

RIKSSTROKE - ACUTE PHASE FOR REGISTRATION OF STROKE

Personal ID number -

Name Gender 1= male 2= female

Reporting hospital Ward/Department

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

Date deceased (YYMMDD)
(relates to death in hospital)

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 result of thrombolysis or thrombectomy for stroke with **complete symptom regression** within 24 hours of onset)

The patient woke up with symptoms
1= yes 2= no 9= not known

Date of onset (YYMMDD)

Time of onset (HRS.MIN)

If the patient woke up with symptoms, specify the time the patient was most recently asymptomatic.
If the admitted patient had suffered a stroke and the time of onset is unknown, specify the time the patient was most recently asymptomatic.
If only a full hour can be determined, specify the minutes **firstly** as the nearest **full or half hour**; then specify **secondly** the minutes as “99” and specify the closest possible *Time interval* below.
If the time of onset is not known, enter “99.99” and specify the closest possible *Time interval* below.

Time interval from onset to arrival at hospital

(Answer if the time of onset is unknown [99.99] or if only the hour can be determined [ex 10.99])

- 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 at the time of stroke
1= yes 2= no

The 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 -----

(refers to the hospital where the patient had first contact for this stroke episode)

Date and time

|_|_|_|_|_|_|_|_|_|_|_|_|_|_| (YYMMDD) |_|_|_|_|_|_|_|_|_|_|_|_|_|_| (hrs.min)

Enter Riksstroke hospital code 888= foreign code 999= unknown hospital code |_|_|_|_|_|_|_|_|_|_|_|_|_|_|

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

Computed tomography brain |_|_|

1= yes 2= no 9= not known

CT - angiography performed in conjunction with the first CT |_|_|

1= yes 2= no 9= not known

CT - perfusion performed in conjunction with the first CT |_|_|

1= yes 2= no 9= not known

THROMBECTOMY centre/on-call contacted for opinion on thrombectomy |_|_|

1= yes 2= no 9= not known

Level of consciousness on arrival |_|_|

1= fully awake (RLS 1) 2= lethargic but responsive (RLS 2-3) 3= unconscious (RLS 4-8) 9= not known

 **Assessment of swallowing function performed** |_|_|

1= yes (documented in medical records) 2= no/not known(not performed or documentation missing in medical records)

3= not examined due to patient's reduced consciousness

----- ADMISSION -----

The patient was admitted to treatment for this stroke episode |_|_|

1= yes 2= no

 **First Admitted to** |_|_|

1 = ward/department other than those specified in choice of response 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= foreign code 999= unknown hospital code |_|_|_|_|_|_|_|_|_|_|_|_|_|_|

Arrival at first stroke unit

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

Date and time

|_|_|_|_|_|_|_|_|_|_|_|_|_|_| (YYMMDD) |_|_|_|_|_|_|_|_|_|_|_|_|_|_| (hrs.min)

Enter Riksstroke hospital code 888= foreign code 999= unknown hospital code |_|_|_|_|_|_|_|_|_|_|_|_|_|_|

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


Points according to NIHSS

9= not known

Enter the NIHSS points for each variable. The total is entered automatically via the Internet.

If item 1a level of consciousness =3 i.e. coma, the total will be entered automatically via the Internet.

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 | LOC Questions 0–2 | | |
| 1c | LOC Commands 0–2 | | |
| 2 | Best Gaze 0–2 | | |
| 3 | Visual 0–3 | | |
| 4 | Facial Palsy 0–3 | | |
| 5a | Motor arm Right 0–4 | | |
| 5b | Motor arm Left 0–4 | | |
| 6a | Motor leg Right 0–4 | | |
| 6b | Motor leg Left 0–4 | | |
| 7 | Limb Ataxia 0–2 | | |
| 8 | Sensory 0–2 | | |
| 9 | Best Language 0–3 | | |
| 10 | Dysarthria 0–2 | | |
| 11 | Extinction and Inattention 0–2 | | |
| | Total | | |

----- THROMBOLYSIS -----

 **Thrombolysis given or started for acute stroke** |_|_|

(If treatment was started but interrupted/not completed, specify response 1=yes)

- 1= yes, treatment with actilyse (Alteplase) 2= no
3= yes, part of a study on thrombolysis or treatment using non-approved
drug e.g. tenecteplase (Metalyse) 9= not known

If no, reason why thrombolysis where 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 abroad 999= unknown hospital code

 **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 initiated for acute stroke** |_|_|

(If treatment was started but interrupted/not completed, specify response 1=yes)

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

Enter Riksstroke hospital code where thrombectomy was performed |_|_|_|_|

- | | |
|------------------|----------------------------|
| 110= Akademiska | 143= Karolinska Solna |
| 116= Sahlgrenska | 147= Linköping |
| 118= NUS Umeå | 888= Foreign code |
| 141= SUS Lund | 999= Unknown hospital code |

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

Questions in this section to be answered only for patients treated at a thrombectomy centre

Ambulance passed thrombolysis hospital (where thrombolysis could have been given at that time) on the way 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

Completed or initiated thrombectomy for acute stroke carried out at

1= anterior circulation 2= posterior circulation (basilar artery) 9= not known

Arrival at the hospital with thrombectomy centre

Arrival date (YYMMDD)

Time of arrival (HRS.MIN)

Start of thrombectomy treatment

Day (YYMMDD)

Start time (HRS.MIN)

Thrombectomy aborted/procedure not completed

1= yes 2= no 9= not known

Enter Riksstroke hospital code for the patient's home in hospital according to registry office records

888= code for abroad 999= unknown hospital code

----- 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 4 points or more according to NIHSS, regardless of how large a haemorrhage the CT/MRI shows)

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 abroad 999= unknown hospital code

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 therapy implemented

1= yes 2= no 9= not known

What reversal agent was given for 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 reversal study following treatment with 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 carried out

888= code for abroad 999= unknown hospital code

Operation 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 unaided 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 -----

Respond using: 1= yes 2= no 9= not known

Previous stroke

Previous TIA /Amaurosis fugax

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

Atrial fibrillation, newly detected upon arrival at hospital or during care
(including intermittent fibrillation or flutter)

Diabetes, previously diagnosed or recently identified

Treated for hypertension at onset of stroke

Smoker (one cigarette or more/day, or quit during the last three months)

----- INFORMATION -----

Smoker informed at onset of need to quit smoking

1= yes 2= no, or the patient has declined information 3= not relevant due to the patient's condition
9= not known

Information provided regarding driving

1= yes 2= no 3= not relevant/lacks driving licence or due to the patient's condition 9= unknown

----- EXAMINATIONS DURING TREATMENT -----

MRI brain scan performed

1= yes 2= no 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

MRI angiography performed

1= yes 2= no 3= no, ordered post discharge 9= 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 minimum 24 hours (telemetry, Holter or equivalent) **performed**

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

----- DRUG TREATMENT -----

Respond using 1= yes 2= no 3= no, intervention planned within 2 w post discharge
 4= yes, part of drug study 9= unknown

| | At onset | Upon discharge |
|---|-------------|-------------------|
|  Antihypertensive drugs (applies to all groups, independent of indication) | _ | _ |
|  Statins (atorvastatin/Lipitor, pravastatin, rosuvastatin/Crestor, simvastatin) | _ | _ |
|  Platelet inhibitors: | | |
| ASA (e.g. Trombyl) | _ | _ |
| Clopidogrel (e.g. Plavix) | _ | _ |
| Dipyridamole | _ | _ |
| Platelet inhibitors other than the above (e.g. Brilique, Efient, Pletal, Possia) | _ | _ |
|  Oral anticoagulants: | | |
| Warfarin (Waran) | _ | _ |
| If warfarin at onset, enter PK (INR) value 9.9=not known | _ , _ | |
| Apixaban (Eliquis) | _ | _ |
| Dabigatran etexilate (Pradaxa) | _ | _ |
| Rivaroxaban (Xarelto) | _ | _ |
| Edoxaban (Lixiana) | _ | _ |

Date for introduction or reintroduction of oral anticoagulants during treatment (YYMMDD)

|_|_|_| || |_|_| || |_|_|

If treatment was ongoing at onset and interruption shorter than 36 hrs during treatment, state day of arrival at hospital.

Main reason for non-intervention with oral anticoagulants during treatment in the event of atrial fibrillation and heart infarction (I63) |_|

- 1= intervention planned after discharge 2= contraindications (in accordance with FASS)
 3= interactions with other drugs/naturopathy (in accordance with FASS)
 4= caution (in accordance with FASS) 5= tendency to fall 6= dementia
 7= patient declines treatment 8= other reason 9= not known

----- FOLLOW-UP -----

Follow-up appointment on the basis of this stroke episode has been made with a nurse or doctor
 (You can choose more than one response)

- |_|_| = yes, at a special stroke unit (at or outside the hospital)
 |_|_| = yes, at another hospital admissions ward/department |_|_| = yes, at a health centre/equivalent
 |_|_| = yes, at arranged accommodation |_|_| = yes, at the outpatient rehabilitation centre
 |_|_| = no |_|_| = not known

----- REHABILITATION DURING INPATIENT CARE -----

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 assessment

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 assessment

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, has need of occupational therapy but has not received any 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, has not had need (e.g. in absence of sensorimotor/cognitive impairments and has not received treatment, and patient in palliative care)
5= patient has declined 9= not known

A physiotherapist evaluated 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 physiotherapy during inpatient care


1= yes
2=no, has need of physiotherapist/physiotherapy but has not received any 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, has not had need (e.g. in absence of sensorimotor/cognitive impairments and has not received treatment, and patient in palliative care)
5= patient has 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

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

I__I = Stroke unit

I__I = Neurosurgery department

I__I = Other

I__I = Intensive care unit

I__I = Admissions/obs. ward

I__I = Not known

If treated outside stroke unit, enter total number of treatment days at stroke unit, intensive care or Department of Neurosurgery

I__I__I__I

(Admission date = day 1) 999= unknown

Patient has been given a written rehabilitation plan

I__I

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

DISCHARGED TO AFTER ACUTE CARE

I__I__I

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.....

----- REHABILITATION FOLLOWING DISCHARGE FROM ACUTE CARE -----

Planned rehabilitation, multiple response options permitted

I__I =  **Early 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 supported discharge to home** where a multidisciplinary stroke team will coordinate the discharge but where ongoing rehabilitation is carried out without a multidisciplinary stroke team by individual caregivers from the municipality/primary health care

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

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

I__I = **Training with speech therapist**

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

I__I = Only **self-training**

I__I = **No need for rehabilitation** according to team assessment
(Also applies to patients living in special accommodation without rehabilitation potential)

I__I = **The patient declines** the rehabilitation offered

I__I = Rehabilitation required, but **rehabilitation is not available**

I__I = not known

----- **DISCHARGE TO AFTERCARE** -----
(applies 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 supported discharge from hospital to home where a multidisciplinary stroke team both coordinates the discharge and carries out ongoing rehabilitation in the home environment

Early supported discharge to home where a multidisciplinary stroke team will coordinate the discharge but where ongoing rehabilitation is carried out without a multidisciplinary stroke team by individual caregivers from the municipality/primary health care

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 need for rehabilitation according to team assessment (also applies to patients living in arranged accommodation without rehabilitation potential)

The patient declines the rehabilitation offered

Rehabilitation required, but rehabilitation is not available

Not known