Guiding Principles for the Development of a Navigation Model to Support Transitions to the Community for Persons with Stroke and their Families

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Assumptions:

It is assumed that health care services to the person with stroke and their care partners will be provided by an interprofessional team using a client centred philosophy of care while respecting self-identified care and support needs.

It is assumed that the navigation model to be developed is for the purpose of enabling seamless care by ensuring access to appropriate and timely services to enable the person with stroke to successfully return to the community.

Definitions:

The following definitions were used in identifying the Guiding Principles.

Community is defined from a multidimensional perspective: as the physical, social, and care environment where individuals reside after experiencing a stroke. Community as an environment would include any setting that is outside the acute care and inpatient rehabilitation settings, where a person would reside and resume life roles and activities following a stroke. Therefore, community may refer to a variety of environment including family home, assisted living, long-term care, and other residential settings (2013 Canadian Best Practice Recommendations for Stroke).

Navigation is the process by which patients are guided through and around barriers in the health care system.

Care Partners are family members, friends or other unpaid caregiving supports for a person with stroke.

Guiding Principle	Guiding Principle Statement	Best Practice Recommendations Alignment *Section 5.0 Stroke Rehabilitation*	Best Practice Recommendations Alignment *Section 6.0 Managing Stroke Care Transitions*
1. Informed by best practice	**1.The core elements comprising the model will be identified based on best available evidence and practice**	*5.2 Stroke Rehabilitation Unit Care* -the interprofessional rehabilitation team follows evidence-based best practices as defined by current consensus-based clinical practice guidelines (5.2.1.i.d)	*6.0 Taking Actions in Stroke Transitions of Care* -the primary underpinning of 'taking action in stroke transitions of care' is to provide patient and family-centered care across all transition points and to ensure effective and efficient transfers of care information to the next stage and setting of care
2. Empowerment of persons with stroke and their care partners through support for autonomous decision making.	**2. The model will promote autonomy and empowerment by engaging the person with stroke and care partner(s) in all aspects of goal setting and care planning.** References: American Medical Association, 2011; Claiborne, 2006; Egan et al.,2010; Freeman, 2012; McCue, 2011; Ontario Stroke Network, 2011; Paskett et al., 2011; Stroke Association, 2012.	*5.2 Stroke Rehabilitation Unit Care* -patient, family and caregiver education is provided both formally and informally, with consideration given to individual and group settings as appropriate (5.2.1.i.f) *5.3 Delivery of Inpatient Stroke Rehabilitation* -patients and families should be introduced to resources which will enable self-management and the ability to navigate through the health care system (5.3.viii.d) *5.4 Outpatient and Community-Based Stroke Rehabilitation* -patients and families should be involved in their management, goal setting, and transition planning (5.4.1.iv.d) *5.11 Life Roles and Activities* -patients, especially those < 65 years of age, should be asked about vocational interests (i.e., work, school, volunteering) and be assessed for their potential to return to their vocation-this initial screening should take place early in the rehabilitation phase, and become included in the individualized patient goal setting and planning for rehabilitation needs (5.11.2.i)	*6.2 Patient, Family and Informal Caregiver Education* -assessment should include inquiry about previous information received, information retention, and new and ongoing learning needs, and ensuring patient and family are active participants (6.2.1.ii) -patient education should promote self-efficacy through mastering self-management skills, including action planning, modeling behaviours, problem-solving and decision-making strategies (6.2.3.i) -education for family and informal caregivers on self-management model to encourage them to allow patient to do things on their own whenever possible (ADL goals and preferences, how to access community services and resources, ongoing health system navigation) (6.2.3.ii) *6.3 Interprofessional Collaboration* -Include client and family in care plan goal setting; care plans must be patient-centered; incorporate patient, family and healthcare team preferences (6.3.iii) *6.4 Discharge Planning* -a process should be established to ensure patients, families and informal caregivers are involved in discharge planning (6.4.i) -identification of possible discharge issues related to the patient, family, caregivers or environment (6.4.i.b) *6.6 Transitions of Patients to LTC Following a Stroke* -patients, families and informal caregivers should receive training on how to advocate for active participation in care planning and shared decision-making (6.6.3.iv.a)
3. Person with Stroke and Care Partner Education	**3. The model will include "right- time" education that reflects individualized topics of interest, considers health**	*5.3 Delivery of Inpatient Stroke Rehabilitation* -caregiver education and training to assist the patient with activities of daily living and increasing the patient's level of independence (5.3.viii.c)	*6.1 Supporting Patients, Families and Informal Caregivers Following Stroke* -patients, families and informal caregivers should be screened at each transition of care point for their readiness to learn and integrate knowledge into the recovery process (6.1.1.i) -patients, families and information caregivers should be assessed at each

	literacy levels and supports a person's ability to identify and address barriers, enabling self-management. References: American Medical Association, 2011; Cameron & Gignac, 2008; Cameron et al., 2013; Claiborne, 2006;Coleman, 2003; College of Nurses of Ontario, 2009; Health Quality Ontario 2014; Manderson et al. 2012; Parry C et al., 2006; Paskett, 2011; Ontario Stroke Network, 2011; Stroke Association,2012; Wells et al., 2008	-patients and families should be introduced to resources which will enable self-management and the ability to navigate through the health care system (5.3.viii.d) *5.11 Life Roles and Activities* -patients may benefit from education sessions that address expected changes in sexuality, strategies to minimize sexual dysfunction, and frequently asked questions (5.11.3.ii) -patients should receive information regarding leisure activities in the community and/or be referred to relevant agencies (5.11.4.iv)	transition point to determine their needs and readiness for information, education, training, support and services (6.1.1.ii) *6.2 Patient, Family and Informal Caregiver Education* -assessment and documentation of patient, family and caregiver learning needs and goals throughout each stage along stroke care continuum (6.2.1.i) -assessment should include inquiry about previous information received, information retention, and new and ongoing learning needs, and ensure patient and family are active participants (6.2.1.ii) -patient, caregiver and family educational needs should be assessed before leaving one healthcare setting and when entering another to ensure changing educational needs are met (6.2.1.iii.b) -education to include information sharing, teaching self-management skills, and training family and caregivers to participate in and provide safe care (6.2.2.i) -patient education should promote self-efficacy through mastering self-management skills, including action planning, modeling behaviours, problem-solving and decision-making strategies (6.2.3.i) *6.3 Interprofessional Collaboration* -written discharge instructions should be included as a component of patient care plans- should address functional ability at time of transfer, risks and safety considerations, action plans for recovery, medications at discharge and instructions for adjustment, follow-up care, follow-up care provider contact information (6.3.iv) *6.5 Community Reintegration following Stroke* -caregivers of stroke survivors should receive education and support to assist them in their role as a caregiver (6.5.4.ii) -community-based healthcare professionals across disciplines should provide patients and families with information and linkages regarding access to disability support services in their regions (6.5.3.c.i) -patients and families should be provided with information regarding peer-support groups in their community (6.5.4.ii) *6.6 Transitions of Patients to LTC Following a Stroke* -all patients and family members should be provided interactive and timely education on stroke, recovery and prevention, based on individualized learning needs (6.6.3.ii) *6.7 Post Stroke Fatigue*

			-stroke survivors, their families and informal caregivers should be provided with basic information regarding the frequency and experience of post-stroke fatigue (6.7.i) -patients, who experience post-stroke fatigue, and their families and informal caregivers should be provided with strategies for energy conservation and fatigue management (6.7.iv)
4. Timely involvement	**4. The model will support timely connections to appropriate resources and supports to optimize community reintegration.** References: Freeman, 2012; Ontario Stroke Network, 2011; Stroke Association, 2012	*5.1 Initial Stroke Rehabilitation Assessment* -all patients **admitted to hospital** with acute stroke should have an initial assessment, conducted by rehabilitation professionals, as soon as possible after admission (5.1.i) -initial assessment should be conducted within 48 hours of admission and include an evaluation of patient function, safety, physical readiness, and ability to learn and participate in rehabilitation therapies (5.1.ii) *5.2 Stroke Rehabilitation Unit Care* -the interprofessional rehabilitation team should assess patients within 48 hours of admission and develop a comprehensive individualized rehabilitation plan which reflects the severity of the stroke and the needs and goals of the patient (5.2.2.i) *5.4 Outpatient and Community-Based Stroke Rehabilitation* -outpatient and/or community based rehabilitation services should be available and provided by a specialized interprofessional team, when needed by patients, within 48 hours of discharge from an acute hospital or within 72 hours of discharge from inpatient rehabilitation (5.4.1.ii) -early supported discharge services must be provided within 48 hours of discharge from an acute hospital or within 72 hours of discharge from inpatient rehabilitation (5.4.2.ii)	*6.2 Patient, Family and Informal Caregiver Education* -ongoing education should be individualized and coordinated across transition points, and across the continuum, and include reinforcement of information previously taught and not retained (6.2.2.ix) *6.3 Interprofessional Collaboration* -all members of interdisciplinary stroke team should share timely and up-to-date information with healthcare providers at next stage of care; ideally within one week of patient discharge or transfer (6.3.i) -patient care plan should be utilized to facilitate timely discussion with healthcare providers, family and informal caregivers at next stage of care to ensure continued progress towards goals (6.3.iii.b) *6.4 Discharge Planning* -initiated as soon as possible after patient is admitted at each phase of care (6.4) *6.6 Transitions of Patients to LTC Following a Stroke* -all patients who transition to LTC setting following stroke should have an initial assessment, conducted by medical, nursing and rehabilitative professionals, as soon as possible after admission (to update individualized care plans, address issues, and potential needs for referrals to appropriate healthcare professionals) (6.6.1.i) -follow-up assessments should be conducted on a regular basis (every 3-6 months) and when changes in health status occur (6.6.1.i.c)
5.Integration/Collaborati	**5. The model facilitates**	*5.2 Stroke Rehabilitation Unit Care*	*6.1 Supporting Patients, Families and Informal Caregivers Following Stroke*

on/Communication	**communication across the care continuum engaging clinical, non-clinical and community services to support client-centered care planning.** References: American Medical Association, 2011; Coleman, 2003; Esperat, 2012; Manderson et al.,2012; Ontario Stroke Network, 2011; Paskett et al., 2011; Sinha, 2013; Stroke Association, 2012; Vedel et al., 2009; Walkinshaw, 2011	-Stroke unit teams should conduct at least one formal interprofessional meeting per week to discuss the progress and problems, rehabilitation goals, and discharge arrangements for patients on the unit- individualized rehabilitation plans should be regularly updated based on review of patient status (5.2.2.ii) *5.3 Delivery of Inpatient Stroke Rehabilitation* -stroke rehabilitation unit teams should conduct at least one formal interprofessional meeting per week, during which rehabilitation goals are set, problems are identified, progress is monitored, and support after discharge is planned (5.3.vii) *5.4 Outpatient and Community-Based Stroke Rehabilitation* -a case coordination approach including regular team communication to discuss assessment of new clients, review client management, goals, and plans for discharge or transition (5.4.1.iv.b)	-support for patients, families and informal caregivers should begin at the time of admission and continue throughout the healthcare episode until discharge to the next healthcare setting or back to community (6.1.2.ii) *6.2 Patient, Family and Informal Caregiver Education* -ongoing education should be individualized and coordinated across transition points, and across the continuum, and include reinforcement of information previously taught and not retained (6.2.2.ix) *6.3 Interprofessional Collaboration* -coordinated transfer of information; information should be complete, up-to-date, accurate and appropriate to setting (6.3.i.b) -all members of the healthcare team should share timely and up-to-date information to next stage of care (6.3.i) -written discharge instructions should be included as a component of patient care plans- should address functional ability at time of transfer, risks and safety considerations, action plans for recovery, medications at discharge and instructions for adjustment, follow-up care, follow-up care provider contact information (6.3.iv) *6.4 Discharge Planning* -meetings between the interdisciplinary team, patient, family/caregiver to set goals of care, expectations for discharge dates, and identify potential transitional care needs and living setting (6.4.iii.c) -formulate goal orientated discharge plan with individual and family in collaboration with the interdisciplinary team for transition to community, rehabilitation, retirement home and LTC facilities (6.4.i.a) -communication with team members at the next phase of care (6.4.iii.g) *6.6 Transitions of Patients to LTC Following a Stroke* -families of stroke patients living in LTC should have regular meetings with healthcare team to review health status, quality of life, improvements or declines, opportunities for training and participation in care, and updated goals of care (6.6.3.i) *6.7 Post Stroke Fatigue* -stroke patients should be cared for by healthcare professionals knowledgeable in symptoms of fatigue and its management, where such knowledge does not exist among care providers referrals for expert consultation is appropriate (6.7.v)
6. Holistic Approach	**6. The model will support a holistic approach to**	*5.2 Stroke Rehabilitation Unit Care* -Stroke rehabilitation should be delivered by	*6.3 Interprofessional Collaboration* -patient and family should be given an up-to-date care plan at time of

	care that addresses uniqueness of the individual, considers the patient/care partners' physical, emotional, psychological, linguistic and cultural needs and their environment. References: Freeman, 2012; Guadagnolo, A et al. 2011; Ontario Stroke Network, 2011 ; Walkinshaw, 2011;	a full complement of health professionals, experienced in providing post-stroke care, regardless of where services are provided, to ensure consistency and reduce the risk of complications (5.2.2)	discharge that defines ongoing medical, functional, rehabilitative, cognitive, communication and psychosocial needs (6.3.iii) -care plans must be culturally sensitive (6.3.iii.a) *6.5 Community Reintegration following Stroke* -interprofessional team should have appropriate communication skills and knowledge to address the physical, spiritual, psychological, ethical, and social needs of stroke patients, their families and informal caregivers (6.5.3.d.iv) -respective discussion of a patients values, wishes and decisions should be balanced with information regarding stroke management (6.5.3.d.iv.a) *6.6 Transitions of Patients to LTC Following a Stroke* -assessment should be used to develop an individualized plan of care for each patient who transitions to LTC setting following stroke to optimize quality of life and meet physical, functional, emotional, cognitive and social needs (6.6.1.i.b) *6.7 Post Stroke Fatigue* -patients, families and informal caregivers should be provided with strategies for energy conservation and fatigue managements that address the following components: structure/planning of day, organizing physical environment, engaging in exercise appropriate to tolerance level, etc. (6.7.iv)
7. Address transition barriers through intervention and advocacy across health and social services.	**7. The model will enable effective community transitions by identifying and addressing barriers to successful re-integration.** References: Dohan & Schrag, 2005; Egan M., et al., 2010; Freeman, 2012.	*5.1 Initial Stroke Rehabilitation Assessment* -issues related to transition planning should be considered during the initial assessment (5.1.iii)	*6.1 Supporting Patients, Families and Informal Caregivers Following Stroke* -patients, families and informal caregivers should be prepared for their transitions between care environments by being provided with information, education, training, emotional support, and community services specific to the transition they are undergoing (6.1) *6.2 Patient, Family and Informal Caregiver Education* -education provided in a variety of languages and formats, address varying levels of health literacy (6.2.2.iv) *6.3 Interprofessional Communication* -written discharge instructions should be included as a component of patient care plans- should address functional ability at time of transfer, risks and safety considerations, action plans for recovery, medications at discharge and instructions for adjustment, follow-up care, follow-up care provider contact information (6.3.iv)

8. Leverage technology and existing regional resources and tools for stroke and other populations.	**8. The model will optimize the use of technology to support information-sharing and access to resources. Existing tools and resources that align with the core elements of the navigation model will be leveraged.** References: Canadian Medical Association, 2011; Freeman, 2012; Moore, 2013; Ontario Stroke Network, 2011.	*5.11 Life Roles and Activities* -patients can be referred to training programs, such as simulator based training, to help prepare for a road test or the resumption of driving (5.11.iv)	*6.1 Supporting Patients, Families and Informal Caregivers Following Stroke* -the use of telemedicine technology should be considered to increase access to ongoing support services, healthcare services and rehabilitation therapies following transition to community or those unable to travel for care (6.1.2.vii) *6.5 Community Reintegration Following Stroke* -use of telemedicine technology modalities to support return to work and skill attainment, functional and psychological health management (6.5.2.v, 6.5.3.a.v) *6.7 Post Stroke Fatigue* -Assessment and routine check-ins, use of telemedicine, telephone and web-based support (6.7 System Implications) -patients, families and informal caregivers should be provided with strategies for energy conservation and fatigue management that address using energy-saving equipment and technology to reduce physical efforts (6.7.iv.h)

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