

SUPPLEMENTAL MATERIAL

An International Standard Set of Patient-Centered Outcome Measures After Stroke

Supplemental Table I. Stroke Working Group member specialties and register/institutional affiliations

Country	Clinical Specialty	Name	Register/Institutional affiliation
Australia	Neuro-Rehabilitation	Julie Bernhardt, PhD	The Florey Institute of Neuroscience and Mental Health
Brazil	Vascular Neurology	Sheila C.O. Martins, MD, PhD	Hospital Moinhos de Vento, Brazil National Stroke Registry
Canada	Vascular Neurology	Eric E. Smith, MD, MPH, FRCPC, FAHA	Hotchkiss Brain Institute and Department of Clinical Neurosciences, University of Calgary
Canada	Vascular Neurology	Frank L. Silver, MD, FRCPC	University of Toronto, Ontario Stroke Registry
Canada	Stroke Nursing	Patrice Lindsay, RN, PhD	Heart and Stroke Foundation of Canada, Ontario Stroke Registry
China	Vascular Neurology	Liping Liu, MD	Capital Medical University, Beijing Tiantan Hospital
The Netherlands	Neuro-Rehabilitation	Gerard Ribbers, MD, PhD	Erasmus University MC, Rijndam Rehabilitation Center
Sweden	Vascular Neurology	Bo Norrving, MD, PhD	Department of Clinical Sciences, Neurology, Lund University, Swedish Stroke Register (Riksstroke)
UK	Stroke Occupational Therapy	Stephanie Gething, Dip COT, MSc	Advanced Practitioner Occupational Therapist, Aneurin Bevan University Health Board
UK	Vascular Neurology	Charlie Davie, MD, FRCP	UCLPartners Academic Health Science Network, Royal Free London NHS Foundation Trust
USA	Vascular Neurology	Lee H. Schwamm, MD	Department of Neurology, Massachusetts General Hospital, Harvard Medical School, American Heart Association Get With The Guidelines-Stroke registry, Centers for Disease Control and Prevention Paul Coverdell National Acute Stroke Registry, Joint Commission Primary & Comprehensive Stroke Center Certification Technical Expert Panels
USA	Neurology	Joel Salinas, MD, MBA	Department of Neurology, Massachusetts General Hospital, Harvard Medical School,
USA	Senior Medical Officer and Deputy Associate Director for Science	Mary G. George, MD, MSPH, FACS	Paul Coverdell National Acute Stroke Registry, Centers for Disease Control and Prevention Division for Heart Disease and Stroke Prevention
USA	Vascular Neurology	Adam G. Kelly, MD	University of Rochester Medical Center
USA	Stroke Patient Representative	Teri Ackerson, SCRN, BSN	American Heart Association/American Stroke Association, Liberty Hospital
USA	Vascular Neurology	Linda S. Williams, MD	Veteran's Administration Stroke QUERI Project
USA	Cardiovascular Nursing and	Louise Morgan, MSN, CPHQ	American Heart Association/American Stroke Association, Get With The Guidelines-Stroke

	Director, International Quality Improvement; Stroke Patient Representative		Registry
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Supplemental Table II. Voting percentages of modified Delphi method by working group members by individual outcome domains. A majority vote was required for consideration for inclusion.

	Outcome	Final vote in favor of inclusion (final vote)
Included	All-cause mortality	100%
	Patient reported general health status	100%
	Global patient reported health-related quality of life	100%
	Mood	100%
	Self-care and grooming	100%
	Mobility	100%
	Symptomatic intracranial hemorrhage after ischemic stroke	100%
	Pain and other unpleasant sensations	91%
	Ability to return to usual activities	91%
	Global cognitive function	90%
	Readmission for ischemic stroke	90%
	Readmission for ICH	90%
	Feeding	82%
	Ability to communicate (including nonverbal means)	82%
	Social participation	73%
	Fatigue	70%
Smoking cessation	70%	
Excluded	Stroke due to carotid artery intervention	57%
	Major systemic hemorrhage	50%
	Early neurological worsening	44%
	Hospital acquired pneumonia	43%
	Sexual function	40%
	Effort required to return to usual activities	30%
	Sleep quality	20%

Supplemental Table III. Summary of the demographic data elements, risk adjustment variables and other covariates included in the ICHOM Standard Set for stroke, and the recommended data source and timing.

	Measure	Timing	Data Source
General patient demographics			
Age	What is your date of birth?	Admission ^a	Administrative or patient-reported
Sex	Please indicate your sex at birth	Admission	Administrative or patient-reported
Race/Ethnicity	To be determined by country	Admission	Patient-reported
Prestroke functional status	Are you able to ambulate?	Admission	Medical record or patient-reported
	Do you receive help from anybody to go to the toilet?		
	Do you receive help with dressing/undressing?		
Living location	Where were you staying prior to your stroke or TIA?	Admission	Patient-reported
	Where are you staying now?	90 days ^b	Patient-reported
Living alone	Do you live alone?	Admission and 90 days	Patient-reported
Stroke type and severity			
Stroke severity	National Institutes of Health Stroke Scale (NIHSS)	Admission	Medical record
Stroke severity	What is the patient's level of consciousness?	Admission	Medical record
Stroke type	Indicate stroke type	Admission	Medical record
Duration of symptoms	Indicate the duration of symptoms	Admission	Patient-reported
Vascular and systemic			

Prior stroke	Prior to this hospitalization, have you ever been told by a doctor that you have had a stroke?	Admission	Medical record or patient-reported
Prior TIA	Have you ever been told by a doctor that you have had a transient ischemic attack (this is sometimes called a TIA or mini-stroke)?	Admission	Medical record or patient-reported
Prior MI	Have you ever been told by a doctor that you have had a heart attack (this is sometimes called a myocardial infarction, or MI)?	Admission	Medical record or patient-reported
Coronary artery disease	Have you ever been told by your doctor that you have coronary artery disease?	Admission	Medical record or patient-reported
Atrial fibrillation	Have you ever been told by your doctor that you have atrial fibrillation?	Admission	Medical record or patient-reported
Diabetes mellitus	Have you ever been told by your doctor that you have diabetes?	Admission	Medical record or patient-reported
Hypertension	Have you ever been told by a doctor that you have high blood pressure (this is sometimes called hypertension)?	Admission	Medical record or patient-reported
Hyperlipidemia	Have you ever been told by your doctor that you have high cholesterol (this is sometimes called hyperlipidemia or dyslipidemia)?	Admission	Medical record or patient-reported
Smoking	Do you currently smoke, or have you smoked over the past year?	Admission	Patient-reported
Alcohol use	Do you drink more than one standard alcoholic drink a day?	Admission	Patient-reported
Treatment/care related			
Length of stay	Date of admission for index event and date of discharge from acute care hospital	Admission and Discharge ^c	Administrative data
Diagnostic process	Indicate how the diagnosis was made	Discharge	Medical record

Rehabilitation	<p>Did the acute inpatient care include dedicated stroke rehabilitation?</p> <p>Did the post-acute care (hospital-based or not) include dedicated stroke rehabilitation, either hospital-based or outpatient/home-based?</p>	Discharge	Administrative data
Discharge destination	What type of place was the patient discharged to?	Discharge	Administrative data
Comfort care (optional item)	At any point in the hospitalization, did the goals of care shift from treatment and recovery to emphasize comfort? ["Comfort care" is defined as care for a patient who is dying that helps or comforts with the goal of preventing or relieving suffering.]	Discharge	Administrative data

^a Admission for index event

^b 90 days after admission for index event within a 30-day window (i.e., 90 to 120 days after index admission)

^c Discharge or 7 days after admission for index event (whichever occurs first)
