

Establishing a Foundation for Sustainable Community Stroke Rehabilitation Evaluation in Ontario:

A Review of Current State and Future Recommendations

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ONTARIO REGIONAL STROKE NETWORKS' REHABILITATION COORDINATOR GROUP

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While many individuals were consulted which led to the opinions and content in the report, the recommendations and opinions expressed within are those of the Ontario Regional Stroke Networks Rehabilitation Coordinators.

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For abbreviations and terms specific to the report, please refer to the Glossary and Acronyms section on p. 36.

1. Executive Summary

Community Stroke Rehabilitation (CSR) is an integral part of the stroke care continuum, and is supported within the Canadian Stroke Best Practice Recommendations (CSBPR) (Teasell, et al., 2020) and Quality-based Procedures (QBP) (Health Quality Ontario; Ministry of Health and Long Term Care, 2016). In Ontario, CSR programs offer a mix of in-home, outpatient and virtual services for people living with stroke, with programming designed to address the unique needs of the patient within the context of their respective health region. CSR services contribute to minimizing hospital stay, helping stroke survivors live more successfully in their community and reduce caregiver burden resulting in both direct patient/family and system benefits. Currently, there is wide variability between CSR programs across the province, with respect to funding models, the organizations that deliver the respective programs, service delivery models, data collection, and program evaluation.

This report has been authored by the Ontario Regional Stroke Networks' Rehabilitation Coordinator Group, to draw attention to the lack of provincially consistent and valid CSR data. This report highlights the fundamental need for reliable data as a key requirement for a robust CSR measurement, monitoring and reporting system and next steps to create the foundation for a CSR evaluation system. This system is an essential enabler for decision makers and clinicians to measure access and service use, allocate resources and ultimately evaluate quality of care and patient outcomes.

Currently in Ontario, there is no standardized and defined set of CSR data elements and indicators, to evaluate the performance of in-person CSR and the emerging virtual care modality. Virtual care has had a surge in adoption in CSR programs, given the need for physical distancing and prioritization of select in-person services during the COVID-19 pandemic. This variation and lack of standardized data creates challenges when attempting to understand and evaluate access to services, quality of care and patient outcomes in CSR in Ontario. As a result, this poses a significant problem for the provincial and regional stroke system stakeholders and decision makers, particularly in the current health system crisis.

Key Recommendation and Next Steps*:

The Ministry of Health (MOH) must recognize the important role of CSR and the need to address the significant data gap within the rehabilitation system of care, needed for performance data and reporting. The MOH must facilitate the development of a standard data collection and reporting infrastructure, that is ideally compatible with and linkable to other existing health information databases enabling an understanding of the patient journey following stroke. The ability to report on the care continuum will inform resource allocation, quality of care improvement and patient outcomes. To achieve provincial CSR program evaluation, the following foundational recommendations and associated actions which consider the current reality of the healthcare system need to be made a provincial priority:

Leadership and Partnerships:

- Multiple stakeholder groups, including, but not limited to, CorHealth Ontario, Rehabilitative Care Alliance (RCA), Canadian Institute of Health Information (CIHI), Health Shared Services Ontario (HSSO), CSR Programs and Regional Stroke Networks need to collaborate to ensure successful development and implementation of a provincial CSR data infrastructure.

- Ontario Regional Stroke Networks' Rehabilitation Coordinator Group will share and discuss report findings and recommendations with CorHealth Ontario, RCA and MOH to inform future activity.
- CorHealth Ontario and MOH are encouraged to create a working group of stakeholders (including Ontario Regional Stroke Network's Rehabilitation Coordinators) to jointly develop next steps and guide future implementation.

Standardized Data Collection:

- CorHealth Ontario and MOH are encouraged to enact a mechanism to validate and develop consensus on the proposed minimum data set (MDS) and indicators referenced within this report, through a structured process with stakeholders (e.g. a modified Delphi method).
- Modify or refine existing data bases (National Ambulatory Care Reporting System Clinic Lite (NACRS Clinic Lite) and Home Care Database (HCD)) where needed, to include recommended standard data fields (in-home and outpatient) that enable CSR measurement evaluation including enhanced fields to capture virtual care.
- Create the capacity to identify patients enrolled in a CSR program within data collection systems to differentiate from general in-home or outpatient rehabilitation services.

Provincial Data Collection Platform:

- MOH direction and approval is required to create access to existing data collection systems for multiple service providers (NACRS Clinic Lite and HCD) for all CSR programs in Ontario.
- Given CSR delivery location may not align with the historical organization setting (e.g. hospitals may deliver home care or home care agencies may deliver outpatient service), data systems need to be responsive to in-home and outpatient visit types.
- Ensure that processes are in place that makes data available for integration with other stroke data (e.g. CIHI, Discharge Abstract Database (DAD), National Rehabilitation Reporting System (NRS)) for analysis at local, regional and provincial levels.

**Report will highlight full recommendations and next steps in detail.*

CSR programs are an integral part of the stroke system. The enablement of CSR measurement, monitoring and reporting across the province will provide the needed system evaluation component that has been missing to fully understand the performance of the stroke system as a whole. The proposed recommendations and next steps will allow the province to take the foundational steps needed to address the CSR evaluation gap, while also advancing the long-term vision of the ideal solution. Ideally, there would be a centralized database across all rehabilitation care partners that enables robust process and outcome evaluation, is integrated with data across the continuum and can be accessed and analysed in a timely manner. The expertise of several program and health information stakeholders, and MOH endorsement, is needed to advance this work collaboratively with the Regional Stroke Networks and CorHealth Ontario, all of whom have a vested interest in improving the quality of stroke care in Ontario. Having a provincially-based CSR evaluation system in place would support providers, decision makers and health system planners to ensure optimal patient outcomes and system effectiveness. A focused and collective effort is needed to implement coordinated CSR data collection and evaluation in Ontario.

2. Background / Introduction

2.1 What is Community Stroke Rehabilitation?

Community Stroke Rehabilitation (CSR) is identified within the Canadian Stroke Best Practice Recommendations (CSBPR) as an essential component of the stroke survivor's journey in the post-acute/post-hospital phase. CSR services aim to deliver specialized stroke rehabilitative care by an interprofessional care team to support stroke survivors in continuing to make gains toward their rehabilitation goals and improved functional outcomes while living in the community. CSR programs in Ontario are delivered in hospital-based (outpatient) settings, home-based settings, and via hybrid models that provide both in-home and outpatient visits. For this work, the above definition will be used. More recently, many teams have added virtual care as a delivery mode in their programs. CSR models of delivery continue to evolve based on patient need, resources available, regional characteristics and situational variance (e.g. pandemic).

Research supports the critical role that CSR programs (as defined by best practice criteria) play in helping patients reaching their maximum recovery and contribute to the efficiency of the broader healthcare system. CSBPR include the following components in a CSR program (Teasell, et al., 2020):

- Services should be initiated within 48 hours of discharge from an acute hospital and 72 hours of discharge from inpatient rehabilitation
- Minimum visit duration of 45 minutes
- Therapy visits 2-5 days per week per required discipline
- Ideally, services provided for at least eight weeks
- Interprofessional care team includes an Occupational Therapist (OT), Physiotherapist (PT), Speech Language Pathologist (SLP), Social Worker (SW). Additional allied health expertise may be accessed through Psychologist, Dietitian, and Recreation Therapist
- A case coordination approach is utilized, including regular interprofessional communication and care planning (which includes the patient and family/caregiver)

Using the CSBPR as a guideline, the Ontario Stroke Evaluation Report 2016 (Hall, et al., 2016) defined comprehensive outpatient stroke services as services delivered in a hospital setting, provided by an interprofessional team (at a minimum, an occupational therapist, physiotherapist and speech-language pathologist) specifically assigned to the service, using a case-coordination approach with regular team meetings and the capacity to provide 2–3 visits a week for 8–12 weeks.

Reflection from a Patient Experience:

"Both my husband and I are so thankful for the outpatient program, as he was able to enjoy the comfort and familiarity of home and family, while still receiving relevant therapy. This was especially important to us, as this allowed our family to play an integral role in supporting and encouraging him to achieve his therapy goals. Upon completion of his rehab therapy program, he has now resumed driving, his speech deficits have greatly improved and he has returned to normal everyday activities. We truly feel that he would not have progressed so far in such a short time were it not for this program."

Spouse, Outpatient Stroke/Neuro Rehabilitation Program,

2.2 Status of CSR in Ontario

The 2018/19 Ontario Stroke Report Card revealed that the number of stroke survivors accessing home-based rehabilitation is increasing across the province (CorHealth Ontario, 2020). Comparative data for outpatient hospital-based rehabilitation is unfortunately not available, but anecdotally appears to be on a rise. Although the lack of data makes evaluation difficult, our stakeholders suggest that due to COVID-19, the use of CSR has increased substantially during 2020. During this time, there was an increased reliance on home-based programs to offset the temporary suspension or reduction of services of many inpatient and outpatient hospital stroke programs to increase inpatient capacity and services for COVID-19. The COVID-19 pandemic was also an opportunity to further develop and leverage virtual care within CSR to support timely access to stroke rehabilitation and maximize patient outcomes in compliance with COVID-19 restrictions. Considering the uptake of virtual care across Ontario, and its emerging evidence aligning with stroke best practice, it is essential that virtual care elements be accurately captured and included in CSR evaluations.

2.3 Project Impetus

The availability of standardized and high-quality process and outcome data for evaluations in CSR/ has repeatedly been identified as a shortcoming in the evaluation of Ontario's stroke system. The need to rectify the lack of outpatient/community rehabilitation data has been identified in various reports including the Auditor General's report on Rehabilitation in 2013 (Office of the Auditor General of Ontario, 2013), Ontario Stroke Reports (Hall, et al., 2016), (CorHealth Ontario, 2020)), and RCA (Rehabilitative Care Alliance, 2019), (Rehabilitative Care Alliance, 2017)) (see Appendix A). In 2017, the proof of concept work completed by the RCA marked the first time that comparable, standardized data were collected and reported across outpatient/ ambulatory rehabilitative care programs in Ontario. Despite the recommendations and successful proof of concept for multiple patient cohorts, the full implementation of the data collection system, "NACRS Clinic Lite" for all outpatient rehabilitation services has not yet been realized. NACRS Clinic Lite has only been made available to use for the hip/knee bundle cohort.

CSR plays an increasingly crucial role in planning for transitions from hospital to home yet there is no evaluation system in place to measure: 1) utilization /resources, 2) patient outcomes, or 3) patient experience. In 2017/18, the Ontario stroke report card indicated that 74.2% of acute stroke patients were discharged home (CorHealth Ontario, 2020); however, without available in home/outpatient data, an accurate utilization of CSR services is unknown. With the health system heavily relying on outpatient and in-home services to preserve inpatient bed capacity, data must become available to ensure these services result in quality patient outcomes.

The longstanding gap in CSR data was amplified recently in planning for integrated/bundled funding. A one-time survey by CorHealth Ontario of CSR providers found that data collection is inconsistent and incomplete negating the capacity to create a baseline understanding of the availability of services for outpatient and/or in-home stroke rehabilitation. Significant limitations due to variability in data available were found to result in the inability to compare data between CSR programs in Ontario. Lessons learned through the survey process and data review suggested a need to review available data collection tools with a more detailed stroke lens. There remains a need for the development of a provincially mandated data collection system for all CSR patients, to understand and report on the current state of CSR.

The Ontario Regional Stroke Networks' Rehabilitation Coordinator Group identified a need to undertake this project to help address this long-standing data gap. This project was intended to facilitate a deeper understanding of the current state of CSR Program evaluation (outpatient, in-home and hybrid (both outpatient and in-home services) and identify feasible opportunities and actions to support future evaluation of CSR in Ontario at program, regional, and provincial levels.

3. Objectives and Process

3.1 Objectives

The objectives for this project were:

1. To understand the current state of CSR program evaluation in Ontario; and
2. To identify immediate opportunities that will facilitate future evaluation of CSR programs in an impactful and strategic manner.

Ultimately, the vision is to enable fulsome evaluation of Ontario CSR programs through one common and linkable database, which will be used by all CSR programs regardless of location or mode of service delivery. This project is intended to augment current understanding of CSR evaluation in Ontario and inform next steps towards standardized, high-quality data in CSR to enable program evaluation and ongoing improvement.

3.2 Process

More than 70 Ontario CSR evaluation resources were collected and reviewed through the Regional Stroke Networks. Eight categories related to CSR evaluation were identified:

1. Process data elements
2. Outcome measures
3. Patient or caregiver experience
4. Systems used to collect and store data
5. Virtual care
6. Impacts on data quality
7. Summary of CSR programs' existing evaluations/reports
8. Early Supported Discharge

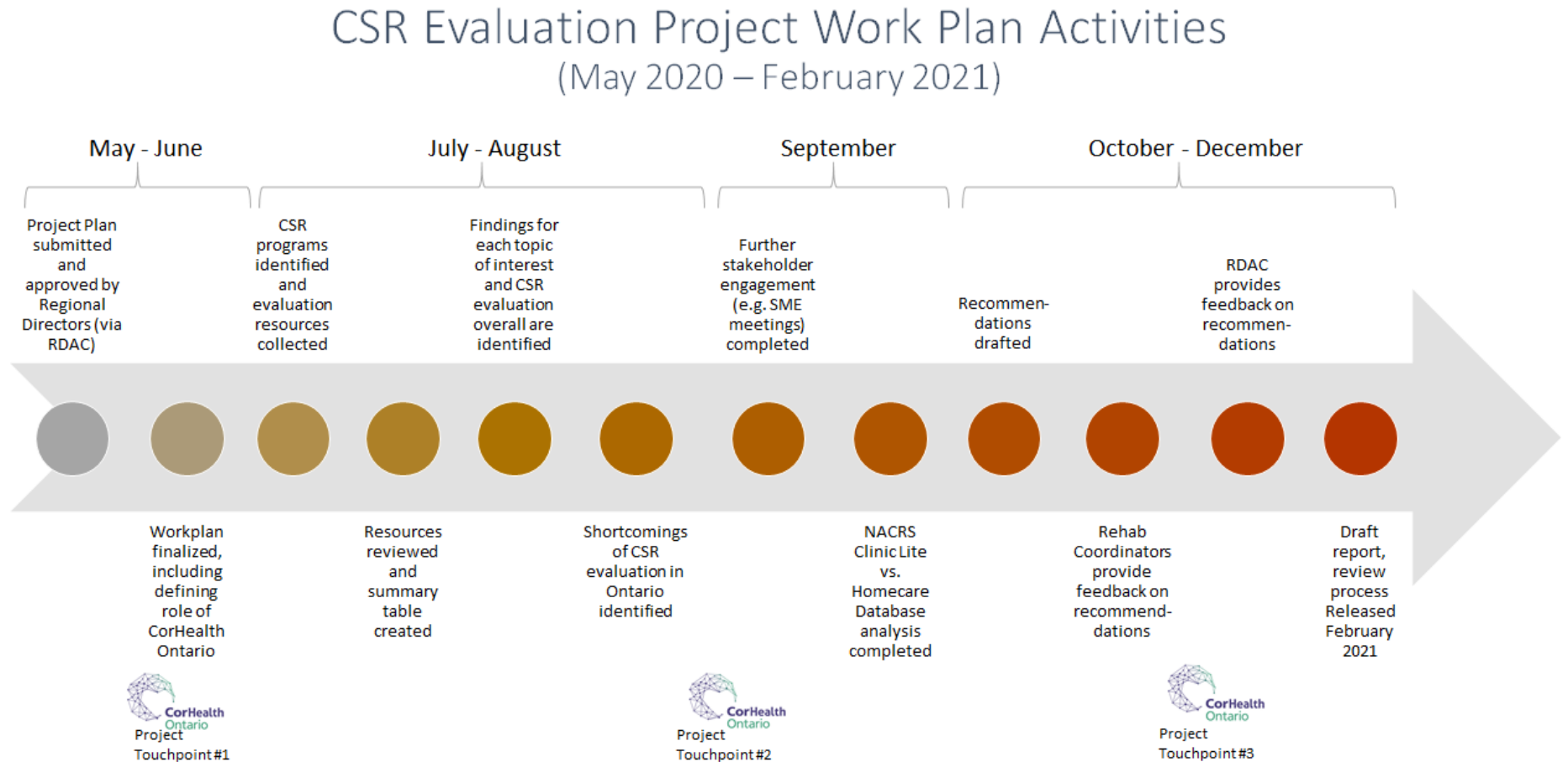
Findings and shortcomings for each category and for CSR evaluation overall were identified. Further investigative steps such as consultation with subject matter experts, requests for more CSR evaluation resources, and discussion with CorHealth Ontario and Regional Stroke Networks' members were undertaken to solidify understanding of each category.

As the project progressed and more was learned about CSR evaluation in Ontario, some foci and outputs pivoted. A greater focus was put on systems used to collect data (i.e. NACRS Clinic Lite and HCD) and virtual care evaluation opportunities. Some intended outputs, such as the development of detailed indicators with standard definitions in both outpatient and in-home CSR programs or the recommendation of one standardized outcome measure for CSR across Ontario, were out of scope for this project. Where applicable, advice on these evaluation categories is included within this report and its appendices.

Recommendations were based on findings and additional consultations and are influenced by the realities of our provincial and national health systems (e.g. resources, mandate for national CSR data collection) and need to find strategic opportunities to facilitate CSR evaluation in the immediate future. The final recommendations were validated by the 11 Regional Stroke Networks and CorHealth Ontario.

The project workplan is summarized in Figure 1.

Figure 1. Workplan activity timeline (2020-2021)



3.3 Limitations

More than 70 CSR evaluation-related resources were collected and reviewed. The method to collect these resources was inclusive, though not exhaustive (refer to Appendix B: CSR Evaluation Resources – Collection and List). Some CSR programs may have additional reports that were not shared or available, and though several academic articles were included in the review, a formal literature review was out of scope for the project.

This project was completed during the COVID-19 pandemic, which may have had impacts on the work (e.g. omitted resources, fewer engagements for content development) due to competing demands at healthcare organizations.

3.4 Intended Audiences

The report content may be used by CorHealth Ontario in discussion with the Ontario MOH to enable connections to appropriate MOH representatives to advocate for enhanced stroke system evaluation. Other organizations such as the RCA, CIHI, HSSO, Heart and Stroke Foundation (HSF), and Ontario Health Teams (OHT) may also find this information useful to advance their mandates.

This report will be informative for regional, provincial, and national organizations involved in the planning and delivery of stroke care. The findings and recommendations herein should be reviewed by Ontario Stroke System partners, including CorHealth Ontario, Regional Stroke Networks, and CSR Programs in support of the shared goal of delivering and evaluating best practice stroke care.

4. Findings

4.1 Current State 2019-20: Evaluation of CSR Programs in Ontario

CSR programs in Ontario are delivered in hospital-based (outpatient) settings, home-based settings, and via hybrid models (i.e. both in-home and outpatient visits). Data collection and reporting processes differ between hospital-based CSR and home-based CSR programs. A standard database for reporting hospital-based CSR data does not exist at time of this writing, though the implementation of NACRS Clinic Lite is a possible solution. Home-based CSR programs operated by Local Health Integration Network (LHIN), Home and Community Care (HCC) (and its contractors) report data to the HCD. This report assumes that NACRS and HCD will be the two available options for CSR data reporting for the foreseeable future.




4.2 Overall CSR Program Evaluation Findings

Overall, program evaluations demonstrated the positive impact of CSR on individual patient recovery (outcomes) and the stroke system while reporting process measures such as number of patients served, number of visits provided, and length of stay (LOS) or service duration. See Figure 2 -CSR Program (CSRP) Evaluations Demonstrate Positive Impacts on Patients and Healthcare System.

There was variation in the focus of the CSR programs' evaluations. For example, some program evaluations included only process measures (e.g. average LOS, number of visits per patient and discipline, number of patients served) while others were more robust and included patient outcome measures (e.g. gains in Canadian Occupational Performance Measure (COPM®), Reintegration to Normal Living Index (RNLI)), impact on the stroke system (e.g. estimated avoided inpatient rehabilitation LOS days). Process data elements were more likely to be available than outcome measure data.

Program age, funding source, and human resources may have impacted the robustness of each evaluation: For example, the motivation to collect and report data differs depending on many variables (e.g. funding source and associated expectations). In-home CSR programs implemented more recently had more robust evaluations than long-standing outpatient programs. Newer programs may have had the benefit of lessons learned from early adopters of CSR and were able to launch with sustainable evaluation plans in response to more robust recommendations within CSBPR and QBP.

Figure 2: CSR Program (CSRP) Evaluations Demonstrate Positive Impacts on Patients and Healthcare System

Outcome	Selected Findings
<p data-bbox="207 590 303 646">Patient Outcome</p> 	<ul style="list-style-type: none"> <li data-bbox="342 590 1377 793">• Statistically significant improvements Functional Independence Measure (FIM™) , RNLI, Stroke Impact Scale (SIS), Strength, Communication, Activities of Daily Living (ADL), Mobility, Hand Strength, Social Participation, and composite physical score), Hospital Anxiety and Depression Scale (HADS) (Anxiety and Total), Caregiver Assistance and Confidence Scale (CACCS) - Assistance, and Bakas Caregiving Outcome Scale (BCOS) between admission and discharge - All gains maintained at follow up (<i>SouthWest, CSRP</i>) <li data-bbox="342 800 1317 863">• Clinically significant improvement in COPM© (performance and satisfaction) and RNLI scores (<i>Champlain CSRP</i>) <li data-bbox="342 869 1154 900">• Greater gains in FIM™ Scores sustained at 1 year (<i>SouthEast CSRP Pilot</i>)
<p data-bbox="207 911 303 968">System Outcome</p> 	<ul style="list-style-type: none"> <li data-bbox="342 911 1295 1010">• With implementation of the program (2009), Parkwood Hospital experienced a 32% reduction in ALC days and 44.9% decrease in days waiting for admission to inpatient rehabilitation (<i>SouthWest, Thames Valley CSRP</i>) <li data-bbox="342 1016 1373 1079">• Patients showed improvements in the 30 days following hospital discharge on the Resident Assessment Instrument – Home Care (RAI-HC) (Waterloo Wellington CSRP) <li data-bbox="342 1085 1333 1184">• Decrease in hospital LOS and decreased hospital readmission rates were observed after enhanced service implementation (<i>SouthEast CSRP, Southlake Regional Health Centre (SRHC) Outpatient</i>) <li data-bbox="342 1190 1357 1253">• Early findings indicate that since this program began, stroke patients have returned home an average of 7 days earlier from the in-patient program (<i>SouthWest, HDGH CSRP</i>)
<p data-bbox="207 1268 303 1325">Provider Experience</p> 	<ul style="list-style-type: none"> <li data-bbox="342 1268 1373 1472">• “We provide an essential service that was previously lacking, a link between hospital and community. We are able to identify and treat patients at risk for falling through the cracks of our medical system, patients with ‘hidden disabilities’ (cognitive issues masked by ability to independently mobilize and engage in simple conversation). I am so proud to be a part of a program that has a positive impact on the lives of patients and their families.” – <i>Communicative Disorders Assistant</i> <li data-bbox="342 1478 1365 1577">• “I have seen the need for this outpatient clinic for years. Working in the clinic, I know I am making a difference in my patients’ current well-being and their future life achievements.” – <i>Occupational Therapist</i>

4.3 Findings

The project identified 8 categories related to CSR evaluation at the outset. This section provides a high-level summary of findings for each category:

4.3.1. Process Data Elements/Indicators

(e.g. number of visits, time to first visit, duration of service)

During the review, it was noted there was a lengthy listing of data elements/indicators collected from the numerous reports that varied between in-home, outpatient, and hybrid programming. Despite this variety, there were some common data elements used across programs, for example, program duration/LOS and number of visits. However, it was noted that most metrics or indicators were not defined in reports, and for the few that were defined, the definition was not consistent across programs. A summary table of indicators can be found in Appendix C.

4.3.2 Outcome Measures

In-home programs were more likely to use patient functional outcomes measures compared to outpatient programs. Patient functional outcome measures reported to be used are:

Patient Functional Outcome Measures	In-Home Based	Outpatient	Hybrid
Reintegration to Normal Living Index (RNLI)	✓ ✓ ✓ ✓ ✓	✓	✓
Canadian Occupational Performance Measure (COPM®)	✓	✓	✓
Functional Independence Measure (FIM™)	✓ ✓ ✓ ✓	✓	
Resident Assessment Instrument (Inter-RAI)	✓ ✓ ✓		
Stroke Impact Scale (SIS)	✓		
Barthel Index for Activities of Daily Living	✓✓		

✓ = one program reporting using tool

The administration of outcome measures was not standardized within or between CSR programs (e.g. timing of administration at admission or discharge, rate of administration).

Most program clinicians chose individualized and discipline-specific outcome measures as a part of their clinical assessment and to measure and monitor patient goals and progress. The administration of these outcome measures is generally guided by clinical judgement, patient needs and best practice. They also tended to address a specific function or activity domain(s) (e.g. Montreal Cognitive Assessment [MoCA], Berg Balance Scale, etc.) A data field to report a patient functional outcome measure or any other outcome measure currently does not exist in either NACRS Clinic Lite or HCD.

4.3.3. Patient or Caregiver Experience

This category was added to the resources review activity as it was noted that some programs, albeit few of them, reported on patient and/or caregiver experience. In general, in-home and hybrid CSR were more likely to measure patient experience using home-grown surveys. For the few programs that did report on patient or caregiver experience, the response rates were low or the response rate was not provided. It should be noted that CSR programs may capture patient experience via generic organizational or corporate satisfaction/experience surveys.

"As a stroke recovery patient, I have experienced both the in-patient and out-patient rehab facilities. I found that the out-patient rehab was much more beneficial because I was able to find out what I was struggling at home and work on it in rehab. I was able to improve on skills that help me in everyday life..."

*Patient, Outpatient Stroke/Neuro Rehabilitation Program,
Southlake Regional Health Centre*

4.3.4. Systems Used to Collect and Store Data

The CSR evaluation resources reviewed did not include descriptions of any particular system used to collect and store data. Refer to NACRS Clinic Lite & HCD Findings section below for more specific details on these two databases.

Hospital-based programs use varying methods of reporting and collecting data. These methods include Excel Spreadsheets, electronic patient record modules and ambulatory care scheduling software. NACRS Clinic Lite is used by other disease groups (e.g. orthopaedic bundles) for ambulatory reporting, however, it is unavailable for CSR (outpatient)) at the time of this writing.

Most home-based programs report to HCD; however, some programs use additional methods of internal data collection to enhance the robustness of their data. For example, the ability to identify that a patient was in the CSR program or information on visit duration are sometimes collected via other methods (e.g. Excel spreadsheet or specialized local coding within patient records).

Location of CSR Delivery & Reporting Database

Not all in-home CSR programs report to HCD. For example, South-West Parkwood CSR employs hospital staff to complete in-home therapy; however, the program does not report to HCD. Service delivery setting and employer are important considerations to ensure any CSR evaluation is interpreted in context. This becomes increasingly important to consider as the health system expands to include more CSR programs (e.g. via integrated funding models and OHT).

4.3.5. Virtual Care

During this project, the COVID-19 pandemic shifted the health care landscape and led to virtual care becoming one of the common modalities of service provision in CSR and therefore, an important aspect of stroke care that needs to be accurately depicted in data collection and evaluation.

Virtual care was infrequently mentioned in CSR evaluation resources reviewed. Data collection for any elements related to the provision or evaluation of virtual care was manual and program-specific.

Collection of virtual care data in NACRS Clinic Lite or HCD is not optimal to report at a “per visit” (versus episode of care) level. Data collection nuances to properly evaluate the delivery of virtual care in CSR would be complex and need to consider various factors such as therapy time definitions and how assistant visits are captured. Refer to NACRS Clinic Lite & HCD Findings section below for more specific details on these two databases.

4.3.6. Impacts on Data Quality

Standardized data elements or indicators for CSR evaluation in Ontario do not exist. Indicators that are used for evaluation do not have standard definitions across Ontario. There is no mandated data collection for CSR and no database to report to for hospital-based programs.

Robust evaluations of CSR were more likely during the pilot or implementation of a program to demonstrate its impact. Process data elements and indicators (e.g. LOS, number of visits) are more likely to continue longer-term. It is well known that data collection is resource intensive, and dedicated evaluation resources in CSR programs are limited.

4.3.7. Summary of CSR Programs’ Existing Evaluations and/or Reports

Many CSR programs demonstrate the positive impact on patient and system outcomes such as improved access, avoided hospital admission, and reduced hospital LOS. Overall, evaluations of CSR programs are very different, with variations seen in all categories reviewed for this report.

It should be noted that CSR evaluation resources are not often published or publicly available, limiting awareness of the potential impact of CSR programs within our stroke system.

4.3.8. Early Supported Discharge (ESD)

No ESD programs are currently operational at the time of this writing. However, one pilot evaluation was incorporated in this review, which showed similar reporting methods and benefits to other CSR programs (e.g. reduced hospital LOS).

Future ESD programs in Ontario can use this report in addition to the Ontario Stroke Network’s Provincial Integrated Working Group: Early Supported Discharge Final Report (Ontario Stroke Network, 2015) as a basis for program evaluation.

4.4 NACRS Clinic Lite & HCD Findings

An in-depth review and comparison of NACRS Clinic Lite and HCD was undertaken to inform this project. It is assumed these two databases are where CSR program evaluation data are reported and mostly likely to be used in the future.

In 2019, CorHealth Ontario completed a review of NACRS Clinic Lite data fields for input on an MDS for stroke bundled care evaluation, which supported the need to capture or modify the following elements: direct therapy time, method/code to capture when a patient is enrolled in CSR program and involved disciplines are captured.

There are several data fields that are common between the two databases: some are extremely similar (see #1 below), while others match but have differences in definitions (see #2 below). The writers did not discover any data fields that appear in one database and not the other that would be desirable from the perspective of a CSR evaluation.

The following are interpretations by the writers after engagement with subject matter experts. Future activities should validate these interpretations as both systems have complex definitions for some fields and/or may have had alterations in use for various populations or have been changed since this review.

1. Straightforward/Relative Alignment

- a. **Disciplines** – PT, OT, SLP, SW, Nursing are reported by both databases (see also 2.a.i.).
- b. **Date of Service/Therapy Delivery** – both databases have the capacity to record the date of each visit; however, there may be significant impacts on visit count depending on some factors (e.g. episode of care-level reporting in NACRS, cost centers in NACRS).
- c. **Assessment** – Assessment visits are not differentiated from rehabilitation therapy visits in reporting to either database.
- d. **Admission Date** – HCD reports admission date, NACRS reports date of admission. There are additional data elements that could be considered as well. A LOS indicator should consider all options (e.g. first treatment date).
- e. **Patient identifiers** and other information are similar between databases. The CSR Evaluation Report will not address this in its recommended list of data elements to be captured.

2. Nuanced (e.g. not measured or reported in the same manner)

- a. **Disciplines**
 - i. Rehabilitation assistant visits are included under the appropriate therapist in HCD, whereas they are reported separately in NACRS Clinic Lite (PTA, OTA, CDA).
 - ii. Nursing is an available field in both databases. HCD simply reports nursing (includes both RN and RPN), whereas NACRS Clinic Lite differentiates between RN and RPN.
- b. **Duration of Each Therapy/Service Visit**
 - i. Therapy/Visit duration likely not accurate or reliable in HCD; programs may use a range or have a standard visit time for reporting in CHRIS (e.g. 60 min per appointment is the standard to record in Champlain).
 - ii. Reliability for NACRS Clinic Lite is uncertain as it is reported for the entire episode of care rather than at visit-level. Aligns with Management Information System (MIS) workload measurement guidelines reporting in NACRS Clinic Lite.

Note – neither database is aligned with the current collection of NRS rehabilitation time definition for inpatient stroke rehabilitation, which is quite specific to direct therapy time

from a patient perspective, so need to use caution with interpretation (see glossary for detailed definition).

- c. **Location(s)/Mode of Service/Therapy Delivery** – both databases have a menu of options, but they are not the same.
 - i. Location can be viewed per visit in HCD; however, in NACRS Clinic Lite, the mode is reported as the most frequent location for the entire episode of care.
 - ii. Both databases record in-person visits and a variety of other options, but the list of other options is not the same between databases.
 - iii. Mode can be viewed per visit in HCD; however, in NACRS Clinic Lite, the mode is reported as the most frequent for the entire episode of care.
- d. **Referral Source** - both databases record a referral source. Neither allows you to determine whether a referral was from acute care or inpatient rehabilitation as a generic location.
- e. **Discharge Information**
 - i. Discharge Disposition (HCD) and Reason for Discharge (NACRS Clinic Lite) are similar fields, though menu options differ between databases, so could not be compared. The disposition will be for discharge from the program/service overall, not necessarily discharge from CSR program.
 - ii. Discharge Date – both report a discharge date; however, the date may not be the discharge from CSR vs services overall.

4.5 Limitations Observed in CSR Evaluation Review

Despite some excellent individual program evaluations and results, our findings highlighted several limitations in the ability to evaluate CSR programs in Ontario and provided stronger evidence and need for a standardized approach to CSR evaluation. Relatively few CSR programs in the province have completed formal evaluation reports to assess their services. Some of the major limitations include (1) lack of standard set and definition of data elements and indicators, (2) inability to compare CSR program delivery across programs or time, and (3) major challenges around data collection.

Limitations observed are summarized below:

- Overall, the **CSR program evaluations available are for a relatively small sample size** within the scope of all patients receiving community stroke rehabilitation in Ontario.
- There is **minimal hospital-based (outpatient) CSR evaluation resources or reports**. The ability to collect or report data is limited (i.e. no database). The fact that hospital-based CSR programs tend to have pre-existing funding models that did not require robust stroke specific data collection may explain the lack of CSR evaluation in this setting.
- There is **no standard set of data elements or indicators** to evaluate the performance of CSR programs. Definitions for data elements and indicators are not available or standardized within or across settings. Even when a similar data element exists in more than one CSR program (e.g. referral date), the measurement and/or recording of this element may be different between programs making comparing across programs difficult.
- **Reporting and evaluating the delivery of virtual care is not possible** across settings or at the visit (versus episode of care) level. Where virtual care data is collected, modality is not recorded.
- CSR evaluation reports **do not describe the program's service delivery or model of care**, nor is there an ability to differentiate between stroke rehabilitation team visits versus any

rehabilitation for other populations. It is not possible to identify whether a patient was treated under a **specialized CSR program or via general homecare** service delivery.

- Current **resources** (e.g. staff, training, time) **allocated to data collection and evaluation is insufficient to support and sustain high-quality data.**
- A variety of **outcome measures, which are not administered in any standard way** across CSR programs, are in use. In-home programs are more likely to use patient functional outcome measures for all patients, compared to outpatient programs.

At the provincial or aggregate level, the fundamental challenge remains the inability to “roll up” data and evaluation from all CSR programs (in-home, outpatient, hybrid) into one summary report for system evaluation. Hospital-based and home-based programs are provided by different institutional groups with different reporting mandates, different (or non-existent) tools or systems to record data, and report different data elements. Even where there is overlap on data elements, definitions may not exist or are inconsistent. The need to standardize data collection for all CSR programs across settings is clear.

5. Recommendations

To enable the evaluation of CSR at program, regional, and provincial levels, standardized and accurate data should be reported to centralized databases by all CSR programs in Ontario. Action on the following recommendations will require significant effort and partnership to establish data collection systems that meet key requirements across hospital and home care sectors, and to support organizations with CSR programs that would be tasked with their ultimate implementation. Activities required to achieve the recommendations should be completed in collaboration with multiple stakeholder groups, including CorHealth Ontario, RCA, CIHI, HSSO, MOH, CSR Programs and Regional Stroke Networks.

NACRS Clinic Lite and the HCD are assumed to be the two available options for CSR data reporting for the foreseeable future and are therefore referenced in the recommendations. One common database for CSR data that is linked with existing databases and permits timely access and analysis for CSR programs, is the ideal solution. However, this solution was not deemed feasible at this time, but remains to be the long-term vision as we advance community rehabilitation evaluation in Ontario.

The following recommendations may not meet all evaluation needs at local, regional, and provincial levels; however, their implementation would be a significant advancement for CSR measurement, monitoring and reporting in Ontario. Implementation of these recommendations moves the system towards a credible and core baseline data set that can evolve to meet evaluation needs.

5.1 Detailed Recommendations

Recommendations one through four listed below should occur in conjunction with each other as there are intricate dependencies in finalizing an MDS, and definitions for key indicators while leveraging an existing database.

- 1. All CSR programs should have access to a centralized, standardized data collection system for all stroke patients (i.e. NACRS Clinic Lite or HCD)**
 - a. Data base should be part of the broader stroke system data collection to enable linkage to all parts of the stroke patient journey (e.g. acute care (DAD), inpatient rehabilitation (NRS)) as key

elements such as stroke onset, hospital discharge, stroke severity, inpatient LOS will be critical for overall system monitoring/evaluation.

- b. Data should be captured for all CSR patients in Ontario, regardless of any predefined subset (such as funding model inclusion/exclusion). This removes some administrative burden from reporting organizations, as they would report in the same manner for all CSR patients, and eventually all rehabilitation services ideally.
- c. All CSR programs should have access to report to either NACRS Clinic Lite or HCD at a minimum regardless of outpatient, in-home or hybrid model (implications may need further exploration in data base selection). Limitations of NACRS Clinic Lite and HCD should be transparent and understood by those reporting and using the data, especially in terms of data elements and comparing or merging evaluation between the two. Consideration for stroke-specific and virtual rehabilitation adjustments to each database should be considered if feasible for timely implementation.
- d. NACRS Clinic Lite should become available for hospital-based/outpatient CSR programs to begin reporting data for all stroke patients immediately to address immediate outpatient data gap.
- e. Hospital-based CSR programs should begin to collect data in alignment with the existing RCA MDS for NACRS Clinic Lite in the interim until CSR MDS is established.

To support implementation of a centralized, standardized solution, common metrics prior to implementation will need to be established.

2. A standard minimum number of indicators and definitions, which have been vetted and validated by an expert panel, should be used for all CSR programs.

- a. The suggested indicators to consider for monitoring and reporting are described in Appendix D. Further expert opinion and validation will be needed to standardize definitions and may be impacted by the feasibility for modification within available databases.

3. A standard minimum number of data fields should be reported across all CSR programs (outpatient and in-home), including fields to capture virtual care.

- a. The suggested data fields to report are described in Appendix D:
- b. Data fields should have standard definitions, which have been vetted and validated by an expert panel.
- c. It is recognized that definitions may differ between NACRS Clinic Lite and HCD, at least initially. Data definitions should become aligned between the two databases.
- d. Any new data fields (e.g. virtual care elements) should be standardized between the two databases before implementation.
- e. The location/type of each visit should be reported (i.e. outpatient, in-home, or virtual).
- f. A virtual visit should further be defined by its modality (e.g. video or phone).
- g. Visit location and modality of virtual care should be available at the visit level, not only at an episode of care level.
 - i. At minimum, an episode of care summary should indicate that both virtual and in-person care was provided.
- h. A minimum threshold for a CSR visit should be defined (e.g. at least 15 minutes) and implemented in both the hospital-based and home-based settings.

4. Data reported should enable the identification of patients enrolled in a CSR program compared to other in-home or outpatient services.

- a. The previously-established provincial definition for comprehensive outpatient services¹, which was based on CSBPR, should be re-validated and used to identify Ontario's CSR programs.
- b. HCD and NACRS Clinic Lite should include a mechanism (field or special code) to identify CSR patients. Interim plans to identify CSR patients could include:
 - i. CSR programs develop a process to identify their patients (e.g. assign special code to CSR patients for easy identification).
 - ii. Establish a list of CSR programs in Ontario to reference when evaluating existing data at a provincial level. This could be similar to the acute stroke unit process.

To enable implementation at the local level, CSR Programs need to be engaged and ideally resourced to implement.

5. CSR programs should have adequate resources to enable high-quality data reporting and ongoing, timely program evaluation.

- a. CSR programs should have the ability to access their own data in a timely manner.
- b. CSR staff should be trained and supported to accurately report required data fields. Programs should have a dedicated resource for data collection and support.
- c. CSR staff should be trained and supported to administer clinical outcome measures.
- d. Monitoring and feedback on data quality should be provided on an ongoing basis.
- e. Data should be regularly reviewed by the CSR team, with any findings incorporated into process or program changes, as appropriate. Ongoing evaluation should happen frequently (e.g. quarterly), with a fulsome program evaluation completed at least annually.
- f. CSR programs should consider implementing a recognized patient and caregiver experience measure as part of their data collection, which could assist in quality improvement efforts and monitoring of programs.

In addition to the metrics described above for access and utilization measurement, patient outcomes need to be monitored in addition. There may be opportunities for higher level system measures, but to truly evaluate performance and future quality improvements, patient level outcome measures should be incorporated.

6. One patient functional outcome measure should be administered for all patients in CSR programs that is standard for all patients. This is in addition to discipline-specific outcome measures that may be used. Selection of one patient functional outcome measure is out of this project's scope and requires provincial leadership and involvement of multiple stakeholders. Refer to Appendix E for additional findings about outcome measures used in the ambulatory and community setting, as well as considerations to support future work to select one or more standard outcome measures for use in the CSR setting.

¹ Ontario Stroke Evaluation Report (2016) defined comprehensive outpatient services as: delivered in a hospital setting that are provided by an interprofessional team (at a minimum, an occupational therapist, physiotherapist and speech-language pathologist) specifically assigned to the service, using a case-coordination approach with regular team meetings and the capacity to provide 2–3 visits a week for 8–12 weeks.

Lastly, stroke system stakeholders at all levels should advocate for research funds to be allocated to study the effectiveness of CSR programs in Ontario. The focus would be to continue knowledge translation in this emerging component of the stroke system including a focus on effectiveness of virtual rehabilitation. Research on a more robust scale would be enabled with provincially standardized data, thus providing opportunity to further improve evidence-based practice for CSR.

6.0 Next Steps

Multiple reports by various rehabilitation stakeholders have identified and highlighted the necessity of CSR evaluation and the evaluation of post hospital rehabilitation. The need to resolve the data gap has been further reinforced by CorHealth Ontario's Stroke Regional and District Advisory Committee (RDAC) and Stroke Evaluation Quality Committee (SEQC), as identified in their 2021/22 provincial priority plan. The Ontario Regional Stroke Networks' Rehabilitation Coordinator Group anticipates further dialogue and collaboration with its stakeholders to share the report's findings and to move toward achieving its recommendations.

Striving for completion in 1 – 2 years, the immediate next steps are focussed on supporting recommendations one to four above, in order to implement the infrastructure that would enable a base level of CSR measurement, monitoring and reporting in Ontario.

1. Ontario Regional Stroke Networks' Rehabilitation Coordinator Group will:
 - a. Share and discuss report findings and recommendations with CorHealth Ontario (including but not limited to the RDAC and SEQC, RCA and MOH to inform future activity
 - b. Support CorHealth Ontario in advancing their workplan priority to resolve the CSR data gap
2. CorHealth Ontario is encouraged to use the findings in this report as baseline information to inform the project-based CSR data gap priority work in their operating plan.
3. CorHealth Ontario and MOH are encouraged to create a working group of stakeholders (including Ontario Regional Stroke Network's Rehabilitation Coordinators) to jointly develop next steps and guide future implementation.
4. CorHealth Ontario and MOH are encouraged to enact a mechanism to validate and develop consensus on the proposed MDS and indicators referenced within this report, through a structured process with stakeholders (e.g. a modified Delphi method).
5. MOH direction and approval is required to:
 - a. Enable the use of NACRS Clinic Lite for all stroke patients receiving outpatient rehabilitation at a minimum.
 - b. Enable review of data fields for possible enhancements in both NACRS Clinic Lite and HCD as described in this report.
 - c. Ensure that processes are in place that makes data available for integration with other stroke data (e.g. CIHI DAD, NRS) for analysis at local, regional and provincial levels.

These initial steps will help to fill an immediate baseline information gap. Looking further in the future, it would be ideal to have a centralized database across all rehabilitation care partners that enables robust

process and outcome evaluation, and is integrated with data across the continuum. The latter, coupled with a functional patient outcome measure and patient experience measure will together create a complete CSR evaluation opportunity.

7.0 Implementation Considerations

A key consideration for future data collection and program evaluation is the recognition that CSR **delivery location may not align with the historical organization** setting (hospitals may deliver home care; home care agencies may establish outpatient programs or they may create a collaborative service). As such, **reporting needs to be flexible to capture CSR from the patient perspective** rather than the organizational perspective.

Consideration of special project fields to help sort and pull the correct data sets may be a solution. In the shorter term, **modifications to existing databases (NACRS Clinic Lite and HCD) to recognize this evolution can support evaluation efforts**. Opportunities to improve existing databases and implementation plans that support the recommendations should be assessed for **feasibility and impact by experts/data base owners and rehabilitation stakeholders**. Expertise and **lessons learned from the RCA** in facilitating NACRS Clinic Lite implementation across the province for orthopaedic bundled care and original proof of concept work should be explored to maximize the opportunity for success. Community by nature has a broad definition and our data sources need to evolve with the health system transformation of care occurring in a variety of setting, based on patient needs.

Immediate goals target a modest MDS within existing data systems which may evolve over time to enable a broader scope of evaluation. All evaluation questions will not be in scope of a provincial data set. In the short term, programs with unique data strategies and access to direct patient files may have greater capacity for some aspects of evaluation. **Local evaluations may allow for measurement of factors that affect service delivery**, which add valuable context to program evaluation and quality improvement initiatives, for example, including the impact of patient preference on wait time or location/modality of visits.

Data collected and submitted should be available to sites for their own quality improvement purposes. Where possible, sites should consider any opportunity to build standardized reports, ease the burden of implementation and retain the benefit for local quality monitoring and improvement work.

8.0 Conclusion

CSR programs are an integral part of the stroke system and care provided post hospital discharge is crucial to optimal patient recovery post stroke. Optimal community-based programs help to ensure inpatient capacity is reserved to meet increasing demands. By enabling CSR measuring, monitoring and reporting across the province this will provide a needed system evaluation component that has been missing to understand the performance of the stroke system as whole. The expertise of several program and health information stakeholders, and MOH endorsement, is needed to advance this work collaboratively with the Regional Stroke Networks and CorHealth Ontario, all of whom have a vested interest in improving the quality of stroke care in Ontario. Having a provincially-based CSR evaluation system in place would support providers, decision makers and health system planners to ensure optimal patient outcomes and system effectiveness. A focused and collective effort is needed to implement coordinated CSR data collection and evaluation in Ontario.

Appendix A - Outpatient Rehabilitation Data Gap References 2013-2020

Year	Report	Relevant Reference in Report
2013	Office of the Auditor General of Ontario, "Reports on Value-for-Money Audits: Rehabilitation Services at Hospitals" (2013)	Variation in performance measures limits the ability of hospitals, the LHINs and the Ministry to compare performance and thereby identify better rehabilitation practices. Hospitals should collect information to better ensure that available outpatient resources are utilized efficiently and effectively, such as information on the number of appointment cancellations and patient no-shows, and on the change in patient functionality between when outpatients start and when they complete outpatient rehabilitation.
2015	Ontario Stroke Network: Interpretation of the Stroke Report Card - Ontario	The OSN will work with the Ministry of Health and Long-Term Care and the Canadian Institute for Health Information to inform a sustainable stroke data collection and data quality strategy. This strategy will aim to inform the three report card indicators where data is not currently available (i.e. anticoagulation therapy for atrial fibrillation, rehabilitation intensity and dysphagia screening) and to support Rehabilitative Care Alliance work to address availability of outpatient rehabilitation data. <i>Note: Data now available for all but outpatient rehabilitation.</i>
2016	Ontario Stroke Network: Focus on Stroke Rehabilitation	Gaps in data quality and availability prevent a complete evaluation of the Ontario stroke rehabilitation system. The OSN/CCN [now CorHealth] should collaborate with the Ministry of Health and Long-Term Care, Health Quality Ontario, the Canadian Institute for Health Information and the Rehabilitative Care Alliance to improve data availability and strive for consistency in quantifying rehabilitation outcomes across settings to better evaluate the system of rehabilitative care. Priorities for data enhancement should include outcome indicators that evaluate patient/survivor experience and quality of life, and the Rehabilitative Care Alliance's pilot to gather standardized data across Ontario's outpatient rehabilitation clinics for the National Ambulatory Care Reporting System (NACRS Clinic Lite)."
2017	Rehabilitative Care Alliance: Transforming Rehabilitative Care 2015-2017 Report	There is a lack of cross-continuum data that captures rehabilitation activity outside of designated rehabilitation beds. This absence of comparable, standardized data makes it impossible for health service providers (HSPs) and LHINs to evaluate and benchmark their performance. The RCA then conducted phase one of a provincial proof of concept in 2016/17 to pilot the minimum data set and the use of three data collection and reporting tools: National Ambulatory Care Reporting System (NACRS) Clinic Lite (access and service utilization measure), the Community Rehabilitation Assessment (CRA) (functional outcome measure) and the WatLX™ (patient experience measure). This marked the first time that comparable, standardized data were collected and reported across outpatient/ambulatory rehabilitative care programs in Ontario.
2017 /18	CorHealth Ontario: Ontario and Local Health Integration Network (LHIN) 2017/18 Stroke Report Cards and Progress Reports	74.2% of acute patients were discharged home; however, without available outpatient data an accurate evaluation of this service is unknown
2019	Rehabilitative Care Alliance: Driving System Change,	Sites participating in the MOHLTC's hip and knee bundled funding pilot have successfully implemented NACRS Clinic Lite to gather utilization and wait time data for outpatient rehabilitative care. The value of the data has highlighted

	2017-19 Report	the need for similar data for other rehabilitation populations, and with the foundational work completed (onboarding, training, process development, data quality steps, etc.), it would be easy to expand data collection to additional populations. Outpatient data will play a crucial role in planning for transitions from hospital to home and in the renewed focus on community options for health care.
2019	CorHealth Ontario: Stroke Bundle Planning, Survey of CSR Providers	Efforts for one-time survey of CSR providers found that data is incompatible and incomplete for a baseline understanding of availability of services for outpatient and/or in-home services. To improve the dataset, it will require the application of standardized data collection definitions to avoid faulty interpretation and misleading data.

Appendix B - CSR Evaluation Resources – Collection and List

Collection Method

In June 2020, rehabilitation coordinators (RC) representing all Ontario stroke networks agreed to collect and submit existing resources related to the current evaluation of their region's CSR programs and /or any other related CSR evaluation documents of interest (e.g. publications, reports). Email instructions were sent to each RC to facilitate collection of resources to support the initial step to: *Identify and collect existing CSR evaluation resources to inform summary of current state of data collection, availability, and quality across hospital- and home care-based programs.*

List of Resources/Documents Reviewed: Grouped by Stroke Network Region

The collection process resulted in 73 resources with variation in size, type, region, organization. A second and third request was made through the RCs to help with filling gaps from certain regions and/or for hospital outpatient resources with additional resources being forwarded into September.

The following 73 resources were reviewed by a core group of RCs. Information related to our eight categories was extracted and recorded in a summary table of information for later review and summarization by topic.

*Note: ** indicates a publication and full reference can be found in reference list*

Champlain

- Champlain LHIN Community Stroke Rehabilitation Program Annual Report – Fiscal Year 2018-2019
- Outpatient (OP) Ottawa Bruyere Evaluation data collection template (not in use) (2019)
- OP Ottawa Bruyere List of Indicators (proposed not collected) (2019)
- Community-based Rehabilitation Program in Stormont, Dundas, Glengarry and Akwesasne: What makes this an exemplary program? (2019)
- Champlain CCAC - L Allen Individual Program Report (2016)

South East

- Community Stroke Rehabilitation Program Annual Report – June 2019
- Enhancing Community-Based Rehabilitation for Stroke Survivors: Creating a Discharge Link (2014)**
- South East Enhanced Stroke Rehab - - L Allen Individual Program Report (2016 & 2019 update)

Central East

- NSM CCAC (in Central East) - L Allen Individual Program Report (2016)
- NSM Integrated Stroke Program - L Allen Individual Program Report (2016)
- Central East LHIN Community Stroke Pathway (2019)
- Southlake Regional Health Centre – Outpatient Neuro Rehabilitation Program (2018 &, 2019, 2020 reports)
- NSM LHIN Stroke Pathway (2018)
- Saving Inpatient Hospital Bedded Days Through Access To Multidisciplinary Outpatient Neurological Rehabilitation Services Post Stroke: An Individualized, Outpatient Approach – Southlake Regional Health Centre 2019 (Abstract and Poster)

Central South

- Brant/Haldimand-Norfolk Home and Community Care Stroke Scorecard 2019/2020
- Regional Rehab Outpatient Program Changes (HHSC Eligibility & Referral) (Nov 2019)
- OP HHSC Program Review Matrix - Central South (2019)
- OP HHSC Regional Rehabilitation Centre Neuro Stroke Visits FY15-16 to FY19-20 Q2
- OP HHSC Stroke Distinction (2019) Central South
- OP HHSC Stroke Distinction Stroke Client and Family Education Session November 26, 2019
- The HNHB LHIN's Community Stroke Rehabilitation Model - L Allen Individual Program Report (2016 & 2019 update)
- The Waterloo Wellington LHIN's Community Stroke Program L Allen Individual Program Reports (2016 & 2019 update)

North-East

- Hybrid NE Post Stroke Transitional Care Program Visit Data (2018/19)
- NE Community Model of Care - L Allen Individual Program Report (2016)

North-West

- NW SLP Tele-rehabilitation Pilot - L Allen Individual Program Report (2016)
- NW SLP Tele-rehabilitation Pilot (2015)
- OP St. Joseph's Hospital Neuro Outpatient Evaluation Summary NW (July 21, 2020)

South-West

- Community Stroke Rehabilitation: How do rural residents fare compared to their urban counterparts? ** (2016)
- Community Stroke Rehabilitation Teams: Providing Home-Based Stroke Rehabilitation in Ontario, Canada (2014) **
- Community Stroke Rehabilitation Team: Outpatient and Community Stroke Rehab (2016)
- Stroke Rehab Patient's Care and Outcomes in the Community (2016)
- Making an Impact for Stroke Patients & their Families in Windsor-Essex (2019)
- CSRT Data 2016-2018
- Community Stroke Rehabilitation Team: What makes this an exemplary program? Regional results from the project: Community-based rehabilitation: towards ethical design and allocation (2019)
- South West Community Stroke Rehab Teams - L Allen Individual Program Report (2016 & 2019 Update)
- South West eRehab SWO (Update to L Allen 2019)
- South West LHIN Pilot of Early Supported Discharge for Stroke: Final Report and Program Evaluation (2019)
- Piloting an Early Supported Discharge Model in Huron and Perth Counties for Stroke Survivors - GTA Rehab Conference Slides (2019)
- A Preliminary Analysis of a Home-Based Stroke Rehabilitation Program in Windsor, Ontario (2019) **

Toronto Stroke Networks

- Indicators for Outpatient Rehabilitation and Community Standards of Care (2020)
- OP TSN Outpatient Rehabilitation Standards of Care (2019)
- Community Standards of Care (July 2019)
- Toronto Stroke Networks E-Stroke data points (2020)
- TSN Community. Model of Care - L Allen Individual Prog. Report (2016)
- Cost-effectiveness of a high-intensity rapid access outpatient stroke rehabilitation program (2018)**

West GTA

- The Importance of Clinical Champions in Quality Work: An Example of Improving Access to Outpatient Rehab Post- Stroke - IH Mississauga Halton LHIN Stroke Pathway Data Slides (2019)
- Mississauga Halton LHIN Stroke Pathway Data: For West GTA Stroke Network (2019)
- Community Outreach Stroke Rehab Program: A Partnership Between William Osler Health System and Home and Community Care (2019)
- Mississauga Halton CCAC (in West GTA) - L Allen Individual Program Report (2016 & 2019 update)
- Community Outreach Stroke Rehabilitation Program- Update to 2016 Community Stroke Rehab Models in Ontario (2019)

Summary Reports

- Community Stroke Rehabilitation Models in Ontario (Laura Allen) (2016) and recent provincial updates (Feb 2019)

Rehabilitative Care Alliance

- Driving System Change 2017-2019 Report
- Transforming Rehabilitative Care in Ontario 2015-2017 Report
- NACRS Clinic Lite (NCL) Bundled Care Data Requirements Document (2019)
- Hip and knee Bundled Funding Pilot Outpatient/Ambulatory Rehab Service Utilization Patient Level Tracker (2019)
- Implementation of the National Ambulatory Care Reporting System (NACRS) Clinic Lite in the Bundled Care Program (19/20) Technical FAQ
- Outpatient Data Collection Technical Report (2015)
- Rehabilitative Care Alliance Outpatient Ambulatory Provincial Proof of Concept - Phase I Report (2018)
- RCA's Community-Based Rehabilitation White Paper (2020)

CorHealth Ontario and Ontario Stroke Network

- Stroke Community and Outpatient Rehabilitation Provincial Integrated Work Plan (PIWP completed June 2018)
- Current State of Stroke Community-Based Rehabilitation: Summary of Preliminary Results from Survey for Validation (2020)

- SEQC Outpatient Indicators Working Group Summary/Minutes (2014)
- A Focus on Stroke Rehabilitation (2016)

Other:

- CSBPR indicators for OP/CSR
- Home Care Database CCAC Guidelines – Version 3.6 (2008)
- Home-Based Versus Centre-Based Rehabilitation for Community Dwelling Post- acute Stroke Patients: A Rapid Review (2015)**
- International Consortium for Health Outcomes Measurement (ICHOM), Stroke Data Collection Reference Guide Version 2.0.1 (2018)**
- Evaluation of an Extended Stroke Rehabilitation Service (EXTRAS): A Randomized Controlled Trial and Economic Analysis (2019)**

Appendix C - Summary of Indicators/Metrics Reported in Materials Reviewed

Indicators/Metrics (in home/outpatient/hybrid) Most common in bold. Note: Many similar indicators reported. Intent of indicator captured (standard definitions were typically not reported).			
T H E M E S	Access	<ul style="list-style-type: none"> - # waiting for service - # new referrals - # not eligible - # eligible who declined service - # of patients served (patient volumes) - Referral source/% by each type - Date of Stroke to First Visit - % patients receiving each service - General patient demographics (e.g. Age) - Time from “referral” to start of service ** (varied definitions or no definition of referral provided) - % patients who receive visit within 48 hours - % patients who receive visit within 72 hours - % patients receiving OT home assessment in 48 hours 	<ul style="list-style-type: none"> - Median time from hospital discharge to initiation of aphasia therapy in community** - # patients receiving service in Long Term Care (LTC) - # of patients who received discharge link (hospital team to community team) by referral site - # of staff members in each rehabilitation setting trained on supportive communication** - % patients with adjunct SW session - % patients with adjunct RN session - Average # cancellations/no shows per episode of care - % patients who accessed single service - % of those single services accessed - % of patients who access stroke day rehabilitation - # patients who left program
	Amount of Therapy	<ul style="list-style-type: none"> - total visits for all therapies received, average per patient, total visits delivered by program - total by discipline/per patient (OT, PT, SLP, SW) - average by discipline/per patient (OT, PT, SLP, SW) - total days attended program - service duration/minutes for each discipline - average # of therapy visits received per week - Proportion of visits by each discipline 	<ul style="list-style-type: none"> - # visits by discipline for LTC residents - # of patients who completed program/pathway/stroke type - # of visits in 3 months (all, mild, moderate, severe) - Median hours per day of direct task specific therapy** - Average days per week of direct task specific therapy - % of time each patient with stroke and communication issues spends in therapy with communication specialist (SLP, CDA etc.)** - % OTA/PTA or total OTA/visits - Total OT/PT consults - # of face to face/telephone/video visits and proportions
	Outcome or Balancing Metrics	<ul style="list-style-type: none"> - LOS in hospital - Readmission rates/30-day readmission - Avg rehabilitation algorithm score - Discharge disposition after program - Admission/Discharge/Change in FIM™ 	<ul style="list-style-type: none"> - Therapist time on administration tasks - Linkages with community service/resources - Interdisciplinary goals and patient progress - Patient/Caregiver Experience - Various patient/clinical outcome measures – discipline level or program level

** Referenced in Canadian Stroke Best Practice Recommendations

Appendix D - Suggested Data Elements & Indicators

Minimum Data Set Suggested for collection across ALL outpatient and in-home CSR programs for ALL stroke patients			
	Indicator	Data Elements	Comments
Access	Patient Volume	Unique patient ID Health Card Number	Need to count unique patients Suggest by discharge/completion of program Enable linkage between acute/rehabilitation dataset (DAD, NRS) for system evaluation across continuum and enable reporting by stroke type or severity
	Time to First Visit	Referral Source/Discharge location Hospital Discharge Date* Date of First Visit for Program Date of First Visit for each therapy Referral Date Date of Stroke*	To determine proportion seen within best practice targets: post-acute (48 hours)/post rehabilitation access (72 hours) – may consider database matching as NACRS or HCD do not necessarily track hospital discharge date. Both could establish proxies. For programs to evaluate independently will need to collect hospital discharge date and discharge location/type to assess target of 48hrs post-acute or 72 hours post-rehabilitation to first visit
	Patient Enrolled in Comprehensive CSR (vs other rehabilitation service)	Field to record Y/N/Unknown	Consider MIS functional centre adaptations/additions and develop standard definition
Amount of Therapy (services utilization, amount of therapy)	# of visits/discipline/patient Total # of visits for all therapies/patient	Record by individual visit including: discipline treating, date of visit, mode of visit (outpatient, in-home, virtual by video, virtual by phone) Consider subtype of 1:1 or Group <i>** Key that both traditional hospital and home care databases support collection of all visit types (outpatient/in-home/virtual)</i>	NACRS lite in Ontario Hip/Knee bundle have moved to episode reporting and for therapy it is called an attendance. Total number of attendances by discipline reported but not individual dates or mode per visit. Only can report the most common type of visit. HCD can report by individual visit. Suggest rolling up therapist and assistant time for now – consider opportunity to break out in future. If reporting by discipline available – include all services along with core therapies (PT, OT, SLP, SW)
	Duration of service (days or weeks)	First and last therapy visit	With core data elements can calculate by discipline and program. Consider in definition – how nursing and non-core therapies fit in definition. Recommend at minimum that first therapy visit is a core metric.

Minimum Data Set Suggested for collection across ALL outpatient and in-home CSR programs for ALL stroke patients			
	Indicator	Data Elements	Comments
Outcome	Minimum of 1 patient functional outcome measure (selection out of scope of this group)	Standard collection format and time of administration (e.g. start and end of program)	Future consideration to also include recording of clinical outcome measure within utilization database (i.e. NACRS or HCD) <i>Note - Measuring the change in patient function during outpatient therapy was noted as important in the Auditor General's Report (Office of the Auditor General of Ontario, 2013)</i>
Additional/Future Considerations	<p>Time Post Stroke or Time to First Visit post discharge</p> <p><i>Stratification by Stroke Severity</i></p> <p>Rehabilitation Intensity – Minutes/Service Duration</p> <p>Program Discharge Date - HCD</p>	<p>*Stroke Onset</p> <p>*Hospital Discharge Date</p> <p>*Stroke Severity</p>	<p>These data elements are important for context of CSR evaluation. Stroke Onset Date and Hospital Discharge date may need to be considered in the data set. These along with stroke severity such as Alpha FIM™ and FIM™ scores could be linked from other data bases and key to selection of data base.</p> <p>While it may be desired to have a specialized rehabilitation intensity metric in the community to align with the inpatient setting it is likely not feasible in the short term. It needs to be recognized that a “visit” in NACRS may not equal a “visit” in HCD as the base unit may be different.</p> <p>Considering visits to be a minimum amount of time with some consistency across platform may be a first step (e.g. ability to count visits with a similar definition/cut-off (e.g. >15 mins). A future phase may be to break down the minutes within a visit by agreed upon definitions.</p> <p>In HCD – may not be able to identify the discharge date from the CSR program as “regular” homecare service may continue from the same provider. Looking at standard lengths of therapy time (i.e. 3 months) or enabling a coding mechanism for CSR program would help in the interim to at least separate “true” CSR service evaluation from more random homecare services. Longer term, it would be desirable to pull out data based specifically on a “rehabilitation” episode vs ongoing “maintenance”.</p>

Appendix E - Outcome Measures: Future Considerations

The report's final recommendation #6 is that one patient functional outcome measure should be administered for all patients in CSR programs that is standard for all patients. This is in addition to discipline-specific outcome measures that may be used. *Selection of one patient functional outcome measure is out of the scope of this project and requires provincial leadership and the involvement of multiple stakeholders.*

Ontario CSR programs report the use of the following outcome measures: RNLI (5 programs), COPM© (2 programs), Inter-RAI (4 programs), SIS (1 Program) and FIM™ (3 programs). The use of outcome measures in a program can change over time, making it challenging to compare program outcomes from the beginning of program development to the current state.

Throughout this work, advice was collected regarding the use of outcome measures in CSR programs. It is shared here for future consideration, noting that this work would require robust collaboration.

- a. CorHealth Ontario and the RCA should consider partnering to lead an outcome measures task group of stroke rehabilitation experts to select and recommend one outcome measure that can be used by CSR programs.
 - i. Work and recommendations related to the implementation of a stroke-specific outcome measure should consider previous and current work by the RCA (e.g. rehabilitation Patient Reported Outcome Measures (PROM)), CorHealth (e.g. Stroke Bundle PROM and Patient Reported Experience Measure (PREM)), and Ontario Stroke Network (2014 Stroke SEQC Outpatient Indicators Working Group²).
 - ii. Task group membership should include front-line clinicians, researchers, rehabilitation administrators, representatives from Regional Stroke Networks (i.e. Rehabilitation Coordinators, Community & Long-Term Care Coordinators, RDAC).
 - iii. In selecting one standard outcome measure, consideration should be given to: the measure's use in other disease groups (potential spread), tools or equipment and time needed for administration, and validity to be administered across settings: outpatient, home, and virtual.
- b. A patient functional outcome measure should be administered in a standard way across CSR programs. This includes time and frequency of administration. Instances where the outcome measure was not administered as prescribed should be reported.
- c. Therapists should use valid, standardized, discipline-specific outcome measures to measure and monitor patient goals and progress, as recommended in the Canadian Stroke Best Practices for Rehabilitation ([CSBPR Table 1](#))
- d. NACRS Clinic Lite and HCD should introduce mandatory data fields to report patient functional outcome measure results, as required by recommendations 4.a and 4.b above.
 - i. Additional, optional data fields should be made available for discipline-specific outcome measure result(s)

² In 2014, the SEQC Outpatient Indicators Working Group recommended the following outcome measures: 1) Outpatient Therapy Core Outcome Instrument (CORE), a FIM™-based tool.; 2) the RNLI, 3) the COPM©, and 4) re-admissions and re-visits to the ED.

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Glossary and Acronyms

ADL	Activities of Daily Living (e.g. eating, dressing, mobility etc.)
CIHI	Canadian Institute for Health Information (An independent, national organization that collect and reports data and information to improve the health system. They have developed several data collection systems including NACRS clinic lite and National Reporting System (NRS))
CHRIS	Client Health and Related Information System (A web-based patient information management system designed and built by the HSSO, that supports and coordinates the delivery of care in the home)
CorHealth Ontario	Provincial Organization with mandate that spans across stroke, cardiac and vascular care. CorHealth provides leadership across stakeholders to improve and advance stroke care.
CSR	Community Stroke Rehabilitation (For the purposes of this project, “Community Stroke Rehabilitation” or “CSR” refers to stroke programs delivered as outpatient, in-home, and hybrid (both in clinic and in home))
DAD	Discharge Abstract Database (captures administrative, clinical and demographic information on hospital discharges)
Data field	A single point of data input into a database (e.g. admission date, visit date, visit duration, visit modality)
Early supported discharge (ESD)	Designed to accelerate the transition from hospital to home through the provision of rehabilitation therapies delivered by an interdisciplinary team, in the community (outpatient or in-home), as soon as possible following discharge. Services should be provided five days per week at the same level of intensity as what would have been received in the inpatient setting
HCC	Home and Community Care (Provides health care services at home and in the community, delivered by the LHIN)
HCD	Home Care Database (Data source that contains demographic, administrative, and some clinical and service data for everyone receiving services from the Local Health Integration Networks (LHINs) in Ontario)
HSF	Heart and Stroke Foundation (a leading funder of life-saving research. HSF’s work is driven by collaboration — with our volunteers and donors, researchers, people who have lived experience, healthcare professionals, governments and others)
HSSO	Health Shared Services Ontario: (Agency of the Government of Ontario that supports Ontario's 14 LHINs in meeting the health care needs of their local communities. Oversees Ontario digital health platform of CHRIS)

Indicator (also called metric)	A measure using two or more “data fields” in its calculation (e.g. LOS, number of visits, wait time)
LHIN	Local Health Integration Network (There are 14 LHINs across Ontario. These are crown agencies that plans, integrates and funds local health care as well as delivers and coordinates HCC)
LOS	Length of Stay
MDS	Minimum Data Set (A coherent set of explicitly defined data elements designed to optimally represent and capture data at the microsystem, meso and macrosystem level)
MIS	Management Information System (Collecting and reporting of financial and statistical data on the day-to-day operations of health service organizations)
MoH	Ministry of Health
MOHLTC	Ministry of Health and Long-Term Care
NACRS Clinic Lite	National Ambulatory Care Reporting System Clinic Lite (A low-cost, low-burden data collection and reporting option for Canadian ambulatory clinics. Has been endorsed by the MOH for the Hip and Knee Bundled Funding for sites providing outpatient/ambulatory rehabilitation. Not in use for Stroke yet)
NRS	National Reporting System (Collects data from participating adult inpatient rehabilitation facilities and programs across Canada)
NRS Rehabilitation on Time	The amount of time the patient spends in individual, goal-directed rehabilitation therapy, focused on physical, functional, cognitive, perceptual and social goals to maximize the patient’s recovery, over a seven day/week period. It is time that a patient is engaged in active face-to-face treatment, which is monitored or guided by a therapist” This is captured for OT, PT, S-LP, OTA, PTA and CDA. Reference: The Rehabilitation Intensity definition was developed through literature review, expert consensus, and stakeholder engagement by the Stroke Reference Group, and was approved by the Ontario Stroke Network
OHT	Ontario Health Team (introduced in Ontario to provide a way of organizing and delivering care that is more connected to patients in their local communities. Teams will consist of health care providers (including hospitals, doctors and home and community care providers) who work as one coordinated team - no matter where they provide care)
Outcome measures	<i>Discipline specific outcome measures:</i> Chosen and administered by clinician as part of the clinical assessment to measure and monitor patient goals and progress. These often address a specific body function/structure (e.g. MOCA, PHQ-9 etc.) or activity

	domains (e.g. Berg Balance Scale, FIM™) <i>Functional patient outcome measures:</i> designed to be administered to <u>all</u> patients serviced by CSR program quantifiable measure of the effect of the treatment on patient recovery. In addition to body function and activity, it also tends to address participation domain (e.g. COPM©, RNLI, SIS)
RCA	Rehabilitative Care Alliance (Organization who works with partners across the province to strengthen and standardize rehabilitative care in Ontario)
RDAC	Regional and District Advisory Committee (A group of clinical experts comprised of front-line clinicians and Regional Stroke Network representatives from across the 11 Regional Stroke Networks)
Regional Stroke Network	There are 11 stroke networks in Ontario providing leadership and planning to implement best practice stroke care across the continuum of care.
Special project field or code	Where extra data fields are added to a data system, to supplement the data already being collected

Common Outcome Measures used in CSR Evaluation:

BCOS	Bakas Caregiving Outcomes Scale
CACS	Caregiver Assistance and Confidence Scale
COPM©	Canadian Occupational Performance Measure
FIM™	Functional Independence Measure
HADS	Hospital Anxiety and Depression Scale
InterRAI	Resident Assessment Instrument (A “core” set of assessment items considered important in all care settings. These items have identical definitions, observation time frames, and scoring. Additional items specific to a particular care population or care setting are then added to the core item set)
PHQ-9	Patient Health Questionnaire -9
PREM	Patient Reported Outcome Measure (Captures the patient’s perception of their experience with health care or service)
PROM	Patient Reported Experience Measure (Measures of health information that capture the patient’s perception of their own health status)
RNLI	Return to Normal Living Index
SIS	Stroke Impact Scale

Allied Health Professional by Discipline:

OT	Occupational Therapist
OTA	Occupational Therapist Assistant
PT	Physiotherapist
PTA	Physiotherapist Assistant
S-LP	Speech Language Pathologist
CDA	Communication Disorders Assistant
SW	Social Worker

Infographic

The following full page infographic can be used as a supporting document and has been formatted to print as a standalone page.



Establishing a Foundation for Sustainable Community Stroke Rehabilitation Evaluation in Ontario



Community Stroke Rehabilitation (CSR) provides specialized stroke rehabilitation in outpatient and in-home settings that has resulted in a positive impact on patient recovery and health system performance (e.g. decreased inpatient stay).

Currently wide variability exists in CSR data collection and program evaluation methods. Standardized evaluation of CSR is required to support health system planners and providers to make improvements and ensure optimal patient outcomes.

Summary of Recommendations

Stroke Stakeholders need the Ministry of Health to facilitate a data reporting infrastructure to enable standardized data to be reported to centralized databases to support the evaluation of CSR in Ontario.

Implementation of these recommendations moves the system towards a credible and core baseline data set that can evolve to meet evaluation needs.

Data collection system in place for all CSR stroke patients



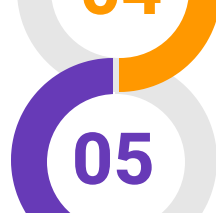
Standard minimum data fields and definitions across ALL CSR programs including virtual care elements



Standard number of indicators for all CSR programs



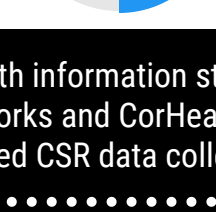
Include identification of patients specifically enrolled in a CSR program



CSR programs should have adequate resources for evaluation



One patient functional outcome measure in all CSR programs



The expertise of several program and health information stakeholders is needed to advance this work collaboratively with the Regional Stroke Networks and CorHealth Ontario. A focused and collective effort is needed to implement coordinated CSR data collection and evaluation in Ontario.