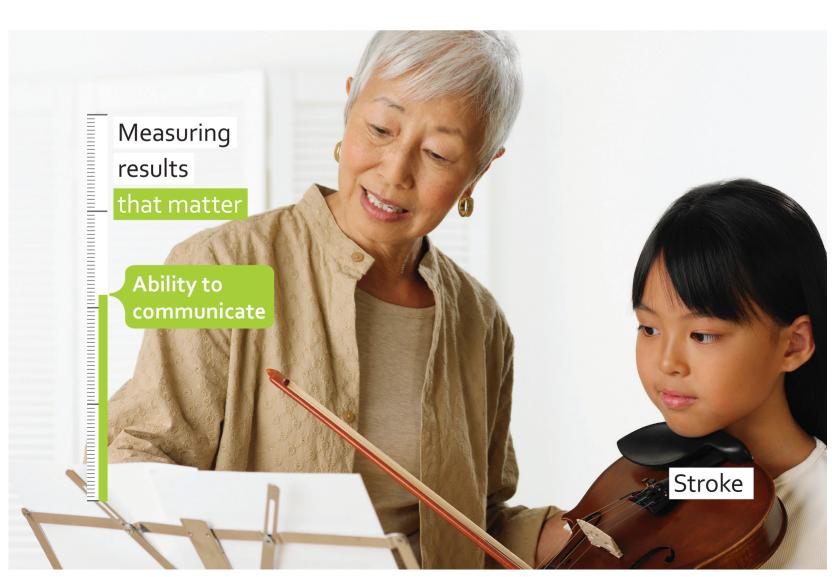


Version 2.0.1 Revised: June 21st, 2018





We are thrilled that you are interested in measuring outcomes for your stroke patients according to ICHOM standards. It is our hope that this Reference Guide will facilitate the process of implementing our Standard Set and ensure collection of comparable data for global benchmarking and learning.

© 2018 ICHOM. All rights reserved. When using this set of outcomes, or quoting therefrom, in any way, we solely require that you always make a reference to ICHOM as the source so that this organization can continue its work to define more standard outcome sets.

Introducing ICHOM and the Reference Guide

ICHOM brings together patient representatives, clinician leaders, and registry leaders from all over the world to develop Standard Sets, comprehensive yet parsimonious sets of outcomes and case-mix variables we recommend all providers track.

Each Standard Set focuses on patient-centered results, and provides an internationally-agreed upon method for measuring each of these outcomes. We do this because we believe that standardized outcomes measurement will open up new possibilities to compare performance globally, allow clinicians to learn from each other, and rapidly improve the care we provide our patients.

Our Standard Sets include initial conditions and risk factors to enable meaningful case-mix adjustment globally, ensuring that comparisons of outcomes will take into account the differences in patient populations across not just providers, but also countries and regions. We also include high-level treatment variables to allow stratification of outcomes by major treatment types. A comprehensive data dictionary is included in the appendix.

Our aim is to make Standard Sets freely accessible to healthcare institutions worldwide to begin measuring, and ultimately benchmark the outcomes they achieve. In order to have a guide from which we can benchmark outcomes, we require feedback from initial implementation efforts. As such, this Reference Guide may undergo revisions on a regular basis. If you have any suggestions or would like to provide feedback, please contact implement@ichom.org

Working Group Members for Stroke

The following individuals dedicated both time and expertise to develop the ICHOM Standard Set for Stroke in partnership with ICHOM, under the leadership of Dr. Lee Schwamm, Professor of Neurology at Harvard Medical School and Vice Chairman of Neurology at Massachusetts General Hospital in Boston.

Australia	Canada	Netherlands	United States
Julie Bernhardt	Patrice Lindsay	Gerard Ribbers	Teri Ackerson
Brazil Sheila Martins	Frank Silver Eric Smith	Sweden Bo Norrving	Mary George Adam Kelly Louise Morgan
	China	United Kingdom	Joel Salinas
	Liping Liu	Charlie Davie Stephanie Gething	Lee Schwamm Linda Williams

Supporting Organizations

The Stroke Standard Set is made possible only through the support of the American Heart Association and American Stroke Association.

Thank you.



Conditions and Treatment Approaches Covered for Stroke

For stroke, the following conditions and treatment approaches (or interventions) are covered by our Standard Set.

Conditions	Patients who have been hospitalized for an index ischemic stroke (IS) or intracereberal hemorrhage (ICH). Patients with subarachnoid hemorrhage (SAH) are excluded. Inclusion of transient ischemic attack (TIA) or patients with IS or ICH who are evaluated but not hospitalized is not required.
Treatment Approaches	IV Thrombolysis Thrombectomy Hemicraniectomy

A Note on Patient-Reported Questions in the Stroke Standard Set

ICHOM's work focuses on health outcomes and the measurement of what matters most to patients. A large component of all our Standard Sets, therefore, is the collection of patient-reported outcomes.

All patient-reported forms in the Stroke Standard Set are designed to be completed by the patient. However, for some stroke patients, answering questions and/or completing questionnaires can be challenging. If a patient is unable to respond to parts or all of a survey, answers should be provided by a proxy, his or her clinician, or abstracted from medical records.

DATA COLLECTION REFERENCE GUIDE

ICHOM Standard Set for Stroke

Case-Mix Variables

Patient Population	Measure	Supporting Information	Timing	Data Source
Demographic Factors				
	Age	Date of birth	_	Administrative
	Sex	Sex at birth		data
		Note that regulations on	Admission for index stroke event: Admission for index stroke event; go days + 7 days post admission for index event Admission for index stroke event Clinical Patient-reported Clinical Patient-reported Clinical Patient-reported Clinical Admission for index stroke event Patient-reported Admission for index stroke event Admission for index stroke event	
	Ethnicity	reporting ethnicity may differ		
		per country	A 1 · · · C	_
All patients	Living location	Most recent place of		
	Living location	residence pre stroke and 90 days post admission		Patient-reported
		days post admission	_ ′	
		Living situation pre stroke and	Admission for index stroke event Admission for index stroke event; go days + 7 days post admission for index event Admission for index stroke event Clinical Patient-reported Clinical Patient-reported Patient-reported	
	Living alone	90 days post admission		
		3 , 1	index event	
Stroke Type and Sev	•			
	Stroke type	Response options: IS; ICH; TIA	- Admission for	
All patients	Stroke severity	Measured by NIHSS & Level	index stroke	Clinical
		of consciousness		
	Duration of symptoms	N/A		Patient-reported
Vascular and System	nic			
vascolal alla system	Prior Stroke			
	Prior TIA	-		
	Prior MI	-		
	Coronary artery	-		
	disease			Clinical
	Atrial fibrillation	-	A dualisation for	
All patients	Diabetes mellitus	- - N/A		
All patients	Hypertension	- N/A		
	Hyperlipidemia	_	CVCIIC	
	Smoking status			
	(current or in past			
	year)	_		Patient-reported
	Alcohol use (>1 drink a			
	day)			
Treatment/Care Rela	ated			
Treatment Care Nei		Date of index admission and		
	Length of stay	date of discharge from acute		
	<i>3</i> /	care hospital	days	data
	Diagnostic suidenes	·	Admission for	
All patients	Diagnostic evidence	N/A	index stroke	Clinical
All patients	base		event	
		Dedicated stroke		
	Rehabilitation	rehabilitation during acute or	Discharge + 7 Administrative	
	B. 1	post-acute care	_ days data	
	Discharge destination	N/A		

Treatment Variables

Patient Population	Measure	Supporting Information	Timing	Data Source
Treatment Variables				
Ischemic stroke patients	Thrombolytic therapy			
Ischemic stroke patients	Thrombectomy	N/A	Discharge + 7	Clinical
Intracereberal hemorrhage patients	Hemicraniectomy	_	days	

Outcomes

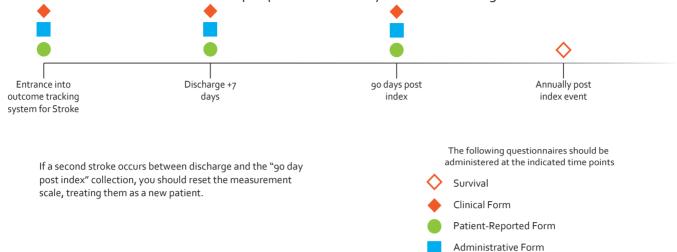
Patient Population	Measure	Supporting Information	Timing	Data Source
Acute Complications	of Treatment			
Patients who received thrombolytic therapy or thrombectomy	Symptomatic intracranial hemorrhage after thrombolysis or thrombectomy	N/A	Discharge + 7 days	Clinical
Survival and Disease	Control			
All patients	Overall survival	All-cause mortality	Discharge + 7 days; 90 days + 7 days post admission for index event; Annually	Administrative data
	Ability to return to usual activities	Tracked via smRSq	Discharge + 7 days; 90 days +/- 7 days post- discharge	Clinical

Patient-Reported Outcomes

Patient Population	Measure	Supporting Information	Timing	Data Source
Patient-Reported He	ealth Status			
	Overall mental wellbeing (including cognitive and psychiatric functioning, social functioning)	Tracked via PROMIS Global Health	90 days + 7 days post admission for	
	Overall physical wellbeing (including pain, fatigue, and general health status)	Tracked via PROMIS Global Health	index event	
All patients	Mobility	Tracked via single item	Admission for index stroke event: Discharge + 7 days; 90 days +/- 7 days post-discharge	Patient-reported
•	Feeding	Tracked via single item	Discharge + 7	- ·
	Ability to communicate	Tracked via single item	days; 90 days +/- 7 days post- discharge	_
	Self care (including grooming, toileting & dressing)	Tracked via RIKS stroke functional items	Admission for index stroke event: Discharge + 7 days; 90 days +/- 7 days post-discharge	_
	Self-reported new stroke	Tracked via single item	90 days + 7 days post	
	Smoking cessation	Adherence to smoking cessation advise	admission for index event	

Follow-Up Timeline

The following timeline illustrates when Standard Set variables should be collected from patients, clinicians, and administrative sources. Links to the sample questionnaires may be found in the legend below.



Collecting Patient- and Clinician-Reported Outcome Measures

Survey(s) Used	Licensing Information	Scoring Guide
Patient Reported Outcomes Measurement Information System Short Form version 1.1 Global Health (PROMIS-10) - Patient/ Proxy	The PROMIS-10 is free for all health care organizations, and a license is not needed. There are translations available for Spanish, French, German, and Dutch. Translations will soon be available for Portugese and Mandarin. More information may be found at http://www.nihpromis.org/measures/translations	The scoring guide may be found on page 9, as well as at https://www. assessmentcenter.net/ documents/Scoring%20 PROMIS%20Global%20 short%20form.pdf
Simplified Modified Rankin Scale Questionnaire (smRSq) - Clinician	There is no patent on thes smRSq or fee for using it in clinical practice; however Lippincott Williams & Wilkins (LWW) own the rights to the published article where the smRSq is introduced. There is a cost of USD700 to use the flow chart diagram from within this article but permission is not needed for the assessment of the questions in patients. The smRSq is also a sub-section of the regular smRSq, which is also without license fee. The smRSq flow chart can be found at http://stroke.ahajournals.org/content/42/8/2276 "Simplified Modified Rankin Scale Questionnaire Reproducibility Over the Telephone and Validation With Quality of Life" Stroke 2011; 42: 2276-2279 © 2011 American Heart Association, Inc. Wolters Kluwer Health	To facilitate the use of the smRSq, instructions are provided in the Appendix on page 11.

The Growing ICHOM Community

By implementing the ICHOM Standard Sets, you become part of an expanding, international community of innovative health care providers dedicated to improving value for patients. To learn more about how ICHOM can assist your organization in implementing outcome measurement, contact us at implement@ichom.org, or visit http://www.ichom.org/measure.

Appendix

Scoring Guide for the PROMIS Short Form version 1.1 Global Health (PROMIS-10)

Scoring: The PROMIS Global Health short form is a 10-item instrument representing multiple domains. It can be scored into a Global Physical Health component and Global Mental Health component using the tables below. Because a scoring table is prepared for a fixed set of items, it can only be used when an examinee responds to all of the items in the set. *One or more missing responses will render such scoring tables unusable.*

The Global scores require re-coding of three items so that high scores reflect better functioning.

			5=0 No pain
			4=1
			4=2
			4=3
			3=4
Clabala	In the mast - days	How would you rate your	3=5
Globalo7	In the past 7 days	pain on average	3=6
			2=7
			2=8
			2=9
			1=10 Worst pain imaginable
			imaginabic
Globalo8	In the past 7 days	How would you rate your fatigue on average?	5=None 4=Mild 3=Moderate 2=Severe 1=Very severe

After recoding, the Global Physical Health score is generated by summing responses to Globalo3, Globalo6, Globalo7rescored, and Globalo8rescored. The Global Mental Health score is generated by summing responses to Globalo2, Globalo4, Globalo5, and Globalorescored.

Raw score to T-score conversion tables: The following conversion tables allow a user to convert simple summed raw scores from PROMIS global into T-score values on an individual respondent or group of respondents. In all cases, these conversions only work accurately when all questions on the short form have been answered. T-score distributions are standardized such that a 50 represents the average (mean) for the US general population, and the standard deviation around that mean is 10 points. A high score always represents more of the concept being measured. Thus, a person who has T-scores of 60 for the Global Physical Health or Global Mental Health scales is one standard deviation better (more healthy) than the general population

Short F	Physical Short Form Conversion Table		
Raw.Score	T.Score	SE*	
4	16.2	4.8	
5	19.9	4.7	
6	23.5	4.5	
7	26.7	4.3	
8	29.6	4.2	
9	32.4	4.2	
10	34.9	4.1	
11	37.4	4.1	
12	39.8	4.1	
13	42.3	4.2	
14	44.9	4.3	
15	47.7	4.4	
16	50.8	4.6	
17	54.1	4.7	
18	57.7	4.9	
19	61.9	5.2	
20	67.7	5.9	

Ch	Mental			
	Short Form Conversion Table			
Raw.Score	T.Score	SE*		
4	21.2	4.6		
5	25.1	4.1		
6	28.4	3.9		
7	31.3	3.7		
8	33.8	3.7		
9	36.3	3.7		
10	38.8	3.6		
11	41.1	3.6		
12	43.5	3.6		
13	45.8	3.6		
14	48.3	3.7		
15	50.8	3.7		
16	53.3	3.7		
17	56.0	3.8		
18	59.0	3.9		
19	62.5	4.2		
20	67.6	5.3		

^{*}SE = Standard Error

Conversion Table applies only when ALL questions on the subdomain have been answered

Hays, R. D., Bjorner, J., Revicki, R. A., Spritzer, K. L., & Cella, D. (2009). Development of physical and mental health summary scores from the Patient Reported Outcomes Measurement Information System (PROMIS) global items. Quality of Life Research, 18(7),873-80. (PMCID: PMC2724630)

Estimating EuroQoL (EQ-5D) index scores: Revicki et al (2009) outlined how to use the PROMIS Global Health short form to calculate a EuroQoL (EQ-5D) index score. To begin, use the instructions on page 1 to re-score Globalo7, Globalo8, and Global10. Then, use the following formula:

 $EQ5D \ score = 0.19123 + (0.00672 * Global2) + (0.00527 * Global3) + (0.00830 * Global4) + (0.04550 * Global6) + (0.02713 * Global7rescored) + (0.01305 * Global8rescored) + (0.00613 * Global9) + (0.02502 * Global10rescored)$

Revicki, D. A., Kawata, A., Harnam, N., Chen, W-H., Hays, R. D., & Cella, D. (2009). Predicting EUROQOL (EQ-5D) scores from the Patient Reported Outcomes Measurement Information System (PROMIS) global items and domain item banks in a United States sample. Quality of Life Research, 18(6), 783-91. (PMCID: PMC2704290)

*SE = Standard Error

Instructions for the simplified modified Rankin Scale questionnaire (smRSq)

Simplified modified Rankin Scale questionnaire: The simplified modified Rankin questionnaire (smRSq) was developed as a tool to improve the assessment of the modified Ranking scale [1]. An updated version of the smRSq was published in 2011 [2]. The smRSq flow chart can be found at http://stroke.ahajournals.org/content/42/8/2276 to provide the interview procedure for clinicians.

Assessment recommendations: The assessment time with the smRSq is relatively short, less than 2 minutes. The smRSq has been validated for phone assessment [2] and with quality of life [2], stroke severity [3, 4], and stroke size [5].

Instructions for using the smRSq:

- 1. Ask each question in order from top to bottom following the arrows in the flow chart in the link above.
- 2. One may repeat and clarify the questions if needed, but to maintain consistency across raters do not elaborate or provide examples or quide the interviewee.
- 3. To enhance accuracy, use all available sources of information, especially caregivers when available.
- 4. When the answer is not clear (falls between two scores), use the higher score.

Translations: The smRSq was originally developed in English. The smRSq has been translated and validated in Chinese stroke patients versus the standard mRS interview and stroke severity [6].

smRSq contact information:

Dr. Askiel Bruno abruno@gru.edu

Department of Neurology Medical College of Georgia 1120 15th St BI 3076, Augusta, GA 30912 USA

References

[1] Bruno A, Shah N, Lin C, Close B, Hess DC, Davis K, Baute V, Switzer JA, Waller JL, Nichols FT. *Improving modified Rankin Scale assessment with a simplified questionnaire*. Stroke. 2010 May;41(5):1048-50.

[2] Bruno A, Akinwuntan AE, Lin C, Close B, Davis K, Baute V, Aryal T, Brooks D, Hess DC, Switzer JA, Nichols FT. Simplified modified rankin scale questionnaire: reproducibility over the telephone and validation with quality of life. Stroke. 2011 Aug;42(8):2276-9.

[3] Bruno A, Close B, Switzer JA, Hess DC, Gross H, Nichols FT 3rd, Akinwuntan AE. Simplified modified Rankin Scale questionnaire correlates with stroke severity. Clin Rehabil. 2013 Aug;27(8):724-7.

[4] Bruno A, Close B, Gomadam A, Akinwuntan AE, Switzer JA. The simplified mRS questionnaire reflects stroke severity. Int J Stroke 2013;8:E55.

[5] Bruno A, Shah N, Akinwuntan AE, Close B, Switzer JA. Stroke size correlates with functional outcome on the simplified modified Rankin Scale questionnaire. J Stroke Cerebrovasc Dis. 2013 Aug; 22(6):781-3.

[6] Yuan JL; Bruno A; LiT; Li SJ; Zhang XD; Li HY; Jia K; Qin W; Chen AC; Hu WL. Replication and extension of the simplified modified Rankin scale in 150 Chinese stroke patients. European Neurology, 2012; Vol. 67 (4), pp. 206-10.

Introduction to the Data Dictionary

This data dictionary is designed to help you measure the ICHOM Stroke Standard Set as consistently as possible to the Working Group recommendation. ICHOM is actively preparing for benchmarking efforts based on this data, and all data submitted for comparisons will need to be transformed into the following data structure if not already structured as such. We are happy to provide an Excel version of this data dictionary for technical use.

Please timestamp all variables. Some Standard Set variables are collected at multiple timepoints, and we will ask you to submit these variables in a concatenated VARIABLEID_TIMESTAMP form for future analyses. For example, VARIABLEID_BASE (baseline); VARIABLEID_6MO (6 month follow-up); VARIABLEID_1YR (1 year follow-up), etc.

Case-Mix Variables

Variable ID: N/A
Variable: Patient ID

Definition: Create a unique patient identifier (e.g. medical record number)

Supporting Definition: This number will not be shared with ICHOM. In the case patient-level data is

submitted to ICHOM for benchmarking or research purposes, a separate ICHOM Patient Identifier will be created and cross-linking between the ICHOM Patient Identifier and the medical record number will only be known at the treating

institution

Inclusion Criteria: All patients

Timing: On all forms

Data Source: Administrative or clinical

Type: Numerical

Response Options: According to institution

Demographic Factors

Variable ID: AGE Variable: Age

Definition: Date of birth

Supporting Definition: N/A

Inclusion Criteria: All patients

Timing: Admission for index event

Data Source: Clinical, patient-reported, or administrative data

Type: Date by DD/MM/YYYY

Response Options: DD/MM/YYYY

Variable ID: SEX Variable: Sex

Definition: Please indicate the patient's sex at birth

Supporting Definition: N/A
Inclusion Criteria: All patients

Timing: Admission for index event

Data Source: Clinical, patient-reported, or administrative data

Type: Single answer

Response Options: o = Male

1 = Female 999 = Undisclosed

Variable ID: ETHNIC
Variable: Ethnicity

Definition: Varies by country and should be determined by country (not for cross country

comparison)

Supporting Definition: N/A

Inclusion Criteria: All patients

Timing: Admission for index event

Data Source: Patient-reported

Type: Single answer

Response Options: N/A

Variable ID: LIVINGLOCPRE

Variable: Living location pre index event

Definition: Where were you living prior to your stroke or transient ischaemic attack (TIA)?

Supporting Definition: Most recent place of residence pre stroke

Inclusion Criteria: All patients

Timing: Admission for index event

Data Source: Patient-reported **Type:** Single answer

Type. Single answer

Response Options: 1 = At home, with no community support

2 = At home with community support

3 = In an assisting living home in the community (senior's home)

4 = In a rehabilitation hospital or skilled care facilities (SNIF, IRF, LTACH)

5 = In long term care (nursing home, chronic care hospital)

888 = Other 999 = Unknown

Variable ID: LIVINGLOCPOST

Variable: Living location post index event **Definition:** Where are you living now?

Supporting Definition: N/A

Inclusion Criteria: All patients

Timing: 90 days post admission for index event

Data Source: Patient-reported

Type: Single answer

Response Options: 1 = At home, with no community support

2 = At home with community support

3 = In an assisting living home in the community (senior's home)

4 = In a rehabilitation hospital or skilled care facilities (SNIF, IRF, LTACH)

5 = In long term care (nursing home, chronic care hospital

6 = In an acute care hospital

888 = Other 999 = Unknown

Variable ID: LIVEALONEPRE

Variable: Living alone pre-index event

Definition: Did you live alone prior to your stroke or transient ischaemic attack (TIA)?

Supporting Definition: N/A

Inclusion Criteria: If "1 = At home, with no community support"

Timing: Admission for index event

Data Source: Patient-reported

Type: Single answer

Response Options: 1 = Yes, I lived alone

2 = No, I shared my household with spouse/partner or other person (e.g. sibling,

children, parents) 999 = Unknown

Variable ID: LIVEALONEPOST

Variable: Living alone post-index event **Definition:** Do you live alone now?

Supporting Definition: N/A

Inclusion Criteria: All patients

Timing: 90 days post admission for index event

Data Source: Patient-reported

Type: Single answer

Response Options: 1 = Yes, I live alone

2 = No, I share my household with spouse/partner or other person (e.g. sibling,

children, parents)

999 = Unknown

Variable ID: PRESTROKEAMB

Variable: Prestroke functional status - Ambulation

Definition: Were you able to walk prior to your stroke or transient ischaemic attack (TIA)?

Supporting Definition: N/A

Inclusion Criteria: All patients

Timing: Admission for index event

Data Source: Patient-reported **Type:** Single answer

Response Options: 1 = Able to walk without help from another person with or without a device

2 = Able to walk with help from another person

3 = Unable to walk

Variable ID: PRESTROKETOILET

Variable: Prestroke functional status - Toileting

Definition: Did you need help from anybody to go to the toilet prior to your stroke or transient

ischaemic attack (TIA)?

Supporting Definition: N/A

Inclusion Criteria: All patients

Timing: Admission for index event

Data Source: Patient-reported **Type:** Single answer

Response Options: 1 = I could manage going to the toilet without assistance

2 = I needed help to go to the toilet

Variable ID: PRESTROKEDRESS

Variable: Prestroke functional status - Dressing

Definition: Did you need help with dressing/undressing prior to your stroke or transient

ischaemic attack (TIA)?

Supporting Definition: N/A

Inclusion Criteria: All patients

Timing: Admission for index event

Data Source: Patient-reported

Type: Single answer

Response Options: 1 = I could manage dressing/undressing without help

2 = I needed help dressing/undressing

Stroke Type and Severity

Variable ID: STROKETYPE Variable: Stroke type

Definition: Indicate stroke type

Supporting Definition: N/A

Inclusion Criteria: All patients

Timing: Admission for index event

Data Source: Clinical

Type: Single answer

Response Options: 1 = Ischemic stroke (IS)

2 = Intracereberal hemorrhage (ICH)
 3 = Transient ischemic attack (TIA)
 999 = Stroke of unknown type

Variable ID: STROKESEV_NIHSS
Variable: Stroke severity: score

Definition: Stroke severity as measured by the NIH Stroke Scale (NIHSS)

Supporting Definition: Report the raw (uncategorized) NIHSS score

Inclusion Criteria: All patients

Timing: Admission for index event

Data Source: Clinical

Type: Numeric value

Response Options: Numeric value of the NIHSS score between 1 and 42

999 = Unknown

Variable ID: EST_STROKESEV_NIHSS_CAT
Variable: Estimated stroke severity: category

Definition: Indicate the estimated stroke severity category by the NIH Stroke Scale (NIHSS)

Supporting Definition: NIHSS categories:

NIHSS score o = Category 1: No stroke symptoms

NIHSS score 1-4 = Category 2: Minor NIHSS score 5-15 = Category 3: Moderate

NIHSS score 16-20 = Category 4: Moderate to severe

NIHSS score 21-42 = Category 5: Severe

Note: if no NIHSS score was recorded and/or insufficient documentation exists to abstract the full score, then indicate a category based on symptom severity.

Inclusion Criteria: All patients

Timing: Admission for index event

Data Source: Clinical

Type: Single answer

Response Options: 1 = No stroke symptoms

2 = Minor 3 = Moderate

4 = Moderate to severe

5 = Severe 999 = Unknown

Variable ID: STROKESEV_LOC

Variable: Stroke severity: consciousness

Definition: Indicate the patient's level of consciousness measured on hospital arrival

Supporting Definition: N/A
Inclusion Criteria: All patients

Timing: Admission for index event

Data Source: Clinical

Type: Single answer

Response Options: o = Fully awake

1 = Somnolent 2 = Coma 999 = Unknown

Variable ID: SYMPTDUR

Variable: Duration of symptoms

Definition: Indicate the duration of the symptoms measured on hospital arrival

Supporting Definition: N/A
Inclusion Criteria: All patients

Timing: Admission for index event

Data Source: Clinical

Type: Single answer

Response Options: o = Less than 4.5 hours

1 = More than 4.5 hours

999 = Unknown

Vascular and Systemic

Variable ID: PRIORSTROKE
Variable: Prior Stroke

Definition: Prior to this hospitalization, have you ever been told by a doctor that you have had

a stroke?

Supporting Definition: Item is phrased as a patient reported measure. However, if the patient is unable to

answer, this information can be abstracted from the medical records.

Inclusion Criteria: All patients

Timing: Admission for index event

Data Source: Patient-reported, clinical, or administrative

Type: Single answer

Response Options: o = No

1 = Yes

999 = Unknown

Variable ID: PRIORTIA
Variable: Prior TIA

Definition: 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)?

Supporting Definition: Item is phrased as a patient reported measure. However, if the patient is unable to

answer, this information can be abstracted from the medical records.

Inclusion Criteria: All patients

Timing: Admission for index event

Data Source: Patient-reported, clinical, or administrative

Type: Single answer

Response Options: o = No

1 = Yes

999 = Unknown

Variable ID: PRIORMI
Variable: Prior MI

Definition: Have you ever been told by your doctor that you've had a heart attack (this is

sometimes called a myocardial infarction, or MI)?

Supporting Definition: Item is phrased as a patient reported measure. However, if the patient is unable to

answer, this information can be abstracted from the medical records.

Inclusion Criteria: All patients

Timing: Admission for index event

Data Source: Patient-reported, clinical, or administrative

Type: Single answer

Response Options: o = No

1 = Yes

999 = Unknown

Variable ID: CAD

Variable: Coronary artery disease

Definition: Have you ever been told by your doctor that you have coronary artery disease?

Supporting Definition: Item is phrased as a patient reported measure. However, if the patient is unable to

answer, this information can be abstracted from the medical records.

Inclusion Criteria: All patients

Timing: Admission for index event

Data Source: Patient-reported, clinical, or administrative

Type: Single answer

Response Options: o = No

1 = Yes

999 = Unknown

Variable ID: AFIB

Variable: Atrial fibrillation

Definition: Have you ever been told by your doctor that you have atrial fibrillation?

Supporting Definition: Item is phrased as a patient reported measure. However, if the patient is unable to

answer, this information can be abstracted from the medical records.

Inclusion Criteria: All patients

Timing: Admission for index event

Data Source: Patient-reported, clinical, or administrative

Type: Single answer

Response Options: o = No

1 = Yes

999 = Unknown

Variable ID: DIAB

Variable: Diabetes mellitus

Definition: Have you ever been told by your doctor that you have diabetes?

Supporting Definition: Item is phrased as a patient reported measure. However, if the patient is unable to

answer, this information can be abstracted from the medical records.

Inclusion Criteria: All patients

> Admission for index event Timing:

Data Source: Patient-reported, clinical, or administrative

> Single answer Type:

Response Options: o = No

1 = Yes

999 = Unknown

Variable ID: **HYPERTENS** Variable: Hypertension

Definition: Have you ever been told by a doctor that you have high blood pressure (this is

sometimes called hypertension)?

Supporting Definition: Item is phrased as a patient reported measure. However, if the patient is unable to

answer, this information can be abstracted from the medical records.

Inclusion Criteria: All patients

> Timing: Admission for index event

Data Source: Patient-reported, clinical, or administrative

> Single answer Type:

Response Options: o = No

1 = Yes

999 = Unknown

Variable ID: **HYPERLIP** Variable: Hyperlipidemia

Definition: Have you ever been told by your doctor that you have high cholesterol (this is

sometimes called hyperlipidemia or dyslipidemia)?

Supporting Definition: Item is phrased as a patient reported measure. However, if the patient is unable to

answer, this information can be abstracted from the medical records.

Inclusion Criteria: All patients

> Admission for index event Timing:

Data Source: Patient-reported, clinical, or administrative

> Type: Single answer

Response Options: o = No

1 = Yes

999 = Unknown

Variable ID: **SMOKE**

> Variable: Smoking status

Definition: Do you currently smoke, or have you smoked cigarettes or tobacco over the past

year?

Supporting Definition: Smoking status (of cigarettes or tobacco). Item is phrased as a patient reported

measure. However, if the patient is unable to answer, this information can be

abstracted from the medical records.

Inclusion Criteria: All patients

> Timing: Admission for index event

Data Source: Patient-reported

> Single answer Type:

o = No **Response Options:**

> 1 = Yes999 = Unknown

Variable ID: **ALCOHOL** Variable: Alcohol use

Definition: Do you drink more than one alcoholic drink a day?

Supporting Definition: One standard alcoholic drink is:

12 ounces of regular beer (about 5% alcohol)

5 ounces of wine (about 12% alcohol)

1.5 ounces of distilled spirits (about 40% alcohol)

Item is phrased as a patient reported measure. However, if the patient is unable to

answer, this information can be abstracted from the medical records.

Inclusion Criteria: All patients

Timing: Admission for index event

Data Source: Patient-reported, clinical, or administrative

Type: Single answer

Response Options: o = No

1 = Yes

999 = Unknown

Treatment/Care Related

Variable ID: DIAGNOSIS

Variable: Diagnostic evidence base

Definition: Indicate how the diagnosis was made

Supporting Definition: N/A

Inclusion Criteria: All patients

Timing: Admission for index event

Data Source: Clinical

Type: Single answer

Response Options: o = Clinical symptoms alone

1 = Clinical + CT 2 = Clinical + MRI

Variable ID: ADMDATE

Variable: Date of index admission

Definition: Date of admission for index event

Supporting Definition: N/A

Inclusion Criteria: All patients

Timing: Admission for index event

Data Source: Administrative data

Type: Date by DD/MM/YYYY

Response Options: DD/MM/YYYY

Variable ID: DISCHDATE

Variable: Date of discharge

Definition: Date of discharge from acute care hospital

Supporting Definition: N/A

Inclusion Criteria: All patients
Timing: Discharge

Data Source: Administrative data **Type:** Date by DD/MM/YYYY

Response Options: DD/MM/YYYY

Variable ID: REHAB IN

Variable: Rehabilitation inpatient acute care

Definition: Did the acute inpatient care include dedicated stroke rehabilitation?

Supporting Definition: Dedicated stroke rehabilitation during acute care

Inclusion Criteria: All patients
Timing: Discharge

Data Source: Administrative or clinical

Type: Single answer

Response Options: o = No

1 = Yes

999 = Unknown

Variable ID: REHAB_OUT

Variable: Rehabilitation post acute care

Definition: Did the post-acute care include dedicated stroke rehabilitation?

Supporting Definition: Dedicated stroke rehabilitation during post-acute care, either hospital based or out

patient/home based

Inclusion Criteria: All patients

Timing: Discharge

Data Source: Administrative data

Type: Single answer

Response Options: o = No

ı = Yes

999 = Unknown

Variable ID: DISCHDEST

Variable: Discharge destination following acute care hospitalization

Definition: What type of place was the patient discharged to?

Supporting Definition: Indicate the patient's discharge destination from acute care hospital

Inclusion Criteria: All patients
Timing: Discharge

Data Source: Administrative data **Type:** Single answer

Response Options: 1 = Home or community dwelling (not home hospice)

2 = Residential facility

3 = Dedicated inpatient rehabilitation facility

4 = Another acute care hospital 5 = Patient died in hospital

888 = Other 999 = Unknown

Treatment Variables

Treatment Variables

Variable ID: THROMBOLYTICTX

Variable: Thrombolytic therapy

Definition: Indicate if the patient received intravenous thrombolytic therapy

Supporting Definition: Intravenous tissue plasminogen activator

Inclusion Criteria: Ischemic stroke patients

Timing: Discharge **Data Source:** Clinical

Type: Single answer

Response Options: o = No

1 = Yes

999 = Unknown

Variable ID: THROMBOLYTICTXDATE

Variable: Date of thrombolytic therapy

Definition: Indicate the date of thrombolytic therapy

Supporting Definition: N/A

Inclusion Criteria: If "1 = Yes" to THROMBOLYTICTX

Timing: Discharge **Data Source:** Clinical

Type: Date by DD/MM/YYYY

Response Options: DD/MM/YYYY

Variable ID: THROMBECTTX Variable: Thrombectomy

Definition: Indicate if the patient underwent thrombectomy

Supporting Definition: Endovascular mechanical clot removal

Inclusion Criteria: Ischemic stroke patients

Timing: Discharge **Data Source:** Clinical

Type: Single answer

Response Options: o = No

1 = Yes

999 = Unknown

Variable ID: THROMBECTTXDATE
Variable: Date of thrombectomy

Definition: Indicate the date of thrombectomy

Supporting Definition: N/A

> Inclusion Criteria: If "1 = Yes" to THROMBOLYTICTX

Timing: Discharge Data Source: Clinical

> Date by DD/MM/YYYY Type:

Response Options: DD/MM/YYYY

> Variable ID: **HEMICRANITX** Variable: Hemicraniectomy

Definition: Indicate if the patient underwent hemicraniectomy

Supporting Definition: N/A

Inclusion Criteria: All patients Timing: Discharge Data Source: Clinical

Type: Single answer

Response Options: o = No

> 1 = Yes999 = Unknown

Variable ID: **HEMICRANITXDATE** Variable: Date of hemocraniectomy

Definition: Indicate the date of hemicraniectomy

Supporting Definition: N/A

> If "1 = Yes" to HEMICRANITX Inclusion Criteria:

> > Timina: Discharge Data Source: Clinical

> > > Date by DD/MM/YYYY Type:

Response Options: DD/MM/YYYY

Outcomes

Acute Complications of Treatment

Variable ID: SYMPICHTHROMBOLYSIS

Variable: Symptomatic intracranial hemorrhage after IV thrombolysis

Definition: Indicate if the patient developed symptomatic intracerebral hemorrhage after

treatment of ischemic stroke with intravenous thrombolysis?

Supporting Definition: N/A

> **Inclusion Criteria:** If "1 = Yes" to THROMBOLYTICTX

Timing: Discharge Data Source: Clinical Type: Single answer

Response Options: o = No

1 = Yes

Variable ID: **SYMPICHTHROMBECTOMY**

Variable: Symptomatic intracranial hemorrhage after thrombectomy

Definition: Indicate if the patient developed symptomatic intracerebral hemorrhage after

treatment of ischemic stroke with thrombectomy?

Supporting Definition: N/A

> **Inclusion Criteria:** If "1 = Yes" to THROMBOLYTICTX

Timing: Discharge Data Source: Clinical Type: Single answer

o = No

Response Options:

1 = Yes

Survival and Disease Control

Variable ID: OVERALLSURV Variable: Overall survival

Definition: Indicate if the patient has died

Supporting Definition: All cause mortality TREATMENTVARIABLES

Inclusion Criteria: All patients

Timing: Discharge;

90 days post admission for index event;

One year after index event;

Tracked ongoing annually for 5 years (when hospital is able to track this ongoing)

Data Source: Administrative data (e.g. death registry)

Type: Single answer

Response Options: o = No

ı = Yes

999 = Unknown

Variable ID: DATEOFDEATH
Variable: Date of death

Definition: Indicate date of death

Supporting Definition: N/A

Data Source:

Inclusion Criteria: If "1 = Yes" to OVERALLSURV

Timing: Discharge;

90 days post admission for index event;

One year after index event;

Tracked ongoing annually for 5 years (when hospital is able to track this ongoing) Administrative data (e.g. death registry)

Type: Date by DD/MM/YYYY

Response Options: DD/MM/YYYY

99/99/9999 = Unknown

Variable ID: STROKERECUR

Variable: Report of new stroke within 90 days after admission for stroke

Definition: After your hospitalization for stroke, have you been told by a doctor that you have

had a new stroke?

Supporting Definition: New stroke within 90 days of stroke

Inclusion Criteria: All patients

Timing: Admission for index event

Data Source: Patient-reported or administrative data

Type: Single answer

Response Options: o = No

1 = Yes

999 = Unknown

Variable ID: SMOKECESS
Variable: Smoking cessation

Definition: Since your hospitalization for stroke, have you smoked tobacco or cigarettes?

Supporting Definition: N/A

Inclusion Criteria: If "1 = Yes" to SMOKE

Timing: 90 days post admission for index event

Data Source: Patient-reported

Type: Single answer

Response Options: o = No

1 = Yes

999 = Unknown

Patient-Reported Health Status

Variable ID: POSTSTROKEAMB

Variable: Poststroke functional status - Ambulation

Definition: Are you able to walk?

Supporting Definition: This item is also measured at baseline, as PRESTROKEAMB

Inclusion Criteria: All patients

Timing: Discharge + 7 days;

90 days post admission for index event

Data Source: Patient-reported

Single answer Type:

Response Options: 1 = Able to walk without help from another person with or without a device OUTCOMES

2 = Able to walk with help from another person

3 = Unable to walk

POSTSTROKETOILET Variable ID:

Variable: Poststroke functional status - Toileting

Definition: Do you need help from anybody to go to the toilet?

Supporting Definition: This item is also measured at baseline, as PRESTROKETOILET

Inclusion Criteria: All patients

> Timing: Discharge + 7 days;

> > 90 days post admission for index event

Data Source: Patient-reported

Type: Single answer

Response Options: 1 = I can manage going to the toilet without assistance

2 = I need help to go to the toilet

Variable ID: **POSTSTROKEDRESS**

Variable: Poststroke functional status - Dressing Definition: Do you need help with dressing/undressing?

Supporting Definition: This item is also measured at baseline, as PRESTROKEDRESS

Inclusion Criteria: All patients

> Timina: Discharge + 7 days;

> > 90 days post admission for index event

Data Source: Patient-reported

Single answer Type:

1 = I can manage dressing/undressing without help **Response Options:**

2 = I need help dressing/undressing

Variable ID: **FEEDING** Variable: Feeding

Definition: Do you need a tube for feeding?

Supporting Definition: For example: a nasogastric tube or a gastrostomy tube

Inclusion Criteria: All patients

> Timing: Discharge + 7 days;

> > 90 days post admission for index event

Data Source: Patient-reported Single answer

Type:

Response Options: o = No1 = Yes

> Variable ID: COMMUNIC

> > Variable: Ability to communicate

Definition: Do you have problems with communication or understanding?

Supporting Definition: N/A

> **Inclusion Criteria:** All patients

Discharge + 7 days; Timing:

90 days post admission for index event

Data Source: Patient-reported

> Type: Single answer

Response Options: o = No

1 = Yes

Variable ID: PROMIS-10_Qo1

Variable: Globalo1

Definition: In general, would you say your health is:

Supporting Definition: N/A

> **Inclusion Criteria:** All patients

> > Timing: Discharge + 7 days;

> > > 90 days post admission for index event

Data Source: Patient-reported Type: Single answer

Response Options: 5 = Excellent

4 = Very good 3 = Good 2 = Fair 1 = Poor

Variable ID: PROMIS-10_Q02

Variable: Globalo2

Definition: In general, would you say your quality of life is:

Supporting Definition: N/A

Inclusion Criteria: All patients

Timing: Discharge + 7 days;

90 days post admission for index event

Data Source: Patient-reported

Type: Single answer **Response Options:** 5 = Excellent

4 = Very good 3 = Good 2 = Fair 1 = Poor

Variable ID: PROMIS-10_Q03

Variable: Globalo3

Definition: In general, how would you rate your physical health?

Supporting Definition: N/A

Inclusion Criteria: All patients

Timing: Discharge + 7 days;

90 days post admission for index event

Data Source: Patient-reported

Type: Single answer

Response Options: 5 = Excellent

4 = Very good 3 = Good 2 = Fair 1 = Poor

Variable ID: PROMIS-10_Q04

Variable: Globalo4

Definition: In general, how would you rate your mental health, including your mood and your

ability to think?

Supporting Definition: N/A

Inclusion Criteria: All patients

Timing: Discharge + 7 days;

90 days post admission for index event

Data Source: Patient-reported **Type:** Single answer

Response Options: 5 = Excellent

4 = Very good 3 = Good 2 = Fair 1 = Poor

Variable ID: PROMIS-10_Q05

Variable: Globalo5

Definition: In general, how would you rate your satisfaction with your social activities and

relationships?

Supporting Definition: N/A

Inclusion Criteria: All patients

Timing: Discharge + 7 days;

90 days post admission for index event

Data Source: Patient-reported

Type: Single answer

Response Options: 5 = Excellent

4 = Very good 3 = Good 2 = Fair 1 = Poor

Variable ID: PROMIS-10 Qo6

Variable: Globalo9

Definition: In general, please rate how well you carry out your usual social activities and roles.

(This includes activities at home, at work and in your community, and responsibilities as a parent, child, spouse, employee, friend, etc.)

Supporting Definition: N/A

Inclusion Criteria: All patients

Timing: Discharge + 7 days;

90 days post admission for index event

Data Source: Patient-reported

Type: Single answer

Response Options: 5 = Excellent

4 = Very good 3 = Good 2 = Fair 1 = Poor

Variable ID: PROMIS-10_Q07

Variable: Globalo6

Definition: To what extent are you able to carry out your everyday physical activities such as

walking, climbing stairs, carrying groceries, or moving a chair?

Supporting Definition: N/A

Inclusion Criteria: All patients

Timing: Discharge + 7 days;

90 days post admission for index event

Data Source: Patient-reported

Type: Single answer

Response Options: 5 = Completely

4 = Mostly 3 = Moderately 2 = A little 1 = Not at all

Variable ID: PROMIS-10_Q08

Variable: Global10

Definition: In the past 7 days, how often have you been bothered by emotional problems such

as feeling anxious, depressed or irritable?

Supporting Definition: N/A

Inclusion Criteria: All patients

Timing: Discharge + 7 days;

90 days post admission for index event

Data Source: Patient-reported

Type: Single answer

Response Options: 1 = Never

2 = Rarely 3 = Sometimes 4 = Often 5 = Always

Variable ID: PROMIS-10_Q09

Variable: Globalo8

Definition: In the past 7 days, how would you rate your fatigue on average?

Supporting Definition: N/A

Inclusion Criteria: All patients

Timing: Discharge + 7 days;

90 days post admission for index event

Data Source: Patient-reported

Type: Single answer

Response Options: 1 = None

2 = Mild 3 = Moderate 4 = Severe 5 = Very severe

Variable ID: PROMIS-10_Q10

Variable: Globalo7

Definition: In the past 7 days, how would you rate your pain on average?

Supporting Definition: Indicate pain level on a scale of o-10, where o = No pain, and 10 = Worst imaginable

pain

Inclusion Criteria: All patients

Timing: Discharge + 7 days;

90 days post admission for index event

Data Source: Patient-reported **Type:** Single answer

Response Options: Numerical value between o and 10

Clinician-Reported Health Status

Variable ID: smRSq

Variable: Simplified modified Rankin Scale Questionnaire (smRSq)

Definition: Indicate the degree of disability or dependence by obtaining the smRSq **Supporting Definition:** The link to the smRSq flow chart and instructions for use can be found in this

Reference Guide on page 11

Inclusion Criteria: All patients

Timing: Discharge + 7 days;

90 days post admission for index event

Data Source: Clinical

Type: Single answer

Response Options: o = No symptoms at all

1 = No significant disability despite symptoms; able to carry out all usual duties and

activities

2 = Slight disability; unable to carry out all previous activities but able to look after

own affairs without assistance

3 = Moderate disability; requiring some help, but able to walk without assistance 4 = Moderately severe disability; unable to walk without assistance and unable to

attend to own bodily needs without assistance

5 = Severe disability; bedridden, incontinent and requiring constant nursing care

and attention

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Reference Guide Revisions

Reference Guide Version	Location within Reference Guide	Content Change
1.0.1	Contact Information	Removed inactive email address: ichomteam@ichom.org
1.0.1	Collecting Patient- and Clinician- Reported Outcome Measures	Changed licensing information for smRSq
2.0.0	Follow-Up Timeline	Time point definitions changed
2.0.0	Data Dictionary	Changes were made to the following variables: LIVINGLOCPOST, LIVEALONEPRE, LIVEALONEPOST, PRESTROKEAMB, PRESTROKETOILET, PRESTROKEDRESS, EST_ STROKESEV_NIHSS_CAT, STROKESEV_LOC, SYMPTDUR, CAD, REHAB_IN, DISCHDEST, THROMBOLYTICX, OVERALLSURV, STROKERECUR, SMOKECESS. COMFCARE was removed.
2.0.1	Data Dictionary	Amended response option for PROMIS-10_Q10

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