



## Addendum to the September 2013 Privacy Impact Assessment of the Canadian Multiple Sclerosis Monitoring System: End of Data Collection, April 2016



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Cette publication est aussi disponible en français sous le titre *Addenda à l'évaluation des incidences sur la vie privée de septembre 2013 du Système canadien de surveillance de la sclérose en plaques : fin de la collecte de données en avril 2016.*

# Addendum to the September 2013 Privacy Impact Assessment of the Canadian Multiple Sclerosis Monitoring System: End of Data Collection, April 2016

The development of the Canadian Multiple Sclerosis Monitoring System (CMSMS) began in 2011 with federal funding and input from an extensive network of experts, including the Canadian Network of MS Clinics, the MS Society of Canada, federal and jurisdictional representatives, clinicians and individuals living with MS. Starting in 2012, the CMSMS was ready to receive data from MS clinics across Canada.

The intended objectives of the CMSMS were to be a comprehensive database to provide comparable pan-Canadian MS data, and to support the care and quality of life of Canadians living with MS as well as evidence-based policy-making. Participation was voluntary, at the discretion of individual clinics and provinces/territories. Due to limited participation, the CMSMS did not obtain the coverage necessary to provide meaningful data at the national level. CIHI ceased collection of CMSMS data in April 2016. At the time of closing, the CMSMS contained data on approximately 7% of persons living with MS in Canada from 3 MS clinics in Manitoba, Saskatchewan and Alberta.

The use, disclosure, retention and destruction of CMSMS data currently held by CIHI continue to be governed by CIHI's [Privacy Policy, 2010](#) and the agreements under which the data was originally collected. Accordingly, CIHI intends to continue using the data, and it will also be available through CIHI's third-party data request process for a period of time. CIHI will review the retention of the data in 2018, at the next review cycle of this privacy impact assessment, to determine whether the data will be further retained or securely destroyed. In compliance with CIHI's [Privacy Impact Assessment Policy](#), this addendum will be updated accordingly.

The CMSMS Minimum Data Set, which was developed in collaboration with MS stakeholders, is a key output of this initiative. This national standard for MS data collection will continue to be available on CIHI's website (as part of the [CMSMS Resource Manual, Version 2012: Data Dictionary Module](#)) for use by MS stakeholders as needed. Inquiries about the CMSMS can be directed to [ms@cihi.ca](mailto:ms@cihi.ca).



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