

Establishing Child and Youth Health Indicators Workshop “Part Deux”

**November 10, 2004 from 2:30 – 8:30pm
The Grand Salon at the Fairmont Queen Elizabeth Hotel, Montreal, Quebec**

Expert Panel Presentation of Recommendations

- 1. Name of the Expert Panel: *Chronic Conditions Expert Panel***
- 2. We would like to thank the following Expert Panel members for their time and support:**

Jonathan Kronick (Co-Chair), IWK Health Centre

Peter Steer (Co-Chair), McMaster Children's Hospital

Tim Frewen (Co-Chair), Children's Hospital of Western Ontario

**Marilyn Booth, Ontario Children's Health Network (OCHN), and The Hospital
for Sick Children**

Linda Côté-Brisson, Centre mère enfant du CHUQ, Quebec

Debbie Cameron, Canadian Association of Occupational Therapists

Christopher Dean, Council for Canadian Health Services Accreditation

Ciaran Duffy, Montreal Children's Hospital

Pat Elliot-Miller, Children's Hospital of Eastern Ontario

Margaret Lawson, Children's Hospital of Eastern Ontario

Indra Pulcins, Canadian Institute of Health Information (CIHI)

**Peter Rosenbaum, CanChild Centre for Childhood Disability Research,
McMaster University**

Sarah Shea, IWK Health Centre

Sheldon Spier, Alberta Children's Hospital

Teresa To, The Hospital for Sick Children

Shirley Vande Wetering, Asthma Care, Calgary Health Region

3. Review of process

- **Literature review - performed search for current literature on effectiveness of care indicators for asthma, diabetes and technology dependent in children**
- **Panel members reviewed potential sources, which were then compiled in a reference list**
- **Expert Panel members divided into three subgroups (asthma, diabetes, technology dependent children) based on panel member's area of expertise and interest**
- **Subgroups met separately to develop action plan for the identification of current indicators and the development of recommendations for future directions**
- **Subgroup searched for current indicators**
 - **Information gathered by panel members and other contacts**
- **Each subgroup mapped current indicators to CIHI framework**
 - **Gaps in current indicators/ information were identified and recommendations for new indicators/ future directions were developed**
- **Subgroups provided regular updates to expert panel members during teleconferences**
- **Final recommendations were developed based on the key question/goal, "to measure the effectiveness of care", and specific areas of priority**

Asthma Health Indicators

Recommendations from the Asthma Subgroup

We would like to thank the following Asthma Subgroup members for their time and support:

Peter Steer (Co-Chair), McMaster Children's Hospital

Sheldon Spier, Alberta Children's Hospital

Teresa To, The Hospital for Sick Children

Shirley Vande Wetering, Asthma Care, Calgary Health Region

Key Deliverables

Deliverables	Points to Consider
<p>a.) Key goals/questions to be addressed</p> <p>Overall Goal: to measure the <i>burden</i> of childhood asthma and its health <i>outcomes</i>.</p> <p>Specific Goals:</p> <p>1. Characterization of “burden of illness”:</p> <p>(1) What is the burden of childhood asthma in Canada? (“Burden” will be characterized by prevalence, incidence, morbidities and mortality associated and attributable to childhood asthma in Canadian children and youths).</p> <p>(2) What is the trend (changes) of burden of childhood asthma in Canada?</p> <p>(3) Does the burden of childhood asthma differ in different sub-populations of children (e.g. SES, First Nations, rural residents etc.)</p> <p>2. Appropriateness of asthma management: How knowledgeable and compliant are asthma health care providers with the current Canadian Asthma Consensus Guidelines in asthma management?</p> <p>This will be measured by: health care providers’ involvement/role in:</p> <ul style="list-style-type: none"> • Device technique review asthma 	<ul style="list-style-type: none"> ▪ Why were these issues as the goals/questions to be addressed? <ol style="list-style-type: none"> 1. Asthma is the most prevalent chronic conditions in children. 2. Despite the establishment of consensus guidelines in asthma management and the availability of effective medications, the prevalence of childhood asthma in Canada continues to rise. 3. The first step to understanding the quality of care provided to children with asthma is to characterize the burden; secondly to measure the appropriateness, effectiveness and efficiency in their asthma management and thirdly to assess the health outcomes associated with asthma management. 4. Mortality associated with asthma is rare, therefore it would be important to focus on morbidity measures when we characterize the effectiveness and efficiency of asthma management.

<ul style="list-style-type: none"> • Management plan/patient attitude/knowledge • Assessment of control/patient visit • Use of inhaled corticosteroids (ICS)/patient (average dose/patient, # of ICS canisters/patient, # of ICS prescriptions filled/patient) • Physician attitudes towards asthma <p>3. <i>Effectiveness of asthma care (proxy health outcome measures):</i></p> <ol style="list-style-type: none"> (1) What are the levels of acute and ambulatory health services used by children with asthma? (2) How much of these health services use could be attributable to asthma? (3) Are there changes over time in the pattern of health services use in children with asthma? <p>These questions will be addressed by measuring the following:</p> <ul style="list-style-type: none"> • Hospital admission/re-admission rates • Emergency room visits • Unscheduled visits to family physician • Reported Control of Asthma by physician <p>(4) How accessible are health care resources to families and children with asthma?</p> <p>This will be measured by:</p> <ul style="list-style-type: none"> • Asthma educators/capita • Asthma specialists/capita <p>(5) What is the overall well-being of children with asthma?</p> <p>This will be measured by the level of asthma control in:</p> <ul style="list-style-type: none"> • Beta2 agonist/wk • Symptom days/wk • Symptom nights/wk • School absenteeism • Activity limitations • FEV1 	<ol style="list-style-type: none"> 5. While typical morbidity measures include health services use, it is also important to assess the quality of life in children with asthma. 6. Since availability (accessibility) of health services (and the type of them) is associated with the likelihood of them being more/less utilized, it would be important to measure the number of asthma health care providers (such as specialists and educators) per capita and by provinces and regions. 7. Both incidence/prevalence, health services use and health outcomes could be confounded by social and health determinants, co-morbidities, risk factors outside those related to the health system, it would be important to assess all the above by sub-groups (e.g. SES, smokers, rural vs. urban etc.) whenever data are available. 8. Monitoring over time the burden, morbidity & mortality and health outcomes in children with asthma will aid in assessing the impact of interventions and management programs delivered to these children. 9. Asthma health indicator could be used to track the impact of health policy, prevention and asthma management strategies.
<p>b.) Recommendations on existing/available indicators to address the key goals/questions</p>	<ul style="list-style-type: none"> ▪ Sources of the current indicators ▪ Validity and reliability of the sources and indicators

<p>Specific existing/available indicators include:</p> <p><i>Prevalence (and/or incidence) data:</i> The National Longitudinal Survey of Children and Youth (NLSCY) followed children from birth to adulthood started in 1994 currently have data available through to 2002 (children were re-surveyed every 2 years).</p> <p>The ISAAC Questionnaire could also be considered in identifying physician-diagnosed asthma per capita, wheezing in the past year per capita.</p> <p><i>Morbidity (health services use) in children with asthma:</i></p> <ul style="list-style-type: none"> • <u>Inpatient health services use</u>: The CIHI has inpatient data at the population-level and since 2002 emergency department data have been routinely collected. • <u>Outpatient health services use</u>: physician visits and laboratory tests performed (such as PFTs) could be captured at the provincial level (e.g. in Ontario, the OHIP data could be used) <p><i>Mortality data:</i> Asthma as an underlying cause and/or contributing cause of death could be obtained through death certificates from Vital Statistics and/or through Health Canada's National Mortality Database.</p> <p><i>Health Outcomes:</i> NLSCY has measures on health status, and activity limitations. More standard measure of quality of life should consider a standard measure such as the Juniper Quality of Life questionnaire.</p>	<ul style="list-style-type: none"> ▪ Extent to which indicators are supported by evidence <ol style="list-style-type: none"> 1. The NLSCY has included 5 questions related to asthma. Previous studies have showed that the use of these questions yielded reliable/consistent estimate of asthma prevalence. The advantage of NLSCY is that it is a national longitudinal survey with children sampled that represent the general population. 2. CIHI data are collected in a systematic fashion across institutions and across Canada. Inpatient data dated back to 1992 (that are linkable). It provides a solid source of both cross-section and longitudinal assessment. 3. Physician billing data (such as the OHIP billings) are available in a number of provinces, but the accuracy of relating a service to a specific diagnosis such as asthma is often being challenged. 4. Health status as measured in a single question (how well do you rank your child's health?) has been shown to have high correlation to more detailed measures of quality of life measures.
<p>c.) Recommended process to validate indicators at a national level</p>	<ul style="list-style-type: none"> ▪ Opportunities for partnerships ▪ Potential funding agencies ▪ Timelines

<p>Prevalence data using national population based survey such as the NLSCY could be very powerful. Validation of such data/statistics will require complete access to the NLSCY. Furthermore, future incorporation of ISAAC questions into the NLSCY would be important to allow for cross-country (or international) comparisons. The use of administrative database such as the CIHI and physicians billings to identify asthmatics would be efficient (affordable) if proven accurate.</p> <p>Morbidity: The use of administrative databases such as the CIHI: DAD (discharge abstract database) and NACRS (national ambulatory care registration system) to measure health services use as a proxy measure of severity.</p> <p>Appropriateness of asthma management</p> <p>Accessibility of care</p>	<p>Partnership: Health Canada and Statistics Canada: To have access to the NLSCY and also provide feedback and input to “better” utilize this survey to capture information relevant to children with asthma. Funding: Health Canada</p> <p>Partnership: Currently, the Ontario Asthma Surveillance Information System (OASIS) is in the process of developing and validating an algorithm in identifying children with asthma from the CIHI database. Funding: Provincial Ministry of Health, CIHI, CIHR/CHSRF (Canadian Health Services Research Foundation)</p> <p>Partnership: OASIS, CIHI, ICES and ICES equivalent health services institutes in other provinces. Funding: Provincial Ministry of Health, CIHI, CIHR/CHSRF (Canadian Health Services Research Foundation)</p> <p>Partnership: Two Ontario initiatives currently underway in assessing the effectiveness of guidelines in asthma management, both are supported by the Ministry of Health. The Asthma Alberta Strategy is another template and potential partner to be considered. Funding: Provincial Ministries of Health</p> <p>Partnership: Canadian Network of Asthma Care (CNAC) has an up-to-date list of asthma educators, which could be collated with population statistics to yield number of educators/capita. Canadian Lung Association (CLA) and Canadian Thoracic Society (CTS) also are potential partners to evaluate the materials available and utilized by health care professionals, families and patients. Funding: CLA, CTS</p> <p>Partnership: National Association of Children’s Hospitals and Related Institutions (NACHRI)</p>
<p>d.) Recommendations for new indicators</p>	<ul style="list-style-type: none"> • Research questions

SEE BELOW	<ul style="list-style-type: none">• Validation process at a national level See above and below
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Future Directions for Asthma Indicators and Monitoring:

The 2004 report entitled “*Review of Proposed National Health Priority Area Asthma Indicators and Data Sources*” produced by The Australian Centre for Asthma Monitoring, Woolcock Institute of Medical Research supported by the Australian Institute of Health and Welfare (AIHW) Canberra suggested **23** asthma indicators to monitor asthma. These indicators were developed by the AIHW in consultation with consumers and representatives from clinical, academic, statistical, policy, and prevention backgrounds. Areas covered by these 23 indicators span across:

- Prevalence
- Health care utilization
- Co-morbidities
- Impact (quality of life, disability, disease severity and mortality)
- Risk factors
- Management practices.

Our current recommendations as outlined above built upon the AIHW model while recognizing the limitation of data sources we have in Canada. Our recommended asthma health indicators covered 4 of these 6 areas thoroughly. The remaining two areas: co-morbidities and risk factors are important, they are included in our framework, but data may not be available at the national level.

Specific indicators that we currently do not have solid data on but are included in the AIHW model and should be considered in our future development are:

Proportion of people with asthma who:

- have a recent, written asthma action plan, developed in consultation with their GP;
- attend a health professional or carer at least six-monthly for review of their asthma action plan;
- have had spirometry measurements in the last 6 months

Suggestions: These questions could potentially be incorporated in the national population surveys and/or the Canadian Community Health Survey (CCHS). Long-term validation will be a joint effort between researchers and the suggested partners. Funding will have to be sought through agencies such as the CIHR, CHSRF and Health Canada.

Diabetes Health Indicators

Recommendations from the Diabetes Subgroup

We would like to thank the following Diabetes Subgroup members for their time and support:

Marilyn Booth, Ontario Children's Health Network (OCHN), and The Hospital for Sick Children

Margaret Lawson, Children's Hospital of Eastern Ontario

Key Deliverables

Deliverables	Points to Consider
<p>d.) Key goals/questions to be addressed</p> <p>Identify indicators of effectiveness for the care of diabetes</p>	<ul style="list-style-type: none"> Why were these issues as the goals/questions to be addressed?"
<p>e.) Recommendations on existing/available indicators to address the key goals/questions</p> <p>Well-being</p> <ul style="list-style-type: none"> HgbA1c Diabetes Quality of Life Scale for Youth Days of school missed <p>Health Conditions</p> <ul style="list-style-type: none"> Prevalence of diabetes-related complications (e.g. nephropathy, retinopathy) Incidence of cerebral edema in DKA Incidence of obesity and Type II Diabetes in aboriginal and non-aboriginal children <p>Deaths</p> <ul style="list-style-type: none"> Incidence of death from DKA, or severe hypoglycemia 	<ul style="list-style-type: none"> Sources of the current indicators Validity and reliability of the sources and indicators Extent to which indicators are supported by evidence <p>CPSP Survey</p> <p>Stats Canada, CIHI</p>

<p>Health Behaviors</p> <ul style="list-style-type: none"> • Teen smoking <p>Living & Working Conditions</p> <ul style="list-style-type: none"> • Access to diabetes camp • Restrictions at school/extracurricular activities related to diabetes <p>Personal Resources</p> <ul style="list-style-type: none"> • Provincial/private insurance funding for diabetes supplies <p>Acceptability</p> <ul style="list-style-type: none"> • Patient Satisfaction <p>Appropriateness</p> <ul style="list-style-type: none"> • Compliance with the Canadian Diabetes Association guidelines: <ul style="list-style-type: none"> - Frequency of HgbA1c measurements - HgbA1c levels vs. targets for age - Frequency and appropriateness of complication screening <p>Competence</p> <ul style="list-style-type: none"> • Access to <i>certified</i> diabetes educators (CDA) <p>Continuity</p> <ul style="list-style-type: none"> • Program for transition to adult diabetes care <p>Effectiveness</p> <ul style="list-style-type: none"> • HgbA1c levels vs CDA targets for age • Admission for DKA (a) at diagnosis and/or (b) post diagnosis • Emergency visits for hypoglycemia and/or intercurrent illness <p>Efficiency</p> <ul style="list-style-type: none"> • Admissions (and LOS) at diagnosis for those not in DKA (reflecting access to multidisciplinary team for outpatient education) 	<p>CDA</p> <p>CIHI</p> <p>NACRS</p> <p>CIHI</p>
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<p>Resources</p> <ul style="list-style-type: none"> • Paediatric diabetes educators/capita • Paediatric diabetes specialists/capita <p>Population</p> <ul style="list-style-type: none"> • Days of school missed for diabetes related illnesses/visits <p>Health Services</p> <ul style="list-style-type: none"> • Access to 24 hour hotline for urgent medical advice • Availability of team support for school issues • Access to a standard education curriculum <ul style="list-style-type: none"> • Number of sessions • Taught by? 	<p>PCC – Academic Workforce Database CDA Provincial sources (NOPDP – Ontario, Nova Scotia Diabetes Programs)</p>
<p>f.) Recommended process to validate indicators at a national level</p> <ul style="list-style-type: none"> • Better organize internal capacity and collaborative opportunities • Explore partnership with CIHR, CIHI, etc. • Tap into respective expertise (CIHR, etc) to develop an RFA 	<ul style="list-style-type: none"> • Opportunities for partnerships • Potential funding agencies • Timelines <p>CIHR</p> <p>CIHI</p> <p>Stats Can</p> <p>CDA</p> <p>NOPDP</p>

Technology Dependent Children Health Indicators

Recommendations from the Technology Dependent Children Subgroup

We would like to thank the following Technology Dependent Children Subgroup members for their time and support:

Peter Rosenbaum, CanChild Centre for Childhood Disability Research, McMaster University

Tim Frewen (Co-Chair), Children's Hospital of Western Ontario

Linda Côté-Brisson, Centre mère enfant du CHUQ, Quebec

Debbie Cameron, Canadian Association of Occupational Therapists

Ciaran Duffy, Montreal Children's Hospital

Pat Elliot-Miller, Children's Hospital of Eastern Ontario

Sarah Shea, IWK Health Centre

Key Deliverables

Deliverables	Points to Consider
<p>a.) Key goals/questions to be addressed</p> <p>First key question to be asked in this subtheme was <u>to define who was being discussed</u> under the issue of 'Technology Dependent Children' and how was that being defined. Decided to expand the group being discussed to 'Children with Multiple Complex Needs'. Decision was made to define this group as 'Children with multiple health/developmental needs are those that require multiple services from multiple sectors, in multiple locations' An ecological, family centred framework was chosen as the framework through which to look at indicators</p>	<ul style="list-style-type: none"> ▪ Why were these issues chosen as the goals/questions to be addressed? <p>Wide recognition that, despite the fact that complex needs may arise from a host of conditions that affect children's health or development, the impact of these conditions on children, their families and the community has much more in common than the various disparate diagnoses would imply. This idea, known as non-categorical approach has conceptual (Pless & Pinkerton, 1975) and data-based support (Stein & Jessop, 1982) in the literature.</p> <p>Framework chosen because: Huge impact of issues experienced by children with multiple complex needs on parents and families <u>and</u> No easily identifiable common biomedical or functional outcomes that can be applied to this varied group</p>
<p>b.) Recommendation of <u>existing/available indicators</u> to address key goals/questions</p>	<ul style="list-style-type: none"> ▪ Sources of the current indicators ▪ Validity and reliability of the sources and

<p>Suggest using measures of family-centred service.</p> <p>1. Measure of Processes of Care (MPOC) – measures parents’ experience of family centred care – developed and published by <i>CanChild</i></p> <p>2. Amount of respite services available – type and numbers of hours</p> <p>3. Use of respite services by families</p> <p>4. Number of needs identified by families</p> <p>5. Number and nature ‘technology’ devices utilized by children with complex needs (of course there is a need to define ‘devices’)</p> <p>6. Amount of mental health services utilized by families</p>	<p>indicators</p> <ul style="list-style-type: none"> ▪ Extent to which indicators are supported by evidence <p>Measures of family centred-service represent a common metric across varied disorders, disabilities and diagnoses. This approach to measurement can be applied to any situation of chronic health or development.</p> <p>MPOC is reliable and valid MPOC is strongly correlated with parental satisfaction with services and inversely correlated with stress (in dealing with services) and with parental mental health. Published peer-reviewed studies are available and have been replicated in other countries</p> <p>There are likely data available on some of these indicators in at least some of the jurisdictions within Canada but time has not allowed an opportunity to explore the literature in this regard</p>
<p>c.) Recommended <u>process to validate indicators</u> at a national level</p> <p>Due to the complexity of the issues in this sub-theme, additional work is needed to look further into the literature on all indicators mentioned above as well as to explore any missing indicators. There is also a need to develop more specific and clear ideas about the nature of ‘technology’ use in this broad and disparate population.</p> <p>A start up grant is suggested as a way to do a complete literature search in these areas.</p>	<ul style="list-style-type: none"> ▪ Opportunities for Partnerships ▪ Potential funding agencies ▪ Timelines <p>Partnerships with various funding organizations are possible, including Hospital for Sick Children Foundation, Bloorview MacMillan Foundation, CIHR etc. This work can also be done in partnership with existing (e.g., <i>CanChild</i>) and emerging (e.g., Ontario Rehabilitation Research Network) groups</p> <p>STATS CAN</p> <p>Health Canada</p> <ul style="list-style-type: none"> • Secretariat of Palliative and End-of-Life Care <p>CIHR</p> <ul style="list-style-type: none"> • Canadian Institute of Health Services and Policy Research
<p>d.) Recommendations for new indicators</p> <p>Indicators # 2 to 6 above should be considered as potential new indicators depending on evidence available</p>	<ul style="list-style-type: none"> • Research development • Partnerships and funding • Validation process at a national level <p>Key partners in any new development of measures and indicators should include parents of children with multiple complex needs</p>

<ul style="list-style-type: none">• Explore the relationship between families' experiences and models of service delivery (eg. Coordination across professionals, coordination between professionals and families, coordination between tertiary and community based services)• Explore coordination of services across systems such as health, education, social services, recreation, vocational.• Explore policy and legislative dimensions of these issues and how they do or do not support family well-being.	<p>parents of children with multiple complex needs to ensure that the 'right' things are being assessed and valued.</p> <p>Funding sources as above.</p>
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