



CANADIAN STROKE BEST PRACTICE RECOMMENDATIONS

Rehabilitation, Recovery and Community Participation following Stroke

Part Two: Transitions and Community Participation Following Stroke

Update 2019

Anita Mountain, Jill I Cameron (Writing Group Chairs) and the Canadian Stroke Best Practice Recommendations Transitions and Community Participation following Stroke Writing Group: Naresh Bains, Rebecca Bowes, Donna Cheung, Helene Corriveau, Lynn Joseph, Dana Lesko, Ann Millar, Beena Parappilly, Aleksandra Pikula, David Scarfone, Annie Rochette, Trudy Taylor, and Tina Vallentin. In collaboration with the Canadian Stroke Consortium and the Canadian Partnership for Stroke Recovery

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Part Two: Transitions and Community Participation following Stroke Sixth Edition (Updated 2019)

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INTRODUCTION AND OVERVIEW

Introduction to the Canadian Stroke Best Practice Recommendations

The *Canadian Stroke Best Practice Recommendations (CSBPR)* are intended to provide up-to-date evidence-based guidelines for the prevention and management of stroke, and to promote optimal recovery and community participation for people with stroke, their family and caregivers. The *CSBPR* are under the leadership of Heart & Stroke. They are intended for use by all members of the interdisciplinary team members who, together, care for people with stroke across the continuum from prevention and symptom onset to long term recovery. These best practice recommendations address issues relevant to all stroke types, including acute ischemic stroke, transient ischemic attack, intracerebral hemorrhage and subarachnoid hemorrhage.

The theme of the Sixth Edition of the *CSBPR* is **Partnerships and Collaborations**. This theme stresses the importance of integration and coordination across the healthcare system to ensure timely and seamless care of people with stroke to optimize recovery and outcomes. Working with people with stroke, their family and caregivers, stroke experts, emergency medical services, other vascular care groups, community care providers, educators and researchers will strengthen our ability to reduce risk factor prevalence and mortality from stroke. This theme also includes consideration of people with stroke who may also have multiple comorbidities such as heart conditions, as well as collaborations to support stroke care in rural and remote settings.

The goal of disseminating and implementing these recommendations is to optimize stroke care across Canada, reduce practice variations in the care of people with stroke, and close the gap between current knowledge and scientific evidence and clinical practice.

Heart & Stroke works closely with national and provincial stakeholders and partners to develop and implement a coordinated and integrated approach to stroke prevention, treatment, rehabilitation, and community participation in every province and territory in Canada. The *CSBPR* provides a common set of guiding principles for stroke care delivery, and describes the infrastructure necessary at a system level, as well as the clinical protocols and processes that are needed to achieve and enhance integrated, high-quality and efficient stroke services for all people in Canada. Through the innovations embodied within the stroke best practices, these guidelines contribute to health system reform in Canada and internationally.

The *CSBPR* are developed and presented within a continuous improvement model and are written for health system planners, funders, administrators, and healthcare professionals, all of whom have important roles in the optimization of stroke prevention and care and who are accountable for results. A strong stroke research literature base is drawn upon to guide the optimization of stroke prevention and care delivery. Several implementation tools are provided to facilitate uptake into practice and are used in combination with active professional development programs. By monitoring performance, the impact of adherence to best practices is assessed and the results are then used to direct ongoing improvement. Recent stroke quality monitoring activities have compelling results which continue to support the value of adopting evidence-based best practices in organizing and delivering stroke care in Canada.

Profile of Stroke Care in Canada:

- Every year, approximately 62,000 people with stroke and transient ischemic attack are treated in Canadian hospitals. Moreover, it is estimated that for each symptomatic stroke, there are approximately nine covert strokes that result in subtle changes in cognitive function and processes.
- Stroke and other cerebrovascular diseases are the third leading cause of death in Canada and the second leading cause of death globally. While the number of deaths from stroke is decreasing in North America and parts of Europe, it is increasing in most other countries.
- Stroke is a leading cause of adult disability, with more than 400,000 people in Canada living with the effects of stroke.
- More than half the people who experience a stroke require some amount of assistance in daily activities during recovery.
- The annual cost of stroke is approximately \$3.6 billion, considering both healthcare costs and lost economic output.
- The combined Canadian healthcare system costs and out-of-pocket caregiver costs for dementia amounted to \$10.4 billion in 2016. By 2031, this figure is expected to increase to \$16.6 billion ^a
- The human cost of stroke is immeasurable.

Rehabilitation, Recovery and Community Participation following Stroke:

Part Two: Transitions and Community Participation Following Stroke Module Overview

Successful transitions and community participation following stroke requires integrated and coordinated person-centred efforts by all members of care teams involved with people who have had a stroke, their families and caregivers, and the broader community. The primary underpinnings of **Partnerships and Collaborations** in stroke transitions of care are to provide person and family-centered care across all transition points, and to ensure effective and efficient transfers of care and information to the next stage and setting of care. Careful monitoring and efforts to meet the needs of people throughout recovery from stroke are essential components to delivering a coordinated and seamless system of care that supports progress achieved during the initial recovery stages and enables people to successfully resume life roles and leisure activities.

In Canada, one-third of people with stroke, usually with TIA and milder strokes, are discharged back to the community directly from the emergency department. Of those individuals admitted to acute inpatient care, 42% will be discharged to their homes independently, and an additional 17% will be discharged home with arrangements for home care services, 16% will be transferred to an inpatient rehabilitation service, 10% will be transferred to long-term care or complex continuing care, and 13% will be transferred to another acute care facility (usually back to community hospital from a tertiary hospital) (HSFC Stroke Technical Report 2019). Ultimately most people who survive a stroke will return to the community, to live independently or with varying degrees of support. Their physical, emotional, psychological, social and environmental needs are considered throughout this set of CSBP recommendations.

^a Public Health Agency of Canada. Mapping connections: an understanding of neurological conditions in Canada: the National Population Health Study of Neurological Conditions. Ottawa (ON): Public Health Agency of Canada; [modified 2014 Dec 09; cited July 30, 2015]. <http://www.phac-aspc.gc.ca/publicat/cd-mc/mc-ec/index-eng.php>.

All members of the healthcare team engaged with people with stroke and their families are responsible for **partnerships and collaborations** to ensure successful transitions and return to the community following stroke. This responsibility also extends to caregivers. Caregivers are essential members of the circle of care, providing many forms of support and direct care following discharge from hospital. The needs of a caregiver with serious health issues, a relatively typical situation among older spouses, may be quite different and require more intensive intervention in order to ensure appropriate support for the person recovering from stroke.

Key components of successful transitions and community participation include:

- ✓ Collaborative goal setting between the healthcare team, people with stroke and their families, where there is active participation in discussions, planning, and shared decision-making
- ✓ Ongoing education for people with stroke, their families and caregivers that reinforces key information and verifies understanding, regardless of setting; education should take place in the emergency department, primary care, acute inpatient care (regardless of location within the hospital), rehabilitation services, outpatient and community settings
- ✓ Skills training appropriate to individual needs and goals – for both people with stroke and their families and informal caregivers - to facilitate safe transitions
- ✓ Discharge planning that begins soon after stroke admission and includes the coordination of all relevant support services, such as home assessments and access to ambulatory and community-based rehabilitation
- ✓ Transition planning that includes the provision of a comprehensive resource list and ensuring that people with stroke, their families and caregivers are aware of stroke and community services
- ✓ Ongoing assessment of family and caregiver capacities to provide care for the person with stroke, their individual support needs and potential burden of care
- ✓ Timely transfer of medical and recovery information between stages and settings of care
- ✓ Appropriate medical support by primary care physicians and community team members, as well as stroke team members and stroke prevention services
- ✓ Access to full scope of rehabilitation services within the community
- ✓ Stroke navigators or case managers in place to facilitate transitions of care and ensure continuity of care across settings, as well as appropriate access to needed resources and services
- ✓ identification of and linkages to community resources, long-term care and home-based care
- ✓ Accessible transportation and options for driver's licensing
- ✓ Ongoing surveillance of physical, psychological, social and emotional recovery, coping and adaptation following discharge from inpatient acute care and rehabilitation settings.

A coordinated and seamless system taking all these components into account will minimize challenges and complications when transitioning between stages and settings for stroke care, and lead to better recovery outcomes, and increased participation in daily activities, self-management and the resumption of life and social roles. Stroke case managers and/or stroke system navigators are valuable additions to the stroke care team, and where resources permit, should be made available to the person with stroke, their family and caregivers. Stroke navigators empower people to be involved in their own care, build self-management skills and confidence, and aid in access to community resources, support groups and linkages. Providing supports such as navigators may reduce the burden to the health system and to health care professionals providing reactive care.

Partnerships and Collaborations in the area of stroke care transitions is also directed to researchers and research funding organizations. The body of evidence for many of the topics addressed in this module is based on observational studies, small qualitative research initiatives, observational studies and cohort studies. Randomized controlled trials and systematic reviews are lacking in this area of stroke management. Despite the lower levels of evidence, the topics covered in this module have high importance for people who experience a stroke, their families and caregivers, and are therefore presented based on moderate evidence and expert opinion. Where evidence is not available, clinical considerations have been included to draw attention to important aspects of care and provide guidance based on the expert opinion of leading care providers and researchers in this field.

Definitions and Descriptions

Transition refers to the movement of people across various healthcare locations, settings, and providers.

Transition management includes working with persons with stroke, their families, and caregivers to establish and implement a transition plan that includes goal setting and has the flexibility to respond to evolving needs. Successful transition management requires transfer of accountability through interdisciplinary collaboration and handover between healthcare providers, persons with stroke, their families, and caregivers. It encompasses the organization, coordination, education, and communication required as people move through the stages and settings for stroke treatment, recovery, reintegration, adaptation, and end-of-life care. Note that a transition plan includes discharge planning.

The goal of transition management is to facilitate and support seamless movement across the continuum of care, and to achieve and maintain optimal treatment, outcomes, adaptation, and quality of life for persons with stroke, their families and caregivers. This incorporates physical, cognitive, emotional, environmental, financial and social factors.

Support for individuals, families and caregivers following stroke generally includes assisting with meeting *emotional* (e.g., providing comfort, listening to problems), *instrumental* (e.g., providing training, organizing services, helping with household chores), *informational* (e.g., providing information about illness and services), and *appraisal* (e.g., providing feedback about their caregiving activities) needs. In addition, support refers to providing direct care, access to required services, and facilitating linkages to resources to ensure that the needs of the individual, family and caregiver are met throughout the continuum of stroke care.

Support needs change across the illness and recovery trajectory and are most beneficial if it is closely matched to individuals' current needs. The goal of individual, family and caregiver support is to enable each person to manage their recovery or the recovery of after the person with stroke and optimize participation and fulfillment of life roles.

An **Advance Care Plan** is defined as written communication by a competent individual imparting their preferences regarding potential future healthcare decisions. These plans are to be referred to in the event of future incapacity of said individual.

An advance care plan can involve two key factors: "Instructional Directives" and "Proxy Directives". According to the Health Law Institute¹:

"Instructional directives state what (or how) health care decisions are to be made when you are unable to make these decisions yourself. This type of directive may set out specific instructions or it may set out general principles to be followed for making your health care decisions. Instructional advance directives are also known as 'living wills'. Proxy directives specify who you want to make decisions for you when you are no longer able to make the decisions yourself" (Health Law Institute, 2018). This designation is also known as 'power of attorney' or 'substitute decision maker'.

Caregiver refers to a family member or friend who is unpaid and involved in the care of a person who has had a stroke across their illness and recovery trajectory. They assist with many aspects of care including activities and instrumental activities of daily living, attending to health care needs, supporting emotional needs, advocacy, rehabilitation, and community re-integration and resuming life roles. As an integral member of the care team, they need to be recognized and supported in their caregiving role and their capacity to provide the many facets of care.

Case Managers enable people, their families, and caregivers to maintain and achieve their highest

level of functioning and independence. Case managers maintain an ongoing assessment process, which involves identifying the changing needs of the person and helps to facilitate optimal outcomes. They oversee, coordinate, and integrate the delivery of care. Case managers possess the knowledge, skill, and judgement to ensure that people receive the highest possible quality of care when they need it.

Community is defined as the physical and social care environment where individuals may live after having a stroke. It includes any non-hospital setting, where one would reside and resume life roles and activities following a stroke such as a family home, assisted living facility, long-term care, or other residential settings.

Community Reintegration involves return to participation in desired and meaningful instrumental activities of daily living, community interests and life roles following a stroke. The term encompasses the return to active community living and contributing to one's social groups and family life. Community reintegration is a component in the continuum of stroke care; rehabilitation includes identifying meaningful goals for community reintegration and through structured interventions facilitates resumption of these activities to the best of the persons abilities. The person with stroke, their family, friends, caregivers, stroke recovery associations, rehabilitation programs and the community at large are all integral to successful community reintegration.

Community-based care programs are services and programs that are based in the community, in the home of the person receiving services, or in group living situations (Canadian Centre for Accreditation).

Home Care is defined as providing medical, nursing, rehabilitation and personal care services to people in a home setting rather than in a medical facility. Home care services enable people to remain safely in their home by continuing their rehabilitation therapy and increasing their independence.

Long-term care is the provision of organized institutional care for three or more unrelated people in the same place. Long-term care is provided for people of all ages who need assistance with the activities of daily living (ADL) in order to enjoy a reasonable quality of life. The need for long-term care following a stroke may be due to changes in physical, psychological and/or cognitive abilities. The goal of long-term care is to ensure that an individual who is not fully capable of self-care can maintain the best possible quality of life, with the greatest possible degree of independence, autonomy, participation, personal fulfilment and human dignity.

The need for long-term care following a stroke is influenced by changing physical, psychological and/or cognitive functional capacities, their abilities and level of independence prior to the stroke, and the availability of family and caregivers. Many people may regain lost functional capacities over a shorter or longer period of time following stroke, while others decline. The type of care needed, and the duration of such care are thus often difficult to predict.

Self-management refers to the ability of individuals to manage their health following a stroke to optimize rehabilitation and prevent recurrent stroke. It includes knowledge, skills, attitudes and behaviours to enhance self-efficacy for managing physical, cognitive and lifestyle changes. It involves active participation of the individual, families and caregivers and may include a plan developed collaboratively with healthcare providers.

Stroke Navigators are individuals who provide holistic case management support and guidance to people with stroke and their families, friends, and caregivers. Navigators provide guidance throughout the stroke recovery experience to help improve the quality of life through education and improved access to, and/or coordination of, healthcare services as well as other needed resources.

Supported Living Environments refers to residential living locations where individuals may transition following stroke, and where they continue to receive healthcare services within a coordinated and organized system. The levels of support and service received are dependent on the individual's physical and cognitive abilities and ongoing health care needs, as well as available support from family members and caregivers. Supported living environments are settings where individuals can maintain as much control over their lives as possible, while receiving the supports they need to maintain their health and safety.

Supportive living environments may include a range of settings and support service levels, such as: a private home or residence where health care services are provided; group settings such as lodges, transitional care or respite centres where the person with stroke resides with others with similar care and support needs; assisted living settings where the individual has a private room(s) within a residential setting and access to personal care support, group meals, organized social activities, and transportation.

Training refers to collaborative activities aimed at acquiring knowledge and skills necessary for the person with stroke, families and caregivers.

Notable Changes in Transitions and Community Participation Following Stroke 2019 Update

The 2019 update of the *CSBPR* Transitions and Community Participation following Stroke module reinforces the growing and changing body of research evidence available to guide ongoing screening, assessment and management of persons with stroke, their families, and caregivers to ensure they move from one phase and stage of care to the next without 'falling through the cracks' or 'getting lost out of the system'.

The Canadian Stroke Best Practice Recommendations (CSBPR) Transitions and Community Participation following Stroke 2019 Sixth Edition module supersedes all recommendations contained in the CSBPR Managing Stroke Transitions of Care 2015 Fifth Edition module.

Highlights of the moderate and significant updates as well as new additions to Transitions and Community Participation Following Stroke module recommendations for 2019 include:

- ✓ Addition and revision of comprehensive recommendations for community participation and resuming life roles following stroke. This section addresses the rehabilitation and community participation aspects of issues including return to driving, vocational roles, leisure activities and relationships and sexuality.
- ✓ New clinical considerations have been added to each section, acknowledging emerging therapies and consensus-based practices.
- ✓ Emphasis on the need to include social rehabilitation as an important component of assessments and interventions
- ✓ Inclusion of recommendations that discuss the involvement of Telestroke in transitions of outpatient and community-based care.

Guideline Development Methodology

The *CSBPR* present high-quality, evidence-based stroke care guidelines in a standardized framework to support healthcare professionals across all disciplines. Implementation of these recommendations is expected to reduce practice variations and close the gaps between evidence and practice.

The recommendations are targeted to health professionals throughout the health system who care for those affected by stroke. Health system policy makers, planners, funders, senior managers, and administrators who are responsible for the coordination and delivery of stroke services within a province or region will also find this document relevant and applicable to their work.

The methodology for updating the recommendations includes 14 distinct steps to ensure a thorough and rigorous process. These include the following (details available online):

1. Establish an expert interprofessional writing group representing relevant disciplines across the continuum of care and range of settings ([Appendix One](#));
2. Establish Community Consultation and Review Panel comprised of people with lived experience, including people with stroke, caregivers and family members;
3. Systematic search, appraisal and update of research literature up to May 2019;
4. Systematic search and appraisal of external reference guideline recommendations;
5. Create and or update of evidence summary tables;
6. Writing group review and revision of existing recommendations, development of new recommendations as required, adhering to all elements defined within the Agree 2 criteria where appropriate. Please see <https://www.agreetrust.org/resource-centre/agree-ii/> for more information.
7. Writing group review and revision of existing recommendations, development of new recommendations as required, then final voting to achieve consensus;
8. Submission of proposed module update to the;
9. Internal review of proposed module update by the Canadian Stroke Best Practice and Quality Advisory Committee.
10. External review by leading experts in Canada and internationally, and final edits as required ([Appendix One](#));
11. Update of educational materials and implementation resources;
12. Final approvals, endorsement and translation of chapter;
13. Publication, public release and dissemination of final module update;
14. Continue with ongoing review and update process.

The detailed methodology and explanations for each of these steps in the development and dissemination of the *CSBPR* is available in the *Canadian Stroke Best Practice Recommendations Overview and Methodology* manual available on the Canadian stroke best practices website at <https://www.strokebestpractices.ca/recommendations/overview-methods-and-knowledge-exchange>

Management of Conflicts of Interest within CSBPR: All potential participants in the recommendation development and review process are required to sign confidentiality agreements and to declare all actual and potential conflicts of interest in writing prior to participation. Any conflicts of interest that are declared are reviewed by the Chairs of the CSBPR Advisory Committee and appropriate Heart & Stroke staff members for their potential impact. Potential members of any writing group who have conflicts that

are considered to be significant with respect to the topics within the module of interest are not selected for writing group or reviewer roles. Participants who have conflicts for one particular topic area are identified at the beginning of discussions for that topic and are recused from voting. If the persons in conflict are one of the cochairs then they are recused from chair responsibilities for that discussion, and another non-conflicted participant assumes the chair role for that discussion and voting to ensure balanced and unbiased discussions. Heart & Stroke senior staff members, who do not have any conflicts of interest, participate in all writing group discussions and will intervene if there is any perceived untoward bias by a writing group member. Declarations of Conflict of interest for writing group members can be found in [Appendix One](#).

Assigning Evidence Levels: The writing group was provided with comprehensive evidence tables that include summaries of all high-quality evidence identified through the literature searches. The writing group discusses and debates the value of the evidence and through consensus develops a final set of proposed recommendations. Through their discussions, additional research may be identified and added to the evidence tables if consensus on the value of the research is achieved. All recommendations are assigned a level of evidence ranging from A to C, according to the criteria defined in Table 1. When developing and including “C-Level” recommendations, consensus is obtained among the writing group and validated through the internal and external review process. This level of evidence is used cautiously, and only when there is a lack of stronger evidence for topics considered important system drivers for stroke care (e.g., transport using ambulance services or some screening practices). An additional category for Clinical Considerations has been added for the Sixth Edition. Included in this section are expert opinion statements in response to reasonable requests from a range of healthcare professionals who seek guidance and direction from the experts on specific clinical issues faced on a regular basis in the absence of any evidence on that topic.

Table 1: Summary of Criteria for Levels of Evidence Reported in the *Canadian Best Practice Recommendations for Stroke Care (Sixth Edition)*

Level of Evidence	Criteria*
A	Evidence from a meta-analysis of randomized controlled trials or consistent findings from two or more randomized controlled trials. Desirable effects clearly outweigh undesirable effects or vice versa.
B	Evidence from a single randomized controlled trial or consistent findings from two or more well-designed non-randomized and/or non-controlled trials, and large observational studies. Meta-analysis of non-randomized and/or observational studies. Desirable effects outweigh or are closely balanced with undesirable effects or vice versa.
C	Writing group consensus on topics supported by limited research evidence. Desirable effects outweigh or are closely balanced with undesirable effects or vice versa, as determined by writing group consensus.
Clinical Consideration	Reasonable practical advice provided by consensus of the writing group on specific clinical issues that are common and/or controversial and lack research evidence to guide practice.

* (adapted from Guyatt et al. 2008) [12]

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Community Consultation and Review Panel (CCRP) Members

H&S is especially grateful to the members of the Community Consultation and Review Panel who reviewed all sections of this module, shared their personal experiences and insights on what did or would have made their journey optimal. The members of the Rehabilitation, Recovery and Community Participation CCRP included: Steve Archer, Rob Claydon, Debbie Chow, Daniel Franco, Amanda Horner, Bruce Hughes, Edith Lambert, Cathy Livingstone, David Livingstone and Michelle McGroty.

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Citing the Transitions and Community Participation Following Stroke 2019 Module

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The recommendations included in this module are also published in the International Journal of Stroke:

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Comments

We invite comments, suggestions, and inquiries on the development and application of the *CSBPR*. Please forward comments to the Stroke Team at Heart & Stroke: strokebestpractices@heartandstroke.ca.

CANADIAN STROKE BEST PRACTICE RECOMMENDATIONS

Rehabilitation, Recovery and Community Participation following Stroke

Part Two: Transitions and Community Participation following Stroke Sixth Edition (Updated 2019)

Note about Assignment of Levels of Evidence:

The authors recognize that for many of the topics and associated recommendations for transitions of care, reintegration and community participation, there is a paucity of Level A evidence. Randomized controlled trials are difficult to conduct in this area of care, and the evidence for most of the following recommendations is based on qualitative and observational studies and expert opinion. The language used in these recommendations may appear less congruent with the assigned levels of evidence. This has been done purposefully as people with stroke, families and caregivers have expressed, both through formal and informal assessment, that transitions in care represent some of the greatest challenges faced after stroke. Although the evidence is ongoing, the needs are real and our goal is to raise awareness and attention to these areas. The CSBPR are responsive to this need; the inclusion of these recommendations is intended to facilitate a holistic approach to person and family-centred care to promote optimal outcomes, as well to highlight the importance of further research into this important aspect of stroke care.

Section 1: Supporting People with Stroke, their Families and Caregivers

Recommendations

1.0 Persons with stroke, their families and caregivers, should be assessed and prepared for transitions between care stages and settings through information sharing, provision of education, skills training, psychosocial support, awareness of and assistance in accessing community services and resources [Evidence Level B]. Interventions must be person- and family-centered and tailored to their individual values and needs [Evidence Level C].

1.1 Screening and Assessment

- i. People with stroke, their families and caregivers, should be **screened** for their level of coping, risk for depression, and other physical and psychological issues [Evidence Level B]. Ideally screening should take place at each transition and additionally when indicated. *For additional information, refer to the following CSBPR modules: [Mood, Cognition and Fatigue following Stroke](#); [Rehabilitation and Recovery following Stroke](#); and [Acute Stroke Management](#).*
 - a. Validated screening tools or approaches can be used whenever possible to ensure a consistent approach to identifying potential issues during transitions [Evidence Level C]. *Refer to [Appendix, Table 1: Tools to Assess Participation and Health-Related Quality of Life](#).*
- ii. People with stroke, their families and caregivers, should undergo **in-depth assessment** to determine readiness for education and ability to integrate knowledge, training, and psychosocial support, and ability to access appropriate health information and social services [Evidence Level B]. *Refer to [Section 2](#) for additional recommendations on education and training.*

- a. Consider assessment of the following issues as they relate to a family member's or caregiver's ability to care for the person with stroke:
 1. Current health status, employment and social responsibilities, and how those will be managed in providing stroke care [Evidence Level B];
 2. Capabilities and experience in providing care to the person affected by stroke [Evidence Level C];
 3. Resource issues such as financial situation, housing, transportation, insurance, healthcare benefits, medication cost coverage [Evidence Level C];
 4. Support from other family members, relatives and social networks [Evidence Level C];
 5. Ability to cope and manage the added stress of caring for another person following stroke [Evidence Level C].
- b. The type and depth of assessments should be appropriate to the individual person's needs, issues identified during screening, and stage of transition [Evidence Level C].
- iii. When issues are identified through screening and assessments, referrals to appropriate experts and services to address issues and optimize outcomes should be made for people with stroke [Evidence Level B], their families and caregivers [Evidence Level C].

1.2 Supporting People with Stroke, Their Families and Caregivers

- i. Support should be initiated from the onset of stroke and continue throughout all transitions and stages of care. [Evidence Level B].
- ii. The use of telemedicine (e.g., video, and web-based technologies and services such as web-based support groups, tele-rehabilitation), should be considered to increase access to ongoing support services, healthcare services and rehabilitation therapies following transitions to the community; especially in settings where people with stroke and their family members are unable to travel to access care and services [Evidence Level B]. [Refer to CSBPR Telestroke Toolkit for additional information](#)
- iii. People with stroke, their families and caregivers should be provided with information about peer support groups in their community where available, descriptions of the services and benefits they offer, and be encouraged to consider participation [Evidence Level C].

Box One: Transitions of Care Checklist

This checklist is provided as a guide to help ensure evidence- and consensus- based recommendations are applied to develop a collaborative action plan for each person as they transition to different settings and phases of care.

This checklist is applicable to primary care, the emergency department, acute care, rehabilitation settings, complex care/transitional bed settings, long-term care and community settings. The transitions of care checklist should enable the health care team member to work with the person with stroke and their family to have meaningful dialogues regarding necessary information and services to ensure positive and successful care transitions.

Support for people with stroke, families and caregivers may include:

- Shared decision making/participation regarding transitions across stages of care.
- Accurate and up to date information about the next care setting, what can be expected, and how to prepare.
- Access to restorative care and active rehabilitation to improve and/or maintain function based on the individualized care plan.

- Advance care planning, palliative care and end-of-life care as applicable.
- Counseling, preparation and ongoing assessment for adjustment to change of: living setting; abilities; social roles and relationships; participation, leisure and vocational activities; and, home environment. Also consider impact on family (e.g., spouse or partner, children); potential resource issues (financial), and independence (e.g., driving).
- Written discharge instructions and recommendations should be included in collaborative action plans, and include goals and follow-up care.
- Access to a designated contact person in the hospital or community for continuity of care and questions.
- Access to and advice from health and social service organizations appropriate to needs and stage of transition and recovery.
- Links to and information about local community agencies such as stroke groups, peer visiting programs, meal provider agencies, and other services and agencies.
- Where possible, access to peer supports who have had a stroke and experienced transitions following the acute phase.
- All communications should be available in aphasia-friendly formats as required and appropriate to the health literacy of people with stroke, their families and caregivers.

Rationale

This recommendation supports the following goals: to emphasize the need for a holistic approach to care; to help people with stroke, families and caregivers to navigate the healthcare system, particularly following the initial acute stage of stroke care; to define the various components of support; to focus on persons with stroke and their families, highlighting the person with stroke and family-centered care approach; and to address needs beyond the physical impact of stroke.

Stroke is a life-altering event that may require an extended recovery period and often leaves persons with stroke with ongoing functional impairments. It also has an impact on others close to the person with stroke, as increasingly, families and caregivers are expected to assume roles, tasks and responsibilities that may be beyond their current skills and knowledge or beyond their physical, financial or time resources. This increases the caregiver burden, which can result in depression among caregivers of persons with stroke (as high as 60 percent has been reported). Similar post-stroke depression rates occur in persons with stroke and are linked to poorer recovery outcomes.

Increased screening, assessment and surveillance of person with stroke, family and caregiver needs and coping will provide a holistic person- and family-centered approach to stroke care and optimally lead to better outcomes and adaptation.

System Implications

Care transitions take place across the stroke continuum, including primary care, the emergency department, acute care, rehabilitation settings, complex care/transitional bed settings, long-term care and community settings. Processes and mechanisms should be in place in all these settings to address persons with stroke, family and caregiver support using an individual approach, including:

- Protocols to involve persons with stroke and families in healthcare team transition planning meetings and collaborative decision-making regarding goal setting at all transition points.
- Resources and mechanisms to plan and deliver community-based services which consider the needs of the person with stroke and family/caregiver (e.g., home care services, psychological support).
- Models of care that include technology such as telemedicine, regular telephone follow-up and web-based support.
- Appropriately resourced hospitals, rehabilitation facilities, home care services, long-term care and other community facilities that care for persons with stroke, with identified contact people and case managers/system navigators to coordinate manage stroke care transitions.
- Ongoing education and training of healthcare professionals on person- and family-centred stroke care in all settings that care for persons with stroke.
- Opportunities for education and training for persons with stroke, families and caregivers to provide peer support when requested.
- Access to self-management support services through telemedicine technologies, especially in rural areas and where there are local resource gaps.

Performance Measures

Clinical and Health System Performance Measures

1. The number and proportion of persons with stroke diagnosed with post-stroke depression, measured at each transition point as a proportion of all persons with stroke.
2. The number and frequency of persons with stroke readmitted to an emergency department or acute inpatient care for reasons related to physical decline or failure to cope, following an initial stroke hospital stay.

Person-Oriented Measures (PREMS, PROMS)

3. The change in burden of care for family members and caregivers measured at transition points throughout the recovery period and following changes in person with stroke health status.

Measurement Notes

- Standardized and validated measures of depression and caregiver burden should be used to track occurrence and changes to these areas.
- Failure to cope diagnosis should be made based on appropriate ICD10 codes.
- Data on readmissions can be accessed through the Canadian Institute for Health Information NACRS and DAD databases.

Implementation Resources and Knowledge Transfer Tools

Health Care Provider Information

- Taking Action for Optimal Community and Long-Term Stroke Care: A resource for healthcare providers: available on www.strokebestpractices.ca

- Timing it Right (Cameron & Gignac 2008): <http://www.ncbi.nlm.nih.gov/pubmed/?term=18155388>
- RNAO Best Practice Guideline *Care Transitions*: <http://rnao.ca/bpg/guidelines/care-transitions>
- Registered Nurses' Association of Ontario Guideline: Person and Family-Centred Care: <http://rnao.ca/bpg/guidelines/person-and-family-centred-care>

Resources for People with Stroke, Families and Caregivers

- Rehabilitation and Recovery infographic: Guide to taking charge of your stroke recovery: <https://www.heartandstroke.ca/-/media/1-stroke-best-practices/rehabilitation-nov2019/csbp-infographic-rehabilitation.ashx>
- Transitions and community participation infographic: Guide to taking charge of your stroke recovery: <https://www.heartandstroke.ca/-/media/1-stroke-best-practices/transition-of-care-nov2019/csbp-infographic-transitions-and-participation.ashx>
- Your Stroke Journey: A guide for people living with stroke: <https://www.strokebestpractices.ca/-/media/1-stroke-best-practices/resources/patient-resources/en-your-stroke-journey-v21.ashx>
- Post-Stroke Checklist: <https://www.strokebestpractices.ca/resources/patient-resources>
- Heart & Stroke Services and Resources Directory: <https://www.heartandstroke.ca/services-and-resources>
- Living with Stroke™ program: <https://www.heartandstroke.ca/stroke/recovery-and-support/living-with-stroke>
- A Family Guide to Pediatric Stroke: <https://www.strokebestpractices.ca/resources/patient-resources>
- Canadian Partnership for Stroke Recovery Patient Resources: <https://www.canadianstroke.ca/en/tools-resources/patients>
- Stroke in Young Adults: <https://www.strokebestpractices.ca/resources/patient-resources>
- National Stroke Association: <https://www.stroke.org/>
- World Stroke Organization Stroke Support Site: <http://www.world-stroke.org/for-patients/stroke-support-organizations>
- Stroke Engine: www.strokingengine.ca

Summary of the Evidence

Following stroke, patients, families and informal caregivers are typically faced with multiple life changes and challenges as the person with stroke transitions between the stages of recovery. Gallacher et al. (2013) reviewed 69 qualitative studies examining the concept of patient burden following stroke, highlighting the impact it may have on the effectiveness of interventions and patient satisfaction with health care services. The authors identified the components of stroke recovery that were particularly burdensome to patients including receiving information, interacting with others, comparing treatment options, managing in different environments (acute care, inpatient rehabilitation, community, society) and adjusting to daily activities. Caring for a person following a stroke may also have a considerable impact on the health and vocational status of caregivers. Caregivers reported spending significantly longer periods of time providing caring for persons with stroke, relative to pre-stroke levels (Olai et al. 2015). Depression and anxiety may also be increased. Loh et al. (2017) estimated the prevalence of depressive symptoms and anxiety among stroke caregivers to be 40.2% and 21.4%, respectively. Hayes et al. (2009) conducted telephone interviews with 275 veterans who had sustained a first-ever stroke and their informal caregivers to explore the association between caregiver characteristics and

the development of injuries. Caregivers who reported a physical injury were more likely to report higher levels of burden, provided more hours of care per week, exhibited more depressive symptoms and fewer healthy days per month compared to carers reporting no injury. The most common type of injury reported was a back injury and 53% of injured carers stated that the injury interfered with their ability to provide care. Significant predictors of injury were higher caregiver burden (OR=1.62, 95% CI 1.14-2.31, $p=0.008$) and depression (OR=1.10, 95% CI 1.04-1.17, $p=0.001$). Ko et al. (2007) interviewed 132 caregivers and reported that while 52% were working full time or part-time, prior to the stroke, the majority of working caregivers reported reducing their hours of paid work, or missing work, while 9 caregivers retired or resigned. Rochette et al. (2007) reported that 6 months following stroke, 35.2% of spouses, of a sample of 54 had a high level of burden (Caregiver Strain Index score ≥ 7) and 17% were identified with possible depression (Beck Depression Inventory BDI score ≥ 10).

The needs of patients and their informal caregivers has been explored in several qualitative studies using in-person or telephone interviews. Similar themes emerged across studies. Cameron et al. (2014) included 16 patients recruited from an inpatient rehabilitation stroke facility and 15 informal caregivers, who were interviewed following their first weekend pass from inpatient rehabilitation and again 4 weeks following discharge home. Twenty health-care professional (HCP) were also interviewed. Three key themes emerged including issues surrounding preparing patients for safe return home. Patients discussed the need to feel safe in the home environment while caregivers discussed their need to feel supported. Assessing the patient for readiness was a key theme discussed by HCPs. Patients noted gaining insight into what life would be like, and caregivers evaluated their abilities to care for the person with stroke. Patients and caregivers discussed the range of emotions they experienced and how their experienced changes before and after the weekend pass. In a similar study including 24 informal caregivers to persons with stroke and 14 HCP (Cameron et al. 2013), the themes emerged from both the caregivers and the HCP concerned the type and intensity of support needed, who provides support and the method of providing support and the primary focus of care. Creasy et al. (2013) interviewed 17 family caregivers close to the point of discharge from hospital and the again within 4 months of discharge. In the first interview, caregivers expressed information needs related to their role as caregiver in preparation for discharge home and expressed concerns for their own emotional support needs and their ability to provide emotional support. During the second interview caregivers discussed their experiences with caregiver-provider interactions, some of which were positive, others, negative. The caregivers of 90 patients were interviewed one year following stroke (Smith et al 2014). Caregivers reported delays and barriers waiting for applications/funding for alterations to make the home more accessible, having to provide care in the immediate post-discharge period with no skills training and lack of follow-up with GPs. They also described difficulties coping with patients' quick anger and emotional lability and lack of attention to their physical and emotional ability to provide care.

The feasibility and effectiveness of telestroke has also been evaluated in the context of rehabilitation therapy, where it is often referred to as "telerehabilitation" or "telerehab". The results of these studies have been ambiguous. Chen et al. (2016) included the results of 7 RCTs that included patients who received rehab therapies through telemedicine systems for a minimum of 4 weeks in duration via virtual reality-based training, telephone, or the internet. There was no additional benefit associated with telerehab, compared to usual care. The mean Barthel Index scores, Berg Balance Scale scores and Fugl-Meyer (Upper Extremity) scores were similar between groups. A Cochrane review (Laver et al. 2013) included the results of 10 RCTs examining telerehabilitation. The number of trials which could be pooled were limited as the treatment contrasts and outcomes assessed were highly variable. Although the authors reported no significant differences between groups in upper-limb function or performance in ADL, they concluded that there was insufficient evidence to support or refute the effectiveness of

telerehabilitation following stroke. Chumbler et al. (2012, 2015) evaluated the effectiveness of a Stroke Telerehabilitation program (STeleR) among 52 veterans who had suffered a stroke within the previous two years. The intervention, which focused on improvement of functional mobility, included 3 components: 3x 1 hour televisits to the participant's home, 5 telephone calls and an in-home messaging device system to instruct patients on functional exercises and adaptive strategies. At 6 months, there were no significant differences in the primary outcomes, the Telephone Version of FIM, the Late-Life Function and Disability Instrument or Falls Efficacy Scale, between groups. There was a significant difference between groups, from baseline to 6 months, in the mean Stroke-specific Patient Satisfaction with Care Scale (hospital care sub score) at 6 months, favouring the STeleR group.

Supporting People with Stroke, their Families and Caregivers Evidence Tables and Reference List available at www.strokebestpractices.ca

Section 2: Education for People with Stroke, Their Families and Caregivers

Recommendations

2.0 Education for people with stroke, their families and caregivers, is an integral part of stroke care that should be included as part of all healthcare encounters, and during transitions [Evidence Level A]. Individualized educational needs change over time and may need reassessment and updating on an ongoing basis [Evidence Level B].

2.1 Assessment of Learning Needs

- i. Individualized learning needs and goals should be assessed and documented by members of the healthcare team [Evidence Level B]; and updated regularly as people move through the stages of care following stroke [Evidence Level B].

Note: This applies to all settings including ambulatory care and emergency departments where there is shorter interaction time and greater risk of learning needs being unmet.

2.2 Delivery of Education

- i. An individualized education plan should be developed and implemented based on the assessment of learning needs and goals of people with stroke and their families [Evidence Level B].
- ii. It is recommended that the individualized education plan:
 - a. Cover all relevant aspects of stroke care and recovery [Evidence Level A], and include content specific to level of readiness and setting and stage of care [Evidence Level B]. [Refer to Appendix Two, Table 2: Core Education across the Continuum for People with Stroke.](#)
 - b. Be goal-oriented and facilitate shared decision-making regarding care and recovery [Evidence Level B].
 - c. Include information sharing, teaching of self-management skills, and training of family and caregivers to participate in and provide safe stroke care [Evidence Level B].
 - d. Be interactive, evidence-based, accurate and available in a variety of languages and formats (e.g. written, oral, pictorial, instructive, and group counseling approaches); it should address varying levels of health literacy and be accessible for people with aphasia and cognitive deficits or impairments [Evidence Level A].
- iii. Education provided should be documented in the health record and accessible by all members of the healthcare team [Evidence Level B].
- iv. Assess and document understanding and retention of information regularly [Evidence Level A].
- v. Include reinforcement of information that has not been retained (e.g., medication information and management) [Evidence Level B].
- vi. Education and information for people with stroke, family and caregivers should be provided both formally and informally in individual and group settings as appropriate [Evidence Level B].
- vii. Family and caregiver education, hands on training, and skills development should be provided using an interdisciplinary approach based on the individual's learning needs [Evidence Level A].

2.3 Supporting Self-Management following Stroke through Skills Training

Refer to Definitions and Descriptions within the Introduction and Overview for [the definition of self-management](#).

- i. Self-efficacy can be supported by providing opportunities to learn and master self-management skills [Evidence Level B]. *Refer to [Box 2](#) for additional information regarding self-management topics for people who had a stroke, their family and caregivers.*
- ii. With consent, family members and caregivers may be invited and encouraged to attend care and therapy sessions and given the opportunity to learn proper skills to support self-management [Evidence Level C].
- iii. All care settings should have up-to-date inventories of community resources available to support self-management and offer guidance and assistance in obtaining needed services [Evidence Level C].
- iv. People with stroke, their families and caregivers should be provided with resources and information which will enable self-management and the ability to navigate through the health care and social system [Evidence Level B].

Box 2: Education and Self-Management Checklist

Education topics:

- Secondary stroke prevention
- Medication management
- Risk factor management (including adherence to pharmacotherapy)
- Role and importance of exercise, information on community-based exercise programs
- Symptom and stress management techniques
- Fatigue, sleep management, and energy conservation strategies
- Nutrition, healthy eating strategies
- Coping with physical changes
- Coping with emotions such as fear, anger and depression
- Coping with cognitive and memory changes
- Coping with perceptual deficits
- Health-related problem-solving and decision making
- Relationships, intimacy and sexuality
- Community participation and resuming valued activities
- Leisure and social participation
- Supports available in the community, such as housing/supported living options
- Driving regulations and rehabilitation, and community-based transportation services
- Considerations and strategies related to return to work
- Financial resources
- Advanced care planning, end-of-life and palliative care options
- Respite care options
- Peer support

Skills training and self-management topics:

- Self-management education to encourage independence, increase confidence and skills to better manage their health
- Personal care techniques (e.g., feeding and bathing techniques)
- Communication strategies and supportive communication

- Safe transfers, lifts, and repositioning (e.g., transfers from bed to chair, positioning of a hemiplegic limb)
- Food preparation and modifications for dysphagia
- Cognitive strategies such as problem-solving techniques
- Stress management techniques (e.g., exercise, mindfulness and meditation)
- Accessing community services and resources
- Ongoing health system navigation
- Awareness of the importance of self-care and caregiver burnout

Rationale

Education is an ongoing and vital part of the recovery process for persons with stroke, family members and caregivers. Research demonstrates that persons with stroke generally retain less than 25% of information and education provided in hospital. Education about stroke facilitates better understanding and supports coping and self-management, and must be repeated and reinforced with consistency across transitions of care. Skills training for caregivers may increase participation and safety, clarify expectations, improve quality of life, and reduce depression and perceived burden. The information provided at each phase of acute care, rehabilitation, community participation, long-term recovery and end-of-life should be relevant to the person with stroke and the family's changing needs. Simple distribution of pamphlets is not sufficient; the delivery should be interactive and adapted to the cognitive and communication challenges faced by some people following stroke, including receptive and expressive language, processing speed, hearing, or visual impairment.

People with stroke emphasized the importance of an inclusive process by involving themselves and their family members in conversations where information is relayed by healthcare team members. However, they have reported that they were not always able to retain the information given to them due to multiple reasons, such as exhaustion and denial. They describe that it was helpful to receive a package containing copies of all this information in one place that they can review when needed. Examples of information that people with a lived experience of stroke, their families and caregivers specifically noted as useful or would have liked to have had includes a summary of health information, contact numbers, available resources, and information to address financial challenges and funding opportunities.

System Implications

Transitions of care support and actions are applicable across the continuum of care, including in primary care, the emergency department, acute care, rehabilitation settings, complex care/transitional bed settings, long-term care and community settings. Processes and mechanisms should be in place in all these settings to address educational needs of the person with stroke, families and caregivers, including:

- Coordinated efforts among stakeholders such as the Heart and Stroke Foundation, Canadian Partnership for Stroke Recovery, public health agencies, ministries of health, non-government organizations (NGOs), hospitals and clinics, and individual care providers across the continuum of stroke care to produce education materials with consistent information.
- Community resources, such as stroke recovery support groups, to provide ongoing support and education following hospital discharge.
- Coordinated processes for ensuring access to and awareness of educational materials, programs, activities and other media related to stroke by healthcare professionals, persons with stroke and caregivers, including advertising the availability of educational material, effective dissemination mechanisms and follow-up.
- Coordinated processes for ongoing communication between departments/organizations/agencies of learning needs and education that has been provided.

- Access to training for care providers learn communication strategies for aphasia.
- Access to educational resources that are culturally, ethnically, and linguistically appropriate.
- Access to self-management support services through telemedicine technologies, especially in rural areas and where there are local resource gaps.
- Training of healthcare providers in self-management skills that they can then share with people with lived experience.
- The development and implementation of an equitable and universal pharmacare program, implemented in partnership with the provinces, designed to improve access to cost-effective medicines for all people in Canada regardless of geography, age, or ability to pay. This program should include a robust common formulary for which the public payer is the first payer.

Performance Measures

Clinical and Health System Performance Measures:

1. Proportion of persons with stroke with documentation of education provided at each stage throughout the stroke management and recovery process (core).
2. Total number of encounters focused on education for each person with stroke, and the time spent on education during a healthcare encounter for stroke.
3. Percentage of persons with stroke discharged with a copy of their discharge plan and educational materials.
4. Change in self-management behaviour at 6 weeks, 3 months and 6 months following stroke, using validated measurement tools.

Person-Oriented Measures (PREMS, PROMS)

1. Change in person with stroke and family knowledge of stroke-related content before and after teaching session.
2. Changes in quality of life measured at regular intervals during recovery and participation, and reassessed when changes in health status or other life events occur (e.g., at 60, 90- and 180-days following stroke).
3. Percentage of people with stroke who reported feeling adequately prepared for self-care and self-efficacy.

Measurement Notes

- Quantity and method of education are very important elements of this recommendation. Measurement of education for persons with stroke and families should be expanded when feasible to capture these aspects, although this is challenging to accomplish.
- For Indicator #3, here possible, standardized mechanisms for testing person with stroke, family and caregiver knowledge pre- and post-education should be included in the education sessions.
- Data sources include all documents, charts, and records related to care across the healthcare system (primary care, acute care, follow-up clinics, inpatient and outpatient rehabilitation programs, community programs and services) and may be obtained through primary chart audit or review, and various logging and audit practices of individual groups.
- Documentation quality (generally weak) by healthcare professionals involved in the persons care may affect ability to monitor this indicator reliably.

Implementation Resources and Knowledge Transfer Tools

Health Care Provider Information

- Taking Action for Optimal Community and Long-Term Stroke Care: A resource for healthcare providers: <https://www.strokebestpractices.ca/resources/professional-resources>
- Accreditation Canada Stroke Distinction Program: <https://accreditation.ca/stroke-distinction/>
- Timing it Right study (Cameron & Gignac 2008):
[\[http://www.ncbi.nlm.nih.gov/pubmed/?term=18155388\]](http://www.ncbi.nlm.nih.gov/pubmed/?term=18155388)
- Aphasia institute: <http://www.aphasia.ca/health-care-professionals/>

Resources for People with Stroke, Families and Caregivers

- Rehabilitation and Recovery infographic: Guide to taking charge of your stroke recovery: <https://www.heartandstroke.ca/-/media/1-stroke-best-practices/rehabilitation-nov2019/csbp-infographic-rehabilitation.ashx>
- Transitions and community participation infographic: Guide to taking charge of your stroke recovery: <https://www.heartandstroke.ca/-/media/1-stroke-best-practices/transition-of-care-nov2019/csbp-infographic-transitions-and-participation.ashx>
- Your Stroke Journey: A guide for people living with stroke: <https://www.strokebestpractices.ca/-/media/1-stroke-best-practices/resources/patient-resources/en-your-stroke-journey-v21.ashx>
- Post-Stroke Checklist: <https://www.strokebestpractices.ca/resources/patient-resources>
- A Family Guide to Pediatric Stroke: <https://www.strokebestpractices.ca/resources/patient-resources>
- Heart & Stroke Services and Resources Directory: <https://www.heartandstroke.ca/services-and-resources>
- Heart & Stroke Recovery and Support Health Information: <https://www.heartandstroke.ca/stroke/recovery-and-support/>
- Living with Stroke™ program: <https://www.heartandstroke.ca/stroke/recovery-and-support/living-with-stroke>
- Canadian Partnership for Stroke Recovery Patient Resources: <https://www.canadianstroke.ca/en/tools-resources/patients>
- Canadian Partnership for Stroke Recovery Patient Resources: <https://www.canadianstroke.ca/en/tools-resources/patients>
- Stroke in Young Adults: <https://www.strokebestpractices.ca/resources/patient-resources>
- Stroke Engine: strokengine.ca

Summary of the Evidence

Education across the continuum of care is an important component of support for patient, families and informal caregiver, particularly with regard to secondary stroke prevention and chronic disease self-management. A 2012 Cochrane review (Forster et al. 2012) assessed interventions related to the provision of information, compared with usual care and included the results from 21 RCTs. In 14 trials, the intervention was focused on either the patient or carer exclusively. In the remaining trials, the intervention was focused on both groups. Patients and caregivers receiving an intervention had improved knowledge of stroke services and patients expressed greater satisfaction with stroke

information compared to patients in the control group. Patients receiving an intervention also experienced improvements in depression scores (MD=-0.52, 95% CI -0.93 to -0.10, P<0.05) with greater effects associated with interventions that were considered “active”, meaning there was patient or carer engagement during the sessions. Engagement could include the opportunity to ask questions, request additional information, be provided with hands-on training, or involve the use of an interactive workbook and/or some means of follow-up reinforcement.

Several randomized trials have evaluated the effects of information and support packages for patients and their caregivers following stroke. Those trials that simply provided participants with written information as the intervention tended to be less effective compared with programs that included additional components. Eames et al. (2013) randomized 138 patients and their carers to receive an individually tailored education and support package with verbal reinforcement for 3 months, or to a usual care group, which received unstructured, informal education. Patients in the intervention group reported significantly greater self-efficacy (access to stroke information domain, $p<0.04$), feeling of being informed ($p<0.01$), and satisfaction with medical ($p<0.001$), practical ($p<0.01$), service/benefit ($p<0.05$), and secondary prevention ($p<0.001$) information received. Lowe et al. (2007) evaluated the use of a “CareFile”, an information package containing relevant support services and secondary prevention resources that was individualized for each patient. One hundred patients participated in the study, 50 randomized to the intervention group and 50 to the control group. At six months, 98% patients in the intervention group reported that the CareFile provided useful information and 53% said that they used it as reference material regarding their stroke. Patients in the intervention group demonstrated greater knowledge of stroke risk factors than patients in the control group at both 3 and 6 months after stroke. Hoffman et al. (2007) randomized 138 patients to receive either computer-generated tailored written information or generic written information. At three months, there were no significant differences between groups in mean change scores for stroke knowledge, self-efficacy or depression.

Telephone- based interventions have also been examined as a method of providing support and education, Bakas et al. (2009) randomized 50 caregivers with ongoing needs to a Telephone Assessment and Skill Building Kit (TASK) group or to a usual care group. Participants in the TASK group received a notebook containing skill building tips, a stress management workbook and a brochure on family caregiving, plus weekly phone calls from a nurse for a period of 8 weeks that involved discussion of patient identified priority areas. Participants in the control group received a brochure on family caregiving, as well as weekly calls from a nurse who did not provide any advice or information. Caregivers in the intervention group were significantly more optimistic at 4, 8 and 12 week follow up, experienced significantly lower levels of task difficulty at 4 weeks and had significantly improved threat appraisal skills at 8 weeks and 12 weeks, although there were no significant changes in depressive symptoms, life changes or general health perception.

Studies assessing the impact of caregiver education and skills training have also reported the benefits of active or “hands-on” interventions. A randomized controlled trial by Kalra et al. (2004) allocated patient/caregiver dyads to receive structured caregiver training (hands-on training in basic nursing techniques that emphasized skills essential for daily management of ADL) or conventional instruction (information and advice). The length of the intervention was dependent on patient need, ranging from three to five sessions in the inpatient rehabilitation setting. Patients experienced reductions in anxiety and depression at 12 months ($p<0.001$) and increased quality of life at 3 and 12 months ($p<0.05$). No differences between mortality, institutionalization or functional ability were reported between intervention and control groups. Using a similar intervention, Forster et al. (2013) randomized 928 patients, expected to return home following acute stroke, to participate in the London Stroke Carers Training course

(LSCTC) (same protocol as Kalra et al. 2004), or to usual care. At 6 months there was no significant difference in the mean patient Nottingham EADL scores between groups (27.4 vs. 27.6, $p=0.866$) or Caregiver Burden Scores (45.5 vs. 45.0, $p=0.660$). While the intervention did not appear to be effective, the authors speculated that the timing, in the immediate period after stroke, might not be ideal.

The implementation of education and skills training programs ultimately aim to increase the self-efficacy of patients and informal caregivers for their own self-management. Lennon et al. (2013) conducted a systematic review of studies (including randomized and non-randomized controlled trials) that assessed “self-management” interventions for patients recovering from stroke. Interventions included in the review were quite variable, ranging from group programs to one-on-one interventions consisting of workbooks, DVDs or exercise sessions. Several interventions were based on the Stanford Chronic Disease Self-Management programme, which consists of workshops, a companion book and a relaxation CD. However, due to the variability in outcomes assessed, pooling of results was not possible. Some of the largest randomized controlled trials included in the review demonstrated improvement in physical domains, quality of life, and dependency. A Cochrane review (Forster et al. 2007) included the results from 18 studies examining self-management programs for participants with multiple chronic conditions (e.g. arthritis, chronic pain, stroke, hypertension, heart failure etc.). There were small but statistically significant improvements in pain, disability, fatigue and depression and anxiety associated with the intervention group. There were also small but statistically significant increases in levels of exercise and in the frequency of practice of cognitive strategies for symptom management associated with the intervention.

Education for People with Stroke, Their Families and Caregivers Evidence Tables and Reference List available at www.strokebestpractices.ca

Section 3: Interprofessional Care Planning and Communication

Recommendations

3.0 Interprofessional care planning and effective communication is essential to ensure continuity of care, safety, and to reduce risk of complications and adverse events during stroke care particularly at transition points [Evidence Level C].

3.1 Individualized Care Plan: The person with stroke, their family and caregivers should be actively engaged in development of an up-to-date care plan:

- i. The care plan should be person-centered; culturally appropriate; include person-centered goals; and defines ongoing individualized care needs [Evidence Level C].
- ii. The care plan should be reviewed with the person with stroke and updated to reflect changing needs, evolving goals, progress at each transition, when changes and/or improvements in health status occur and when the person is not progressing in recovery. [Evidence Level B].

3.1 Clinical Consideration:

- i. The care plan should be initiated at the first point of contact with the healthcare system, such as the emergency department, and be refined and updated as the person progresses through the continuum of care.

3.2 Transition planning should begin as soon as possible following initiation of care at each applicable stage and setting [Evidence Level B].

- i. Transition planning discussions, decisions, and activities should be ongoing to reflect changing needs, evolving goals, and progress through the recovery process [Evidence Level B].
- ii. A transition planning process should be established as a well-organized collaboration between health professionals, the person with stroke, their family, and caregivers [Evidence Level B].
- iii. The following should be considered throughout transition planning:
 - a. Formulation of a goal-oriented transition plan (e.g., discharge date) with the person with stroke, family, and caregivers [Evidence Level B].
 - b. Identification of possible transition issues for the person with stroke and their family, and other needs which could potentially delay discharge. These should be addressed early in transition planning [Evidence Level B].
 - c. Assessment of caregiver capacity, decision-making ability, and ability to meet the physical and psychosocial needs of the person with stroke [Evidence Level C]. *Refer to [Section 1](#) and [Section 2](#) for additional information.*
 - d. Addressing transition planning needs and booking of appointments prior to leaving current setting, especially short stay settings including emergency department and acute care for those discharged directly back to the community [Evidence Level C].
 - e. Utilization of telemedicine modalities where available to increase access to timely and appropriate stroke care follow-up [Evidence Level B]. *Refer to [CSBPR Telestroke Toolkit](#) for additional information.*
- iv. Specific transition planning activities that should be completed as appropriate include:
 - a. A home assessment to identify home modifications required for accessibility and safety [Evidence Level B].
 - b. Caregiver skills training specific to the current and ongoing needs of the person with stroke [Evidence Level B]. *Refer to [Section 1](#) and [Section 2](#) for additional information.*

- c. Planned and goal-oriented day, weekend and or overnight visits to the identified discharge location [Evidence Level B], in order to:
 - help identify potential barriers,
 - assess readiness for discharge,
 - and to inform therapy and discharge planning activities.
- d. Written discharge instructions as a component of an individualized care plan that addresses the following issues as appropriate: functional ability at the time of discharge, risks and safety considerations, action plans for recovery, medications at discharge and instructions for adjustment, follow-up care, follow-up care provider contact information and information for one point of contact post-discharge [Evidence Level B].
- e. All communications should be available in aphasia-friendly formats as required and appropriate to the health literacy of people with stroke, their families and caregivers [Evidence-Level B].
- f. A post-discharge follow-up plan, initiated by a designated team member, such as a case manager or stroke navigator, to ensure continuity of care [Evidence Level B].

3.3 Health Professional Communication: Processes should be in place to ensure timely and effective transfer of relevant information at all points of access and transition in the healthcare system, to ensure seamless transitions and continuity of care [Evidence Level B].

- i. All members of the interdisciplinary stroke team should share timely and up-to-date information with healthcare providers at the next stage of care [Evidence Level B].
- ii. The transfer of information should be:
 - a. Comprehensive with all relevant information on the person with stroke including medications, and progress to date, planned appointments, ongoing recovery needs and goals [Evidence Level B].
 - b. Provided to the primary care physician in a formal, typed, detailed, discharge summary (from the most responsible physician) [Evidence Level B]. *Note, not all patients may have a primary care provider, and if not, this should also be addressed. Refer to [Box 3](#) for core content to be considered for inclusion in discharge summaries.*
 - c. Timely and occur prior to the time of transition to next care setting [Evidence Level C].
 - d. When possible, accessible through electronic health records [Evidence Level C].
 - g. Include the use of telemedicine technology when appropriate [Evidence Level C]. *Refer to [CSBPR Telestroke Toolkit](#) for additional information.*
- iii. A designated member of the team should facilitate the transfer of information and referrals to appropriate follow-up services for the person with stroke [Evidence Level B].

Box 3: Checklist of Core Transition Summary Information

Transition Summary to next care setting and primary care provider should include:

- Stroke diagnosis, etiology and date of stroke
- Stroke risk factors
- Secondary prevention strategies
- Past medical history
- Social and family history
- Medications on discharge

- Summary of hospital course including secondary complications, co-morbid illnesses, relevant investigations (e.g., labs and diagnostic imaging) and any follow-up required
- Identification of urgent care needs and priority issues
- Advanced care plan status
- Summary of stroke impairments and treatments/therapies received
- Level of function on transition for ADLs, functional mobility, and iADLs including any supervision or assistance required
- Community Home care services arranged and any crisis placement recommendations
- Equipment and resources prescribed, including what has been provided, and what is pending
- Recommended future management plan, including therapies, home program, community activities and outstanding medical consultations
- Return to driving recommendations/plan if applicable
- Return to work recommendations/plan if applicable
- Ongoing and long-term goals
- Follow up appointments planned/pending
- Specific identification of primary care provider follow-up responsibilities
- Direct communication between most responsible physician and the primary care provider when needed

Rationale

Stroke care can be complex and requires ongoing monitoring and management. Clear communication in a timely manner is essential to ensure continuity of care, safety, and to reduce risk of complications and adverse events resulting from the confusion and ambiguity that can arise during transition points.

People with a lived experience of stroke have reported that the healthcare system can seem siloed between different specialties or systems of care, with limited integration and interaction between healthcare settings or practitioners. These experiences cause frustration, feelings of being overwhelmed and add burden to families as they transition away from acute inpatient or inpatient rehabilitation settings into the community. These concerns emphasize the importance of communication between healthcare team members and settings throughout the transitions of care.

Effective discharge planning is essential for smooth transitions through the continuum of stroke care. Delayed or incomplete planning leads to prolonged hospital stays and an increased risk of adverse events following discharge. People with stroke, family members and healthcare providers involved in each phase of care should all be involved in discharge planning to ensure effective and safe transitions

Using feedback provided by people with a lived experience of stroke, the importance of the timing of discharge planning was emphasized. Ensuring that the discharge planning occurs throughout the stages of care, rather than directly prior to discharge, can improve the experience of the person with stroke, their family and caregivers. Furthermore, this helps to make sure that all services and resources are established ahead of time. People with a lived experience of stroke report difficulties accessing resources post discharge relating to denial of services, for example, being unable to use a service due to an age restriction; accessing accessible transportation, and financial support. These challenges were further complicated when the person did not have a family physician, which should be addressed and taken into consideration during the discharge planning process.

System Implications

Transitions of care support and actions are applicable across the continuum of stroke care, including in primary care, the emergency department, acute care, rehabilitation settings, complex care/transitional bed settings, long-term care and community settings. Processes and mechanisms should be in place in all these settings to address efficient communication between settings and healthcare providers,

including:

- Strong relationships and formal agreements among healthcare providers within and across regions to increase the efficient and timely transition.
- Development of processes across healthcare institutions and settings for the coordination of discharge planning and ongoing medical management through to primary care, community services, follow-up, and access to required healthcare services (e.g., ongoing rehabilitation or acute care).
- Processes, protocols, and resources for conducting home assessments by interprofessional team members prior to discharge.
- Access to self-management and caregiver training and support services as required ensuring a smooth transition.
- Resource capacity to enable appropriate and timely access to services at the next stage of care with the required specialties, intensity, and frequency.
- Strong relationships and formal agreements among healthcare providers within regions to increase the efficient and timely transition of persons with stroke.
- Implementation of standards, processes, and tools to ensure timely discharge summaries sent to primary care and other relevant healthcare professionals and/or agencies to facilitate continuity of care at transition points.
- Adequately resourced community health and support services for persons with stroke.
- Providing the right care and services in the right settings at the right times following stroke.
- Capacity for social workers and other case management or healthcare personnel with dedicated responsibilities for discharge planning.
- Staff who are aware of person's right to privacy and who comply with privacy legislation and preferences when releasing a person with stroke's information.
- The development and implementation of an equitable and universal pharmacare program, implemented in partnership with the provinces, designed to improve access to cost-effective medicines for all people in Canada regardless of geography, age, or ability to pay. This program should include a robust common formulary for which the public payer is the first payer.

Performance Measures

Clinical and Health System Performance Measures:

Transition Planning

1. Proportion of acute stroke patients who have at least one alternate level of care day during their index acute care admission for stroke.
2. Average number of alternate level of care days per in acute care settings.
3. Median length of stay of people with stroke in acute inpatient care (core).
4. Readmission rate for persons with stroke discharged from hospital for all reasons, within 90 days, 6 months and one year.
5. Admission to longterm care within one year of being discharged back to the community following a stroke event.

Interprofessional Communication

1. Percentage of persons with stroke who are given a copy of their completed care plan and discharge summary at the time of discharge from acute inpatient care or inpatient rehabilitation.
2. Percentage of persons with stroke for whom a discharge summary is completed prior to or within 48 hours of discharge from one care setting to the next and received by the care provider at the next stage of care.

Person-Oriented Measures (PREMS, PROMS)

1. Percentage of persons with stroke who are given a copy of their completed discharge plan at the time of discharge from acute inpatient care or inpatient rehabilitation.
2. Proportion of persons with stroke who return to the hospital post-discharge for non-medical reasons (i.e., failure to cope).
3. Quality of life of people after discharge for an acute stroke event, measured at transition points and routinely throughout recovery (for example, at 60, 90, 180 days and 1 year following discharge)

Implementation Resources and Knowledge Transfer Tools

Health Care Provider Information

- Taking Action for Optimal Community and Long-Term Stroke Care: A resource for healthcare providers: <https://www.strokebestpractices.ca/resources/professional-resources>
- Registered Nurses' Association of Ontario *Developing and Sustaining Interprofessional Health Care: Optimizing patients/clients, organizational, and system outcomes*: <http://rnao.ca/bpg/guidelines/interprofessional-team-work-healthcare>
- Health Quality Ontario – Transitioning From Hospital to Home: <https://www.hqontario.ca/evidence-to-improve-care/quality-standards/view-all-quality-standards/transitions-from-hospital-to-home>
- Discharge Summary Outline: <http://mcmasterpa.weebly.com/how-to-discharge-summaries.html>
- Centre for Interprofessional Education (University of Toronto): <http://www.ipe.utoronto.ca>
- Canadian Interprofessional Health Collaborative: <http://www.cihc.ca>
- A National Interprofessional Competency Framework: http://www.cihc.ca/files/CIHC_IPCompetencies_Feb1210.pdf
- Centre for Advancement of Interprofessional Education: <http://www.caipe.org.uk/>
- Re-Engineered Discharge (RED) Toolkit: <http://www.ahrg.gov/professionals/systems/hospital/red/toolkit/index.html>
- GTA Rehab Network Inter-Organizational Transfer of Accountability Guidelines http://www.gtarehabnetwork.ca/uploads/File/tools/GTA_Rehab_Networks_Inter-Organizational_Transfer_of_Accountability_Guideline.pdf

Resources for People with Stroke, Families and Caregivers

- Rehabilitation and Recovery infographic: Guide to taking charge of your stroke recovery: <https://www.heartandstroke.ca/-/media/1-stroke-best-practices/rehabilitation-nov2019/csbp-infographic-rehabilitation.ashx>
- Transitions and community participation infographic: Guide to taking charge of your stroke recovery: <https://www.heartandstroke.ca/-/media/1-stroke-best-practices/transition-of-care-nov2019/csbp-infographic-transitions-and-participation.ashx>
- Heart & Stroke Services and Resources Directory: <https://www.heartandstroke.ca/services-and-resources>
- Your Stroke Journey: A guide for people living with stroke: <https://www.strokebestpractices.ca/-/media/1-stroke-best-practices/resources/patient-resources/en-your-stroke-journey-v21.ashx>
- Post-Stroke Checklist: <https://www.strokebestpractices.ca/resources/patient-resources>
- A Family Guide to Pediatric Stroke: <https://www.strokebestpractices.ca/resources/patient-resources>
- Heart & Stroke Recovery and Support Health Information: <https://www.heartandstroke.ca/stroke/recovery-and-support/>

- Stroke in Young Adults: <https://www.strokebestpractices.ca/resources/patient-resources>
- Talking Care of Myself: A Guide for When I Leave the Hospital: <http://www.ahrq.gov/patients-consumers/diagnosis-treatment/hospitals-clinics/goinghome/goinghomeguide.pdf>
- Stroke Engine: strokengine.ca
- Canadian Partnership for Stroke Recovery Patient Resources: <https://www.canadianstroke.ca/en/tools-resources/patients>

Summary of the Evidence

Discharge Planning

Discharge planning should begin as soon as possible during each phase of care and should involve the patient, family/caregivers, and all members of the interprofessional team. The goal of discharge planning is to ensure a safe and efficient transition between care settings while maintaining a continuity of care and coordination of services that optimize recovery and secondary prevention, as appropriate.

Discharge planning activities should include a pre-discharge needs assessment, home visits, meetings between the care team, patient, and family/caregivers, a post-discharge follow-up plan, and communication with team members at the next phase of care. In a recent Cochrane review Gonçalves-Bradley et al. (2016) identified 30 RCTs including patients admitted to any type of hospital (acute, rehabilitation or community) with any medical or surgical condition (one trial [Sulch et al. 2010] included patients with a diagnosis of stroke). Trials evaluated discharge plans from hospital that included assessment, planning, implementation and monitoring components, initiated at some point prior to discharge. Hospital length of stay (MD -0.73, 95% CI -1.33 to -0.12) and unscheduled three-month readmission rates (RR=0.87, 95% CI 0.79 to 0.97) were both found to be significantly reduced for elderly patients with a medical condition who received discharge planning, compared to care as usual. No significant between group differences were reported in terms of discharge destination or mortality. In the only RCT identified in the Cochrane review, Sulch et al. (2000) randomized 152 patients within two-weeks of stroke onset to receive discharge planning according to an integrated care pathway or care as usual. No significant between group differences were reported with respect to six-month mortality (13% vs. 8%), institutionalization (13% vs. 21%), or length of stay (50±19 vs. 45±23). However, those randomized to receive conventional care experienced significantly greater change on the Barthel Index from 4 to 12 weeks (median change = 6 vs. 2, p<0.01) and reported significantly greater scores on the EuroQol at six-months (72 vs. 63, p<0.01).

Stroke Navigators

Navigating through the post-stroke continuum has been highlighted as a frequent source of dissatisfaction, for patients and informal caregivers, particularly during the transition from hospital to community. Several studies have been conducted to evaluate the benefit of individuals who coordinate access to appropriate services for patients recovering from stroke, who go by many names including stroke navigator, case manager, care coordinator, or system navigator). Manderson et al. (2011) conducted a systematic review including 15 publications, representing 9 RCTs examining system navigation models for older adults living with multiple chronic diseases making transitions across healthcare settings. The services provided included care planning, coordination of care, phone support, home visits, liaison with medical and community services, and patient and caregiver education. In most of the studies, economic, psychosocial and functional benefits were associated with system navigation. While the services of a registered occupational therapist, who functioned as a community stroke navigator, resulted in significant improvements in the mean daily functioning subscale of the Reintegration to Normal Living Index RNLi among 51 patients at the end of four months, (54.1 to 59.3, p=0.02), there were no significant improvements in other outcomes (2-minute walk test, depression

outcomes), or any caregiver outcomes (Egan et al. 2010).

Interprofessional Communication

Transitions between and within health care settings pose a safety and quality of care concern for patients recovering from stroke. A consensus policy statement by the American College of Physicians in 2009 highlighted concerns of patient safety at transition points, particularly between inpatient and outpatient care (Snow et al. 2009). Following stroke, a person is vulnerable to many of these transition points as they progress through the acute, sub-acute and chronic stages of recovery, interacting with a range of physicians in several different health-care settings. Communication between these physicians and care settings is critical for ensuring patient safety and quality of care. In a systematic review (Kattel et al 2018), included 19 studies which described hospital discharge communication between hospital-based providers and primary care physicians (PCPs). While a median of 55.1% of hospital discharge communications were transferred to the PCP within 48 hours, 8.5% of discharge summaries never reached the PCP. Information that was absent from discharge summaries included diagnostic test results (61%), pending tests at discharge (25%), and follow-up plans (41%). PCP received notification of discharge in only 23% of cases. In a controlled study of 3,248 hospitals, Mitchell (2015) explored the association between physician/nurse communication with the patient regarding discharge instructions and readmission. An average of 84% of patients reported receiving discharge instructions. Hospitals that had smaller bed numbers, were non-profit and located in non-urban areas were more likely to provide discharge instructions. Patients reported that, on average, nurses and doctors communicated well with them 78% and 82% of the time. Controlling for other factors, increasing frequency of communication surrounding discharge instructions was associated with significantly lower number of 30-day hospital re-admissions.

Areas of communication deficits were reported in a systematic review by Kripalani et al. (2007), which included the results of 73 studies examining communication deficits between hospitals and primary care providers, and interventions to improve communication during this transition. While a median of 53% of discharge letters had arrived at the physician's office within one week of discharge, only 14.5% of discharge summaries were received the same timeframe. However, 11% of discharge letters and 25% of discharge summaries never reached the primary care physician. Discharge letters were missing a main diagnosis in 7%-48% of cases, hospital treatment details in 22%-45% of cases, medications at discharge for 7%-48% of cases, plans for follow-up in 23%-48% of cases, and notes on patient or family counselling in 92%-97% of cases. In terms of effectiveness of interventions, a significantly higher percentage of discharge summaries that were hand delivered (compared with mailing) were received by week 4 following discharge (80% vs. 57%, $p < 0.001$). The overall quality of the summaries was perceived to be higher and the summaries were longer when computer generated, using a standard template, and were received by the primary care physician sooner.

Halasyamani et al. (2006) described the development of a discharge checklist, based on a literature review, expert committee and peer review, designed to identify the critical components in the process when discharging elderly patients from hospital. The final checklist includes 3 types of discharge documents: the discharge summary, patient instruction and communication on the day of discharge to the receiving care provider. Data elements included on the final checklist were: problem that precipitated hospitalization, key findings and test results, final primary and secondary diagnoses, condition at discharge (functional and cognitive), discharge destination, discharge medications, follow-up appointments, list of pending lab results and person to whom results will be sent, recommendations of sub-specialty consultants, documentation of patient education and understanding, identification of atypical problems and suggested interventions, 24/7 call-back number, identification of referring and

receiving providers, resuscitation status.

Interprofessional Care Planning and Communication Evidence Tables and Reference List
available at www.strokebestpractices.ca

Section 4: Community Participation Following Stroke

** NOTE: The topics covered in this section include elements of active rehabilitation as well as community and participation. They are presented within Part Two: Transitions and Community Participation Following Stroke to consolidate them in one place and present a comprehensive set of recommendations.*

Recommendations

4.0 People with stroke, their families, and caregivers should be provided with information, education, training, support and access to services throughout transitions to the community to optimize the return to life roles, activities and social participation [Evidence Level B].

4.1 Physical and Psychological Health Management Following Stroke:

- i. People living in the community post- stroke should have access to regular and ongoing medical follow-up appropriate to their individual needs, which may address: evaluating progress of recovery, preventing deterioration, maximizing functional and psychosocial outcomes, preventing stroke recurrence, and improving quality of life [Evidence Level B].
 - a. Initial review with the primary care provider would ideally occur within the first month following hospital discharge and address the key secondary prevention, medical and functional issues, and provide ongoing follow-up as required. [Evidence Level C]. [Refer to CSBPR Secondary Prevention of Stroke module for additional information and the post-stroke checklist.](#)
 - b. People with stroke should be screened and treated for new and/or ongoing cognitive concerns, mental health issues (i.e., depression, anxiety), and psychosocial issues as required [Evidence Level B]. [Refer to CSBPR Mood, Cognition & Fatigue following Stroke module for additional information.](#)
- ii. Secondary prevention of stroke should be optimally managed and risk factor reduction strategies optimized in all settings including long term care [Evidence Level A]. [Refer to CSBPR Secondary Prevention of Stroke module for additional information](#)
- iii. Referrals to stroke prevention clinics and services could be initiated where appropriate (i.e., at hospital discharge and once back in the community) [Evidence Level C]. [Refer to CSBPR Secondary Prevention of Stroke module for additional information.](#)

4.2 Functional Health Management:

- i. People with stroke living in the community who experience a decline in functional status should receive targeted interventions, as appropriate [Evidence Level B], even if the decline occurs many months/years post-stroke. [Refer to CSBPR Stroke Rehabilitation and Recovery following Stroke module for targeted interventions.](#)
- ii. Processes should be in place for people following a stroke to re-access rehabilitation or mental health services if required during longer-term recovery [Evidence Level B]. [Refer to CSBPR Stroke Rehabilitation and Recovery following Stroke module and CSBPR Mood, Cognition and Fatigue Following Stroke module for additional information.](#)
- iii. People with stroke should be encouraged to participate in evidence-based community exercise programs as appropriate [Evidence Level A].

4.3 Participation in Social and Life Roles Following Stroke: *Driving*

A. Education and Screening:

- i. People should be advised to stop driving for at least one month after a stroke, in accordance with the Canadian Council of Motor Transport Administrators (CCMTA) Medical Standards for Drivers [Evidence Level B].
- ii. The person with stroke should be made aware whether the local licencing authority has been informed that they have had a change in their medical status that will affect their ability to drive [Evidence Level C].
- iii. People who have had one or multiple TIAs should be instructed to stop driving until a comprehensive neurological assessment (including sensorimotor function and cognitive ability) shows no residual loss of functional ability and discloses no obvious risk of sudden recurrence that could create a hazard while driving, in accordance with the Canadian Council of Motor Transport Administrators (CCMTA) Medical Standards for Drivers [Evidence Level C].
 - a. As well, any underlying cause of stroke has been addressed with appropriate treatment [Evidence Level C].
**Refer to individual provincial and territorial laws for requirements for reporting a person's fitness to drive to driving authorities, and requirements to return to driving.*
- iv. People with stroke may be screened for their interest in returning to driving at transitions and follow-up visits [Evidence Level C].

B. Assessment for Fitness to Drive:

- i. People interested in returning to driving following a stroke should be assessed for driving abilities and rehabilitation needs using valid and reliable methods for any residual functional, sensory-perceptual, motor, or cognitive impairments [Evidence Level B] in accordance with provincial-territorial criteria for return to driving.
 - a. Sensory-perceptual assessment should focus on vision, visual fields, and visual attention;
 - b. Motor assessment should focus on strength, range of motion, coordination and reaction time;
 - c. Cognitive assessment should focus on problem solving, speed of decision making, judgment and reading/symbol comprehension.

Refer to [Appendix Table 3](#) for suggested assessment tools for pre-driving screening.

- ii. For people who have residual neurological deficits impacting driving ability following stroke, a full comprehensive driving evaluation, including a government-sanctioned on-road assessment, should be considered to determine fitness to drive [Evidence Level B].
 - a. People with stroke may be referred to training programs, such as simulator-based training, to help prepare for return to driving [Evidence Level B].

C. Rehabilitation and Management for Return to Driving:

- i. Following a stroke, people who are functionally able and interested in returning to driving should be offered appropriate rehabilitation therapies as individually required to address functional, perceptual and cognitive issues and increase the likelihood of being able to return to driving [Evidence Level B].

- ii. Persons unable to return to driving may be informed about and assisted to access transportation alternatives [Evidence Level C].
- iii. Persons unable to return to driving may be offered support and/or counselling on coping with the loss of the ability to drive [Evidence Level C].

4.4 Participation in Social and Life Roles Following Stroke: *Vocational Roles*

- i. Following stroke, people may be considered for assessment of vocational interests (i.e., work, school, volunteering) and for their potential to return to their vocations [Evidence Level C].
 - a. This initial screening may take place early in the rehabilitation phase and should be reassessed at transitions as appropriate [Evidence Level C].
 - b. Findings can be included as part of the person's individualized goal setting and planning for early and ongoing rehabilitation [Evidence Level C].
- ii. Encourage resumption of vocational interests where possible. A gradual resumption could occur when appropriate [Evidence Level C].
- iii. Initiation of referrals and or counselling may be considered as appropriate (such as to vocational services) to assist with re-engagement in vocational activities as part of transitions to the community [Evidence Level C].
- iv. A detailed cognitive assessment including a neuropsychological evaluation or occupational therapy evaluation, where appropriate and available, can be considered to assist with determining the person's ability to meet the needs of their current or potential employment requirements and contribute to vocational planning [Evidence Level C].
- v. Referral to vocational rehabilitation services may be considered, as appropriate [Evidence Level C].
 - a. A designated member of the care team may provide counseling and information on employment benefits and legal rights to people who have had a stroke [Evidence Level C].
- vi. Review financial concerns, sustainability and benefit options during admission and/or prior to discharge, and later in follow-up assessments and transitions. [Evidence Level C].
- vii. With consent and where possible, the healthcare team may work with employers/educators to devise an appropriate return to work/school plan [Evidence Level C].
 - a. Encourage employers and education providers to follow therapists' recommendations with regards to work/school modifications and provide the flexibility to allow a return to work/school at an appropriate pace [Evidence Level C].

4.5 Participation in Social and Life Roles Following Stroke: *Leisure Activities and Social Participation*

- i. Following stroke, people should be screened for pre-stroke and current leisure goals, interests and social participation [Evidence Level B]
- ii. A comprehensive multi-dimensional assessment for skills and abilities to resume previous or new leisure and social activities should be performed. [Evidence Level B]
- iii. People with stroke who experience difficulty engaging in leisure and other social activities should receive targeted therapeutic interventions and individualized plans for participation based on collaborative goal-setting with their healthcare team [Evidence Level A].

- iv. People with stroke may ideally be provided with information and/or referral to community-based resources for engagement and self-management for ongoing physical, social, emotional, intellectual and spiritual activities and participation in the community [Evidence Level C].

4.6 Participation in Social and Life Roles Following Stroke: *Relationships and Sexuality*

- i. People with stroke, their family and caregivers should be educated and counselled on the potential impact of stroke on relationships [Evidence Level B].
- ii. Following stroke people should be given the opportunity to discuss intimacy, sexuality and sexual functioning with their healthcare provider [Evidence Level B].
 - a. Topics to address in discussions may include safety concerns, changes in libido, physical limitations resulting from stroke, and emotional consequences of stroke [Evidence Level B].
 - b. Consider initiating discussions prior to inpatient discharge and as the person transitions back into the community [Evidence Level C].
 - c. Consider providing verbal and written information adapted according to a person's cognitive or communication abilities or deficits [Evidence Level C].
- iii. Education sessions for people with stroke and/or partners may address expected changes in intimacy and sexuality, strategies to maximize sexual function, and frequently asked questions regarding relationships following a stroke [Evidence Level C].
- iv. Referral to a sexual health specialist can be considered for people with persistent sexual dysfunction. [Evidence Level C].
- v. Medical practitioners may discuss use and contraindications of medications to address sexual dysfunction [Evidence Level C].

4.7 Participation in Social and Life Roles Following Stroke: *Disability Supports in the Community*

- i. Healthcare professionals across settings may provide people with stroke, their families and caregivers with information and linkages regarding access to disability support services within their region [Evidence Level C].
 - a. Healthcare team members, people with stroke, their families, and caregivers should work together to develop an accessibility plan prior to transition to a home or community-based living setting [Evidence Level C].
 - i. This plan should consider the person's physical function, communication, emotional, cognitive and/or perceptual abilities and impairments following stroke.
 - b. Disability legislation and guidelines may be explained to people with stroke, family members and caregivers, by designated healthcare providers in preparation for transitions [Evidence level C].
 - c. Timely completion of appropriate documentation and applications by healthcare team members as required in collaboration with people with stroke, their families and caregivers can help to minimize delays with accessing eligible services [Evidence level C].
 - d. Collaboration between designated members of the healthcare team and persons with stroke, families and caregivers can help navigate systems and ensure appropriate services and equipment are accessed in a timely manner [Evidence Level C].

4.8 Participation in Advance Care Plans

- i. The healthcare team should ensure that person's goals of care and advance care planning decisions are reviewed periodically with the person with stroke, their family and caregivers (as appropriate), and updated if needed, such as when there is a change in health status [Evidence Level B]. [Refer to CSBPR Acute Stroke Management Module Section 10 for additional information.](#)
 - a. Advance care planning may include a substitute decision-maker (proxy or agent) and should reflect provincial legislation [Evidence Level C].
 - b. Advance care planning discussions should be documented and reassessed regularly, including at transition points or when there is a change in status, with the active care team and the person with stroke or substitute decision-maker and included on the transition (discharge) summary [Evidence Level C].
 - c. Respectful discussion of values and wishes should be balanced with information regarding medically appropriate treatment related to ongoing stroke management, prognosis and future medical care [Evidence Level C]. [Refer to CSBPR Acute Stroke Management Module Section 10 for additional information.](#)

4.9 Participation in Community-Based Palliative Care

- i. Referral and liaison with community-based hospice or palliative care services can be coordinated as appropriate based on the person's goals of care and condition [Evidence Level C]. [Refer to CSBPR Acute Stroke Management module Section 11 for additional information.](#)
- ii. The needs of people with stroke, their families and caregivers, including physical, spiritual, cultural, psychological, ethical, and social aspects may be addressed using appropriate communication skills [Evidence Level C].

Rationale

The post-discharge period is consistently reported by people with stroke and their families as a stressful and challenging time as they adjust to new roles and potentially altered functional and cognitive abilities. Participation in life roles and meaningful activity positively contributes to overall sense of wellbeing and purpose. These range from being able to drive again to relationships and intimacy, and re-engaging in leisure and social activities.

People with stroke and their families often lose the social, emotional, and practical support offered by an inpatient stroke service. They have expressed how they would have found a follow-up visit after returning home to be beneficial. They describe difficulties with access services and resources once they are back in the community. Evidence shows that when there is coordination of care beyond the inpatient setting and community support services are provided, outcomes and satisfaction improve. People have a strong desire to regain control and independence, and health systems and services should be designed to support these positive outcomes.

The addition of recommendations for long term care are a response to data showing that people with stroke are among the largest population receiving long-term care, and their number is steadily increasing worldwide. People with stroke who transition to long-term care should continue to have rehabilitation and recovery goals and plans that focus on restorative care, maintenance of function, and support for health declines, and be cared for by staff knowledgeable in stroke to maximize outcome goals.

System Implications

Following stroke, successful transitions and community participation requires:

- Education and training in shared decision-making skills and strategies for all healthcare professionals, persons with stroke, families, and caregivers.
- Adequate and timely follow-up stroke care in all provinces and territories to support community participation.
- Assistance for people with stroke, their families, and caregivers with an evolving care plan and regular follow-up assessments.
- Coordination between primary care provider and community agencies for referral to appropriate programs and services for assessment of ability to resume driving.
- Access to appropriate (public) transportation that supports people with disabilities.
- Programs that support timely and affordable access to mobility and other assistive devices for people with stroke.
- Healthcare professionals and caregivers in the community and long-term care settings with stroke care expertise and access to ongoing education.
- Ongoing support in the form of community programs, respite care, and educational opportunities available to support caregivers who are balancing personal needs with caregiving responsibilities.
- Strategies to assist stroke survivors to maintain, enhance, and develop appropriate social support, and to re-engage in desired vocational, social, and recreational activities.
- Information regarding community resources and processes to access these resources provided to all people with stroke and their family members and caregivers.
- Health professionals should advocate to ensure that feasible alternatives to driving are available in the community.

Performance Measures

Clinical and Health System Performance Measures:

1. Proportion of people with stroke who are discharged from acute care who receive a referral for home care or community supportive services.
2. Proportion of readmissions to acute care for stroke-related causes following discharge to the community, stratified by type of stroke.
3. Proportion of people with stroke who return to the emergency department or hospital setting for non-physical issues following stroke (e.g., failure to cope).
4. Number of persons with stroke with documentation that information was given to them or their family on formal and informal educational programs, care after stroke, available services, process to access available services, and services covered by health insurance.
5. Documentation of shared and collaborative decision-making between healthcare professionals and persons with stroke regarding individualized transition plans.
6. Number of people with stroke referred to a secondary prevention team by the rehabilitation team.
7. Number of visits to primary care within specified time frames for stroke-related issues.
8. Number of visits to an emergency department within specified time frames.
9. Percentage of people with stroke who return home following stroke rehabilitation who require community health services (e.g., home care or respite care).
10. Length of time from hospital discharge (whether from acute care or inpatient rehabilitation) to initiation of community health services.
11. Frequency and duration of community health services, stratified by the type of service provided.
12. Number of readmissions from stroke rehabilitation to acute care for stroke-related causes.

13. Percentage of people with stroke who return to the community from acute hospital stay or following an inpatient rehabilitation stay who require admission to long-term care or a nursing home within six months or one year.
14. Median wait time from referral to admission to nursing home, complex continuing care or long-term care facility.
15. Documentation to indicate that assessment of fitness to drive and related counseling was performed.
16. Number of people with stroke referred for driving assessment by occupational therapist in the community.

Person-Oriented Measures (PREMS, PROMS)

1. Measure of burden of care for family and caregivers living in the community.
Changes in quality of life measured at regular intervals during recovery and participation, and reassessed when changes in health status or other life events occur (e.g., at 60, 90- and 180-days following stroke).

Measurement Notes

- Performance measure 1: data may be obtained from inpatient chart documentation or community support services documentation. Informal education or education received by primary care providers may be difficult to track unless specific audit tools are developed and implemented in local areas. Also refer to some of the performance measures listed in recommendation 2.1.
- Emergency department visits can be tracked through the Canadian Institute for Health Information database for participating institutions or hospital records if the person with stroke returns to the emergency department of the hospital where inpatient stay occurred.
- The Canadian Institute for Health Information holds an administrative data set for complex continuing care and long-term care, which uses a minimal data set that is mandated in several regions across Canada. This data set uses the Resident Assessment Instrument tool for assessing functional status. At this time there are no validated comparison models between the Functional Impact Measure and the Resident Assessment Instrument.
- Hospital readmissions from inpatient rehabilitation to acute care can be obtained from hospital administrative data nationally and provincially.
- Visits to primary care and indicators related to information and education are difficult to measure. They could be obtained through surveys and standardized audit tools at the local or regional level.

Implementation Resources and Knowledge Transfer Tools

Health Care Provider Information

- [Table 1: Tools to Assess Participation and Health-Related Quality of Life \(Appendix Two\)](#)
- [Table 3: Assessment Tools for Pre-Driving Screening and Research Correlating Tools with Driving Risk](#)
- Taking Action for Optimal Community and Long-Term Stroke Care: A resource for healthcare providers: <https://www.strokebestpractices.ca/resources/professional-resources>
- The Functional Independence Measure (FIM®): <https://www.stroking.ca/en/assess/fim/>
- The Chedoke-McMaster Stroke Assessment: <https://www.sralab.org/rehabilitation-measures/chedoke-mcmaster-stroke-assessment-measure>

- The Craig Handicap Assessment and Reporting Technique (CHART): <https://craighospital.org/programs/research/research-instruments>
- The Community Integration Measure: <http://www.disabilitypolicyalliance.ca/community-integration-measure>

Resources for People with Stroke, Families and Caregivers

- Rehabilitation and Recovery infographic: Guide to taking charge of your stroke recovery: <https://www.heartandstroke.ca/-/media/1-stroke-best-practices/rehabilitation-nov2019/csbp-infographic-rehabilitation.ashx>
- Transitions and community participation infographic: Guide to taking charge of your stroke recovery: <https://www.heartandstroke.ca/-/media/1-stroke-best-practices/transition-of-care-nov2019/csbp-infographic-transitions-and-participation.ashx>
- Your Stroke Journey: A guide for people living with stroke: <https://www.strokebestpractices.ca/-/media/1-stroke-best-practices/resources/patient-resources/en-your-stroke-journey-v21.ashx>
- Post-Stroke Checklist: <https://www.strokebestpractices.ca/resources/patient-resources>
- Heart & Stroke Services and Resources Directory: <https://www.heartandstroke.ca/services-and-resources>
- Living with Stroke™ program: <https://www.heartandstroke.ca/stroke/recovery-and-support/living-with-stroke>
- A Family Guide to Pediatric Stroke: <https://www.strokebestpractices.ca/resources/patient-resources>
- Canadian Partnership for Stroke Recovery Patient Resources: <https://www.canadianstroke.ca/en/tools-resources/patients>
- Stroke Engine: strokengine.ca

Summary of the Evidence

The post-discharge period is a difficult time of adjustment for both patients and their families, as they return to vocational and social life roles. For persons returning home, the transition period may be challenging as the social, emotional, and practical support offered by inpatient care is lost.

Return to Work

Return to work (RTW) is one of the most important issues for those who were working at the time of their stroke. Following stroke, the reported rates of RTW vary widely. Using the results from 29 studies, Edwards et al. (2017) reported that the overall frequency of return to either full or part-time work, assessed up to 12 years following stroke ranged from 7.3%–74.5%. Up to 6 months following stroke, 41% of persons had returned to work, increasing to 66% at 4–6 years. Hackett et al. (2012) reported that 75% of persons previously employed at the time of stroke had returned to work at one year. Hannerz et al. (2011) reported that of 19,985 persons included in the Danish Occupational Hospitalization Register who were 20–57 years and had sustained a stroke, 62.1% were employed 2 years post stroke. At 4 years following stroke, Trygged et al. (2011) reported that 4,867 (69%) of 7,081 Swedes who had been employed prior to stroke, aged 40–59 years had successfully returned to work. The most commonly-cited predictors of successful RTW include independence in activities of daily living (ADLs), younger age, milder stroke severity higher cognitive functioning, fewer neurological deficits, strong family support, having realistic and flexible vocational goals, higher income and education, having a white-collar job and being male (Edwards et al. 2017, Wang et al. 2014, Hannerz et al. 2011), while hemorrhagic stroke, increasing age and stroke severity, and depression, have been cited as factors associated with

a decreasing probability of RTW Wang et al. 2014, Hannerz et al. 2011).

Interventions to help improve the odds of successful RTW have not been well studied. Ntsiea et al. (2015) reported that a 6-week individualized workplace intervention program group was associated with an increase in the number of persons who had returned to work following a recent stroke (<8 weeks), compared with persons receiving usual care, at 6 months (60% vs. 20%, $p < 0.001$). Baldwin & Brusco (2011) included the results from 6 studies, which examined rehabilitation programs that included vocational training post stroke. Vocational rehabilitation programs were defined as those that included medical, psychological, social, physical and/or occupational rehabilitation activities with the purpose to return to work. Following completion of the programs, the RTW rates varied among the studies from 12% to 49%. The pre-stroke vocation status was reported in 3 studies and ranged from 48% to 100%.

Leisure Activity

Many people recovering from stroke are unable to resume their previous leisure activities. Factors including physical limitations, attributable to residual disability, decreased motivation, environmental barriers including transportation and affordability have been cited as reasons for decreased participation.

A variety of programs and interventions have been evaluated to help improve participation following stroke, although few have used an assessment of leisure as the primary outcome. A systematic review by Dorstyn et al (2014) including the results from 8 RCTs that examined the benefit of a community-based intervention focusing on leisure therapy, leisure therapy + physical activity or leisure education, which provided an average of 17 sessions over 23 weeks. The majority of participants had experienced a mild or moderately-disabling stroke within the previous year. While no pooled analyses were conducted, within individual trials significant improvement was noted at the end of treatment on measures of quality of life, mood and satisfaction with leisure activity. An 8-week peer-volunteer facilitated exercise and education program was associated with significantly greater improvement in median perceived Subjective Index of Physical and Social Outcome (physical component) scores at both at the end of treatment and at one year, compared with participants who received standard care (Harrington et al. 2010). Desrosiers et al. (2007) included 62 participants residing in the community with a history of stroke within the previous 5 years and who were experiencing some limitations in leisure participation or satisfaction. The intervention involved 8-12, 60-minute, weekly education sessions, while participants in the control groups received home visits from a recreational therapist following the same schedule as the intervention group. At the completion of the study, participants in the intervention group reported significantly more time spent in active leisure activities (MD=14.0 minutes, 95% CI 3.2-24.9, $p=0.01$) and involvement in a greater number of different activities (MD= 2.9, 95% CI 1.1-4.8, $p=0.002$). Participants in the intervention group had also gained significantly more points on the Leisure Satisfaction Scale (MD= 11.9, 95% CI 4.2-19.5, $p=0.003$) and in the satisfaction of leisure needs and expectations (MD=6.9, 95% CI 1.3-12.6, $p=0.02$).

Sexuality

Reports of sexual dysfunction following stroke are common. Among several surveys including small samples, declines in sexual activity have been reported. Stein et al. (2013) surveyed 35 persons who agreed to participate, out of 268 who were included in a stroke rehabilitation research registry. Of those, 100% of men and 58% of women met the criteria for sexual dysfunction, 42% indicated their sexual functioning was worse following stroke, 94% reported that physical limitations impacted their sexual activity and 58.8% reported feeling less sexually desirable following stroke. Buzzelli et al. (2007) also reported that among 60 patients (83.3%) reported a decline in sexual activity during the first year following stroke. Variables associated with disruption of sexual activity included fear of relapse, belief

that one must be healthy to have a sex life and partner who is “turned off” at the prospect of sexual activity with a “sick person”.

Only a few small trials examining interventions designed to address issues relating to sexuality post stroke have been published. Sampson et al. (2015) reported no significant differences between groups on median Sexual Function Questionnaire Short-Form (CSFQ-14) scores following a single 30-minute structured sexual rehabilitation session, conducted by a rehabilitation physician, compared with persons who received a fact sheet. Guo et al. (2015) reported that the percentage of stroke rehabilitation inpatients given the opportunity to talk about sexual issues increased from 0% at months 1-3 to 80% at month 10 following an intervention designed to ensure patients had opportunity to discuss sexual health with one of their healthcare providers. A study assessing a sexuality education intervention found that patients who received a short (40-50 minute) education session that outlined the changes that they can expect in their sexuality post-stroke, addressed frequently asked questions and provided tips to avoid sexual dysfunction were more sexually active and experienced greater sexual satisfaction than patients who did not. (Song et al. 2011).

Return to Driving

Since driving was part of many persons daily routine prior to stroke, returning to driving is often a high priority; however, motor, sensory, and cognitive impairments and visual fields defects can limit a person’s ability to drive safely. Beyond its use for completing everyday tasks and travelling to work, driving is often seen as a symbol of independence and freedom. For those who have had a minor stroke or TIA, temporary restrictions place on driving may be confusing and seem unwarranted. Independent predictors of successful return to driving following stroke include independence in activities of daily living and the return to paid work (Yu et al. 2016). Performance of cognitive measures such as the Trail Making Test and the Snellgrove Maze Test have been shown to predict fitness to drive (Barco et al. 2014, Devos et al. 2011). In one recent study that included 359 participants, 26.7% returned to driving after one month (Yu et al. 2016).

Interventions to help improve driving skills after stroke have not been well studied. A Cochrane review (George et al. 2014) included the results from 4 RCTs. The interventions examined included driving simulators (n=2) and skills development using the Dynavision device (n=1) and Useful Field of View training (n=1). No pooled analyses of the primary outcome, performance (pass/fail) during on-road assessment, were possible due to heterogeneity. Based on the results from a single trial, there was no significant difference in the mean on-road scores between groups at 6 months (MD=15.0, 95% CI -4.6 34.6, p=0.13), although participants in the intervention group had significantly higher scores on road sign recognition test (MD=1.69, 95% CI 0.51-2.87, p=0.0051).

Community Participation Following Stroke Evidence Tables and Reference List available at www.strokebestpractices.ca

Section 5: Transition to Long-Term Care Following a Stroke

Recommendations

Note: These recommendations apply specifically to persons with stroke living in long-term care or chronic or continuing care settings, including those who were already living in long-term care at the time of their stroke. These recommendations are intended to be implemented in addition to standard care (e.g. physical, functional, emotional, cognitive and social needs) provided in chronic, continuing or long-term care. Recommendations included in other sections of this module, such as Supporting People with Stroke, Their Families and Caregivers (Section 1) and Education for People with Stroke, Their Families and Caregivers (Section 2) also apply to these settings.

5.1 Assessment and Care Planning

- i. All people who transition to a long-term care setting following a stroke should have an initial assessment, conducted by medical, nursing and rehabilitation professionals, as soon as possible after admission [Evidence Level A]. *Refer to Rehabilitation module and other sections of this module for information on assessments*
 - a. A discharge summary along with the care plan should accompany the individual to long-term care [Evidence Level B]. *Refer to Box 3 regarding information to include in the discharge summary.*
 - b. Consider aligning the initial assessment of functional, physical, emotional, cognitive, and perceptual status with existing assessment processes (such as the Minimum Data Set-Resident Assessment Inventory (RAI-MDS 2.0); or Multi-clientele Autonomy Assessment in Quebec) where possible [Evidence Level C].
 - c. Assessment results can be used to modify individualized care plans to optimize quality of life and meet functional, physical, emotional, cognitive, and perceptual needs and goals of people who are admitted to long-term care following a stroke [Evidence Level C].
 - d. Individualized care plans may be updated to incorporate changes in care requirements, address issues of safety, and the potential need for referrals to appropriate healthcare professionals for further consultation when declines or improvements are identified during the initial assessment or subsequent reassessments [Evidence Level C].
- ii. Chronic, continuing and long-term care staff members should be knowledgeable in stroke care, maintenance and recovery goals, therapies and stroke best practice recommendations and be provided with updated education in these areas on a regular basis [Evidence Level C]. *Refer to HSF's Taking Action for Optimal Community and Long-Term Stroke Care resource for training content.*

5.2 Rehabilitation and Restorative Care

- i. People who have ongoing rehabilitation goals post-stroke should continue to have access to specialized stroke services (such as physiotherapy, occupational therapy and speech-language therapy) following admission to a community living setting [Evidence Level A], including within a long-term care setting.
- ii. At any point in their recovery, people with stroke living in long-term care who have experienced a change/improvement in functional status and who would benefit from new or additional rehabilitation services should be offered a trial of active inpatient or outpatient rehabilitation [Evidence Level B].

- iii. Residents in long-term care should have access to exercise, leisure opportunities, and support to engage in personally valued activities [Evidence Level B].

5.3 Support and Education for the Person with Stroke and Their Family

- i. To encourage active participation in care-planning consider providing training, education and support on:
- How to advocate and participate in care planning including access to rehabilitation and restorative care as appropriate and how to be involved in shared decision-making [Evidence Level C].
 - Process for appointing a substitute decision-maker (proxy or agent), developing advance directives for care, and palliative care options as appropriate [Evidence Level C]. *Refer to Acute Stroke Management Module 2018 Sections 10 and 11 for additional information.*

Rationale

Health care surveillance data indicates that persons with stroke are among the largest population receiving long-term care, and their number is steadily increasing worldwide. This transition often involves emotional concerns for persons with stroke, their families and caregivers that are not necessarily experienced with other transitions. Persons with stroke who transition to long-term care should be cared for in an environment that is supportive, with staff knowledgeable and competent in meeting their specific needs within this setting. This will enable those with stroke to maintain quality of life and dignity, and have rehabilitation and recovery goals and plans that focus on restorative care, maintenance of function, support for health declines, and sensitivity to family needs. The post-discharge period is consistently reported to be a stressful and challenging time for persons with stroke and their families as they adjust to new roles, altered functional and cognitive abilities, and changes in living setting for people admitted to long-term care following an acute stroke.

System Implications

Successful transition to long-term care for people with stroke, their families, and caregivers requires:

- Processes to support timely and efficient transfer from acute care or inpatient rehabilitation to long term care, avoiding multiple transfers before reaching planned destination.
- Adequate follow-up by care providers in all provinces and territories to support ongoing access to all needed rehabilitation services during transition to long-term care settings.
- Assistance for persons with stroke, their families, and caregivers with an evolving care plan and regular follow-up assessments.
- Communication strategies and processes to ensure timely sharing of information across all healthcare providers, including between long-term care team and community/hospital healthcare teams.
- Programs that support timely and affordable access to mobility and other assistive devices for people with stroke in long-term care.
- Ongoing stroke specific education and training for healthcare professionals and caregivers in the community and long-term care settings to increase stroke care expertise. Training to be provided by a range of healthcare disciplines, such as physiotherapy, occupational therapy, speech language pathology, and dietitians.
- Strategies and services to assist stroke survivors to maintain, enhance, and develop appropriate social support, and to re-engage in desired and or personally valued social and recreational activities.

Performance Measures

Clinical and Health System Performance Measures:

1. Proportion of people with stroke who are discharged from acute care directly to a long-term care setting following an acute stroke.
2. Proportion of people with stroke who were living independently (e.g., at home) prior to stroke who are admitted to long-term care following stroke.
3. Proportion of readmissions to acute care for stroke-related causes following discharge to long-term care, stratified by type of stroke.
4. Changes in functional status from time of admission compared at 3 months, 6 months and one year following admission to long-term care.
5. Number of visits to an emergency department within 3 months, 6 months and one year following admission to long-term care, stratified by reason for visit or hospital admission.

Person-Oriented Measures (PREMS, PROMS)

6. Measure of burden of care for family and caregivers living in the community and change in burden scores from before long-term care admission, and at 3 months, 6 months and one year following admission to long-term care.
7. Changes in quality of life measured at regular intervals during recovery and participation, and reassessed when changes in health status or other life events occur (e.g., at 60, 90- and 180-days following stroke).
8. Onset of new pressure injury, falls or other complications related to stroke.

Measurement Notes

- The Canadian Institute for Health Information holds an administrative data set for complex continuing care and long-term care, which uses a minimal data set that is mandated in several regions across Canada. This data set uses the Resident Assessment Instrument tool for assessing functional status. At this time there are no validated comparison models between the Functional Impact Measure and the Resident Assessment Instrument.
- Hospital readmissions from inpatient rehabilitation to acute care can be obtained from hospital administrative data nationally and provincially.

Implementation Resources and Knowledge Transfer Tools

Health Care Provider Information

- [Table 1: Tools to Assess Participation and Health-Related Quality of Life \(Appendix Two\)](#)
- Registered Nurses' Association of Ontario: Long-Term Care Best Practices Initiative: <http://rnao.ca/bpg/initiatives/longterm-care-best-practices-initiative>
- Registered Nurses' Association of Ontario: Positioning Techniques in Long-Term Care: http://rnao.ca/sites/rnao-ca/files/Positioning_Techniques_in_Long-Term_Care_-_Self-directed_learning_package_for_health_care_providers.pdf
- The Functional Independence Measure (FIM®): <https://www.strokengine.ca/en/assess/fim/>
- The Functional Autonomy Measurement System (SMAF): <https://www.expertise-sante.com/outils-cliniques/outils-rsipa/profils-iso-smaf/>
- The Chedoke-McMaster Stroke Assessment: <http://www.rehabmeasures.org/PDF%20Library/CMSA%20Manual%20and%20Score%20Form.pdf>

Resources for People with Stroke, Families and Caregivers

- Rehabilitation and Recovery infographic: Guide to taking charge of your stroke recovery: <https://www.heartandstroke.ca/-/media/1-stroke-best-practices/rehabilitation-nov2019/csbp-infographic-rehabilitation.ashx>
- Transitions and community participation infographic: Guide to taking charge of your stroke recovery: <https://www.heartandstroke.ca/-/media/1-stroke-best-practices/transition-of-care-nov2019/csbp-infographic-transitions-and-participation.ashx>
- Your Stroke Journey: A guide for people living with stroke: <https://www.strokebestpractices.ca/-/media/1-stroke-best-practices/resources/patient-resources/en-your-stroke-journey-v21.ashx>
- Post-Stroke Checklist: <https://www.strokebestpractices.ca/resources/patient-resources>
- Heart & Stroke Services and Resources Directory: <https://www.heartandstroke.ca/services-and-resources>
- Heart & Stroke Recovery and Support Health Information: <https://www.heartandstroke.ca/stroke/recovery-and-support/>
- Deciding on Long-Term Care: <http://www.strokecenter.org/patients/caregiver-and-patient-resources/caregiving-guide-for-african-americans/deciding-on-long-term-care/>

Summary of the Evidence

Following a stroke event, when community-based supports are not available to support non-institutional living, people may enter a long-term care (LTC) institution. Independent predictors of discharge to a nursing home have been identified and include increasing age, increasing dependency for ADLs and absence of availability of a caregiver (Burton et al. 2018, Pereira et al. 2014, Brodaty et al. 2010, Portelli et al. 2005). The numbers of patients admitted to a long-term care facility, both immediately upon discharge from hospitals, and up to 10 years post stroke have been examined. Pooling the results from 18 studies, Burton et al (2018) reported a median of 17% of patients were transferred directly to a LTC facility following discharge from an acute care hospital with a diagnosis of stroke. Between 10% and 11% of patients admitted to an acute care hospital were residing at an LTC facility at one, three and 6 months following stroke (Chuang et al. 2005). Brodaty et al. (2010) followed 202 participants, mean age of 72 years, without dementia who had suffered an ischemic stroke. Among those who survived, nursing home admission rates were 24% at 5 years and 32% at 10 years. Walsh et al. (2008) reported that among a group of 136 patients admitted to a stroke unit of a single hospital (median age was 77 years), 40.3% of patients were institutionalized at 4 years.

Patients discharged to long term care require discharge planning much like individuals returning to their own homes. Several studies have examined factors for effective discharge communication between inpatient hospital care and institutional care facilities. Clear communication between facilities regarding nutritional needs, functional status, communication abilities, risk assessment, and medical management is necessary for an optimal transition (Sackley & Pound 2002; Sackley & Pound 2002).

Individuals residing in skilled nursing facilities with staff trained in stroke management, and who have access to post stroke therapy resources, may experience better quality of life. In a study (Brajkovic 2009) examining individuals living in a nursing home who received 24-hour care including access to psychiatric care, physician visits, daily physiotherapy, and weekly massage services, nursing home residents experienced greater quality of physical, psychological, social, and environmental quality of life scores compared with individuals living in their own homes receiving many of the same services. Individuals residing in nursing homes also experienced better perceived quality of life and health status than their residentially residing counterparts. However, the authors of a Cochrane review (Fletcher-Smith et al. 2013) stated there was insufficient evidence to support or refute the efficacy of occupational therapy interventions for improving, restoring or maintaining independence in ADL for persons with stroke residing in care homes.

Transition to Long-Term Care Following a Stroke Evidence Tables and Reference List available at www.strokebestpractices.ca

APPENDIX ONE

Canadian Stroke Best Practice Recommendations Transitions and Community Participation Following Stroke Writing Group 2019

NAME	PROFESSIONAL ROLE	LOCATION	COI
Mountain, Anita Co-Chair	Assistant Professor, Dalhousie University Division of Physical Medicine and Rehabilitation; Medical Lead Acquired Brain Injury Program, Queen Elizabeth II Health Sciences Centre, Nova Scotia Rehabilitation Centre Site	Nova Scotia	No conflicts to declare
Cameron, Jill I. Co-Chair	PhD; Associate Professor, Vice-Chair Research, Department of Occupational Science and Occupational Therapy, Rehabilitation Sciences Institute, Faculty of Medicine, University of Toronto	Ontario	No conflicts to declare
Bains, Naresh	BA (Hons), BSW, RSW Social Worker, Neurosciences University of Alberta Hospital	Alberta	No conflicts to declare
Bowes, Rebecca	BA (Hons); Regional Coordinator, Post-Stroke Transitional Care Program; ICAN Independence Centre and Network	Ontario	Potential Conflict: Works for ICAN Independence Centre and Network
Cheung, Donna	OT Reg (Ont); Stroke Program Coordinator, South East Toronto Stroke Network	Ontario	No conflicts to declare
Corriveau, Hélène	PT, PhD; Full professor, School of Rehabilitation, Université de Sherbrooke	Quebec	No conflicts to declare
Joseph, Lynn	RN, MScN, CNN(c); Advance Practice Neuroscience Nurse, Health Care Management, Nurse On Board, Ottawa	Ontario	No conflicts to declare
Lesko, Dana	BA, HBOR; Community Stroke Navigator, West GTA Stroke Network, Trillium Health Partners	Ontario	No conflicts to declare
Millar, Ann	B.A., M.A.; Stroke Navigator, Health PEI	PEI	No conflicts to declare
Parappilly, Beena	RN, MSN, PhD Candidate, UBC; Clinical Nurse Specialist, Medicine/Ambulatory Program; Providence Health Care, Vancouver	BC	No conflicts to declare
Pikula, Aleksandra	MD, Assistant Professor of Medicine, Neurology, University of Toronto, Clinic Lead, CNS Vasculitis and Stroke in Young, TWH/MSH, Director, Stroke Neurology Research Program, UHN	Ontario	No conflicts to declare
Scarfone, David	MD, Family Physician	Ontario	No conflicts to declare

<p>Rochette, Annie</p>	<p>OT(c), PhD, Professor, School of Rehabilitation, University of Montreal and Investigator at Centre for Interdisciplinary Research in Rehabilitation of Greater Montreal (CRIR)</p>	<p>Quebec</p>	<p>Potential conflict: Advisory board or equivalent with a commercial organization: Heart & Stroke (Stroke Council), Canadian Partnership for Stroke Recovery (Priority and Planning Committee) Potential conflict: Canadian Partnership for Stroke Recovery – receives funding for www.strokengine.ca</p>
<p>Taylor, Trudy</p>	<p>RN BN, Nurse Clinician, Carewest Dr. Vernon Fanning Centre</p>	<p>Alberta</p>	<p>No conflicts to declare</p>
<p>Vallentin, Tina</p>	<p>M.Sc(A), SLP(C), Reg. CASLPO, Speech Language Pathologist, Patient Experience Specialist, Quality & Performance Portfolio Hamilton Health Sciences</p>	<p>Ontario</p>	<p>No conflicts to declare</p>

Canadian Stroke Best Practice Recommendations Transitions and Community Participation Following Stroke External Reviewers 2019

EXTERNAL REVIEWER	PROFESSIONAL ROLE	LOCATION	CONFLICT OF INTEREST
Biggs, Krista	RN MN NP Nurse Practitioner Neurology QEII Health Sciences Center Nova Scotia Health Authority	Nova Scotia	No conflicts to declare
Bonnell, Jeanne	O.T.Reg (Ont.) Acting Director Home and Community Care, Champlain LHIN	Ontario	No conflicts to declare
Dean, Catherine Mary	BAppSc (physiotherapy) with Distinction (Cumberland College of Health Sciences), MA (Columbia University), PhD (University of Sydney) Professor, Deputy Dean and Associate Dean Learning and Teaching, Faculty of Medicine and Health Sciences, Macquarie University, Sydney, Australia	Australia	Potential conflict : Clinical trial: Chief investigator on Falls after stroke trial
Egan, Mary	PhD, OT Reg (Ont) Professor, School of Rehabilitation Sciences, University of Ottawa Scientist, Bruyere Research Institute	Ontario	No conflicts to declare
Fage, Maria	OT Reg. (Ont.) Manager Patient Services, Waterloo Wellington Local Health Integration Network, Stroke Lead	Ontario	No conflicts to declare
Guest, Dana	BSc., PT Best Practice Physiotherapist, Champlain Regional Stroke Network	Ontario	No conflicts to declare
Joachimides, Jennifer	MSc OT Reg (Ont) Status-only Appointment: Department of Occupational Science and Occupational Therapy, Lecturer, Providence Health Centre	Ontario	No conflicts to declare
Keon, Lisa	RN, BScN Stroke Prevention and Heart Failure Nurse, Pembroke Regional Hospital	Ontario	Potential conflict: Canadian Stroke Congress Nursing Working Group
Lasuita, Catherine	BScOT Occupational Therapist, Carewest Neuro-Rehab, Dr. Vernon Fanning Centre	Alberta	No conflicts to declare
Nelson, Michelle LA	MA, PhD Scientist, Lunenfeld-Tanenbaum Research Institute, Assistant Professor, IHPME, University of Toronto	Ontario	No conflicts to declare

Sharp, Kelly	MResc, BScOT Regional Lead, Rehab Program and Stroke System Redesign Vancouver Coastal Health	British Columbia	No conflicts to declare
Sreenivasan, Barathi	MD, FRCPC Physiatrist, Staff Physician, Toronto Lecturer, Department of Medicine, University of Toronto	Ontario	No conflicts to declare
Subramanian, Sandeep	BPTH, PhD Assistant Professor, Tenure Track Department of Physical Therapy, School of Health Professions, UT Health, San Antonio, TX, USA	Texas, United States	No conflicts to declare
Tee, Alda	MHS., BSC.PT reg. PT Regional Community and LTC Coordinator, Central East Stroke Network	Ontario	No conflicts to declare
Yang, Christine	MD, FRCPC Medical Director, Stroke Rehabilitation Program, Elizabeth Bruyere Hospital, Bruyere Continuing Care, Ottawa	Ontario	No conflicts to declare

Appendix Two

Table 1: Tools to Assess Participation and Quality of Life

Assessment Tool	Purpose	Items and Administration	Additional Considerations	Availability
Health Status				
<p>Stroke Impact Scale (SIS)</p> <p>Duncan et al. 2003</p>	<p>The SIS is a measure of health status following stroke</p>	<p>59-items representing 8 domains: strength, hand function, ADL/IADL, Mobility, Communication, Emotion, Memory and Thinking, and Participation/Role Function. Each item is rated on a 5-point ordinal scale, with the exception of a single item rated on a 100-point visual analog scale.</p> <p><u>Score Interpretation:</u> Scores are summed for each domain and range from 0-100, with higher scores indicating more recovery.</p> <p><u>Administration:</u> Self-report; 15-20 minutes to administer</p>	<p>The SIS is easy to administer, does not require any additional equipment, and can be administered by mail or telephone. The measure can also be completed by proxy respondents, although there is some evidence that proxies tend to rate patients as being more impaired.</p> <p>Some ceiling effects have been observed for individuals with mild impairment, particularly, in the Emotion, Communication, and Memory and Thinking domains.</p> <p><u>Specialized Training:</u> None required.</p>	<p>Free for non-profit use after signing a licensing agreement</p> <p>http://www.stroking.ca/assess/sis/</p>
<p>Medical Outcomes Study Short Form 36</p> <p>SF-36</p> <p>(Ware & Sherbourne 1992)</p>	<p>The SF-36 was designed as a generic health survey for the assessment of health status in the general population.</p>	<p>36 items are organized into 8 subscales; physical functioning, role limitations- physical, bodily pain, social functioning, general mental health, role limitations – emotional, vitality, and general health perceptions. 2 additional questions estimate change in overall health status over the past year. With the exception of the general change in health status questions, subjects are asked to respond with reference to the past 4 weeks.</p> <p>Items are scored using a weighted Likert system. Items are summed to provide subscale scores which are transformed linearly to provide a score from 0-100 for each subscale. In addition, a</p>	<p>The SF-36 questionnaire can be administered by self-completion questionnaire or by interview (either on the telephone or in-person). It has been used as a mail survey with reasonably high completion rates reported, however, data obtained are more complete when interview administration is used. It should be noted that some items have been questioned as less relevant for use in the assessment of elderly populations.</p>	<p>Available without charge</p> <p>http://www.rand.org/health/surveys_tools/mos/mos_core_36item.html</p> <p>There are terms and conditions for use posted on the site.</p>

Assessment Tool	Purpose	Items and Administration	Additional Considerations	Availability
		<p>physical component (PCS) and mental component (MCS) score may be derived. The 2 health status questions remain separate from the 8 subscales and are not scored.</p> <p><u>Score Interpretation:</u> There are normative subscale scores based on population data available for a number of different countries. In addition, component scores have also been standardized with a mean of 50 and a standard deviation of 10.</p> <p><u>Administration:</u> Approx. 10 minutes. Self-report or by interview.</p>	<p>The SF-36 has been studied for use by proxy, however, reliability of the test decreased when proxy respondents completed assessments.</p> <p><u>Specialized training:</u> None required.</p>	
Participation/Extended Activities of Daily Living				
<p>Assessment of Life Habits (LIFE-H 3.1)</p> <p>Fougeyrollas et al. 2001</p>	<p>The LIFE-H is a measure of the accomplishment of daily activities and social roles.</p>	<p>77-items representing 12 domains. Items are rated on two-scales: 1) level of difficulty/type of assistance required (10-point ordinal scale) and 2) satisfaction with performance (5-point ordinal scale).</p> <p><u>Score Interpretation:</u> Scores are summed and presented as an average of items answered, with lower scores indicating less optimal subjective participation. Ratings on the Satisfaction with Performance scale are not included as part of the total score.</p> <p><u>Administration:</u> self-report; 20-30 minutes to administer.</p>	<p>The LIFE-H is easy to administer and does not require specialized equipment.</p> <p>The scale is not available for free, is somewhat lengthy, and some concern has been expressed regarding ceiling effects in patients with mild stroke (Rochette et al. 2007).</p> <p><u>Specialized Training:</u> Recommended.</p>	<p>Available for purchase by request</p> <p>http://www.strokengine.ca/assess/lifeh/</p>
<p>Frenchay Activities Index (FAI)</p>	<p>The FAI provides an assessment of a broad range of</p>	<p>The FAI contains 15 items or activities that can be separated into 3 factors; domestic chores, leisure/work and outdoor activities. The frequency with which each item or activity is undertaken over</p>	<p>Simple and brief. Well suited to use in most clinical settings. However, lack of standardized guidelines for administration or interpretation may</p>	<p>Free of charge</p>

Assessment Tool	Purpose	Items and Administration	Additional Considerations	Availability
(Holbrook & Skilbeck 1983)	activities associated with everyday life.	<p>the past 3 or 6 months (depending on the nature of the activity) is assigned a score of 1 – 4 where a score of 1 is indicative of the lowest level of activity.</p> <p><u>Score Interpretation:</u> Summed scores range from 15-60.</p> <p><u>Administration:</u> 5 minutes or less. Self-report or interview.</p>	<p>reduce comparability between settings, groups or studies.</p> <p>The FAI extends information about function along the ADL continuum in terms of item difficulty. It should be noted that FAI scores may be influenced by both gender and age.</p> <p>The FAI is suitable for use with proxy respondents. The scale is based on behaviour and the emphasis placed on frequency rather than quality of activity. This reduces elements of subjectivity which can undermine reliability of proxy assessment.</p> <p><u>Specialized Training:</u> None required.</p>	http://www.strokenine.ca/assess/fai/
London Handicap Scale (LHS) Harwood & Gompertz, 1994	The LHS is a measure of the degree of disadvantage perceived by an individual as the result of an illness/handicap.	<p>6-items, each representing a single dimension: Mobility, Physical Independence, Occupation, Social Integration, Orientation, and Economic Self Sufficiency. Responses are rated on a 6-point ordinal scale relating to the degree of perceived disadvantage.</p> <p><u>Score Interpretation:</u> The LHS provides a profile of handicap based on the responses within each of the 6 dimensions as well as a weighted total handicap score. This overall weighted score should be interpreted as an estimate of the desirability of the health state described by the respondent's profile.</p> <p>Scale weights are used to calculate total scores, which range from 0 to 1.0, with lower scores indicating more disability.</p>	<p>LHS appears to facilitate the assessment of 'participation', though response statements span all domains of the ICF. Statements that describe body functions are typically associated with greater degrees of restriction in participation (Perenboom and Chorus 2003).</p> <p>The LHS is brief, easy to administer and does not require any specialized equipment. It can be administered via mail or completed by a proxy respondent.</p> <p>Use of a weighted scale makes calculation of total scores relatively arduous, as compared to other</p>	<p>Free</p> <p>http://www.rehabmeasures.org/Lists/RehabMeasures/DispForm.aspx?ID=929</p>

Assessment Tool	Purpose	Items and Administration	Additional Considerations	Availability
		<p><u>Administration:</u> Self-report; approximately 5 minutes to administer</p>	<p>measures. More independent research is required to assess the psychometric properties of the LHS (Salter et al. 2012).</p> <p><u>Specialized Training:</u> Not required.</p>	
<p>Reintegration to Normal Living Index (RNLI)</p> <p>Wood-Dauphinee et al. 1988</p>	<p>The RNLI is a measure of reintegration to normal activities following illness of trauma.</p>	<p>11 declarative statements rated by respondents on a 10cm visual analogue scale.</p> <p><u>Score Interpretation:</u> Summed scores are reported as a percentage out of 100, with lower scores indicating poorer perceptions of reintegration. Scores can also be calculated for Daily Functioning and Perceptions of Self subscales.</p> <p><u>Administration:</u> Self-report; approximately 10 minutes to administer.</p>	<p>The tool focuses on the perception of the individual with regard to personal capability and/or autonomy. It may be considered a person-centred assessment of re-integration.</p> <p>Quick, easy to administer, and does not require any additional equipment.</p> <p>The visual analogue response format may not be appropriate for use with some stroke patients (e.g., those with neglect or visuospatial deficits). Concern has been expressed regarding the use of proxy respondents (Tooth et al. 2003).</p> <p><u>Specialized Training:</u> Not required.</p>	<p>Free</p> <p>http://www.strokengine.ca/assess/rnli/</p>
Health-related Quality of Life				
<p>EuroQoL Quality of Life Scale (EQ-5D)</p> <p>EuroQoL Group, 1990</p>	<p>The EQ-5D is a measure of health-related quality of life.</p>	<p>Part 1 consists of 5 domains: Mobility, Self-care, Usual Activities, Pain/Discomfort, and Anxiety/Depression. For each domain, respondents are asked to indicate which 1 of 3 statements best describes their current health</p>	<p>The EQ-5D is short, easy to administer, and does not require any specialized equipment. The measure can be administered in person or by mail</p>	<p>Licensing fees may be required</p> <p>http://www.euroqol.org/</p>

Assessment Tool	Purpose	Items and Administration	Additional Considerations	Availability
		<p>state. Part 2 consists of a 100 cm visual analog scale representing “your own health state today.”</p> <p><u>Score Interpretation:</u> Weights are applied to calculate a summary index score, which range from 0 to 1, with higher scores indicating more quality of life.</p> <p><u>Administration:</u> Self-report; approximately 3 minutes to administer.</p>	<p>Although the EQ-5D can be completed by a proxy respondent, decreased reliability has been reported (Dorman et al. 1998). Patient-proxy agreement rates have also been reported to be low on the more subjective domains (e.g., anxiety/depression, and pain/discomfort) (Picard et al. 2004).</p> <p><u>Specialized Training:</u> Not required.</p>	
<p>Stroke Specific Quality of Life Scale (SS-QOL)</p> <p>Williams et al. 1999</p>	<p>The SS-QOL is a measure of health-related quality of life.</p>	<p>49-items representing 12 domains: energy, family roles, language, mobility, mood, personality, self-care, social roles, thinking, upper extremity function, vision, and work/productivity. Items are rated on a 5-point ordinal scale.</p> <p><u>Score Interpretation:</u> Summation yields a total score ranging from 49 to 245, with higher scores indicating better functioning. Subscale scores can also be calculated.</p> <p><u>Administration:</u> Self-report; approximately 10-15 minutes to administer.</p>	<p>Quick, easy to administer, and does not require any additional equipment.</p> <p>The SS-QOL can be completed by proxy respondents; however, agreement rates have been reported to be weaker for items that are more subjective as compared to those that are more observable (Williams et al. 2000). Some concern has been expressed regarding floor and ceiling effects (Czechowsky & Hill, 2002).</p> <p><u>Specialized Training:</u> Not required.</p>	<p>Free</p> <p>http://www.stroking.ca/assess/ssqol/</p>
<p>Stroke-Adapted Sickness Impact Profile (SA-SIP-30)</p> <p>Van Straten et al. 1997</p>	<p>The SA-SIP-30 is a measure of health-related quality of life</p>	<p>30-items representing 8 domains: Body Care and Movement, Social Interaction, Mobility, Communication, Emotional Behavior, Household Management, Alertness Behavior, and Ambulation. Respondents are asked to mark “yes”</p>	<p>The SA-SIP-30 is much shorter and easier to administer than the original 136-item scale. However, evidence suggests that the shorter version may not perform as well when used with</p>	<p>Free</p> <p>http://www.stroking.ca/assess/sasip30/</p>

Assessment Tool	Purpose	Items and Administration	Additional Considerations	Availability
		<p>for each item that is descriptive of the impact of illness on their daily life.</p> <p><u>Score Interpretation:</u> Items are weighted, summed, and expressed as a percentage, with higher scores indicating less quality of life. Subscale cores can also be calculated. The scale authors have suggested a cut-off score of >33 as being indicative of poor health.</p> <p><u>Administration:</u> Self-report; approximately 10 minutes to administer.</p>	<p>patients with more severe stroke (van Straten et al. 1997).</p> <p>No specialized equipment is required.</p> <p><u>Specialized Training:</u> Not required.</p>	
Assessment of Caregiver Burden				
<p>Bakas Caregiving Outcomes Scale</p> <p>(Bakas et al. 1999, 2006)</p>	<p>Assesses adaptation to caregiving in informal carers of individuals with stroke.</p>	<p>Originally a 10 item scale, the 15-item version is used more often. Items reflect changes in social functioning, subjective well-being and perceived health attributable to fulfilling the role of informal carer. Each item is rated on a 7-point Likert scale ranging from -3 (changed for the worst) to +3 (changed for the best).</p> <p><u>Scores and interpretation:</u> Item scores transformed to 1-7, then summed to provide total scale scores ranging from 15 – 105.</p> <p><u>Administration:</u> Self-report. Requires 2-4 minutes to complete</p>	<p>Assesses both the positive and negative aspects of the caregiving role. Emphasis is placed on the subjective, social aspects of change associated with caregiving.</p> <p><u>Specialized training:</u> None required</p>	<p>The 15-Item BCOS is available upon request from Dr Tamilyn Bakas (Bakas et al. 2006)</p>
<p>Caregiver Strain Index</p>	<p>Originally developed as a screening instrument to</p>	<p>13 items rated as yes or no. Positive responses receive 1 point; negative receive no score.</p>	<p>Short and simple. Most commonly used scale for the assessment of</p>	<p>Free.</p>

Assessment Tool	Purpose	Items and Administration	Additional Considerations	Availability
(Robinson 1983)	detect strain (stress) in carers of individuals with hip surgery and heart disease.	<p>Scores and Interpretation: Item scores are summed to create total scores out of a possible 13.</p> <p>Administration: Self-report.</p>	<p>burden, particularly in research settings.</p> <p>Although used frequently, its psychometric properties have not been well-studied in populations of individuals with stroke.</p> <p>Specialized Training: None required.</p>	<p>Available via: http://www.rehabmeasures.org/Lists/RehabMeasures/DispForm.aspx?ID=1099</p>
Zarit Burden Interview (Zarit et al. 1980)	Measures the degree to which responsibilities associated with informal caregiving role have affected health, personal and social well-being. Originally developed to assess carers of individuals with dementia.	<p>29-item instrument includes items addressing caregiver health, well-being, finances, social life and the relationship between carer and the individual being cared for. 25 questions represent negative aspects of caring; 4 items represent positive aspects. Items are scored on a 5-point Likert scale (0-4). There are no subscales.</p> <p>Scores and Interpretation: Scores for 'negative' items are totaled, then 'positive' items subtracted to create an overall total score. Total scores are intended to reflect degree of burden.</p> <p>Administration: Self-report. Pen and paper or interview-administered.</p>	<p>Shorter 22, 18 and 12-item versions of the interview are also available. The 22-item version is used most frequently. Scores appear unaffected by age, gender language, marital or employment status, geographic locale suggesting the scale may be acceptable for a variety of assessment populations (Hebert et al. 2000).</p> <p>The Interview examines burden that is associated with both functional and behavioural impairments and with the situation in the home. Items focus on the subjective response of the carer.</p> <p>Specialized training: None required.</p>	<p>Free for use in non-funded studies only. Funded research or commercial use requires purchase/permission.</p> <p>http://www.proqolid.org/instruments/zarit_burden_interview_zbi</p>

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Table 2: Core Education Across the Continuum for People with Stroke

STROKE AWARENESS AND ACTION	HYPERACUTE CARE	ACUTE INPATIENT CARE	STROKE REHABILITATION	STROKE PREVENTION	TRANSITIONS	COMMUNITY INTEGRATION
Review and reinforce all information previously provided that is relevant to the person and their unique situation						
<ul style="list-style-type: none"> • Signs of Stroke <ul style="list-style-type: none"> • Face • Arms • Speech • Time • Call 911 immediately if signs of stroke observed • Never drive self or someone with stroke to hospital on your own • Risk factors for stroke <ul style="list-style-type: none"> • High Blood Pressure • Atrial Fibrillation • Obesity • High Sodium Diet • Diabetes • High Cholesterol • Lack of Exercise • Smoking • Sleep Apnea • Family History • Risk of stroke for all age groups from newborns to children, young adults and older adults 	<ul style="list-style-type: none"> • Types of Stroke • Cause of stroke for individual patient • Diagnostic tests <ul style="list-style-type: none"> • CT Scan • MRI • Carotid imaging • ECG for AFib detection • Acute thrombolysis • Endovascular interventions • Involvement of neurosurgery if applicable • Potential outcomes – expectation management • For patients discharged directly from the ED: <ul style="list-style-type: none"> • Need for follow-up with primary care and stroke specialists (refer to prevention education) • Risk of recurrence and review of stroke signs and symptoms • Accessing resources and stroke support following discharge 	<ul style="list-style-type: none"> • Current deficits – what areas may be involved • Patient safety • Family and caregiver safety • Tests and interventions • Initiate transition planning • Potential for home modifications prior to discharge • Discuss potential pathway for care and likely next setting of care • Focus on self-management and involvement of family and informal caregivers in daily activities • Medications: purpose, schedule, interactions, adherence • Activities to prevent complications • Accessing resources and stroke support following discharge from acute care • Expectations for recovery following 	<ul style="list-style-type: none"> • Educate people with stroke about goal-setting so they can actively participate in goal setting and care planning across settings • Information regarding specific individualized rehabilitation needs • Roles of each of the rehabilitation team members involved in care • The types or rehabilitation exercises and activities that could and should be done between scheduled sessions with therapists • Patient, family caregiver safety while participating rehabilitation • Self-management skills for mobility and activities of daily living • Discharge planning, type of care needed after discharge, and required modifications to 	<ul style="list-style-type: none"> • Signs of Stroke <ul style="list-style-type: none"> • Face • Arms • Speech • Time • Importance of calling 911 if any stroke signs and symptoms appear again after initial stroke • Risk factors for stroke <ul style="list-style-type: none"> • High Blood Pressure • Atrial Fibrillation • Obesity • High Sodium Diet • Diabetes • High Cholesterol • Lack of Exercise • Smoking • Sleep Apnea • Family History • Effects of stroke in months following index event – risk for depression, cognitive changes, sleep apnea, post-stroke fatigue; and provide strategies and self-management skills so patients, families and caregivers can 	<ul style="list-style-type: none"> • Self-management skills for activities of daily living • Types of services and primary contact for health care professionals at the next stage and/or setting • Appropriate expectations for recovery of deficits, time frames and likely transition points appropriate to the individual • Physical adjustments including medication adherence, post-stroke fatigue, strategies to prevent complications and recurrent stroke • Address functional issues – ongoing rehabilitation and physical activity recommendations, personalized plan of care and goal setting • Address psychosocial 	<ul style="list-style-type: none"> • Self-management skills for mobility, symptom management, medication adherence and activities of daily living • Types of services available in the community and how to access them – e.g., mobility assistance, meal delivery, communication support • Need for follow-up with primary health care providers for ongoing monitoring and management • Appropriate expectations for recovery of deficits, time frames as appropriate to individual situations • Physical adjustments including medication adherence, post-stroke fatigue, preventing complications,

STROKE AWARENESS AND ACTION	HYPERACUTE CARE	ACUTE INPATIENT CARE	STROKE REHABILITATION	STROKE PREVENTION	TRANSITIONS	COMMUNITY INTEGRATION
Review and reinforce all information previously provided that is relevant to the person and their unique situation						
		<p>discharge, addressing issues including depression, post-stroke fatigue, rehabilitation needs and access, and issues for social reintegration</p> <ul style="list-style-type: none"> • Access to community resources and stroke support groups • Re-access to healthcare system • Advance care planning and personal health directives 	<p>living setting prior to discharge from inpatient rehabilitation</p> <ul style="list-style-type: none"> • Information regarding resuming vocational, educational and driving activities • Information regarding relationships and sexuality post-stroke • Access to therapists and programs for ongoing rehabilitation in out-patient and community settings • Access to community resources and stroke support groups • Re-access to healthcare system • Advance care planning and personal health directives 	<p>manage in community and home settings</p> <ul style="list-style-type: none"> • Medication management • Atrial fibrillation risks and management as appropriate • Adherence to drug therapy • Access to community resources and stroke support groups • Re-access to healthcare system • Advance care planning and personal health directives 	<p>issues, i.e., depression, family support, referrals to community resources</p> <ul style="list-style-type: none"> • Self-management preparation for the next phase of care • Timeframes for transitions • Importance of information transfer and provision of written core information about previous stroke related episodes of care to share with stroke experts and recovery team members in next phase of care • Advance care planning and personal health directives 	<p>preventing recurrent stroke</p> <ul style="list-style-type: none"> • Addressing functional issues – ongoing rehabilitation and physical activity recommendations, personalized plan of care and goal setting • Social and leisure activity review and importance of resuming social interactions • Information regarding resuming vocational, educational and driving activities • Information on sexuality following stroke • Advance care planning and personal health directives

Table 3: Assessment Tools for Pre-Driving Screening and Research Correlating Tools with Driving Risk

Data was aggregated by the Toronto Rehabilitation Driving Best Practice Group under the leadership of Geoff Law OT Reg. (Ont) with the contributions from student occupational therapist Luisa Cao. Current document was summarized by Debbie Hebert OT Reg. (Ont).

Assessment/ Domain	Cut-Off Scores Correlated with Driving Risk/Return to Driving and Patient Populations	References																														
<p>Dynavision</p> <p>Domain: visual scanning, peripheral visual awareness, visual attention, visuomotor reaction time, execution of visuomotor response sequence, basic cognitive skills (short term memory), and physical and mental endurance</p> <p>Administration Time 15 – 20 min.</p>	<p>The following Dynavision tests were used in the research to determine fitness to drive:</p> <table border="1" style="width: 100%; border-collapse: collapse;"> <thead> <tr> <th style="text-align: center;">Test Mode</th> <th style="text-align: center;">Pass Criterion based on a pass/fail “behind the wheel test”</th> <th style="text-align: center;">Accuracy In predicting outcome</th> <th style="text-align: center;">False Positives</th> <th style="text-align: center;">False Negatives</th> </tr> </thead> <tbody> <tr> <td>Mode A 60 sec.</td> <td>50 responses/min</td> <td style="text-align: center;">66%</td> <td style="text-align: center;">4%</td> <td style="text-align: center;">30%</td> </tr> <tr> <td>Mode B 60 sec. with 1 sec. light speed</td> <td>40 responses/min.</td> <td style="text-align: center;">68%</td> <td style="text-align: center;">4%</td> <td style="text-align: center;">28%</td> </tr> <tr> <td>Mode B 60 sec. with on sec. light speed presented every 5 sec.</td> <td>30 responses/min.</td> <td style="text-align: center;">68%</td> <td style="text-align: center;">4%</td> <td style="text-align: center;">28%</td> </tr> <tr> <td>Mode A 4 min.</td> <td>195 responses/4 min.</td> <td style="text-align: center;">75%</td> <td style="text-align: center;">7%</td> <td style="text-align: center;">18%</td> </tr> <tr> <td>Mode A 60 sec. + Mode A 4 min</td> <td></td> <td style="text-align: center;">77%</td> <td style="text-align: center;">7%</td> <td style="text-align: center;">16%</td> </tr> </tbody> </table>	Test Mode	Pass Criterion based on a pass/fail “behind the wheel test”	Accuracy In predicting outcome	False Positives	False Negatives	Mode A 60 sec.	50 responses/min	66%	4%	30%	Mode B 60 sec. with 1 sec. light speed	40 responses/min.	68%	4%	28%	Mode B 60 sec. with on sec. light speed presented every 5 sec.	30 responses/min.	68%	4%	28%	Mode A 4 min.	195 responses/4 min.	75%	7%	18%	Mode A 60 sec. + Mode A 4 min		77%	7%	16%	<p>Klavora, P., Gaskovski, P., Martin, K., Forsyth, R.D., Heslegrave, R. J., Young, M., et al. (1995). The effects of Dynavision rehabilitation on behind-the-wheel driving ability and selected psychomotor abilities of persons after stroke. <i>The American Journal of Occupational Therapy</i>, 49, 534-542.</p> <p>Klavora, P., Gaskovski, P., & Forsyth, R. (1995). Test-retest reliability of three Dynavision tasks. <i>Perceptual Motor Skills</i>, 80(2), 607-610.</p> <p>Klavora, P., Heslegrave, R.J., & Young., M. (2000). Driving skills in elderly persons with stroke: comparison of two new assessment options. <i>Archives of Physical Medicine & Rehabilitation</i>, 81(6), 701-705.</p> <p>Vrkljan, B.H., McGrath, C.E., & Letts, L.J. (2011). Assessment tools for evaluating fitness to drive: A critical appraisal of evidence. <i>Canadian Journal of Occupational Therapy</i>, 78(2): 80-96.</p>
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<p>Motor Free Visual Perceptual Test (MVPT) Domains: visual perceptual skills, including spatial relations, visual discrimination, figure-ground, visual closure, and visual memory (McCane, 2006).</p>	<p>The use of the MVPT to inform ability to return to driving depends on the version used.</p> <p>The original version of MVPT, which is no longer commercially available, has the greatest amount of research evidence and at one time was considered the most predictive test of on-road performance (Bouillon, 2006). Findings linking MVPT performance with fitness to drive are inconsistent (Dickerson, 2014) and should not be used as a sole screening tool (Korner-Bitensky, 2000). Note: Positive predictive value was also found to vary with hemisphere</p>	<p>Ball, K., Roenker, D., Wadley, V., Edwards, J., Roth, D., McGwin, G., . . . Dube, T. (2006). Can high-risk older drivers be identified through performance-based measures in a department of motor vehicles setting? <i>J Am Geriatr Soc</i>, 54(1), 77-84.</p>																														

lesioned with the right hemisphere lesions having greater accuracy than the left hemisphere lesions (Mazer, 1998).

Version	Study	Suggested cut-off scores	Positive Predictive Value/ Negative Predictive Value	Time cut-off scores
MVPT	Bouillon et al., 2006; Korner-Bitensky et al., 2000; Mazer et al., 1998)	≤ 30 = needs further driving evaluation	86.1%/58.3 %	
	Oswanski, 2007 (older drivers)	≤ 32 = needs further driving evaluation		> 6.27s = predicts on-road failure Pass on road = 7.1 +/- 6.5; Fail on road = 10.6 +/- 5.5
	Ball et al., 2006	≤ 32 = older drivers 78+ years as likely to be involved in at-fault crashes.		
	Bouillon et al., 2006			>6.11 sec fail on road test Pass on road = 4.63 mean (2.30 SD); Fail on road = 6.11 mean (2.45 SD)
MVPT-3 (Third Ed.)	Gibbons, et al., (2017)	> 57 = predicts on-road test pass		

Bouillon, L., Mazer, M., & Gelinas, I. (2006). Validity of the Cognitive Behavioral Driver's Inventory in predicting driving outcome. *American Journal of Occupational Therapy*, 60(4), 420-427.

Dickerson, A.E., Meuel, D.B., Ridenour, C.D., & Cooper, K. (2014). Assessment tools predicting fitness to drive in older adults: A systematic review. *American Journal of Occupational Therapy*, 68, 670-680.

Gibbons, C., Smith, N., Middleton, R., Clack, J., Weaver, B., Dubois, S., & Bedard, M. (2017). Using serial trichotomization with common cognitive tests to screen for fitness to drive. *American Journal of Occupational Therapy*, 71

Korner-Bitensky, N.A., Mazer, B.L., Sofer, S., Gelina, I., Meyer, M.B., Morrison, C., ... & White, M. (2000). Visual testing for readiness to drive after stroke: A multicenter study. *American Journal of Physical Medicine & Rehabilitation*, 79(3): 253-259.

Mazer, B., Korner-Bitensky, N.A., & Sofer, S. (1998). Predicting ability to drive after stroke. *Archives of Physical Medicine & Rehabilitation*, 79(7), 743-749.

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McCane, S. (2006). Test review: Motor-Free Visual Perception Test. *Journal of Psychoeducational Assessment*, 24(3): 265-272.

Oswanski, M.F., Sharma, O.P., Raj, S.S., Vassar, L.A., Woods, K.L, Sargent, W.M., & Pitock, R.J. (2007). Evaluation of two assessment tools in predicting driving ability of senior drivers. *American Journal of*

	<table border="1"> <tr> <td data-bbox="606 207 835 289"></td> <td data-bbox="835 207 1012 289"></td> <td data-bbox="1012 207 1203 289">< 41 = predicts on-road test failure</td> <td data-bbox="1203 207 1360 289"></td> <td data-bbox="1360 207 1514 289"></td> </tr> <tr> <td data-bbox="606 289 835 594">MVPT – 4 (Fourth Ed.) For those using this test version, a conversion method of equating these score to MVPT – 3 scores was suggested Shurr et al. (2019)</td> <td data-bbox="835 289 1012 594"></td> <td data-bbox="1012 289 1203 594"> ≥ 38 – fit to drive 19-37 = “grey zone” ≤ 18 + unfit to drive </td> <td data-bbox="1203 289 1360 594"></td> <td data-bbox="1360 289 1514 594"></td> </tr> </table> <p>○ MVPT and Trail Making B, poor performance on both tests 22 times more likely to fail on-road evaluation (Mazer, 1998)</p>			< 41 = predicts on-road test failure			MVPT – 4 (Fourth Ed.) For those using this test version, a conversion method of equating these score to MVPT – 3 scores was suggested Shurr et al. (2019)		≥ 38 – fit to drive 19-37 = “grey zone” ≤ 18 + unfit to drive			<p>Physical Medicine & Rehabilitation, 86(3): 190-199.</p> <p>Schurr, Stephanie. <i>Driving After Stroke: Clinical Use of Pre-Driving Screen Data</i>. http://tbrhsc.net/wp-content/uploads/2017/01/S.Schurr-Driving-and-Stroke-OutPatient-Clinic.pdf accessed Jan 25, 2019</p>
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<p>Trail Making Test A – (TMT-A)and B (TMT-B)</p> <p>Domains: TMT-A: visual scanning, planning and motor processing speed (Roy & Molnar, 2013) TMT-B: visual scanning, planning, processing speed and attention/cognitive flexibility (Roy & Molnar, 2013)</p>	<p>This test has been highly correlated with driving performance. Time and errors both correlate with driving after stroke (Marshall et al., 2007). At an earlier point in time, the combination of the MVPT and the TMT-B resulted in the most predictive model: poor performance on both tests = 22x more likely to fail on-road evaluation (Mazer, 1998). There is however, a large amount of variability in determining in cut-off points. A conservative estimate from the data below would be a 3 min or 3 error cut-off. It is suggested that there shouldn't be strict adherence to a cut-off, but instead considering performance on Trails B in the context of how a person scores on other measures. It has also suggest that method of establishing the cut-off is important. Those established based on on-road performance vs. crash history may be more directly related to a screening process</p> <ul style="list-style-type: none"> Note: Several published guidelines have recommended use of the TMT-B to assess driving safety. TMT-A may also be used to discriminate between safe and potentially unsafe cognitively impaired older drivers (Lee & Molnar, 2017). See chart below: <table border="1"> <thead> <tr> <th data-bbox="611 1268 821 1349">Author</th> <th data-bbox="821 1268 1129 1349">Cut-off indicating needs further Driving Evaluation</th> <th data-bbox="1129 1268 1297 1349">Strength of association</th> <th data-bbox="1297 1268 1514 1349">Method of Evaluation</th> </tr> </thead> <tbody> <tr> <td data-bbox="611 1349 821 1498">Bedard et al., 2008</td> <td data-bbox="821 1349 1129 1498">TMT-A: >48 sec = indicative of unsafe driving TMT- B: >39.5 sec = needs further driving evaluation</td> <td data-bbox="1129 1349 1297 1498">PPV: 60.3%, NPV: 57.6%</td> <td data-bbox="1297 1349 1514 1498">Statistical correlation and ROC curve analysis for</td> </tr> </tbody> </table>	Author	Cut-off indicating needs further Driving Evaluation	Strength of association	Method of Evaluation	Bedard et al., 2008	TMT-A: >48 sec = indicative of unsafe driving TMT- B: >39.5 sec = needs further driving evaluation	PPV: 60.3%, NPV: 57.6%	Statistical correlation and ROC curve analysis for	<p>Bedard, M., Weaver, B., Darzins, P., & Porter, M.M. (2008). Predicting driving performance in older adults: we are not there yet! <i>Traffic Injury Prevention</i>, 9(4): 336–41.</p> <p>Classen, S., Wang, Y., Crizzle, A.M., Winter, S.M., & Lanford, D.N. (2013). Predicting older driver on-road performance by means of the Useful Field of View and Trail Making Test Part B. <i>American Journal of Occupational Therapy</i>, 67(5): 574–582.</p> <p>Devos, H., Akinwuntan, A.E., Nieuwboer, A., Truijen, S., Tant, M., & De Weerd, W. (2011). Screening for fitness to drive after stroke: A systematic review and meta-analysis. <i>Neurology</i>, 76(8), 747-756.</p> <p>Dickerson, A.E., Meuel, D.B., Ridenour, C.D., & Cooper, K. (2014). Assessment tools predicting fitness to drive in older adults: A systematic review. <i>American Journal of Occupational Therapy</i>, 68, 670-680.</p> <p><u>Gibbons, C., Smith, N., Middleton, R., Clack, J., Weaver, B., Dubois, S., and Bédard,</u></p>		
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Classen et al.	TMT- B: >106 sec predictive of poor on-road performance	PPV: 80%, NPV: 48.1%	On-road	
Devos et al.	TMT- B: >90 sec predictive of unsafe driving	PPV: 69%, NPV: 52%	Unsafe driving	
Gibbons et al.	TMT-A ≥ 69= Pass ≤ 25 Fail (100% sensitivity) TMT-B ≥178 = Pass (100% sensitivity) ≤ 80 Fail (100% sensitivity) (see chart p.5 for tri-chotomization))		In-clinic assessment and On-road	
National Highway Traffic Safety Admin (2003) Authors Staplin, L , Lococo, K.H., Gish, K. w., Decina , L. E.	TMT- B: >80 sec indicative of an “early warning” (prevention measure) of unsafe driving of unsafe driving. Score of 180 sec indicate an “immediate danger” (intervention measure)		Crash Risk	
Mazer et al. 1996	TMT-A: ≥ 1 error = needs further driving evaluation TMT- B: ≥3 errors = need for driving evaluation	p<.01, PPV = 85.2%, NPV = 48.1%	On-road	
Papandonatos et al., 2015 (older adults)	TMT-A: > 48 sec = indicative of unsafe driving TMT-B 108sec = indicative of unsafe driving		On-road	

		<p>scores in assessing fitness-to-drive. <i>Canadian Geriatrics Journal</i>, 16(3): 120-142.</p> <p>Tombaugh, T.N. (2004). Trail making Test A and B: normative data stratified by age and education. <i>Archives of Clinical Neuropsychology</i>, 19(2), 203-214.</p>
<p>Color Trails Test: Domains: selective attention, motor speed, visuospatial abilities, and executive functions (Elkin-Frankston et al., 2007)</p> <p>Similar to TMT, but involves alternation between numbers and two colors (1-pink, 2-yellow, 3-pink, etc.)</p>	<p><u>Evidence on predicting driving performance:</u></p> <ul style="list-style-type: none"> - The CTT can be used as an alternative to the TMT to predict on-road performance. The CTT may be particularly useful for those individuals who are less familiar with the Latin alphabet (Elkin-Frankston et al., 2007) <p><u>Suggested time cut-offs:</u></p> <ul style="list-style-type: none"> - > 60s = predicts road test failure (Hartman-Maeir et al., 2008) 	<p>Elkin-Frankston, S., Lebowitz, B.K., Kapust, L.R., Hollis, A.M., & O'Connor, M.G. (2007). The use of the Color Trails Test in the assessment of driver competence: Preliminary report of a culture-fair instrument. <i>Archives of Clinical Neuropsychology</i>, 22(5): 631-635.</p> <p>Hartman-Maeir, A., Bar-Haim Erez, A., Ratzon, N., Mattatia, T. & Weiss, P. (2008). The validity of the Color Trail Test in the pre-driver assessment of individuals with acquired brain injury. <i>Brain Injury</i>, 22(13-14): 994-998.</p>
<p>Clock drawing test: Domains: visual-spatial construction, visual perception, and abstract conceptualization (Oswanski et al., 2007)</p> <p>Currently, The Ontario Ministry of Transportation requires completion of a version of the Clock-Drawing Test as part of its Senior Driver Renewal Program that targets drivers aged 80 and older (Ontario Ministry of Transportation, 2017).</p>	<p><u>Evidence on predicting driving performance:</u></p> <ul style="list-style-type: none"> • The Clock Drawing Test is a significant predictor of seniors' driving capabilities (Oswanski et al., 2007) • Predicts on-road driving performance (Vanlaar et al., 2014) <p><u>Suggested cut-offs:</u></p> <ul style="list-style-type: none"> • Four Point Scale: $\leq 3/4$ = need further driving evaluation (Oswanski et al., 2007) • Seven Point Scale: \leq = Unfit to drive, \geq = Fit to drive (Gibbons, 2017) <p>Methods of administration and scoring of Clock Drawing Test can vary. See <i>AMA Physician's Guide to Assessing and Counseling Older Drivers</i> found in the Candrive website for 1 method (Freund Clock Scoring) of administering and scoring The Clock Drawing Test: http://www.ama-assn.org/ama1/pub/upload/mm/433/phyguidechap3.pdf</p>	<p>American Medical Association. <i>AMA physician's guide to assessing and counseling older driver's</i>. http://www.ama-assn.org/ama/pub/physician-resources/public-health/promoting-healthy-lifestyles/geriatric-health/older-driver-safety/assessing-counseling-older-drivers.shtml</p> <p>Gibbons, C., Smith, N., Middleton, R., Clack, J., Weaver, B., Dubois, S., & B'edard, M. (2017). Using serial trichotomization with common cognitive tests to screen for fitness to drive. <i>American Journal of Occupational Therapy</i>, 71</p> <p>Schurr, Stephanie. <i>Driving After Stroke: Clinical Use of Pre-Driving Screen Data</i>. http://tbrhsc.net/wp-content/uploads/2017/01/S.Schurr-Driving-</p>

		<p>and-Stroke-OutPatient-Clinic.pdf accessed Jan 25, 2019</p> <p>Oswanski, MF. et. al. (2007). Evaluation of Two Assessment Tools in Predicting Driving Ability of Senior Drivers. <i>American Journal of Physical Medicine and Rehabilitation</i>, 86, 3.</p> <p>Vanlaar, W., McKiernan, A., McAteer, H., Robertson, R., Mayhew, D., Carr, D., ...& Holmes, E. (2014). <i>A meta-analysis of cognitive screening tools for drivers aged 80 and over</i>. Ottawa, ON: Traffic Injury Research Foundation.</p>
<p>Useful Field of View (UFOV)</p> <p>Domain: Tests visual memory, visual attention, and divided attention with structured and unstructured components.</p> <p>The concept of “useful field of view” refers to the brain’s ability to comprehend visual info with the head and eyes in a stationary position. This test is administered on a computer.</p>	<p>The UFOV is one of the most extensively researched and promising predictor tests for a range of driving outcomes measures, including driving ability and crash risk (Wood & Owsley, 2014).</p> <ul style="list-style-type: none"> • Performance on the UFOV corresponds with crash history (Novack et al., 2006), future crashes (Owsley, 1994), and pass/fail on-road driving test (Myers et al., 2000; Novack et al., 2006; Stav et al., 2008) <p>Suggested cut-off scores (UFOV-2):</p> <ul style="list-style-type: none"> • ≥ 300 ms = need further driving evaluation <p>PPV: 61.9% NPV: 86.1% (Bedard et al., 2008)</p> <ul style="list-style-type: none"> • Drivers aged 75+: > 353 ms = 2x as likely to be involved in at-fault crashes (Ball et al., 2006) 	<p>Ball, K., Owsley, C., Sloane, M.D., Roenker, D.L., & Bruni, J.R. (1993). Visual attention problems as a predictor of vehicle accidents in older drivers. <i>Investigative Ophthalmology and Visual science</i>, 34, 3110-3123.</p> <p>Ball, K., & Owsley, C. (1993). The useful filed of view test: A new technique for evaluating age-related declines in visual function. <i>Journal of the American Optometric Association</i>, 64, 71-79.</p> <p>Ball, K., & Rebok, G. (1994). Evaluating the driving ability of older adults. <i>The Journal of applied Gerontology</i>, 13, 20-38.</p> <p>Ball, K.K., Roenker, D.L., Wadley, V.G., Edwards, J.D., Roth, D.L., McGwin, G., ...& Dube, T. (2006). Can high-risk older drivers be identified through performance-based measures in a department of motor vehicles setting? <i>Journal of the American Geriatrics Society</i>, 54(1), 77-84.</p> <p>Bedard, M., Weaver, B., Darzins, P., & Porter, M.M. (2008). Predicting driving</p>

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Owsley, C., & Ball, K. (1993). Assessing visual function in the older driver. *Clinics in Geriatric Medicine: Medical Considerations in the older driver*, 9, 389-401.

Myers, R. S., Ball, K. K., Kalina, T. D., Roth, D. L., & Goode, K. T. (2000). Relation of useful field of view and other screening tests to on-road driving performance. *Perceptual & Motor Skills*, 91: 279-290.

Novack, T.A., Banos, J.H., Alderson, A.L., Schneider, J.J., Weed, W., Blankenship, J., & Salisbury, D. (2006). UFOV performance and driving ability following traumatic brain injury. *Brain Injury*, 20: 455-461.

Stav, W.B., Justiss, M.D., McCarthy, D.P., Mann, W.C., & Lanford, D.N. (2008). Predictability of clinical assessments for driving performance. *Journal of Safety Research*, 39: 1-7.

Wood, J.M., & Owsley, C. (2014). Useful Field of View Test. *Gerontology*, 60(4): 315-318. Owsley, C., Ball, K., McGwin, G. Jr., Sloane, M.E., Roenker, D.L., White, M.F., et al. (1998). Visual processing impairment and risk of motor vehicle crash among older

		adults. <i>Journal of the American Medical Association</i> , 279(14), 1083-1088.
<p>Single-Letter Cancellation Test Domains: visual scanning and visual attention</p> <p>Administration time: <5 minutes</p> <p>Norms: 18–91 yrs</p>	<p><u>Evidence on predicting driving performance:</u></p> <ul style="list-style-type: none"> Single-Letter Cancellation Test is significantly associated with on-road test outcome (Mazer et al., 1998) <p><u>Suggested cut-off scores:</u></p> <ul style="list-style-type: none"> ≥ 5 errors = 3x more likely to fail on-road test (Mazer et al., 1998) <ul style="list-style-type: none"> PPV: 78.9% NPV: 44.6% 	Mazer, B., Korner-Bitensky, N.A., & Sofer, S. (1998). Predicting ability to drive after stroke. <i>Archives of Physical Medicine & Rehabilitation</i> , 79(7), 743-749.
<p>Bells Test:</p> <ul style="list-style-type: none"> Domains: selective attention and visual scanning 	<p><u>Evidence on predicting driving performance:</u></p> <ul style="list-style-type: none"> Bells Test is significantly associated with on-road test outcome (Mazer et al., 1998) <p><u>Suggested cut-off scores:</u></p> <ul style="list-style-type: none"> ≥ 4 errors = predictive of unsafe driving (Mazer et al., 1998) <ul style="list-style-type: none"> PPV: 77.8% NPV: 44.6% 	<p>Bouillon, L., Mazer, B., & Gelinas, I. (2006). Validity of the Cognitive Behavioural Driver's Inventory in predicting driving outcome. <i>American Journal of Occupational Therapy</i>, 60(4): 420-427.</p> <p>Mazer, B., Korner-Bitensky, N.A., & Sofer, S. (1998). Predicting ability to drive after stroke. <i>Archives of Physical Medicine & Rehabilitation</i>, 79(7), 743-749.</p>
Cognitive Screening		
<p>Mini-Mental State Exam Domains: Orientation to time and place, immediate recall, short-term verbal memory, calculation, language, and construct ability.</p>	<p>Current best practice suggests utilization of the MMSE with other tests to predict on-road performance as it is not adequate as a benchmark on its own (Hollis et al., 2015).</p> <p><u>Suggested cut-off scores:</u></p> <ul style="list-style-type: none"> ≤ 24/30 may indicate the presence of a cognitive impairment, but determining fitness to drive would require additional assessment (Molnar et al., 2009) <20/30 = likely unsafe to drive (Molnar et al., 2009) <p>If the MMSE has already been administered, and the clinician has concerns about driving capacity, a score of 24 would equate a score of 18 on the MoCA and could be used as a benchmark for driving risk (Hollis et al., 2015). However, ≤ 24 on the MMSE is not adequately sensitive to predict on-road performance.</p>	<p>Bedard, M., Weaver, B., Darzins, P., & Porter, M.M. (2008). Predicting driving performance in older adults: we are not there yet! <i>Traffic Injury Prevention</i>, 9(4): 336–41.</p> <p>Hollis, A.M., Duncanson, H., Kapust, L.R., Xi, P.M., & O'Connor, M.G. (2015). Validity of the Mini-Mental State Examination and the Montreal Cognitive Assessment in the prediction of driving test outcome. <i>Journal of the American Geriatric Society</i>, 63(5): 988-992.</p> <p>Molnar F.J., Byszewski, A.M., Rapoport, M., & Dalziel, W.B.. (2009). Practical experience-based approaches to assessing fitness to drive in dementia. <i>Geriatric and Aging</i>, 12(2): 83-92.</p>

<p>Montreal Cognitive Assessment (MoCA):</p> <p>Domains: attention and concentration, executive functions, memory, language, visuoconstructional skills, conceptual thinking, calculations, and orientation (Nasreddine et al., 2005).</p>	<p>While one study found that MoCA was predictive of fitness to drive, It is recommended to work best in combination with other cognitive tools and not as a stand-alone test. (Bowers et al., 2013; Esser et al., 2016; Kwok et al., 2015)</p> <p><u>Suggested cut-off scores:</u></p> <ul style="list-style-type: none"> • < 25 = discriminate pass/fail on-road (Kwok et al., 2015) • ≤ 18 = should raise concerns about driving (Hollis et al., 2015) • < 12 = likely to fail (Esser et al., 2016) • ≥ 27 = pass, ≤16 fail (Gibbons et al, 2017) 	<p>Bowers, A.R., Anastasio, R.J., Sheldon, S.S., O’Connor, M.G., Hollis, A.M., Howe, P.D., & Horowitz, T.S. (2013). Can we improve clinical prediction of at-risk older drivers? <i>Accident Analysis & Prevention</i>, 59(2013): 537-547.</p> <p>Esser, P., Dent, S., Jones, C., Sheridan, B.J., Bradley, A., Wade, D.T., & Dawes, H. (2016). Utility of the MoCA as a cognitive predictor for fitness to drive. <i>Journal of Neurology, Neurosurgery, and Psychiatry</i>, 87(5): 567-568.</p> <p><u>Gibbons, C., Smith, N., Middleton, R., Clack, J., Weaver, B., Dubois, S., and Bédard, M.I. (2017) Using Serial Trichotomization With Common Cognitive Tests to Screen for Fitness to Drive</u> <u>The American journal of occupational therapy : official publication of the American Occupational Therapy Association, 71(2): 1-8</u></p> <p>Kwok, J.C.W., Gelinas, I., Benoit, D., & Chilingaryan, G. (2015). Predictive validity of the Montreal Cognitive Assessment (MoCA) as a screening tool for on-road driving performance. <i>British Journal of Occupational Therapy</i>, 78(2): 100-108.</p> <p>Nasreddine, Z.S., Phillips, N.A., Bedirian, V., Charbonneau, S., Whitehead, V., Collin, I., ...& Chertkow, H. (2005). The Montreal Cognitive Assessment, MoCA: A brief screening tool for mild cognitive impairment. <i>Journal of the American Geriatric Society</i>, 53(4): 695-699.</p>
<p>Driving Batteries</p>		
<p>DriveABLE® Competence Screen Domains:</p>	<p>While recent evidence on the DriveABLE® tool supports its utility with regard to predicting on-road performance using its own standardized protocol, there</p>	<p>Vrklijan, B.H., McGrath, C.E., & Letts, L.J. (2011). Assessment tools for evaluating fitness to drive: A critical appraisal of</p>

<p>motor speed & control, visual attention, spatial judgement; executive function</p> <p>Computer-based tasks used in concert with on-road DriveABLE test</p> <p>Administration time: 50 minutes</p>	<p>is no evidence available in the peer-reviewed literature concerning its psychometric properties or validating its corresponding on-road evaluation (Vrkljan, McGrath, & Letts, 2011)</p> <p><u>Suggested cut-off scores:</u></p> <ul style="list-style-type: none"> The positive predictive validity of the DriveABLE® Office Competence Screen in identifying those who would fail the DriveABLE® Road Test was 97% (n = 32 of 33). - Negative predictive validity was 47% - The sensitivity was 76% with a specificity of 90% (Vrkljan, McGrath, & Letts, 2011) 	<p>evidence. <i>Canadian Journal of Occupational Therapy</i>, 78(2): 80-96.</p>
<p>Cognitive Behavioral Driver's Inventory (CBDI)</p> <p>Domains: cognitive and behavioural skills required for driving</p> <p>Administration time: 1–1.5 hours.</p> <p>Available at https://www.cbdionline.com/</p>	<p>CBDI involves a comprehensive protocol with strong psychometric to determine fitness to drive (Vrkljan, McGrath, & Letts, 2011)</p> <p><u>Suggested cut-off scores:</u></p> <ul style="list-style-type: none"> < 45/50 = predicts failures on-road (Bouillon et al., 2006) PPV: 62% NPV: 83% 	<p>Bouillon, L., Mazer, B., & Gelinias, I. (2006). Validity of the Cognitive Behavioural Driver's Inventory in predicting driving outcome. <i>American Journal of Occupational Therapy</i>, 60(4): 420-427.</p> <p>Vrkljan, B.H., McGrath, C.E., & Letts, L.J. (2011). Assessment tools for evaluating fitness to drive: A critical appraisal of evidence. <i>Canadian Journal of Occupational Therapy</i>, 78(2): 80-96.</p>
<p>Vision Assessment</p>		
<p>Ministry of Transportation Requirements</p> <p>Province specific websites http://www.mto.gov.on.ca/english/dandv/driver/medical-review/standards.shtml</p> <p>Canadian Council of Motor Transport Administrators</p>	<p><u>Vision Standards - Class G and M</u></p> <p>“Ontario Regulation 340/94 (s. 18) requires that an applicant for or a holder of a Class G, G1, G2, M, M1 or M2 licence must have,</p> <ul style="list-style-type: none"> • A visual acuity as measured by Snellen Rating that is not poorer than 20/50, with both eyes open and examined together with or without the aid of corrective lenses; and • A horizontal visual field of at least 120 continuous degrees along the horizontal meridian and at least 15 continuous degrees above and below fixation, with both eyes open and examined together” <p>http://www.mto.gov.on.ca/english/dandv/driver/medical-review/standards.shtml</p> <p>In Ontario, a vision waiver can be applied for people seeking Class G licenses who lack 120 degrees of horizontal vision as long as certain</p>	

	<p>conditions are met.</p>	
Sensori - Motor Assessment		
<p>Range of Motion (ROM) & Strength</p>	<ul style="list-style-type: none"> • Range of motion assessments should be made of any joints required to operate a vehicle for example neck, spine, upper and lower limbs. Restrictions and painful range of motion should be noted. • Strength of the muscle groups should also be assessed to determine any restrictions which might limit action • Potential ability to participate with of impaired limbs should be considered and need for devices or strategies anticipated identified. 	
<p>Sensation</p>	<ul style="list-style-type: none"> • Somatosensory impairment of the limb should be assessed to determine ability of the limbs to move with adequate speed and strength with vehicle. Somatosensation of the in the foot and proprioception of the ankle/foot will be of particular interest for braking and acceleration. (Vrkljan et al., 2011) 	<p>Vrkljan, B.H., McGrath, C.E., & Letts, L.J. (2011). Assessment tools for evaluating fitness to drive: A critical appraisal of evidence. Canadian Journal of Occupational Therapy, 78(2): 80-96.</p>
<p>Gait and Physical Performance Tests</p>	<p>Rapid Pace Walk (Marottoli et al. 1994) in Mielenz et al., (2017)</p> <ul style="list-style-type: none"> • > 7 seconds = Red Flag <p>The Short Physical Performance Battery (Guralnik et al.,1994) in Mielenz et al., (2017)</p> <ul style="list-style-type: none"> • associated with reduced driving exposure and increased cessation in older drivers 	<p>Guralnik JM, Branch LG, Cummings SR, Curb JD. Physical performance measures in aging research. J Gerontol. 1989;44(5):M141–6.</p> <p>Marottoli RA, Ostfeld AM, Merrill SS, Perlman GD, Foley DJ, Cooney LM. Driving cessation and changes in mileage driven among elderly individuals.J Gerontol. 1993;48(5):S255–60.</p> <p>Marottoli RA, Cooney LM, Wagner R,</p>

		<p>Doucette J, Tinetti ME. Predictors of automobile crashes and moving violations among elderly drivers. <i>Ann Intern Med.</i> 1994;121:842–6.</p> <p>Mielenz, T. J. Durbin, L.L., Cisewski, J., A., Guralnik, J. M. and Li, G. (2017). <i>Inj Epidemiol.</i> Published online 2017 May 8. doi: 10.1186/s40621-017-0110-2</p>
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