



## Use of registry and health economics

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Number of studies has documented the significant burden of sickle cell disease on health costs [1, 2]. Lifetime costs of providing care for a patient living with sickle cell disease has been estimated to approach 9 million US\$ according to such studies. Based on such evaluation, health care costs of SCD individuals living in Canada may therefore be as high as 1 Billion Can\$ per year<sup>1</sup> (corresponding to a realistic average of 20'000 Can\$/patient/year).

Implementation of national newborn screening and comprehensive care centers will require to be thoroughly evaluated. Use of registry could be a useful tool to evaluate how such health measure implementation may reduce global health cost. As an example, the creation of a registry on the use of joint replacement (the Canadian joint replacement registry) has progressively allowed the development of best clinical practice. Once developed as a voluntary repository, it has become mandatory in several provinces [3]. Surveillance program such as CYP-C program (Cancer in young people in Canada), developed as partnership program between the Public Health Agency of Canada and the C<sup>17</sup> council (a non profit organization regrouping all pediatric hematology and oncology centers) is an example of national database aimed at following epidemiology of cancer in childhood and young adults. We believe that similar partnership between institutions such as health statistics division of statistics Canada and private non-profit organization such as SCDAC could help better understand the epidemiology of SCD in Canada.

There are other examples of collaboration between scientific societies and federal government. The haemophilia society (CHS) was created in 1953 to improve the health and quality of care of all people with inherited bleeding disorders. In 2015, the CHS is now implicated at all local, provincial and national level. The development of registry has helped define the epidemiology of haemophilia in Canada, and greatly improve quality of life of patients with severe inherited bleeding disorders. The model of care developed by CHS represents an excellent example of successful partnership between health care system, patients, families and funders [4]. Patients with sickle cell disease share some similarities with patients with such rare bleeding disorders: both diseases are orphan, multisystem and complex disorders, requiring a well coordinated care through well defined dedicated centers and appropriate use of resources. The successful advancement of quality of care in Canada achieved by CHS represents an example for the sickle cell community.

We believe that there is an urgent need to better coordinate the care of individuals with SCD, in order to improve access to care, allow prompt neonatal diagnosis and early intervention, in order to reduce global SCD health-related costs, improve quality of life and life expectancy, and better follow use of

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<sup>1</sup> 3500 - 5000 (estimate of individuals living with SCD in Canada) x 9 Mio US\$ x 1.24 (current rate change) / 50 years (average life expectancy of an individual with SCD).



blood resources in our patients. Of importance, there are also currently a large drug development targeting haemoglobin disorders which will likely ensure better life to SCD individuals, as long as patients have access to adequately funded comprehensive care centers [5-9].

#### References:

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