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Developing an Implementation Plan to Operationalize a Provincial Rare Disease Strategy

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BACKGROUND

Ontario's "*Patients First: Action Plan for Health Care*" seeks to create a more patient-centred health care system in Ontario.

In 2012, Ontario embarked on an ambitious health care approach to create a more patient-centred health care system. The current rare disease system contains some of the components required to provide care. However, the system lacks connectivity, resources, and governance. The available support services include large academic hospitals positioned as 'central hub' sites which function with inconsistent linkages to clinically support patients through the continuum of care.

Critical Care Services Ontario (CCSO) was tasked with developing an implementation plan for the rare disease strategy outlined in the RDWG report, which considered existing programs, resources, and current initiatives to address the following three objectives:

1. Establishing a "hub-and-spoke" care provision network for people living with rare diseases;
2. Developing a plan to improve access to novel genomic diagnostics; and
3. Defining the specifications and requirements for a rare diseases registry.

AIM

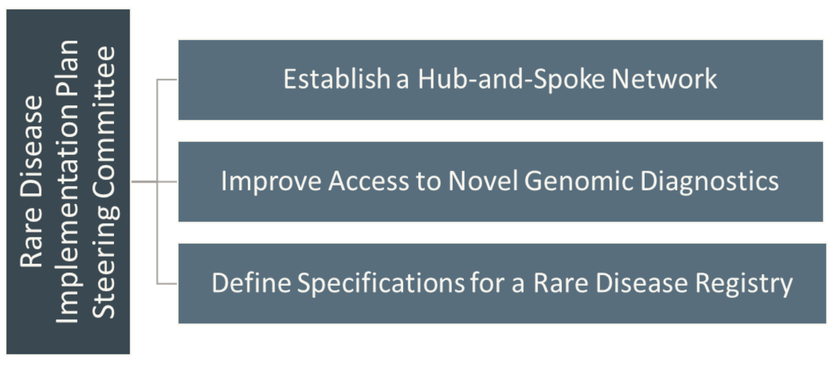
Develop an implementation plan with key components to operationalize the objectives outlined in the provincial strategy to improve the delivery of healthcare and outcomes for Ontarians with rare diseases.

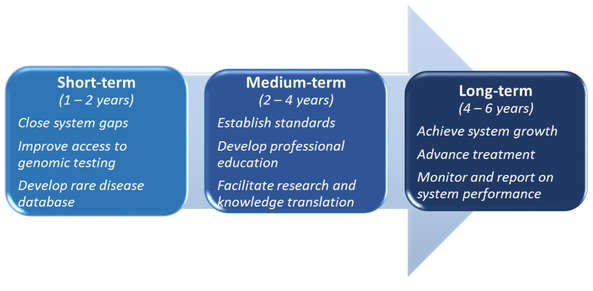
ACTIONS TAKEN

CCSO developed the Ontario Rare Disease Strategy Implementation Plan (ORDSIP) in collaboration with multidisciplinary clinicians, health care administrators, content experts, patient representatives, and Ministry of Health and Long-Term Care (MOHLTC) Laboratories and Genetics Branch (LGB) to address the recommendations outlined in the RDWG report and align with the Patient and Family Advisory Council (PFAC).

The development of the ORDSIP was governed by a Steering Committee and informed by three sub-groups with expertise towards each of the strategy's objectives. The Rare Disease Implementation Plan Steering Committee (RDIPSC) comprised of six members with extensive experience aligned to each of the objectives. Each sub-group was co-led by two of the RDIPSC members and tasked with developing a plan to address the specific objective.

Over the course of eight months, the RDIPSC and sub-groups conducted 14 meetings, including 1 full-day working retreat, which resulted in the development of the ORDSIP.





The ORDSIP will be implemented in two-year increments with parallel execution of key goals in a phased approach over a period of five to six years. Key to the implementation and ongoing program oversight will be the Ontario Rare Disease Program (ORDP) with responsibilities to develop system stewardship and a governance structure with clear accountabilities. The ORDP would be responsible for ongoing rare disease system coordination, monitoring and sustainability.

Sustainability of the rare disease system will be achieved through staff and educational initiatives, development of evidence-based best practices, and identification of areas for potential improvement to align with performance criteria established by epidemiological trends.

OUTCOMES

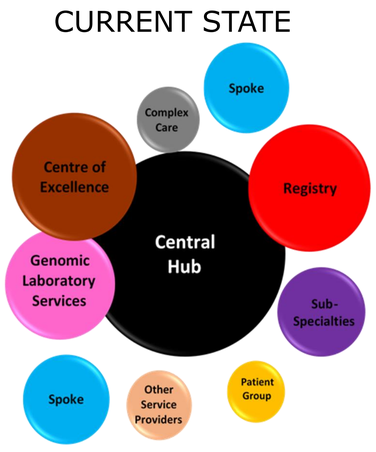
The ORDSIP was developed to provide a framework for the province to implement the strategy and recommendations in the RDWG report. This was achieved by leveraging existing resources, identifying gaps, and developing an integrated system network focused on:

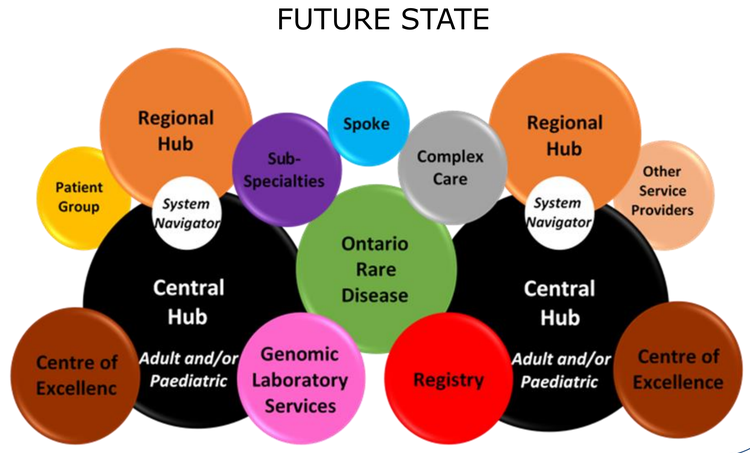
Connectivity and access to expert consultation; advancing timely diagnosis; improving patient care; and maintaining a standardized system of care.

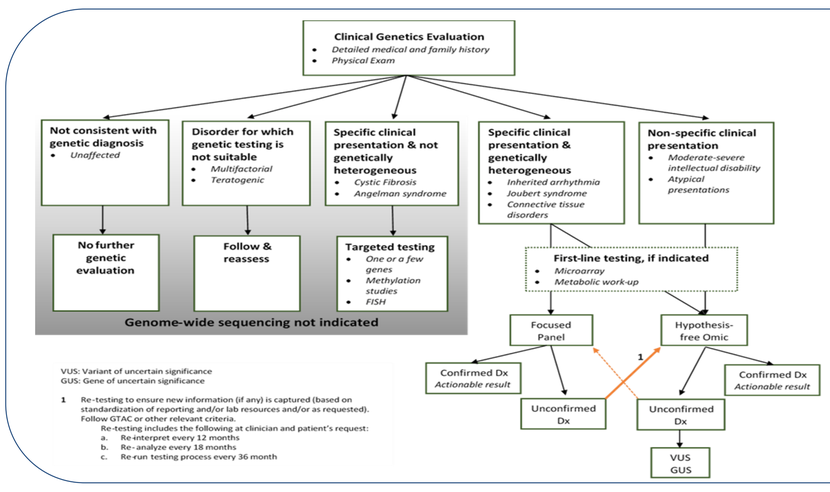
The proposed hub-and-spoke model closes gaps in the rare disease system; serves patients at any care provider within the system; supports clinicians at any geographic location; integrates sharing of best practices, expertise, and knowledge; and facilitates management of patients by their health care providers.

The overwhelming success of similar projects, such as Extensions for Community Healthcare Outcomes (ECHO®), is evidence that this is a successful approach to providing standardized care over large geographic areas with care providers who have various levels of expertise.

The structural change will leverage Ontario Telehealth Network (OTN) to facilitate bimonthly e-rounds and educational initiatives to drive systemization and standardization of patient care regardless of geographic location.



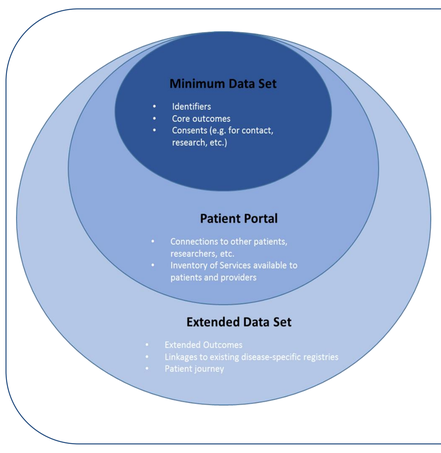




Concurrent with the work of the RDIPSC, a branch of the provincial government (MOHLTC-LGB) was developing a short-term feasibility study to assess access implementation and determine appropriate longer-term access to genome-wide diagnostic testing for Ontario.

Outcomes of the feasibility study include identification of appropriate patients for testing, clinical assessment information required to accompany test specimens, standardized reporting, and establishment of a federated system for data sharing and interpretation for the province. The results will become a blueprint for access to novel diagnostic technologies and determine an appropriate longer-term delivery model for genomic testing such that the experience of patients and providers would be of the same high quality, no matter where the service is accessed.

Leveraging the results of the feasibility study and a genomic testing structure developed from published literature and evidence-based best practices, the system will be able to address re-testing of patients that remain undiagnosed after genome-wide sequencing.

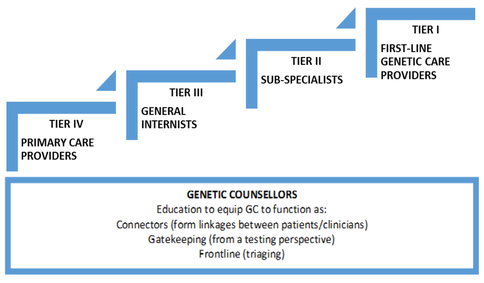


The rare disease registry will be developed in a phased transition. The Better Outcomes Registry & Network (BORN) is Ontario's pregnancy, birth, and childhood registry, which functions as a prescribed registry. Newborn Screening Ontario (NSO) tests all babies in the province to assess their risk of rare but treatable diseases. Access to BORN data allows NSO to identify newborns who missed screening.

A database expansion to include Ontario's adult population is a feasible approach to build a rare disease registry inclusive of all Ontarians, regardless of age. Data from the patients undergoing genome-wide sequencing as part of the feasibility study can be used to pilot the registry.

Once the rare disease system foundation has been created, the ORDP will focus its work on the promotion of standards, education, research, knowledge translation and global system alignment.

The strategies for educational engagement include content and tiered delivery to each care provider group, with a platform of Genetic Counsellors forming the core support for the system.



LESSONS LEARNED

In developing a regional program which supports a range of resources and users, it is beneficial to ensure appropriate representation and manage expectations. Including first line staff and patient representation allowed us to gain perspective from lived experience to ensure the strategies would have the desired impact on all users, regardless of location.

Ensuring broad geographic representation assisted in developing adaptable strategies to meet specific regional needs of patients and providers. An example was adapting the definition of a "hub" from the traditional academic centres in urban regions to allow leveraging of the existing Northern Regional Genetic Program (NRGP) which provides services to families located in northeastern and northwestern Ontario.

NEXT STEPS

The ORDSIP and corresponding business case have been submitted to MOHLTC. Upon approval, the Hospital for Sick Children (HSC) will initiate the implementation plan by establishing the ORDP. A Program Manager, Development Associate, and Performance Associate will be responsible for the core operations of the ORDP and implementation.

The ORDP is key to the system network to facilitate collaboration, growth, and sustainability. It will report within a governance structure comprised of representation by a clinical expert and facility administrator from each central hub.

Acknowledgements

The Ontario Rare Disease Strategy Implementation Plan is the result of Critical Care Services Ontario (CCSO) oversight, coordination and the collaboration of the Rare Disease Implementation Plan Steering Committee (RDIPSC), the Hub-and-Spoke Network Sub-Group, the Access to Genomic Diagnostics Sub-Group, the Rare Disease Registry Sub-Group, and the Ministry of Health and Long-Term Care (MOHLTC). For additional information, contact CCSO at info@ccso.ca.