

Version **18.a** To be used for all acute stroke registrations from **1 January 2018 and onwards**.

To register a TIA diagnosis without thrombolysis or thrombectomy, please use the separate TIA form.

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 in hospital)

Stroke diagnosis

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)

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, record “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

If the patient woke up with symptoms, specify the time interval from when the patient was most recently asymptomatic.

If the admitted patient had suffered a stroke and the time of onset is unknown (the last time without symptoms), specify the closest possible time interval from onset to identification of this stroke episode.

Patient arrived by ambulance I__I
1= yes 2= no 9= not known

The patient was already admitted at the hospital at the time of the stroke episode I__I
1= yes 2= no

Thrombosis/thromectomy alarm "Save the brain/stroke alarm" I__I
1= yes 2= no 9= not known

THROMBECTOMY centre/on-call contacted for opinion on thrombectomy I__I
1= yes 2= no 9= not known

----- **ARRIVED AND ADMITTED** -----

Arrival at hospital for initial treatment
(refers to the hospital where the patient initially received treatment for this stroke episode)

Arrival date at hospital (YYMMDD) I__I__II__I__II__I__I

Time of arrival at hospital (hrs.min) I__I__I.I__I__I

Specify Riksstroke hospital code 888= code for overseas 999= unknown hospital code I__I__I__I

The patient was admitted for treatment for this stroke episode I__I
1= yes 2= no

Initially admitted at I__I

- 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

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

Date of arrival at stroke unit (YYMMDD) I__I__II__I__II__I__I

Time of arrival att stroke unit (HRS.MIN) I__I__I.I__I__I

Specify Riksstroke hospital code 888= code for overseas 999= unknown hospital code I__I__I__I

----- ADL/Accommodation **BEFORE ONSET** of stroke -----

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

Accommodation

I__I

- 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

I__I

- 1= patient lives entirely on his/her own
- 2= patient shares his/her household with spouse/partner or other person e.g. sibling, child or parents

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

I__I

- 1= patient can cope on his/her own without assistance
- 2= patient requires assistance from another person

Mobility

I__I

- 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

I__I

- 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

I__I

- 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

----- ACUTE CARE/DIAGNOSIS -----

----- RISK FACTORS -----

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

Previous stroke I__I
Previous TIA / Amaurosis fugax? (Does not apply to G45.4 transitory global amnesia) I__I
Atrial fibrillation, previously diagnosed I__I
(including intermittent fibrillation or flutter)
Atrial fibrillation, recently identified on arrival at hospital or during treatment time I__I
(including intermittent fibrillation or flutter)
Diabetes, previously diagnosed or recently identified I__I
Treated for hypertension at onset of stroke I__I
Smoker (1 cigarette or more/day, or quit during the last three months) I__I

----- STROKE LEVEL OF SEVERITY -----

Level of consciousness on arrival at hospital I__I
1= fully awake (RLS 1) 2= drowsy but responding to stimulus (RLS 2-3) 3= unconscious (RLS 4-8) 9= not known
NIHSS (National Institute of Health Stroke Scale) at admission (within 24 hrs) using
Riksstroke NIHSS form (no modified or abbreviated scales) I__I__I
Specify total points (if 24 points or more, please put 24 p) 99= not known/not examined

----- EXAMINATION OF BRAIN AND VESSELS -----

CT brain scan during treatment 1= yes 2= no 9= not known I__I
MRI brain scan during treatment 1= yes 2= no 9= not known I__I
If yes and diagnosis is brain infarction (I63), MRI brain scan during treatment: I__I
1= showed new cerebral infarction 2= showed no new cerebral infarction 9= examination result uncertain or not known

CT angiography performed (does not refer to CT perfusion) I__I__I
1a= yes, directly related to the initial CT scan 1b= yes, later during treatment
2= no 3=examination within 28 days before onset of stroke 9= not known
Examination date (YY-MM-DD) I__I__II__I__II__I__I

MR angiography performed I__I
1= yes 2= no 3= examination within 28 days before onset of stroke
4= planned after discharge 9= not known
Examination date (YY-MM-DD) I__I__II__I__II__I__I

CT or MR angiography performed of vessels affected I__I

(always ask a doctor if uncertain about which vessels)

1= carotid vessels 2= intracranial vessels 3= both carotid and intracranial vessels 9= not known

Carotid ultrasound performed I__I

1= yes 2= no 3= examination within 28 days before onset of stroke

4= planned for after discharge 9= not known

Examination date (YY-MM-DD) I__I__II__I__II__I__I

----- **SWALLOWING FUNCTION/SPEECH EXAMINATION** -----

Swallowing function tested I__I

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

Evaluated by a speech therapist or another dysphagia specialist for swallowing function during treatment I__I

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

Evaluated by speech therapist for difficulties with speech during treatment I__I

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

----- **HEART EXAMINATION** -----

Long term ECG at least 24 hrs (telemetry, Holter or equivalent) performed during period of treatment I__I

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

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

Smoker informed at onset of need to quit smoking I__I

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

9= not known

Information provided regarding driving I__I

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

----- PHARMACEUTICAL TREATMENT -----

Respond using 1= yes 2= no 3= no, planned intervention within 2 weeks after discharge 9= not known

| | At onset | At discharge* |
|--|-------------|------------------|
| Antihypertensive agents (applies to all groups, independent of indication) | I__I | I__I |
| Statins (e.g. Atorvastatin, Crestor, Lipitor, Pravastatin, Simvastatin) | I__I | I__I |
| Platelet inhibitors: | | |
| ASA (e.g. Trombyl) | I__I | I__I |
| Clopidogrel (e.g. Plavix) | I__I | I__I |
| Dipyridamol (Persantin) | I__I | I__I |
| Platelet inhibitors other than the above (e.g. Brilique, Efient, Pletal, Possia) | I__I | I__I |
| Oral anticoagulant: | | |
| Warfarin (Waran) | I__I | I__I |
| If yes, treatment with warfarin at onset state PK (INR) value regardless of diagnosis 9.9=not known | I__I, I__I | |
| Apixaban (Eliquis) | I__I | I__I |
| Dabigatran (Pradaxa) | I__I | I__I |
| Rivaroxaban (Xarelto) | I__I | I__I |
| Edoxaban (Lixiana) | I__I | I__I |

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

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)** I__I

- 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

* Do NOT state medication at discharge if patient died during the acute phase.

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

Site of cerebral haemorrhage (I61)

I__I

- | | |
|---|--------------------------------|
| 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 I__I

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

1= yes 2= no 9= not known I__I

Medicine on reversal of cerebral haemorrhage (I61)

1= yes 2= no 9= not known

Prothrombin complex concentrate, PCC (Ocplex, Confindex) I__I

Vitamin-K (Konakion, antidote to Waran) I__I

Idarucizuman (Praxbind, antidote to Pradaxa) I__I

Neurosurgical operation performed for stroke

I__I

1= yes 2= no 9= not known

Operation date (YY-MM-DD) I__I__II__I__II__I__I

Specify Riksstroke hospital code for the hospital where neurosurgery for cerebral haemorrhage was carried out

888= code for overseas 999= unknown hospital code I__I__I__I

----- **THROMBOLYSIS** -----

Thrombolysis – given or started for emergency stroke I__I

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

- 1= yes, treatment using Actilyse (Alteplase®) 2= no
3= yes, part of a study on thrombolysis or treatment using unapproved medication
such as tenecteplase (Metalyse®) 9= not known

If no, reason why thrombolysis is not given (you can choose more than one response)

- I__I= cerebral haemorrhage
I__I= symptoms too mild
I__I= symptoms too serious
I__I= not possible to give treatment within 4.5 hrs from onset
I__I= other contraindication for thrombolysis
I__I= other reason (e.g. unknown onset time)
I__I= incorrectly omitted alarm routine to save the brain
I__I= necessary expertise not available (e.g. doctor with thrombolysis experience, assessment of scans)
I__I= not known

Please state date and time of start of thrombolytic therapy

I__I__II__I__II__I__I (YYMMDD) I__I__I.I__I__I (hrs.min)

Enter Riksstroke hospital code where thrombolysis was performed I__I__I__I

888= code for overseas 999= unknown hospital code

----- **THROMBECTOMY** -----

If admitted to a hospital with a thrombectomy centre, transferred there from another hospital* I__I

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

*This question can be ignored if the patient has NOT received therapy at a thrombectomy centre

Thrombectomy – carried out or started for emergency stroke I__I

(Does not apply to carotid endarterectomy for secondary prevention)
(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

If yes, thrombectomy carried out or started for emergency stroke in I__I

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

Please state date and time of start of thrombolytic therapy

I__I__II__I__II__I__I (YYMMDD) I__I__I.I__I__I (hrs.min)

Enter Riksstroke hospital code where thrombectomy was performed I__I__I__I

888= code for overseas 999= unknown hospital code

----- **EVALUATION OF THROMBOLYSIS/THROMBECTOMY** -----

Riksstroke NIHSS form (no modified or abbreviated scales)

Specify total points (if 24 points or more, please put 24 p)

88= thrombolysis or thrombectomy only started **99**= unknown/not examined

- At start of thrombolysis I _ I _ I
- At start of thrombectomy I _ I _ I
- One day after thrombolysis I _ I _ I
- One day after thrombectomy I _ I _ I

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

I _ I

(Respond using **1**= yes only if the patient has clinically deteriorated by 4 points or more on NIHSS, irrespective of how large a haemorrhage shown on the CT/MRI scan)

1= yes **2**= no **9**= not known

----- **HEMICRANIECTOMY** -----

Hemicraniectomy performed for expansive ischaemic stroke (cerebral infarction)

I _ I

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

Date for hemicraniectomy (YYMMDD)

I _ I _ II _ I _ II _ I _ I

Enter Riksstroke hospital code where hemicraniectomy was performed

I _ I _ I _ I

888= code for overseas **999**= unknown hospital code

----- **DISCHARGE after EMERGENCY TREATMENT** -----

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

I _ I _ II _ I _ II _ I _ I

Enter Riksstroke hospital code for hospital responsible for discharge

I _ I _ I _ I

888= code for overseas **999**= unknown hospital code

Treatment ward during acute phase, also relates to treatment wards in other hospitals during acute phase
(Entire period of treatment including initial ward. You can choose more than one response)

I _ I = ward/department other than those specified in choice of response below

I _ I = stroke unit

I _ I = admissions/obs. ward

I _ I = intensive care ward

I _ I = other

I _ I = Department of Neurosurgery

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

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 of the place to which the patient is discharged please be specific as regards

alternatives **1, 2, 4, 5, 7**

.....

----- REHABILITATION PLAN after discharge from ACUTE CARE -----

You can choose more than one response

I__I= **Early supported discharge with ongoing coordinated rehabilitation from stroke unit** with a multidisciplinary rehabilitation team (including available doctor) with specialist knowledge in stroke care

I__I= **Rehabilitation in the home** without coordination from stroke unit.

I__I = **Outpatient rehabilitation** or equivalent (refers to team-based rehabilitation for a defined period of time)

I__I = **Polyclinical rehabilitation** (refers to rehabilitation with individual visits)

I__I= **Planned speech therapy**

I__I = **Care accommodation with rehabilitation** (e.g. arranged accommodation, service flat with full board, temporary 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 arranged accommodation without rehabilitation potential)

I__I = **patient does not want** the rehabilitation offered

I__I = rehabilitation is needed **but not available**

I__I = not known

----- **AFTERCARE** refers to institutional care funded by the County Council-----

Admission date

Discharge date

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 PLAN AFTER DISCHARGE FROM AFTERCARE** -----

You can choose more than one response

I__I= Early supported discharge with ongoing coordinated rehabilitation from stroke unit with a multidisciplinary rehabilitation team (including available doctor) with specialist knowledge in stroke care

I__I= Rehabilitation in the home without coordination from stroke unit.

I__I = Outpatient rehabilitation or equivalent (refers to team-based rehabilitation for a defined period of time)

I__I = Polyclinical rehabilitation (refers to rehabilitation with individual visits)

I__I= Planned speech therapy

I__I = Care accommodation with rehabilitation (e.g. arranged accommodation, service flat with full board, temporary 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 arranged accommodation without rehabilitation potential)

I__I = patient does not want the rehabilitation offered

I__I = rehabilitation is needed but not available

I__I = 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)

I__I =yes, at a special stroke unit (at or outside the hospital)

I__I = yes, at another hospital admissions ward/department **I__I = yes, at a health entre/equivalent**

I__I = yes, at arranged accommodation **I__I = yes, at the outpatient rehabilitation centre**

I__I = no **I__I = not known**

----- **REHABILITATION IN CLOSED CARE** -----

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

I__I

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 the closed care period

I__I

The answer should specify the total time on average spent in occupational therapy per day, during that portion of time when treatment for the patient was considered necessary (applies to 7 days of the week).

1= yes ≥ 30 min **2=** yes < 30 min
3= no, needed it but did not receive any occupational therapy during treatment (e.g. because of isolation, patient not reached)
4= no, needed it but could not take in rehabilitation (e.g, due to extreme cognitive impairment/dementia or language difficulties)
5= no, has not needed it (e.g. in absence of sensorimotor/cognitive impairments and not received treatment, and patient in palliative care)
6= patient has refused
9= not known

Date for start of treatment (YYMMDD)
(not including assessment)

I__I__II__I__II__I__I

A physiotherapist evaluated the patient after arrival in the ward/department

I__I

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

I__I

The answer should specify the total time on average spent in physiotherapy per day, during that portion of time that is was considered necessary for the patient (applies to 7 days of the week).

1= yes ≥ 30 min **2=** yes < 30 min
3= no, needed it but did not receive any physiotherapy during treatment (e.g. because of isolation, patient not reached)
4= no, needed it but could not take in rehabilitation (e.g, due to extreme cognitive impairment/dementia or language difficulties)
5= no, has not needed it (e.g. in absence of sensorimotor/cognitive impairments and not received treatment, and patient in palliative care)
6= patient has refused
9= not known

Date for start of treatment (YYMMDD)
(Not including assessment)

I__I__II__I__II__I__I

Riksstroke hospital codes

| <i>RS hospital codes for 2018</i> | | | |
|-----------------------------------|-----|---------------------------------------|-----|
| Alingsås | 411 | Motala | 434 |
| Arvika | 412 | Mälarsjukhuset (Eskilstuna) | 212 |
| Avesta | 413 | Mölndal | 223 |
| Bollnäs | 414 | Norrköping(Vrinnevi) | 225 |
| Borås | 210 | Norrtälje | 435 |
| Danderyd | 211 | Nyköping | 436 |
| Enköping | 415 | NÄL (Norra Älvsborgs sjukhus) | 324 |
| Falun | 213 | Oskarshamn | 457 |
| Gällivare | 418 | Piteå | 484 |
| Gävle | 438 | Sahlgrenska | 116 |
| Halmstad | 215 | Skellefteå | 440 |
| Helsingborg | 216 | Sollefteå | 441 |
| Hudiksvall | 460 | S:t Görän (Capio S:t Görän) | 228 |
| Hässleholm | 455 | Sunderbyn | 222 |
| Höglandssjukhuset- Eksjö | 454 | Sundsvall | 329 |
| Jönköping - Ryhov sjukhuset | 273 | Södertälje | 445 |
| Kalix | 420 | Södersjukhuset | 230 |
| Kalmar | 218 | Torsby | 446 |
| Karlshamn | 421 | Trelleborg | 447 |
| Karlskoga | 475 | Umeå | 118 |
| Karlskrona | 219 | Uppsala, Akademiska | 110 |
| Karlstad | 342 | Varberg | 449 |
| Karolinska-Solna | 143 | Visby | 232 |
| Karolinska-Huddinge | 145 | Värnamo | 450 |
| Kiruna | 423 | Västervik | 451 |
| Kristianstad | 221 | Västerås | 333 |
| Kullbergsgka (Katrineholm) | 422 | Växjö | 234 |
| Kungälv | 473 | Ystad | 352 |
| Skaraborgs sjukhus (SkaS) | 327 | Ängelholm | 456 |
| Köping | 326 | Örebro | 146 |
| Landskrona | 427 | Örnsköldsvik | 453 |
| Lidköping | 461 | Östersund | 236 |
| Lindesberg | 429 | Östra sjukhuset | 235 |
| Linköping | 147 | Hospital with no RS code = Overseas | 888 |
| Ljungby | 430 | Hospital with unknown Riksstroke code | 999 |
| Lund (SUS Lund) | 141 | | |
| Lycksele | 432 | | |
| Malmö (SUS Malmö) | 115 | | |
| Mora | 433 | | |