ICHOM

International Consortium for
Health Outcomes Measurement

STROKE
DATA COLLECTION REFERENCE GUIDE

Version 1.0.1
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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.

© 2015 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.

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.

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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.

ICHOM Standard Set for Stroke

Case-Mix Variables

Patient Population	Measure	Supporting Information	Timing	Suggested Data Sources
Demographic Factors				
All patients	Age	Date of birth	Admission for index stroke event	Administrative data
	Sex	Sex at birth		
	Ethnicity	Note that regulations on reporting ethnicity may differ per country		Patient-reported
	Living location	Most recent place of residence pre stroke and 90 days post admission	Admission for index stroke event; 90 days post admission for index event	
	Living alone	Living situation pre stroke and 90 days post admission		
	Prestroke functional status	Captured with Mobility, Toileting and Dressing items	Admission for index stroke event	
Stroke Type and Severity				
All patients	Stroke type	Response options: IS; ICH; TIA	Admission for index stroke event	Clinical
	Stroke severity	Measured by NIHSS & Level of consciousness		
	Duration of symptoms	Response options: < 1 hour; 1 hour - 1 day; > 1 day; Unable to determine		Patient-reported
Vascular and Systemic				
All patients	Prior Stroke	Yes/No	Admission for index stroke event	Patient-reported, clinical, or administrative data
	Prior TIA			
	Prior MI			
	Coronary artery disease			
	Atrial fibrillation			
	Diabetes mellitus			
	Hypertension			
	Hyperlipidemia			
	Smoking status (current or in past year)			Patient-reported
	Alcohol use (>1 drink a day)			
Treatment/Care Related				
All patients	Length of stay	Date of index admission and date of discharge from acute care hospital	Discharge	Administrative data
	Diagnostic evidence base	Response options: Clinical alone; Clinical + MRI; Clinical + CT	Admission for index stroke event	Clinical
	Rehabilitation	Dedicated stroke rehabilitation during acute or post-acute care	Discharge	Administrative data
	Discharge destination	Discharge destination following acute care hospitalization		
	Comfort care*	At any point in the hospitalization, did the goals of care shift from treatment and recovery to one that emphasized comfort?		

IS: Ischemic stroke; ICH: Intracerebral hemorrhage; TIA: Transient ischemic attack; NIHSS: NIH Stroke Scale
*** Optional item**
All patient-reported forms are meant to be completed by the patient. However, if the patient is unable to answer the items, the information should be completed by a proxy or (when appropriate) by the clinician, or abstracted from medical records.

Treatment Variables

Patient Population	Measure	Supporting Information	Timing	Suggested Data Sources
Ischemic stroke patients	Thrombolytic therapy	Indicate if and when the patient received intravenous thrombolytic therapy	Discharge	Clinical
	Thrombectomy	Indicate if and when the patient underwent thrombectomy		
Intracereberal hemorrhage patients	Hemicraniectomy	Indicate if and when the patient underwent hemicraniectomy		

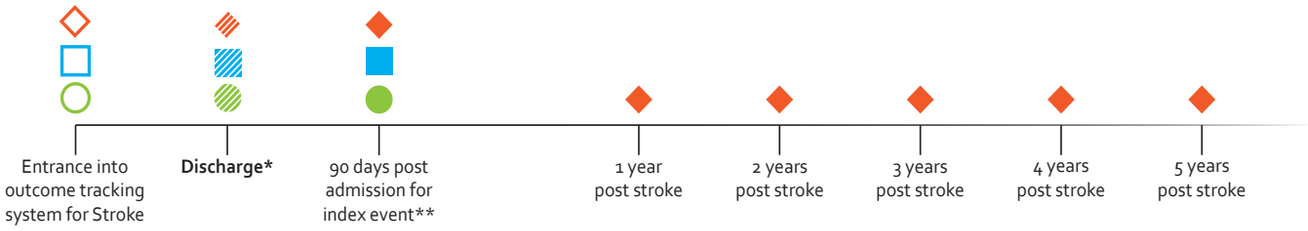
Outcomes

Patient Population	Measure	Supporting Information	Timing	Suggested Data Sources
Acute Complications of Treatment				
Patients who received thrombolytic therapy or thrombectomy	Symptomatic intracranial hemorrhage after thrombolysis or thrombectomy	Did the patient develop symptomatic intracerebral hemorrhage after treatment of ischemic stroke with thrombolysis or thrombectomy?	Discharge	Clinical
Survival and Disease Control				
All patients	Overall survival	All-cause mortality	Discharge; 90 days post admission for index event; One year after index event; Recommended to tracked ongoing annualy for 5 years	Administrative data (e.g. death registry)
	Recurrence of disease	Report of new stroke after index admission	90 days post admission for index event	Patient-reported or administrative data
	Smoking cessation	Adherence to smoking cessation advise		Patient-reported
Patient-Reported Health Status				
All patients	Cognitive and Psychiatric functioning	Includes Mood and Global cognitive function (tracked via PROMIS-10)	90 days post admission for index event	Patient-reported
	Non-motor functioning	Includes Pain and Fatigue (tracked via PROMIS-10)		
	Motor functioning	Includes Mobility, Feeding, Ability to return to usual activities and Self care and grooming (tracked via PROMIS-10 and smRSq, with additional single items)	Discharge*; 90 days post admission for index event	
	Social functioning	Includes Ability to communicate (single item) and Social participation (tracked via PROMIS-10)	Discharge**; 90 days post admission for index event	
	General health status	Patient-reported general health status (tracked via PROMIS-10)	90 days post admission for index event	
	Health related quality of life	Global patient reported health-related QOL (tracked via PROMIS-10)		

PROMIS-10: Patient Reported Outcomes Measurement Information System Shortform version 1.1 Global Health; smRSq: Simplified modified Rankin Scale Questionnaire
*** Discharge: Mobility, Feeding and Self care and grooming**
**** Discharge: Ability to communicate**
All patient-reported forms are meant to be completed by the patient. However, if the patient is unable to answer the items, the information should be completed by a proxy or (when appropriate) by the clinician, or abstracted from medical records.

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.



* Discharge or 7 days, whichever comes first
** 90 days post admission + 30 days window (90 to 120 days post index event)

The following questionnaires should be administered at the indicated time points

- Admissions Administrative Form (link)
- Admissions Patient-Reported Form (link)
- Admissions Clinical Form (link)
- Discharge Administrative Form (link)
- Discharge Patient-Reported Form (link)
- Discharge Clinical Form (link)
- 90 Days and Annual Administrative Form (link)
- 90 Days Patient-Reported Form (link)
- 90 Days Clinical Form (link)

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**	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%20PROMIS%20Global%20short%20form.pdf
Simplified modified Rankin Scale Questionnaire (smRSq) - **Clinician**	There is no patent on the 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 mRS, 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.

Global07	In the past 7 days	How would you rate your pain on average	5=0 No pain 4=1 4=2 4=3 3=4 3=5 3=6 2=7 2=8 2=9 1=10 Worst pain imaginable
Global08	In the past 7 days	How would you rate your fatigue on average?	5=None 4=Mild 3=Moderate 2=Severe 1=Very severe
Global10	In the past 7 days	How often have you been bothered by emotional problems such as feeling anxious, depressed or irritable?	5=Never 4=Rarely 3=Sometimes 2=Often 1=Always

After recoding, the Global Physical Health score is generated by summing responses to Global03, Global06, Global07rescored, and Global08rescored. The Global Mental Health score is generated by summing responses to Global02, Global04, Global05, and Global10rescored.

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

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

*SE = Standard Error

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 Global07, Global08, 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)

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**

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.
2. May repeat and clarify the questions if needed, but to maintain consistency across raters do not elaborate or provide examples or guide 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:

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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; Li T; 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:	0 = 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 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
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
Variable ID:	LIVEALONEPRE
Variable:	Living alone pre-index event?
Definition:	Did you live alone prior to your stroke or TIA?
Supporting Definition:	N/A
Inclusion Criteria:	All patients
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 TIA?
Supporting Definition:	This item is also measured at discharge and 90 days, as POSTSTROKEAMB
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 TIA?
Supporting Definition:	This item is also measured at discharge and 90 days, as POSTSTROKETOILET
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 TIA?
Supporting Definition:	This item is also measured at discharge and 90 days, as POSTSTROKEDRESS
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
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 0 = 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
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:	0 = Fully awake 1 = Somnolent 2 = Coma
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:	Patient-reported
Type:	Single answer
Response Options:	0 = Less than 1 hour 1 = Between 1 hour and 1 day 2 = Longer than 1 day 3 = Unable to determine

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:	0 = 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:	0 = 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:	0 = 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:	Did the patient receive coronary bypass surgery or a coronary stent? 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:	0 = 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:	0 = 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
Timing:	Admission for index event
Data Source:	Patient-reported, clinical, or administrative
Type:	Single answer
Response Options:	0 = 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
Type:	Single answer
Response Options:	0 = 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
Timing:	Admission for index event
Data Source:	Patient-reported, clinical, or administrative
Type:	Single answer
Response Options:	0 = 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
Type:	Single answer
Response Options:	0 = No 1 = Yes 999 = 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
Type:	Single answer
Response Options:	0 = 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:	0 = 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 data
Type:	Single answer
Response Options:	0 = 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:	0 = No 1 = 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 6 = Discharged to home or facility with the expectation that the patient would die (e.g., hospice) 888 = Other 999 = Unknown
Variable ID:	COMFCARE
Variable:	Comfort care*
Definition:	At any point in the hospitalization, did the goals of care shift from treatment and recovery to one that emphasized comfort?
Supporting Definition:	"Comfort care" is defined as care for a patient who is dying that helps or comforts with the goal of preventing or relieving suffering
Inclusion Criteria:	Optional item
Timing:	Discharge
Data Source:	Administrative data
Type:	Single answer
Response Options:	0 = No 1 = Yes, comfort care decided before arrival at hospital or prior to acute intervention or admission (day 0) 2 = Yes, anytime in first 48 hours of hospital admission 3 = Yes, anytime after first 48 hours of hospital admission 4 = Yes, but timing uncertain 999 = Not documented

*** Optional item**

Treatment Variables

Variable ID:	THROMBOLYTICTX
Variable:	Thrombolytic therapy
Definition:	Indicate if the patient received intravenous thrombolytic therapy
Supporting Definition:	Intravenous tissue plasminogen activator (Alteplase)
Inclusion Criteria:	Ischemic stroke patients
Timing:	Discharge
Data Source:	Clinical
Type:	Single answer
Response Options:	0 = No 1 = Yes
Variable ID:	THROMBOLYTICTXDATE
Variable:	Date of thrombolytic therapy
Definition:	Indicate the date of thrombolytic therapy
Supporting Definition:	N/A
Inclusion Criteria:	Ischemic stroke patients If answered 'yes' to thrombolytic therapy (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:	0 = No 1 = Yes
Variable ID:	THROMBECTTXDATE
Variable:	Date of thrombectomy
Definition:	Indicate the date of thrombectomy
Supporting Definition:	N/A
Inclusion Criteria:	Ischemic stroke patients If answered 'yes' to thrombectomy (THROMBECTTX)
Timing:	Discharge
Data Source:	Clinical
Type:	Date by DD/MM/YYYY
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:	0 = No 1 = Yes
Variable ID:	HEMICRANITXDATE
Variable:	Date of hemocraniectomy
Definition:	Indicate the date of hemicraniectomy
Supporting Definition:	N/A

Inclusion Criteria:	All patients If answered 'yes' on hemicraniectomy (HEMICRANITX)
Timing:	Discharge
Data Source:	Clinical
Type:	Date by DD/MM/YYYY
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:	Ischemic stroke patients If answered 'yes' to thrombolytic therapy (THROMBOLYTICTX)
Timing:	Discharge
Data Source:	Clinical
Type:	Single answer
Response Options:	0 = 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:	Ischemic stroke patients If answered 'yes' to thrombectomy (THROMBECTTX)
Timing:	Discharge
Data Source:	Clinical
Type:	Single answer
Response Options:	0 = No 1 = Yes

Survival and Disease Control

Variable ID:	OVERALLSURV
Variable:	Overall survival
Definition:	Indicate if the patient has died
Supporting Definition:	All cause mortality
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:	0 = No 1 = Yes
Variable ID:	DATEOFDEATH
Variable:	Date of death
Definition:	Indicate date of death
Supporting Definition:	N/A
Inclusion Criteria:	All patients If answered 'yes' to overall survival (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)
Data Source:	Administrative data (e.g. death registry)
Type:	Date by DD/MM/YYYY or by

	MM/YYYY (in case exact day is unknown)
Response Options:	DD/MM/YYYY or MM/YYYY
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:	90 days post admission for index event
Data Source:	Patient-reported or administrative data
Type:	Single answer
Response Options:	0 = No 1 = Yes
Variable ID:	SMOKECESS
Variable:	Smoking cessation
Definition:	Since your hospitalization for stroke, have you smoked tobacco or cigarettes?
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:	0 = Not applicable, I don't smoke 1 = No, I stopped smoking after my stroke 2 = Yes

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 90 days post 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:	POSTSTROKETOILET
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 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
Timing:	Discharge 90 days post admission for index event

Data Source:	Patient-reported
Type:	Single answer
Response Options:	1 = I can manage dressing/undressing without help
	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
	90 days post admission for index event
Data Source:	Patient-reported
Type:	Single answer
Response Options:	0 = No
	1 = 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
Timing:	Discharge
	90 days post admission for index event
Data Source:	Patient-reported
Type:	Single answer
Response Options:	0 = No
	1 = Yes
Variable ID:	PROMIS-10_Q01
Variable:	Global01 - Patient reported general health status
Definition:	In general, would you say your health is:
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:	5 = Excellent
	4 = Very good
	3 = Good
	2 = Fair
	1 = Poor
Variable ID:	PROMIS-10_Q02
Variable:	Global02 - Global patient reported health-related QOL
Definition:	In general, would you say your quality of life is:
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:	5 = Excellent
	4 = Very good
	3 = Good
	2 = Fair
	1 = Poor
Variable ID:	PROMIS-10_Q03
Variable:	Global03 - Patient reported general health status
Definition:	In general, how would you rate your physical health?
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:	5 = Excellent 4 = Very good 3 = Good 2 = Fair 1 = Poor
Variable ID:	PROMIS-10_Q04
Variable:	Global04 - Mood, global cognitive function
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:	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:	Global05 - Social participation
Definition:	In general, how would you rate your satisfaction with your social activities and relationships?
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:	5 = Excellent 4 = Very good 3 = Good 2 = Fair 1 = Poor
Variable ID:	PROMIS-10_Q06
Variable:	Global09 - Social participation
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:	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:	Global06 - Mobility
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:	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 - Mood
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:	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:	Global08 - Fatigue
Definition:	In the past 7 days, how would you rate your fatigue on average?
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 = None 2 = Mild 3 = Moderate 4 =Severe 5 = Very severe
Variable ID:	PROMIS-10_Q10
Variable:	Global07 - Pain and other unpleasant sensations
Definition:	In the past 7 days, how would you rate your pain on average?
Supporting Definition:	Indicate pain level on a scale of 1-10, where 0 = No pain, and 10 = Worst imaginable pain
Inclusion Criteria:	All patients
Timing:	90 days post admission for index event
Data Source:	Patient-reported
Type:	Single answer
Response Options:	Numerical value between 1 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:	90 days post admission for index event

Data Source: Clinical
Type: Single answer
Response Options: 0 = 0
1 = 1
2 = 2
3 = 3
4 = 4
5 = 5
6 = 6

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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

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