Version **14.a** To be used for all acute stroke registrations from **1 January 2014** onwards.

To register a TIA diagnosis without thrombolytic therapy please use separate TIA form.

# **RIKS-STROKE - ACUTE PHASE FOR REGISTRATION OF STROKE**

Personal ID number I_I_I_I_I_I_I_I_I_I_I_I_I_I
Gender 1= male 2= female II
Name
Address*
Telephone no.*
<b>Optional information*</b> (e.g. name and telephone number of next of kin or other)
* Address, telephone number and optional information are available in printed form only and should not be recorded electronically
Date of onset II_II_I_I_I_I
I 61 = cerebral haemorrhage I / G I_I_I_I.I_I I 63 = cerebral infarction I 64 = acute cerebrovascular illness UNS
<b>G 45.x</b> = thrombolytic therapy for stroke with <u>complete symptom regression</u> within 24 hours (optional) (The decimal <b>x</b> is used only for technical purposes for registration.)
SEQUENCE OF CARE
 Reporting hospital III Ward/department III
Completed by (name of person completing this form)
Date deceased IIIIIII (Complete only if patient died during treatment period)
Home municipality code at time of onset (Completed automatically in the reg.module)
Home county code at time of onset (Completed automatically in the reg.module)

# A Acute Management

Has the patient been admitted for treatment for this stroke episode?	1= yes 2= no
If no, please state main reason for non-admission	II
<ul> <li>1= mild symptoms / symptom regression</li> <li>2= onset of stroke several days prior to arrival</li> <li>3= elderly person with more than one illness, already in institutional care</li> <li>4= lack of space</li> <li>5= other reason     reason (optional)</li></ul>	

Note: Registration of non-admitted patients is optional. Please refer to the Guide.

Was the patient already admitted at the hospital at the time of this stroke episode? 1= yes 2= no I\_\_\_I

### Time of onset

**1**= ves

If the patient woke up with symptoms, please state the last time without symptoms. Enter the code "9999" if the time is not known.

If the time can only be given to the nearest hour, the minutes should be recorded <u>in the first instance where</u> **possible** to the nearest whole or half hour, or else enter the code **"99"** for minutes.

If the patient admitted had suffered a stroke and the time of onset is not known, please state **where possible** the last time without symptoms.

If the time of onset is not known, specify the closest possible time interval below.

#### Number of hours from onset to arrival at hospital I\_\_\_I

If the time of onset is not known (**9999**) or if only the hour can be given, (e.g. 10**99**), specify the closest possible time interval from onset to arrival at hospital.

If the patient woke up with symptoms, state the last time without symptoms.

If the patient admitted had suffered a stroke and the time of onset is not known (the last time without symptoms is not known), choose the closest possible time interval from onset to identification of this stroke episode.

 $1 = \le 3$  hrs  $2 = \le 4.5$  hrs  $3 = \le 24$  hrs 4 = > 24 hrs 9 = not known

Did the patient wake up with symptoms? 1= yes 2= no 9= not known	II
Thrombolysis alarm "save the brain/stroke alarm" (refers to the alarm for thrombolytic therapy if needed)	II
<b>1</b> =yes <b>2</b> = no <b>9</b> = not known	
Did the patient arrive by ambulance? 1= yes 2= no 9= not known	II
Initially admitted to another hospital at the time of this stroke episode	II

**2**= no **9**= not known

A Date of arrival II_I_IIII (refers to date of arrival at the hospital where the patient initially received treatment for <u>stroke</u> )
<b>Time of arrival at hospital</b> II.II.II (hrs.min) (refers to time of arrival at the hospital where the patient initially received treatment for <u>stroke</u> )
Date of arrival at stroke unit II_I_I_I_I_I_I_I (refers to the first stroke unit where the patient received treatment for this medical event)
Time of arrival at stroke unit II_I_I_I_I (hrs.min) (refers to time of arrival at the first stroke unit where the patient received treatment for this medical event)
First admitted to a
1= general ward or ward other than those specified in choice of response 2 or 3, 4 or 6
2= stroke unit 3= admissions/obs. ward 4= intensive care unit 5= other (please specify)
Other 6= Department of Neurosurgery 9= not known

#### First clinical department

- 1= Medicine 2= Neurology 3= Geriatrics or Rehab 4= other
- 5= Medicine/Geriatrics 6= Acute-Care Department 9= not known

# Continued care during the acute phase; also applies to care provided in other hospitals during the acute phase

#### (You can choose more than one response)

- I\_\_\_\_I = ward/department other than those specified in choice of response 2 or 3, 4 or 6
- I\_\_\_I = stroke unit
- I\_\_\_\_I = admissions/obs. ward
- I\_\_\_\_I = intensive care unit
- I\_\_\_\_I = other (please specify) Other.....
- I\_\_\_\_I = Department of Neurosurgery
- I\_\_\_\_I = not known

A Date of discharge	(final date of discharge after	acute phase)	I	<u> </u>	_11	_I	_11	_I	_ <b>I</b>
Number of days at stroke up	nit (day of admission = day 1)	999=not known							

If treatment took place at several stroke units, enter the total treatment time at the stroke units.

# After A ACUTE CARE THE PATIENT IS DISCHARGED TO I\_\_\_I

1= own accommodation 2= arranged accommodation (e.g. service flat with full board, temporary
accommodation, old people's home or nursing home)
<b>4</b> = other acute-care department (=complete B Aftercare) <b>5</b> = Geriatrics/Rehab (= complete B Aftercare)
6= deceased during treatment 7= other acute-care department (e.g. the patient is resident in another
country) <b>9</b> = not known <b>11</b> = still in hospital
12= other stroke unit for aftercare (= complete B Aftercare) 13= health centre with emergency beds (=
complete B Aftercare)

# A Address and phone number of the place to which the patient is discharged (please be specific as

regards alternatives) 1, 2, 4, 5, 7 .....

.....

# PLANNED REHABILITATION after discharge from A ACUTE CARE (you can choose more than one

# response)

I\_\_\_\_I = home rehabilitation provided by a multidisciplinary rehabilitation team with specialist knowledge in stroke care, whose staff are attached to the stroke unit.

 $I\_I$  = home rehabilitation provided by a multidisciplinary rehabilitation team with specialist knowledge in stroke care, whose staff are <u>not</u> attached to the stroke unit.

- I\_\_\_\_I = other home rehab
- I\_\_\_I = day rehab
- I\_\_\_\_I = polyclinical rehab
- I\_\_\_\_I = no need for rehabilitation in team's opinion

I\_\_\_\_I = care accommodation with rehab (e.g. arranged accommodation, service flat with full board, temporary accommodation or nursing home)

- I\_\_\_\_I = patient does not want the rehabilitation offered
- I\_\_\_\_I = rehabilitation is needed but not available
- I\_\_\_\_I = not known

# B AFTERCARE refers to institutional care funded by the County Council

B Date of arrival I		B Date of discharge III	III
AFTER B AFTERCAR	E THE PATIENT IS DISCH	HARGED TO	III
1= own accommodatio	n <b>2</b> = arranged accomm	modation (e.g. service flat with full board	l, temporary
accommodation, old pe	eople's home or nursing ho	<b>4</b> = other acute-care de	partment <b>6</b> =
deceased during treatr	nent <b>7</b> = other (e.g. the p	atient is resident in another country)	<b>9</b> = not
known <b>11</b> =	still in hospital <b>13</b> = health c	centre with emergency beds	

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

.....

# PLANNED REHABILITATION after discharge from B AFTERCARE (you can choose more than one response.)

II = home rehabilitation provided by a multidisciplinary rehabilitation team with specialist knowledge in
stroke care, whose staff are attached to the stroke unit.
II = home rehabilitation provided by a multidisciplinary rehabilitation team with specialist knowledge in
stroke care, whose staff are <b>not</b> attached to the stroke unit.
II = other home rehab
II = day rehab
II = polyclinical rehab
II = no need for rehabilitation in team's opinion
II = care accommodation with rehab (e.g. arranged accommodation, service flat with full board, temporary
accommodation or nursing home)
<pre>II = patient does not want the rehabilitation offered</pre>
II = rehabilitation is needed but not available
II = not known
ADL/Accommodation BEFORE ONSET of stroke

# Accommodation

I\_\_\_I

1= own accommodation without home help (home help does <u>not</u> mean home nursing or advanced home nursing)
 2= own accommodation with home help (home help does <u>not</u> mean home nursing or advanced home nursing)
 3= arranged accommodation (e.g. service flat with full board, temporary accommodation, nursing home or

1 1

1 1

1 1

#### equivalent)

<b>5</b> = other (please specify)	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

#### 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
- 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	
Please respond using 1= yes 2= no 9= not known	
Previous stroke	
<b>Previous TIA / Amaurosis fugax</b> (Does not apply to <b>G45.4</b> transitory global amnesia)	
Auricular fibrillation, previously diagnosed (Including intermittent fibrillation or flutter)	
Auricular fibrillation, recently identified (including intermittent fibrillation or flutter)	II
Diabetes, previously diagnosed or recently identified	II
Treated for hypertension at onset of stroke	II
<b>Smoker</b> (>1 cigarette/day, or quit during the last three months)	
ACUTE CARE/DIAGNOSIS	
<ul> <li>Level of consciousness on arrival at hospital</li> <li>1= fully awake (RLS 1) 2= drowsy but responding to stimulus (RLS 2-3)</li> <li>3= unconscious (RLS 4-8) 9= not known</li> </ul>	L_1
<b>NIHSS admission</b> (National Institute of Health Stroke Scale) (Please state total score, maximum of 42 points excluding hand, within 24 hours) <b>99</b> = not known/not examined	III
Is the NIHSS assessment (excluding hand)) complete? 1= yes 2= no 9= not known	
Has the ability to swallow been tested? 1= yes 2= no 3= not examined due to patient's reduced consciousness 9= not known	II
Has the patient been evaluated by a speech therapist or ear-nose-throat specialist for speech or swallowing during the period of treatment ?(Optional question) II	difficulties with
1 = yes $2 = no$ $3 = no$ , but arranged for period after discharge $9 = not$ known	
CT brain scan during treatment 1= yes 2= no 9= not known	
<pre>MR brain scan during treatment 1= yes 2= no 9= not known</pre>	LI

# Carotid ultrasound performed

- I\_\_\_\_I = yes, within seven days <u>after</u> or within one month <u>prior</u> to onset
- I\_\_\_\_I = yes, after seven days
- **I\_\_\_\_I** = no
- I\_\_\_\_I = not known

## CT angio performed (does not mean CT perfusion)

- I\_\_\_I = yes, within seven days <u>after</u> or within one month <u>prior</u> to onset
- I\_\_\_\_I = yes, after seven days
- **I\_\_\_\_I** = no
- I\_\_\_\_I = not known

### MR angio performed

- I\_\_\_\_I = yes, within seven days <u>after</u> or within one month <u>prior</u> to onset
- I\_\_\_\_I = yes, after seven days
- **I\_\_\_\_I** = no
- I\_\_\_\_I = not known

CT or MR angiography performed of vessels affected (always ask a doctor if uncertain about which vessels)

- I\_\_\_I = carotid vessels
- I\_\_\_\_I = intracranial vessels
- I\_\_\_\_I = both carotid and intracranial vessels
- I\_\_\_I = not known

#### Long term ECG (telemetry, Holter or equivalent) performed during period of treatment

- I\_\_\_I = yes
- I\_\_\_\_I = no, arranged for period after discharge
- **I\_\_\_\_I** = no
- I\_\_\_I = not known

PHARMACEUTICAL TREATMENT	
See also FASS, Guidance and list of pharmaceuticals	

**Please respond using 1**= yes **2**= no **3**= no, intervention planned at time of follow-up appointment within two weeks after discharge **9**= not known

C C	At onset	At discharge*
Antihypertensive drugs (applies to all groups, independent of indication)	LI	
Statins (e.g. Crestor, Lipitor, Pravastatin, Simvastatin, Zocord)	II	II
ASA (e.g. Trombyl)	II	II
Clopidogrel (e.g. Plavix)	II	II
ASA + dipyridamole (Asasantin)	II	II
Dipyridamole (Persantin)	II	II
Antithrombotic drugs other than ASA, clopidogrel and dipyradimole (e.g. Brilique, Efient, Pletal, Possia)		
Warfarin (Waran)		L_1
<b>Peroral anticoagulants other than Warfarin</b> (e.g. Eliquis, Pradaxa and Xarelto)	II	L_1

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

# Main reason for non-intervention of Warfarin or peroral anticoagulants other than Warfarin at the time of discharge in the case of atrial fibrillation and diagnosis 163

1= intervention planned for period 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= fall-prone 6= dementia 7= patient does not want treatment 8= other reason 9= not known

THROMBOLYSIS
Thrombolysis – performed for stroke e.g. Actilyse
(if treatment was started but interrupted / not completed please respond using <b>1</b> = yes)
<b>1</b> = yes <b>2</b> = no <b>3</b> = yes, included in study <b>9</b> = not known
Please state date and time of start of thrombolytic therapy
IIIIII(YY-MM-DD) III_II (hr.min)
NIHSS <u>prior to</u> thrombolysis (State total score, maximum of 42 points excluding hand) 99= not known/not examined
Is the NIHSS assessment (excluding hand) complete?II1= yes2= no9= not known
NIHSS within 24 hours <u>after</u> thrombolysis II_II (State total score, maximum of 42 points excluding hand) 99= not known/not examined
Is the NIHSS assessment (excluding hand) complete?II1= yes2= no9= not known
<b>Cerebral haemorrhage with</b> <u>clinical deterioration</u> <36 hrs after start of therapy 1= yes 2= no 9= not known Respond using <b>1</b> = yes only if the patient has clinically deteriorated by 4 points or more on the NIHSS, irrespective of how large an haemorrhage the CT scan shows).
Enter Riks-Stroke hospital code where thrombolysis was performed

# Enter Riks-Stroke hospital code where thrombolysis was performed 888= code for overseas 999= hospital code not known I\_\_I\_I\_I

THROMBECTOMY
Thrombectomy or other catheter-based (endovascular) stroke therapy <b>(for intracranial vessels)</b> All the questions below are applicable.
Thrombectomy or other catheter-based (endovascular) stroke therapy II (for intracranial vessels)
1= yes 2= no 3= yes, included in study 9= not known
Please state date and time of start of treatment in the form of a thrombectomy or other catheter-based (endovascular) therapy
IIIIII(YY-MM-DD) II_I_I_I (hr.min)
NIHSS prior to thrombectomy       or other catheter-based (endovascular) therapy       II         (State total score, maximum of 42 points excluding hand)       99= not known/not examined
Is the NIHSS assessment (excluding hand) complete?II1= yes2= no9= not known
NIHSS prior to thrombectomy or other catheter-based (endovascular) therapy
(State total score, maximum of 42 points excluding hand)
99= not known/not examined
Is the NIHSS assessment (excluding hand) complete?II1= yes2= no9= not known
Enter Riks-Stroke hospital code where the thrombectomy or other catheter-based       III         (endovascular) therapy was performed       III         888= code for overseas       999= hospital code not known
HEMICRANIECTOMY
Hemicraniectomy for stroke
1= yes 2= no 3= yes, included in study 9= not known
Please state date of hemicraniectomy (YY-MM-DD)       II_II_I_I_I_I
Enter Riks-Stroke hospital code where thrombolysis was performedIII888= code for overseas999= hospital code not known

#### ----- REHABILITATION ---

#### Did a physiotherapist evaluate the patient after arrival in the ward/department?

The answer should specify how long after arrival at the ward the patient was evaluated by a physiotherapist. The evaluation should be based on a face-to-face meeting and should determine any need for physiotherapy during the patient's stay in hospital. Evaluation day 1 is counted as of the date of the patient's admission to hospital, irrespective of ward/department. The time spent in the emergency department should not be included. If the patient was already admitted to hospital at the time of the onset of stroke, count day 1 from date of onset. If the patient has come from another hospital, the first evaluation should be recorded as not known if no handover of the physiotherapist's evaluation has taken place.

2 = yes, > 24 hrs but  $\leq 48$  hrs 9= not known  $1 = yes, \le 24 hrs$ **3**= yes, > 48 hrs **5**= no

#### Has the patient received physiotherapy?

(Question refers to the total time spent in hospital and also rehab while in hospital.)

The answer should specify how much physiotherapy the patient received during the total time spent in hospital. Please note that the time spent by the patient receiving treatment in the rehab ward while in hospital should also be included. The answer should specify the total time on average spent in physiotherapy per day, during that portion of time when treatment for the patient was considered necessary. Physiotherapy refers to evaluation/treatment carried out by a physiotherapist or physiotherapy assistant following transfer of tasks from the physiotherapist. Ongoing assessments during the care event are included in the period of treatment. Administration relating to the patient is not included in the period of treatment.

- Other influencing factors; e.g. isolation, or patient unavailable due to his/her undergoing examination, are assessed as 3.

- Patients unable to respond because of severe cognitive impairment/dementia or aphasia are assessed as 4.

- Patients who have neither sensorimotor nor cognitive impairment and who have not received treatment, and also patients in palliative care, are assessed as 5.

 $1 = yes \ge 30 min$ **2**= yes < 30 min 3= no, but has needed it

**4**= no, has needed but not been able to take advantage of rehabilitation 5= no, has not needed it

6= patient has refused 9= not known

#### Did an occupational therapist evaluate the patient after arrival in the ward/department?

The answer should specify how long after arrival on the ward the patient was evaluated by an occupational therapist. The evaluation should be based on a face-to-face meeting and should determine any need for occupational therapy during the patient's stay in hospital. Evaluation day 1 is counted as of the date of the patient's admission to hospital, irrespective of ward/department. The time spent in the emergency department should not be included. If the patient was already admitted to hospital at the time of the onset of stroke, count day 1 from date of onset. If the patient has come from another hospital, the first evaluation should be recorded as not known if no handover of the occupational therapist's evaluation has taken place.

1 = yes,  $\leq 24$  hrs 2 = yes, > 24 hrs but  $\leq 48$  hrs **3**= yes, > 48 hrs 9= not known **5**= no

# Has the patient received occupational therapy?

(Question refers to the total time spent in hospital and also rehab while in hospital.)

The answer should specify how much occupational therapy the patient received during the total time spent in hospital. Please note that the time spent by the patient receiving treatment in the rehab ward while in hospital should also be included.

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. Occupational therapy refers to evaluation/treatment carried out by an occupational therapist or occupational therapy assistant following transfer of tasks from the occupational therapist. Ongoing assessments during the care event are included in the period of treatment. Administration relating to the patient is not included in the period of treatment.

- Other influencing factors; e.g. isolation or patient unavailable due to his/her undergoing examination, are assessed as 3.

- Patients unable to respond because of severe cognitive impairment/dementia or aphasia are assessed as 4.

- Patients who have neither sensorimotor nor cognitive impairment and who have not received treatment, and also patients in palliative care, are assessed as 5.
- $1 = \text{ves} \ge 30 \text{ min}$ **2**= yes < 30 min **3**= no, but has needed it

**4**= no, has needed but not been able to take advantage of rehabilitation **5**= no, has not needed it 6= patient has refused 9= not known

1 1

1

I I

L 

INFORMATION, COMPLICATIONS and FOLLOW-UP	
Smoker informed at onset of need to quit smoking	_ <b>I</b>
<b>1</b> = yes <b>2</b> = no <b>3</b> = not relevant given patient's condition <b>9</b> = not known	
Information provided regarding driving I 1= yes 2= no 3= not relevant/no driving licence 9= not known	_I
Complications arisen during acute care and aftercare at hospital (If no information is available during period of aftercare, please responding using 9= not known)         1= yes       2= no       9= not known         Deep venous thrombosis/pulmonary embolism       I	_1 _1 _1

# Has a follow-up appointment on the basis of this stroke episode 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 admissions ward/department
- I\_\_\_\_I = yes, at a health centre/equivalent
- I\_\_\_\_I = yes, at arranged accommodation
- I\_\_\_\_I = yes, at day rehab
- **I\_\_\_\_I** = no
- I\_\_\_\_I = not known