

Community Consultation

What we Heard about Stroke Care



Stroke Network of SEO
www.strokenetworkseo.ca

Regional Stroke Symposium
Kayla Purdon
Community and Long-Term Care Coordinator



Objectives

- Understand the **purpose** and **steps** of the community consultation
- Review the **demographics** of participants
- Discuss the **preliminary results** of the community consultation
- Identify the **common themes** of the community consultation
- Discuss the **next steps** and what will be done with the results



Community Consultation

STROKE STRATEGY
of Southeastern Ontario

Building Capacity to Enhance Community Reintegration of People with Stroke

Final Report

December 14, 2007

Submitted to the Regional Stroke Steering Committee of Southeastern Ontario

STROKE NETWORK
of Southeastern Ontario

**WHAT WE HEARD:
CHARTING A COURSE FOR
SUCCESSFUL COMMUNITY
REINTEGRATION AFTER STROKE**

2015 CONSULTATION REPORT



Goals of Consultation

- Build on work completed in previous consultations (2007 and 2015)
- Identify **priority areas of change** to improve community reintegration following stroke
- Continued **collaboration** with stroke survivors and their caregivers (Community Reintegration Leadership Team)



Steps for Consultation

1. Stroke Support Groups

2. Survey/1:1 Interviews

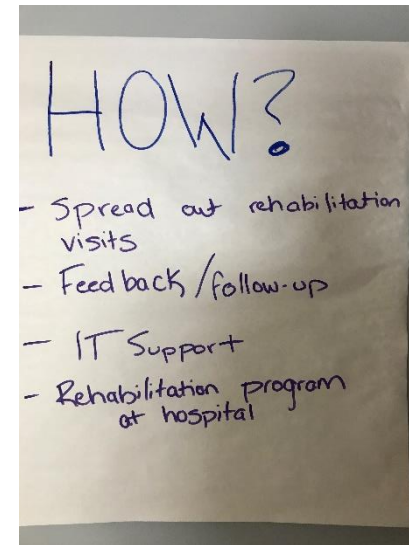
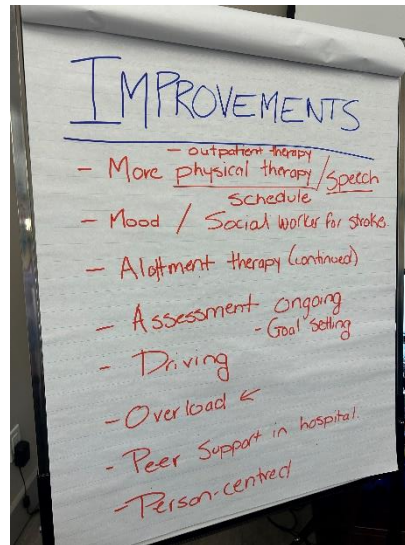
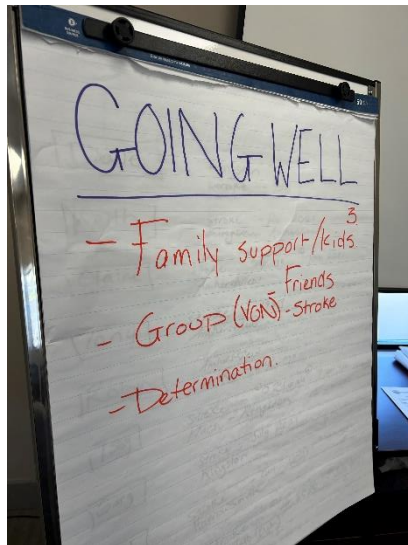
3. Fill the Gaps

4. Webinar for Healthcare Providers



Interview Questions

1. What works well? **Going Well**
2. What needs to be improved (challenges)? **Improvements**
3. How could your experience be improved? **HOW**





WE NEED YOUR HELP

ARE YOU A STROKE SURVIVOR, CAREGIVER OR HEALTHCARE PROVIDER?



We want to hear about your experience in the community. Please complete the survey using one of the 3 options below

Scan QR CODE OR [CLICK HERE](#)



Contact StrokeNetworkSEO@kingstonhsc.ca to complete the survey by phone or video

www.strokenetworkseo.ca



ÊTES-VOUS SURVIVANT D'UN AVC, PROCHE AIDANT OU FOURNISSEUR DE SOINS DE SANTÉ? VOTRE OPINION EST IMPORTANTE POUR NOUS.



Faites-nous part de votre expérience dans la communauté. Répondez à notre sondage à l'aide d'une des 3 options suivantes:

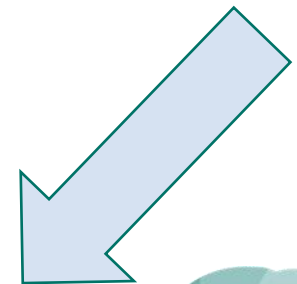
Balayez ce CODE OU CLIQUEZ ICI



Écrivez à StrokeNetworkSEO@kingstonhsc.ca pour répondre au sondage par téléphone ou vidéoconférence.

www.strokenetworkseo.ca

Posters Available in English and French



Feedback

1. Stroke Support Groups

- 14 Stroke Support Groups across the region
- In-person and virtual
- **104** total Participants



StrokeUnderstood

2. Survey/1:1 Interviews

- **86** survey responses
- English and French
- Demographics
- 3 key interview questions



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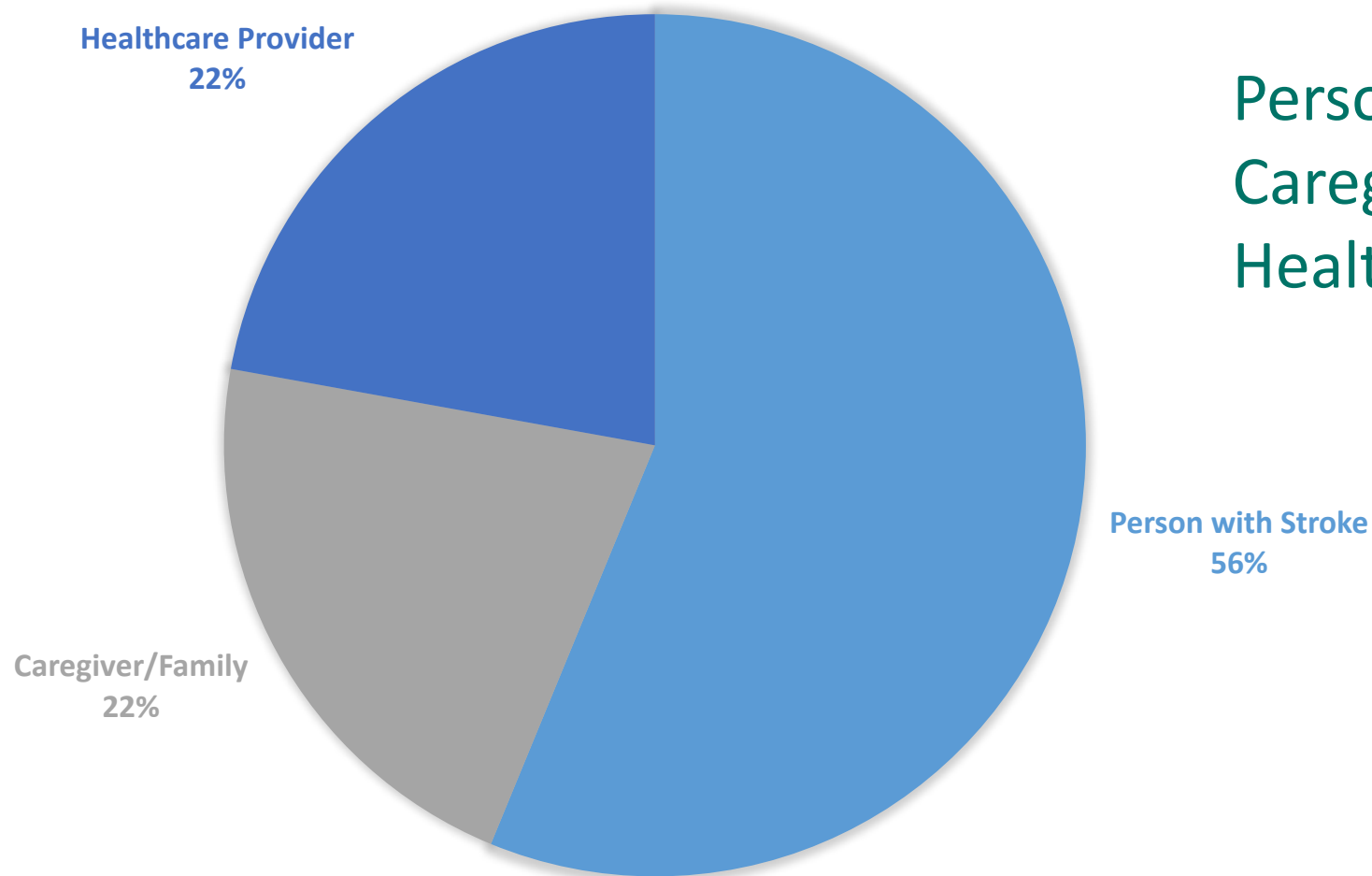
English

We want to hear about YOUR experience with stroke care in the community so that improvements can be made!



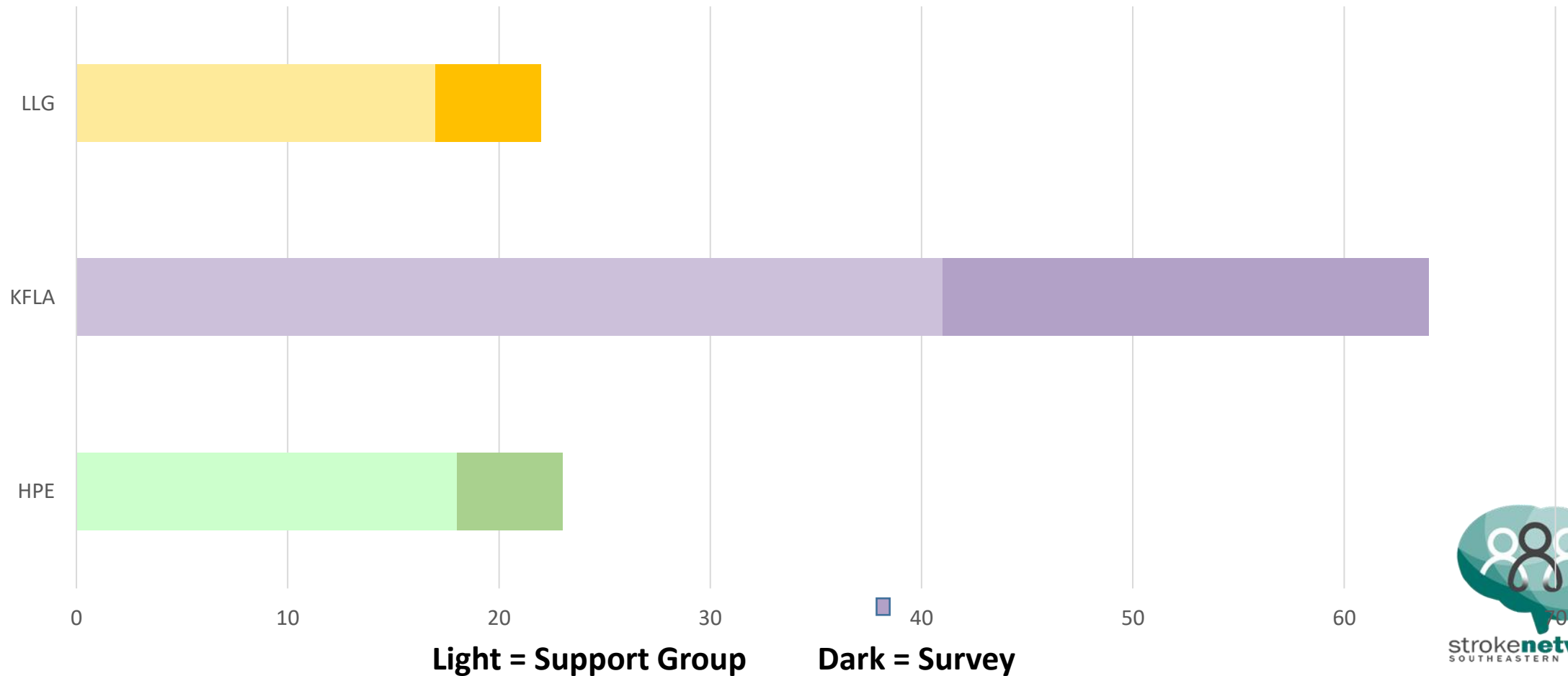
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Demographics – Who Responded?

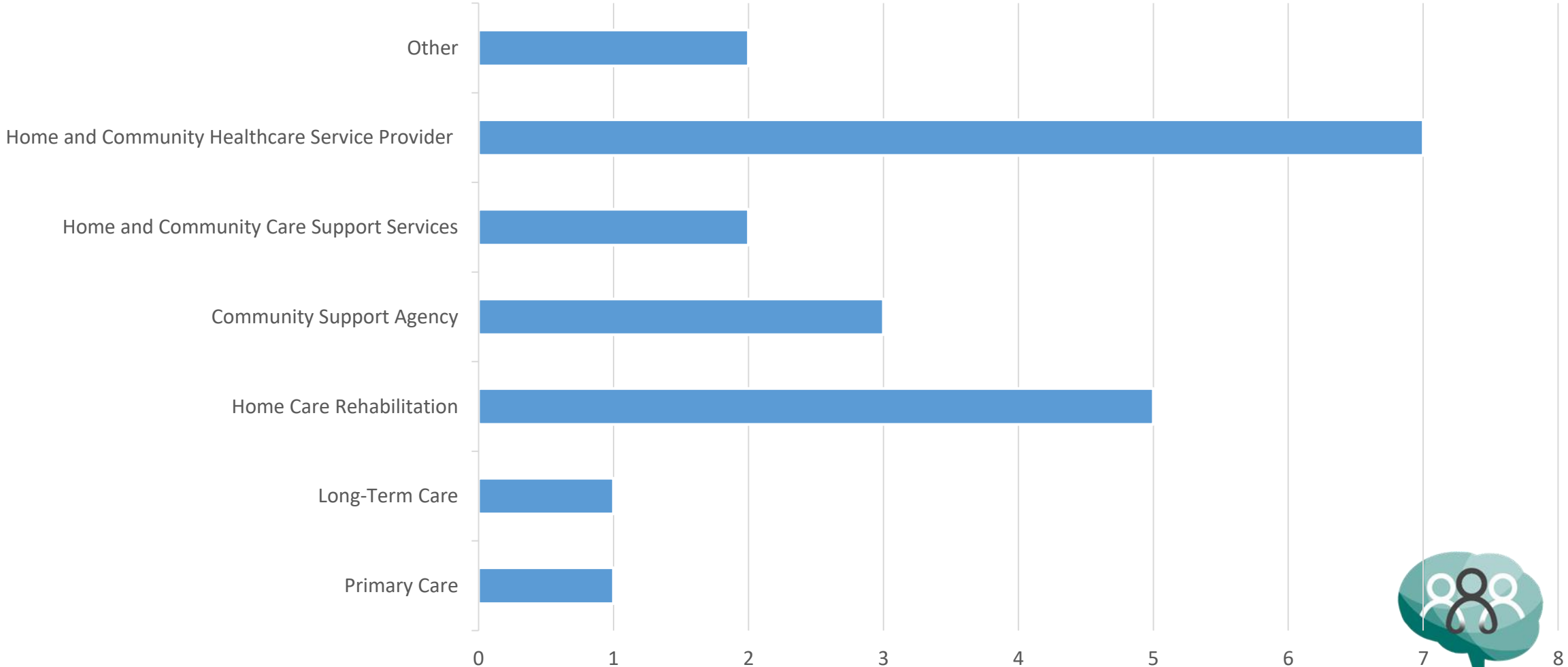


Person with Stroke = 104
Caregiver/Family = 40
Healthcare Provider = 41

Demographics – Regional Data



Healthcare Provider Data

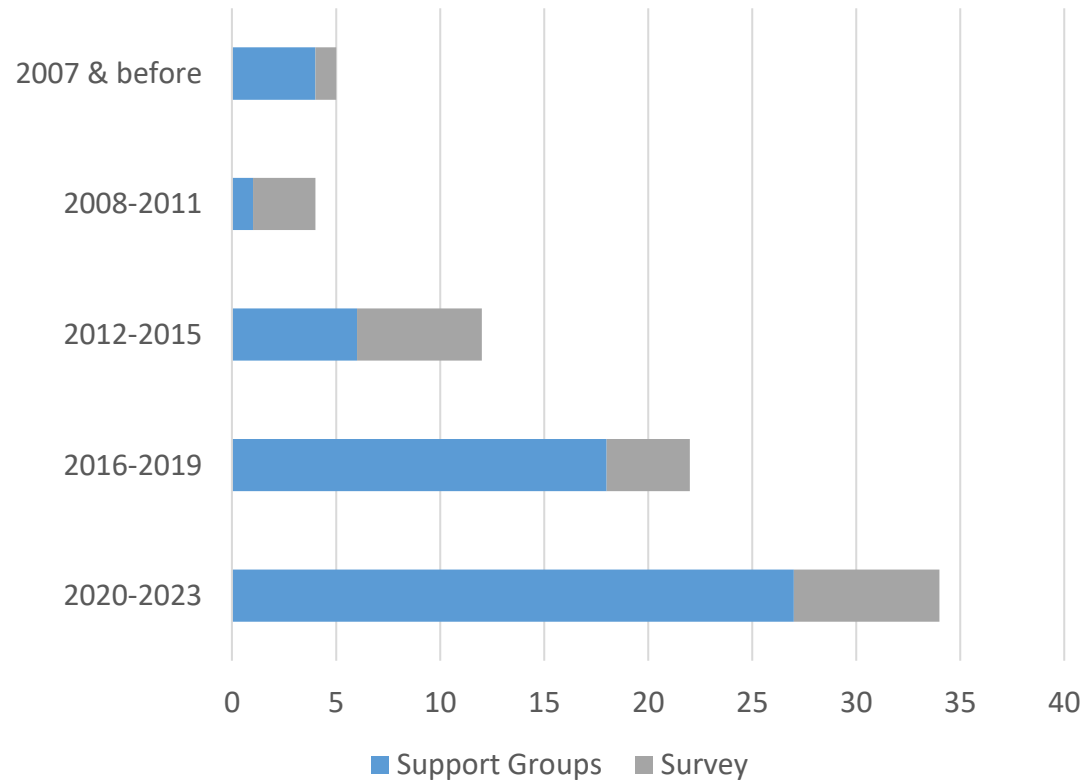


Represents those that completed all survey responses

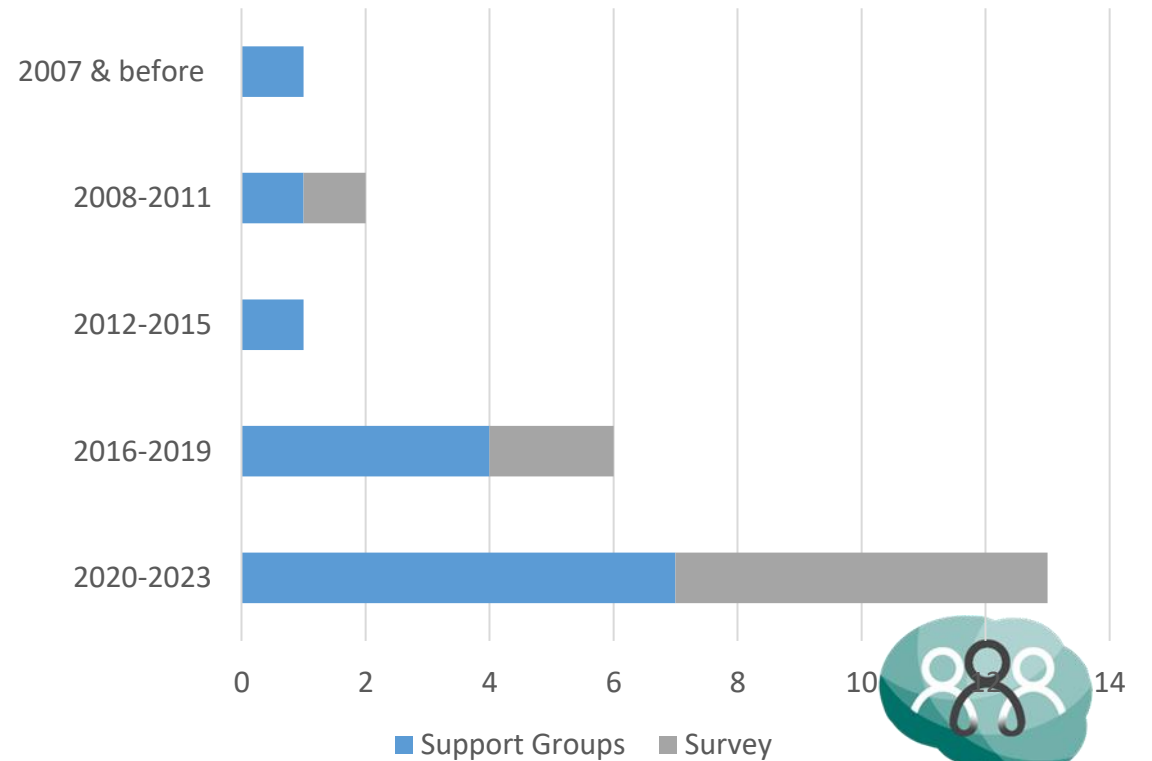


Demographics – Time Since Stroke

Stroke Survivors

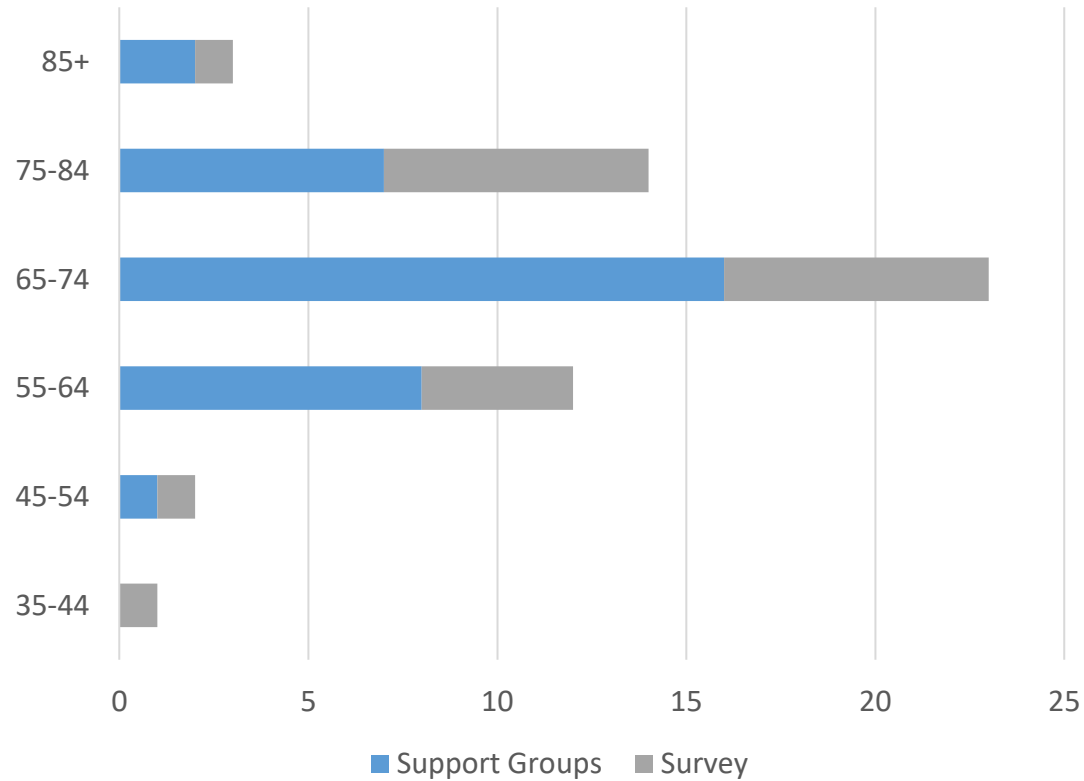


Caregivers

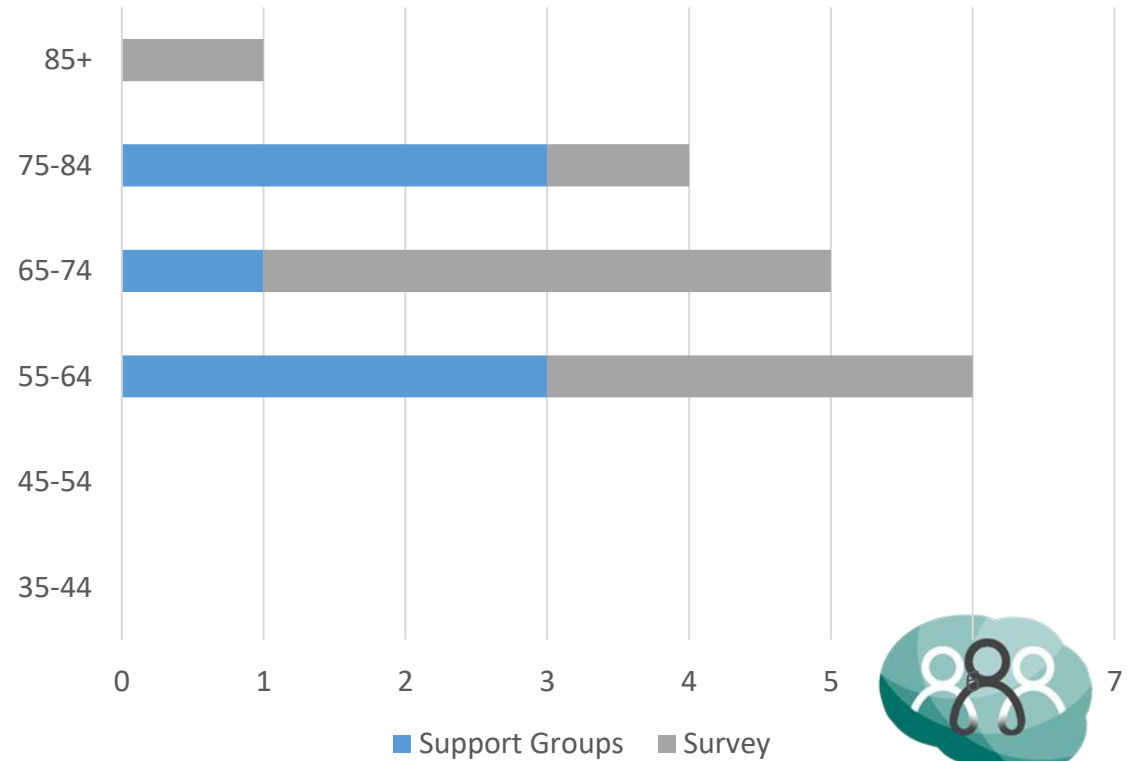


Demographics – Age

Stroke Survivors



Caregivers



Feedback Across the Continuum



- *“Services in Ontario are excellent”*
- *“The best thing that happened was I met two of the nicest men - the paramedics, they stayed right with me, stood right by my bed, talked to me all the time”*
- *Great care in the Stroke Unit*
- *“Afraid I was going to disappoint them after that good procedure”*
- Thankful that SLP in hospital knew community resources and sent referral, *“hats off to her”*
- *Stay at PCH, “Excellent, wonderful staff, beautiful facility”*

Feedback Across the Continuum



- *“Things just fell into place when we left hospital but we know of so many people who don’t know what they can access”*
- *“Really improving there”*
- *“Therapists come to our house, nice, pleasant, polite, professional, helpful people, ask us how things are going”*
- *“Given me exercises to do, it’s tiring”*
- *“Would have drove to Kingston or Timbuctoo for time with SLP”*
- *“The groups are great for helping you get through this maze”*
- *“Zooms are essential”*



Feedback Across the Continuum



- *“This group is my lifeline”*
- *“The group I’m in is fantastic, we’re a family, I call us a family”*
- *“She is my rock; she encouraged me to do stuff I couldn’t do before”*
- *“Open window instead of a closed door”*
- *“Nice to talk to someone that is non-judgemental and understands”*
- *“By coming out here I’ve learned how to talk, what to say; make an effort to encourage others too”*



Transitions and Connections
Community Stroke Rehabilitation Program

Information
Access
Wraparound Approach
Physiotherapy
Team Approach

Exercise
Timing

Education
Funding

Discharge Planning
Awareness of Services

Staffing
Communication

Referrals
Independence

In-person Services
Webinars

Workshops
Driving

Overwhelming

Frequency of Visits

Recreation

Person-Centred care

Support Groups



Access and Equity

Meaningful Activities

Transitions and Navigation

Invisible Impacts

Resiliency
Exercise

Transportation

Assessment and Follow-Up

COVID-19 Impacts

IT Support

Rehabilitation

Aphasia Supports

Education

Virtual Support

Home Care

Caregiver Support

Person-Centred Care

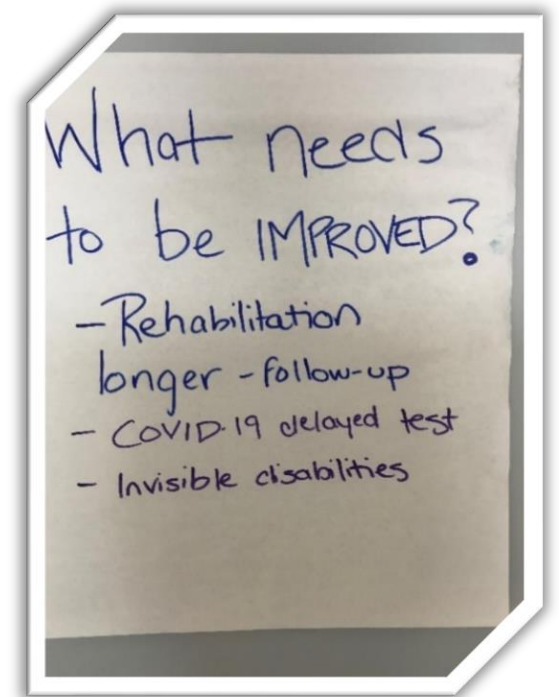
Social Connections

Support Groups



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Preliminary Results



Themes

1. Support Groups and Social Connections
2. Person-Centred Rehabilitation Services
3. Individual Wellbeing, Mental Health and Meaningful Engagement
4. Transitions and Navigation
5. Implications of COVID-19
6. Education for Stroke Survivors, Family, Healthcare Providers and Public



Support Groups and Social Connections

“When you find out who your friends are and who walks away”

GOING WELL	IMPROVEMENTS	HOW
<ul style="list-style-type: none"> ● Stroke support groups <ul style="list-style-type: none"> ○ Information/learning/encouragement ○ Sharing knowledge/experiences ○ Meeting others, peers ○ Aphasia Supportive Conversation Groups ● Peer support/mentoring/educating others ● Family and friends/social events ● Community ● Aphasia Buddies 	<ul style="list-style-type: none"> ● No service if not interested in group ● Overwhelming – too many participants ● Limited support/Family dynamics ● Lack of caregiver support ● Loss of support/friends ● Lack of support for young caregivers <p style="text-align: center;">“We’d like our childhood back”</p>	<ul style="list-style-type: none"> ● In-person groups ● Group size ● Regional meetings ● Location/group atmosphere ● Funders observe group ● More caregiver groups (group for young caregivers) ● Social outings ● More aphasia groups



Person-Centred Rehabilitation Services

GOING WELL	IMPROVEMENTS	HOW
<ul style="list-style-type: none"> • Hospital <ul style="list-style-type: none"> ○ Therapists/Speech Therapy • Outpatient therapy • Home care <ul style="list-style-type: none"> • Exercises/small goals • Holistic care • Equipment • Aphasia Resources <div data-bbox="326 886 741 1250" style="background-color: #008080; color: white; padding: 10px; border-radius: 15px; text-align: center; margin-top: 20px;"> <p>“Your book is 2D and I’m 3D”</p> </div>	<ul style="list-style-type: none"> • Hospital <ul style="list-style-type: none"> ○ Lack of therapy at hospital • Outpatient therapy • Home Care <ul style="list-style-type: none"> ○ Targeted services ○ More rehabilitation (SLP/PT) ○ Wait times ○ Short visits ○ Lack of follow up/feedback • Long-Term Care <ul style="list-style-type: none"> ○ Recovery-oriented 	<ul style="list-style-type: none"> • <i>Person-centred</i> <ul style="list-style-type: none"> ○ Assessment and reassessment ○ Ongoing rehabilitation ○ Individualized ○ Communication/feedback (write it down) ○ Report/Communication book ○ “Work with me” ○ Listen to the patient ○ Goal setting ○ Spread out visits

Individual Wellbeing and Meaningful Activities

GOING WELL	IMPROVEMENTS	HOW
<ul style="list-style-type: none"> • Exercise/pool • Mood • Hobbies/routine/leisure activities • Projects of interest • Volunteer work <div data-bbox="198 815 608 1162" style="border: 1px solid #008080; border-radius: 15px; background-color: #e0ffe0; padding: 10px; margin-top: 20px;"> <p style="text-align: center; color: #008080;">The exercise class we have is “awesome”</p> </div>	<ul style="list-style-type: none"> • Mental health supports <ul style="list-style-type: none"> ○ Mood/depression/anxiety/isolation ○ Stroke-specific knowledge ○ Coping/grief/dealing with loss ○ “Shutting off old self” • Invisible impacts of stroke (i.e. emotional) • Post-Stroke Fatigue • Too much emphasis on stroke, can’t escape it <div data-bbox="886 908 1322 1312" style="border: 1px solid #008080; border-radius: 15px; background-color: #008080; color: white; padding: 10px; margin-top: 20px;"> <p style="text-align: center; color: white;">“Life is upside down right now”</p> </div>	<ul style="list-style-type: none"> • Mental health supports <ul style="list-style-type: none"> ○ Stroke-specific Mental Health Nurse/social worker ○ Awareness of/support for invisible impacts of stroke ○ Someone to talk to 1:1 • More exercise <ul style="list-style-type: none"> ○ In-person • Interests <ul style="list-style-type: none"> ○ Musical group, camera club • Vocational support/parenting

Transitions and Navigation

“The people that need it most won’t access it”

GOING WELL	IMPROVEMENTS	HOW
<ul style="list-style-type: none"> • Awareness of community services • Stroke Support Group Facilitator presence in hospital 	<ul style="list-style-type: none"> • Gap from Hospital to PCH, timing of information received • Lack of communication (transition to PCH) • Hospital to Community transition • Feeling alone when leave hospital • Unaware of services/not knowing where to go • Waitlists • Found resources/support on own (e.g. VON, MOD, ARC, Revved Up) • Awareness of services/overlap • Reach individuals not accessing services (support groups) 	<ul style="list-style-type: none"> • Assessment and follow-up • Improved communication/preparation regarding transitions • Better linkages to support • Calendar/notebook • Knowledge of services in other regions • Work with other regions • Improved communication within region (different services) • Phone number to call • Case Manager • Stroke Prevention Clinic ongoing

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



Implications of COVID-19

GOING WELL	IMPROVEMENTS	HOW
<ul style="list-style-type: none"> Virtual services <p>“The COVID period was bad, I couldn’t do anything right”</p>	<ul style="list-style-type: none"> Lonely at hospital No Stroke Support Group Facilitator/Peer support in hospital No home care Limited access to support groups Challenges with Zoom Impacts <ul style="list-style-type: none"> Impacts to progress Environment not conducive to recovery Delayed testing/equipment <p>“He will not do online”</p>	<p>“Don’t need to drive half an hour for a 10-minute visit that can be said over the phone”</p>



Education

“People with stroke end up in hospital for other things”

GOING WELL	IMPROVEMENTS	HOW
<ul style="list-style-type: none"> ● Stroke Education <ul style="list-style-type: none"> ○ Living with Stroke ○ Your Stroke Journey 	<p><i>Stroke Survivors/Caregivers:</i></p> <ul style="list-style-type: none"> ● Education/Communication ● Limited information on stroke and aphasia ● Lack of information for children <p><i>Healthcare Providers:</i></p> <ul style="list-style-type: none"> ● Healthcare Professionals not having stroke-specific knowledge ● Aphasia training <p><i>General Public:</i></p> <ul style="list-style-type: none"> ● Lack of understanding of aphasia <div data-bbox="779 996 1294 1282" style="border: 1px solid #008080; border-radius: 15px; background-color: #e0f2f1; padding: 10px; text-align: center; margin-top: 20px;"> <p>“We need to educate the public!”</p> </div>	<p><i>Stroke Survivors/Caregivers:</i></p> <ul style="list-style-type: none"> ● Individualized resources ● Information Package ● Improved communication and information at hospital <ul style="list-style-type: none"> ● <u>Involve family</u> <ul style="list-style-type: none"> ○ Letter, notes, hard copies, write down, bring someone <p><i>Healthcare Providers:</i></p> <ul style="list-style-type: none"> ● Know your patient ● Recovery not limited ● Education <p><i>General Public:</i></p> <ul style="list-style-type: none"> ● Education Curriculum ● Education/Awareness



Preliminary Results - Other Identified Themes

- 7. **Transportation**
- 8. **Home Care Services**
- 9. **Access and Equity Services**
- 10. **Personal Resiliency**

“Luckily we have those people coming in to our house”

“She is positive all the time”

“I am not a person to give up”

“I live in the middle of here and nowhere”



Next Steps

- Webinar for Stroke Survivors and Healthcare Providers

- Continue to review gaps in demographics

- Complete Final Report

- Update Workplan and action findings with advice from community advisors



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WE NEED YOUR HELP

ARE YOU A STROKE SURVIVIOR, CAREGIVER
OR HEALTHCARE PROVIDER?

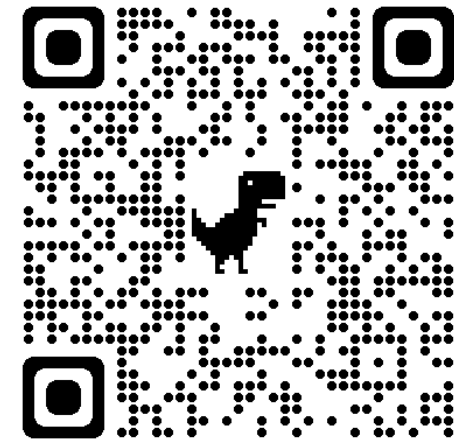


- ***Webinar for Stroke Survivors and Caregivers:*** June 29th at 1pm
[Click here](#) to attend
- ***Webinar for Healthcare Providers:*** June 29th at 3pm
[Click here](#) to attend



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Fewer Strokes Better Outcomes



Thank you to everyone who participated!

