

## **How Many Sickle Cell Disease Patients Are There in Ontario? Results of a Query of Health Services Administrative Databases**

Eliane Kim<sup>1</sup>, Erin Graves<sup>1</sup>, Lanre Tunji Ajayi<sup>2</sup>, Jacob Pendergrast<sup>2,3,4</sup>

<sup>1</sup>Institute for Clinical Evaluative Sciences, Toronto, ON, Canada; Sickle Cell Awareness Group of Ontario, Toronto, ON, Canada; Dept. of Medical Oncology and Hematology, University Health Network, Toronto, ON, Canada; Dept. Laboratory Medicine and Pathobiology, University of Toronto, Toronto, ON, Canada

**Introduction:** While it is recognized that the number of sickle cell patients in Canada is significant and growing, the absence of a unified patient registry has limited the ability of health care workers and policy analysts to determine how many individual patients there are.

**Hypothesis:** By cross-referencing inpatient and outpatient health services administrative databases maintained by Ontario hospitals with a) ICD codes indicating a diagnosis of sickle cell disease and b) individual Ontario Hospital Insurance Plan (OHIP) numbers, it will be possible to approximate the total number of patients residing in the province with a diagnosis of sickle cell disease.

**Method:** For the period ranging from FY 2007/08-2016/17, the Ontario Discharge Abstract Database and National Ambulatory Care Reporting System were queried for ICD9 code 2826 and ICD10 codes D570, D571, D572, and D578, while the Newborn Screening Ontario database was queried for diagnoses of Hb SS, Hb S $\beta$ , SC, SE and S/HPFH. Duplicate entries were eliminated through cross-referencing of OHIP numbers. The final report was anonymized to patient-level information but included basic demographic information obtained from the Registered Persons Database and Postal Code Conversion File.

**Results:** A total of 3 345 individuals with sickle cell disease were identified. Average age was  $24 \pm 21$  years and 56% were female. Patients resided within every provincial Local Health Integration Network (LHIN) area but were predominantly found in the areas surrounding Toronto and Ottawa. Income was reported as being in the lowest quintile for 40.5% of patients, and an average of  $6.5 \pm 22$  emergency room visits per patient were documented during the 10 year period of review.

**Conclusion:** While a review of Health Services Administrative Databases can produce only limited clinical information, will not capture non-insured individuals (e.g., recent immigrants) and cannot account for patients who have died or left the province, it nonetheless allows for a rapid approximation of the number of sickle cell patients in Ontario. Similar methodology may be considered for other Canadian healthcare jurisdictions.

*This project was supported by funding from the Ontario Ministry of Health and Long-Term Care*