



Project Charter

Development of a National Data Set Paediatric Outpatient Rehabilitation

October 24, 2011

Background

Children with disabilities have been identified as an important group for improvements in health care services delivery and may require extremely high levels of case coordination across the continuum of care. Costs services for this group can be high and yet there is a lack of data to ensure that care and costs are being managed effectively and to ensure consistent and equitable access to high quality care. It is also not known where care is being provided (e.g. in the home, community, outpatient, acute care, school etc.).

In a 2007 Health Canada report by Dr. K. Leitch, *Reaching for the Top: A Report by the Advisor on Healthy Children and Youth*, it is stated:

“Better coordination is required among the national data collection agencies and large research projects associated with child and youth health. A key recommendation in this area is standardizing data sets. Mechanisms of coordination and improved access must be created between Statistics Canada, the Canadian Institute for Health Information and the Public Health Agency of Canada in order to create appropriate comparable data sets that are easily accessible to clinicians, researchers, and organizations that are involved with child and youth programs and policy development”¹

To address this information gap, a national data set (NDS) is being developed and implemented to monitor, evaluate and improve paediatric rehabilitation services. A national rehabilitation dataset will facilitate provincial comparisons and identification of best practices and benchmarks across Canada.

Vision

To create a high quality national database includes functional/developmental outcomes and service delivery data on infants, children and youth who access rehab services to improve their functioning and participation. To promote reliable and consistent data capture and facilitate benchmarking across Canada.

Mission

To make information available to support and improve decision-making at the clinical, facility, provincial and federal government levels to support program planning and evaluation for client outcomes and family centred service provision.

¹Leitch, K. (2007). *Reaching for the Top: A Report by the Advisor on Healthy Children & Youth*. Health Canada. <http://www.hc-sc.gc.ca>

Purpose

The purpose of this phase of the project is to create an NDS and determine the feasibility of collecting the data in paediatric rehabilitation centres.

Goal NDS Development Phase

At the end of the NDS development phase we will have a set of data elements that can be used to populate indicators related to accessibility, service effectiveness, efficiency, safety, family centered care, service integration, coordination, and continuity. The initial priority is on the first three items listed.

In Scope

The NDS will be a data collection tool that can be used in inpatient and outpatient rehabilitation centres across Canada. It will include both mandatory and optional data elements. It will support peer facility comparisons, national comparisons, benchmarking and trending over time.

The NDS will be used to collect data on outpatient rehabilitation services for children with cerebral palsy and autism for the NDS development phase of the project. At a later date, additional conditions will be added.

The NDS will provide data that will emphasize the ability to measure outcomes (e.g. changes in function) as well as key process measures to support interpretation of the outcome measures (e.g. number of staff required to achieve outcomes). Measures of structure may also be included.

Priority will be given to indicators related to efficiency, accessibility and effectiveness. However, consideration will also be given to indicators related to safety, family centered care, service integration, coordination and continuous care.

The feasibility assessment will focus on using 2-3 centres as pilot sites and will expand to additional sites in later phases. The feasibility assessment will include:

- Privacy
- Data quality/availability
- Resource availability at the pilot site
- Data storage and collection models
- Rehabilitation centre's data storage methods and needs
- Ethics approval
- Training/education
- Change management

Ideally, pilot sites will submit de-identified record-level data for the pilot test to CAPHC/CN-CYR, however, if this is not possible, other options will be explored. The purpose of the pilot test is to establish that the proposed NDMS tool is meaningful and useful. Data collection for the pilot will use a paper-based or electronic data collection tool that will be created for the pilot and will be completed in parallel with the organization's existing data collection processes. In addition, the feasibility of extracting existing administrative data from electronic medical records (EMRs) may be discussed with pilot sites, and data extraction may be conducted from existing databases.

Opportunities to capture data from existing data sources will be explored.

Out of Scope

It is anticipated that data collection will start small and will grow at a later time. As such the following will be considered out-of-scope for this phase:

- indicators and data elements specific to other conditions
- creating new data collection instruments (data collection will leverage existing data collection instruments that have been tested and found to be reliable and useful).

The purpose of the information is for use at the facility, regional, provincial or national level for program planning, system planning and decision making. At this time, it is not intended that clinicians will be able to use the information for decision making with individual patients. It will not be intended for use to compare clinicians within a given facility.

While it is anticipated that data may eventually be collected from data sources outside of the health care system such as the education system, it is out of scope for this phase.

The development of reports and benchmarks for indicators is out of scope for this phase, but will be included in later phases.

Requesting changes to data fields in databases at pilot sites to collect NDS data elements will be time consuming in terms of administrative processes both within the facility and with vendors that would be asked to make changes. As such it is out of scope for this phase to request changes to database fields in EMRs at the facility level.

For this phase of the project, the NDS will not be translated into French.

Assumptions and Constraints

CAPHC/CN-CYR will partner with another organization that will collect and hold data based on the NDS. In addition, CAPHC/CN-CYR will require funding for future phases and this will be obtained through partners and other fund raising opportunities. These stakeholders will have significant input on the final content of the NDS.

The final NDS will be based on existing coding systems and tools, such as the World Health Organization's International Classification of Functioning, Disability and Health – Children and Youth (ICF-CY) and Measures of Processes of Care (MPOC) survey. In addition, it will focus on data elements that are commonly available in rehabilitation centres.

In order to minimize the data collection and reporting burden, the NDS will include only data elements that provide key information required by stakeholders. Data collected will focus on factors that are useful at both the clinical level and at the system level (i.e. data that clinicians can use as part of their daily workflow). This will also facilitate the collection of high quality data.

The long-term vision for the project is that organizations that participate in the NDMS will be required to use software to collect data that meets required specifications. This approach is similar to the approach used by the National Rehabilitation System (NRS) at the Canadian Institute for Health Information. CAPHC/CN-CYR and partner organizations will work with vendors on data collection software in future phases.