

Version 19.b To be used for all acute stroke registrations from 1 January 2019 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)
(refers to death during the period of treatment)

Stroke diagnosis

I 61= Cerebral haemorrhage I / G

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 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 **in the first instance** the minutes as the nearest **full or half hour**; **in the second instance**, specify the minutes as “99” and then 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 2a= 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 most recent time without symptoms is unknown), specify the closest possible time interval from the most recent time without symptoms to identification of this stroke episode.

The patient was already admitted to hospital/emergency department at time of the stroke episode

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 first hospital the patient was taken to for this stroke episode)

Arrival date at hospital (YYMMDD)

Time of arrival at hospital (HRS/MIN)

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

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

CT brain scan
1= yes 2= no 9= not known

CT angiography performed in conjunction with first CT scan
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 at hospital
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) on admission to first hospital using Riksstroke NIHSS form
Specify total points (if 24 points or more, please put 24 p) 99= not known/not examined
(no modified or abbreviated scales)

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 for treatment for this stroke episode
1= yes 2= no

Initially admitted at

1 = ward/department other than those specified in choice of responses 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

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

Arrival at first stroke unit

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

Date of arrival at stroke unit (YYMMDD)

Time of arrival at stroke unit (HRS.MIN)

Specify Riksstroke hospital code 888=international code 999=unknown hospital code

----- THROMBOLYSIS -----

Thrombolysis – given or started for emergency stroke

(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 has not been given (you can choose more than one response)

= cerebral haemorrhage

= symptoms too mild

= symptoms too serious

= not possible to give treatment within 4.5 hrs from onset (if onset time is known)

= other contraindications for thrombolysis

= other reason (e.g. unknown onset time, wake-up stroke)

= incorrectly omitted alarm routine to save the brain

= necessary expertise not available (e.g. doctor with thrombolysis experience, assessment of scans) = not known

Date and time of start of thrombolytic therapy

(YYMMDD) (hrs.min)

Enter Riksstroke hospital code where thrombolysis was performed

888= overseas code 999= unknown hospital code

----- THROMBECTOMY -----

Thrombectomy – performed or started 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= Overseas code
141= SUS Lund 999= Unknown hospital code

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

The questions in this section are to be answered only for patients treated at a thrombectomy centre.

The ambulance with the patient drove past a thrombolysis hospital (where thrombolysis could have been provided at that point in time) **on its way to the thrombectomy centre**

|__|

1= yes 2= no 9= not known

Transferred to a thrombectomy centre from another hospital

|__|

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

State Riksstroke hospital code for the patient's nearest hospital according to the national population register

888= overseas code 999= unknown hospital code

|__|__|__|

Thrombectomy for acute stroke performed or commenced in

|__|

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

Arrival at hospital with thrombectomy centre

Date of arrival (YYMMDD)

|__|__||__|__||__|__|

Time of arrival (HRS.MIN)

|__|__|.I__|__|

Commencement of thrombectomy therapy

Day (YYMMDD)

|__|__||__|__||__|__|

Time (HRS/MIN)

|__|__|.I__|__|

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

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

(Only state **1= yes** 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) |_|

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

Date for hemicraniectomy (YYMMDD) |_|_| || |_| || |_|_|

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

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

----- 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 and 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)

Idarucizuman (Praxbind, antidote to Pradaxa)

Medicine included in reversal study or treatment with non-approved medicine (e.g. Andexanet)

Neurosurgical operation performed for stroke
1= yes 2= no 9= not known

Operation date (YY-MM-DD)

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

888= overseas code 999= unknown hospital code

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

The following applies to all choices of response related to ADL and 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 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)

|__|

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 -----

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, recently identified on arrival at hospital or during treatment time

(including intermittent fibrillation or flutter)

Diabetes, previously diagnosed or recently identified

Treated for hypertension at onset of stroke

Smoker (1 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 patient has declined information 3= not relevant due to patient's condition

9= not known

Information provided regarding driving

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

----- EXAMINATIONS -----

MRI brain performed during period of treatment

1= yes 2= no 9= not known

If yes and diagnosis is cerebral infarction (I63), MRI brain showed:

1= new cerebral infarction 2= no new cerebral infarction 9= uncertain/unknown findings

MRI angiography performed during treatment period

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

Date of examination (YY-MM-DD)

CT angiography performed more than 24 hours after ARRIVAL or after first CT

(Does not refer to CT perfusion)

1= yes 2= no 9= unknown

Date of examination (YY-MM-DD)

Ultrasound carotid arteries performed during period of treatment

1= yes 2= no 3= no, planned for after discharge 9= unknown

Date of examination (YY-MM-DD)

Long term ECG, at least 24 hours (telemetry, Holter or the equivalent) performed during the period of care

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

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

Respond using 1= yes 2= no 3= no, planned intervention within 2 weeks after discharge
 4=yes, included in pharmaceutical study 9= not known

At onset	At discharge
---------------------	-------------------------

Antihypertensive agents

(applies to all groups, independent of indication)

_	_
---	---

Statins (atorvastatin/Lipitor, pravastatin, rosuvastatin/Crestor, simvastatin)|_|

_

Platelet inhibitors:

ASA (e.g. Trombyl)

_	_
---	---

Clopidogrel (e.g. Plavix)

_	_
---	---

Dipyridamol

_	_
---	---

Platelet inhibitors other than the above
 (e.g. Brilique, Efigent, Pletal, Possia)

_	_
---	---

Oral anticoagulants:

Warfarin (Waran)

_	_
---	---

If warfarin at onset, state PK (INR) value
 9.9=not known

_ , _

Apixaban (Eliquis)

_	_
---	---

Dabigatranetexilat (Pradaxa)

_	_
---	---

Rivaroxaban (Xarelto)

_	_
---	---

Edoxaban (Lixiana)

_	_
---	---

Date for introduction or reintroduction of oral anticoagulants during treatment period (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 period in the event of atrial fibrillation and heart infarction (I63)

|_|

1= intervention planned for 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

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 the period of institutional care

The answer should specify the total time on average spent in physiotherapy per day, during the part of the treatment period when it 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 declined

9= not known

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

----- **REHABILITATION AFTER DISCHARGE FROM EMERGENCY CARE** -----

The patient has been given a written rehabilitation plan

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

Planned rehabilitation; you can choose more than one response

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

= **Early supported discharge to the home** where a multidisciplinary stroke team coordinates the discharge but where continued rehabilitation is performed without a multidisciplinary stroke team of individual care providers from the municipality/primary care services.

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

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

= **Planned speech therapy**

= **Care accommodation with rehabilitation** (e.g. arranged accommodation, service flat with full board, temporary 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)

= **Patient does not want** the rehabilitation offered

= Rehabilitation is needed **but not available**

I__I = Not known

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

Date of discharge (Final date of discharge from acute phase) I__I__I||__I__I||__I__I
YYMMDD

Enter Riksstroke hospital code for hospital responsible for discharge I__I__I__I
888= overseas code 999= unknown hospital code

***Treatment ward during acute phase** (Refers to the entire period of treatment including initial ward and wards in other hospitals). 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 FROM AFTERCARE TO 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 AFTER DISCHARGE FROM AFTERCARE-----

The patient has been given a written rehabilitation plan

I__I

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

Planned rehabilitation; you can choose more than one response

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

I__I= **Early supported discharge to the home** where a multidisciplinary stroke team coordinates the discharge but where continued rehabilitation is performed without a multidisciplinary stroke team of individual care providers from the municipality/primary care services.

I__I = **Outpatient rehabilitation** or the 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

----- DISCHARGE AFTERCARE -----

(refers to institutional care funded by County Council)

Date of admission I__I__I__I__I__I__I__I__I__I

Date of discharge I__I__I__I__I__I__I__I__I__I

DISCHARGED FROM AFTERCARE TO 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 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

Riksstroke hospital codes

<i>RS hospital codes for 2019</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		