policy makers and producers of the knowledge. Knowledge must be transferred through widespread communications that could include a variety of methods including but not limited to websites, newsletters, professional publications and media.

5. *The RFA needs to demonstrate early and long-term wins.*

There is a need for early wins and longer-term gains. Quick wins should help change practice and improve outcomes.

6. *The RFA needs to address critical privacy, ownership and data access issues.*

The RFA needs to address privacy concerns, ownership of the information, access to the information, and storage and distribution of the information.

7. *The RFA needs to assess the impact of new technologies on the development of indicators.*

The RFA needs to assess the impact of new technologies – such as telemedicine and electronic health records – on the development of indicators and the systems that will be required to collect data.

8. *The RFA process needs to support collaboration and encourage participation.*

If a number of researchers are proposing to conduct the same research, the RFA process should connect the researchers and encourage them to collaborate. Furthermore, the RFA should address a number of clusters, where possible.

If a Letter of Intent is required as part of the application process it should be a “true” LOI rather than a mini-proposal. As well, the CV process for decision makers needs to be streamlined to encourage participation.

NEXT STEPS

As noted earlier, the workshop organisers emphasized that developing child and youth health indicators is complex and needs to be understood as an evolving long-term process. The initiative must be understood as collaboration between partner organisations, researchers, service providers, and policy decision makers. To that end, CIHR and the NCYHC will approach organisations to determine their interest in being decision-making and/or funding partners.

COMMUNICATION STRATEGY

CIHR–IHDCYH and the NCYHC will develop a Communication Strategy to inform the broad child and youth health research community about the upcoming RFA and its anticipated outcomes. Workshop participants will also communicate information about the workshop and the impending RFA with their respective colleagues and research communities.

Under the leadership of the CIHR–IHDCYH, a small RFA writing group will be convened to develop the first RFA using the draft blueprint as a guide. The writing group will be guided by the advice and “blueprints” developed by the workshop participants.

The RFA will:

- ❑ Be broad enough to get the interest and endorsement of providers and organisations;
- ❑ Be focused enough to receive funding and support;
- ❑ Be relevant enough to be useful to policy and decision makers;
- ❑ Encourage research collaborations; and
- ❑ Include a requirement to develop research and training capacity.

From the perspective of CIHR’s Institute of Human Development Child and Youth Health, the indicators RFA will be their “flagship knowledge transfer endeavour” over the next couple of years.

OUR STRENGTH IN COLLABORATION

This document is a reflection and summary of a truly Pan-Canadian collaboration. The National Child and Youth Health Coalition would like to acknowledge the leadership and contribution of our colleagues and partners from across the country that have participated in the various stages of development leading up to this RFA. We encourage our workshop participants to disseminate this document within their respective communities.

ATTACHMENT 1: WORKSHOP AGENDA

**National Child and Youth Health Coalition (NCYHC)
And
CIHR The Institute of Human Development, Child and Youth Health (IHDCYH)**

Child and Youth Health Indicators RFA Workshop

Wednesday, May 31 – Thursday, June 1, 2006
Delta Hotel and Suites – Champlain Room
Ottawa, Ontario

DAY ONE: Wednesday, May 31st, 2006 – Delta Hotel: Champlain Room		
8:00 – 8:30am	Breakfast	
8:30 – 8:45am	Welcome & Overview of Workshop Objectives	Michael Kramer, Scientific Director, IHDCYH
8:45 – 9:00am	Workshop Agenda	Joann Trypuc, Facilitator
9:00 – 9:30am	Roundtable Introductions	Joann Trypuc
9:30 – 10:00am	Why This RFA: Where We've Come From – Where We're Going	Robert Armstrong, Chair – NCYHC
10:00 – 10:20am	<i>Break</i>	
10:20 – 11:25am	Panel 1: Mental Health & Development <i>Organisations – Mandate & Use of / Need for Indicators Researchers – Commentary on common themes, priorities & gaps // How to address from a research perspective</i>	Partners, Stakeholders & Researchers
11:25am – 12:00pm	Open Discussion: Questions & Comments (Re: Clusters, Common Themes and RFA Call)	All Participants
12:00 – 1:00pm	Lunch	

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DAY ONE: Wednesday, May 31st, 2006 – Delta Hotel: Champlain Room		
1:00 – 2:05pm	Panel 2: National & FTP (Federal / Provincial / Territorial) Perspectives: <i>Organisations</i> – Mandate & Use of / Need for Indicators <i>Researchers</i> – Commentary on common themes, priorities & gaps // How to address from a research perspective	Partners, Stakeholders & Researchers
2:05 – 2:35pm	Open Discussion: Questions & Comments (Re: Clusters, Common Themes and RFA Call)	All Participants
2:35 – 2:55pm	<i>Break</i>	
2:55 – 4:00pm	Panel 3: Chronic Health Conditions, Injury & Health Services: <i>Organisations</i> – Mandate & Use of / Need for Indicators <i>Researchers</i> – Commentary on common themes, priorities & gaps // How to address from a research perspective	Partners, Stakeholders & Researchers
4:00 – 4:30pm	Open Discussion: Questions & Comments (Re: Clusters, Common Themes and RFA Call)	All Participants
4:30 – 5:00pm	Synopsis: Clusters, Themes & RFA Call	Shoo Lee, Scientific Director, iCARE
5:00 – 5:15pm	Review of Thursday's Agenda	Joann Trypuc
5:15 – 5:30pm	Concluding Remarks	Michael Kramer
7:00 – 9:00pm	Dinner at "The Empire Grill" (Provided for all workshop participants)	

DAY TWO: Thursday, June 1, 2006 –Delta Hotel: Champlain Room		
8:00 – 8:30am	Breakfast	
8:30 – 8:45am	Where We've Landed – Overview of Day One	Bob Armstrong
8:45 – 9:15am	Cluster Consensus & Group Work Instructions	Joann Trypuc & All Participants
9:15 – 9:30am	RFA Funding	Louise Poulin, Asst. Director Partnerships, IHDCYH
9:30 – 11:00am	<p>Breakout Groups (Maximum 3 – 4 groups) Respond to the following questions:</p> <ol style="list-style-type: none"> 1. What are the key content/dimensional themes? 2. What form of support is needed? (i.e. team development grants, pilot study, systematic reviews) 3. What level of funding is required to meet these needs? 4. Who else needs to be at the table? 	All Participants (self-assign to breakout groups)
11:00 – 11:30am	Break and Check out	
“Blueprint” for the RFA: Objectives and Recommendations		
11:30am – 12:30pm	Breakout Groups: Reports & Discussion	All Participants
12:30 – 1:30pm	Lunch	
1:30 – 2:00pm	Where We've Landed: Synopsis of RFA Objectives & Recommendations	Joann Trypuc
2:00 – 2:30pm	Group Consensus	Joann Trypuc & All participants
2:30 – 3:00pm	Next Steps & Closing Remarks	Michael Kramer
3:00pm	Adjournment	

ATTACHMENT 2: WORKSHOP PARTICIPANTS

Participant Name	Title & Affiliation	Contact Information
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ATTACHMENT 3: OVERVIEWS OF 16 NATIONAL AND PROVINCIAL ORGANISATIONS

Representatives from 16 national and provincial organisations presented brief overviews of their respective organisation's mandate, their organisation's interest in child and youth health indicators, and an assessment of where indicators need to be developed and validated. The organisations were grouped into three panels according to similar or complementary mandates and/or interests.

PANEL 1: MENTAL HEALTH & DEVELOPMENT

Panel Organization: Human Resources & Social Development Canada (HR-SDC)

Representative: Raynald Létourneau
Assistant Director, Strategic Monitoring and Reporting Division
Strategic Analysis, Partnership and Dissemination Directorate

Mandate of HR-SDC:
To monitor statistical trends in human resources and social development

Interest in Indicators:
We are using indicators to monitor various dimensions of Canadian life and present evidence of individual and social well being across the country. Individual and societal well-being is determined by a complex array of interdependent processes and outcomes, taking into consideration individual well-being (or quality of life), the role and sustainability of social institutions, and interactions among individuals and institutions.

Panel Organization: Canadian Council on Learning (CCL)

Representative: Marc Lachance
Associate Director, Monitoring and Reporting

Mandate of CCL:
Improve lifelong learning across the country by:

- ❑ Informing Canadians about the progress of learning in Canada;
- ❑ Promoting a Canada-wide learning culture with our partners; and
- ❑ Promoting and facilitating the exchange of knowledge and information to ensure that success stories are shared and repeated.

The Canadian Council on Learning (CCL) is an independent, non-profit corporation that promotes and supports research to improve all aspects of learning—across the country and across all walks of life.

Interest in Indicators:

CCL will be developing early childhood development indicators in order to report and monitor progress of learning for young children. CCL will be reporting, annually, a report on the Status of Early Childhood and Learning in Canada.

Panel Organization: Child Welfare League of Canada (CWLC)

Representative: Gord Phaneuf
Director of Strategic Initiatives

Mission & Objectives of CWLC:

The Child Welfare League of Canada (CWLC) is a membership-based national organization dedicated to promoting the well-being and protection of all children, especially vulnerable children and youth (0 - 18 years). The CWLC in particular plays a significant role in promoting best practices among those in the field of child protection, child welfare, children's mental health and youth justice. As a membership organization the CWLC provides leadership and support to its members, including technical assistance, timely information on research findings and best practices, and opportunities for networking across provincial/territorial borders.

The CWLC member organizations include provincial/territorial ministries of child and family services, child and family service agencies, health and social services, youth services and university research units and faculties. CWLC members serve over a million families and children each year.

Membership and the services of the CWLC are open and accessible to organizations and persons of all cultures, ethnic origins and social classes. The CWLC provides services, publications and information in both official languages.

Goals of the CWLC:

- ❑ To increase public awareness of the needs of all children, youth and their families;
- ❑ To provide research and information about at-risk children and families;
- ❑ To encourage excellence through the development of standards, particularly for child welfare, mental health and youth justice programs;
- ❑ To promote training for caregivers, volunteers and professionals working with at-risk children and families; and
- ❑ To advocate for values, policies and actions which promote optimal child development.

CWLC Programs:

Standards of Excellence

The CWLC promotes standards of excellence for child and family service organizations.

- Identify quality standards for accessible and available child and family services
- Promote the identification and evaluations of exemplary program and services
- Encourage accreditation of all child and family serving agencies
- Provide consultation and training activities that increase skills and competence of members, board leaders, care providers, staff and volunteers
- Collaborate with national and international organizations to maintain leading-edge standards in programs and services

Best Practices

The CWLC strives to enhance the practical capabilities of child and family service organizations through the support of research and best practices policies and programs.

- Create effective partnerships with other bodies to facilitate research into best practices, identify promising approaches and evaluate service outcomes
- Set research-to-practice as a priority for the Centre of Excellence for Child Welfare and develop a comprehensive program of implementation
- In collaboration with Aboriginal communities conduct and promote research with is reflective of their values as they work to improve the outcomes for children involved with the child welfare and youth justice systems
- Provide consultation and training to support the implementation of effective practices and programs, which enhance the well-being of children, youth and families

Advocacy

The CWLC advocates for public policies, legislation and funding to achieve a supportive, respectful, effective, coordinated, rational and accountable system of support for children and families.

- ❑ Work with other national, provincial/territorial, local and Aboriginal organizations to identify shared goals to ensure that the needs of vulnerable children, youth and families are met;
- ❑ Monitor Canadian public policy and legislative activities and propose effective and accessible initiatives on behalf of children, youth and families;
- ❑ Develop the advocacy capacity of the CWLC, its Board of Directors and member agencies through training, educations and information sharing; and
- ❑ Promote the realization of children's rights articulated in the Convention on the Rights of Child.

Interest in Indicators:

We are committed to enhancing the development of indicators to evaluate how children and youth who come in contact with the Child welfare system are doing.

To that end we have entered into partnerships with a range of organizations to advance the development of the evidence-base in this area. Our partners are drawn from across a number of sectors and include:

- ❑ Provincial / Territorial Directors of Child Welfare
 - ❑ Public Health Agency of Canada
 - ❑ Centre of Excellence for Child Welfare
 - ❑ CIDA
 - ❑ Big Brother and Big Sisters
 - ❑ World Health Organization
-

Panel Organization: The Provincial Centre of Excellence for Child & Youth Mental Health at CHEO

Representative: Ian Manion, Ph.D.
Executive Director, Operations

Mandate of the Provincial Centre of Excellence for Child & Youth Mental Health at CHEO:

The Centre of Excellence believes that an integrated system that meets the holistic mental health needs of children, youth and their families/caregivers in ways that are evidence-based and understood by the community at large is possible. As such, our mission is to be a catalyst for capacity building to improve child and youth mental health in the Province of Ontario. This mission is accomplished through activities relating to the four iterative pillars of the Centre: networks and partnerships, research and development, intervention, and education and training among professionals and the wider community.

Strategic Directions include:

- ❑ Along with other leaders in the field, champion the development of a fully integrated and collaborative child and youth mental health system for the Province of Ontario;
- ❑ Develop and disseminate evidence-based child and youth mental health knowledge and practices;
- ❑ Provide reliable and valid knowledge to support advocacy;
- ❑ Educate all levels of society to reach understanding of child and youth mental health in the whole life of a child; and
- ❑ Break down stigma around child and youth mental illness.

Interest in Indicators:

The Centre of Excellence has been a partner in the National Indicators Initiative from its inception. It provided leadership through the Mental Health Expert Panel and continues its involvement both as a proposed funding partner and through its content expertise. Indicators are key to the development of a fully integrated and collaborative child and youth mental health system. The Centre has undertaken a review of existing information on child and youth mental health care

indicators (frameworks, models, indicators and their measurement) and plans on building on this to support the continued move towards indicator identification and uptake provincially.

PANEL 2: NATIONAL & FEDERAL/PROVINCIAL/TERRITORIAL (FTP) PERSPECTIVES

Panel Organization: Statistics Canada (StatCan)

Representative: Marc Hamel
Assistant-Director, Health Statistics Division

Mandate of StatCan:

The mandate and program objectives of Statistics Canada are to:

- ❑ collect and publish in aggregate formats statistical information on the characteristics and behaviour of Canadian households, businesses, institutions and governments for research, policy development, program administration, decision-making and general informational purposes;
- ❑ collaborate with other participants in the broader national statistical system in extending the system's scope, usefulness and use; and
- ❑ provide leadership, professional expertise and coordination in such efforts.

Interest in Indicators:

Through various surveys, Statistics Canada collects information on several aspects of children's health (for example, the Participation and Activity Limitation Survey (PALS 2001), the National Longitudinal Survey on Children and Youth, the Canadian Community Health Survey (health region component - .1 cycles) and the Canadian Community Health Survey (thematic component on mental health (2002) and nutrition (2004)).

Although the information collected through these surveys can help profile children's health; a recent consultation completed by the Health Statistics Division at Statistics Canada indicates that this information remains fragmented, not standardized, and doesn't target all age groups associated with infants, children, and youth.

Findings from the recent consultation indicate that children's health is a priority. There is a critical need to have comparable data on children's health at various geographical levels, including health region, provincial and national. More specifically, it was reported that both physical and mental health should be addressed. The information should cover the full continuum of health; that is from a disorder perspective to well being. Finally, it should also target the complete spectrum of health care activities, including promotion, prevention, treatment and rehabilitation.

Some initiatives have been developed in recent years to respond to this critical data gap. For example, cycle 2.2 of the Canadian Community Health Survey on nutrition was the first-ever

national survey, which collected provincially comparable data on the nutritional status of children aged 0 through 15 in Canada. In addition to the information collected on nutrition, the survey also collected information on children's measured height and weight, and leisure physical activity.

Statistics Canada, in collaboration with Canadian Institute for Health Information also produces on a regular basis health indicators that are designed to provide comparable information at the Canada, provincial/territorial and health region level. These indicators are based on standard definitions and methods.

Currently, few indicators target specifically children's health. Since most of the indicators are based on survey information collected through the regional component of the Canadian Community Health Survey (.1 cycles), the information is usually available on Canadians aged 12 years and over.

Panel Organization: Canadian Institute for Health Information (CIHI)

Representative: Indra Pulcins, Ph.D.
Director, Health Reports and Analysis

Mandate of CIHI:

CIHI provides Canadians with essential statistics and analysis about their health and their health care system. CIHI is a source of information for those seeking answers to critical questions around the performance of the Canadian health system, the delivery of health care, and the status of Canadians' health.

Specifically, CIHI:

- ❑ Identifies and promotes national health indicators;
- ❑ Coordinates and promotes the development and maintenance of national health information standards;
- ❑ Develops and manages databases and registries: health care services, health human resources, and health spending;
- ❑ Examines what factors determine good health (Canadian Population Health Initiative);
- ❑ Conducts analysis and special studies, and participates in research;
- ❑ Publishes reports and disseminates health information; and
- ❑ Coordinates and conducts education sessions and conferences.

Interest in Indicators:

CIHI, in collaboration with Statistics Canada, develops and disseminates health indicators aim to support Regional Health Authorities in monitoring the health of their population and the functioning of their local health system through quality comparative information on:

- ❑ The overall health of the population served;
- ❑ The major non-medical determinants of health in the region;

- ❑ The health services received by the region's residents; and
- ❑ Characteristics of the community or the health system that provide useful contextual information.

CIHI also produces indicators at the facility level (e.g. Ontario Hospital Report), and to feed into a variety of initiatives such as F/P/T Comparable Health and Health System Performance Indicators. CIHI in particular focuses on the development of indicators related to health system performance, such as quality of care, patient safety, outcomes, etc.

Panel Organization: Public Health Agency of Canada (PHAC) -
Childhood & Adolescence Division

Representative: Mary Johnston
Manager, Fetal Alcohol Spectrum Disorder Team

Mandate of PHAC – Childhood & Adolescence Division:

Development, testing and evaluation of policies, programs and tools and resources to facilitate policy development, program development and evaluation and practice changes.

Interest in Indicators:

Indicators are necessary as the evidence base to identify emerging issues and to make decisions regarding effective policy and program approaches to these issues. Indicators are necessary to identify promising practices and to evaluate whether changes in policies, programs and/or practices are effective or need adjustment.

Indicators are needed regarding the healthy development of children throughout the developmental continuum from pre-conception to conception through the transitions to adulthood.

Panel Organization: Federal/Provincial/Territorial (F/P/T) Committee on Early Childhood Development (ECD) Knowledge, Information and Effective Practices

Representative: Rob Santos
P/T Committee Co-Chair

Mandate of F/P/T Committee on Early Childhood Development:

Based on September 2000 First Ministers' commitment to "work together, where appropriate, on research and knowledge related to early childhood development, share information on effective practices that improve child outcomes and work together to disseminate the results of research"

Three primary functions of the Knowledge Committee:

- ❑ Share ECD knowledge, information and effective practices
- ❑ Influence Canadian ECD research
- ❑ Influence ECD data collection

Reporting:

Knowledge Committee → F/P/T ECD Working Group → F/P/T Deputy Ministers of Social Services and Health → F/P/T Ministers of Social Services and Health

Includes representation from other F/P/T and P/T committees:

e.g., F/P/T Advisory Committee on Population Health and Health Security (ACPHHS); F/P/T Directors of Child Welfare; F/P/T Working Group on Social Development, Research and Information (SDRI); P/T Directors of Early Childhood Education and Care (ECEC)

Interest in Indicators:

The Knowledge Committee supports federal, provincial, and territorial (F/P/T) governments across Canada in their use of indicators for reporting on Early Childhood Development (ECD), in accordance with the September 2000 First Ministers' ECD Communiqué (see excerpt below). These indicators include ECD expenditures, activities, and outcomes of child well-being for the purposes of accountability, monitoring progress, informing policy-making, and improving action for ECD (i.e., the development of children under age 6 years). The Knowledge Committee is interested in improving indicators in order to improve the quality of ECD reporting over time across Canada.

Panel Organization: Ontario Ministry of Children and Youth Services (MCYS)

Representative: Jill Rettinger, Ph.D.

Mandate of MCYS:

To work with other ministries, other levels of government and community partners to develop and implement policies, programs and a service system that: help give children the best start in life; prepare youth to become productive adults; and make it easier for families to access the services they need at all stages of a child's development.

Interest in Indicators:

We use indicators for business planning in the Ministry as well as to monitor the effectiveness of new investments. Examples of indicators used for these purposes include:

- ❑ Reduced wait times;
- ❑ Decrease in problematic behaviour and improved social functioning of clients;
- ❑ Shorter time from referral to service commencement for highest risk cases compared to lower risk cases;
- ❑ Extent to which partners and collaborators believe that service duplication exists and the frequency of duplication;
- ❑ Extent to which partners and collaborators believe that coordination has improved; and
- ❑ Percentage and number of families who report little or no difficulty in "transitioning" from one service or sector to another.

It would be useful to have systematic, standardized comparisons across Canada of decreases in problematic behaviour and improved social functioning of clients – post intervention.

**PANEL 3:
CHRONIC HEALTH CONDITIONS, INJURY & HEALTH SERVICES**

Panel Organization: Public Health Agency of Canada (PHAC) -
Epidemiology & Surveillance Division

Representative: Reg Sauve
Chair, Canadian Perinatal Surveillance System
(Neonatologist & Visiting Scientist, PHAC)

Mandate of PHAC – Epidemiology & Surveillance Division:

PHAC has a mandate to protect the health and safety of Canadians. Its' mission is to promote and protect the health of Canadians through leadership, partnership, innovation and action in public health. It is one of the five areas overseen by the Minister of Health; the areas are CIHR, Hazardous Materials Information and Review Commission, Health Canada, Patented Medicine Prices Review Board and the Public Health Agency of Canada.

Interest in Indicators:

The Canadian Perinatal Surveillance System (CPSS) is one area within PHAC that uses indicators to drive its activities. Other areas within PHAC may use indicators but we are not aware of others related to child and youth health that have taken this approach. The CPSS is designed around a framework that includes perinatal data collection, data analysis and interpretation and communication of information for action. In this case, the data analysis and interpretation and the communication of information for action are based on indicators that were identified when the CPSS began about 10 years ago.

Originally 52 indicators were identified by the national CPSS steering committee using an approach that included consideration of the scientific properties of suggested indicators such as their validity, the feasibility of collecting required data and the importance of the health problems represented by the indicators. They were ranked in a multistage process based on importance of the health issues. They reflect broad determinants of health including but not limited to health care variables.

Currently CPSS is reporting on 27 of the indicators using vital statistics data (including the birth/infant death files linked by Stats Canada), Hospitalization data and national health surveys. The indicators are organized according to broad areas:

Behaviours & Practices – such as rate of maternal smoking and alcohol intake during pregnancy, rate of live births to teenage mothers, rates of live births to older mothers

Health Services – such as rate of labour induction, rate of cesarean delivery, rates of early maternal and neonatal discharge after delivery

Maternal Health Outcomes – such as rates of maternal mortality and severe morbidity, rate of ectopic pregnancy, rate of maternal readmission after discharge following delivery

Fetal & Infant Health Outcomes – such as preterm birth rate, post-term birth rate, small-for-gestational age rate, infant mortality rate and causes of death, prevalence of congenital anomalies

Other indicators (such as prevalence of postpartum depression) were not included because national data have not been available. The upcoming Maternity Experiences Survey will enable the CPSS to report on additional indicators.

Recently the CPSS has undergone an extensive internal and external review and the suggestion was made to revisit the total number of indicators and to reconsider them in terms of practicality (quality of data available) and health impact perspectives.

Panel Organization: Canadian Council on Health Services Accreditation (CCHSA)

Representative: Christopher Dean
Research and Product Development Specialist

Mandate of CCHSA:

CCHSA plays a unique role in health service delivery by assisting health service organizations, across Canada and internationally, to examine and improve the quality of care and service they provide to their clients. We provide an accreditation program that is based on national standards of excellence developed and updated by experts in the field, peer review, and knowledge exchange. Through self-assessment and external evaluation, this accreditation program helps drive improvements in health care.

Interest in Indicators:

CCHSA Standards recognize and include indicators as a key component. The Standards require organizations to use indicators to monitor, assess, and improve the services they offer. At present indicators are developed within individual organizations. However, in response to feedback from member organizations CCHSA is currently in the process of assembling a core set of indicators that will be common across the accreditation program.

As such, CCHSA is interested in the development and validation of indicators that:

- Are national in scope;
- Act as a tool to monitor, evaluate, and improve the quality of services on an ongoing basis;
- Support decision making and be useful for service providers and organizations across the service delivery continuum;
- Promote the use of leading practices; and
- Are linked to CCHSA standards of excellence.

Panel Organization: Health Canada

Representative: Susan Ecclestone
Senior Policy Analyst, Vulnerable Populations Division
Safe Environments Programme

Mandate of Health Canada – Safe Environment Programme:

The Safe Environments Programme promotes healthy living, working and recreational environments by identifying and assessing health risks to Canadians posed by environmental factors. SEP develops national risk management strategies that: help reduce risks to human health from the environment; are supported by scientific research; and directly align with Health Canada's Sustainable Development Strategy.

Within the Safe Environments Programme, the Vulnerable Populations Division serves as a focal point within Health Canada for activities aimed at identifying groups of people in Canada whose health is particularly vulnerable to environmental hazards, improving understanding of the nature and extent of this vulnerability, and taking action to reduce the environmental risks faced by these populations. Work to date has focused on pregnant women and children and is expanding to include other populations that are particularly vulnerable to environmental hazards, such as older adults.

Interest in Indicators:

Health Canada, along with other governments in Canada and North America, recognizes the value of indicators of children's health and the environment in setting priorities, designing interventions and measuring progress. However, the availability of indicators of children's health and the environment is limited and is hampered by lack of data.

The Government of Canada contributed to the development of North American indicators of children's health and the environment via the Commission for Environmental Cooperation. The first report on these indicators is located at <http://www.cec.org/news/details/index.cfm?varlan=english&ID=2693>

The Government of Canada is now working with federal, provincial and territorial governments in Canada to develop indicators of children's health and the environment that are relevant in Canada. A report from a committee of experts proposing a set of such indicators was recently completed (Report Name: Recommended Indicators of Children's Environmental Health (CEH) in Canada).

While still under consideration, the set of indicators put forward in this report provide a rough idea of the indicators that the Vulnerable Populations Division is interested in populating and tracking. For example, indicators related to the following issues are of particular interest to the Vulnerable Populations Division:

- Prevalence/incidence of birth defects;
- Learning disabilities;
- Asthma among children;

- ❑ Incidence of food/water borne illnesses by type among children;
- ❑ Children's body burden of environmental chemicals;
- ❑ Levels of contaminants in drinking water and food;
- ❑ Indoor and outdoor air pollution;
- ❑ Soil quality;
- ❑ Noise; and
- ❑ Ultra violet radiation.

The following are two key initiatives underway outside of Canada related to indicators of children's health and the environment.

America's Children and the Environment – indicators tracked by the US Environmental Protection Agency <http://www.epa.gov/envirohealth/children/>
The Global Initiative on Children's Environmental Health Indicators – under the World Health Organization <http://www.who.int/ceh/indicators/en/>

Panel Organization: Transport Canada

Representative: Paul Boase
Chief, Road Users
Road Safety and Motor Vehicle Regulation

Mandate of Transport Canada:

The Road Safety Directorate ensures the federal government plays a significant leadership role to respond to the road safety challenge in Canada. Almost 200,000 people have perished on our roads in the last 50 years. Transport Canada, in cooperation with provincial governments and national safety organizations, continues its efforts to improve road safety in Canada through Canada's Road Safety Vision 2010, with the goal of giving Canada the safest roads in the world. RSV 2010 targets a 30% reduction in deaths and serious injuries due to motor vehicle collisions by 2010 and is comprised of a number of sub-targets.

In addition, the Canada Motor Vehicle Safety Act empowers the Directorate to establish national safety standards for the design and construction of motor vehicles, tires and child restraints.

The Directorate has a broad range of responsibilities that are of interest to the public. Our mandate is to reduce the number of deaths, injuries, damage to property and the environment, health impairment and energy consumption resulting from the use of motor vehicles in Canada

Interest in Indicators:

Transportation related issues are one of the leading causes of death and injury in youth. The department, along with other road safety partners endeavours to reduce transportation related risk through research, standards and policy. In the area of child restraints, the anthropocentric measurements of Canadian children are important to ensure that the standards and testing related to forward facing, rear-facing and booster seats provide the maximum protection to children in the

event of a crash and also be comfortable and easy to use in order to increase compliance with use laws. Physical characteristics of children, the age/weight/standing height/seated height are important elements of these standards.

Other indicators that are important are the numbers and mechanisms of fatalities and injuries in transportation related collisions.

In addition, a number of use and compliance indicators are important to gauge the correct and appropriate use of safety systems for children, such as all levels of restraint systems and bike helmets. Actual exposure measures to different risks, such as time in vehicle, time on bike, time walking and other less popular transportation options such as scooters and roller blades are also valuable indicators.

Panel Organization: Canadian Diabetes Association

Representative: Donna Lillie
Vice President, Research & Professional Education

Mandate of Canadian Diabetes Association:

The Canadian Diabetes Association works to promote the health of Canadians through diabetes research, service, education and advocacy. With a presence in more than 150 communities across Canada, the Canadian Diabetes Association's strong national network of assistance includes volunteers, employees, healthcare providers, researchers and partners.

Interest in Indicators:

The Canadian Diabetes Association in 2003 published the first North American evidence based Clinical Practice Guidelines for the Prevention and Management of Diabetes in Canada. This critical work has provided the support for clinical indicators in the management of diabetes for all ages of individuals with diabetes in Canada. Our strong commitment to this work continues in the hope that such indicators influence standards of practice and improved health outcomes for people with diabetes. It is also our perspective that such work has the potential to influence public policy agenda's as well.

Panel Organization: Canadian Lung Association

Representative: Anne Van Dam
Manager, National Research Programs

Mandate of Canadian Lung Association:

For over 100 years, The Lung Association has been dedicated to its mission of promoting and improving lung health for all Canadians. A non-profit and volunteer-based health charity, The Lung Association depends on donations from the public to support lung health research, education, prevention and advocacy.

The Lung Association movement began in 1900 to control the spread of tuberculosis and provide better services for TB patients. Today, The Lung Association focuses on all issues that affect the ability of Canadians to breathe every day.

The mission of the Canadian Lung Association is to lead nationwide and international lung health initiatives, prevent lung disease, help people manage lung disease and promote lung health. Our Provincial and national offices work together to help the one in five Canadians who have breathing problems.

Interest in Indicators:

The Lung Association works at the national, provincial and community levels to improve and promote lung health. We focus on chronic lung disease like asthma and COPD, infectious diseases like TB, flu, pneumonia, and breathing disorders like sleep apnea. We provide reliable and trusted information to both citizens and governments, and we advocate for improvements when lung disease patients are getting inadequate care.

Recognizing that many lung diseases can be prevented, we inform people about the health effects of air pollution, indoors and out. We help smokers who are trying to quit, and we provide educational material and programs to make sure fewer people take up smoking. We encourage governments at every level to create laws and policies that promote clean air and protect our lungs.

We fund world-class medical research in Canada to find treatments – and ultimately a cure – for lung diseases. Through the Canadian Thoracic Society and Canadian Respiratory Health Professionals, we help doctors and allied health professionals set the highest standards in patient care, and continue to expand their knowledge about lung diseases and treatments.

On the international stage, we continue the fight against infectious lung diseases. The Lung Association and its partners manage a tuberculosis treatment project in Ecuador that has cured over 1,000 people of this highly infectious disease.

The work of The Lung Association is made possible through the generous donations of Canadians. We need your help to continue our fight against lung disease.