

Rights to individual privacy and professional confidentiality – A Canadian Paediatric Surveillance Program ongoing commitment

Whether you are a treating physician, a research ethics board member or a parent of a child with a severe, rare condition, you might have wondered: “Does the Canadian Paediatric Surveillance Program (CPSP) respect patient confidentiality?” The answer is definitely

yes. The CPSP is dedicated to improving the health of Canadian children and youth by gathering valuable epidemiological public health data on uncommon high impact conditions without compromising patient confidentiality.

IMPORTANT STEPS

- The CPSP Steering Committee has scrupulously endeavoured to balance the goal of data collection for the common good against the essential need to respect the privacy and confidentiality of patients.
- A review of the Compendium of Canadian Legislation Respecting the Protection of Personal Information in Health Research, prepared by the Canadian Institutes of Health Research, states that information can be used or disclosed for research purposes if it is non-nominal and nonidentifiable, as is the case with the CPSP studies. This is also in agreement with the Canadian Medical Association and the Tri-Council guidelines.
- To further ensure accordance with published guidelines, an independent Canadian research ethics board (REB) must approve a new study before its addition to the program. So far, CPSP studies have been approved by REBs from the following universities and hospitals: University of British Columbia, University of Calgary, University of Manitoba, McGill University, McMaster University, Memorial University, Children’s Hospital of Eastern Ontario, Hamilton Health Sciences Corporation, Hôpital Sainte-Justine, The Hospital for Sick Children, IWK Health Centre, Ottawa Hospital, North York General Hospital, and Health Canada’s REB.
- Because CPSP studies only ask for the date of birth and sex, patient confidentiality is maintained. Every attempt is made to ensure the child’s right to privacy, especially because these are very rare conditions; in fact, neither the CPSP nor the study investigator could link a specific child to any report. Similarly, the CPSP ensures that only aggregate pan-Canadian data are published and presented.
- CPSP’s primary concern is collecting and analyzing pre-existing epidemiological scientific health data for advancing knowledge on rare diseases. The health impact of such surveillance research is beneficial not only to the individual patient but also to the community at large.

The Canadian Paediatric Surveillance Program (CPSP) is a joint project of the Canadian Paediatric Society and Health Canada’s Centre for Infectious Disease Prevention and Control that undertakes the surveillance of rare diseases and conditions in children. For more information visit our Web site at <www.cps.ca/english/cpsp> or <www.cps.ca/francais/pcs>.