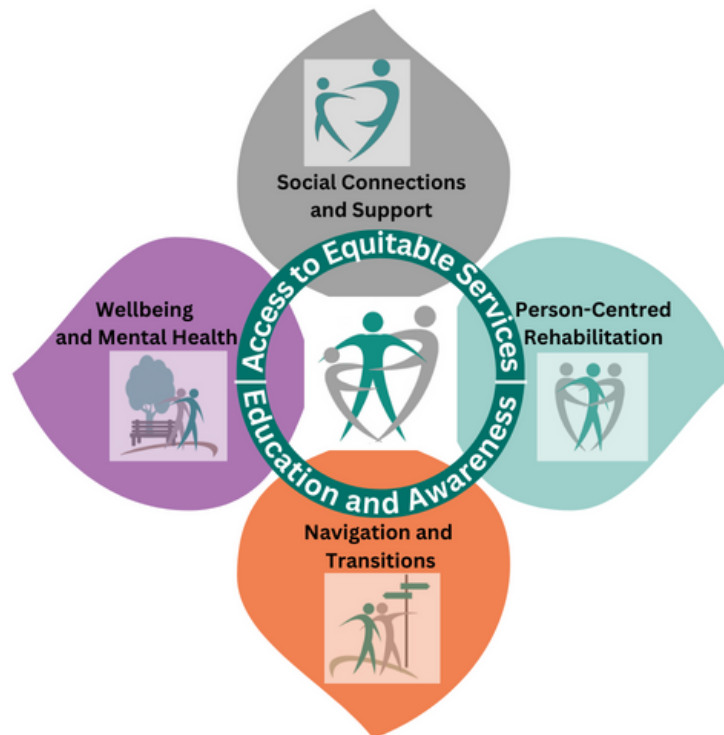


**2023 Consultation
Report**

**WHAT WE HEARD:
ENHANCING INDIVIDUALIZED
COMMUNITY STROKE
SERVICES**



Acknowledgements

The Stroke Network would like to thank everyone who provided input.

We are grateful to the stroke survivors and caregivers that told their stories and participated in the focus groups, survey, interviews and webinars.

Thank you to the healthcare providers who took time out of their day to provide input and participate in the survey and/or webinar.

Members of the Community Reintegration Leadership Team (CRLT) were instrumental in designing the consultation process and reviewing the results. Their advisory role will be central to the ongoing response.

Thank you to the team at the Stroke Network of Southeastern Ontario for supporting this work and providing input throughout the process.

This feedback provides valued input that helps prioritize future actions to strengthen community reintegration for persons with stroke and their families.

**We thank you for your continued support
in our efforts to improve community
stroke care**

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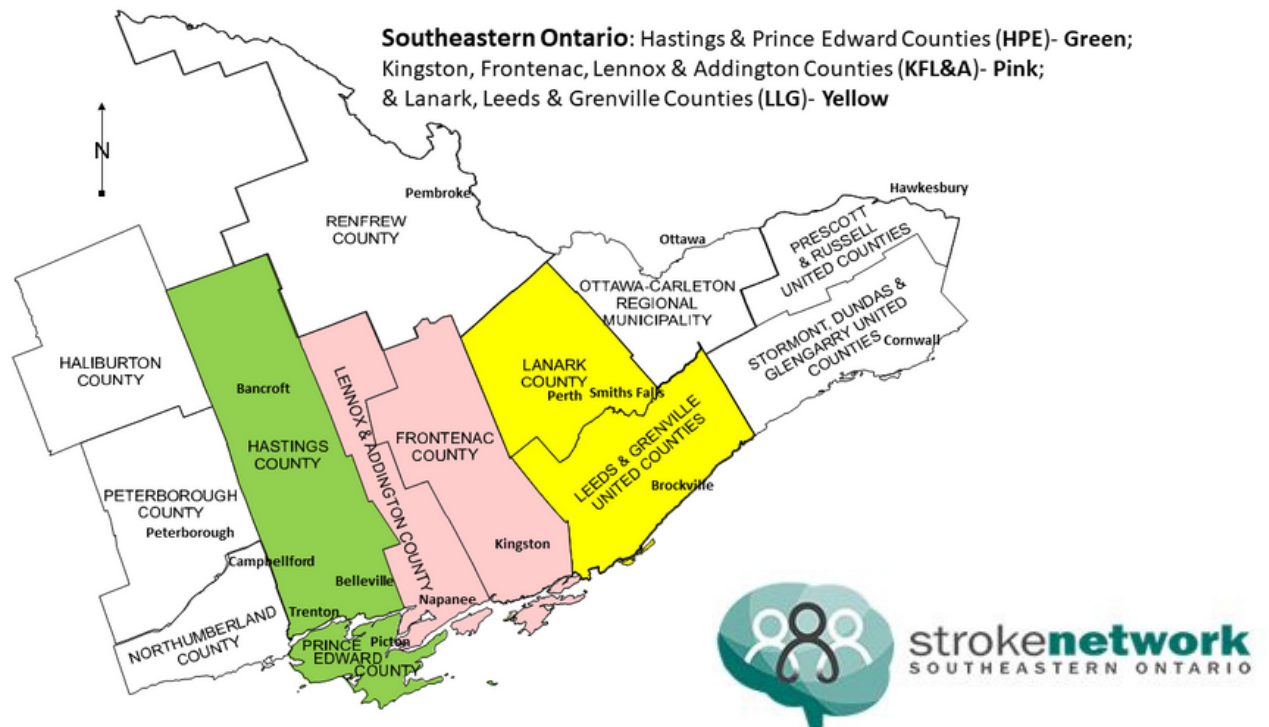
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Background

Over 2000 individuals sustain a new stroke across Southeastern Ontario annually and volumes are increasing at a rate of over 20% per year. Stroke can lead to social, physical and psychological challenges for individuals and their family members. It abruptly changes lives and can impact quality of life and independence. It is estimated that 70% of individuals who experience stroke are discharged to the home setting.¹ Inadequate support and care in the community can leave stroke survivors and their caregivers feeling lost and abandoned following discharge from hospital.² Given the level of disability experienced by stroke survivors and the added stress on their caregivers, stroke support in the community is an essential part of the healthcare system.

The Stroke Network of Southeastern Ontario has completed two previous community consultations (2007, 2015), with the aim to **improve community reintegration for stroke care** in the region.^{3,4} Community consultations led to the initiation of stroke support groups and the Community Reintegration Leadership Team (CRLT). The CRLT is a patient advisory group that advises on improving community reintegration after stroke. The goals of this current consultation were to build on work completed in previous consultations, identify priorities for ongoing change and continue to collaborate with persons with stroke and their caregivers. In Southeastern Ontario, this work helps us to better understand the experience of persons with stroke, enhance services and improve community reintegration.



Methodology

The community consultation was completed utilizing a multifaceted approach. Multiple options for providing feedback were incorporated into the consultation including focus groups, a survey, webinars and interviews. Feedback was collected at various stroke support groups across Southeastern Ontario. Some of the focus groups were virtual and others were in-person. A survey was created in Qualtrics and made available in French and English. There was also an option of one-to-one interviews.

Three key interview questions were created with advice from the CRLT. The questions captured what is going well in community stroke care, what could be improved and how to make improvements. The questions were open-ended and consistent across the survey and focus groups. A poster was created and distributed in both French and



English. Participants were recruited in many ways; through community support agencies, home and community care, Ontario Health Teams, long-term care homes and the Stroke Network of Southeastern Ontario website.

Two webinars were facilitated to review preliminary findings and validate results from the survey and focus groups. One webinar was intended for stroke survivors and caregivers and the other for healthcare providers. Responses were reviewed and gaps were identified. Indigenous populations and young stroke survivors were noted as gaps. To address these gaps, a consultation was completed at a support group for younger stroke survivors and an interview was completed to gain the perspective of Indigenous populations.

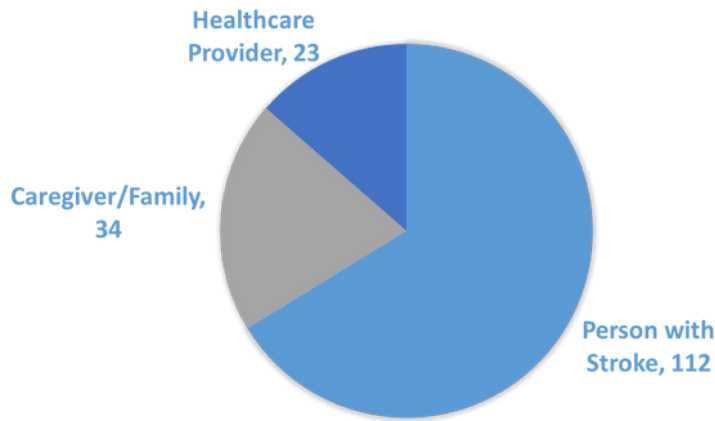
The CRLT provided guidance and advice throughout the process. Participatory action research was the methodology that helped to guide the community consultation, engaging stakeholders throughout the process.⁵

Demographics

The Stroke Network of Southeastern Ontario attended 16 different stroke support groups across the region with a total of 115 participants. Fifty-three individuals responded to the online survey. The two webinars had a total of 69 participants.

Please Note: Not all 115 focus group participants were unique.

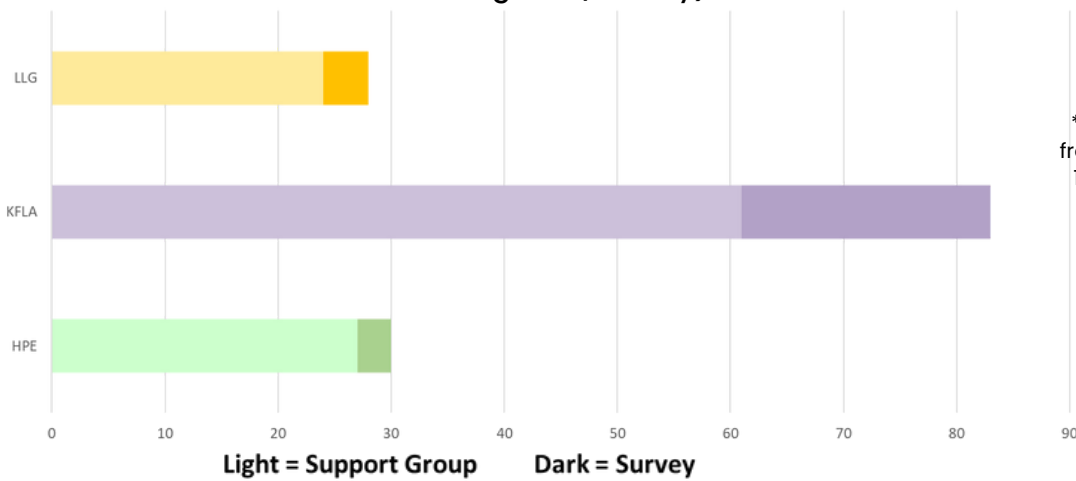
Participants



66%

of participants were persons with stroke

Participants Represented by Area (Persons with Stroke and Caregivers/Family)



*4 participants were from out of region and 1 participant did not respond to this question

51

Participants attended a webinar for healthcare providers to validate the results

169

Total Number of Participants
not all unique

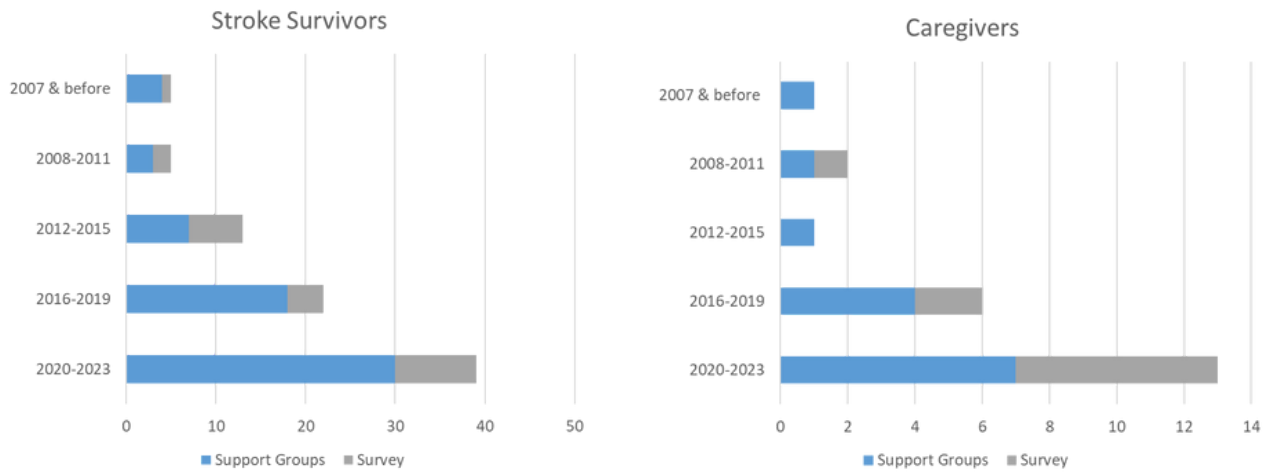
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Participants attended a webinar for persons with stroke to validate the results



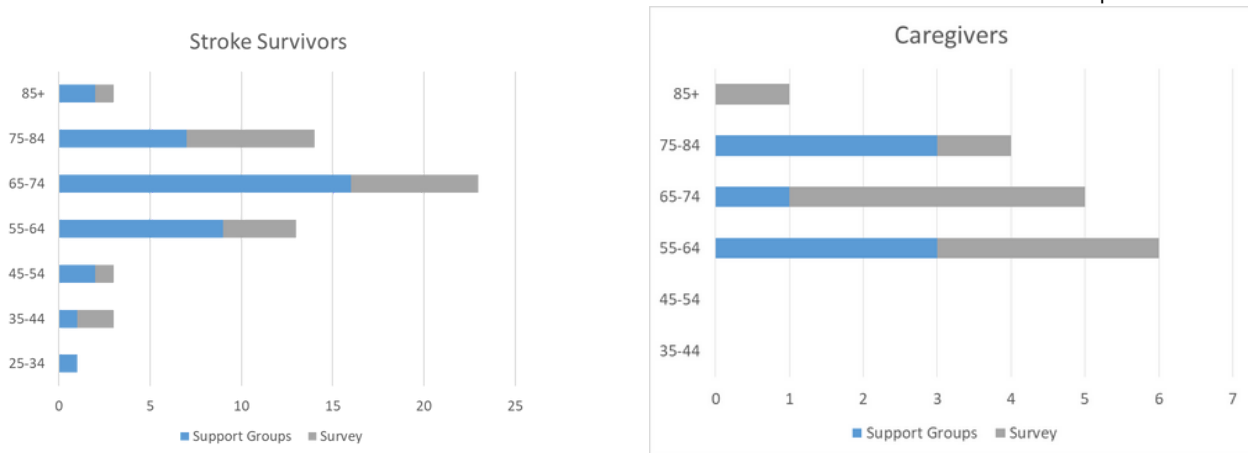
Demographics Continued

Participants by Time of Stroke

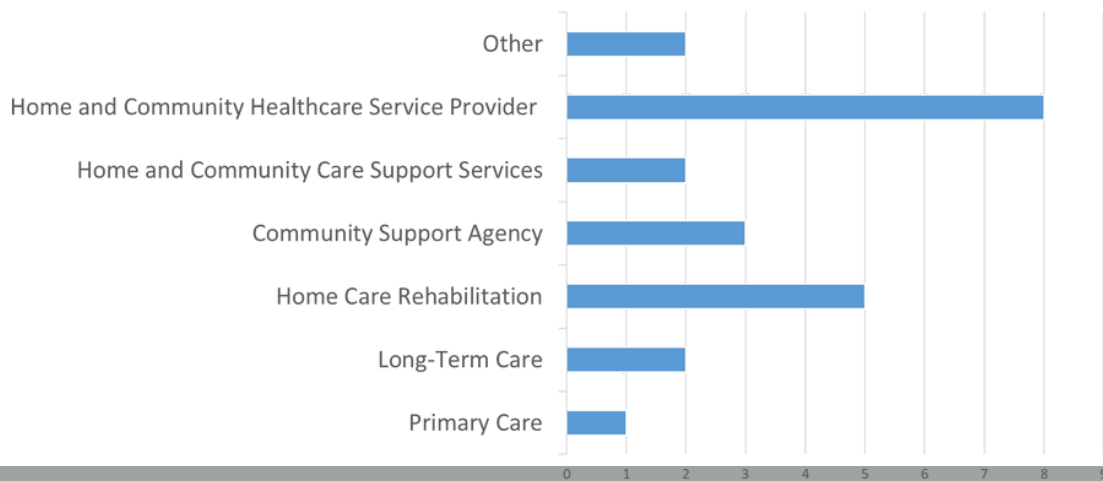


Participants by Current Age

*Time of Stroke and Age data are incomplete



Survey Participants (Healthcare Providers) by Area of Work



49%

report having their stroke in the last 3 years

The majority of Healthcare Providers that responded to the survey work in Home Care

37%

of participants (stroke survivors/caregivers) were age 65-74



Findings: Themes

It was clear that many were appreciative of the care they received with one individual stating “services in Ontario are excellent.” Many existing challenges and areas for improvement were also noted. Findings align with stroke best practice and previous community consultations.^{3,4,6} COVID-19 was noted to have impacted all themes and principles. Although the results have been divided into themes, it is quite evident that the themes are interrelated and overlapping.

The four themes that emerged from the consultation were:



01. Social Connections and Support

Social connections and support include stroke support groups as well as connections to family, friends and community. The need for more stroke support groups was frequently expressed.



02. Person-Centred Rehabilitation

Person-centred rehabilitation includes outpatient rehabilitation and home care rehabilitation. The importance of listening to the person with stroke was emphasized. Individualized care is key.



03. Wellbeing and Mental Health

Wellbeing and mental health include meaningful activity, exercise, nutrition and mental health supports. The desire for more mental health support was apparent, specifically from professionals who understand stroke.



04. Navigation and Transitions

Navigation and transitions include navigating the healthcare system and transitioning out of hospital and community stroke rehabilitation. Many reported being unaware of services and having difficulty transitioning across healthcare services.

Two underlying Principles

Two underlying principles were identified within all four themes.

Access to Equitable Services

- Equitable service based on need
- Transportation/parking/return to driving
- Access to expert stroke care follow-up
- Affordability of services

Education and Awareness

- Stroke Survivors/Caregivers
- Healthcare Providers
- General Public

1. Social Connections and Support

Things that are going well to continue...

- **Stroke support groups**
 - o Support and connections
 - o Information and learning
 - o “Safe place”; non-judgmental
 - o Variety of groups
 - o Virtual groups
 - o Aphasia support
 - o Stroke support group facilitator
 - o Regional stroke support groups
- Mentoring/educating others
- **Social connections**
 - o Family/friends
 - o Social events
 - o Community

Challenges/Things to Improve...

- **Stroke support groups**
 - o Lack of service if not interested in group
 - o Large groups; therapeutic size
- **Lack of social connections**
 - o Loneliness/isolation
 - o Family dynamics
 - o Lack of caregiver/support
 - o Lack of support for young caregivers/young stroke survivors
 - o Isolation due to COVID-19



“When you have a stroke, you find out who your friends are and who walks away”

“Being able to talk to a group of people that have been through something similar makes one feel not alone”

“I have a new understanding because of this group”

“We all work together to make things better”

“We’re two boats drifting apart”

“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.”

(Heart and Stroke Foundation of Canada, 2023)



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2. Person-Centred Rehabilitation

Things that are going well to continue...

- **Rehabilitation across the continuum of care**
- Speech therapy/Aphasia Supportive Conversation Groups
- **Person-centred care**
 - Proactive and holistic care
 - Exercises/activities with achievable goals
 - Patience and clear communication
 - Knowing the patient; collaborative approach
 - Promoting independence
- Assistive devices

Challenges/Things to Improve...

- **More rehabilitation**
 - Therapy duration
 - Lack of therapists; therapy intensity
 - More aphasia supportive conversation
- Wait times
- Targeted/goal-oriented/individualized
- Importance of stroke expertise
- Challenges with virtual services
- Challenges with access related to COVID-19



“The post-stroke physiotherapy and occupational therapy care following my release from hospital was very good, as well as the ongoing care that I received from my physiatrist”

“Therapists come to our house, nice, pleasant, polite, professional, helpful people, they ask us how things are going”

“Having the person living with stroke assist in planning their care.”

“Work with me”

“Outpatient and/or in-home rehabilitation services should be provided by specialized interdisciplinary team members as appropriate to patient needs and in consultation with the patient and family”

(Heart and Stroke Foundation of Canada, 2023)



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3. Wellbeing and Mental Health

Things that are going well to continue...

- **Routine/meaningful activity**
 - Hobbies/leisure activity
 - Volunteering
- Resiliency/motivation
- Nutrition
- Exercise

Challenges/Things to Improve...

- **Invisible impacts of stroke/mental health**
 - Mood, anxiety, isolation, fatigue
 - Stroke-specific support
 - Personal/life changes
 - Frustration, grief, guilt, dealing with loss, coping
 - Asking for help
 - Loss of purpose, relationships, jobs
- Caregiver support
- Younger stroke survivors: Caring for children, relationships, return to work
- More exercise
- Difficulty with motivation to exercise
- Isolation related to COVID-19



“Life is upside down right now”

“You have to take care of yourself, do things you like doing”

“I feel so rotten that I can’t be the Mom I should be, I feel it’s failure”

“Illness changes things in a flash, the loss and grief that comes with it”

“Don’t quit, everyday gets better”

“I wish that there had been some support from perhaps a social worker”

“All people who have experienced a stroke should be screened for post-stroke depression if deemed medically appropriate, given the high prevalence of post-stroke depression and the evidence for treating symptomatic depression post stroke”

(Heart and Stroke Foundation of Canada, 2023)



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4. Navigation and Transitions

Things that are going well to continue...

- Paramedicine, primary care, home care, orthotic and prosthetic services
- Connecting with stroke support group facilitator in hospital
- **Communication/referral**
 - From hospital to community
 - Timely information
 - Included in discharge planning/ Community Rehabilitation Planning meetings
 - Awareness of services
 - Family conferences
 - Team approach
- Connection with Stroke Network

Challenges/Things to Improve...

- Awareness of services, overlap, waitlists for OT
- Discharge not always well planned
- Hospital to community transition
- Transition out of community rehabilitation
- Unaware of services
- Lack of communication with person with stroke/caregiver
- Lack of support in home leading to LTC admission



“Those were the most overwhelming days of my life”

“The minute you walk out that door you fall off a cliff”

“It’s a long road, travelling more or less on our own”

“When you first go home you don’t know what services are available”

“Stronger links between community rehabilitation, hospital inpatient and outpatient and community providers - a wrap around approach”

“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”

(Heart and Stroke Foundation of Canada, 2023)

Summary of Key Recommendations

Recommendations for action were established using suggestions from the community consultation and prioritized through consultation with the CRLT.



Social Connections and Support

1. **Secure funding to sustain and expand stroke support services.**
2. Improve supports for those caring for persons with stroke (e.g. young caregivers).
3. Promote awareness of stroke support groups.



Person-Centred Rehabilitation

1. **Improve equitable access to rehabilitation in the community setting.**
2. Initiate a method to provide communication/feedback to the person.
3. Increase the frequency of Aphasia Supportive Conversation Groups.



Wellbeing and Mental Health

1. **Improve supports for mental health.**
2. Increase the frequency of stroke-specific exercise classes.
3. Provide support for leisurely activities and interests in the community.



Navigation and Transitions

1. **Provide a tool/support for persons with stroke to navigate the system.**
2. **Focus on stroke prevention, living well with stroke and follow-up care.**
3. Improve the communication and referral process.

Underlying Principles (Access to Equitable Services/Education)

1. Improve resources for returning to driving.
2. Educate healthcare providers on stroke-specific knowledge.
3. Incorporate stroke awareness into the school curriculum.



Further Recommendations

Listed below are further recommendations to be considered for future action.

Recommendations related to all Four Themes

- Increase the frequency of in-person stroke support groups.
- Ensure that stroke support group size is therapeutic.
- Ensure that funders fully comprehend the value of stroke support groups by inviting them to attend a session.
- Increase the frequency of caregiver stroke support groups.
- Enable caregiver/family to attend stroke support groups alongside the person with stroke.
- Incorporate pet therapy into stroke support services.
- Promote the presence of peer support in the hospital setting.
- Support social outings for persons with stroke and their family.
- Improve supports for pediatric stroke.
- Work to improve transitions out of hospital through follow-up phone calls post-discharge and case management.
- Promote smooth transitions out of hospital through follow-up with a peer volunteer post-discharge.
- Increase knowledge of services and work collaboratively with other regions.



Underlying Principles (Access to Equitable Service/Education)

- Increase awareness of stroke symptoms in the community and the importance of calling 911.
- Improve public awareness of stroke and aphasia (e.g. podcasts, videos).
- Ensure individualized resources for persons with stroke are provided from the start.
- Improve communication/education with family members and involve them in appointments.
- Ensure information package is reviewed with family/caregiver and offered across the care journey.
- Promote healthcare provider awareness of aphasia resources.
- Provide stroke survivors with assistance in technological tasks.
- Improve access to home care services.
- Improve services for vision support.
- Improve funding to support Instrumental activities of daily living.

Action or commitment

Next Steps

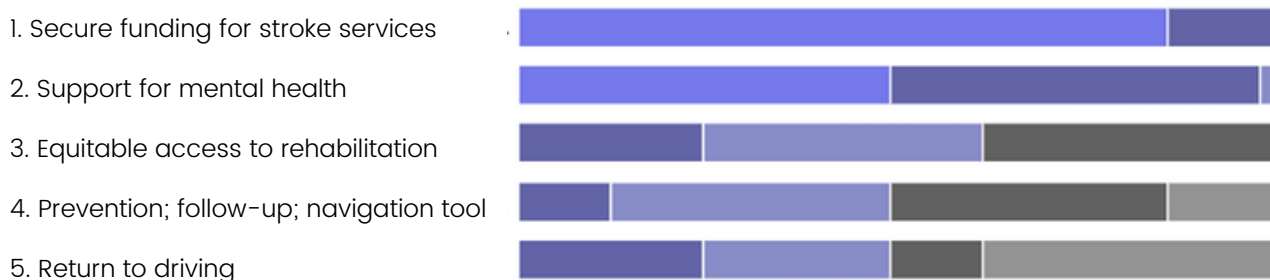
The results of the consultation will help guide the future of community stroke care in Southeastern Ontario and the Stroke Network of Southeastern Ontario's workplan. The CRLT will help determine next steps and prioritize actions. The Stroke Network of Southeastern Ontario will report on progress to both the CRLT and the Regional Stroke Steering Committee. It is crucial that this valuable feedback is put to action.

The CRLT has already provided valued input into the next steps. The CRLT highlighted the key priority of securing funding to expand and maintain stroke support services across our region. A proposal for added funding was submitted in 2022 but was not successful. This is a necessary next step to meet the needs of persons with stroke and their caregivers in Southeastern Ontario. The CRLT also echoed the importance of mental health and how it relates to stroke. There is a clear need for support in this area and AccessMHA is one resource that has been discovered. Access to primary care was acknowledged as a challenge through the consultation and by the CRLT. Ontario Health Teams were identified as a potential connection to support linkages to primary care.

The importance of access to equitable services and education were recognized within all themes. The CRLT suggested educating and communicating in multiple ways. The importance of follow-up and system navigation were acknowledged. One idea was to digitize the patient journey map. Younger stroke survivors specifically highlighted the need for equitable services. Training relative to trauma-informed care and cultural safety were ideas generated through consultation with Indigenous populations to promote inclusivity in current stroke support services.

The following poll was completed at a CRLT meeting and represents priority actions moving forward:

****POLL**:** Top recommendations from each theme were combined and ranked



Throughout the consultation the significance of individualized, person-centred support was clear with one member stating “every stroke is like a snowflake or grain of sand” and requires a unique approach



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