

National Child and Youth Health Coalition



Council of Canadian
Child Health Research
(CCCHR)



National Child and Youth Health Coalition Indicator Program Strategic Pathways

Rationale

The Canadian public and policy-makers alike have recognized the need to address gaps, inequities and the very sustainability of the Canadian healthcare system. We are entering a period of reform.

Several large scale commissions reviewed the state of healthcare in Canada, consulted with the public and key stakeholders and presented their recommendations (Kirby, 2001, 2004; Romanow, 2002). New initiatives and public agencies have been established to move agendas forward (e.g. Primary Health Care Transition Fund, 2003 Health Care Renewal Accord, Health Council of Canada, Public Health Agency, Canadian Patient Safety Institute). A common theme has emerged – the need for indicators to provide accurate assessments of the state of the nation's health, to evaluate the impact of policy, service and other interventions and to address the critical issue of accountability.

As such, the National Child and Youth Health Coalition has an unprecedented and time sensitive opportunity to ensure that the unique needs of Canadian infants, children, youth and their families are clearly represented and addressed in health policy, service and research.

The NCYHC Indicators Program

The Coalition launched the Indicator Program in 2004:

“To identify existing indicators and develop new indicators that will be used to monitor and evaluate the health of, and the health services provided to, infants, children, youth and their families. The aim is to improve services and, thereby, the health and wellbeing of infants, children, youth and their families”.

Six expert panels were created, harnessing the expertise of over 80 professionals from coast-to-coast: Patient Safety, Injury Prevention/Trauma, Mental Health, Primary Care, Chronic Conditions and Efficiency. Borrowing from the CIHI / Statistics Canada Indicator Framework (see below), each Panel identified key questions that needed to be addressed to advance the health and healthcare of Canadian infants, children and youth, reviewed the literature for existing indicators and recommended the development of new indicators with a focus on future research. Potential partners and funding sources were also identified.

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Health Indicator Framework



Better Health Information for Better Health

www.cihi.ca



Canadian Institute
for Health Information
Institut canadien
d'information sur la santé



Statistics
Canada
Statistique
Canada

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A Steering Committee was then created, comprised of the co-chairs of the six Expert Panels and key partner organizations - the Canadian Institute of Health Information (CIHI), the Canadian Institutes of Health Research (CIHR), the Canadian Council on Health Services Accreditation (CCHSA) and the Public Health Agency of Canada. With input from an expert consultation community of over 100 health researchers, practitioners, administrators, and decision-makers a “Strategic Pathways” plan was developed to transform the Expert Panels’ visions and recommendations into concrete strategies that could yield both immediate successes and long term impact.

Indicators Strategic Pathways

I. Immediate Uptake of Selected Existing Indicators

The uptake of indicators is a primary objective of the NCYHC Indicator Program. Where indicators exist, and are valid, and reliable, uptake by organizations like CCHSA, CIHI and others can provide a powerful mechanism for advancing national paediatric health service standards. This pathway can yield immediate concrete results with long term impact.

Work is currently underway with CCHSA to identify and incorporate a number of the indicators identified by the Expert Panels. The focus at this time is on patient safety with a plan to incorporate other valid indicators as CCHSA’s indicator program grows.

II. Development of an RFA for “Child and Youth Health Indicator Development and Validation”

There is a serious gap in our knowledge of child and youth health and healthcare as a result of the lack of nationally validated and empirically derived indicators. The Expert Panels have underscored the need for indicator development and validation to support empirically-based decision-making; the NCYHC Indicators Program has adopted the stance that scientifically validated/developed indicators must set the standard.

To this end, the NCYHC is seeking collaboration with CIHR and other national partners to develop an RFA for the development and national validation of child and youth health indicators.

The following eight areas were identified as cross cutting themes derived from the priority research questions of the six Expert Panels and consultation with our broad expert community. The purpose of the RFA will be to develop and validate indicators that can address these key areas.

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Cross Cutting Indicator Research Priorities

1. How can we reliably measure wait lists for services for infants, children and youth with different conditions? How can we measure the impact of these wait lists on prognosis and outcome, including the range of outcomes for the family and the health care system? What are the unintended outcomes of wait times? How can we measure which wait lists are the most significant and have the greatest impact on outcome in order to set priorities?
2. How can we measure the burden of illness and burden of care for infants, children and youth with different conditions at different developmental stages, in different cultural groups and geographic regions? What is the burden for the affected individual, his/her family and for society? How can we measure “complexity” both from the biological and higher level system perspectives? How can we measure the needs of families with children with complex needs?
3. How can we measure well-being and resilience in infants, children, youth and their families with respect to health i.e., physical, mental and social well-being? How do we measure resilience with respect to coping with or recovering from illness and trauma? How do we measure the capacity to benefit from interventions or treatment?
4. How can we measure the uptake of condition-specific care guidelines and evidence-based treatments for different conditions for generalists and specialists? How can we measure the impact of this uptake on quality of care, in particular primary care, health care utilization and health outcome?
5. Health care utilization is affected by a variety of factors within the child, family, community and culture and health care system. How do we identify and measure these determinants and factors across the continuum of care? How do we measure “inequality” within the system and its impact on health and system outcomes?
6. How do we measure adverse events across the continuum of health care? How do we measure safe health care?
7. How can we measure the current health resources being expended on infants, children and youth across the continuum of care? How would we know if we were making the best use of resources? How do we determine whether resources are too much, too little and allocated in the right places for particular conditions and patient groups?
8. How can we measure the uptake of indicators and the impact of their utilization on the healthcare system and health outcomes? How can we measure quality improvement?

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III. Research Application: *Addressing the Gaps*

This longer term strategy would build on the RFA pathway and help set the stage for a national research agenda and strategy. The specific objective would be to conduct research using the newly developed and/or validated indicators to address the gaps and key issues identified by the Expert Panels.

This third strategy will be facilitated by the concurrent establishment of a national framework of child and youth health research that will be led by the Canadian Council for Child Health Research (CCCHR) within the National Coalition. This initiative links all of the major child health research bodies with the institutions responsible for delivery of tertiary regional and provincial health care services. These institutions in turn are linked to the community health care system. This will provide a powerful laboratory through which the indicators can be used to define gaps and in turn develop strategies for intervention which can be rigorously evaluated and applied.

Through this strategy we expect to significantly increase research attention to the area of child health and health services and improve the capacity for knowledge translation and uptake across the country. The Coalition support for training child health clinician scientists through the CCHCSP will help to ensure that we have the capacity to provide the research expertise in this field.

In Conclusion

The National Child and Youth Health Coalition has established the framework for significantly advancing our capacity to utilize research to answer the important health and health care issues facing Canadian infants, children, youth and their families. The development, validation and application of paediatric indicators underpin empirically-based decision making at all levels of health/care – the individual, the practitioner, the administrator, the policy-maker.

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