

FEBRUARY 2017



CHILDREN COUNT

ASSESSING CHILD AND YOUTH SURVEILLANCE
GAPS FOR ONTARIO PUBLIC HEALTH UNITS



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PUBLIC HEALTH UNITS

ACKNOWLEDGEMENTS

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We wish to acknowledge the following individuals for their prior contributions to this project:

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The project team greatly appreciates the survey respondents and key informants who took the time to participate in this project.

The project team thanks Public Health Ontario (PHO) for its support of this project. The team gratefully acknowledges funding received from PHO through the Locally Driven Collaborative Projects program. The views expressed in this publication are the views of the project team, and do not necessarily reflect those of PHO.

Suggested citation: Population Health Assessment LDCP Team. Children Count: Assessing Child and Youth Surveillance Gaps for Ontario Public Health Units. Windsor, ON: Windsor-Essex County Health Unit; 2017.

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EXECUTIVE SUMMARY



Supporting good health and positive well-being is fundamental to ensuring children and youth are able to reach their full potential. The need for high-quality health and well-being data is a shared priority across many sectors, and such data is required for targeting resources towards people with the greatest needs, for evaluating the impact of policies, and for planning and delivering equitable evidence-based services. Despite the need for data to drive evidence-informed decision making, there are considerable gaps and limitations related to Ontario's ability to monitor child and youth health, primarily because the province lacks a sustainable and coordinated surveillance system.

To address this issue, the aim of this Locally Driven Collaborative Project (LDCCP) was to determine current practices, identify gaps, and explore novel approaches in regards to the collection, analysis, and reporting of local health status for school-age children and youth (Grade 1-12) in Ontario.

The first phase (March-May 2016) of the project was an environmental scan survey of Ontario PHUs to: (i) determine challenges and barriers to assessing child and youth health status, and (ii) access to and usability of existing data sources for identifying local needs. In total, collaborative input was collected from 377 public health professionals from 34 of 36 Ontario PHUs (94% response rate).

Key findings from the environmental scan survey of Ontario PHUs:

- Most PHUs reported that insufficient data, barriers to accessing data, and analytical capacity gaps are challenges associated with child and youth health data.
- Mental health, healthy eating, growth and development, physical activity, and positive parenting were identified as the areas with the greatest need for more data.
- Data gaps and insufficient sample size for local estimates were compelling PHUs to actively collect their own data on children and youth; 84 examples of surveys were described.
- PHUs were generally aware of the existing data sources for child and youth health, but fewer were actually able to use these data sources to meet their needs for local assessment and surveillance.
- Moving forward, PHUs have requested that secondary data sources in general be improved by: having greater local sample sizes, filling in data gaps, better coordinating of efforts, enhancing accessibility, ensuring useful stratifying variables, and removing financial barriers.
- There was strong support for a coordinated surveillance system in Ontario, particularly if it will provide standardized data at the local PHU level. PHUs thought it ought to be headed by a provincial government body (e.g., ministry, resource centre, or affiliated organization).

The second phase (June-October 2016)

of this project sought a broader perspective on child and youth assessment and surveillance through interviews with key informants from relevant sectors in Ontario. Eleven interviews were completed with key informants from government (n=4), academia and research (n=3), and education (n=4), who were actively engaged in collecting, analyzing, and reporting on child and youth health data in Ontario. The interviews were coded thematically into five categories: needs, challenges and barriers, opportunities for improvement, current approaches, and emerging areas of interest.

Key findings from the interviews with key informants:

- There was a predominant need for high-quality data that could be used for multiple purposes including assessment and surveillance, program planning, evaluation, and decision-making.
- There was a commonly identified need for stronger partnerships and collaboration.
- Key informants identified systemic issues as a major challenge or barrier; particularly the lack of resources and disjointed surveillance efforts.
- Data and methodological limitations (mainly inadequate local sample sizes), survey fatigue among students, and challenges of collaborating effectively were the other dominant themes.
- The majority of key informants thought that expanding or augmenting existing assessment and surveillance efforts was the best opportunity for improvement. Most key informants identified room to improve collaborative work between all sectors. There were also opportunities to implement foundational changes to address systemic issues, particularly the cumbersome and inconsistent research ethics process in schools.
- Key informants identified a variety of techniques and approaches currently being used for assessment and surveillance of children and youth in Ontario. Sampling in school settings and collaboration were common components of many current approaches.
- Child and youth mental health was a common area of interest among nearly all key informants and across all sectors. Healthy eating and physical activity were other frequently identified areas of interest among key informants.



Child and youth mental health, physical activity, and healthy eating were common areas of interest among key informants from all sectors.

This project took great effort to capture perspectives on the system of assessment and surveillance for child and youth health in Ontario from current system users and contributors. Through surveying and interviewing stakeholders from public health, education, academia, and government, the project team feels confident that the following recommendations are essential to improving the system of assessment and surveillance to be more responsive at the local, regional and provincial level.



Recommendation 1:

Establish a Provincial Task Force

Establish a provincial task force, with membership representing key stakeholders, which will aim to identify next steps for improving assessment and surveillance of child and youth health and well-being in Ontario.

- a. Recruit leadership representatives from government, public health, education, and academia to form a provincial task force. This includes, but is not limited to, representatives from public health units, Public Health Ontario, school boards, university and research institutions, the Ontario Ministry of Education, the Ontario Ministry of Health and Long-Term Care, and relevant resource centres. These representatives will meet regularly.
- b. The task force should produce a briefing with recommended next steps for improving the assessment and surveillance of the health and well-being of Ontario children and youth.
- c. Experts and stakeholders should be consulted when necessary, and the task force should build on the work of this report and previous work, as well as coordinate with other current initiatives related to assessment and surveillance of children and youth.
- d. The task force should provide guidance and oversight for the implementation of its recommendations and the recommendations of the present report.

Recommendation 2:

Advocate for Children and Youth

Raise awareness among decision makers about the importance of quality data on children and youth, and the opportunities for improving assessment and surveillance of this population.

- a. The Population Health Assessment LDCP team should actively and regularly engage in knowledge exchange activities with relevant decision-makers, including the dissemination of project deliverables and updates on next steps.
- b. The Province of Ontario, which includes the Ministries of Education and Health and Long-Term Care, should develop a shared mandate that will drive changes in the assessment and surveillance of child and youth health.
- c. Ontario public health units and school boards should collaboratively advocate the needs of their child and youth populations to their respective decision-makers.
- d. The Ontario government and relevant ministries should support assessment and surveillance province-wide so that all child and youth populations are included irrespective of locality.

Recommendation 3:

Support Multi-sectoral Collaborations

Promote meaningful, multi-sectoral partnerships and collaborations that foster effective and efficient assessment and surveillance of children and youth.

- a. The Ontario education system should move towards a more consistent and simplified research process that allows for better collaboration with government and academic researchers and lessens the burden on local boards of education.
- b. Explore implementing a student health and well-being surveillance system within the Ontario education system that is standardized and universal for all Ontario schools in collaboration with public health and academia. School boards should also be allowed to complement such a universal system with individualized assessment efforts.
- c. Improve communication and feedback mechanisms between academic institutions, school boards, and public health units, such that there is open sharing of data and results across sectors.

Recommendation 4:

Strengthen and Coordinate Existing Surveillance Systems

Invest in enhancing and expanding existing approaches to meet the needs of identified stakeholders in Ontario.

- a. Increase the awareness of existing child and youth data sources in Ontario, including the strengths and limitations of these sources, among different sectors and stakeholders.
- b. Prioritize the collection of data for mental health, healthy eating, and physical activity among children and youth in Ontario.
- c. Increase the number of children and youth surveyed to allow for useful and reliable estimates at the local level.
- d. Create mechanisms to foster better response rates, including the use of passive consent.
- e. Ensure that health and well-being data is linked to other variables including age, sex and gender, household income, postal code, and parental education.
- f. Standardize metrics across surveillance systems so that data can be compared across regions and within regions.
- g. Support systems that incorporate direct measures where appropriate and possible.

Stakeholders from local public health, academia, education, and other government agencies described many challenges and gaps related to the assessment and surveillance of child and youth health in Ontario. The current approach as experienced by these stakeholders is seen as inefficient. Individual efforts to address health data gaps drain limited financial and human resources and leads to duplication. Capacity at PHUs, schools, and other institutions is limited by locality and availability of resources, resulting in inequity in the system of surveillance and assessment for children and youth. The primary root cause of these issues is the lack of a dedicated data source for children and youth that is representative and reportable at the local level. Unlike other Canadian provinces and developed countries, Ontario lacks an integrated, sustainable, and coordinated surveillance system to monitor child and youth health. Investing in such a system would enhance the impact of our healthcare dollars, provide evidence to inform decision makers about planning of health services, reduce inefficiencies across sectors, increase accountability, and, most importantly, it would be an invaluable asset to the health and well-being of children and youth in Ontario.

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GLOSSARY

Active Consent – participation requires explicit consent (e.g., verbally or written) to be provided prior to the study; lack of explicit consent in any format precludes the subject from participating in the study.

Assessment – systematic collection, analysis, and reporting of data.

Data Gap – there is inadequate data available or a lack of data for a particular measure.

Environmental Scan – surveying the current industry landscape for a range of data that can be used to identify strengths and weaknesses, opportunities for improvement, and partnerships.

Health Behaviour – knowledge, practice, and attitudes that contribute to health-related actions.

Health Outcome – a specific and measurable health event (e.g., injury, illness) that afflicts an individual or population.

Indicator Gap – adequate data is available, or potentially available, but a relevant indicator definition is lacking.

Key Informant Interview – interview with an individual who has first-hand knowledge or experience in a particular area of interest.

Local level – the geographic region serviced by a public health unit in Ontario.

Longitudinal Data – data collected on the same individual or population at regular frequencies over time.

Passive Consent – subjects are enrolled as participants by default and only those who explicitly refuse to participate are precluded from the study.

Primary Data – data that is collected by the user of the data for a specific purpose.

Public Health Unit – Ontario is divided into 36 regions that are each serviced by a public health unit; each is governed by a Board of Health and Medical Officer of Health, and provides programs pursuant to the Ontario Public Health Standards.

Risk Factor – a determinant (behaviour, exposure, attribute) that is associated with a health outcome.

Secondary Data – data that is collected by an administrator with the purpose of being shared and used by other data users.

Stratifying Variable – variables that are used to divide the data into categories for analysis (e.g., male and female, age, household income).

Surveillance – continuous systematic collection, analysis, interpretation, and reporting of health data.

Qualitative – data or analysis that encompasses non-numerical observations and results.

Quantitative – data or analysis that encompasses numerical observations and results.

ACRONYMS

APHEO – Association of Public Health Epidemiologists in Ontario

BORN – Better Outcomes Registry and Network

CCO – Cancer Care Ontario

CODE – Council of Ontario Directors of Education

COMOH – Council of Ontario Medical Officers of Health

iPHIS – Integrated Public Health Information System

LDCP – Locally Driven Collaborative Project

LHIN – Local Health Integration Network

MCYS – Ministry of Children and Youth Services

MOH – Medical Officer of Health

MOHLTC – Ontario Ministry of Health and Long-Term Care

OPHEA - Ontario Physical and Health Education Association

OPHS – Ontario Public Health Standards

PHO – Public Health Ontario

PHU – Public health unit

STD – Sexually Transmitted Disease

INTRODUCTION

What is the issue?

The health of children and youth significantly influences overall societal well-being. Research has demonstrated that unhealthy childhood exposures, stimuli, and behaviours can have long-lasting effects that can impact all aspects of health and well-being later in life [1-3]. Thus, it is not surprising that child health and well-being is a top priority for the World Health Organization and other public health institutions around the world [4]. In order to effectively protect and promote child and youth health and wellbeing at the local, regional, and provincial level, it is necessary to have data that allow for population health assessment and surveillance activities specifically tailored to this population and their unique and diverse needs.

The Ontario Public Health Standards (OPHS) state that local public health units (PHU) are required to conduct epidemiological analysis of surveillance data specific to child and youth health, which refers to the ongoing, systematic collection, analysis and interpretation of health data for health planning, program implementation, and evaluation. The OPHS Foundational Standards also require monitoring of trends over time, identifying emerging trends, and targeting child and youth priority populations.

Despite this priority and mandate to conduct assessment and surveillance of child and youth health, there are considerable gaps in the current system in Ontario. Individual efforts by PHUs to fill in these assessment and surveillance gaps often leads to duplicated, inefficient, and costly approaches. Without a coordinated approach, local PHUs, as well as other stakeholders, are impacted, including provincial-level government institutions, schools, researchers, and other end-users of the data as there is no interface or forum for stakeholders to communicate and collaborate [5-6]. Moreover, there is a lack of evidence to direct decision makers at the local



level (e.g., MOHs, Boards of Education, LHINs) and a lack of accountability for following through with policies, actions and outcomes [6].

Current approaches to collect behaviour and health status data of children and youth vary and are limited by project scope and availability of resources [7]. Best practices, including the approach, scale, and committed resources, are often debated. For example, the school system represents a vital resource for data collection [8], but others are concerned that the school system may become fatigued and burdened [6]. Furthermore, the scarcity of literature and research related to the assessment and surveillance of child and youth health at the local level indicates that the experiences of PHUs and other local stakeholders have not been well documented within the current body of evidence, particularly as it pertains to the Ontario context.

What has already been done?

Coordinated and sustainable health status surveillance systems are in place in some Canadian provinces, as well as countries such as the United States and Australia [5]. There has been some previous work to address the lack of a comprehensive and coordinated approach to measuring child and youth wellbeing in Ontario. The Association of Public Health Epidemiologists in Ontario (APHEO) has defined core indicators that provide a foundation for population health status reporting in Ontario. Currently, there are 67 core indicators from 27 verified data sources that correspond to the assessment and surveillance requirements of the OPHS for children and youth, which are considered ready-to-report [5, 9].

Previous work by Public Health Ontario (PHO) has identified available data sources and data gaps related to assessment and surveillance of child and youth health. Data gaps – that is, a lack of data to address assessment and surveillance needs – is one of the most significant challenges for local assessment and surveillance efforts, and ultimately these challenges often limit the responsiveness of public health programs to meet local needs. Some of the specific limitations with current data and indicators include: the lack of core indicators for positive parenting and healthy growth and development, data gaps for healthy family dynamics and breastfeeding, inadequate data sources for childhood vaccination coverage, early-childhood tooth decay, self-rated health, and self-reported injury, and a need for further development of indicator definitions for exposure to ultraviolet radiation, healthy eating, and healthy weights [5, 10]. The data that is available reveals variation in health status between PHU regions; these local health status profiles help PHUs prioritize issues in their communities, identify priority populations, and plan targeted programs more effectively. However, the ability to use current indicator data to generate local health profiles and identify priority populations is limited due to either inadequate sample sizes at the local PHU level or lack of reliable regional identifiers [5].

Data gaps – that is, a lack of data to address assessment and surveillance needs – is one of the most significant challenges for local assessment and surveillance efforts, and ultimately these challenges often limit the responsiveness of public health programs to meet local needs.



What are the goals of this project?

This project aimed to synthesize evidence regarding approaches to collecting, analyzing, and reporting local health data for school age children and youth within an Ontario context. The effectiveness and limitations of these approaches were also considered, and any barriers or data gaps were explored in depth. The evidence synthesized from this project will form the foundation for future work in this field and should be utilized to inform future projects that focus on coordinating efforts to monitor child and youth health status.

What is the significance of this project?

Improved population health assessment and surveillance of children and youth is important to the work of PHUs and other stakeholders as it would [5, 11-14]:

- Enable decision-makers to take appropriate and evidence-informed action;
- Help to increase awareness and advocacy for priority health issues;
- Provide benchmarks on the needs of children and youth to aid in planning and evaluating the effectiveness of policy and program interventions;
- Inform priority setting and planning;
- Influence strategic expenditure of public health resources;
- Aid in the development of healthy public policy;
- Support research, collaboration and partnerships between different stakeholders.

This project builds on previous work through collating and analyzing the current evidence and by bridging some of the major knowledge gaps that still exist. This includes the identification of promising potential approaches used by PHUs in Ontario to measure and assess the health of school age children and youth at the local level.

Research Question

What are promising potential approaches to collecting, analyzing and reporting local health status data for school age children and youth (Grade 1 – 12) to meet the needs of public health units in Ontario?

Research Objectives

To work collaboratively with Ontario public health units and related stakeholders to identify:

- Current practices and limitations related to the collection, analysis and reporting of health status data for school age children and youth.
- Effective approaches that enable the efficient collection, analysis and reporting of local health status data for school age children and youth that is meaningful to, and comparable across local public health unit.

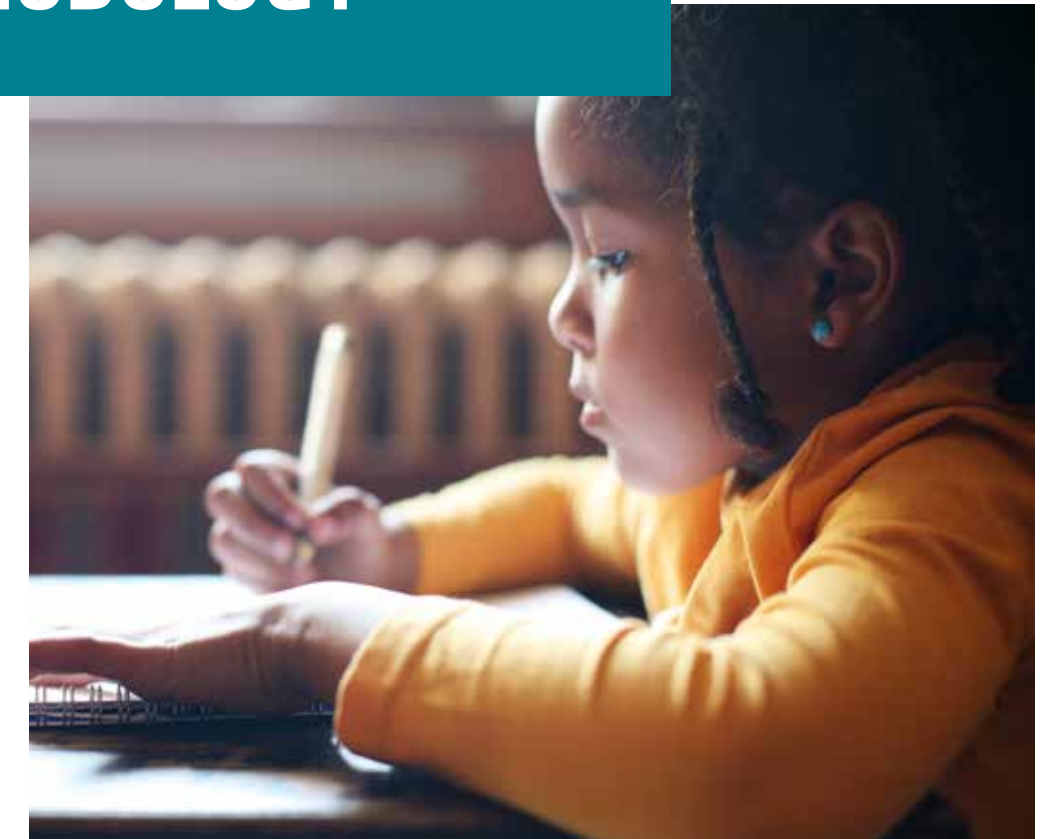
METHODOLOGY

This research project was approved through delegated review by the Windsor-Essex County Health Unit's research ethics chair. In addition, this project was fully reviewed and approved by the Toronto Public Health Research Ethics Board.

The project used a two-phased, mixed-methods approach.

The first phase was an environmental scan of Ontario public health units (PHUs) using an online survey tool.

The second phase of this project aimed to gain the perspective of key sectors through semi-structured interviews with key informants.



Environmental Scan of Ontario Public Health Units

The first phase of the research project (March-May 2016) was an environmental scan of Ontario PHUs that aimed to capture the perspective of PHUs regarding approaches to collecting, analyzing, and reporting local health data for school age children and youth in Ontario.

The project team developed a comprehensive survey in an online tool (FluidSurveys™) utilizing previous work to guide the creation of content questions [5, 9]. Survey questions were divided into five content areas:

- 1. Background information:** organization and profession of respondents, and capacity and size of the organization.
- 2. Overview of gaps in child and youth health data:** general attitudes and perceptions on child and youth data relative to the responding organization, particularly within a local context.
- 3. Primary data sources:** the collection and use of primary data, reasons for primary data collection, and examples of approaches for primary data collection.
- 4. Secondary data sources:** awareness and use of secondary data, and potential improvements of secondary data sources.
- 5. Coordinated surveillance system:** perceptions around the need and priority for a coordinated surveillance system in Ontario.

The survey was developed with the purpose of PHUs submitting a collaborative response; that is, PHU employees (excluding emergency medical services), who are involved in the assessment and surveillance of child and youth health, were asked to work together to provide one joint response on behalf of their PHU. The research team developed guidelines to assist PHUs in providing a collaborative response. A survey coordinator (preference for an epidemiologist) was appointed at each participating PHU and was responsible for coordinating a collaborative response within their organization, including arranging meetings, collating answers, and submitting the collaborative response through the online tool.

The survey was pilot tested by a small northern PHU and a large PHU in February 2016. The survey coordinator at each pilot site provided feedback to the research team regarding the logistics and content of the survey, and necessary changes were made.

Recruitment of PHUs occurred during February 2016: invitations were sent via e-mail directly to the Medical Officers of Health (MOHs) of the 36 Ontario PHUs and to epidemiologists through the Association of Public Health Epidemiologists in Ontario (APHEO). The survey was launched in March 2016 and participating PHUs were given four weeks to complete the survey; reminders were sent via e-mail one week after the launch and one week before the deadline. Survey coordinators were also provided with a guidance document that provided instructions for completing the survey, including the coordination and submission of collaborative input.

Survey data were extracted from FluidSurveys™ into Microsoft Excel (MS). The data were coded and analyzed in Microsoft Excel® and STATA®/SE 12.0 to determine frequencies for quantitative questions. Qualitative questions were analyzed in MS Excel® using inductive thematic analysis. The research team contacted with the survey coordinator from the PHU if there were responses that needed to be clarified.



Key Informant Interviews

The second phase of the research project (June-September 2016) consisted of semi-structured interviews with key informants from the government, academic, and education sectors. The goal was to capture the perspective of relevant sectors regarding the assessment and surveillance of child and youth health in Ontario through 10-12 key informant interviews.

An interview protocol with semi-structured interview questions and prompts were developed by the research team based on the findings from phase one. The interview questions and consent form were provided to key informants in advance of the interview. Interviews were conducted in-person or via telephone (depending on convenience and preference) and audio recorded. Verbal consent was recorded at the time of the interview. The project's research coordinator was the interviewer for every interview and was assisted by a note-taker. The interviews were 30-45 minutes in length.

The audio recordings of each interview were transcribed by a professional transcriptionist from an external agency. The transcripts were then used for inductive thematic analysis. The first step of the analysis was to determine categories that themes could be sorted into for better compartmentalization of the findings. Five categories were developed based on the project objectives: (i) needs; (ii) challenges and barriers; (iii) opportunities for improvement; (iv) current approaches; and (v) emerging areas of interest. The coding of key messages ('by hand') was piloted on one transcript by two coders; the entire research team then provided feedback on the pilot coding exercise. The two coders proceeded to independently identify and code the key messages, through an inductive approach, for the remaining transcripts. The coders compared results and first attempted to resolve disagreement through discussion. When discussion failed to resolve disagreement, a third party was consulted for a resolution.

The coding results were inputted into a MS Excel spreadsheet under their assigned category and grouped into sub-themes (specific key messages). The sub-themes were then grouped into themes (broad topics of key messages) under each category and summarized in a tabular format. The origins of the sub-themes were linked to the sector (government, academic, or education) of the key informants that described that particular sub-theme during their interview. Themes and sub-themes were described as major, common, or frequent if identified by a majority ($\geq 50\%$) of key informants; minor or uncommon themes and sub-themes were identified by a minority of key informant ($< 50\%$).

RESULTS:

Environmental Scan of Ontario Public Health Units

Most PHUs reported that insufficient data, barriers to accessing data, and analytical capacity gaps are challenges associated with child and youth health data.

Summary of the Environmental Scan of Ontario public health units:

- The survey gathered input from 377 public health professionals from 34 of the 36 Ontario PHUs (94% response rate).
- Most PHUs reported that insufficient data, barriers to accessing data, and analytical capacity gaps are challenges associated with child and youth health data.
- Mental health, healthy eating, growth and development, physical activity, and positive parenting were identified as the areas with the greatest need for more data.
- Household income, geographical location, sex and gender, and age were the most highly desired stratifying variables to have collected alongside child and youth health data.
- Many PHUs actively collected their own data on children and youth (84 examples of surveys and 43 examples of surveillance methods) for the primary purposes of filling in data gaps and to generate local level estimates.
- Regarding primary collection of child and youth data, there was identified value in partnering with most organizations, but school boards were clearly identified as being one of the most valuable partners to work with.
- Some of the common features of the most effective primary data collection methods included: active consent, paper-based questionnaires, and partnership with school boards.
- PHUs were generally aware of many of the secondary data sources for child and youth health; fewer were actually able to use these data sources to meet their needs, which is primarily to generate local estimates.
- It was generally indicated that there are useful sources for health outcomes, but sources for health behaviours and risk factors need improvement.
- PHUs frequently reported using the Canadian Community Health Survey and the Ontario Student Drug Use and Health Survey; however, they also cited improvements that are required to make these data sources more useful, including better availability of local data, larger local sample sizes, improved accessibility, and more stratifying variables.
- Moving forward, PHUs have requested that data sources in general be improved by: having greater local sample sizes, filling in data gaps, better coordinating of efforts, enhancing accessibility, ensuring useful stratifying variables, and removing financial barriers.
- There was strong support for a coordinated surveillance system, particularly if it will provide standardized data at the local PHU level.
- PHUs thought that either a provincial organization or ministry should lead any coordinated surveillance system, although there is still an essential need for meaningful collaboration and partnership between all stakeholders.

Moving forward, PHUs have requested that data sources in general be improved by: having greater local sample sizes, filling in data gaps, better coordinating of efforts, enhancing accessibility, ensuring useful stratifying variables, and removing financial barriers.

Who completed the survey?

Of the 36 Ontario PHUs that were invited to participate, 34 provided a collaborative response to the environmental scan survey (response rate of 94%). On average, 11 individuals within each of the 34 PHUs provided collaborative input; this ranged from a minimum of two to a maximum of 46 individuals per survey. In total, 377 public health professionals contributed to the information provided in the 34 survey responses. Thirty-one out of 34 (91.2%) survey responses had contributions from the PHU's Epidemiologist and from Managers/Supervisors, but there was a wide range of different public health professionals that contributed to the survey responses, including Health Promoters (44.1%), Public Health Nurses (44.1%), Nutritionists/Dieticians (38.2%), Analysts (26.5%), Evaluators/Planners (23.5%), Directors (23.5%), Dental Staff (11.8%), Public Health Inspectors (11.8%), Medical Officers of Health (11.8%), Associate Medical Officers of Health (5.9%), and Research Assistants/Coordinators/Associates (2.9%). Seven out of 34 (20.6%) survey responses included input from "other" staff, which included Foundational Standards Specialists, Community Developers, Program Coordinators/Officers, Tobacco Coordinators, Continuous Quality Improvement specialists, Physical Activity Specialists, and Integrated Services for Children Information System (ISCIS) Specialists.

Quick Facts: public health units (PHUs) in Ontario

- All PHUs are responsible for providing public health programs and services pursuant to the Health Promotion and Protection Act, following the Ontario Public Health Standards.
- Each PHU has a Medical Officer of Health (MOH) who is a public health leader in the community.
- There are 36 PHUs in Ontario that serve populations ranging from 34,000 to 2.8 million residents.
- The largest geographic area covered by an Ontario PHU is bigger than the United Kingdom.

The survey was completed by PHUs located throughout Ontario and of various staffing size and capacity. Of the 34 PHUs that responded, 17.6% employ 100 staff or less, 41.2% employ 101-200 staff, 35.3% employ 201-600 staff, and 5.9% employ more than 600 staff (this does not include staff from emergency medical services). Duties relating to assessment and surveillance were associated with a number of positions at PHUs in Ontario (see **Table 1**). Most (91.2%) PHUs had at least one Epidemiologist who was responsible for assessment and surveillance duties; in total, there were 82 Epidemiologists spread across the 34 responding PHUs (median of two Epidemiologists per PHU). Other positions with assessment and surveillance duties included Analysts, Evaluators, Planners, and Research Assistants/Coordinators/Associates.



Table 1. Staff positions at public health units (n=34) in Ontario that have assessment and surveillance responsibilities.

Staff Position	Total number of staff	Percentage of PHUs with at least one staff
Epidemiologist	82	91.2%
Analyst (e.g., health analyst, data analyst)	47	50.0%
Research Assistant/Coordinator/Associate	6	14.7%
Evaluator	28	44.1%
Planner	30	26.5%

THE SURVEY GATHERED INPUT FROM 377 PUBLIC HEALTH PROFESSIONALS FROM 34 PUBLIC HEALTH UNITS IN ONTARIO .



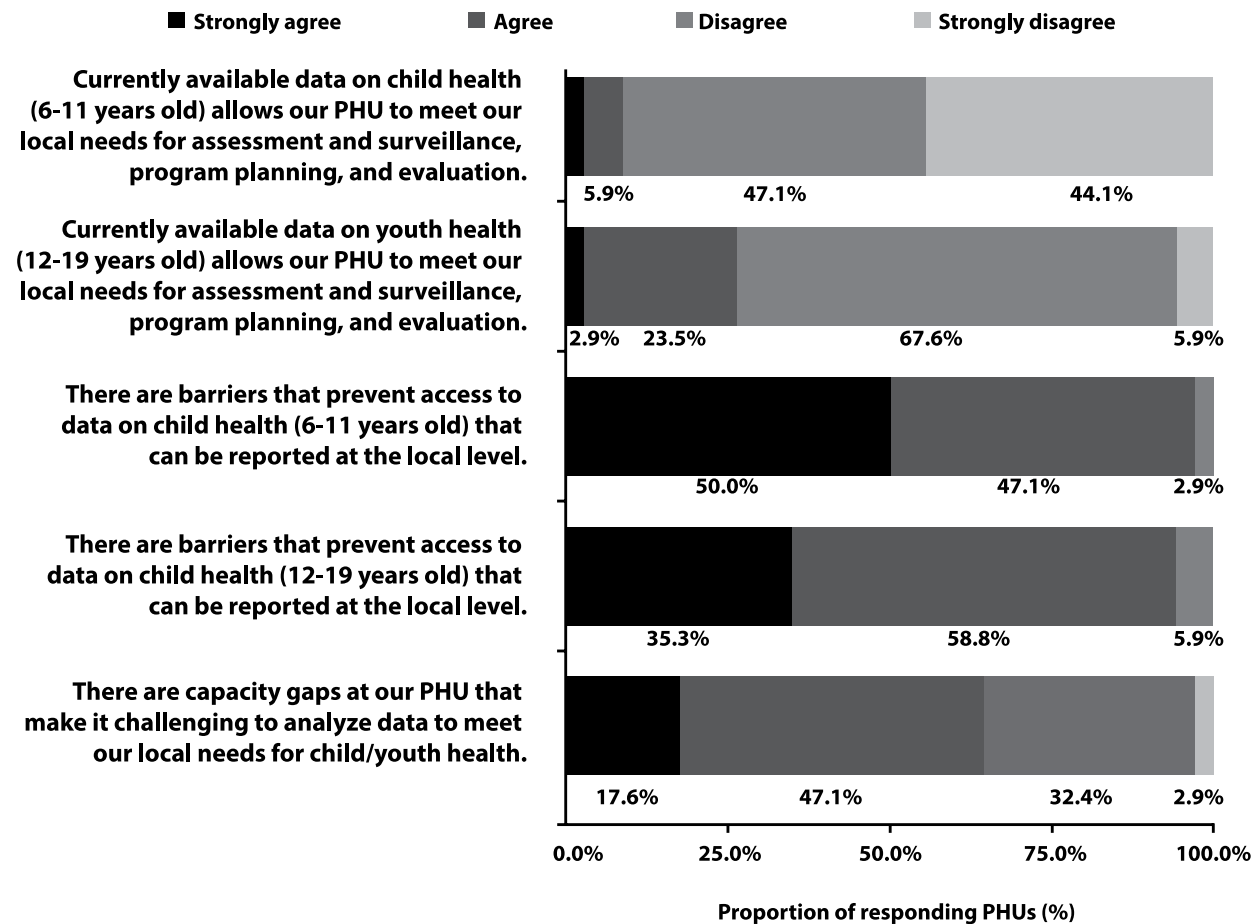
Overview of Gaps in Child and Youth Health Data

This section provides a broad evaluation of overall PHU attitudes and perspectives related to assessment and surveillance of children and youth (grades 1-12).

Generally, as it relates to child and youth health status, most PHUs indicated that currently available data does not meet their needs and there are barriers that prevent access to data (see **Figure 1**). When asked whether currently available data allows PHUs to meet their local assessment and surveillance, program planning, and evaluation needs, only 8.8% and 26.4% of PHUs indicated agreement with this statement as it relates to children (6-11 years old) and youth (12-19 years old), respectively. Further, there was nearly unanimous agreement that there are barriers preventing access to local health data on children (97.1% agreement) or youth (94.1% agreement).

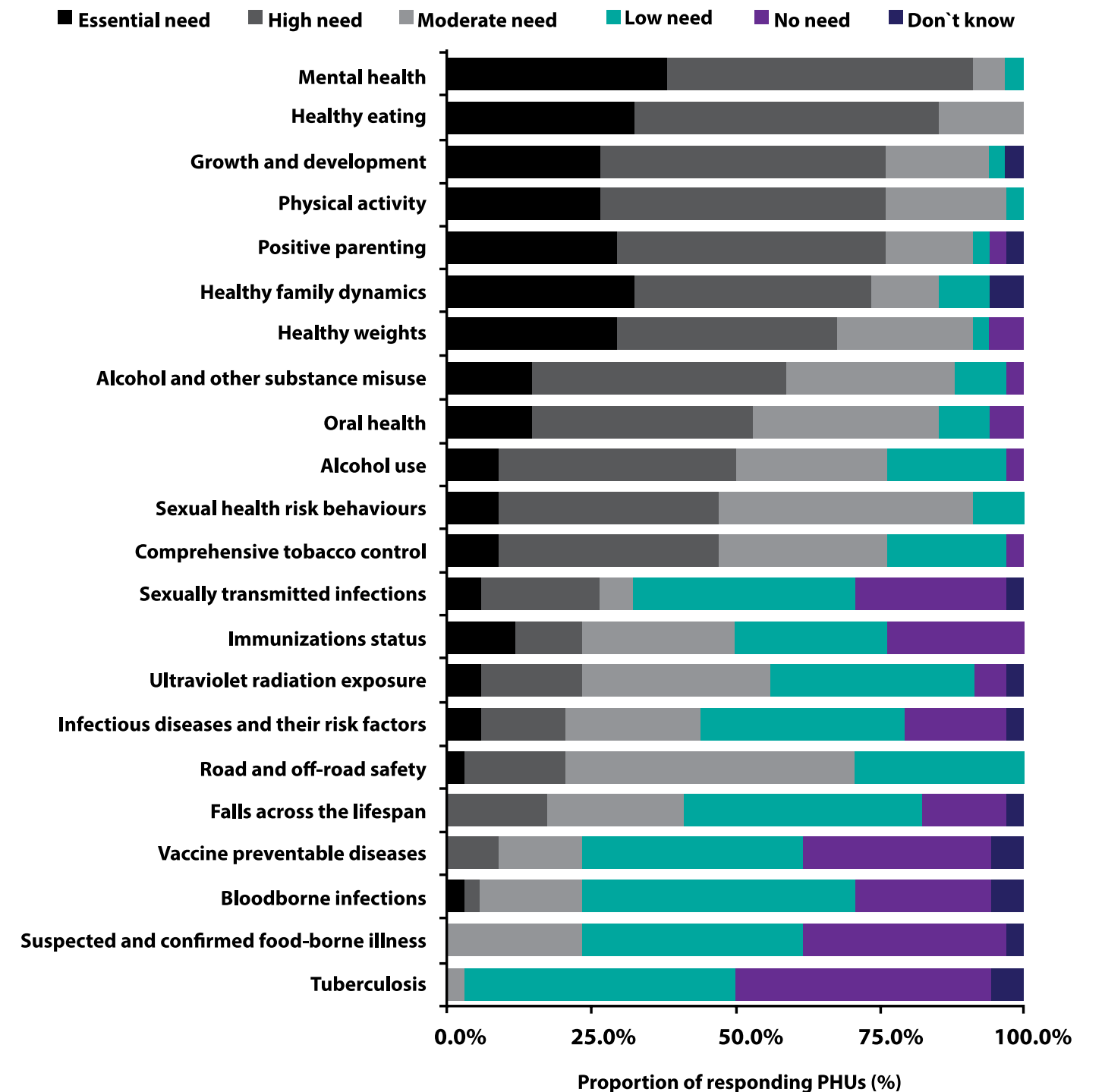
Capacity gaps were identified as a challenge for the analysis of child and youth health data. Nearly two-thirds (64.7%) of PHUs agreed or strongly agreed that there are capacity gaps that make it challenging to analyze data to meet local needs for child/youth health. As expected, agreement related to the issue of capacity gaps differed by PHU staffing size and epidemiological support. Three-quarters (75%) of small PHUs (200 staff or less) agreed that capacity gaps were an issue compared to 50% of large PHUs (>200 staff). Similarly, 79% of those PHUs with one or fewer epidemiologist identified capacity gaps as a challenge compared to 53% of those PHUs with at least 2 epidemiologists.

Figure 1. Overall attitudes and perspectives of public health units related to assessment and surveillance of child and youth health status.



Public health units were asked based on their perspective, to identify whether there is a need for more child and youth data in the various assessment and surveillance requirements of the OPHS. The results from this inquiry are reported in **Figure 2**. The area with the greatest need for data was mental health; 91.2% of PHUs indicated a high or essential need for more data. The next areas identified by more than 75% of PHUs as having a high or essential need for more data were healthy eating, growth and development, physical activity, and positive parenting. The area with the lowest need for more data was tuberculosis (91.2% of PHUs indicated no or low need). Food-borne illness, blood-borne infections, vaccine preventable diseases, and falls across the lifespan were the next areas with the lowest need for more data.

Figure 2. Public health units' need for more data in OPHS assessment and surveillance requirements.

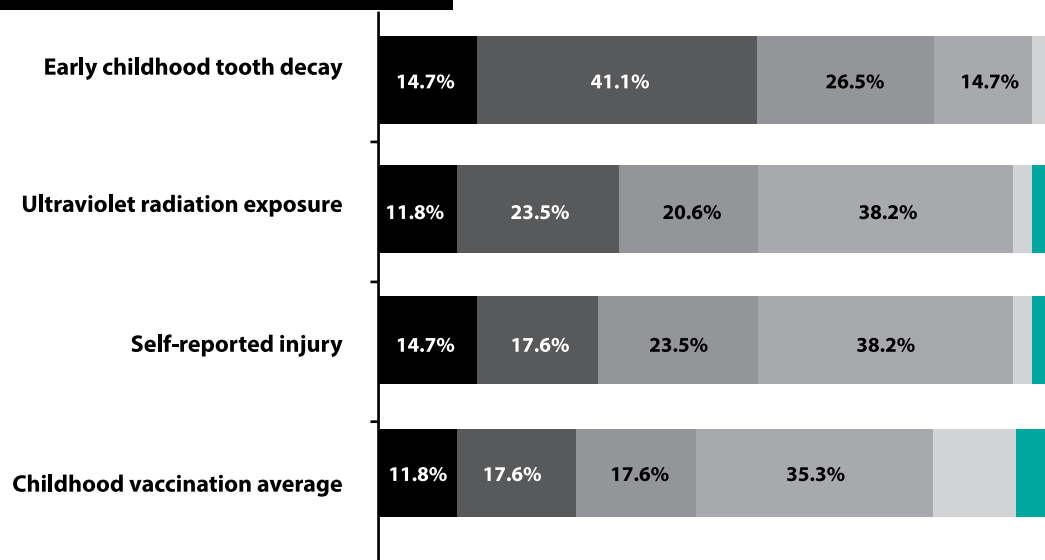


Previous work that assessed gaps in child and youth health data identified various data gaps and indicator gaps related to the core population health indicators developed by the Association of Public Health Epidemiologists in Ontario (APHEO). Early childhood tooth decay, ultraviolet radiation exposure, self-reported injury, and childhood vaccination coverage have indicator definitions developed by APHEO but are missing data sources for children and/or youth (i.e., data gap). Public health units indicated their need for these data gaps to be resolved and the results are summarized in **Figure 3**. On the other hand, PHUs identified that data is collected to some extent on fruit and vegetable consumption, screen time, leisure-time physical activity, frequency of condom use and condom used last time among at-risk individuals, age of sexual debut, and number of sexual partners, but those indicator definitions have not yet been fully developed by APHEO (i.e., indicator gap), or lack relevance, for child (6-11 years old) or youth (12-18 years old) populations. The need to develop indicator definitions was reported by PHUs and the results are summarized in **Figure 3**.

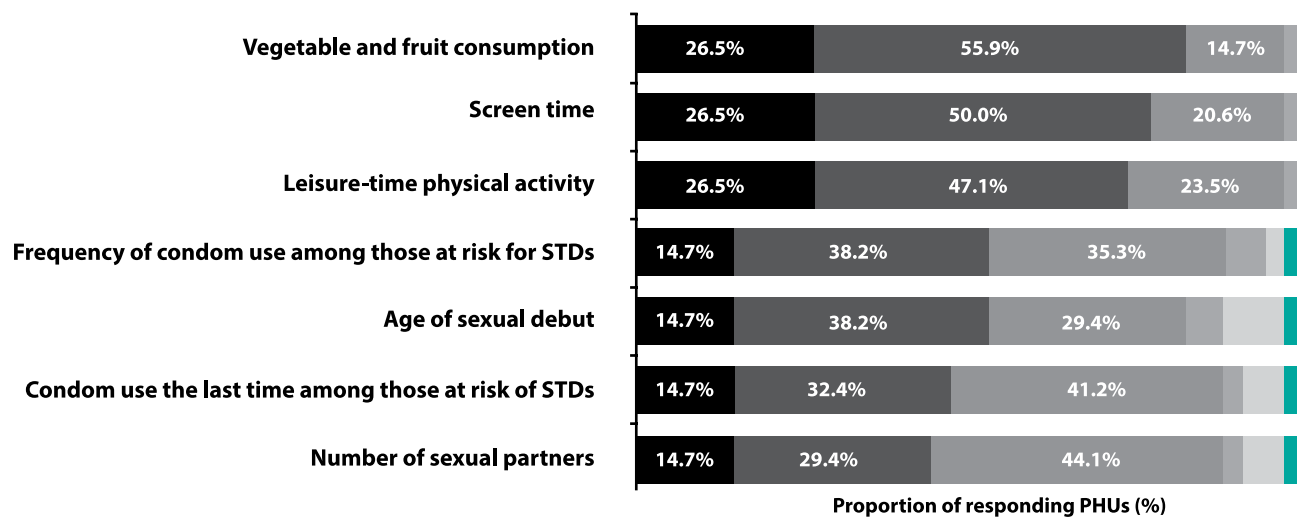
Figure 3. The need to resolve gaps associated with the APHEO core indicators.

■ Essential need ■ High need ■ Moderate need ■ Low need ■ No need ■ Don't Know

APHEO indicators with data gaps:

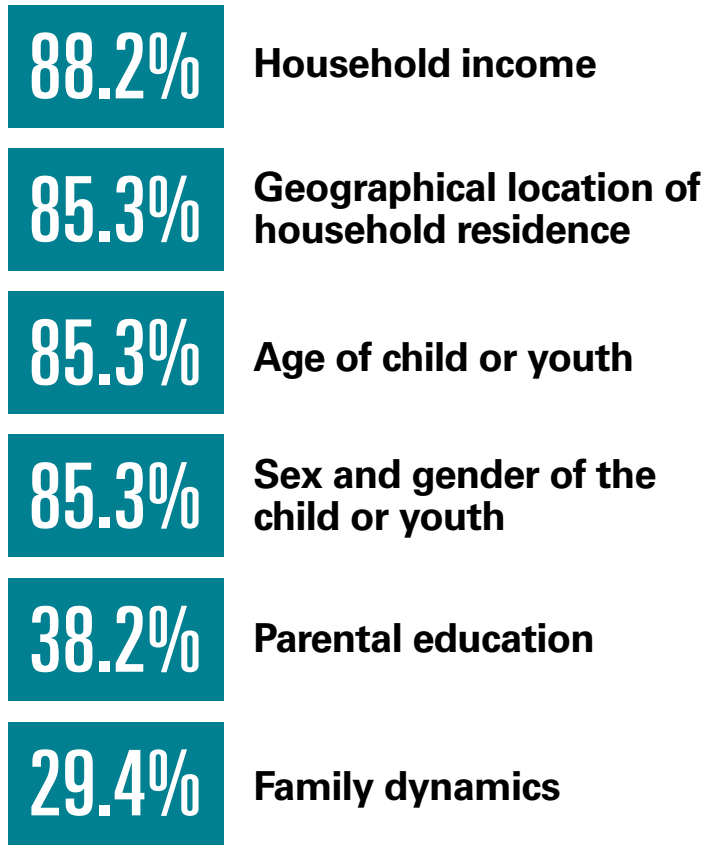


APHEO indicators without a definition



The last part of this section was an assessment of stratifying variables (variables that allow data to be grouped or cross-tabulated into different categories) associated with child and youth health data, which is a population health assessment and surveillance requirement under the OPHS. Public health units were able to identify up to five stratifying variables that they considered important to collect alongside child and youth health data. The most common responses and frequency of those responses are listed to the right:

There was a minority of other responses that included ethnicity, immigration status, Aboriginal identity, disability, sexual orientation, mental health, and marginalization.



Primary Data Sources

The purpose of this section was to describe and explore the primary data sources used by PHUs for the assessment and surveillance of child and youth health. There was a particular focus on primary data collection using surveys and surveillance systems (defined in detail under relevant sections).

For this section, primary data sources were defined as data sources having been designed, administrated, and/or collected by a PHU (either independently or in collaboration with other stakeholders) for the specific purpose of assessment or surveillance of child and/or youth health. Both one-time surveys and on-going surveillance are included, but mandatory data routinely collected by all 36 PHUs in Ontario are excluded (such as OHISS, Panorama, iPHIS).

Twenty-eight (82.4%) PHUs indicated they had collected primary data on child or youth health in the past 10 years using a one-time survey or an on-going surveillance system. Of these 28 PHUs that had collected primary data relevant to children and youth in the past 10 years, filling data gaps and insufficient data for local level estimates were cited as the main reasons for primary data collection (see **Figure 4**). In addition, PHUs generally indicated that partnerships with most sectors were valuable to successfully collect primary data on children and youth, but school boards were clearly identified as the most valuable partner (see **Figure 5**).

Twenty-eight (82.4%) PHUs indicated they had collected primary data on child or youth health in the past 10 years using a one-time survey or an on-going surveillance system.



Figure 4. Reasons PHUs collect primary data relevant to child and youth health.

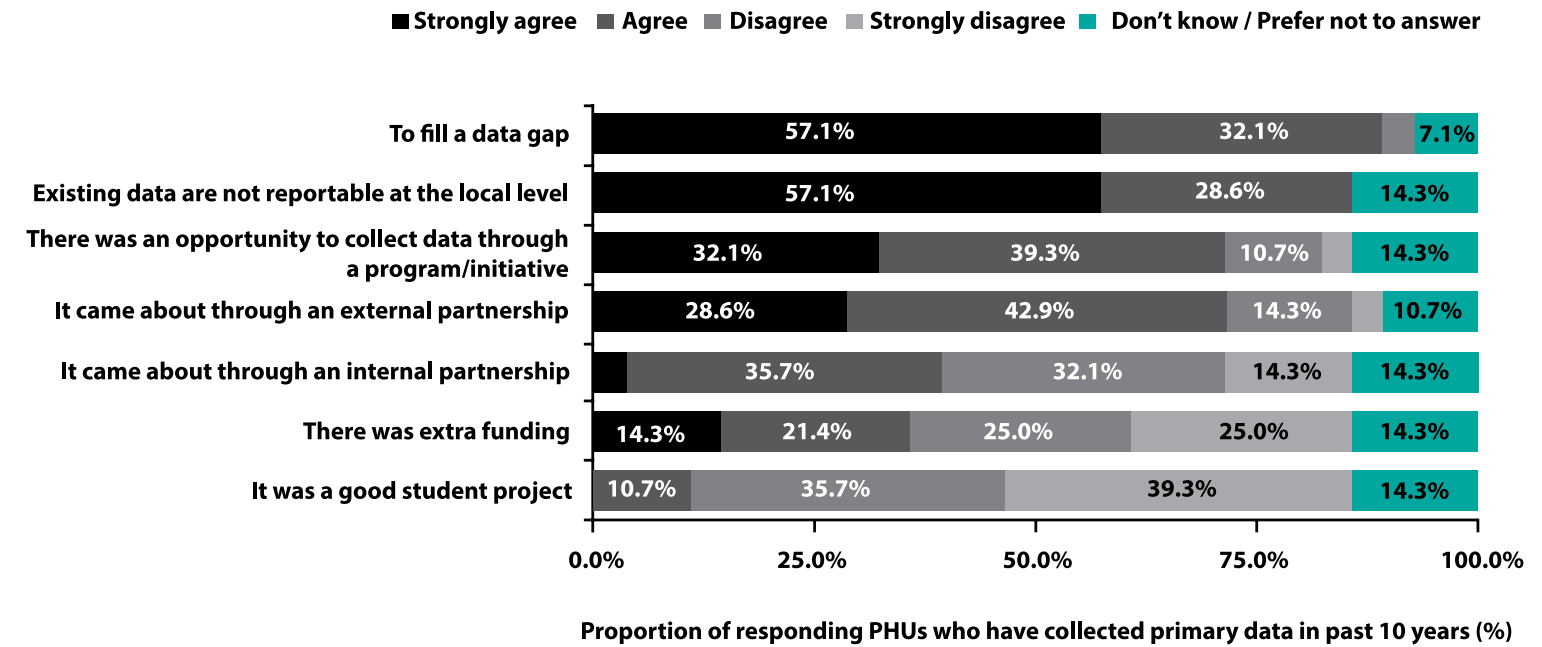
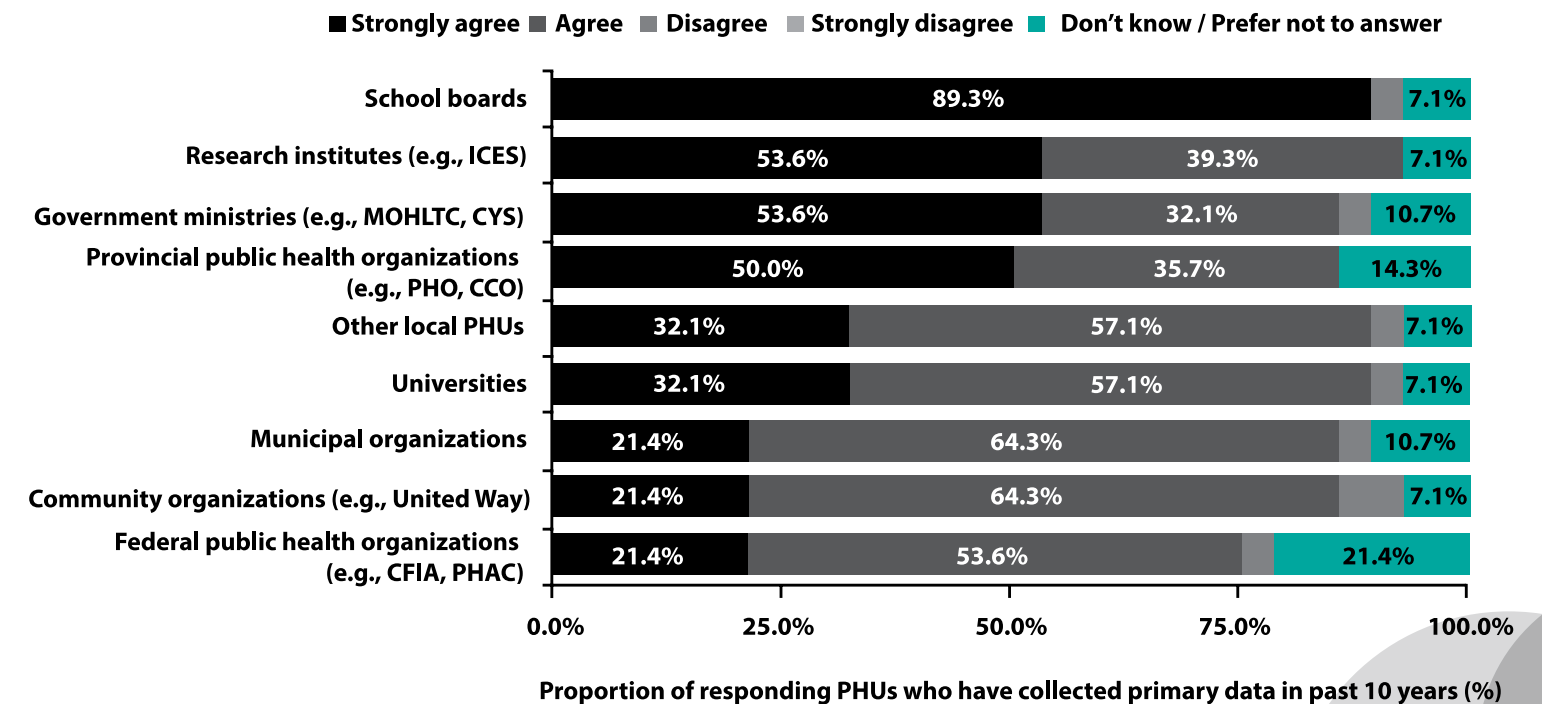


Figure 5. Partners identified by PHUs as being valuable to work with for collecting primary data on children and youth.



Primary Data from Surveys

For the purposes of this section, a survey was defined as a one-time survey, or a survey repeated non-routinely, that collects information specifically on child and/or youth health, or with child and/or youth included in the study population.

Twenty-five (73.5%) of the 34 PHUs indicated that they had collected primary data on children and youth in the past 10 years using a survey. When asked to estimate the number of surveys conducted in the past 10 years, 22 PHUs were able to provide a numerical estimate and 3 were unsure. For the 22 PHUs that did provide an estimate, an average of 4.5 surveys were conducted per PHU in the past 10 years (minimum of 1 to maximum of 10 surveys per PHU).

In total, PHUs in Ontario conducted an estimated 99 surveys to collect primary data related to child and youth health in the past 10 years.

These 25 PHUs were then asked to provide up to 10 examples of their surveys; in total, 81 examples of surveys were provided. Furthermore, these PHUs were asked to identify their most effective survey on child and/or youth health and provide an overview of its methodology. An 'effective survey' was qualified as having the following attributes: high response rate, large sample size, good validity, reliable, and informative. In total, 22 PHUs provided an example of their most effective survey; the features of these identified surveys are summarized in **Table 2**. Select examples of the most effective surveys completed by PHUs are provided in **Appendix A**.

Table 2. Frequency of survey features among those identified as most effective by public health units (n=22).

Survey Features	Summary of PHU Responses (% of responses)
Study Population	<ul style="list-style-type: none"> • Exclusively children, 6-11 years old (13.6%) • Exclusively youth, 12-19 years old (54.5%) • Children and youth, 6-19 years old (22.7%)
Consent	<ul style="list-style-type: none"> • Active consent (45.5%) • Passive consent (22.7%) • Combined passive and active consent (9.1%) • Complete via proxy and did not require child/youth consent (13.6%)
Data Collection	<ul style="list-style-type: none"> • Paper-based survey (40.9%) • Electronic/online survey (18.2%) • Both paper-based and electronic/online survey (4.5%) • Telephone survey (18.2%) • Direct measure of physical attributes (9.1%)
Content	<ul style="list-style-type: none"> • In total, the 22 survey examples collected information that relates to 15 different OPHS assessment and surveillance areas. • The five most common topics for which data were collected: <ul style="list-style-type: none"> o Physical activity (59.1%) o Healthy eating (54.5%) o Alcohol and other substance misuse (45.5%) o Tobacco use (31.8%) o Mental health (27.3%)
Partnerships	<ul style="list-style-type: none"> • School board (68.2%) • University (18.2%) • Community organization (18.2%) • Other PHU (13.6%)
Feasibility	<ul style="list-style-type: none"> • Nineteen (86.4%) surveys were indicated as being feasible to implement, but only if certain conditions were in place (i.e., resources, capacity, support, partnerships).

Primary Data from Surveillance Systems

For this section, surveillance was defined as a system or method which continuously or routinely collects information on child and/or youth health, or with child and/or youth included in the study population.

Seventeen (50.0%) of the 34 PHUs indicated that they had collected primary data on children and/or youth in the past 10 years using a surveillance method. The number of surveillance systems used by these 17 PHUs ranged from 1 to 15 (mean of 5.4; median of 3.5).

The 17 PHUs provided 43 examples of surveillance systems used in the past 10 years to collect primary data on children and youth. Among those examples of surveillance systems, 14 identified as the 'most effective' (high response rate, large sample size, good validity, reliable, and informative) surveillance systems run by PHUs were reported in detail. The features of these identified surveillance systems are summarized in **Table 3** and select examples are reported in **Appendix A**.

Table 3. Frequency of surveillance system features among those identified as most effective by public health units (n=14).

Surveillance Method Features	Summary of PHU Responses (% of responses)
Study Population	<ul style="list-style-type: none"> • Exclusively children, 6-11 years old (21.4%) • Exclusively youth, 12-19 years old (50.0%) • Children and youth, 6-19 years old (21.4%)
Consent	<ul style="list-style-type: none"> • Active consent (42.9%) • Passive consent (28.6%) • No consent required (7.1%)
Data Collection	<ul style="list-style-type: none"> • Paper-based data collection (42.9%) • Electronic/online data collection (7.1%) • Face-to-face interviews (7.1%)
Content	<ul style="list-style-type: none"> • In total, these 14 surveillance systems collected information that relates to 12 different OPHS assessment & surveillance areas. • The three most common topics for which data were collected: <ul style="list-style-type: none"> o Mental health (35.7%) o Alcohol and other substance misuse (35.7%) o Growth and development (14.3%)
Partnerships	<ul style="list-style-type: none"> • School board (78.6%) • Community organization (28.6%) • Others (University, other PHU, healthcare providers) (21.4%)
Feasibility	<ul style="list-style-type: none"> • Twelve (85.7%) indicated that their surveillance method was feasible to implement, but usually only if certain conditions were present (i.e., available funding, resources, capacity, and support).

Secondary Data Sources

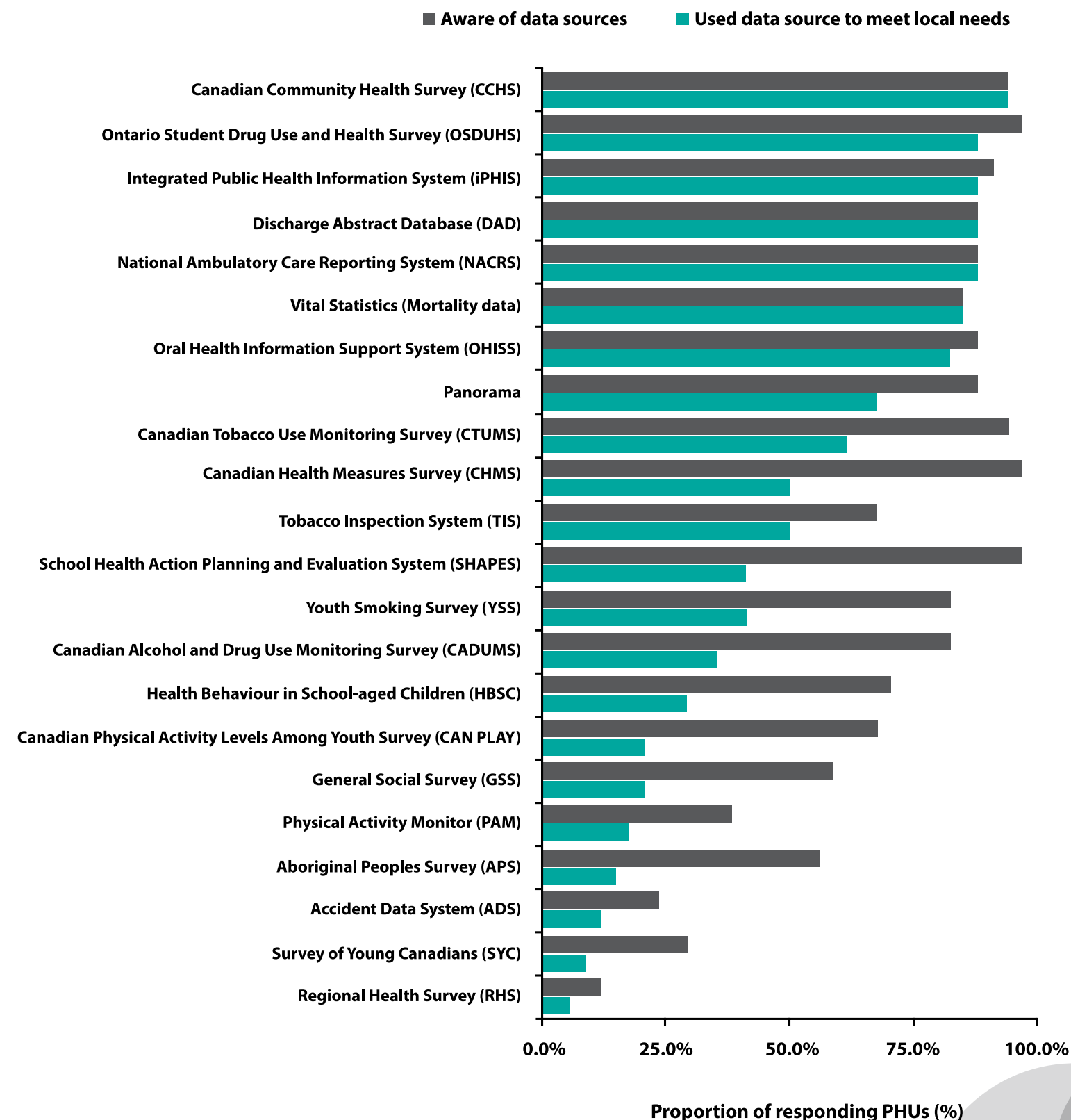
The purpose of this section was to describe and explore the secondary data sources used by PHUs for the assessment and surveillance of child and youth health. There was a particular focus on databases and datasets that are administered by another organization and databases that are populated collectively by PHUs.

Public health units were asked about their awareness of secondary data sources relevant to child and youth health, as identified in a previous report [9], and whether they have ever used the data sources to meet their local assessment and surveillance needs. In general, PHUs were aware of most secondary data source for child and youth data; 80% of PHUs were aware of at least 13 of the 22 secondary data sources. The top three data sources that PHUs were most aware of include the School Health Action Planning and Evaluation System (SHAPES), the Canadian Health Measures Survey (CHMS), and the Ontario Student Drug Use and Health Survey (OSDUHS).

Although many PHUs were aware of secondary data sources, fewer have actually used the data to meet local needs. Only seven (31.8%) of the 22 data sources have been used by over 80% of PHUs to meet local needs. The Canadian Community Health Survey (CCHS) was used most frequently to meet the local needs of PHUs. The Integrated Public Health Information System (iPHIS), Discharge Abstract Database (DAD), National Ambulatory Care Reporting System (NACRS), and OSDUHS were the second most used data sources for local needs.

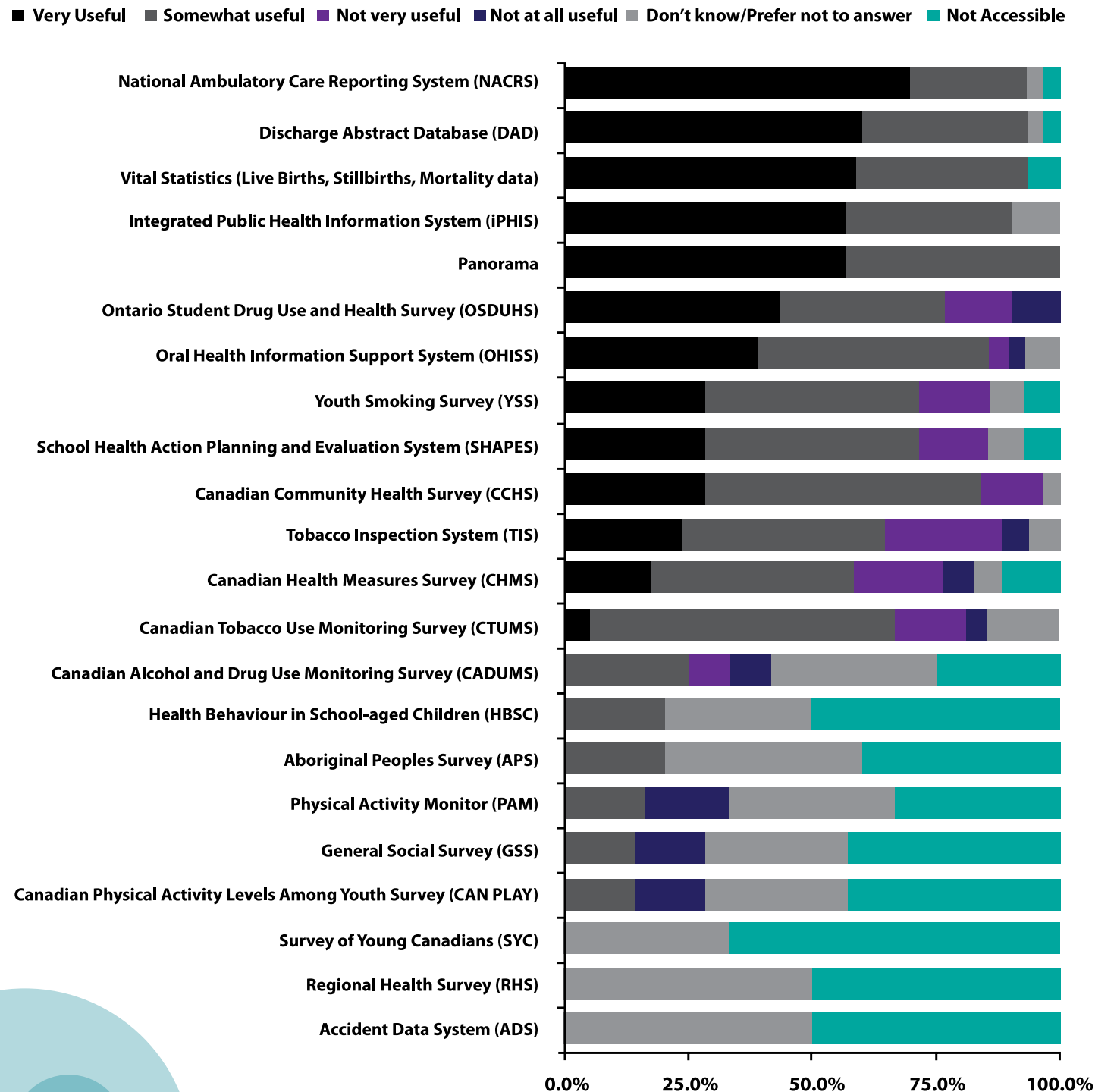
These findings indicate possible challenges and limitations to using available secondary data to meet local assessment and surveillance needs for children and youth.

Figure 6. Awareness and use of secondary data sources for child and youth health data among PHUs.



Those PHUs that had experience using each secondary data source provided input regarding the general usefulness of the data source for assessing child and youth health (see **Figure 7**). Panorama, iPHIS, Vital Statistics, DAD, and NACRS (all of which primarily focus on health outcomes) were seen as somewhat or very useful data sources by almost all PHU users. However, PHU users indicated that many of the other secondary data sources (particularly sources of health behaviour data) need improvement to enhance their usefulness for assessing child and youth health.

Figure 7. Usefulness of secondary data sources for assessing child and youth health among public health units (PHUs) who have used the data source for local assessment and surveillance.



Each PHU was provided the opportunity to indicate which secondary data sources they would like to see improved in regards to four categories: availability of local data, sample size, accessibility, and stratifying variables. The top five data sources in each category, ranked according to the proportion of PHUs that identified a need for improvement, are reported in **Table 4**. The CCHS and OSDUHS were the most commonly identified as needing improvements across each category. It is worth noting that PHUs nearly unanimously identified that the CCHS needs a larger sample size.

Table 4. Proportion (%) of PHUs that identified a need for improvements among secondary data sources relevant to child and youth health.

Rank	Secondary data sources that need...			
	Better availability of local data	A larger sample size	Improved accessibility	More stratifying variables
1	Ontario Student Drug Use and Health Survey (61.8%)	Canadian Community Health Survey (91.2%)	Ontario Student Drug Use and Health Survey (26.5%)	Ontario Student Drug Use and Health Survey (26.5%)
2	Canadian Health Measures Survey (44.1%)	Ontario Student Drug Use and Health Survey (44.1%)	Canadian Community Health Survey (20.6%)	Canadian Community Health Survey (23.5%)
3	Health Behaviour in School-aged Children (32.4%)	Canadian Health Measures Survey (32.4%)	Canadian Health Measures Survey (17.6%)	Integrated Public Health Information System (8.8%)
4	Canadian Community Health Survey (23.5%)	Health Behaviour in School-aged Children (17.6%)	National Ambulatory Care Reporting System (11.8%)	Vital Statistics (5.9%)
5	School Health Action Planning and Evaluation System (20.6%)	School Health Action Planning and Evaluation System / Rapid Risk Factor Surveillance System (8.8%)	Health Behaviour in School-aged Children (11.8%)	National Ambulatory Care Reporting System (5.9%)

Note: The proportions (%) in each cell are the proportion of PHUs that indicated a need for improvement for that particular data source and category.

Public health units were given the opportunity to provide a “wish list” of improvements for the existing secondary data sources relevant to child and youth health (each PHU could provide up to 3 requests). In total, 32 PHUs provided a total of 89 requests. Six common themes were identified through qualitative analysis:

Theme 1. Local Level Data

The most common request was related to increasing sample size of existing local data to allow for estimates at the PHU level and at smaller areas within the PHU region (40.4% or 36 of the 89 requests).

Theme 2. Fill in Data Gaps

The next most common request was filling in data gaps. Nineteen (21.3%) requests referenced general or specific data gaps that should be bridged in secondary data sources. Some specific topics requested included mental health and resiliency, healthy eating, healthy development, positive parenting, and physical activity.

Theme 3. Collaboration and Coordination of Efforts

The concept of collaboration between agencies and streamlining assessment of child/youth health was a common theme throughout the requests. Fifteen (16.8%) requests cited the benefit of collaboration and partnership between agencies, and the value in instituting a coordinated system.

“Ability for health units to have a say in types of questions included in the survey tool.”

“Create a centralized system of data collection, particularly for those <12 years of age, that provides data at the local PHU level.”

Theme 4. Improve Data Accessibility

Another common request was improved and easier access to secondary data sources. There were 12 (13.5%) requests that referenced (i) an inability to access certain secondary data sources, and (ii) the benefits of sharing data between health agencies.

“Allowing open access to PHUs, many of the data sets are proprietary.”

Theme 5. Useful Stratifying Variables

There were also 12 (13.5%) requests that specifically indicated the importance of having useful stratifying variables included in secondary data sources. Specifically, some PHUs would like to see an expansion of stratifying variables in existing databases to allow for stratification by determinants of health (i.e., income, education, geography).

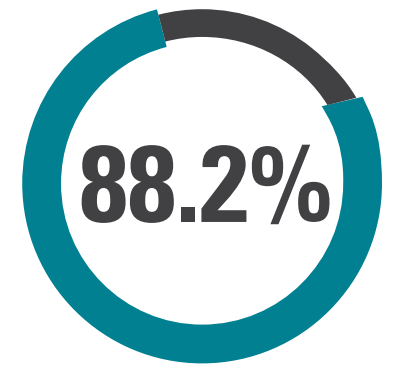
Theme 6. Remove Financial Barriers

The last theme identified was financial barriers. Ten PHUs (11.2%) cited cost as a barrier to obtaining data.

“Not needing to request/purchase oversampling for our specific health unit region would provide financial relief as well as save time and resources.”

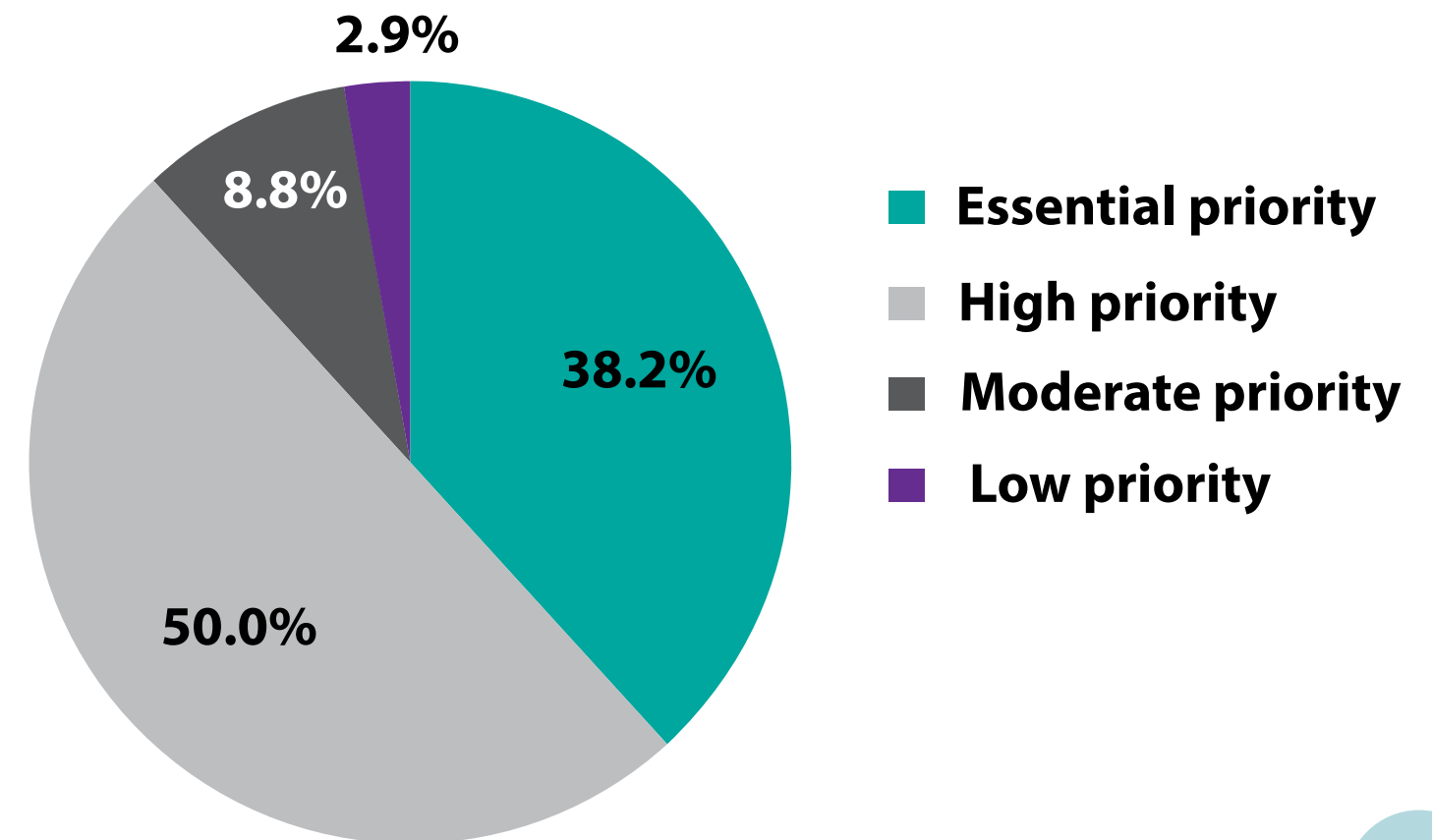
Coordinated Surveillance System

There was unanimous agreement (11.8% agreed and 88.2% strongly agreed) by PHUs that a coordinated surveillance system for child and youth health in Ontario would be an asset to local public health. When PHUs were surveyed about the priority of having such a system, 88.2% of PHUs indicated that having such a system would be a high or essential priority for them (see **Figure 8**).



STRONGLY AGREED that a coordinated surveillance system for child and youth health in Ontario would be an asset to local public health.

Figure 8. Level of priority for having a coordinated, provincial-level surveillance system for child and youth health according to public health units.



PHUs were also asked about who should take the lead on forming a coordinated, provincial-level surveillance system for child and youth health in Ontario. Most PHUs indicated either a provincial organization or government ministry; 47.1% of PHUs indicated that a provincial organization (e.g., PHO, CCO) should take the lead and 32.4% indicated that a government ministry (e.g., MOHLTC, MCYS) should take the lead. Seven (20.5%) PHUs provided other responses: three indicated a “provincial organization or government ministry,” two did not specify any particular organization or sector, one indicated a partnership between universities and PHUs, and one indicated that PHUs should take the lead.

Twenty-eight (82.3%) of the PHUs provided additional open-ended comments related to having a coordinated surveillance system for child and youth health in Ontario. Responses were coded into common themes using an inductive approach and the identified themes are summarized to the right.

Theme 1. Local Level Data

The most prominent theme was ensuring that PHUs would have access to local level data and statistics through a coordinated surveillance system; 10 out of 28 (35.7%) cited this concern..

“At the local level we have a strong need for better data... it would be important to us that the coordinated system is available with local data.”

Theme 2. Collaboration and Partnership

The next most prominent theme was collaboration and partnership. Eight (28.6%) responses referenced the importance of collaboration between stakeholders (all levels of government, academic institutions, and school boards) if such a coordinated surveillance system were to be established. Specifically, six (21.4%) responses identified the important potential role of schools in establishing such a system.

“[A coordinated surveillance system] will need to be a joint effort between the provincial government, academic institutions, provincial organizations, prescribed entities and other health custodians.”

“A good surveillance system is likely to access children and youth within the school environment.”

Theme 3. Leverage or Augment Existing Data Sources

Another common theme was the potential to leverage or augment existing data sources to make them more useful and accessible. Seven (25.0%) responses provided suggestions or examples on how existing data sources may be changed to provide more valuable child/youth health data.

“Improve access to existing data sources ... increase sample size for child population for existing data sources.”

Theme 4. Standardization

Four (14.3%) responses indicated that the role of such a coordinated surveillance system would be to provide standardized data that is comparable across regions.

“There are a lot of gaps... [we] cannot compare local data to other regions ... [there] is no standardized process/indicators/procedures on collecting data. Easier to coordinate if we have one surveillance system and allows for consistent standards to be developed.”

Theme 5. Pooling Resources

Some responses indicated that pooling resources and efforts into a coordinated surveillance system would be efficient and beneficial to many different stakeholders as long as cost was not a barrier to users.

“If we can have one surveillance system by pooling our resources that would be helpful to all public health units.”

RESULTS:

Key Informant Interviews

The interviews were themed and results grouped under one of five categories: needs, challenges and barriers, opportunities for improvement, current approaches, and emerging areas of interest. Many of the themes overlap across each category.

Summary of the key informant interviews:

- Eleven semi-structured interviews were completed with key informants from government (n=4), academia (n=3), and education (n=4), who are currently engaged in collecting, analyzing, and reporting on child and youth health data in Ontario.
- The interviews were themed and results grouped under one of five categories: needs, challenges and barriers, opportunities for improvement, current approaches, and emerging areas of interest. Many of the themes overlap across each category.
- There was a predominant need for high-quality data that could be used for multiple purposes including assessment and surveillance, program planning, evaluation, and decision-making.
- There was a commonly identified need for stronger partnerships and collaboration.
- Key informants identified systemic issues as a major challenge or barrier; particularly the lack of resources and disjointed surveillance efforts.
- Data and methodological limitations (mainly inadequate local sample sizes), survey fatigue among students, and challenges of collaborating effectively were the other dominant themes.
- The majority of key informants thought that expanding or augmenting existing assessment and surveillance efforts was the best opportunity for improvement. Most key informants identified room to improve collaborative work between all sectors. There were also opportunities to implement foundational changes to address systemic issues, particularly the cumbersome and inconsistent research ethics process in schools.

- Key informants identified a variety of techniques and approaches currently being used for assessment and surveillance of children and youth in Ontario. Sampling in school settings and collaboration were common components of many current approaches.

Child and youth mental health was a common area of interest among nearly all key informants and across all sectors. Healthy eating and physical activity were other frequently identified areas of interest among key informants.



Who were the Key Informants?

Eleven semi-structured interviews were completed with key informants who are currently engaged in collecting, analyzing, and reporting on child and youth health data in Ontario. The key informants were purposefully selected to ensure representation of the key relevant sectors: government, academic, and education. The definition of each sector and the key informants included under each sector are outlined below:

Government sector – Representatives from resource centres, agencies, and ministries that are actively engaged in assessment and surveillance of child and youth health status in Ontario.

Academic sector – Academics and researchers who hold a position at a post-secondary institution and are leaders in assessment and surveillance of child and youth health status in Ontario.

Education sector – Directors of Education from urban, rural, and northern school boards throughout Ontario.

The key informant interviews were analyzed as previously described in the methodology section. The themes that stemmed from these interviews were sorted into five categories that align with the objectives of this project:

- Needs
- Challenges and Barriers
- Opportunities for Improvement
- Current Approaches
- Emerging Areas of Interest

The findings under each of these themes are explored in detail in the following sections.

Needs

Themes were categorized as a ‘need’ if the key informant identified or described it as something that is lacking, but necessary for the assessment and surveillance of child and youth health. It is important to note that the framing of whether something is a need is based on the perspective and experiences of each key informant and sometimes specific to a particular sector. The themes identified as a need are summarized in **Table 5** and key findings are discussed in more detail below.

Data and Methodology

The most common theme that was evident in all interviews was the identification of needs related to data and methodology. Most of the key informants, representing all sectors, described a need for high-quality data that can be used for multiple purposes including assessment and surveillance, program planning, evaluation, and decision-making:

“We use data to inform policy and programs, sort of investments, so the more compelling data that speaks to the areas of interest for the populations that are falling behind, for example, that might have higher risk factors, would be of great value”

“If you don’t have good data upon which to make those decisions, you’re making bad decisions, you’re making bad investments.”

In addition, key informants from all sectors described a need for data collected longitudinally or at regular frequencies. In particular, representatives from the education sector cited the need for longitudinal data to measure student outcomes as they progress through the school system, and whether these outcomes are responsive to policies or programs:

“Schools actually really value longitudinal data; there’s no point in doing cross-sectional data collections anymore because it has no more sale value for informing what programs work, or what’s working over time.”

One government key informant identified a need for “locally representative” data that could provide estimates for PHU regions and within PHU regions; however, some key informants from the academic sector disagreed with this:

“I think we get over-zealous that we need our own, own, own, own, own local data... people say we need, we need our local data as if their local data are going to be a lot different from everybody else’s... at what level we actually need the data given that there are similarities across health unit regions”

“I find the need for smaller geographic resolution data overrated. There are much more similarities than are differences.”

Working Together

The next most common theme was the need to work together. Collaboration and partnerships were seen as essential to the assessment and surveillance of child and youth health:

“We have to have cooperation between public health units and schools to collect these data... we have to work together if we want to get this information.”

In particular, key informants identified a need for better communication between stakeholders, and that engagement with the experts is essential to any collaborative efforts.

The last major theme identified by key informants from every sector was a need for a coordinated, streamlined system for assessing child and youth health.

Administrative and Operational Needs

Administrative and operational needs were a minor theme in this category. Strategies for effective assessment, increased capacity, and a provincial mandate were needs identified by key informants.

Awareness

Awareness was another minor theme described by government key informants; particularly, the need to increase awareness about the priority of child and youth surveillance in Ontario:

“People have to actually think collecting data on children is a priority and make it a priority”

Table 5. Needs related to the assessment and surveillance of child and youth health as expressed by key informants

Themes	Sub-Themes	G	A	E
Awareness	Awareness about the priority of child and youth surveillance	X		
Data and Methodology	Quality, multipurpose data	X	X	X
	Longitudinal data collection	X		X
	Regular frequency of data collection	X	X	
	Standardized measures		X	
	Larger sample sizes		X	
	Ability to link data sets	X		
	Open access to data		X	
	PHU-level estimates	X		
Administrative and Operational	Stratification of data	X		
	Effective strategies for assessment			X
	Increased capacity	X	X	
Working Together	Provincial mandate	X		
	Collaboration and partnerships		X	X
	Coordinated, streamlined system	X	X	X
	Better communication		X	
	Engage and consult the experts		X	

G – Government sector; A – Academic sector; E – Education sector.

Challenges and Barriers

Themes were categorized as a 'challenge or barrier' if the key informant identified or described a limitation or other difficulties that prevents or hinders the assessment and surveillance of child and youth health. The themes identified as challenges or barriers are summarized in **Table 6** and key findings are discussed below.

There were four major themes that emerged under the challenges and barriers category: systemic issues, data and methodological limitations, survey fatigue, and challenges of collaborative work.

Systemic Issues

Systemic issues were a dominant theme in this category, particularly for the government and academic sectors. The primary systemic issue identified by all sectors was the financial barriers associated with assessment and surveillance of children and youth; many organizations simply do not have the funds or resources to collect, analyze, and report data to meet the needs of data users. Key informants also identified systemic issues that made it challenging to collaborate with PHUs including the inconsistent organizational structure of PHUs and the opposition to direct measures asserted by some PHUs:

"A barrier to collecting data on school-aged children is differences of opinion among public health unit staff... some Health Units and some Health Unit staff are very opposed to collecting direct measures"

Key informants from the government sector also described the current "patchwork" or "piecemeal" assessment and surveillance approach in Ontario as a significant barrier that hinders effective assessment and surveillance of child and youth health:

"I think the current piecemeal approach, well I'm just kind of shaking my head; I think you end up with have and have not Health Units"

"You have to go to 15 data sources to be able to pull out the pieces that were relevant"

Data and Methodological Limitations

Data and methodological limitations was another frequent theme among key informants. The majority of key informants representing all sectors described the analytical challenges commonly encountered with small sample sizes, particularly as it related to being able to report estimates for small geographical areas or priority populations. Further, several key informants, representing all sectors, had concerns about the challenge of accurately measuring certain aspects of health and well-being (e.g., mental health, family dynamics) and whether self-reported measures were a valid approach:

"The quality of data that comes from self-report is generally sufficiently poor that I don't trust it, and our more robust direct measures almost always shows that that hypothesis is correct."

Key informants from government and academia also shared concerns about the unwillingness of data collectors to share data sets, which were described as being "territorial". The lack of standardization in methodology was also a common concern among government and academic key informants:

"[It's] a very disjointed system where you have different teams of researchers trying to collect data that answer a lot of the same things, but they're all doing it differently."

Additional data and methodological limitations identified by a minority of key informants from the government sector included data gaps and inability to link data sets. Key informants from the education sector also described language barriers and expressed concern about the usefulness of cross-sectional measurements.

Survey Fatigue

Another common theme under this category was survey fatigue. It was frequently asserted by several key informants from all sectors that students are overburdened with surveys and, consequently this has resulted in restrictions in sampling within the school setting:

"Schools are feeling a little bit inundated with surveys... our biggest challenge is recruitment, getting into schools and getting a sufficient sample size"

Key informants also noted survey fatigue among participants outside the school setting and that there are times when the amount of data collected from different surveys is overwhelming to the end user, such as school administrators.

Challenges of Collaborative Work

The next major theme identified was the challenges of collaborative work. Under this theme key informants described some of the difficulties associated with collaboration and partnerships for the assessment and surveillance of child and youth health. Multiple key informants from all sectors asserted that certain stakeholders can hinder progress on resolving issues. Some key informants cautioned against being "overly inclusive" in terms of which stakeholders are involved in collaboration.

Key informants from academia and education also identified that certain stakeholders, particularly from government, just do not work well together or just do not communicate, often resulting in inefficiencies and duplication of efforts: "Ontario likes to reinvent the wheel." Academic key informants also described how competitiveness between research groups is hindering assessment and surveillance of child and youth health:

"We've got a level of competition across groups rather than the spirit of collaboration."

Some key informants also described the challenge of communicating assessment and surveillance results to stakeholders from other sectors; specifically, when researchers or government collect data in schools, there are times when the findings are not relayed back to school officials. Academic key informants had concerns about any singular stakeholder taking the lead on a provincially coordinated surveillance system for children and youth and they also noted that sometimes "resources outside of Toronto" are not recognized. Lastly, key informants

from the education sector mentioned that misalignment of geo-spatial boundaries (e.g., PHU regions, schoolboard districts, LIHN boundaries) can make it challenging to work together.

There were three minor themes that emerged under the challenges and barriers category: ethical and privacy barriers, competing priorities, and operational challenges.

Ethical and Privacy Barriers

Under the first minor theme of ethical and privacy barriers, key informants, primarily from government and academia, identified a number of sub-themes. The inconsistent and burdensome nature of the research ethics process for school boards was noted as a major barrier by several key informants:

"One of the other issues with collecting through the school board is that each of the 72 school boards in the province of Ontario, in fact school boards across the country, have different ethical clearance procedures."

"Every [research ethics boards] is different and it's just an absurd thing to me; that that's how research surveillance works in the country"

The academic and education sectors also described challenges with surveying on sensitive topics such as sexual behaviour and substance misuse, and the opposition that is commonly encountered when trying to collect data in these subject areas:

"We would have parents who would be very bothered if their children in grade 7 or 8 were answering questions around drugs and alcohol and sex."

Other key informants described how privacy and ethical barriers limit data accessibility and the unethical use of open data sets. It was noted that some perceived ethical dilemmas, such as measuring childhood BMI in schools, may be driven by personal prejudices or politics, rather than evidence, which can hinder the assessment and surveillance of child and youth health:

Competing Priorities

The second minor theme was competing priorities. Several key informants from all sectors commented on the challenge of balancing the length of surveys while maintaining meaningful content that will be useful to most end users. This challenge of trying to provide a balance of data that meets the needs of multiple stakeholders often stems from differing mandates between sectors and unknown or differing data priorities for each stakeholder.

Operational Challenges

The last minor theme for this category was operational challenges. A number of key informants from the education sector identified the lack of capacity and expertise within their organizations for assessment and surveillance of children and youth:

"[We] don't have the expertise or the capacity built within our organization. So it is a challenge, and we do our best, but by no means, do we have the expertise, or the level of knowledge necessary for data collection, data interpretation"

Turnover of human resources and technical issues related to data collection were other operational challenges noted. Based on previous experiences, key informants from the academic sector described how poor communication within organizations makes it challenging to work collaboratively on assessment and surveillance efforts, particularly as it applies to Ontario PHUs:

"The other challenge we've found is there's a lot of poor communication within a public health unit... it's quite comical and embarrassing how little communication happens within individual public health units."

"The mechanisms within our own structures are such that they prevent, or make it very difficult, for us to actually get the measures we need in order to improve the health of the population. I think that the pendulum has swung way too far, that we're way too politically correct."



Table 6. Challenges and barriers related to the assessment and surveillance of child and youth health as expressed by key informants.

Themes	Sub-Themes	G	A	E
Challenges of Collaborative Work	Some stakeholders can hinder progress	X	X	X
	Lack of partnership and collaboration		X	X
	Lack of communication of findings to partners		X	
	Competitiveness between groups		X	
	Duplication of efforts / unwillingness to work together	X	X	
	Changes in data collection approach could nullify previous baseline measurements			X
	Being too inclusive of stakeholders		X	
	Geo-spatial challenges in collaboration			X
	Surveillance should not be led by any singular stakeholder		X	
Competing Priorities	Balancing meaningful survey content and length	X	X	X
	Conflicting and/or undefined mandates			X
	Lack of prioritization of data		X	
	There are other competing priorities			X
Data and Methodological Limitations	Small sample sizes	X	X	X
	Accuracy of self-reported health and well-being measures	X	X	X
	Data is not shared or made accessible	X	X	
	Lack of coordination and/or standardization	X	X	
	Data gaps hinder reporting	X		
	Measurements at single time-point have limited usefulness			X
	Unable to link data sets	X		
	Existing youth surveys were not designed for youth	X		
	Language barrier			X
Ethical and Privacy Barriers	The ethics processes of school boards	X	X	
	Opposition to sensitive content		X	X
	Privacy considerations limits data access	X		
	Open or shared data is being used unethically		X	
	There is taboo around direct measures		X	
Operational Challenges	Lack of capacity			X
	Turnover of human resources			X
	Poor communication in public health units		X	
	Technical issues			X
	Labour disruptions	X		

Themes	Sub-Themes	G	A	E
Survey Fatigue	Schools are overburdened with surveys	X	X	X
	Schools unwilling to allow sampling of students	X	X	X
	People are unwilling to participate in surveys	X		
	End user unaware of and overwhelmed by amount of data			X
Systemic Issues	Cost, lack of funding	X	X	X
	Dissimilarities between PHUs	X		
	Public health deters participation in direct measures	X	X	
	Patchwork system of data sources	X		
	Research process makes it difficult		X	

G – Government sector; A – Academic sector; E – Education sector.

Opportunities for Improvement

Themes were categorized as ‘opportunities for improvement’ if the key informant identified or described a specific situational intervention that could improve the assessment and surveillance of child and youth health; these themes tended to take the form of suggestions or recommendations, usually in reference to an alternative approach. The themes identified as opportunities for improvement are summarized in **Table 7** and key findings are discussed in more detail below.

Data-related and Methodological Improvements

One of the most frequently identified themes was data-related and methodological improvements in the assessment and surveillance of child and youth health. More specifically, many key informants, representing all sectors, described an opportunity to expand sampling or augment existing surveys that collected data on the health of children and youth:

“The best research-grade data collection system for youth health in the world currently exists in Ontario, and is currently being used in a small sample of schools. The data are being fed to schools, and they’re being fed to the public health units that want to partner. We have the Gold Standard model, it

works. If the province really wants to improve youth health surveillance, we just need to find mechanisms to expand it.”

“The most important message is that there is a national data source coming, and there is an option available to get data at the PHU level if they’re willing to buy extra samples.”

Data collection in schools was another common recommendation identified under data-related and methodological improvements. Key informants from all sectors described the opportunity to acquire representative data on children and youth by utilizing the school system:

“School is the ideal place to collect data on school-aged children because children of all socio-economic strata are represented there”

Other data and methodology-related improvements identified by key informants included: ensuring surveys are a reasonable length, collecting longitudinal data, increasing accessibility of data, increasing standardization of surveillance data, ensuring that dissimilar data sets are linkable, and centralizing data collection and analyses:

“I think a lot of these problems could be solved just by having a centralized system that does this work and shares it with all the stakeholders, whether it be Public Health, Ministry of Ed, Ministry of Health, the research community; this could very, very easily effectively, and cost effectively be centralized in one research hub.”

Awareness

Key informants commonly identified awareness and prioritization as a theme in this category. Many key informants from all sectors identified opportunities to build awareness and interest in child and youth assessment and surveillance, and for leaders to make this issue a priority:

“The most important message there is that tremendous data gaps for children in Ontario that will have to be closed; this starts with a provincial vision around child health”

“Public health units, they do make a lot of public announcements for; regarding you know, wash your hands and things like that. If they could communicate to the public, that we need your help to get this data to help make your health better; and so that would help [our survey]... if they’re able to help us get response rates up, and we can turn around and help them by giving them more samples for analysis.”

Collaboration and Partnerships

Another common theme identified across all sectors was the opportunities to improve engagement across all sectors through the establishment of meaningful collaborations and partnerships. In general, key informants from government, academia, and education thought that there is room to improve collaborative work between all sectors.

Some examples of ways to improve collaboration included: better coordination to reduce duplication of efforts, cross-sectoral networking and discussion between relevant stakeholders, and being mindful of existing work and the needs of others:

“I think if we can coordinate, harmonize, linearize things, it has all kinds of good possibilities, like avoiding duplication, being more cost effective, reducing redundancies, reducing conflicting findings, those sorts of things.”

“It would be very important that, moving forward, understanding the desire for something that’s more consistent. That it would really have to be respectful of previous work being done and fit in with, as opposed to, being another initiative.”

Systemic Changes

One minor theme under this category was systemic changes; that is, a number of key informants identified a variety of systemic issues that could be addressed. For example, making the ethics process more consistent and streamlined across school boards, was identified by both government and academia:

“We’ve had to put in 72 ethics applications, 12 in French, 60 in English; and that’s a mess as well. So I think there’s that end of things as well, that could potentially be cleaned up.”

Other systemic changes described by key informants included mandated or legislated surveillance activities for the province of Ontario, stronger leadership to move this issue forward, better planning for the future, ensuring data needs have been prioritized by relevant sectors, and framing data collection efforts in a positive perspective:

“And to not be thinking about your surveillance system planning with that future lens, just means that you’re building something for yesterday, and so, I would pay a lot of attention to key landmark documents coming out, higher orders of jurisdiction beyond the province of Ontario, that will likely have influence on things.”

Table 7. Opportunities for improvement related to the assessment and surveillance of child and youth health as expressed by key informants.

Themes	Sub-Themes	G	A	E
Awareness	Build awareness and interest in child and youth surveillance	X	X	X
Data-related and Methodological Improvements	Expand or augment sampling of existing surveys	X	X	X
	Collect data in the school setting	X	X	X
	Centralize data source and/or centralize data analysis	X	X	
	Collecting longitudinal data		X	X
	Data should be openly accessible or shared	X	X	
	Standardize surveillance data	X		X
	Surveys need to be a reasonable length	X		X
Engage in Meaningful Collaboration and Partnerships	Create linkable data sets	X		
	Better collaboration and partnerships	X	X	X
	Coordination of efforts	X	X	
	Cross-sectoral networking and discussion between stakeholders	X	X	X
	Avoid working with certain partners		X	X
	Be mindful of existing work and other's needs	X		X
Systemic Changes	Bridge knowledge gaps about existing data sources		X	
	Improved and streamlined ethics processes across school boards	X	X	
	Mandate and/or legislate surveillance activities at the provincial level	X	X	
	Stronger leadership; have leaders move this forward		X	X
	Plan with a future lens		X	
	Prioritize data needs across relevant sectors	X		
	Surveillance should be from a positive perspective			X

G – Government sector; A – Academic sector; E – Education sector.

Current Approaches

Themes were categorized as ‘current approaches’ if the key informant identified or described current practices, techniques, or methods used by either themselves or others for assessment and surveillance of child and youth health (this is a factual statement or observation; not an opinion or suggestion). When interpreting these findings, it should be noted that the current approaches identified in this section are not necessarily the most effective approaches for assessment and surveillance of child and youth health. The themes identified as current approaches are summarized in **Table 8** and key findings are discussed in more detail below.

Data collection was the dominant theme under this category and covered a variety of techniques that are currently being used for assessment and surveillance of children and youth. The majority of key informants across all sectors identified collection of data in a school setting as a current practice, although others described representative sampling of households. It was also common practice to share data sets with other partners and stakeholders, within the current ethically and legislative boundaries.

Some key informants relied on primary data collection, mainly through online tools and telephone surveys, while others relied on secondary sources for data. There were a variety of other approaches described, including proxy reporting for children, longitudinal data collection, standardization of surveys, and legally-enforced survey participation.

The assessment and surveillance processes were another major theme for current approaches. For most key informants across all sectors, collaboration with other stakeholders was a vital process-related element of their current approaches:

“We also work with the Health Units, and we have formal meetings three times a year, between our Board and our co-terminus the Catholic Board, where we work with the Health Units to set up projects for physical issues such as dental screening

and that kind of thing; and this year we’ve actually done a pilot on visual screening and eye testing in JK for students.”

Using a passive consent process in data collection was another common element across all sectors as it tends to result in greater response rates and better representation. Other less frequently described processes included supporting other organizations in assessment and surveillance activities, utilizing an external consultative service for support, and building leadership and buy-in within organizations to drive data collection.

Knowledge exchange was a common theme associated with current approaches. Several key informants, primarily from government and academia, identified actively disseminating assessment and surveillance results, particularly through peer-reviewed publications, reports, presentations, and, in one case, community outreach. When involved in collaborative assessment and surveillance activities, academics and the education sector both noted the value in effectively communicating results back to all stakeholders involved:

“The information we collect from each of our participating schools, we immediately feedback to those schools... Then we make evidence-based suggestions given what’s going on with your student populations.”



The application of assessment and surveillance data was a minor theme. In addition to research and population health assessment, some key informants from all sectors were also using child and youth health data to evaluate the impact of programs and policies. Academics noted that they rely on assessment and surveillance results to substantiate and guide their research and research proposals.

Lastly, two other minor themes were results and analysis. Key informants from government and academia described their use of direct measures for health status estimates for children and youth.

Key informants also produced health status estimates for various geo-political populations: the education and government sectors were focused on sub-provincial estimates whereas academics were more focused on provincial, national, and international estimates.



Table 8. Current approaches related to the assessment and surveillance of child and youth health as expressed by key informants.

Themes	Sub-Themes	G	A	E
Applicability	Data primarily used for evaluation	X	X	X
	Surveillance data is used to guide primary research		X	
Data Collection and Acquisition	Data collection in school setting	X	X	X
	Data sharing	X	X	X
	Use of online survey tools	X		X
	Rely on secondary data sources	X		
	Rely on proxy reporting for children	X	X	
	Use of telephone survey tool	X		
	Augment existing surveys	X		
	Data collection outside school setting (representative households)	X		
	Legally-enforced survey participation	X		
	Longitudinal data collection		X	
	Standardized survey			X
Knowledge Exchange	Publication/Reporting of work	X	X	
	Presentation of work to stakeholders/partners		X	X
	Community outreach			X
Processes	Collaboration with stakeholders	X	X	X
	Passive consent	X	X	X
	Support assessment and surveillance activities	X		
	Use of consultant service			X
	Build leadership and buy-in to drive data collection			X
Results	Broad health outcomes	X	X	
	Interest in direct measures	X	X	
	Interest in local level estimates	X		X
	Interest in estimates comparable to national/international estimates		X	
	Interest in provincial estimates		X	
	Well-being outcomes			X

G – Government sector; A – Academic sector; E – Education sector.



Emerging Areas of Interest

Themes were categorized as ‘emerging areas of interest’ if the key informant identified or described specific topics related to child and youth health where there is a need for information (data gaps) or the topic is of interest to stakeholders. The themes identified as emerging areas of interest are summarized in **Table 9** and key findings are discussed in more detail below.

In total, there were 25 areas of interest described by key informants. Key informants from the government sector identified 20 areas of interest, the academic sector identified 14 areas of interest, and the education sector identified 15 areas of interest.

Child and youth mental health was identified by nearly all key informants from all sectors as a prime area of interest. Some key informants provided examples of assessment of mental health in child and youth populations; although, several key informants emphasized the challenge with assessing the mental health of this population.

Healthy eating and physical activity were also identified by a majority of key informants, representing all sectors. Other areas of interest that were less common, but still identified across all sectors, included parenting, sexual health, and growth and development.

Key informants described a number of other areas of interest related to assessment and surveillance of children and youth, many of which align with the Ontario Public Health Standards. Key informants from both the academic and education sectors identified some unique areas of interest including health literacy, disability, environmental health, social media, and vision.

Table 9. Emerging areas of interest related to the assessment and surveillance of child and youth health as expressed by key informants.

Themes	G	A	E
Mental Health	X	X	X
Healthy Eating	X	X	X
Physical Activity	X	X	X
Parenting	X	X	X
Healthy Weights	X	X	
Sexual Health	X	X	X
Smoking, Alcohol, and Other Substance Misuse	X		X
Family Dynamics	X		X
Growth and Development	X	X	X
Health Literacy		X	X
Peer Relationships/Bullying	X		X
Sedentary Behaviour	X	X	
Disability		X	X
Immunization	X		X
Injury	X	X	
Oral Health	X		X
Safety	X		X
Sleep	X	X	
Civic Engagement	X		
Employment	X		
Environmental Health		X	
Leadership	X		
Social Media		X	
UV Radiation	X		
Vision			X

G – Government sector; A – Academic sector; E – Education sector.

DISCUSSION, CONCLUSIONS, AND RECOMMENDATIONS

There were several common themes identified by all stakeholders engaged in this project (PHUs and key informants from government, academia, and education). These common themes are discussed in this section.

Discussion

The purpose of this Locally Driven Collaborative Project (LDCP) was to determine current practices, identify gaps, and explore novel approaches with respect to the collection, analysis, and reporting of local health status for school-age children and youth (Grade 1-12) in Ontario. There were several common themes identified by all stakeholders engaged in this project (PHUs and key informants from government, academia, and education). These common themes are discussed below. There are considerable gaps in the current patchwork system in Ontario and the findings of this project are essential to the advancement of a comprehensive health status surveillance system for the province.

There is value in collaboration and coordination of efforts.

Stakeholders from all sectors described many examples of collaborative efforts in the assessment and surveillance of children and youth, and cited the value in working together. Effective communication was identified as a pillar of collaborative work; specifically, knowledge exchange and networking opportunities were described as key components of effective collaborations. For example, school administrators found it very valuable when researchers relayed and interpreted survey results of local student populations.

This is not the first time that partnership and collaboration has been identified as being necessary for moving this work forward. In an Ontario report, titled Youth Population Health Assessment Visioning, partnerships and collaboration were identified as key factors for improving assessment and surveillance of children and youth health status [14]. Similarly, an Ontario Risk and Behaviour Surveillance System (ORBSS) Advisory Committee identified that “collaboration across existing surveillance systems is possible and beneficial” [15]. This identified need is also reflective of a larger movement to strengthen partnerships and collaboration across service providers in Ontario; one example being the proposal in Patients First to formalize a linkage between LHINs and Boards of Health [16].

Existing data sources can be enhanced and expanded to meet the needs of stakeholders.

Most PHUs were aware of existing data sources, but fewer have actually used those existing data sources to meet their local assessment and surveillance needs for child and youth populations. According to PHUs, existing data sources can be improved by: having larger local sample sizes, filling in data gaps, coordinating data collection efforts, enhancing accessibility of data, ensuring useful stratifying variables, and removing financial barriers. Key informants, who represent some of these existing data sources, noted that some of these improvements were feasible and there are opportunities to expand and enhance these data sources in ways that would better meet the needs of local stakeholders, including PHUs. These views align with those captured in the Youth Population Health Assessment Visioning report which identified expanding upon existing efforts as a key theme from a survey of stakeholders and experts in the field of assessment and surveillance:

“Building upon efforts and data collection systems and measures already in place, while linking and aligning these efforts, was considered an integral step to achieving a coordinated and integrated youth population health assessment system” [14].

Likewise, one of the key recommendations of a 2013 report by PHO – titled Measuring the Health of Infants, Children and Youth for Public Health in Ontario – was to enhance data sources relevant to children and youth [5]. The need for the enhancement of such data sources was echoed in the present report by stakeholders from all sectors. Many stakeholders also thought there was an opportunity to improve data accessibility and data sharing, within ethical and legislative boundaries.

Larger local sample sizes would be an asset.

The need for larger samples sizes of local populations was strongly identified by public health professionals and echoed by government key informants. More specifically, larger local sample sizes in secondary sources were described as necessary for: (i) reliably reporting of health status for PHU regions and smaller areas within PHU regions, and (ii) determining health status of sub-populations (e.g., sex, age, and household income). The Canadian Community Health Survey (CCHS) was overwhelmingly cited as needing larger local sample sizes, which is unsurprising as it is one of the most frequently used data sources for Ontario PHUs; although, the CCHS was designed for adults and many of the questions are not applicable to the youth population included in the sample. Statistics Canada plans to address some data gaps for children and youth (1-17 years-old) through the launch of the Canadian Health Survey on Children and Youth (CHSCY). Since the CHSCY is a national data source being funded by federal partners, it was not designed to provide data for generating local level estimates (such as PHU regions), but individual PHUs or the province of Ontario have the option to purchase an oversample of children and youth in their regions.

Increasing local sample sizes would better enable PHUs to meet their OPHS requirements, primarily as it relates to population health assessment and surveillance, but more importantly, larger local sample sizes would allow PHUs and other stakeholders to increase the responsiveness and effectiveness of their services through targeted programming. Given that health care dollars are not infinite, it is important to target resources towards populations with the greatest needs. Targeting funds to prevent disease and maximizing the impact of our health care dollars – which is one of the goals of Patients First [16] – can only be done with quality data that captures the individual needs of local populations.

Data collection in schools is a common approach.

Many stakeholders take advantage of the school system for collecting data on school-age children and youth, and rightfully so; it is an opportune setting to collect representative data and it can be done with relative ease. However, the attractiveness of this approach, according to stakeholders, has resulted in schools being overburdened with data collection, with both staff and students feeling survey fatigued. One of the greatest barriers to collecting in schools is the inconsistent and disjointed research ethics processes that vary considerably between school boards, and this was frequently cited as one aspect of school-based data collection in Ontario that needs improvement.

It is important to note that data collected in schools isn't just valuable to public health professionals and researchers; school boards also have a need for high-quality data on student health and well-being. This data is needed to support decisions and evaluate the impact of policies related to student well-being, as identified in *Achieving Excellence: A Renewed Vision for Education in Ontario* [17].

There is a need for more data on mental health, healthy eating, and physical activity.

There were many health-related topics with an identified need for more data on children and youth, but mental health, healthy eating, and physical activity were identified by all stakeholders as the areas of highest priority. These data needs also align with several key initiatives, including Ontario's renewed vision for education (*Achieving Excellence*) [17], Ontario's comprehensive mental health and addiction strategy (*Open Minds, Health Minds*) [18], and Ontario's *Healthy Kids Strategy* [19]. Each of these initiatives have goals that need supporting data in the areas of mental health, physical activity, and healthy eating. Such data is important to determine the impact of these initiatives on the health and well-being of the children and youth of Ontario, and for future planning and delivery of health-related services.

Some key informants also indicated a preference for direct measures, but also noted the challenges related to the collection of direct measurements in some of these priority areas. It should be noted that direct measures may conflict with other needs such as a standardized passive consent process in schools.

Some changes will require greater resources.

The results from this study indicate that the current approach to assessment and surveillance of children and youth in Ontario is piece-meal and inefficient. Individual efforts to close the data gaps are draining valuable resources and capacity at PHUs. There is a potential for revenue-neutral changes that would improve the efficacy of assessment and surveillance of children and youth in Ontario. Some stakeholders mentioned the centralization of data collection, analysis, and reporting; although there should still be open access to data.

The primary root cause of these issues is the lack of a dedicated data source for children and youth that is representative and reportable at the local level. The *Healthy Kids Panel* report explicitly recommended that Ontario must “develop a surveillance system to monitor childhood weights, risk factors and protective factors over time” [19]. The evidence synthesized in the present report can help to guide the development of such a system. Previous groups, including those stakeholders and experts represented in the *Youth Population Health Assessment Visioning* report [14] and the *ORBSS* advisory committee [15], have also called for sustained funding to assist with a coordinated provincial system for the assessment and surveillance of child and youth health. Investing in such a resource would be valuable to many stakeholders from multiple sectors, and more importantly, an asset to the health and well-being of children and youth in Ontario.



Conclusions

Through surveying and interviewing stakeholders from public health units, directors of education, researchers in academic institutions, and government, the project team feels confident that the following recommendations are essential to addressing gaps for children and youth in Ontario and to improving the system of assessment and surveillance to be more responsive at the local, regional and provincial level.

Recommendations:

- 1. Establish a Provincial Task Force:** Establish a provincial task force, with membership representing key stakeholders, which will aim to identify next steps for improving assessment and surveillance of child and youth health and well-being in Ontario.
 - a. Recruit leadership representatives from government, public health, education, and academia to form a provincial task force. This includes, but is not limited to, representatives from public health units, Public Health Ontario, school boards, university and research institutions, the Ontario Ministry of Education, the Ontario Ministry of Health and Long-Term Care, and relevant resource centres. These representatives will meet regularly.
 - b. The task force should produce a briefing with recommended next steps for improving the assessment and surveillance of the health and well-being of Ontario children and youth.
 - c. Experts and stakeholders should be consulted when necessary, and the task force should build on the work of this report and previous work, as well as coordinate with other current initiatives related to assessment and surveillance of children and youth.
 - d. The task force should provide guidance and oversight for the implementation of its recommendations and the recommendations of the present report.

- 2. Advocate for Children and Youth:** Raise awareness among decision makers about the importance of quality data on children and youth, and the opportunities for improving assessment and surveillance of this population.

- a. The Population Health Assessment LDGP team should actively and regularly engage in knowledge exchange activities with relevant decision-makers, including the dissemination of project deliverables and updates on next steps.
- b. The Province of Ontario, which includes the Ministries of Education and Health and Long-Term Care, should develop a shared mandate that will drive changes in the assessment and surveillance of child and youth health.
- c. Ontario public health units and school boards should collaboratively advocate the needs of their child and youth populations to their respective decision-makers.
- d. The Ontario government and relevant ministries should support assessment and surveillance province-wide so that all child and youth populations are included irrespective of locality.

- 3. Support Multi-sectoral Collaboration:** Promote meaningful, multi-sectoral partnerships and collaborations that foster effective and efficient assessment and surveillance of children and youth.

- a. The Ontario education system should move towards a more consistent and simplified research process that allows for better collaboration with government and academic researchers and lessens the burden on local boards of education.
- b. Explore implementing a student health and well-being surveillance system within the Ontario education system that is standardized and universal for all Ontario schools in collaboration with public health and academia. School boards should also be allowed to complement such a universal system with individualized assessment efforts.
- c. Improve communication and feedback mechanisms between academic institutions, school boards, and public health units, such that there is open sharing of data and results across sectors.

- 4. Strengthen and Coordinate Existing Surveillance Systems:** Invest in enhancing and expanding existing approaches to meet the needs of identified stakeholders in Ontario.

- a. Increase the awareness of existing child and youth data sources in Ontario, including the strengths and limitations of these sources, among different sectors and stakeholders.
- b. Prioritize the collection of data for mental health, healthy eating, and physical activity among children and youth in Ontario.
- c. Increase the number of children and youth surveyed to allow for useful and reliable estimates at the local level.
- d. Create mechanisms to foster better response rates, including the use of passive consent.
- e. Ensure that health and well-being data is linked to other variables including age, sex and gender, household income, postal code, and parental education.
- f. Standardize metrics across surveillance systems so that data can be compared across regions and within regions.
- g. Support systems that incorporate direct measures where appropriate and possible.



Stakeholders from local public health, academia, education, and other government agencies described many challenges related to the assessment and surveillance of child and youth health in Ontario. Unlike other Canadian provinces and developed countries, Ontario lacks an integrated, sustainable, and coordinated surveillance system for children and youth. Some opportunities for improvement, as identified by key stakeholders, include: coordinating efforts and strengthening collaborations, improving existing data sources (increase local sample sizes and accessibility of data), and prioritizing the collection of mental health, healthy eating, and physical activity data. The recommendations outlined in this report provide the first steps towards improving the health of children and youth locally, regionally and provincially.

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APPENDIX A

Select Examples of Primary Data Collection using Surveys

Partnership with school boards to conduct a health survey of high school students:

"The short (5 minute) anonymous survey asked students about tobacco use, alcohol, physical activity, injury prevention, nutrition (Breakfast, Vegetable and Fruit Intake), and sun safety practices. In our survey, 2,291 students participated which gives a margin of error of 1.26%. The survey had a satisfactory response rate with a satisfactory participation rate... The survey was feasible but requires extra funding as [an external source] provided the funds needed to complete this survey as part of the process to build school health champions... Based on preliminary discussions with School Board representatives, the survey did not contain any questions regarding drugs or sexual behaviours so it was easier for all the school boards to approve implementation of this initiative at that time... Participating school boards and schools were sent a board-specific or school-specific feedback report, outlining their results and allowing for strategies to be targeted to specific areas identified."

Telephone health survey of children (4-12 years old) using caregivers as a proxy and conducted in partnership with multiple community partners:

"[Collected] parent attitudes about their child's eating habits, weight, physical activity, sedentary behaviour and access to community resources... Comprehensive 36-item survey instrument used. Contracting of survey service consultant. Surveyed an estimated 7.72% of eligible population. Made more feasible by being partnership-driven, pooled funds, and the contract with a survey consultant... would do it again if there was an opportunity."

Online health survey of students in Grades 7 and 10 conducted in partnership with school boards, municipalities, and community organizations:

"Our response rate was high during both cycles of the survey (above 70%). This was due to the relationships we developed with our three school boards. Once surveys were completed, each school received a school profile, providing school level data from the survey. This helped them with their school improvement planning. All superintendents and directors of education received board profiles, providing them data for their board improvement planning. This was seen as very desirable by our school board partners. We also created survey preparation packages for principals and for teachers, informing them about the survey, outlining the benefits to participation, providing information forms for parents for them to hand out, and giving them step-by-step instructions for having their students complete the survey. Finally, we providing a presentation on the [survey] to all principals at their board-wide meetings, giving them notice and answering questions they had about the survey... We plan on doing the survey every three years."

Health survey of Grade 6-8 students using the SHAPES framework in partnership with school boards:

"Provided very good and comprehensive data... response rate was quite high and sample size was large enough to allow for stratification and detailed analysis. Also filled an important gap in our statistics - health behaviours for youth. We are doing it again in 2017. It was feasible to do only twice (kind of a pre-post in 2013 and 2017) due to the cost... we wouldn't be able to do this routinely."

Health survey of Grade 7-12 students that collected paper-based responses and took direct measurements of health indicators (no official partnerships): “Four years of planning and over 100 staff involved in data collection in 466 class rooms in 165 schools. A dedicated survey lead position was established to work closely with all stakeholders and to lead a project management team... it detracted from other work and services that we normally provide in the schools. Staff and management in program areas involved in data collection found it very disruptive, as many services had to be completely put on hold or reduced. We would do it again but with changes based on lessons learned (see below). To date, there has not been a formal evaluation of the cost-benefit ratio of the project. There is however, a sense that more could be done with the results. Various barriers have prevented this from happening.”

Select Examples of Primary Data Collection using Surveillance Methods

Surveillance (routine sampling every 4 years) of Grade 7-12 students conducted through a collaboration with school boards, other public health units, and CAMH: “[OSDUHS] is a well established survey that school boards are familiar with and uses validated questions and adapts to changing drug/health environment... much of the work is done by ISR and CAMH at a reasonable cost to the health unit. Ongoing participation is not a requirement, so we have chosen to oversample every 2 cycles (every 4 years).”

Surveillance of drug use among youth (12-19 years old) conducted in partnership with school boards and using a local external consultant: “[It was effective] because it was all kept local. Local consultant doing the work, local school boards were engaged and our staff supported them. It was feasible because it was planned (budget and time) to have an

external consultant complete the bulk of the work. This isn’t sustainable because of cost and we do not have the capacity (mainly in knowledge, skills and time) to do this internally.”

Surveillance of Grade 7 and 10 students in partnership with school boards and other community organizations: “[It was effective because]: it was a census of all children in a grade, so less respondent bias; implied consent; support of the school boards and doing it in the school environment; funding for a researcher to help with the data analysis and knowledge translation. [It is feasible/sustainable] if you have very strong and mutually beneficial relationships with the school boards and other community partners that are invested in research and using data to move issues forward in the community. In addition, your organization needs to commit resources and a tremendous amount of staff time to the partnership.”





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