Evaluation

For the **Provincial Stroke Rounds Planning Committee**:

- To plan future programs
- For quality assurance and improvement

For **You**: Reflecting on what you've learned and how you plan to apply it can help you enact change as you return to your professional duties

For **Speakers**: The responses help understand participant learning needs, teaching outcomes and opportunities for improvement.

https://www.surveymonkey.com/r/Z32MWVG

Please take 2 minutes to fill out the evaluation form,

either online or in the room.

Thank you!

Mitigating Potential Bias
(Provincial Stroke Rounds Committee)

The Provincial Stroke Rounds Committee mitigated bias by ensuring there was no Industry involvement in planning or education content.

Stroke in Young Adults: Patient Reported Outcomes & Psychosocial Needs

Dr. Aleksandra Pikula, BSc. (Hon), MD, Dipl. ABPN (USA)
Assist. Prof. of Medicine (Neurology), U of T Division of Neurology, Stroke Program, UHN/TWH
Director, UHN Stroke in Young Adults (SiYA) Program, TWH/MSH
Director, Stroke Research Program, UHN
Co-Director, Women's Neurology Fellowship, U of T
Associate Investigator, Framingham Study, Boston

May 5, 2021   Provincial Stroke Rounds

Disclosure of Affiliation, Financial Support & Mitigating Bias

Grant/Research Support: CIHR, U of T / DON, HSFC

NO other relevant DISCLOSURES

Objectives

- Upon completion, participants will be able to:

1. Identify the current gaps in supporting the needs of young persons with stroke based on available literature

2. Describe the PROMs and psychosocial needs of young persons with stroke through lived-experience

3. Reflect on next steps to address identified gaps to support the needs of young persons with stroke

Stroke in Young – <u>Quick Review</u>

- Definition of young

- What is the incidence/prevalance of stroke in young?

- What about stroke severity?

- What are the short vs long-term outcomes (recurrency, mortality) in young?

- Current practice based on the Canadian stroke best practice recommendations for Managing Transitions of Care (2020)

Stroke in Young – <u>Definition of young</u>

- *Social and public health definition*

    young adults < 40 yo

    young to mid-age 40-64

- **Stroke studies**

    <45-55 (new literature <55)

- **With population aging – there is a shift to include mid-age /working population**

    <65

Stroke in Young – <u>Incidence/Prevalence/Traditional Risk Factors</u>

~ 800.000 hospitalizations
*2003-2004 vs *2011-2012

In the past 10 years there is a ~ **20-35%** relative change in ischemic stroke prevalence for 18-55 yo
-More so in W
-Contributed to higher burden of RFs
-No change ICH and SAH

JAMA Neurology | Original Investigation

Prevalence of Cardiovascular Risk Factors and Strokes in Younger Adults

Mary G. George, MD, MSPH; Xin Tong, MPH; Barbara A. Bowman, PhD

Table 1. Prevalence of Acute Ischemic Stroke as the Principal Diagnosis by Age, Sex, and Race/Ethnicity

Demographic	2003-2004 Weighted No.	2003-2004 Rates/10 000 Hospitalizations (SE)	2011-2012 Weighted No.	2011-2012 Rates/10 000 Hospitalizations (SE)	Relative Change, %[a]	P Value for Trend[b]
Age 18-34 y	8275	6.6 (0.2)	10 178	8.4 (0.3)	27.3	<.001
Male	3787	15.6 (0.7)	4634	18.0 (0.6)	15.4	.003
Female	4483	4.4 (0.2)	5539	5.8 (0.2)	31.8	<.001
Non-Hispanic white	3034	6.1 (0.3)	4974	8.2 (0.3)	34.4	<.001
Non-Hispanic black	1728	11.1 (0.7)	2354	11.9 (0.6)	7.2	.31
Hispanic	845	4.4 (0.5)	1300	6.2 (0.4)	40.9	.001
Other	460	6.4 (0.8)	775	7.9 (0.7)	23.4	.12
Age 35-44 y	25 350	35.1 (0.9)	28 287	47.6 (1.0)	35.6	<.001
Male	12 923	48.2 (1.3)	14 813	68.2 (1.6)	41.5	<.001
Female	12 417	27.5 (0.8)	13 463	35.8 (1.0)	30.2	<.001
Non-Hispanic white	10 052	30.5 (1.0)	13 551	42.1 (1.2)	38.0	<.001
Non-Hispanic black	5594	54.0 (2.7)	7633	72.4 (2.3)	34.1	<.001
Hispanic	1939	28.4 (1.6)	2995	37.3 (1.6)	31.3	<.001
Other	940	29.4 (2.5)	1985	44.5 (2.5)	51.4	<.001
Age 45-54 y	82 271	102.0 (1.7)	102 082	122.9 (1.6)	20.5	<.001
Male	46 275	120.1 (2.3)	59 472	144.1 (2.1)	20.0	<.001
Female	35 896	86.2 (1.7)	42 583	102.1 (1.6)	18.4	<.001
Non-Hispanic white	35 056	90.2 (2.0)	55 229	111.4 (1.7)	23.5	<.001
Non-Hispanic black	16 563	146.1 (5.1)	24 862	160.9 (3.5)	10.1	.003
Hispanic	5604	94.5 (3.7)	9005	112.5 (3.3)	19.0	<.001
Other	3260	117.5 (7.2)	6127	142.6 (5.3)	21.4	.007
Age 55-64 y	167 053	200.9 (0.9)	202 227	202.5 (0.6)	0.8	.44
Male	94 659	228.8 (3.4)	118 598	234.6 (2.7)	2.5	.10
Female	72 353	173.4 (2.7)	83 607	169.5 (2.0)	−2.2	.34
Non-Hispanic white	82 415	189.6 (3.5)	121 360	187.4 (2.4)	−1.2	.78
Non-Hispanic black	23 807	265.0 (6.4)	39 076	252.0 (4.3)	−4.9	.12
Hispanic	9740	181.8 (6.0)	15 147	199.7 (4.6)	9.8	.02
Other	6353	231.6 (11.6)	11 824	240.3 (6.7)	3.8	.29

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JAMA 2017, National Inpatient Sample from 1995 through 2012 by Centers for Disease Control and Prevention

2012

Journal of Neurology & Neurophysiology

Editorial   **Open Access**

Promoting Awareness on Cerebrovascular Disease in Young Adults is a
Work in Progress

Aleksandra Pikula*

2020

Risk Factors for Ischemic Stroke in Younger Adults
A Focused Update

Mary G. George, MD, MSPH, FACS

JAMA Neurology | Original Investigation

Prevalence of Cardiovascular Risk Factors and Strokes
in Younger Adults

Mary G. George, MD, MSPH; Xin Tong, MPH; Barbara A. Bowman, PhD

EDITORIAL

American Heart Association | American Stroke Association

Rising Stroke Incidence in Young Adults: More Epidemiological
Evidence, More Questions to Be Answered

Yannick Béjot, MD, PhD; Benoit Delpont, MD; Maurice Giroud, MD

Trends are seen across many international cohort and hospital-based studies:
- UK studies, Netherland Study, US National Inpatient Sample, the Swedish National Inpatient Register, and the Danish National Patient Register & **across different population-based study:**
– Kentucky, Framingham, REGARDS.

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Trends in hospitalization over the past decade in Canada

Age Group	2007	2008	2009	2010	2011	2012	2013	2014	2015	2016
90plus	0%	5%	8%	18%	21%	25%	35%	45%	45%	63%
80-89	0%	1%	2%	3%	2%	5%	3%	9%	10%	9%
70-79	0%	0%	-3%	-1%	-4%	-2%	0%	6%	11%	16%
60-69	0%	2%	1%	10%	13%	13%	24%	35%	42%	49%
50-59	0%	3%	6%	12%	16%	24%	29%	35%	44%	42%
40-49	0%	-3%	1%	10%	1%	2%	6%	4%	12%	18%
30-39	0%	4%	4%	10%	16%	25%	43%	32%	69%	35%
20-29	0%	-4%	-9%	-3%	-3%	-6%	-16%	7%	17%	28%
01-19	0%	22%	10%	-6%	-20%	0%	-59%	-31%	-39%	-35%

Source Data: Heart & Stroke's analysis of data from the Canadian Institute for Health Information's Discharge Abstract Database for 2007-2017. Data from Quebec, Yukon and
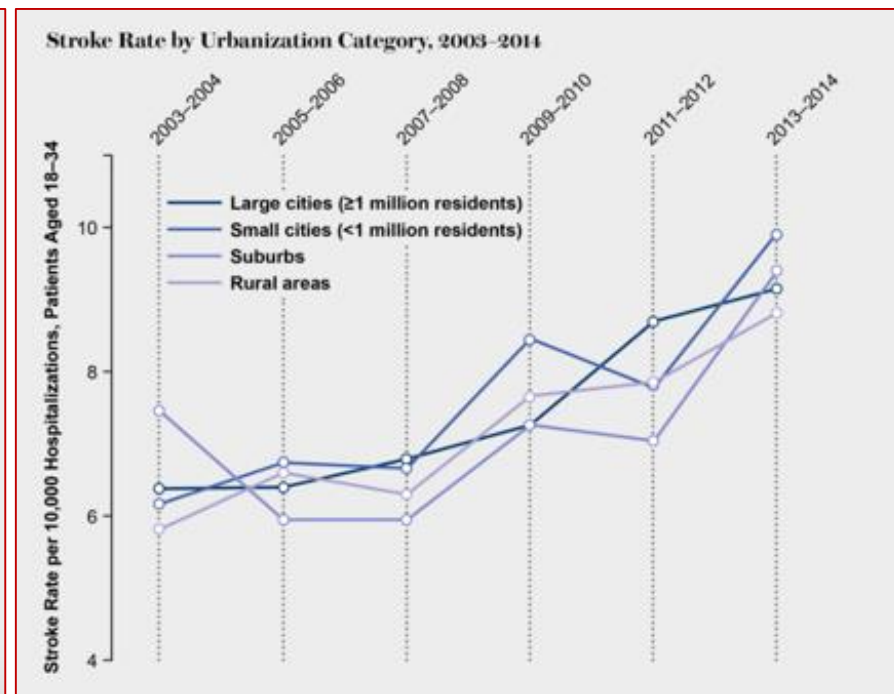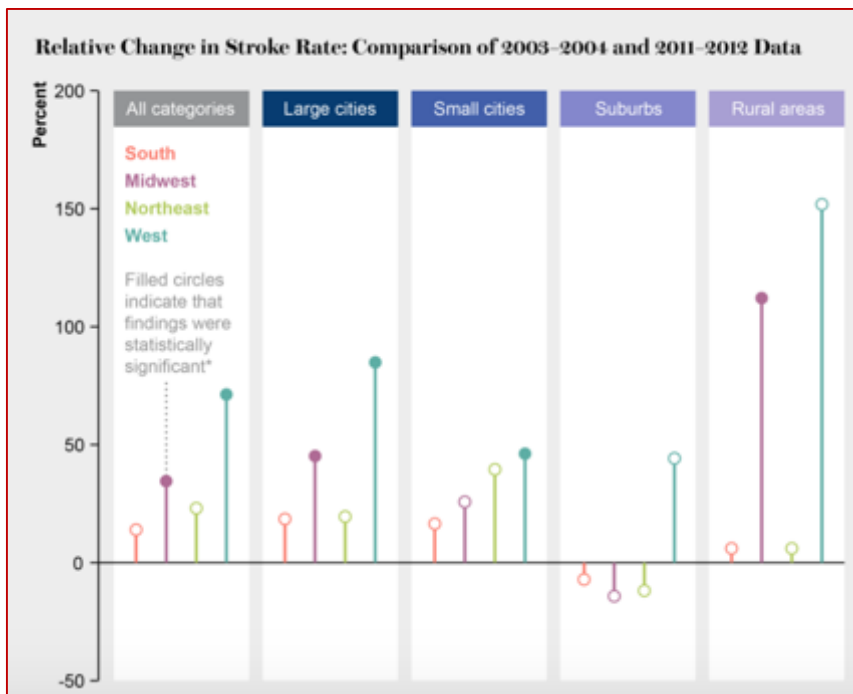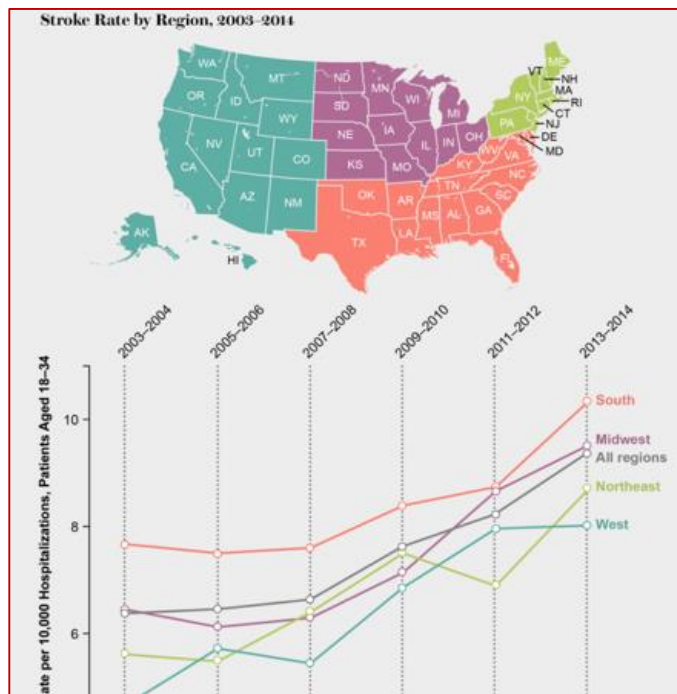
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June 28, 2017

Stroke in Young – <u>Severity</u>

Ontario Stroke Registry (prospective) ~ 2300 pts with IS, <50 yo

- mild in 60% ~ large proportion discharged home,

- moderate in 30%

- severe in 10%

 - So, the overall physical prognosis is good, but is that good enough?

Putaala J. Ischemic Stroke in Young Adults. Continuum (Minneap Minn). 2020 Apr;26(2):386-414.
Aikula A, et al. Stroke Outcomes in Young Adults with Ischemic Stroke. (WSO)
Edwards JD at al. Young stroke survivors with no early recurrence at high long-term risk of adverse outcomes. J Am Heart Assoc. 2019;

Stroke in Young – <u>Outcomes</u>

Ontario Stroke Registry (prospective data on ischemic stroke)

Short Term Recurrence and **mortality rate** was higher then previously reported:

    - **at 30 days** ---- stroke **recurrence ~ 5%** and **mortality 10%**

    - **at 1 year** ---- stroke **recurrence ~ 7%** and **mortality 20%**

Longer Term Recurrence rates also high

    - **at <5 years** ---- **HR 5.2** at 5 years for vascular events vs. **1.3 for older** stroke patients, compared with their matched controls

Original research article

EUROPEAN STROKE JOURNAL

European Stroke Journal 2016, Vol. 1(4) 337–345 © European Stroke Organisation 2016 Reprints and permissions: sagepub.co.uk/journalsPermissions.nav DOI: 10.1177/2396987316673440 eso.sagepub.com

The very long-term risk and predictors of recurrent ischaemic events after a stroke at a young age: The FUTURE study

Renate M Arntz[1], Mayte E van Alebeek[1], Nathalie E Synhaeve[1,2], Jeske van Pamelen[2], Noortje AMM Maaijwee[3], Hennie Schoonderwaldt[1], Maureen J van der Vlugt[4], Ewoud J van Dijk[1], Loes CA Rutten-Jacobs[5] and Frank-Erik de Leeuw[1]

25-yrs cumulative risk of
-    Any ischemic event **45% - 1 in 2**
-    Ischemic stroke **30% - 1 in 3**

JF Varona. Long term Prognosis in Ischemic Stroke in Young Adults, Stroke Research 2011
Pikula A, et al. Stroke Outcomes in Young Adults with Ischemic Stroke. (WSO)
Edwards JD at al. Young stroke survivors with no early recurrence at high long-term risk of adverse outcomes. J Am Heart Assoc. 2019;

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Stroke in Young – <u>RTW, Cognitive and Psychosocial Outcomes</u>

- Overall physical prognosis is good, yet l**ong term functional outcomes** are NOT GOOD ENOUGH

- <50% of young stroke survivors **return to work** + 25% would require **modifications**
- 80% have various **psychosocial complaints** (depression, anxiety, pain, stigma,...)
- 30-40% have objectively measured **cognitive dysfunction** (processing speed, executive)
- 80% **fatigue**
- 50-70 % **sleep disturbances**

- 2020 Canadian Best Stroke Practice on Managing Stroke Transitions of Care:
- ➢ No specific recommendations in place based on age or sex
- ➢ Few updates made with suggested knowledge gaps– such as need for patient-centered care

Kissela BM et al Neurology 2012
AHA 2012, 2016, CBSPR 2016 & 2020

The FUTURE Study. Neurology 2012, 2013, 2016
Sasikumar S., Pikula A. Psychosocial Needs and Occupational Functioning of Younger Adults after Stroke EC Neurology

Edwards J. et al 2018 Apr;13(3):243-256.

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Stroke in Young – <u>RTW and Socioeconomic Outcomes</u>

- Individuals from higher socioeconomic status and with professional backgrounds are more likely to RTW

- Greater independence in ADLs, fewer neurological deficits, and better cognitive ability were the most common predictors of RTW.

- On a societal level, individuals who do not RTW greatly impact the economy through a loss of productive years of employment.

- Public Health Canada reports that stroke costs the Canadian economy more than $3.6 billion per year (ontariostrokenetwork.ca), with the greatest economic impact likely being due to stroke among working population.

- It is of great importance to optimize younger stroke patients' occupational functioning.

The FUTURE Study. Neurology 2012, 2013, 2016
Sasikumar S., Pikula A. Psychosocial Needs and Occupational Functioning of Younger Adults after Stroke EC Neurology, 2018

Kissela BM et al Neurology 2012
AHA 2012, 2016, CBSPR 2016 & 2020   Edwards J. et al 2018 Apr;13(3):243-256.

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Stroke in Young – <u>Quality of Life (QOL) Outcomes</u>

- Few studies reported that the factors affecting **QOL vary with age.**

- **In older** individuals, a **low QOL** is associated with **motor deficits and speech impairment.**
- **In younger** individuals, restrictions in their job and leisure activities have a greater impact on well-being, and the **QOL is measured by life satisfaction**.

- *Life satisfaction* after stroke is associated with occupational status, sexual life, physical and mental health.
- These important distinguishing factors can help determine more focused strategies in young stroke adults, but the studies done in the past are small.

Sasikumar S., Pikula A. Psychosocial Needs and Occupational Functioning of Younger Adults after Stroke EC Neurology, 2018

Palmcrantz Susanne., et al. Long-Term Health States Relevant to Young Persons with Stroke Living in the Community in Southern Stockholm—a Study of Self-Rated Disability and Predicting Factors.. Disability and Rehabilitation 34.10 (2012): 817-823.

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What all this mean to us and our younger patients?

- 30% of all strokes in < 65 yo

- *"We are just seeing those little waves hitting the beach now, but that tsunami will come in the future"*

  ~~ Dr. Mitch Elkind, Columbia University, AHA President

    commentary from 2017 on increased incidence of stroke in young adults

What are the limitations of outcomes studies in contemporary stroke medicine?

Outcome measures

Acute care model vs. Chronic disease care model

Need innovative approach and tools

Age specific outcomes should be always reporter

NIHSS, mRS and BI are great tools to assess short-term outcomes of functional status and help us define EFFECTIVNESS of our acute interventions

But can NOT help us identify long-term individual patient's needs or QOL

Acute Care model could not be necessarily applied to Chronic Disease Care model

Patient-reported outcome measures (PROMs)

Health information collected directly from stroke patients as measures of

- functional status,

- well-being,

- health-related quality of life (HRQOL),

- symptom burden

- patient experiences of care (eg, satisfaction)

- health behaviors (lifestyle, prevention, taking ownership)

- self-identity

A satisfied life is better than a successful life. Because our success is measured by others. But our satisfaction is measured by our own soul mind and heart.
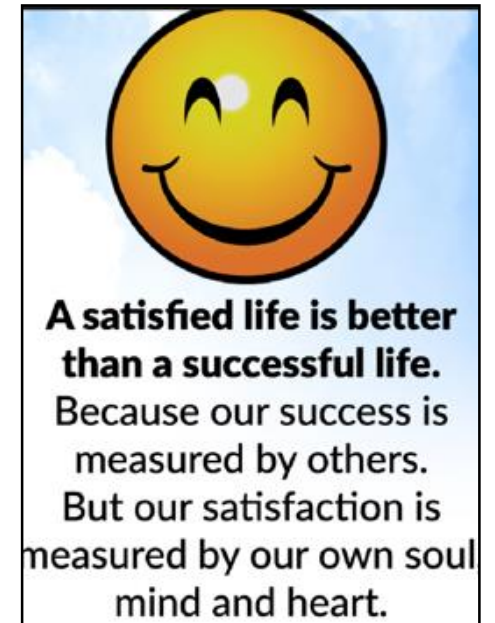
Reeves M, Lisabeth L. et al, Stroke 2018

Patient-Reported Outcome Measures (PROMs) for Acute Stroke: Rationale, Methods and Future Directions

Mathew Reeves, PhD, Lynda Lisabeth, PhD, Linda Williams, MD, Irene Katzan, MD, Moira Kapral, MD, Anne Deutsch, PhD, and Janet Prvu-Bettger, PhD

- **Neuro outcomes/Stroke (NIH)**

- PROMIS 10

- NeuroQOL

- Developed with the intent to be used as outcome measures in trials
- Validated
- Feasible in any setting (short/long forms)
- No celling effect
- T-score generated at the end for each functional domain

- An opportunity to evaluate outcomes through time and with focus on specific domain that may matter the most to individual patient

Table 2. Inventory of Multidimensional Generic and Stroke-Specific PROMs Commonly Used in Stroke Patients

Measure	Purpose or Focus	Time to Administer	Physical	Cognitive	Social	Role*	Depression	Psychological	Mental Health	Somatic	Vitality Energy	Other
Generic												
EQ5D[10]	Assess QALYs+general health	5 min	Mobility, self-care			X	X	Anxiety		Pain		
GHQ-28[10]	Screen for psychological disorders	5 min			X		X	Anxiety		X		Insomnia
MOS SF-36[10]	Assess HRQOL not stroke-specific	10 min	X		X	X		X	X	Pain	X	
Neuro-QOL[11]	Assess QOL	5 min	Mobility, UE/LE, ADL, self-care, B/B	X	X	X	X	Anxiety, emotional behavior, affect	X		Fatigue	Communication, stigma, sleep disturbance
PROMIS 10[12]	Assess general health	10 min	X	Thinking	X	X	X	Mood, emotion	X	Pain	Fatigue	
Stroke-specific												
SS-QOL[13]	Assess HRQOL specific to stroke	15 min	Mobility, UE, self-care	Thinking	X	X		Mood			X	Vision, personality, language
SIS (64 item)[14]	Assess multiple dimensions poststroke	15–20 min	Mobility, function, strength, ADL/IADL	Memory, thinking	X	X		Emotion				Communication
SA-SIP30[15]	Stroke-specific SIP assesses QOL	<30 min	Mobility, body care, movement, ambulation		X	X		Emotional behavior				Communication, alertness, behavior
SATIS-Stroke[16]	Satisfaction with ICF activities and participation	N/R	Mobility self-care	Learning, general tasks	X	X						Communication

Hypothetical Case

- A 50-year-old W, teacher, but also primary caregiver of husband with a 3 -year history of Parkinson's disease, 2 older kids, elderly parents.

- PMH: HTN and DM

- Clinical event: Woke up with mild left sided weakness and dysarthria, presented to primary stroke center with NIHSS = 6, CT confirmed right MCA ischemic stroke. No thrombolytic treatment (uncertain time of onset).

- Uneventful hospital course (5-day length of stay).
- Discharged to home with services & ASA, diuretic, CCB, statin, dipyridamole, pioglitazone.

- GP visit scheduled in 8 days; Scheduled neuro f/u

Traditional Approach – Outcomes collected by provider

Measure	Pre-stroke	Hosp D/C	4-days	8-days	40-days	100-days	Interpretation
Source of data	eMR	eMR	Telephone FU	PCP office visit	Neurology office visit	PCP office visit	
mRS	0	3	2	3	2	1	Both data trends point to progressive recovery in function but with poor concordance between the two sets of scores.
BI	NR	NR	90	90	100	100	

New Approach – Patient reported outcomes (PROMIS System)

Source	Patient	Patient	Patient	Patient	Patient	Patient	
PROMIS Global 10 PH	NR	42	48	46	50	55	Higher scores are better (greater physical function). Data trends point to overall improvement.
PROMIS Global 10 MH	NR	45	54	58	48	42	Higher scores are better (greater mental health function). Data trends point to worrying decline, not reflected in traditional mRS or BI measures.
PROMIS anxiety	NR	46	52	54	58	62	Higher scores are worse (more anxiety). Data trends point to progressive increase that maybe related to observed decline in mental health.
PROMIS self-efficacy to manage ADL	NR	NR	55	50	44	40	Higher scores are better (greater self-efficacy). Data trends point to a decline in function that is not reflected in trends in traditional mRS or BI measures.

PROMs Challenges

- Time and infrastructure for data collection
- Underestimate the needs in high mRS groups (aphasia, neglect)

- Challenges integrating PROMs into electronic health records – available on REDCap
- Generating results in a format and time that are useful to clinicians delivering care
- Addressing all domains would be time consuming, - focus on the most important (from patient's perspective)

2015 User's Guide-Rev 1 (isoqol.org)

Boyce MB, Browne JP, Greenhalgh J. The experiences of professionals with using information from patient-reported outcome measures to improve the quality of healthcare: a systematic review of qualitative research. *BMJ Qual Saf*. 2014

Psychosocial Needs and Outcomes

- Lack of studies in young adults on PROMS and Psychosocial needs

- Few – mostly focused on depression, anxiety and sleep (common)

- Very few looked into stigma, fatigue, positive affect, participation in social activities or life satisfaction… but none into cumulative effect of all aspects of life.

Psychosocial Sequelae of Stroke in Working-Age Adults: A Pilot Study

Lori M Rhudy, Jennifer Wells-Pittman, Kelly D Flemming

Confirmed feasibility of NeuroQOL use in assessing for cognitive and mental health outcomes.

The FUTURE Study. Neurology 2012, 2013, 2016
Sasikumar S., Pikula A. Psychosocial Needs and Occupational Functioning of Younger Adults after Stroke EC Neurology, 2018

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Patient Reported Experience Measures (PREMs)

- Large knowledge gap in stroke care worldwide

- From few small studies (not based on age) there is a need to

- improve access to six month and annual review services;

- better self management and peer support programs;

- lifelong access to specialist assessment and treatment in a timely way

- Need for large studies

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Future

The stroke community will be required to invest in the work needed to ensure that the integration of PROMs data lives up to its promise **of improving the lives (not only outcomes) of patients with stroke.**

Mathew Reeves, PhD

Future

At the system level through integrated team approach

- **CO-OP**

Cognitive Orientation to daily Occupational Performance

a client-centred, performance-based, problem solving approach that enables skill acquisition through a process of strategy use and guided discovery.

- **COPM**

Canadian Occupational Performance Measure a patient-centered and evidence-based outcome measure that enables individuals to identify and prioritize everyday functional issues that restrict or impact their daily lives.

- **Psychosocial and Hopeful Care projects**

Psychological and social services and interventions that enable patients, their families, and health care providers to optimize biomedical health care and to manage the psychological/behavioral and social aspects of illness

12 Enhanced Pathways
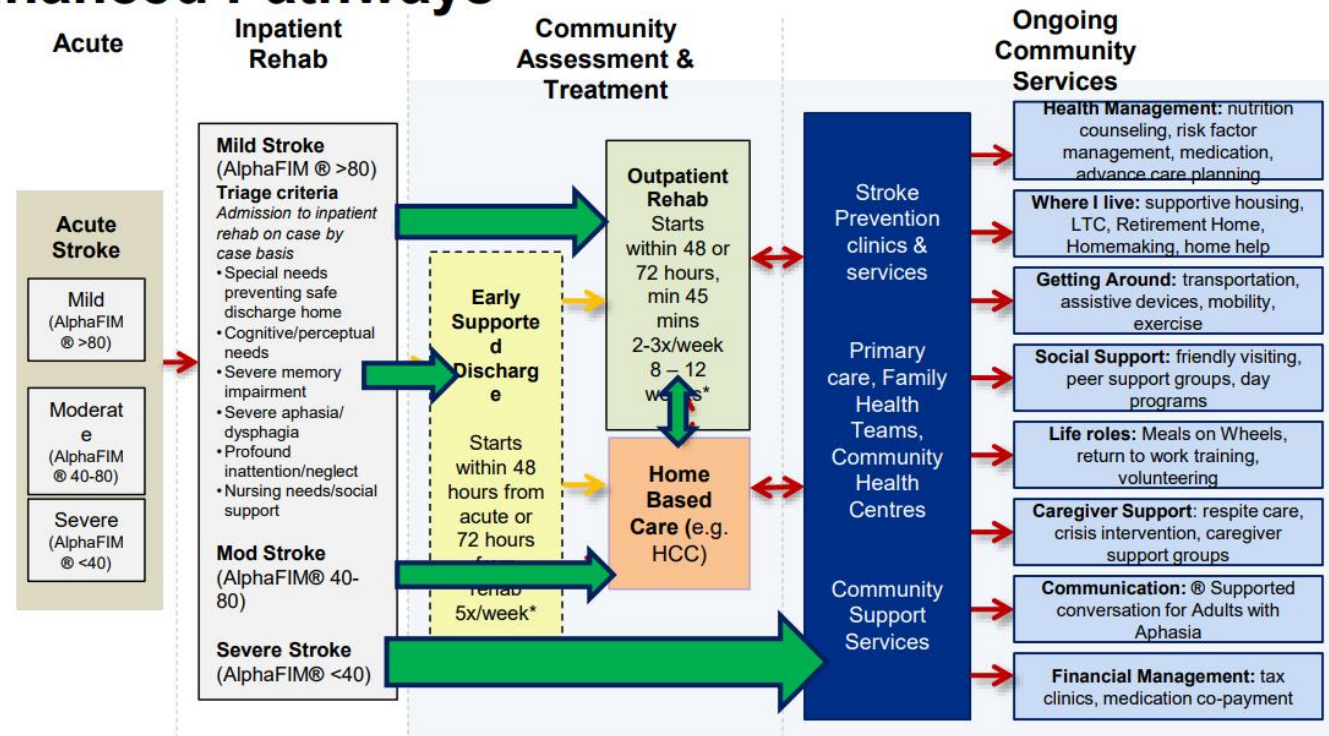
Shared accountability, reciprocal communication, integration of services, community-based, critical mass, sustainable quality of care, equitable access Patient education and self-management to support community re-engagement

* Based on Quality Based Procedures Clinical Handbook for Stroke, Dec 2016

QI data not yet available

Y-STROKE NEEDS Study

Psychosocial and Occupational Functioning
in
Young Stroke Survivors

PI: A. Pikula
Co-PI: Kathryn Sheehan

Why – Y STROKE NEEDS?

The young stroke population represents a significant rehabilitation/societal challenge

Based on available literature and major knowledge gap:

1. Post-stroke HRQoL is an important and comprehensive view of subjective health and a measure of a person's perceived physical, mental, emotional, and social health and well-being following stroke.

2. Urgent need for patient-centered approach to outcomes, but more so for appropriate interventions development

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Study Design

- **Mixed-methods study** using a **sequential explanatory design**

- **Phase 1 - quantitative** data collection (NeuroQOL) – almost completed **(n = 120)**

Aim - To describe HR-QoL, psychosocial and occupational functioning of young stroke survivors

1a) Explore sex, gender and age differences in HR-QoL

1b) Determine impact of sociodemographic and clinical characteristics on HR-QoL, psychosocial, and occupational functioning

1c) Develop a more detailed exploration of survey responses through qualitative interviews

- **Phase 2 - qualitative data is collected through interviews** – started in Jan **(n=20),** follow up interviews in progress

Aim - To describe patients' preferences and needs regarding post-stroke interventions

2a) Explore qualitative dimensions of sex, gender and age differences in preferences and needs based on patients lived experience

2b) Explore the impact of sociodemographic/clinical characteristics on preferences and needs

2c) Determine rehabilitation needs, preferences, and areas for improvement

--- NEW proposal PHASE 3 – Intervention development – RTC

- Patients are involved in the process from the beginning to the end

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Participants and Tools

- Young adult working population <65

- Stroke event (IS,ICH) > 3 months ago

- Able to participate in interviews

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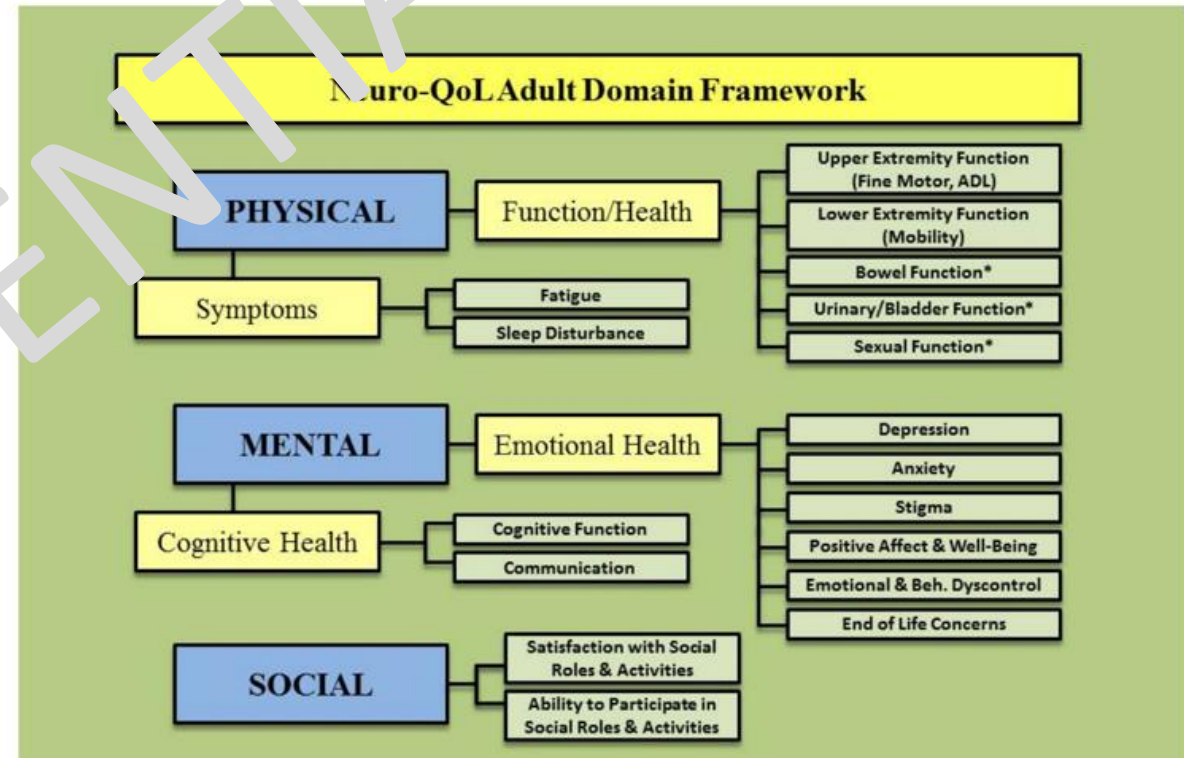
Data Variables

Clinical characteristics	
Date of stroke, time since stroke	
Stroke type and etiology	
Recurrent stroke	
Immediate post-stroke care	
Rehabilitation program post-stroke	
Other intervention post-stroke	
Modified Rankin score	
Medical conditions (pre- and post-stroke)	
Psychiatric conditions (pre- and post-stroke)	
Current medications	

Sociodemographic Characteristics	
Age	Patient survey/cha...
Sex	Chart review
Gender	Patient survey
Ethnicity	Patient survey
Insurance status	Patient survey
Living arrangement	Patient survey
Marital status	Patient survey
Family structure	Patient survey
Highest level of education	Patient survey
Income (pre- and post-stroke)	Patient survey
Occupation (pre- and post-stroke)	Patient survey
Work hours (pre- and post-stroke)	Patient survey
Post-stroke work status	Patient survey

- >90 days (most patients 120-360d)
- 95% from home = 60% went home
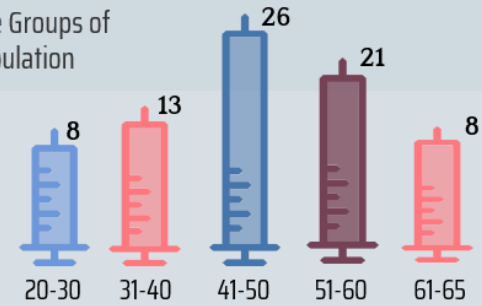
Table 1. Baseline Demographics	N = 76
Woman	46.0% (35)
Man	54.0% (41)
Others	0
AGE	**n=76**
20-30	10.5% (8)
31-40	17.1% (13)
41-50	**34.0% (26)**
51-60	**27.6% (21)**
61-65	10.5% (8)
Ethnicity	**n=60**
Caucasian	**66.6% (40)**
African	1.6% (1)
Indigenous	0.0
Asian	11.6% (7)
Middle Eastern	0.0
Hispanic	5.0% (3)
Other	15.0% (9)
Living Arrangement	**n=70**
Home	**92.8% (65)**
Nursing Facility	2.9% (2)
Assisted Living Facility	1.4% (1)
Other	2.9% (2)
Marital Status	**n=58**
Married	**51.7% (30)**
Divorce/Seperated	10.3% (6)
Living with Partner	**12.1% (7)**
Never Married	25.9% (15)
Widow	0.0

Table 3. Pre and Post Stroke Work Related Characteristics

Work Hours Before Stroke	n=58
<20 Week	13.8% (8)
20-30/week	8.6% (5)
30-40/week	**39.7% (23)**
>40/week	**37.9% (22)**

~80%

Work Hours After Stroke	n=57
<20 Week	**66.7% (38)**
20-30/week	8.8% (5)
30-40/week	14.0% (8)
>40/week	10.5% (6)

~25%

Individual Income before Stroke	n=53
<$20000	22.6% (12)
$20-49,000	17.0% (9)
$50-99,000	**26.4% (14)**
>$100,000	**34.0% (18)**

Individual Income after Stroke	n=52
<$20000	59.6% (31)
$20-49,000	11.5% (6)
$50-99,000	**7.7% (4)**
>$100,000	**21.2% (11)**

NeuroQOL

(frequencies)

~ 20% Depression

~ 40% Anxiety

~ 50% Fatigue

~ 30% Stigma and difficulty with social interactions and family relationships

~ 40% Temper issues and irritability/easily upset over little things

~ 50% Positive affect towards well-being

Only <5% difficulties with mobility

~ 15% reported some cognitive changes (MOCA not yet reviewed)

~ 20% sleep disturbances

T scores across for all domains are below or above average (50) in expected directions

Patient Therapy Preferences *educated about options

25-30% Pharmacological

>70% Non-Pharmacological*

- Solution based Th
- Problem Solving Th
- Music Th
- Yoga
- Mindfulness

Mode of delivery

- 70% in person
- 30 % combined (in person and group)

By Whom

- Professionally led (experience in stroke outcomes)

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Y-Stroke Phase II

Progress with guided interviews

Y-Stroke Phase II: Patient Needs

HEALTHCARE NAVIGATOR

COACHES

MENTAL HEALTH SERVICES

NON-PHARMACOLOGICAL

CARDIAC/EXERCISE PROGRAMS

MORE THEN WHAT'S OFFERED

ACCESS TO LICENSED PROFESSIONALS

APPS – EASY ACCESS

STROKE AWARENESS EDUCATION ON PREVENTION

(GEARED TO YOUNGER AGE

OR EVEN SEX /GENDER FOCUSED)

OTHER THERAPIES

Medicine UNIVERSITY OF TORONTO | Neurology

Y-Stroke Phase III: Intervention

HEALTHCARE NAVIGATOR

MENTAL HEALTH SERVICES

CARDIAC/EXERCISE PROGRAMS

ACCESS TO LICENSED PROFESSIONALS

STROKE AWARENESS EDUCATION ON PREVENTION

OTHER THERAPIES

App Admin

- Groups of 20 stroke patients
- 10 went to rehab
- 10 did not get rehab

Patients

- Y-Stroke Team
- Navigator APP

- Links to categorized resources
- Nudge messages
- Moderated/semi-moderated sessions

Professionals & Resources
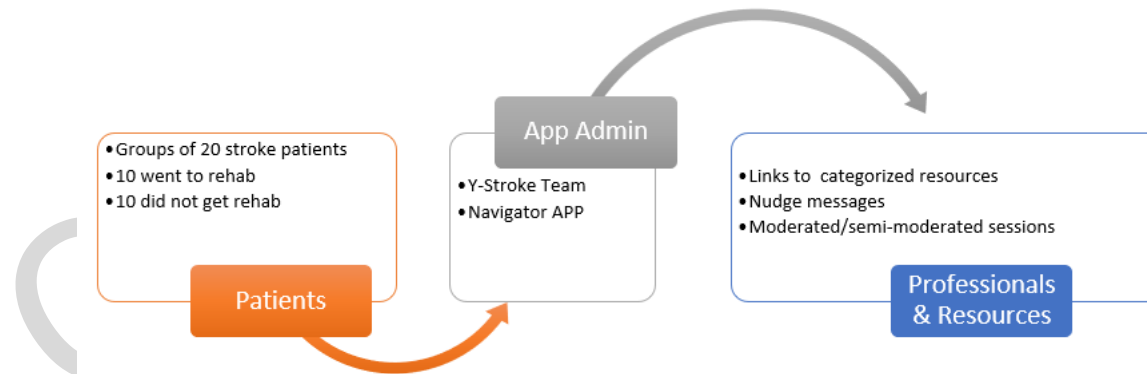
GUIDED PROGRAM THAT HELPS PEOPLE ADOPT A PROACTIVE, SELF-MANAGEMENT APPROACH TOWARD LIFESTYLE CHANGES AND HEALTHY BRAIN AGING AFTER STROKE

12-WEEK NUDGE APP VS STANDARD OF CARE

Y STROKE NEEDS Study

Pilot of new FU schedule @ SiYA Program (n=100)
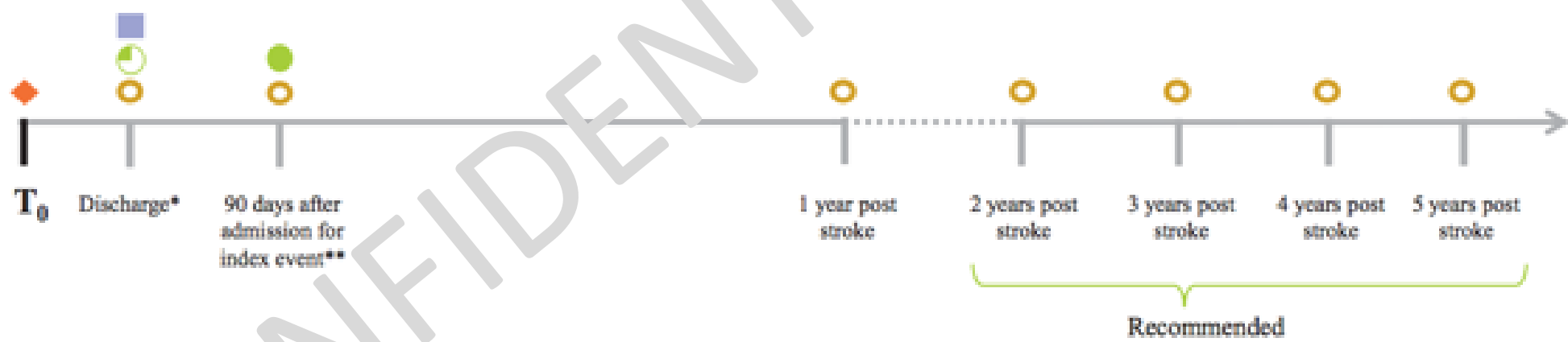
Ongoing education on secondary stroke prevention with interventions assessment that based on proposed lifestyle changes that could positively influence long-term outcomes

** Will work on including KT component with CO-OP and COPM

At the system level through integrated team approach

- **CO-OP**

Cognitive Orientation to daily Occupational Performance

a client-centred, performance-based, problem solving approach that enables skill acquisition through a process of strategy use and guided discovery.
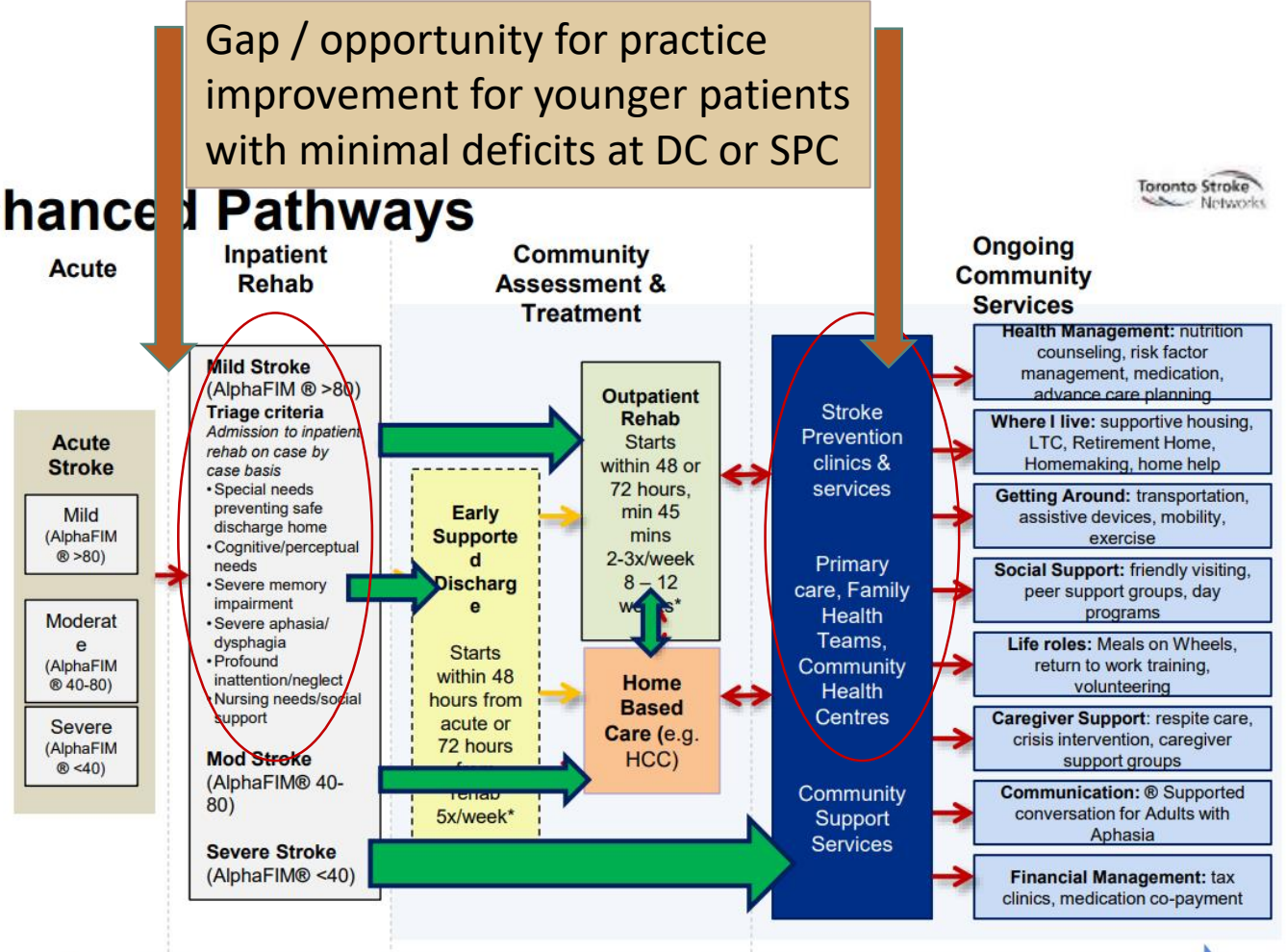
- **COPM**

Canadian Occupational Performance Measure

a patient-centered and evidence-based outcome measure that enables individuals to identify and prioritize everyday functional issues that restrict or impact their daily lives.

- **Psychosocial and Hopeful Care projects**

Psychological and social services and interventions that enable patients, their families, and health care providers to optimize biomedical health care and to manage the psychological/behavioral and social aspects of illness

Gap / opportunity for practice improvement for younger patients with minimal deficits at DC or SPC

12 Enhanced Pathways

Toronto Stroke Networks

* Based on Quality Based Procedures Clinical Handbook for Stroke, Dec 2016

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CONCLUSION

- We need to be more specific and should focus on **age-sex subcategories** when exploring long term stroke outcomes – as these are very different across lifespan

- NIHSS, mRS and BI are great clinical & functional outcome tools, but "not good enough" measures for long term outcomes/recovery and fulsome transitions of care

- PROMs research can improve care and teach us something new about patients, while looking closely into patient reported experience to be able to develop patient-centered interventions and education modules.

- KT within 12 enhanced pathways are needed for younger adults discharged home or first time seen in SPC/GP office

- Secondary Stroke Prevention for all, but more so for young adults need detailed recommendations and education (specifics on lifestyle changes, well-being, self-identity)

- Need for longer interval follow up (at least up to 12 months) to assess the impact on HRQOL and system QI on integration.

Core Study Team

Clinical Team
Aleksandra Pikula MD (PI) – Stroke, UHN
Kathleen Sheehan MD (Co-PI) – Psychiatry, UHN

Mixed-Methods/Patient-Centered Outcomes/PROMS
Sophie Soklaridis PhD – Critical Social Theories, UofT
Jill Cameron PhD - Occupational Medicine, UofT
Susan Berkhout MD, PhD – Psychiatry, UHN
Val Rac, MD PhD – THETA, U of T

PCO/Intervention Development/Education
Csilla Kalocsai PhD – Psychology/Anthropology, U of T

Project Manager: William TO
Lead Research Coordinator: Kay-Anne Alen
Research Data Analyst/Management/: Ammar Baig
Patient Advisory Committee – 3 standing members
Patient Engagement Advisory at UHN – 2 standing members

HSFC: Knowledge translation (Patrice Lindsay)
Statistical team: THETA, U of T

Collaborators:
Julie Silver, MD, MSc – Rehabilitation, Harvard University
Moira Kapral MD, MSc – Medicine, UHN
Leanne Casaubon MD, MSc – Neurology, UHN
Beth Linkewich – Sunnybrook, Provincial/Regional, TSN
Nicola Tahair – TWH, Provincial/Regional, TSN
Amy Yu MD, MSc – Stroke, SHSC
Rick Schwartz MD, PhD – Stroke SHSC

Today's patients' experience will be tomorrow's research question

Aleksandra.Pikula@uhn.ca

Evaluation

For the **Provincial Stroke Rounds Planning Committee**:

- To plan future programs
- For quality assurance and improvement

For **You**: Reflecting on what you've learned and how you plan to apply it can help you enact change as you return to your professional duties

For **Speakers**: The responses help understand participant learning needs, teaching outcomes and opportunities for improvement.

https://www.surveymonkey.com/r/Z32MWVG

Please take 2 minutes to fill out the evaluation form, either online or in the room.

Thank you!