PROVINCIAL NAVIGATION SURVEY

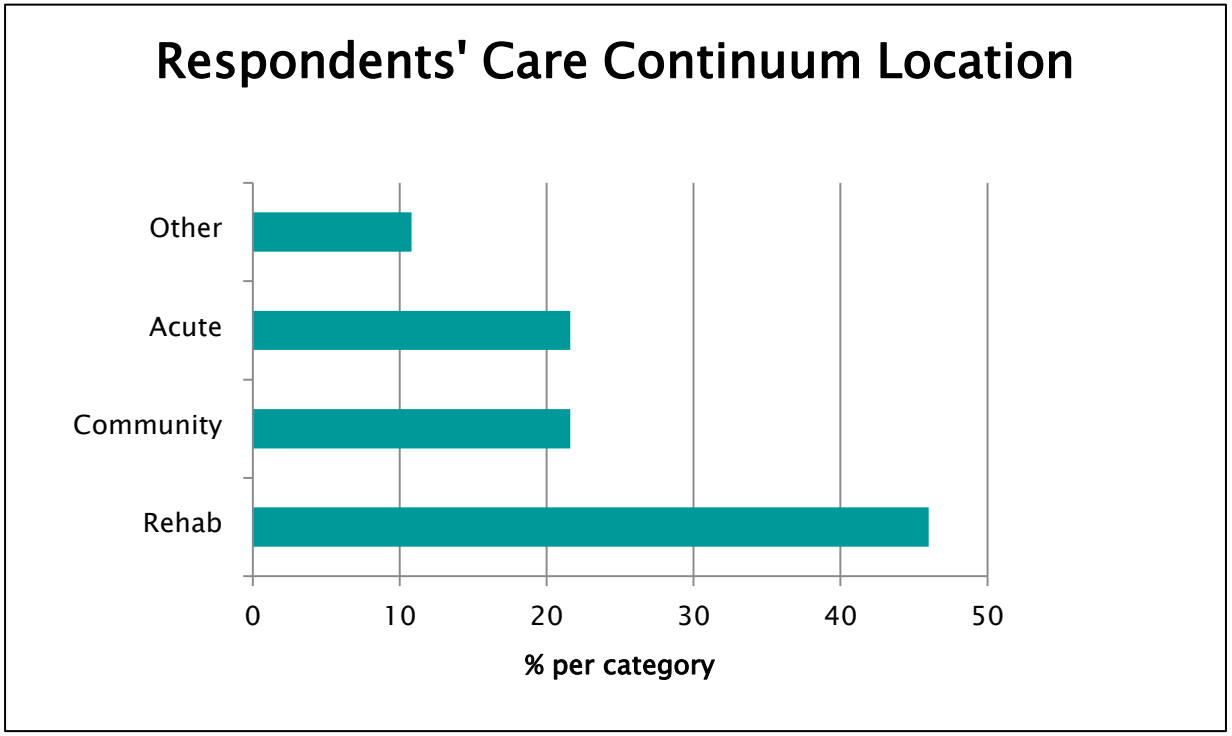
April 2021

SURVEY PROCESS

- Survey link shared with a contact in all stroke networks
- Request to distribute as appropriate
- Twenty-one responses received
- 57% indicated that post-stroke navigation was their primary role

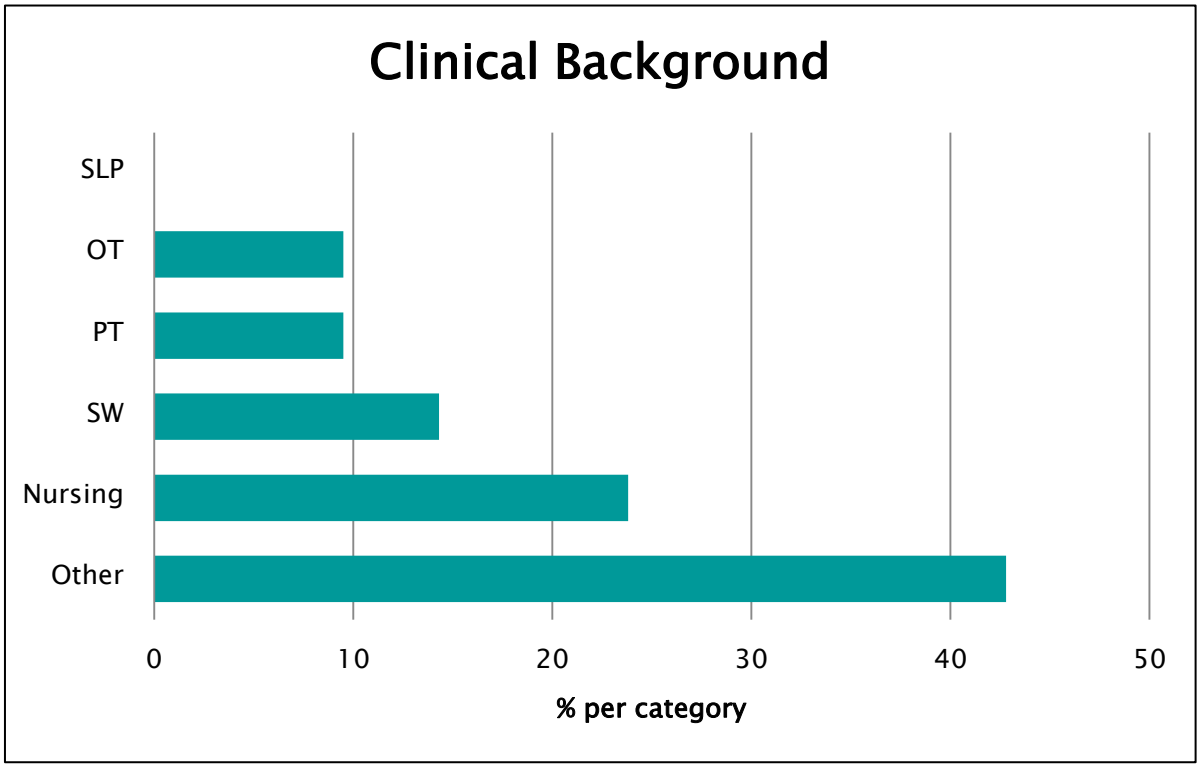
“As a navigator, being able to intervene in a timely manner has helped people settle in more safely and confidently into their discharge destination.”

Care Continuum



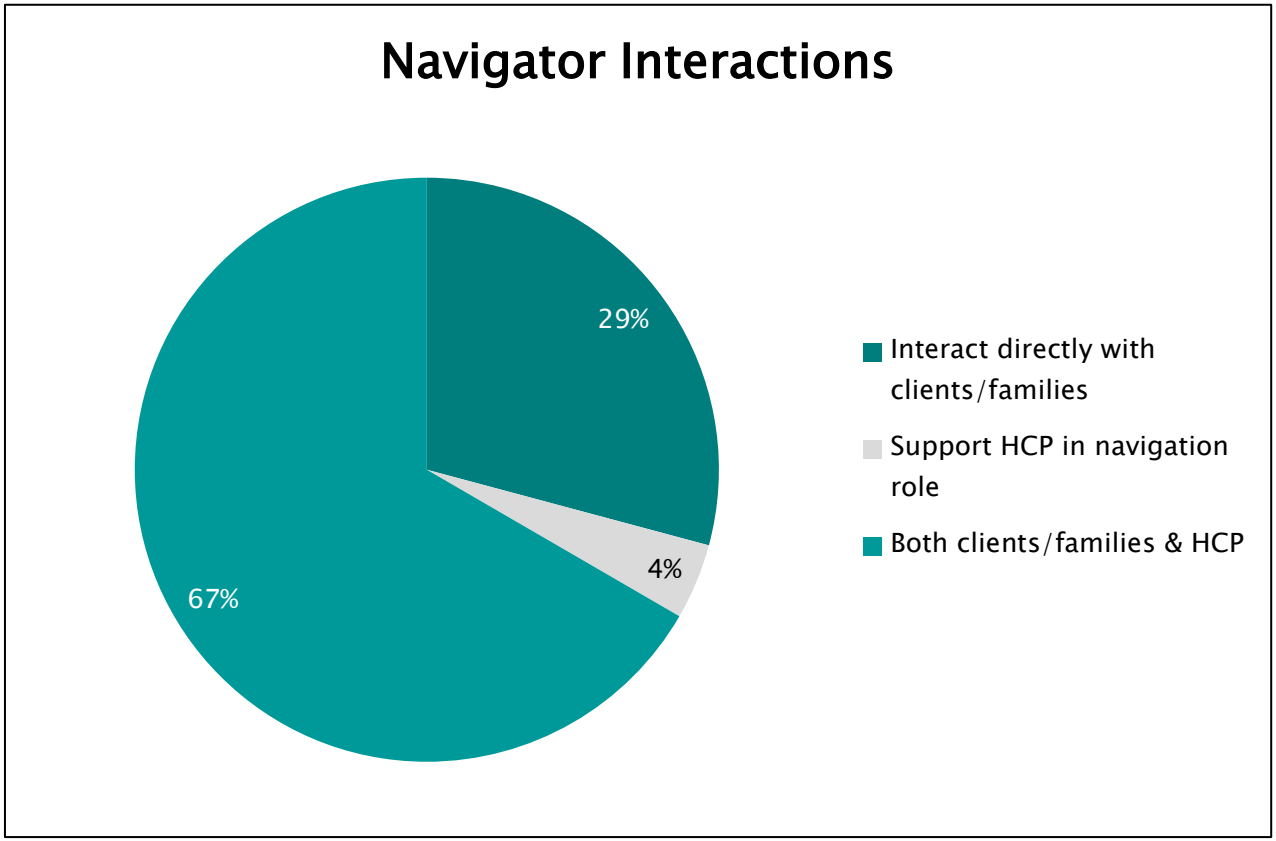
Other: Patient Navigation, General & Stroke Rehab, Admission Screening/Discharge Planning, Integrated Stroke Unit

Respondents' Clinical Background

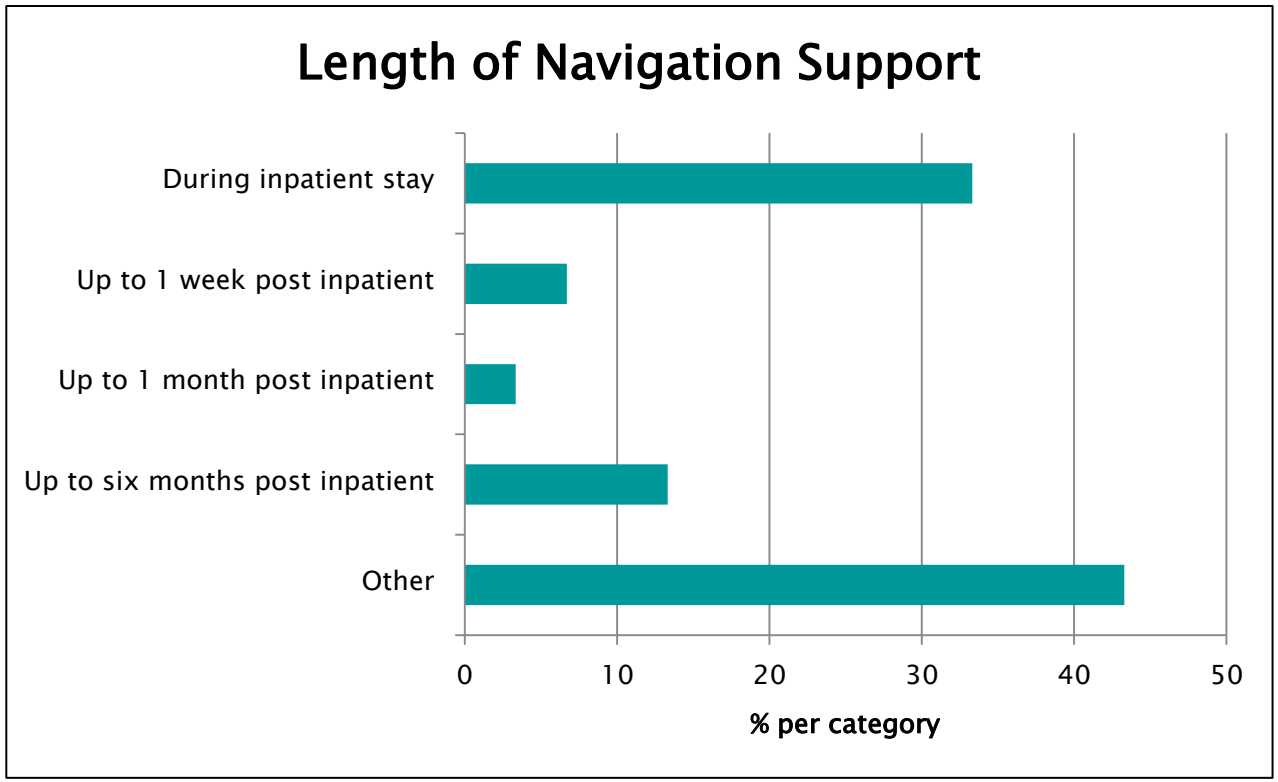


Other: Therapeutic Recreation X 3, Social Service Worker, Registered Nurse, ABI, BSc/MPH, Psychometrist

Navigator Interactions



Length of Navigation Support



	Navigation Time Frame – Other
No specific time frame	• Anytime • Up until clients no longer need navigation services • Support through community rehab until goals area achieved or they are no longer interested in the program (self-discharge) • As long as needed after discharge
~ one year	• Typically one year or longer depending on goal areas • Up to one year post-discharge • Up to one year if required
3-4 months	• Up to 4 months post-inpatient stay and additional point of contact can be initiated by patients/caregivers for further follow-up/support • 4 months post inpatient stay, patient can initiate contact further f/u with Navigator after that • Typically 12 weeks post inpatient stay
Other	• While patient is in hospital till they go somewhere • Willing to assist post-discharge but not a formal process • My navigation role at this time is in the capacity of a research study for 6 months following their inpatient stay. In usual care role, contact of inpatient within 1 week of discharge and screen for outpatient services.

FREQUENTLY ASKED QUESTIONS

Rehabilitation

- Accessing outpatient and community rehab
- Duration of therapy
- Accessing equipment
- Accessing community exercise programs

"Why is the rehab stay so short when my loved one needs months to recover, and where can I send them for more inpatient rehab?"

FREQUENTLY ASKED QUESTIONS

Home Care

- How to access
- What supports are available
- Volume & duration of services

Recovery

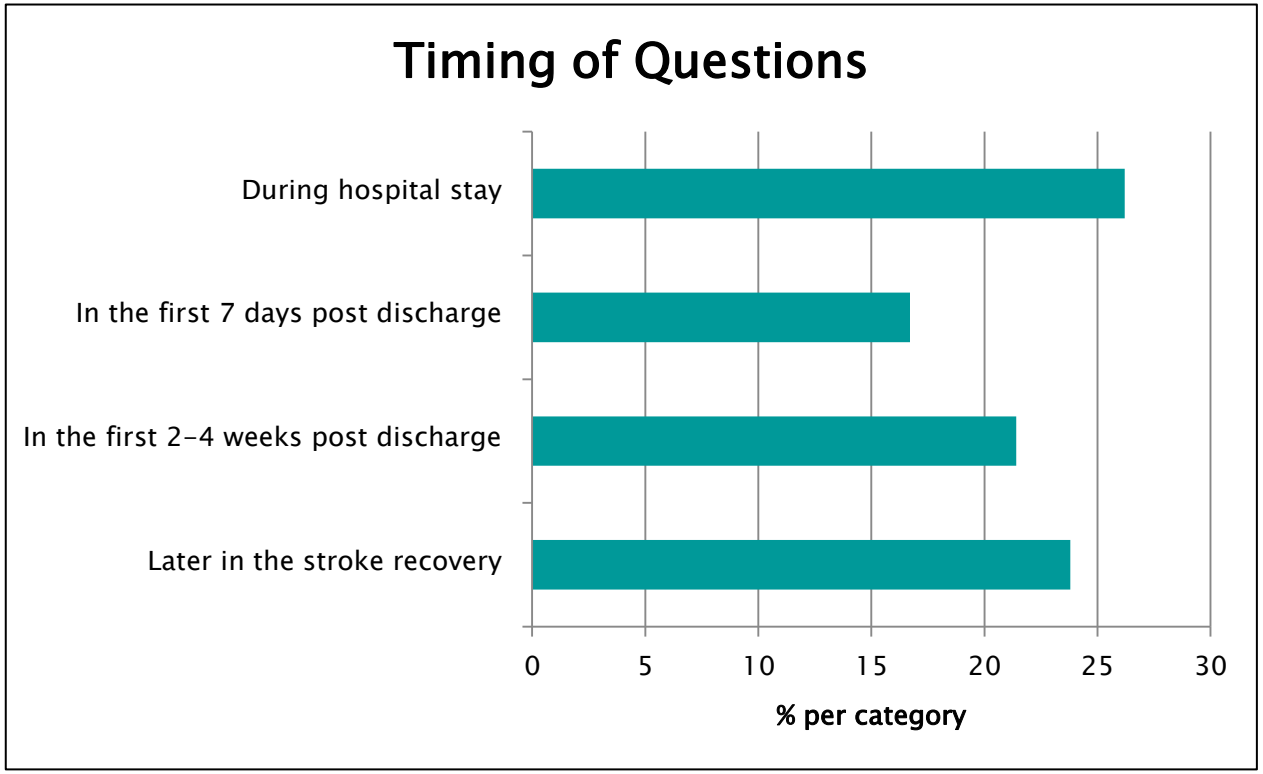
- Education (e.g. stroke, what can I do, when will I plateau/return to baseline)

FREQUENTLY ASKED QUESTIONS

- Finances (costs for programs, equipment, home modifications)
- Caregiver Supports
- LTC & Retirement Homes
- Cognition & Mood
- Transportation
- Medical Updates
- Peer Support
- Return to Driving/Work

Questions did not appear to be correlated to discipline/profession of navigator.

Timing of Questions



Additional comments included timing being dependent on density of stroke and that, while earlier is usually better, it may be difficult to identify needs at that time as well as challenges with LTC placement.

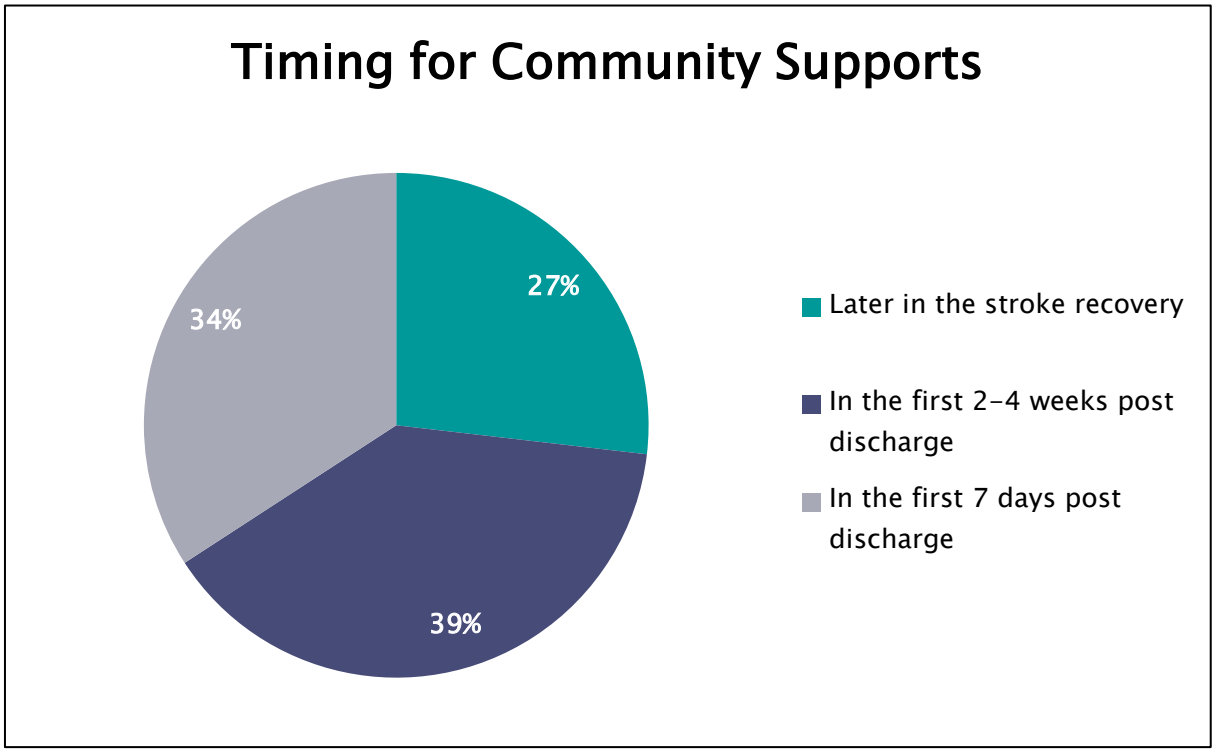
Timing of Questions

- Timing of questions may be influenced by various factors including length of navigation role, where client is in the recovery journey, emerging needs and gaps
- For example, questions related to rehab were asked throughout the recovery journey; financial questions tended to be later than 7 days post-discharge; home care questions pre-discharge

Critical Community Supports

- Accessing & re-accessing outpatient/community rehab
- Accessing community exercise programs
- Accessing equipment
- Mental health/counselling
- Peer support/support groups
- Home Care (PSW)
- Medical follow-up
- Caregiver support
- Ongoing check-ins
- Transportation
- Interim support when waiting for LTC placement

Timing for Community Supports



Additional comments referenced that timing is very specific to individual (readiness, home environment, family/HCC support). Noted that "*receiving early supports assists with the transition from hospital to home and reassures the family.*"

Extra Navigation Support Required

- General navigation challenges for client/family and understanding process
- LTC/RH processes and placement
- Accessing mental health services including peer support & supporting clients with mental health needs
- Limited home care services
- Follow-up for various referrals
- Client understanding of stroke and recovery process
- Waitlists (management & client/family understanding)
- Accessing community exercise programs
- Access to equipment
- Communication barriers (e.g. global aphasia)
- Financial & income supports
- Housing
- March of Dimes
- Lack of family support

Three respondents indicated that there were no specific challenges.

Stroke Resources

Resource	Resource Used	Linked to On-line Resource	Hard Copy Provided	Used for Education	Used to Identify Client Needs
Your Stroke Journey	16	5	14	8	2
Patient Journey Map	3	0	1	3	2
Post Stroke Checklist	6	1	1	3	3
Stroke in Young Adults	4	1	2	3	1

Website	Website Used	Linked to General Website	Linked to Specific Resource/Page	Used for Education	Used to Identify Client Needs
Heart & Stroke	17	13	6	9	1
March of Dimes	14	9	8	8	2
Stroke Engine	8	8	4	7	2
Local/Regional	4	3	1	1	0

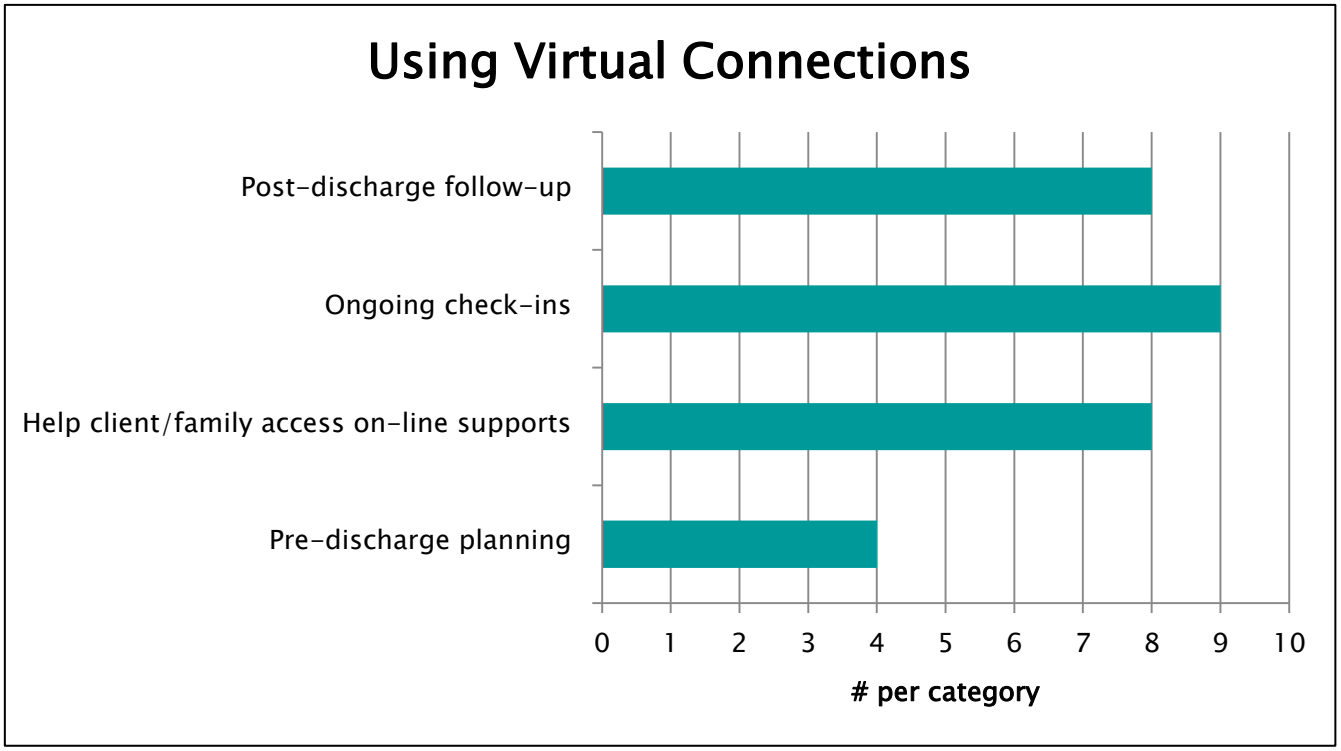
Additional Resource & Website Uses

- Link to support groups & community exercise programs
- Navigation support
- Link to support for vehicle & home modifications
- Link to lifestyle information (e.g. diet, exercise, blood pressure)

Virtual Connections

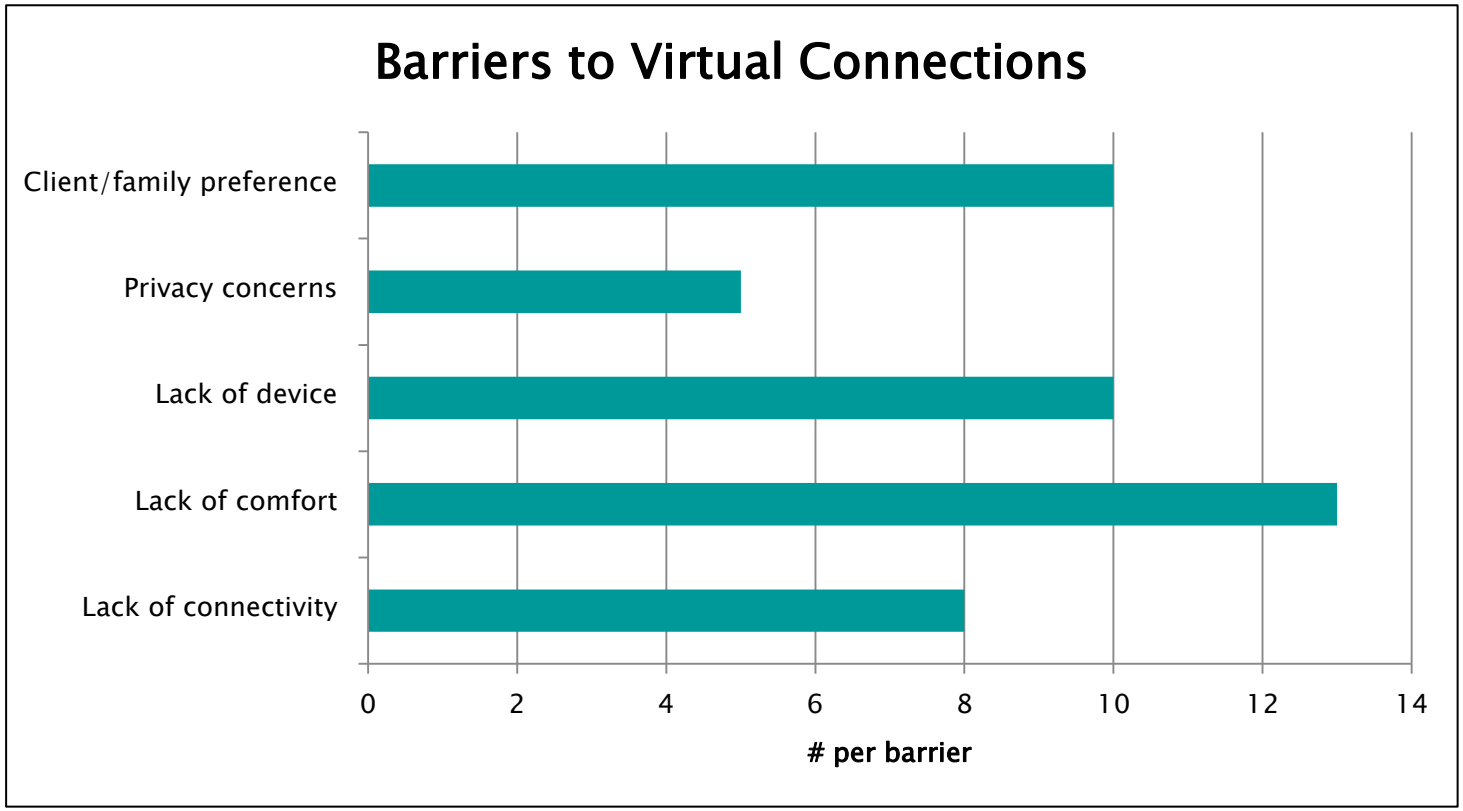
- The majority of respondents (81%) used virtual technology
- Support was provided to assist clients/families to use virtual technology by:
  - providing individual instruction (n=12)
  - leveraging caregiver support (n=11)
  - providing devices (n=5)

Virtual Connections



Additional uses included using a virtual platform so families could join rehab session or visit stroke survivor and for initial screening for outpatient therapy.

Barriers to Virtual Connections



Additional barriers included clients who have hearing impairment and difficult logistics at provider end (adequate & available space, privacy, time-consuming).

Final Respondent Comments

- Need to time/space out sharing of information so as not to overwhelm
- Include key resources/websites in discharge package
- Managing expectations

"Navigating the health care system is even difficult for me at times as a health professional due to discrepancies within the system."

Questions

Appendices

FREQUENTLY ASKED QUESTIONS – THERAPY

- Where to receive out of hospital rehab
- Out-patient physiotherapy
- How long do I receive PT/OT?
- More therapy (i.e. outpatients, LHIN, Community exercise program/TIME Program)
- More therapy, outpatient programs/Community Exercise Programs
- I want to work on my physical rehabilitation.
- How much rehab can they get?
- What equipment is needed?
- How long until they are able to attend therapy?
- How long can they participate in therapy?
- Why is the rehab stay so short when my loved one needs months to recover, and where can I send them for more inpatient rehab?
- When can I start outpatient rehab?
- What services are available to me as an outpatient?
- Will your team be able to provide me exercises to do at home?
- Seeking Therapy (PT/OT/SLP)/exercise
- More community rehab
- Spasticity issues
- Continuing therapy services
- Where are the community exercise programs being offered?

FREQUENTLY ASKED QUESTIONS – HOME CARE
• Assistance with homecare support • How much help can they get at home? • Home care • What supports will I receive at home? • How long will I receive PSW? • What resources are available post-discharge? • How much help [will] LHIN provide? • PSW care post-discharge • Who will support me in the community? • Who will help me if I need help?
FREQUENTLY ASKED QUESTIONS – RECOVERY
• What is stroke recovery? • What can I do to get better? • How long will it take before I plateau? • How long will their recovery to baseline take? • When will I be back to normal? • Will I continue to get better? • Stroke Education x 2

FREQUENTLY ASKED QUESTIONS - FINANCES
• Financial supports • Is there a cost to the program? • How can I get income support or money to pay for equipment and home modifications? • Financial support for accessible devices • Financial assistance if cannot return to work or assistance to modify home/assistive aids • Is there a cost?
FREQUENTLY ASKED QUESTIONS - CAREGIVERS
• Caregiver burnout • Caregiver Support/Resources x 2 • Who is going to help me take care of my loved one with significant impairments?
FREQUENTLY ASKED QUESTIONS - LTC
• Where will patient wait in hospital for LTC bed when they do not have a file started yet? • Who covers the cost of a Retirement Home that does Assisted Living till they get to Long Term Care? • How do I start a Long Term Care file?
FREQUENTLY ASKED QUESTIONS – COGNITION & MOOD
• Further cognitive development • I want to work on my memory • Resources for depression and anxiety
FREQUENTLY ASKED QUESTIONS - OTHER
• Transportation x 2
• Medical updates
• Peer support
• Return to driving/work

MOST CRITICAL COMMUNITY SUPPORTS

MENTAL HEALTH/PEER SUPPORT

- Social/emotional referrals
- Health & Wellness-Psychotherapy/Counselling
- SW
- Post stroke depression resources
- Mental health/mood support
- Mental Health
- Monthly support group interaction
- Peer support/education for Stroke Survivor
- Stroke survivor groups
- Peer Support
- Stroke Recovery Network (March of Dimes)
- March of Dimes supports (groups and funding)
- Providing support to person and family as the travel the stroke journey.
- Community reintegration
- Education and support

HOME CARE

- If home is possible, having enough reliable PSW supports guaranteed to go into home where the family member can rely on help
- PSW X 2
- LHIN X 4 [Home Care]
- Supports for personal care
- Home care supports X 2
- Services addressing essential need (personal support care, food)

MOST CRITICAL COMMUNITY SUPPORTS

REHAB

- Rehab x 2
- Fulsome community stroke rehab or out-patient therapies that meet the best practice guidelines for frequency
- Opportunity to re-enter out-patient therapies in the "chronic phase" if needs have changed
- Continued rehab as required (cognitive and physical)
- Physiotherapy/gym membership
- PT/OT
- Outpatient
- Providing person-centred appropriate rehab
- Allied Health
- 1:1 therapy
- Options for rehab
- Outpatient rehab INCLUDING SOCIAL WORK
- Outpatient rehabilitation
- Outpatient neuro program X 2
- Access to therapy services (PT/OT/SLP) or community programs supporting speech & rehab
- Continuing therapy (OT/PT/SLP)

- Exercise programs
- Ongoing community exercise program X 2
- Moving on after Stroke program
- Equipment

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- GP

HOME CARE

- If home is possible, having enough reliable PSW supports guaranteed to go into home where the family member can rely on help
- PSW X 2
- LHIN X 3 [Home Care]
- Supports for personal care
- Home care supports X 2
- Services addressing essential need (personal support care, food)

Comments on Timing of Questions

- Depends on the density of the stroke - if its really dense we usually need more time for patient to show any recovery they are going to have so difficult to plan for someone who is complete care and was living at home either alone or with a fragile caregiver. Earlier is better but its more difficult to determine what care needs will be ?
- When cost is big decider I usually tell families plan depends on finances - those with lots of money have more choices and is not usually as urgent to start LTC files but those that finances are impossible to manage with, getting the LTC care file is urgent as anyone with income/pension under $2400.00 is difficult/next to impossible to place in a RH that does assisted living as care needs are high and that cost.
- Patient who plan is to be closer to family in [city] find it more difficult to find a RH that can do the level of care at LTC homes. I'm talking about ability to manage toileting, feeding, mechanical lift and complete care. In [city] we have 2 places with the ability to do higher level of care. They also work with us to make exceptions on occasion to help provide for those with extreme financial need.
- I only see people during their inpatient stay. This organization no longer has a social worker for outpatients.
- Patients discharged from the Inpatient Rehab program at [hospital] are contacted within 2-3 days of discharge. Referrals received from family MDs and community partners are contacted within 2-3 months following their CVA.
- It is initially done early on and then prior to discharge. Often the client and myself will partake in a class prior to discharge to ensure a smooth transition.

Timing for Community Supports

ADDITIONAL COMMENTS

- Where the client is at that moment
- How long they need depends on house set up, family or friend supports and how much they are able to do for the patient
- How much help is available through HCC usually very limited to am and pm care so hour of care
- Receiving early supports assists with the transition from hospital to home and reassures the family
- Immediately and as needed
- It is very dependent on the individual, their family supports/situation, etc. There is not a single easy answer for when or what is required.
- Support is needed for the first year following the stroke

Extra Navigation Support Required

- March of Dimes
- Different referrals that are put into place and then follow up required.
- Client understanding services and steps in recovery
- 1) Patients do not live in hospital. They need to find another place to live. 2) LTC files need to be started to access LTC beds. 3) The difference between LTC beds and RHAL beds. 4) The difference between RH beds and RHAL beds 5) The hospital does not cover the cost of equipment or PSW 6) The responsibility of POA to the patient
- Difficult to navigate the entire system as programs change or program criteria change. It's difficult enough for health care practitioners to keep up to date with the changes let alone, the patient and family.
- The extra navigation support or resource may be waitlisted for a lengthy time. The patient/ family would therefore be disappointed as the service is required immediately
- SW
- Access to programs. Navigating the healthcare system. LHIN services. Outpatient wait times
- Community exercise (locating programs). Access to Social Work/Peer Support; supporting caregiver/patient mood/recovery journey/next steps. Wait times for Outpatient Programs.
- Accessing is complicated and family struggles with all the information, lack of support from family or loved ones, patient "falls through the cracks”
- Access to equipment – there is a great shortage of hospital beds and mechanical lifts When there is a communication barrier- ex : global aphasia
- Community resources that are not typically accessed or are less well known
- Income support programs. Funding for equipment and modifications. Access to mental health supports (Social Work and counseling) following the inpatient stay. Explaining the severe limitations for [area] home care services.
- 1. LHIN : often times patients from [hospital] are discharged home with no personal support in place despite being recommended by the health professional team on a designated stroke rehab unit. 2. Outpatient rehab at [hospital], patients often are aware they have been referred but they seem unclear about services offered and the service delivery that will be offered to them.
- Housing, mental health, financial aid, rehabilitation
- Cost associated with services
- Relatively seamless at this point in this location
- None or n/a (x 2)

Stroke Resources

ADDITIONAL USES OF RESOURCES & WEBSITES
• Education and support groups • During navigation at bedside during intake process • Patients are provided with a patient education package that includes materials from Heart & Stroke Foundation and March of Dimes • MOD [to] assist with finding/providing home and vehicle modification info, local support group chapters, community exercise programs • Heart &Stroke [for] peer support, info on diet/exercise/stroke prevention resources, multi-language literature/resources very helpful • Stroke Engine [for] general searches/resources provide based on requests from patient/family/healthcare providers • Used to locate local support groups • Home and vehicle modifications info/funding • Heart Healthy Diet info from H&S - recipes etc. Multilingual info from H&S website. Prevention info -FAST book marks, info sheets, BP monitoring etc. • I also use them for personal education and updates re: services. • Local stroke support guide was developed • During brief Action Planning an education session is given on the available websites. Usually the March of Dimes virtual programming

Use of Virtual Connections

ADDITIONAL COMMENTS
• Connect via phone or iPads are available for Zoom calls. Able to connect virtually to March of Dimes Peers Fostering Hope volunteers as well. • Refer patient/family to appropriate support. • We refer people to March of Dimes virtual support groups • All of our discharge support meetings are virtual or over the phone • Also using virtual meeting to have families see how patients are doing in therapy • Some staff here use a virtual platform to allow families to see a rehab session during the COVID visitation restrictions. We also use this platform to support family virtual visits. • Provide link to [hospital] website about "Guide to Virtual Care". • Education session during brief action planning. Individual support is given if required. It's difficult to do as the clients often can't bring in their devices or remember passwords etc. • Rehab sessions are virtual • Most of the patients we deal with, their families are not either connected to computer to do so but we set up telephone conferences with patient and team and families involved to talk and ask questions. • Education, rehab • Initial screens into outpatient program and for other staff it is used to provide therapy (e.g. SLPs)

Barriers to Virtual Connections

ADDITIONAL COMMENTS

- Patient or family member hard of hearing.
- Patient family member is not able to manage technology.
- Lack of private space that has ability to fit team and have enough space to work in. Sometimes these meeting happen quickly to book a room is too challenging along with organizing and sending invite out once family agree to time.
- Sometimes family members have difficulty utilizing technology at their end and prefer a phone call.
- Often the clients are not interested in pursuing virtual sessions or they are uncomfortable with technology.
- It is time consuming and does not always work well.

Final Respondent Comments

- Remember that at the initial meeting too much information can be overwhelming. Connect with them a few weeks after initial visit and continue to be that support to check in.
- As soon as anyone from the medical team or community says to family or friends, they won't be able to go home, people assume they can stay in hospital. So, you're immediately working against what they believe is accurate information (e.g. you can't kick me out of the hospital).
- Short introduction power point available to review? Short list or layout of navigation with links to resources?
- Having a list of key stroke resources/websites available in patient's d/c package to support their transition home
- It would help if inpatient units did a formal introduction with patients and families re: what to expect from their stay on the unit, and who are the key players (roles) on the team.
- Integral role in rehab. Navigating the health care system is even difficult for me at times as a health professional due to discrepancies within the system. Not all patients and their families are savvy using technology. Being able to provide client centered direct communication with families has seemed to be beneficial.
- As a navigator, being able to intervene in a timely manner has helped people settle in more safely and confidently into their discharge destination.