

What is the Canadian Paediatric Surveillance Program?



The Canadian Paediatric Surveillance Program (CPSP) was created in 1996 to study rare diseases and conditions affecting Canadian children and adolescents. It is a joint project of the Public Health Agency of Canada and the Canadian Paediatric Society.



What does the CPSP do?

The CPSP collects and studies information about rare childhood diseases and conditions from paediatricians across Canada.

How does the CPSP work?

Each month, the CPSP asks about 2,800 paediatricians and medical specialists whether they have seen a child or adolescent affected by one of the diseases or conditions that is being studied. If they have, the doctors are asked to let the CPSP know and then answer a few questions about the case.

Information is collected under the authority of the *Public Health Agency of Canada Act* (Section 3(15)) and the *Department of Health Act* (Section 4(2)).

How is the information used?

The CPSP helps us to better understand rare diseases and conditions so that we can improve medical care and health policies for children and adolescents. The CPSP also helps us learn about new health issues so that we can be ready to take action quickly.

How is the information kept safe?

The CPSP follows strict policies and procedures to keep the information that we collect safe and secure and to comply with the federal and provincial laws that apply to our organization. Both physical and technical safeguards are in place, such as storing the CPSP data in a secure facility and limiting access to the data. For more information about CPSP policies and procedures, please visit <https://www.cpsp.cps.ca/about-a-propos/policies-and-procedures>.

Every effort is taken to protect the privacy of patients. We do not collect directly identifying information, such as name, address, or medical record number. We do not contact families or children/adolescents.

Information collected through the CPSP is governed in accordance with Canada's *Privacy Act*.

Am I required to participate?

No, you are not required to participate. If you do not wish to participate, please tell your health care provider. Opting out will mean that your information will not be used as part of the CPSP and will not affect the medical care you receive in any way.

More information is available at:

www.cpsp.cps.ca

Or contact us at: Tel.: 613-526-9397, ext. 239; E-mail: cpsp@cps.ca



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