



# Severe microcephaly

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## Background

Microcephaly is an anomaly of the central nervous system. It is a condition in which an infant's head is significantly smaller than the head of other children of the same age and sex. Sometimes detected at birth, microcephaly usually results from the brain developing abnormally in the womb or not growing as it should after birth. There are many known causes of microcephaly, including genetic disorders, exposures to known drugs or toxins, hypoxic injury, and congenital infections. There are a variety of outcomes associated with microcephaly; however, many affected children experience developmental delays, ranging from mild to severe. Children with microcephaly also present with a constellation of other health concerns, often requiring intensive, significant, and life-long medical, educational and social supports.

There has been a recent increase in the number of microcephaly cases reported globally, linked to an outbreak of the Zika virus. While the increase has primarily been documented in South America, given the possible modes of transmission of the Zika virus and recognizing the frequent travel of Canadians to warmer climates, it is critical to monitor for potential Zika virus-related cases of microcephaly in Canada. There is currently no comprehensive Canadian data describing the incidence, epidemiology and/or etiology of microcephaly. Conducting this study is highly responsive, timely, and relevant to an emerging public health issue that has received significant international attention and concern. Moreover, this data will provide rich, valuable clinical information about the condition of microcephaly on a broader scale.

Microcephaly in Canada is currently monitored through the Public Health Agency's Canadian Congenital Anomalies Surveillance System (CCASS). Based on CCASS data, the most recent estimates show that in 2013, the rate of microcephaly in Canada (excluding Quebec) was 6.6 per 10,000 births (a total of 198 microcephaly cases). However, it is important to note that the CCASS approach is based on retrospective, secondary data analysis of hospitalization data.

PROTOCOLS



In addition to this project, the Canadian Paediatric Surveillance Program (CPSP) has also partnered with parallel surveillance systems in the United Kingdom, Australia, and New Zealand, through the International Network of Paediatric Surveillance Units (INoPSU). Work is underway to ensure that, whenever possible, data definitions and surveillance methodologies are aligned to facilitate cross-national comparison of results.

### **Methods**

The CPSP's well-established platform for data collection is the ideal mechanism to access the study population and to implement the study swiftly, efficiently, and economically. Paediatricians and paediatric subspecialists will be asked monthly to report cases meeting the case definition, and will subsequently be asked to complete a detailed questionnaire.

### **Objectives**

This study aims to address the following objectives:

- 1) Define the minimum incidence of severe microcephaly in Canada.
- 2) Describe Canadian-specific epidemiology (including etiology, when known) of severe microcephaly.

### **Case definition**

Report any new patient less than 12 months of age, with a head circumference measurement **less than three standard deviations below the mean** (0.13th centile) for gestational age and sex, based on the sex-specific World Health Organization growth parameters:

- Female term infant with a head circumference of less than 30.3 cm.
- Male term infant with a head circumference of less than 30.7 cm.
- Preterm infant (less than 38 weeks' gestation), as per appended INTERGROWTH-21st study standards.

### **Duration**

June 2016 to May 2018

### **Expected number of cases**

The incidence of severe microcephaly in Canada is very low. We anticipate approximately 250 cases for the study period, based on current CCASS data (retrospectively derived from the Canadian Institute for Health Information data).

### **Ethical approval**

Health Canada and the Public Health Agency of Canada's Research Board

### **Analysis and publication**

Study findings will be reported quarterly to the CPSP and to the Public Health Agency of Canada, and on an annual basis in the form of a data summary to be prepared for inclusion in the CPSP Results publication. Final results will be published in peer-reviewed journals and will be presented at national and international conferences.

### **Bibliography**

Available upon request from the CPSP office