Bill S-201

Cost estimate for a national framework on sickle cell disease

At the request of Member of Parliament Dan Mazier, the Parliamentary Budget Office (PBO) estimated the fiscal cost of Bill S-201, *An Act respecting a national framework on sickle cell disease*.

Highlights

The Parliamentary Budget Office (PBO) estimates that implementing and administering Bill S-201 could cost $20.1 million over the five-year period spanning 2026-27 to 2030-31.

The estimate reflects costs associated with the activities contemplated in Bill S-201, An Act respecting a national framework on sickle cell disease, including a national research network, a patient registry, stakeholder engagement, development of national standards, analyses, and administrative activities. It does not include potential future measures, programs, or services that could arise from the framework's recommendations.

Approximately 80 per cent of the estimated cost is attributable to three activities: the creation of a National Research Network (25% of costs), the establishment of a National Patient Registry (25% of costs), and supporting public awareness campaigns to increase diversity in Canada’s blood supply (30% of costs).

Actual implementation costs are uncertain and will ultimately depend on the scope of activities undertaken, as the bill does not prescribe specific funding levels or implementation approaches. Incremental costs could be lower if existing resources are used to support implementation or higher if implementation includes more activities than assumed in this estimate.

Background

At the request of Member of Parliament Dan Mazier, this note estimates the fiscal cost of Senate Public Bill S-201, *An Act respecting a national framework on sickle cell disease*. The Bill was referred to the House of Commons Standing Committee on Health on June 16, 2026. Bill S-201, originally introduced in the Senate by the Honourable Marie-Françoise Mégie and subsequently sponsored by the Honourable Tony Ince, would require the Minister of Health, in consultation with provincial and territorial governments and relevant stakeholders, to develop and implement a national framework to improve awareness, diagnosis, treatment, research, data collection and support for individuals living with sickle cell disease (SCD).[1] As of publication, the Bill has been passed by the Senate and is being considered by the House Standing Committee on Health following second reading in the House.[2]

Sickle cell disease (SCD, also known as sickle cell anemia or drepanocytosis) is a genetic disease characterized by abnormal haemoglobin, the iron-based protein that holds oxygen in the blood, which causes red blood cells to deform into a sickle-shape. Some live with a portion of their red blood cells sickling, while others can live with nearly all cells sickling. These sickled cells can block vessels, which causes painful vaso-occlusive crises, swelling, infections, anemia, tissue death, organ damage, and premature mortality. According to the Canadian Blood Services, over 6,000 Canadians are living with SCD.[3] This disease is more frequent among those whose ancestors are from Africa, the Caribbean, Central and South America, the Middle East and South Asia, and is the most common inherited condition in Canada.

Advocates have identified challenges related to the diagnosis, treatment, awareness and access to care for individuals living with SCD. In Senate testimony, those living with, and working with those that live with sickle cell, testified that they are often unable to work, study, or engage in society due to these painful effects.[4] At this time, the only functional cures for SCD are either a risky bone marrow transplant, or a gene therapy drug called exagamglogene autotemcel.[5] Non-curative treatment options are regular blood transfusions and using the cancer drug Hydroxyurea as an off-label treatment. In response to these challenges, advocates have called for the formation of a national framework to improve awareness and resources to care for the individuals living with SCD.

Based on information provided by federal departments and agencies, and drawing on comparable federal health framework initiatives, PBO estimates that implementing and

administering Bill S-201 could cost $20.1 million over the 5-year period spanning 2026-27 to 2030-31, with an implementation date of January 1, 2027. Incremental fiscal costs could be lower if the Government chooses to rely on existing resources to fund the framework, as was done for the federal framework on Lyme disease.

Approximately 80 per cent of the estimated cost is attributable to three activities: the creation of a National Research Network (25% of costs), the establishment of a National Patient Registry (25% of costs), and supporting public awareness campaigns to increase diversity in Canada's blood supply (30% of costs).

Issues for Parliamentarians

Bill S-201 would establish a disease-specific framework focused on SCD. Parliamentarians may wish to consider how the activities required under the bill, including research coordination, data collection, public awareness initiatives and stakeholder engagement, would interact with existing federal health initiatives, including broader strategies addressing drugs for rare diseases and access to treatment.

Additionally, as Senate Public Bills may require a Royal Recommendation if the bill directly requires the appropriation of funds or a novel expenditure not already authorized in law, PBO has costed potential elements of a framework in order to inform debate on the measure, without taking a view on whether the call to adopt a national framework requires a Royal Recommendation.[6]

Detailed 5-Year Cost

Table 1

Detailed 5-Year Cost ($ millions of CAD)

Fiscal year	2026-2027	2027-2028	2028-2029	2029-2030	2030-2031	Total
National Research Network	0.3	1.5	1.3	1.0	1.0	5.0
Patient Registry	0.3	1.5	1.3	1.0	1.0	5.1
Coordination & Communication: Medical Professionals	0.1	0.3	0.3	0.2	0.2	1.0
Coordination & Communication: Stakeholders & the Public	0.3	1.8	1.5	1.2	1.2	6.0
Analysis & Reporting	0.1	0.6	0.5	0.4	0.4	2.0
Consultations & Engagement	0.1	0.3	0.3	0.2	0.2	1.0
Total cost	**1.0**	**6.0**	**5.0**	**4.0**	**4.0**	**20.1**

Note:
Estimates are presented on an accrual basis as would appear in the budget and public accounts.
Totals may not add due to rounding.

Estimation and Projection Method

To estimate the fiscal cost of Bill S-201, PBO requested data from the Public Health Agency of Canada (PHAC) for comparable federal health frameworks, including those for autism spectrum disorder, diabetes, and Lyme disease.[7] Total federal expenditures associated with these three frameworks were $14.4 million, $16.0 million, and $21.2 million, respectively (Table 2).

While each health condition differs in prevalence, treatment and patient needs, the federal role anticipated under these frameworks is broadly similar. Common elements include administrative costs, public awareness initiatives, research and treatment support, stakeholder engagement, data collection, and fiscal analyses of increasing benefits. Therefore, these frameworks provide a useful benchmark for estimating the costs associated with implementing a national framework.

The primary source of uncertainty in estimating Bill S-201 is the scope. A more extensive approach could increase costs, while greater reliance on existing programs and resources could reduce incremental costs.

Table 2
Variables by fiscal year in millions of dollars

Framework	Initial Year	Estimated Federal Cost	Population Affected	Major Components	Relevance to Bill S-201
Federal Framework for Autism Spectrum Disorder	2023-24	14.4	Prevalence estimates of autism in children and youth were 1 in 44 (2.25%) in 2023–2024.[8]	Screening and diagnosis, financial supports, national research network, national campaigns, analyses, consultations, and conference.	Network set-up costs, analyses, consultations, and administration.
National Framework for Diabetes	2021-22	16.0	3.9 million diagnosed in 2023-24.[9]	Training guidelines, research, data collection, knowledge sharing, disability tax credit analysis, conference.	Knowledge sharing, public awareness, and analyses.
Federal Framework on Lyme Disease	2014-15	21.2	5,809 cases in 2024.[10]	Conference, national medical surveillance, guidelines, educational material, reports.	Research network, communication and coordination with medical professionals.
Proposed Sickle Cell Disease Framework	Proposed (subject to Royal Assent)	20.1	Currently estimated at 6,000 – 6,500 Canadians.[11]	Research network, patient registry, awareness activities, professional education, analysis and reporting	Cost estimate informed by observed expenditures under comparable federal health frameworks.

Source:
Public Health Agency of Canada (PHAC). Parliamentary Budget Office.

Note:
Initial Year refers to the first fiscal year in which funding began. This year may precede the framework's launch because development work began earlier.

Based on information provided by federal departments and agencies, and drawing on comparable federal health framework initiatives, PBO estimates that implementing and administering Bill S-201 could cost $20.1 million over the 5-year period spanning 2026-27 to 2030-31. The estimate was developed by grouping the nine components of the Bill into six implementation categories: (i) coordination and communication with medical professionals, (ii) a national research network, (iii) a national patient registry, (iv) coordination and communication with stakeholders and the public, (v) analysis and reporting, and (vi) consultations and engagement.

The estimate includes only the federal incremental costs associated with implementing a national framework proposed by Bill S-201. Existing federal support for sickle cell disease was excluded from the estimate. For example, the Canadian Institutes of Health Research (CIHR) have provided approximately $13.8 million in grants and contributions from 2015-16 to 2024-25 towards SCD-related research. PBO assumes this funding is independent from the proposed framework.[12]

Coordination and Communication: Medical Professionals

Points relating to professional training, setting national standards, and implementing universal neonatal testing (points (a), (c), and (d)) were grouped together into "Coordination & Communication: Medical Professionals" as presented in Table 1. Evidence presented during Senate debates and committee hearings on Bill S-201 suggested that many educational and clinical resources already exist. Consequently, the primary costs associated with this category are dissemination, coordination, and administration.[13] Based on expenditures for grants observed under the Lyme Disease framework, PBO estimates a total cost of $1.0 million over 5 years.

Universal neonatal screening (provision d) was not assigned a separate implementation cost in this note. At the time of writing, according to information reviewed by PBO, all provincial and territorial health plans currently provide neonatal screening for SCD or are in the process of implementing such screening.[14] Therefore, no additional federal fiscal cost is expected outside of administration of ensuring universal access and encouraging the communication of genetic testing results to families.

National Research Network and Patient Registry

The national research network and patient registry (point (b)) was separated into its two components. These activities represent approximately one-half of the total estimated cost of the framework.

PBO estimates that the cost of a National Research Network will be $5.0 million over 5 years. This estimate is based on the Lyme disease framework having spent $4 million over 5 years for a research network, with additional funds to address a higher cost of setting up a resource network from the autism spectrum disorder framework.

The cost of a national patient registry was informed by published estimates of disease registry implementation and initial operating costs. PBO adopted an upper bound of $5.1 million over five-years, informed by a 2024 paper by Stausberg, Harkener, and Schoenthaler.[15] The upper-bound estimate was selected to account for start-up costs, administration of a national registry, and uncertainty regarding the number of Canadians living with SCD and potential scaling requirements following implementation.[16,17] Additional funds to continue operating the registry following implementation of the framework will be necessary.

Coordination and Communication: Stakeholders and the Public

Points related to setting national standards, public awareness, and a more diverse blood supply (points (c), (e), and (f)) were grouped in Table 1 as "Coordination & Communication: Stakeholders and the Public". These activities would be addressed with engagements with advocacy groups, those living with SCD, and the public. Based on expenditures incurred under the National Framework for Diabetes, PBO estimates costs of $6.0 million over 5 years.

Analysis and Reporting

Points related to an analysis of a tax credit, inclusion in existing disability benefits, and an analysis of drug inclusion in provincial plans (points (g), (h), and (i)) were grouped together as Analysis and Reporting. PBO estimates a federal cost of $2.0 million over 5 years to address the administrative work necessary for the analyses that would be done by the Government across various Departments such as Health Canada and Finance Canada, as well as reports that would be written as per the Bill.

During the Bill's earlier versions and at first reading, SCD was not specifically recognized as a disability for the Disability Tax Credit (DTC). However, the 2026 Spring Economic Update included only severe cases of SCD that require transfusions in a list of proposed fast-tracked DTC certification starting with 2026 tax filings.[18] As a result, no additional cost was assumed at this time for point (h). If the Government were to expand this definition to include more taxpayers living with SCD, there would be an increased cost in response to the analysis required under the framework.

Spotlight: Disability Tax Credit

With expanded eligibility announced in the 2026 Spring Economic Update, an individual newly eligible for the disability tax credit for the 2026 tax year could receive a maximum non-refundable tax credit of up to $10,341, which can reduce taxes owed by up to $1,448.[19] Including the supplement for certificate holders under the age of 18 increases the credit to $16,373 in 2026, which would reduce taxes by up to $2,292. Additionally, they would be eligible for a maximum monthly tax-free Canada Disability Benefit of $204. Finally, caregivers may be able to claim a maximum non-refundable tax credit of $8,773 in 2026, which reduces their taxes owed by $1,228. While Bill S-201 does not itself expand eligibility for these programs, the bill requires the Government to consider the inclusion of individuals living with SCD in existing disability benefit programs. As a result, future policy decisions could have fiscal implications beyond those included in this estimate.

Consultations and Engagement

Finally, an additional component for consultations and stakeholder engagement to administer the Bill, as per Clause 3, was interpreted as administrative efforts in support of research, treatment, and awareness for SCD. PBO estimates the total cost to be $1.0 million over 5 years based on estimated administrative costs from the diabetes and autism spectrum disorder frameworks.

Sources of Uncertainty

The primary source of uncertainty is the scope and level of funding ultimately provided by the Government to implement the framework. Bill S-201 does not prescribe specific funding levels or implementation approaches. Therefore, PBO assumed implementation consistent with comparable federal health frameworks, in ways such as coordination, communication with the public and stakeholders, administration, and grants.

As of publication, the Bill has been passed by the Senate and is being considered by the House Standing Committee on Health following second reading in the House of Commons. Any costs associated with Bill S-201 are contingent on the Bill receiving Royal Assent.

A more extensive approach to stakeholder engagement, public awareness, research coordination, and data collection could increase costs, while greater reliance on existing programs and resources could reduce incremental costs. For instance, the Government used existing departmental resources to partially support the framework on Lyme disease. A similar decision would reduce the incremental cost of the proposed framework.

Additional uncertainty relates to the implementation of the national research network and patient registry. Actual costs could differ depending on the extent of research and projects funded, and the number of patients registered after years of implementation.

Furthermore, there is uncertainty regarding the number of Canadians living with SCD, which would change the extent of work needed for the framework. Current estimates suggest that more than 6,000 Canadians are living with SCD, but witnesses appearing before parliamentary committees noted that the true number may be higher due to limitations in existing data collection. A larger patient population could increase the resources required for data collection, research coordination and stakeholder engagement activities.

Finally, the estimate includes only the costs associated with developing, administering and supporting the framework. It does not include ongoing operating costs, provincial costs, or potential future costs associated with policy measures that may be considered through the framework, including changes to tax measures, disability benefits, public drug coverage or other federal programs. Should the Government choose to implement such measures in the future, additional fiscal costs could arise.

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Notes

[1] From Bill S-201, *An Act respecting a national framework on sickle cell disease*:

(2) The national framework must

(a) include measures to address the training, education and diagnostic and treatment tool needs of health care professionals relating to sickle cell disease;

(b) provide for the creation of a national research network to advance research, improve data collection and establish a national registry on sickle cell disease;

(c) set evidence-based national standards for the diagnosis and treatment of sickle cell disease;

(d) include measures to institute universal neonatal screening, postnatal diagnosis when necessary and the provision of results for affected individuals and organizations;

(e) include measures to support public awareness campaigns on sickle cell disease and blood donation;

(f) provide for measures to promote and support blood donation by every segment of the population and the creation of a diverse blood supply that allows for safe transfusions;

(g) include an analysis respecting the implementation of a tax credit for individuals with sickle cell disease and their caregivers;

(h) ensure the inclusion of sickle cell disease in the eligibility criteria for existing disability benefits; and

(i) contain an analysis of the potential inclusion of treatments essential to sickle cell disease care in public drug insurance plans.

[2] Canada, Parliament, LEGISinfo, S-201 summary.

[3] Canadian Blood Services, Sickle cell disease and blood donation, accessed September 2026.

[4] Canada, Parliament, Senate, Standing Senate Committee on Social Affairs, Science and Technology, *Evidence*, 45th Parliament, 1st Session, October 2, 2025 to consider Bill S-201, An Act respecting a national framework on sickle cell disease.

[5] Canada's Drug Agency, "Exagamglogene Autotemcel (Casgevy)," *Canadian Journal of Health Technologies* 5, no. 1 (January 6, 2025), https://doi.org/10.51731/cjht.25.1052. [canjhealthtechnol.ca]

[6] For further information see: Janse and LeBlanc, *House of Commons Procedure and Practice, Fourth Edition*, 2025 at Chapter 18, Financial Procedures, Financial Prerogative.

[7] PBO (2026), IR0952.

[8] Understanding autism data in the Canadian Chronic Disease Surveillance System

[9] Diabetes in Canada: An interactive report on key statistics

[10] Tick-borne disease surveillance: Explore the data

[11] Canada, Parliament, Senate, Standing Senate Committee on Social Affairs, Science and Technology, *Evidence*, 45th Parliament, 1st Session, October 1, 2025 to consider Bill S-201, An Act respecting a national framework on sickle cell disease.

[12] Canada, Parliament, *House of Commons Debates*, 45th Parliament, 1st Session, Vol 152, No 105 (17 April 2026).

[13] Canada, Parliament, Senate, Standing Senate Committee on Social Affairs, Science and Technology, *Evidence*, 45th Parliament, 1st Session, October 2, 2025 to consider Bill S-201, An Act respecting a national framework on sickle cell disease.

[14] CDA indicates in a 2024 discussion paper, and their implementation being current was confirmed through a phone call to NFLD Genetic Counselling.

[15] Stausberg, Jürgen, Sonja Harkener, and Martin Schoenthaler. "Costs of health registries: an exploration for health services research." In *Digital Health and Informatics Innovations for Sustainable Health Care Systems: Proceedings of MIE 2024*, pp. 1896-1900. 1 Oliver's Yard, 55 City Road, London, EC1Y 1SP: SAGE Publications, 2024.

[16] Bank of Canada Currency Converter for the week of September 17, 2026 to September 23, 2026.

[17] The Honourable Marie-Françoise Mégie, former Senator for Quebec, quoted 6,000 Canadians with SCD in her speech sponsoring the bill. The Honourable Tony Ince, sponsor after her retirement, mentioned 6,500 in his speech. At the same time, advocacy groups and medical practitioners testified that the total number of those living with SCD, in all its forms, was unknown due to a lack of research and data collected. Therefore, additional funds as a contingency would account for establishing a registry where initial estimates may be quite different from final counts.

[18] Government launches consultation on draft legislation for various tax measures - Canada.ca

[19] Non-refundable tax credits are reduced at the lowest tax rate, which in 2026 would be 14%.

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