



Developing DISH - A Data Information System for Hemoglobinopathies



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Background

Sickle cell disease (SCD) and thalassemia are emerging public health problems in Canada. With the implementation of universal newborn screening for hemoglobinopathies in Ontario and increasing immigration from countries with high rates of hemoglobinopathies, it is crucial to develop effective strategies to identify and optimize the medical care for affected individuals. Electronic clinical information systems have been shown to improve health care delivery for hemoglobinopathy patients within the United States but there are currently no validated information systems for monitoring the outcomes of Canadian patients with hemoglobinopathies.

The Children's Hospital of Eastern Ontario's (CHEO's) rapidly growing hemoglobinopathy program cares for approximately 175 children and adolescents with hemoglobinopathy syndromes. There is currently no electronic system to monitor the health outcomes for patients within this program. A clinical hemoglobinopathy database will allow CHEO-based health care providers to assemble information about the patterns of disease-related complications among these children and adolescents and to monitor these events as they transition into adulthood. This Data Information System for Hemoglobinopathies (DISH) will be the first data system of its kind in Canada.

Objectives

1. To identify specific clinical measures for monitoring patients with hemoglobinopathies.
2. To use the identified clinical measures to build a hemoglobinopathy-specific data information system using the Research Electronic Data Capture system (REDCap).

Methodology

Clinical measures for patient monitoring were selected through discussions with the hemoglobinopathy team at the CHEO and meetings with medical directors from pediatric and adult hemoglobinopathy centres across Canada and the Canadian Hemoglobinopathy Association.

The REDCap system was then used to develop the Data Information System for Hemoglobinopathies (DISH) – a user-friendly and comprehensive electronic system for entering and recording patient information related to their clinical visits, hospitalizations and disease-related complications.

Results

Figure 1. Screenshot of Demographic Information section.

Figure 2. Screenshot of Emergency Room Visits section. List of diagnoses include common reasons for emergency room presentation in the hemoglobinopathy population.

Figure 3. Screenshot of Other Tests section.

Discussion/Conclusions

REDCap provides a promising platform for creating a secure and web-based electronic clinical tool for patients with hemoglobinopathies. Patient information will be protected by storing identifying information in a separate password-protected file under their respective REDCap Record ID numbers. At this time, the entry of clinical information is pending review by the CHEO Research Institute.

The overall format of DISH has been endorsed by several hemoglobinopathy centres across Canada and we hope that this database will serve as a model for other local hemoglobinopathy systems within Canada. This system will help to identify resource-deficient areas that require increased attention to adequately address the needs of Canadian SCD and thalassemia patients. It will also enable health care providers to develop a better understanding of the determinants of disease-associated morbidity within our hemoglobinopathy population and to design interventions to improve the health outcomes for these patients.

If this database proves to be successful, it will serve as a platform to develop a national Canadian hemoglobinopathy system, which would be an invaluable public health surveillance tool to improve health systems for individuals with hemoglobinopathies.

References

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Acknowledgements

Thanks to Ms. Yael Kamil from The CHEO Research Institute for her technical assistance with REDCap.

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