



**Commission for Environmental Cooperation
of North America**

Children's Health and the Environment

**Experts Workshop on
Childhood Asthma Surveillance
in North America**

24-25 November

Montreal, Quebec Canada

Workshop Report

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1 Introduction

On November 24-25, 2003 a group of experts in childhood asthma surveillance were brought together by the Commission for Environmental Cooperation (CEC) of North America in Montreal, Quebec for a one and a half day workshop. The workshop was called for as part of the CEC Cooperative Agenda for Children's Health and the Environment in North America.

The workshop objective, rationale and expected outcomes are described in section 2 below.

The background paper prepared for the workshop collected, organized and presented a significant amount of information on childhood asthma surveillance including:

- diagnosis of asthma in children in each country
- existing asthma surveillance activities in each country
- information on other experiences, research, or resources from which lessons could be drawn.

This workshop report provides a summary of workshop discussions and presents the workshop outcomes including a clear set of recommendations for a path forward for collaboration on childhood asthma surveillance in North America. The list of workshop participants is included as an appendix.

A compact disc has been made for all workshop participants and includes the following:

- workshop background paper
- reference papers or reports noted in the background paper
- all presentations made at the workshop
- workshop report.

All workshop information will be made available on the CEC's website at www.ccemtl.org

Please note: This document was prepared as a record of the workshop. The views contained herein do not necessarily reflect the views of the CEC, the governments of Canada, Mexico, or the United States of America.

2 Workshop Objective, Rationale, and Expected Outcomes

Objective

Foster collaboration among the three countries to improve childhood asthma surveillance systems and their comparability to enhance the understanding of asthma in North America particularly in relation to environmental factors.

Rationale

A sound understanding of the prevalence of asthma and its impacts on various socio-economic groups and geographic regions is key to sound policy making to prevent and reduce asthma among North America's children. Each country has developed their own asthma surveillance systems. A collaborative process is needed now to increase comparability and consistency among the three countries. The capacity for surveillance in each country also varies and the identification of needs and a plan for response will improve overall surveillance required to monitor the impact of policies on the three countries. Over the long term, information on asthma and respiratory diseases could be juxtaposed with information on environmental factors (e.g. air pollution data) to convey messages to the public on how best to protect children's health.

Expected Outcomes

- 1) Collaborative network of experts formed with members from each country who could implement the recommendations of the workshop and foster ongoing collaboration on childhood asthma surveillance in North America.
- 2) Workshop report including:
 - a) Background Paper:
 - describing diagnosis of childhood asthma and the current childhood asthma surveillance activities in each country
 - initiating the trilateral exchange of information and experiences regarding childhood asthma surveillance
 - b) Outcomes of workshop discussions including:
 - Benefits and objectives of trilateral collaboration on childhood asthma surveillance in North America
 - Specific recommendations regarding a strategy and recommended path forward for both the short term and the long term toward improved and coordinated childhood asthma surveillance in North America. These recommendations are to be concrete, clear, realistic (from a policy and financial perspective), and include estimates of how they could be operationalized (including roles, responsibilities, and funding).
These recommendations may include:
 - Key issues of data comparability and how they might be addressed
 - A system for collaborative data analysis, sharing, and reporting (addressing issues such as data confidentiality and ownership)
 - Specific surveillance elements
 - Identification of capacity developments required in each country

3 Workshop Summary

3.1 Welcome and Setting the Stage

Participants were welcomed by Doug Wright, CEC Director Of Programs. He noted the high level of importance placed on children's environmental health issues by the CEC Council and also noted the high level of focus placed on childhood asthma at the recent meeting of the Expert Advisory Board on Children's Health and the Environment in North America. He then provided participants with a description of the CEC as an organization, including background, roles, and mandate.

The workshop chair, Vic Shantora, Head of Pollutants and Health at the CEC, proceeded to set the stage for the workshop. Following a round of introductions of all participants, Vic noted the group had been selected to provide a mix of expertise and experience from the three countries, to provide a balance of representation from various government and non-government organizations, while at the same time to keeping the group small enough to allow for plenty of exchange and productive working sessions. Vic also thanked the steering group for their efforts in advance of the workshop to prepare background materials, to guide the design of the agenda, and to identify participants.

The workshop objective, expected outcomes, and agenda were reviewed and participants were given an opportunity to discuss any questions. Vic emphasized the importance of using the expertise in the room to generate some clear recommendations of how to best move forward toward improved and coordinated childhood asthma surveillance in North America.

3.2 Panel: Childhood Asthma Surveillance in North America: Where are we now?

Peter Gergen, of the National Institute of Allergy and Infectious Disease, acted as moderator for the panel session. A representative from each country began the session by making a presentation building on the information presented in the background paper. Each presentation was intended to provide an overview of the current childhood asthma surveillance activities in each country to inform our understanding of surveillance data and differences between countries.

The country presentations addressed the following topics:

- a) diagnosis of childhood asthma in each country
- b) indicators currently used in each country and how they are measured
- c) available data in each country for asthma surveillance
- d) analyses conducted in each country on patterns of childhood asthma
- e) dissemination processes and products of asthma surveillance information
- f) links between providers and users of asthma surveillance data

Paula Stewart, of Health Canada presented for Canada. Pablo Cortes Borrego of the Instituto Nacional de Enfermedades Respiratorias presented for Mexico. Steven Redd, of the Centers for Disease Control and Prevention presented for the United States. Following each presentation

participants were given the opportunity to ask questions to clarify information presented and information in the background paper.

The panel moderator provided a summary of key areas for discussion based on the country presentations and an informative panel and plenary discussion followed. A significant amount of information sharing took place and participants gained a new understanding of the childhood asthma surveillance activities of each country. In addition, common themes began to emerge in terms of goals of asthma surveillance and key issues that needed to be addressed. These were further discussed later in the day and are summarized in section 3.4.

3.3 Learning From Experience

This session was composed of a series of presentations about collaborative surveillance projects, relevant research, or relevant programs or projects that could be linked to.

Malcolm Sears, of the Firestone Institute for Respiratory Health, presented information about the very successful International Study of Asthma and Allergies in Childhood (ISAAC). He described the history of the study and the results from the first two phases. He also described work currently ongoing in the third phase and what lessons could be learned from the ISAAC experience.

Paul Miller, the Program Manager for the Air Quality Program of the CEC, presented information about cooperation on North American air quality issues, programs in this area, lessons from trinational collaboration, and opportunities for linking to children's health issues. He also briefly described the Ciudad Juarez study recently released which examined health impacts on children of the increased truck traffic at this border point.

Alisa Smith, of the US Environmental Protection Agency, provided a brief summary of the Border 2012 agreement and programs in the US and Mexico including initial work completed under the US-Mexico Border Childhood Asthma Surveillance Projects. She also described the El Paso Children's health study that examined the relationship between asthma and various risk factors. Alisa also noted two examples of international collaboration and community intervention the group could look to: the Partnership for Clean Indoor Air and the Cleveland Air Toxics Pilot Project.

Teresa To, of the Hospital for Sick Children, described her research in developing a population based pediatric surveillance system. Her research examined the use and connection of administrative databases in Ontario for childhood asthma surveillance. She described the benefits and limitations to this approach, lessons learned to date, and her ongoing research in the area. While results are preliminary she was very positive about the use of administrative databases for surveillance.

Maria Hoy, of the General Directorate of Epidemiology, described the Mexico Asthma Epidemiological Surveillance Project. This project uses PDAs (e.g. Palm Pilot) for the collection of asthma surveillance data from doctors. The data will then be collected and made available on

the internet and will also be published in a health bulletin. The prototype forms and software have been designed and will be tested in eight hospitals in January.

Neil Johnston, of the Firestone Institute for Respiratory Health, shared his experience with designing a system for internet monitoring of children's respiratory diseases. A cohort of children (or parent) began reporting their symptoms daily via the internet. His experience to date has demonstrated this to be an innovative and effective way to use technology combined with dedicated parents to gather surveillance data.

3.4 Summary of Day 1 Accomplishments and Discussion

The following "as it was heard" summary was provided by Tanis Frame, workshop coordinator. Participants agreed it was an accurate summary of their discussions.

Sharing of Information- There was a tremendous amount of information exchanged and discussion generated on the first day of the workshop. Participants developed an increased understanding of how asthma surveillance is conducted in the three countries and the strengths, limitations, and challenges of each. Participants discussed many technical issues and shared insights from experience and research. Innovative ways to gather data were shared including the use of tools such as PDAs and the internet, and of course invaluable resources such as mothers of asthmatic children.

Network Formed- Both organizers and participants were very pleased with the mix of people in the room. An excellent network of experts was formed and participants appreciated the opportunity to connect with each other. The hope was expressed that this workshop be a starting point to launch a network of experts valuable not only to the CEC but also to each of the participants for their ongoing work in this area to take advantage of and build on each other's strengths.

Build on Existing Surveillance Data- There was general consensus that for our purposes a large new surveillance system is not the answer, but rather we can build a useful system out of the data sources that already exist. From the existing surveillance systems in each country, with some work we could present the data in an integrated manner to provide a broad North American childhood asthma surveillance picture. The data may not be directly comparable across the countries but it can describe how childhood asthma is changing over time in each country. Perhaps then several dedicated research projects could be identified to answer specific research questions such as the link between certain pollutants and asthma. Through increased trilateral exchange, understanding and cooperation, the surveillance systems could be improved and become increasingly compatible and comparable over the long term.

Surveillance Objectives- The group emphasized the importance of both understanding the objectives of existing surveillance systems and of defining our objectives for improved North American childhood asthma surveillance. Some objectives could include: tracking the disease over time in each country, comparing the disease across the three countries, generating hypotheses to test, using it as an indicator or air quality. The need for timeliness was also discussed and is directly related to the objective for surveillance.

What to look at- The group defined the decision of ‘what to look at’ as a key issue in many respects. Naturally, deciding what to look at is linked to your objective. Some of the decision points discussed include: diagnosis vs. symptoms, burden of undiagnosed asthma, disease activity, cause vs. exacerbation, regional vs. national specificity, health care utilization- positive and negative, active care and medication preventing reaction to risk factors.

Common Diagnosis- While participants recognized the issue of a common diagnosis of childhood asthma and the important link to surveillance data, they agreed that many other groups are already working to address this issue, so this group should focus elsewhere. Later it was noted that promotion of the existing guidelines could be done through the health care professionals training project at the CEC.

Multiple Risk Factors- Participants agreed that asthma is a multi-factorial disease and that while environmental pollution is one important factor it is neither the only factor nor likely the most important factor. It is therefore important to keep these other factors in mind to and ensure that systems gather data on many risk factors that than individually.

Harmonizing with Risk Factor Data Systems- Workshop participants discussed the importance of harmonizing the design of health data systems with risk factor data systems to facilitate overlap of the two sets of data produced. Currently systems are designed in isolation resulting in difficulty linking the data.

Regional Differences- The importance of taking into account the various regional differences across North America was emphasized, both within and across countries. Some examples include: regional differences in risk factors, regional differences in health care systems and access, regional differences in technology use.

3.5 Working Session: Developing a Strategy

The objective of this working session was to develop a strategy and recommend a path forward, for both the short term and the long term for collaborating on childhood asthma surveillance in North America and to explore ideas on how to link surveillance data to environmental monitoring in order to better understand exposure and health outcomes. The workshop participants broke up into three simultaneous breakout groups to address specific questions and develop recommendations. A reporter from each breakout group then presented the recommendations developed in each group. This was followed by an open discussion on each group’s recommendations.

The question addressed by each group along with the set of recommendations developed is presented below:

GROUP 1: If we were to develop a coordinated approach to childhood asthma surveillance in North America, what could we collect, and how could we organize and analyze it?

1. TRILATERAL COLLABORATION

- to learn and share from both a policy and research perspective
- a means to link surveillance and research work: to generate and test hypotheses in order to sort out the environment – asthma link
- generate new ideas we wouldn't have otherwise
- to influence country and global activities

2. DATA DICTIONARY

- Build on the background paper
- Document the metadata to better understand the surveillance data available in the three countries.
- Include a summary of the childhood asthma surveillance indicators used and how they are measured. Group them as follows:
 - 1) incidence
 - 2) prevalence
 - 3) symptoms and quality of life
 - 4) health service utilization
 - 5) other asthma related factors e.g. Race, socio-economic status (SES), access to health care, obesity, exposure to environmental tobacco smoke (ETS).
- Objectives: short term: better understanding of how to pull together Nam CAS data, longer term: to trigger moving toward more comparable data in the long term.

GROUP 2: How could we best gather, share, and disseminate the information?

1. CEC INFORMATION CLEARINGHOUSE:

- Diffuse and share expertise and information
- Support/facilitate network of experts
- Network helps CEC to develop next steps

2. PULL TOGETHER DATA HAVE AVAILABLE

- Trilateral NPHS/asthma surveillance (national databases)
- Collect and assemble
- Result- national information for each country that is comparable/compatible
- Limitations: lacks specificity: age, geographic
- Issues around confidentiality, ownership, privacy

3. SENTINEL STUDY

- To relate symptoms to exposure we need to gather new information
- Network of asthma kids- using a common methodology, study design may very slightly i.e. Use of PDA, internet, etc.
- Focus on specific geographical region i.e. a border area

GROUP 3: How could childhood asthma surveillance be linked to environmental monitoring data over the long term?

1. AIR MONITORING NETWORKS

- Good for behaviour less for asthma
- More PM 2.5
- Harmonized btw the three countries

2. INDOOR AIR ENVIRONMENT

- How to continue into measures of air quality in indoor environment
- Standardized survey questions (common)
- Periodic census of indoor environment
- 5 contaminants of concern as well as heating cooking
- surrogate measures e.g. How many propane tanks are sold
- include on questionnaire time activity- where does child spend time
-

3. ASTHMA

- harmonization of medical history and intake data

4. MULTIDISCIPLINARY APPROACH

- including training

3.6 Plenary Discussion

Participants discussed and examined the recommendations made by each breakout group. Several common ideas were identified, and several recommendations fit together or built on one another. The group then spent some time working together to focus the recommendations. They asked whether each was a legitimate three-country project, whether the CEC was the most appropriate institution to take on the work or what role the CEC should play. They also focused the recommendations on the basis of priority or logical sequence. The participants concluded with the development of four clear recommendations for short term action, and a fifth recommendation for action over the longer term. These recommendations agreed to by the participants, along with a description of other workshop outcomes are presented below in section 4.

4 Workshop Outcomes and Recommendations

4.1 Outcomes

Network of experts in childhood asthma surveillance:

A dedicated and dynamic network of experts has been formed who have demonstrated a willingness and aptitude to help guide the work of the CEC in this area. Many new contacts were made that will be useful to participants on an ongoing basis and it is hoped that this network can be an ongoing resource for both the CEC and all workshop participants.

Exchange of information:

A tremendous amount of information was exchanged through the preparatory work and at the workshop itself. It is anticipated that this exchange will continue on both a formal and informal basis.

Agreement on the value of collaboration in this area:

Participants supported collaboration on childhood asthma surveillance and research for the following reasons:

- to learn and share from both a policy and research perspective
- a means to link surveillance and research work: to generate and test hypotheses in order to sort out the environment – asthma link
- generate new ideas we wouldn't have otherwise
- to influence country and global activities

Recommended role for the CEC:

Participants suggested the CEC is best suited to act as a clearinghouse to diffuse and share information and expertise. In addition, the CEC is also suited to support and facilitate the newly formed network of experts. In turn the role of the network is to help the CEC to further develop and take action on next steps, and over the longer term help develop the linkages to other appropriate institutions such as the Pan American Health Organization and the World Health Organization.

4.2 Recommendations

The participants agreed on the following four recommendations for a path forward toward improved and coordinated childhood asthma surveillance in North America.

RECOMMENDATION 1: Integrate Existing North American Childhood Asthma Surveillance Data

This area of work will build on the work initiated by the steering group in the preparation of the background paper. The intention is to expand and improve that collection of information to:

- help the three countries, on an ongoing basis, better understand surveillance of childhood asthma in the three countries,

- to improve the ability of the three countries to pull together the childhood asthma surveillance data in the most comparable way possible,
- to provide a means to understand changes childhood asthma in each country over time, and
- trigger the three countries to move toward more comparable data in the long term.

Step 1: Develop a Data Dictionary

- Build on the information in the background paper
- Document the meta data of each data source to better understand the surveillance data available in the three countries.
- Build on the current descriptions of strengths, limitations, and caveats of each data source.
- Include a summary of the childhood asthma surveillance indicators used in each country and how they are measured. As a means of organizing the report and improving comparability across the countries, group the indicators as follows:
 - 1) incidence
 - 2) prevalence
 - 3) symptoms and quality of life
 - 4) health service utilization
 - 5) other asthma related factors e.g. Race, SES, access to health care, obesity, ETS.
 - 6) environmental monitoring

Step 2: Design a Data Template

- Based on the learning that took place to build the data dictionary, and using the terminology clearly defined in the data dictionary, develop a data template.
- This data template is a tool to help countries organize and input their current childhood asthma surveillance data in a way that is most compatible and comparable between the countries.

Step 3: Populate Template with Data

- Each country will input real childhood asthma surveillance data into the data template.
- This will provide an inventory of all childhood asthma surveillance data from North America organized and presented in a common format.
- Once this third step is reached the media for the collection of data will need to be determined. Workshop participants recommended a internet/web based, rather than paper based report be explored.

Implementation:

- A small dedicated trilateral group of experts should be identified through the CHE team and the Asthma Surveillance Steering Group.
- This small group should have an initial conference call to further scope the time and resources that would be required to complete the three steps. It is estimated to be a small endeavor not requiring a large amount of resources.
- The CEC's role would be to organize, facilitate and provide secretariat support to the group of experts.
- The first two steps would be completed by this small group of experts through a series of conference calls and work over email.

- The third step would be completed by each country.

RECOMMENDATION 2: Sentinel Study

The group recommended that in order to relate symptoms to exposure we need to gather new information rather than rely on general surveillance data. A sentinel study was suggested. This study would include a network of children with asthma across North America and use a common methodology in each country. It was also noted that the study design used in each country may vary slightly to take advantage of the best means for collecting data i.e. the use of PDAs, internet, etc. The study could focus on specific geographical regions such as border areas.

Detailed scoping of such a study would take some work by a trilateral group of experts in this research area. This initial scoping step will help to determine if conducting such a study is of interest to the three countries and if it is feasible from a research design standpoint. Finally, funding for the conduct of the study would need to be identified.

Implementation:

- A small dedicated trilateral group of experts should be identified through the CHE team and the Asthma Surveillance Steering Group.
- This group will begin by further scoping out the research design of the sentinel study, to determine interest in the three countries in conducting the study, and to identify sources of funding to conduct the study.
- It was suggested that work begin with a conference call and the scoping exercise could likely be completed with a 1-2 day experts workshop.
- The role of the CEC would be to organize, facilitate and provide secretariat support to the group of experts in scoping and designing a path forward for conducting this study. The original intent is not for the CEC to take the lead in conducting the actual study, but rather to facilitate.

RECOMMENDATION 3: Common Indoor Air Survey Questions

In response to a lack of indoor air monitoring information that could be linked to health outcomes the group recommended the development of a common set of standardized indoor air survey questions that could be added to the existing national health survey in each country. This approach maximizes use of existing survey mechanisms and moves toward more comparability across the three countries as survey questions are standardized. It was noted that regional differences would need to be taken into account to get data that is relevant broadly but also relevant to the issues of a particular region i.e. wood burning, ETS, ventilation, etc.

Implementation:

- A small dedicated trilateral group of experts should be identified through the CHE team and the Asthma Surveillance Steering Group.
- This group can work within their own countries to examine the current survey questions, process for adding questions and country preferences for new survey questions on indoor air quality.
- The group can then come together to draft a set of common questions for addition to each national survey.

- An initial conference call can be used to best scope the amount of time and effort required to complete this project.
- The CEC's role would be to organize, facilitate and provide secretariat support to the group of experts.

RECOMMENDATION 4: Air Quality Monitoring

Air monitoring networks in North America serve a number of policy and research goals. Measuring pollution in the air provides air quality planners with important information on current air quality and the progress of control measures in meeting air quality goals that are driven by public health concerns. Air monitoring also provides an important “real world” check on the accuracy of air emissions inventories and the relative importance of different pollution sources on air quality. Monitoring also serves a crucial role in pollution forecasting and public outreach efforts. While these are useful for regulatory purposes that arise from public health concerns, air monitoring networks can and should more directly support public health goals through their design and access to information. With regard to children's health, air monitoring networks should include siting criteria that can support investigations assessing children's exposure to ambient air pollution.

The participants recommended that North American air monitoring networks should collaborate with children's environmental health experts in developing uniform North America criteria for appropriately locating air monitors in sites representative of children's exposure to ambient air pollution. Network designers should also develop harmonized criteria for quality control and quality assurance of the measured data and uniform auditing procedures to ensure monitor performance is comparable across North America. Timely and easy access to the measured air quality data should also be a priority for network managers so that children's health investigators will have the information readily at hand to support their studies.

Furthermore, there is an emerging need to acquire greater ambient monitoring information on fine particles, specifically PM_{2.5} (particulate matter 2.5 microns or less in diameter). A more uniform approach to air monitor siting, measurement and data access, as well as increased information on PM_{2.5}, will greatly support studies of children's exposure to ambient air pollution.

RECOMMENDATION 5: Harmonization of Medical History and Intake Questions

As a tool to improve our knowledge of asthma and to improve surveillance data, it would be useful to collect the same information from patients in terms of medical history and intake questions asked. This could be linked to working towards a common diagnosis. It was noted that while there is some work going on in this area, it would be an enormous endeavor and that launching any activities may be premature at this time. It was suggested that this recommendation be put on hold, but be kept in mind for future consideration.

Appendix A: Trilateral Workshop Steering Group Membership

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Appendix B: Workshop Participants



Trinational Experts Workshop on Childhood Asthma Surveillance in North America

Taller trinacional del grupo de expertos en
vigilancia del asma infantil en América del Norte

Atelier tripartite d'experts sur la surveillance
de l'asthme pédiatrique en Amérique du Nord

Montreal, Quebec, Canada
24-25 November 2003

Liste finale des participants / Final List of Participants / Lista final de participantes
26/11/2003

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