

RIKSSTROKE - ACUTE PHASE FOR REGISTRATION OF STROKE

Personal ID number -

Name Gender 1= man 2= woman

Reporting hospital Ward/Department

Completed by (name of person completing this form).....

Date deceased (YYMMDD)
(relates to death during period of care)

Stroke diagnosis I / G

I 61= Cerebral haemorrhage

I 63= Cerebral infarction

I 64= Acute cerebrovascular disease, not specified as haemorrhage or infarction

G 45.X= TIA (as a result of thrombolysis or thrombectomy for stroke with **complete resolution of symptoms** within 24 hours of onset)

Patient woke up with symptoms

1= yes 2= no 9= not known

Date of onset (YYMMDD)

Time of onset (TIM.MIN)

If the patient woke up with symptoms, enter the time when the patient was last symptom-free.

If an inpatient has suffered a stroke and the time of onset is not known, enter the time when the patient was last symptom-free.

The time of onset is given in hours and minutes. If the time of onset is not known or it is only possible to determine the **hour of onset**, enter **99.99** and the closest possible time in *Time interval* below.

Time interval from onset of stroke to arrival at hospital

(To be answered if the time of onset is not known or it is only possible to determine the hour of onset [99.99])

1= within 3 hours 2 a= within 4.5 hours 2b= within 6 hours 3= within 24 hours

4= after 24 hours 9= not known

The patient was already at the hospital/emergency clinic in this stroke episode

1= yes 2= no

Patient arrived by ambulance

1= yes 2= no 9= not known

Thrombosis/thrombectomy alarm 'Save the brain/Stroke alarm'

1= yes 2= no 9= not known

----- ARRIVAL AT FIRST HOSPITAL -----

(the hospital to which the patient was first admitted for this stroke episode)

Date and time

I _ I _ II _ I _ II _ I _ I (YYMMDD) I _ I _ .I _ I _ I (hrs.min)

Enter Riksstroke Hospital Code 888= for overseas 999= hospital code notknown I _ I _ I _ I

----- EMERGENCY EXAMINATIONS / ACTIONS -----

Computed tomography brain I _ I

1= yes 2= no 9= not known

CT angiography performed in connection with the first CT I _ I

1= yes 2 = no 9= not known

CT perfusion performed in connection with the first CT I _ I

1= yes 2 = no 9= not known

Large vessel occlusion shown on CT angiography I _ I

1= yes 2 = no 9= not known

THROMBECTOMY centre/emergency services contacted for opinion on thrombectomy I _ I

1= yes 2 = no 9= not known

Level of consciousness on arrival I _ I

1= fully awake (RLS 1) 2= drowsy but responding to stimulus (RLS 2-3) 3= unconscious (RLS 4-8)

9= not known

 **Assessment of swallowing function performed** I _ I

1= yes (documented in medical records) 2= no/not known (not performed or documentation missing from medical records) 3= not examined owing to patient's reduced consciousness

----- ADMISSION -----

Patient received hospital care for this stroke episode I _ I

1= yes 2= no

 **First admitted to** I _ I

1 = ward/unit other than the options given below (2, 3, 4 or 6)

2= stroke unit 3= admissions/obs. ward

4= Intensive care unit 5= other (please specify)

6= Department of Neurosurgery 9= not known

First hospital to which the patient was admitted

Enter Riksstroke Hospital Code 888= for overseas 999= hospital code not known I _ I _ I _ I

Arrival at stroke unit for initial treatment

(refers to the stroke unit where the patient initially received treatment for this stroke episode)

Date and time I _ I _ II _ I _ II _ I _ I (YYMMDD) I _ I _ .I _ I _ I (hrs.min)

Enter Riksstroke Hospital Code 888= for overseas 999= hospital code not known I _ I _ I _ I

----- NIHSS using Riksstroke's NIHSS form -----

NIHSS Score Scale


9= not known

Total score 99 = not known

Enter the NIHSS score for each variable. The final score is automatically filled in online.

A total score of 99 is automatically filled in when a variable is not known. The total score shown in brackets (online) is the NIHSS score exclusive of 'not known' and not included in the statistical calculation or target level

If item 1a Level of consciousness = 3, i.e. coma, the total score is automatically filled in online. Items 2 and 3 can be changed manually; the other items are locked.

 **NIHSS at arrival/admission** (if the patient is treated/moved to a thrombectomy centre, enter the points before the thrombectomy as points on arrival)

NIHSS 24 hours after thrombolysis and/or thrombectomy

		Points on arrival	24 hours after thrombolysis and/or thrombectomy
1a	Level of consciousness 0–3		
1b	Spatial awareness 0–2		
1c	Comprehension 0–2		
2	Eye motor function/eye position 0–2		
3	Field of vision 0–3		
4	Facial paralysis 0–3		
5a	Paralysis in arm Right 0–4		
5b	Paralysis in arm Left 0–4		
6a	Paralysis in leg Right 0–4		
6b	Paralysis in leg Left 0–4		
7	Ataxia 0–2		
8	Sensibility (pain) 0–2		
9	Language/communication 0–3		
10	Dysarthria 0–2		
11	Tactile extinction /neglect 0–2		
	Total		

-----THROMBOLYSIS-----

 **Thrombolysis performed or started for acute stroke**

(If treatment was started but interrupted/not completed, choose option 1= yes)

- 1= yes, treated with Actilyse (Alteplase) 2= no
- 3= yes, part of thrombolysis study or treated with non-approved drug such as Tenecteplase (Metalyse) 9= not known

If no, reason why thrombolysis not provided (Multiple response options permitted)

- = previously spontaneous (i.e. non-traumatic) cerebral haemorrhage
- = elements of bleeding in fresh cerebral infarction
- = symptoms too mild
- = symptoms too severe
- = Not possible to provide treatment within 4.5 hours from onset (when onset time known)
- = wake up stroke
- = other contraindications for thrombolysis (see guidance for contraindications)
- = other reason (e.g. unknown onset time)
- = incorrectly omitted alarm routine to save the brain
- = necessary expertise not available (e.g. doctor with thrombolysis experience, assessment of scans)
- = not known

Enter Riksstroke hospital code where thrombolysis was performed

888= code for overseas 999= hospital code not known

 **Date and time when thrombolysis treatment initiated**

(YYMMDD) (hrs.min)

Dabigatran (Pradaxa) reversal implemented with idarucizumab (Praxbind) to enable thrombolysis (R&D)

1= yes 2= no 9= not known

-----THROMBECTOMY-----

 **Thrombectomy- completed or started for acute stroke**

(If treatment was started but interrupted/not completed, choose option 1= yes)

1= yes 2= no 9= not known

Enter Riksstroke hospital code where thrombectomy was performed

- 110= Akademiska 146= Örebro
- 116= Sahlgrenska 147= Linköping
- 118= NUS Umeå 329= Sundsvall
- 141= SUS Lund 888= Code for overseas
- 143= Karolinska Solna 999= Hospital code not known

----- THROMBECTOMY - CENTRE -----

The following questions only apply to patients treated at a Thrombectomy Centre

Ambulance transport was triaged directly to the Thrombectomy Centre

1= yes 2= no 9= not known

Transferred to Thrombectomy Centre from another hospital

1= yes, for possible thrombectomy 2= no 3= yes, for reason other than thrombectomy 9= not known

Arrival at hospital with Thrombectomy Centre

Date of onset (YYMMDD) |_|_|||_|_|||_|_|

Time of arrival (HRS.MIN) |_|_|.|. |_|_|

Time of arterial puncture at Thrombectomy Centre. Enter the day and time for initial arterial puncture

Day (YYMMDD) |_|_|||_|_|||_|_|

Time (HRS.MIN) |_|_|.|. |_|_|

Enter the Riksstroke hospital code for the patient's local hospital according to the Swedish Population Register

888= code for overseas 999= hospital code not known

|_|_|_|_|

-----CEREBRAL HAEMORRHAGE FOLLOWING THROMBOLYSIS/THROMBECTOMY -----

Cerebral haemorrhage with clinical deterioration within 36 hours of thrombolysis/thrombectomy

(Respond using 1= yes only if the patient has clinically deteriorated by NIHSS score 4 or above regardless of the size of haemorrhage on CT/MRI scan)

1= yes 2= no 9= not known

----- HEMICRANIECTOMY -----

Hemicraniectomy performed for expansive ischaemic stroke (cerebral infarction)

1= yes 2= no 3= yes, included in hemicraniectomy study 9= not known

Enter Riksstroke hospital code where hemicraniectomy was performed

888= code for overseas 999= hospital code not known

Date for hemicraniectomy (YYMMDD)

----- CEREBRAL HAEMORRHAGE -----

Site of cerebral haemorrhage (I61)

- | | |
|---|--------------------------------|
| 1= cerebrum, central/deep | 2= cerebrum, lobar/superficial |
| 3= cerebrum, unspecified if deep or superficial | 4= brainstem |
| 5= cerebellum | 6= several different sites |
| 7= Other..... | 9= not known |

Haemorrhage with ventricular rupture

1= yes 2= no 9= not known

**If treatment with oral anticoagulants (Warfarin/NOAK) at onset
in cerebral haemorrhage (I61), reversal implemented**

1= yes 2= no 9= not known

Medicine on reversal of cerebral haemorrhage (I61)

1= yes 2= no 9= not known

Prothrombin complex concentrate, PCC (Ocplex, Confindex)

Vitamin-K (Konakion, antidote to Waran)

Idarucizumab (Praxbind, antidote to Pradaxa)

**Drug included in a reversal study or treatment
with a non-approved drug (e.g. Andexanet)**

Neurosurgical operation performed for stroke

1= yes 2= no 9= not known

**Enter Riksstroke hospital code for the hospital where neurosurgery for cerebral haemorrhage was
performed**

888= code for overseas 999= hospital code not known

Action date (YYMMDD)

-----ADL AND ACCOMMODATION BEFORE ONSET OF STROKE -----

The following applies to all choices of response related to ADL/Accommodation: 9= not known

Accommodation

|__|

1= own accommodation without home help (home help does **not** mean home nursing or advanced home nursing)

2= own accommodation with home help (home help does **not** mean home nursing or advanced home nursing)

3= arranged accommodation (e.g. service flat with full board, temporary accommodation, nursing home or equivalent)

5= other

Those living alone

|__|

1= patient lives entirely alone

2= Patient shares the household with spouse/cohabitee or other individual e.g. sibling, child or parents

Requires assistance (includes assistance with personal ADL and/or household ADL)

|__|

1= patient can cope on his/her own without assistance

2= patient requires assistance from another person

Mobility

|__|

1= patient could move around without supervision both indoors and outdoors (use of walking-aid permitted)

2= patient was able to move around by himself/herself indoors but not outdoors (use of walking-aid permitted)

3= patient was assisted by another person when moving around, or was bedridden

Toilet visits

|__|

1= patient managed toilet visits without any help

2= patient was unable to get to the bathroom or go to the toilet without help, used a bedpan or incontinence pads or required assistance when wiping him/herself or getting dressed

Clothes

|__|

1= patient was able to get dressed without help, including outdoor clothes, socks and shoes, or only needed help when tying shoelaces

2= patient needed someone to fetch his/her clothes or needed help with dressing/undressing, or remained undressed

----- **RISK FACTORS** -----

Response options: 1= yes 2= no 9= not known

Previous stroke

TIA / Previous Amaurosis fugax

Atrial fibrillation, previously diagnosed (including intermittent fibrillation or flutter)

Atrial fibrillation - detected upon arrival at hospital or during hospitalisation
(including intermittent fibrillation or flutter)

Diabetes, previously diagnosed or recently identified

Treated for hypertension at onset of stroke

Smoking (one cigarette or more a day or non-smoker for the past 3 months)

----- **INFORMATION** -----

Smoker informed at onset of need to quit smoking

1= yes (documented in medical records) 2= no/ not known (not performed or documentation missing from medical records) 3= not relevant because of patient's condition

Information given regarding driving

1= yes 2= no/ not known (not performed or documentation missing from medical records) 3= not relevant/no driving licence or because of patient's condition

----- **EXAMINATIONS DURING PERIOD OF CARE** -----

MRI brain scan performed

1= yes 2= yes 3= no, ordered post discharge 9= not known

If yes and cerebral haemorrhage diagnosed (I63), MRI brain scan showed:

1= showed new cerebral infarction 2= showed no new cerebral infarction

9= examination result uncertain or not known

CT angiography performed but not in conjunction with the first CT

1= yes 2= no 3= no, ordered post discharge 9= not known

Carotid ultrasound performed

1= yes 2= no 3= no, ordered post discharge 9= not known

Long-term ECG performed, minimum 24 hours (telemetry, Holter or equivalent)

1= yes 2= no 3= no, ordered post discharge 9= not known

-----RISK ASSESSMENTS CARE-----

Risk assessment for malnutrition carried out within 24 hours of arrival at the ward |__|

1= yes 2= no

If yes, risk assessment carried out

Does the risk assessment indicate a risk of malnutrition? |__|

1= yes 2= no

If yes, there is a risk

Have preventive measures been taken? |__|

1= yes 2= no

Risk assessment for oral health carried out within 24 hours of arrival at the ward |__|

1= yes 2= no

If yes, risk assessment carried out

Does the risk assessment indicate a risk of poor oral health? |__|

1= yes 2= no

If yes, there is a risk

Have preventive measures been taken? |__|

1= yes 2= no

During inpatient care, the patient was assessed by a speech therapist or other dysphagia specialist with regard to swallowing function |__|

1= yes 2= no, no need
3= no; patient has need but no speech therapist or other dysphagia specialist available
9= not known or patient declines evaluation

During inpatient care, the patient was assessed by a speech therapist regarding speech function |__|

1= yes 2= no; no need 3= no; patient has need but no speech therapist available
4= no, but ordered for after discharge 5= no 9= not known or patient declines evaluation

An occupational therapist assessed the patient after arrival in the ward/department |__|

Respond using 1= yes, ≤ 24 hrs 2= yes, > 24 hrs but ≤ 48 hrs 3= yes, > 48 hrs
5= no 9= not known

Patient has received occupational therapy during inpatient care |__|

1= yes
2= no, needed but not received during hospital care (due to patient isolation, patient unavailability, etc.)
3= no, needed but not of benefit (due to extreme cognitive impairment/dementia or aphasia)
4= no, not needed (due to absence of sensorimotor/cognitive impairments, need for treatment or patient in palliative care)
5= patient declined 9= not known

A physiotherapist evaluated the patient after arrival at the ward |__|

Respond using 1= yes, ≤ 24 hrs 2= yes, > 24 hrs but ≤ 48 hrs 3= yes, > 48 hrs
5= no 9= not known


Patient has received physiotherapy during the closed care period |__|

1= yes
2=no, has need of physiotherapist/physiotherapy but has received none at all during care period (e.g. due to isolation, patient unavailable)
3= no, has need of but has been unable to benefit from rehabilitation (e.g, due to extreme cognitive impairment/dementia or language difficulties)
4= no, not needed (due to absence of sensorimotor/cognitive impairments, need for treatment or patient in palliative care)
5= patient declined 9= not known

-----DISCHARGE FROM EMERGENCY CARE-----

Date of discharge (final date of discharge after acute phase)
YYMMDD

Enter Riksstroke hospital code for hospital responsible for discharge
888= code for abroad **999**= unknown hospital code

 **Ward during acute phase** (refers to entire care period including the first department and departments at other hospitals) Multiple response options permitted

= ward/department other than those specified in response option below

= Stroke unit = Neurosurgery department = Other

= Intensive care unit = Admissions/obs. ward = Not known

If treated outside stroke unit, enter total number of treatment days at stroke unit, intensive care or Department of Neurosurgery
(Admission date = day 1) **999**= unknown

Patient has been given a written rehabilitation plan
1= yes 2= no 3= no need, fully recovered 9= not known

DISCHARGED TO AFTER ACUTE CARE

1= own accommodation 2= arranged accommodation (e.g. service flat with full board, temporary accommodation, old people's home or nursing home)

4= other acute clinic (=enter Aftercare) 5= geriatric/rehab (=enter Aftercare)

6= deceased during treatment 7= other (e.g. patient who lives in another country)


9= not known

11= still hospitalised 12= other stroke unit for aftercare (=enter Aftercare)

13= medical centre with acute beds (=enter Aftercare)

Address and phone number for Discharged to; clear text for alternatives 1, 2, 4, 5, 7.....

Planned rehabilitation, multiple response options permitted

- I__I =  **Previously supported discharge from hospital to home** where a multidisciplinary stroke team both coordinates the discharge and carries out ongoing rehabilitation in the home environment
- I__I = **Early assisted discharge to home coordinated by a multidisciplinary stroke team but where the continued rehabilitation is carried out by individual caregivers from the municipality/primary care without the support of a multidisciplinary stroke team**
- I__I = **Outpatient rehabilitation** or equivalent (refers to team-based rehabilitation over a defined time period)
- I__I = **Policlinic rehabilitation** (refers to individual rehabilitation visits)
- I__I = **Training with speech therapist**
- I__I = **Rehabilitation at care accommodation** (e.g. special accommodation, serviced accommodation, short-term accommodation or nursing home)
- I__I = Only **self-training**
- I__I = **No rehabilitation necessary** according to team assessment
(Also applies to patients living in special accommodation without rehabilitation potential)
- I__I = **Patient declined** offer of rehabilitation
- I__I = Rehabilitation needed but **not available**
- I__I = Not known

----- **DISCHARGE FROM AFTERCARE** -----
(refers to inpatient care funded by the County Council)

Admission date

Discharge date

Patient has been given a written rehabilitation plan

1= yes 2= no 3= no need, fully recovered 9= not known

DISCHARGED TO from AFTERCARE

1= own accommodation 2= arranged accommodation (e.g. service flat with full board, temporary accommodation, old people's home or nursing home)

4= other acute clinic 6= deceased during treatment 7= other (e.g. patient who lives in another country)


9= not known 11= still hospitalised 13= medical centre with acute beds

Address and phone number of the place to which the patient is discharged please be specific as regards alternatives 1, 2, 4, 7

.....

----- **REHABILITATION FOLLOWING DISCHARGE FROM AFTERCARE** -----

Planned rehabilitation, multiple response options permitted

=  **Early assisted discharge from hospital to home** where a multidisciplinary stroke team both coordinates the discharge and provides continued rehabilitation in the home environment

= **Early assisted discharge to home coordinated by a multidisciplinary stroke team will coordinate the discharge but where the continued rehabilitation is carried out by individual caregivers from the municipality/primary care without the support of a multidisciplinary stroke team**

= **Outpatient rehabilitation** or equivalent (concerns team-based rehabilitation during a defined period)

= **Polyclinic rehabilitation** (concerns rehabilitation during individual visits)

= **Training with speech therapist**

= **Rehabilitation at care accommodation** (e.g. arranged accommodation, sheltered accommodation, short-term accommodation or nursing home)

= Only **self-training**

= **No rehabilitation necessary** according to team assessment (also applies to patients living in arranged accommodation without rehabilitation potential)

= **The patient declines** the rehabilitation offered

= Rehabilitation required, but **no rehabilitation is** available

= Not known