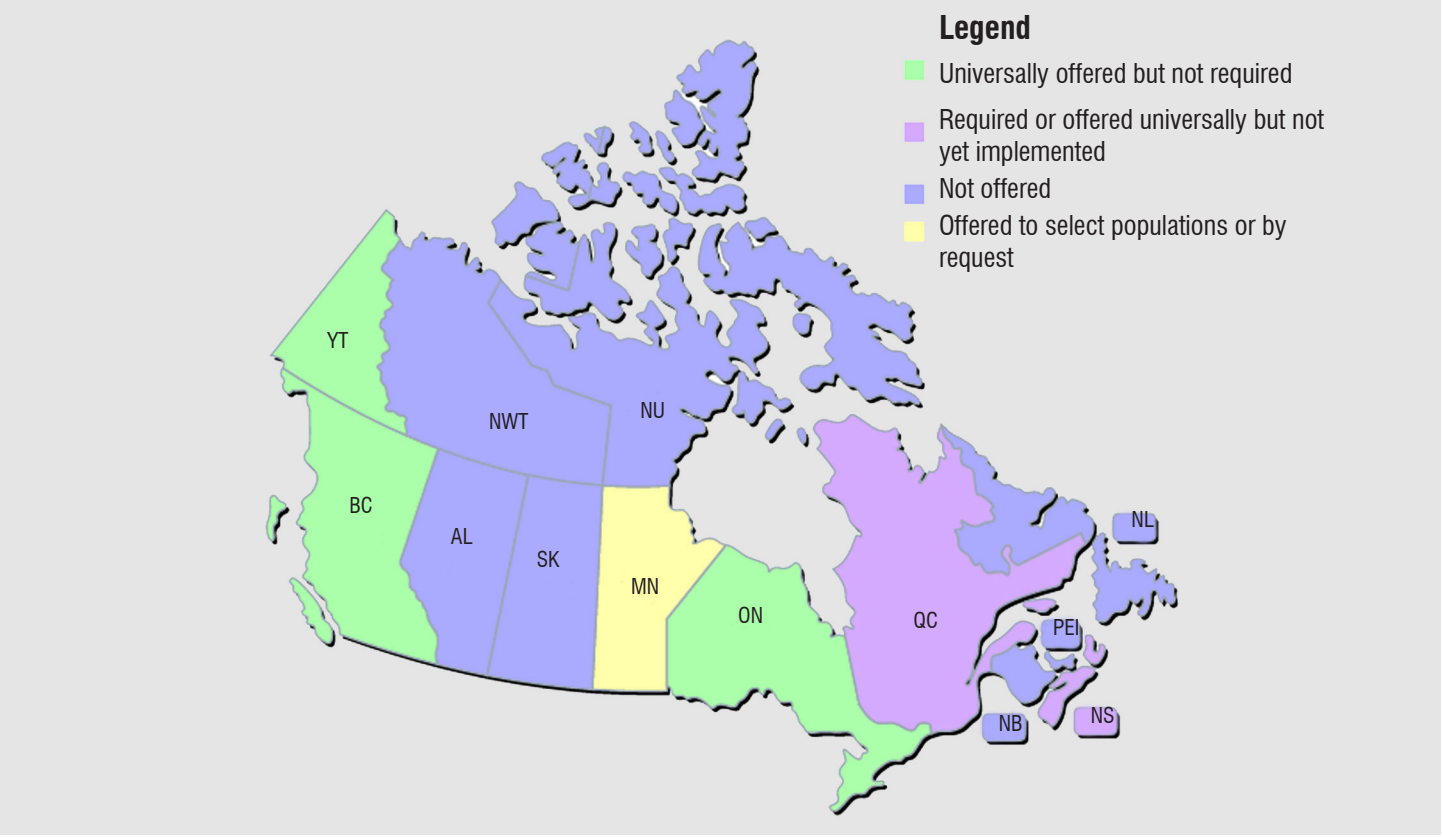
4.3.17 Specific Conditions – Newborn Screening for Sickle Cell Disease



Ontario, British Columbia, and the Yukon are the only provinces/territories in Canada that have universal newborn screening programs for sickle cell disease. Manitoba offers screening for select populations upon request. In Nova Scotia and Quebec, testing is required or offered universally but not yet implemented.[1]

[1] Canadian Organization for Rare Disorders. Newborn Screening in Canada Status Report. June 2013. http://www.raredisorders.ca/documents/CanadaJune21.pdf

Implications

The United Nations and the World Health Organization recognize that sickle-cell disease is one of the world's foremost genetic diseases. As a result, the General Assembly of the United Nations asked member states, including Canada, to support global efforts to address sickle cell disease. Efforts include public health programs for newborn screening and basic research on the disease.[2] In Canada, there has been a call for a National Strategy for Sickle Cell Disease and Thalassemic Disorders. This bill was introduced in the House of Commons in 2011 but has not progressed further than first reading.[3] One of the critical issues related to sickle cell disease screening is that it identifies carriers. This raises dilemmas for parents, has minimal benefit for the child, and, if poorly understood, may impact the child's psychosocial wellbeing.

[2] United Nations. General Assembly. Sixty-third session. Agenda item 155. Resolution adapted by the General Assembly. 2009. http://www.worldlii.org/int/other/UNGARsn/2008/277.pdf.

[3] House of Commons of Canada. Bill C-221. An Act respecting a Comprehensive National Strategy for Sickle Cell Disease and Thalassemic Disorders. http://www.parl.gc.ca/HousePublications/Publication.aspx?DocId=5092338&Language=E&Mode=1&File=4