Important information

- The Riks-Stroke register was established 1994.
- From 1998, <u>all</u> hospitals in Sweden admitting patients with acute stroke, reported data to the Riks-Stroke register
- Variables that are not mandatory
- On the website, under the tab Forms, you find the Riks-Stroke forms that are translated to English

Acute phase form

Year	1994	1995	1996	1997	1998	1999	2000	2001	2002	2003	2004	2005	2006	2007	2008	2009	2010	2011	2012	2013
version	1.0		2.0	3.0	4.0	5.0		6.0			7.0			8.0		9.0	10.0	11.0	12.0	13.0
Personal ID number																				
Gender																				
Name, address, telephone number																				
Municipality code																				
County code																				
Reporting hospital																				
Ward																				
Completed by																				
Has the patient been admitted to hospital for this stroke																				
Reason for not admitting the patient																				
Was the patient already enrolled at the hospital at the time of the stroke episode																				

PRIOR to the onset of stroke

Year	1994	1995	1996	1997	1998	1999	2000	2001	2002	2003	2004	2005	2006	2007	2008	2009	2010	2011	2012	2013
version	1.0		2.0	3.0	4.0	5.0		6.0			7.0			8.0		9.0	10.0	11.0	12.0	13.0
Living arrangements																				
Living alone																				
Mobility																				
Toilet visits																				
Dressing																				

Risk factors

Year	1994	1995	1996	1997	1998	1999	2000	2001	2002	2003	2004	2005	2006	2007	2008	2009	2010	2011	2012	2013
version	1.0		2.0	3.0	4.0	5.0		6.0			7.0			8.0		9.0	10.0	11.0	12.0	13.0
Previous stroke																				
Prior TIA/Amaurosis fugax																				
Atrial fibrillation																				
Diabetes																				
Hypertension, high blood																				
pressure																				
Smoking																				

Acute management

Year	1994	1995	1996	1997	1998	1999	2000	2001	2002	2003	2004	2005	2006	2007	2008	2009	2010	2011	2012	2013
version	1.0		2.0	3.0	4.0	5.0		6.0			7.0			8.0		9.0	10.0	11.0	12.0	13.0
Level of consciousness																				
NIHSS at admission																				
Is the NIHSS assessment complete																				
Is a swallow test performed																				
CT scan – brain																				
MR scan – brain																				
Carotid ultrasound (alt. CT angio)																				
Carotid ultrasound (not CT angio)																				
CT or MR angiography performed																				
CT angiography performed																				
MR angiography performed																				
Angio territory assessed by CT or MR angiography																				
Long-term ECG performed																				
Examined by a speech therapist																				

Pharmaceutical treatment

Year	1994-97	1998	1999	2000	2001	2002	2003	2004	2005	2006	2007	2008	2009	2010	2011	2012	2013
version	1.0-3.0	4.0	5.0		6.0			7.0			8.0		9.0	10.0	11.0	12.0	13.0
Diuretics																	
ACE inhibitors																	
A2 inhibitors																	
Beta blockers																	
Calcium antagonists																	
Other blood pressure medication																	
Blood pressure medication, all groups																	
Statins - lipid lowering agents																	
ASA																	
Clopidogrel																	
ASA + dipyridamole																	
Dipyridamole																	
Other antithrombotic drugs than ASA, clopidogrel and dipyradamole																	
Warfarin																1	
Other peroral anticoagulants than warfarin																	
Heparin											ĺ						
Other medication against stroke																	
Heparin/Fragmin/Innohep/Klexane as progressive stroke treatment																	
Heparin/Fragmin/Innohep/Klexane as prevention for DVT																	
Heparin/Fragmin/Innohep/Klexane as temporary substitute for Warfarin																	
Main reason why warfarin or other oral anticoagulants than warfarin are not prescribed at discharge if the diagnoses are atrial fibrillation and diagnose I63																	

Thrombolysis

Year	1994	1995	1996	1997	1998	1999	2000	2001	2002	2003	2004	2005	2006	2007	2008	2009	2010	2011	2012	2013
version	1.0		2.0	3.0	4.0	5.0		6.0			7.0			8.0		9.0	10.0	11.0		
Thrombolysis alarm																				
Thrombolysis performed for																				
stroke																				
Thrombolysis																				
Cerebral haemorrhage																				
Notable improvement after																				
thrombolysis															-					
NIHSS prior to thrombolysis																				
Is the NIHSS assessment																				
complete																				
NIHSS 24 hours after																				
thrombolysis																				
Is the NIHSS assessment																				
complete																				
Date of thrombolysis therapy																				
Time of thrombolysis therapy																				
Thrombolysis performed <u>ON</u>																				
<u>behalf</u> of another hospital																				
Hospital that performed the																				
thrombolysis																				

Thrombectomy

Year	1994	1995	1996	1997	1998	1999	2000	2001	2002	2003	2004	2005	2006	2007	2008	2009	2010	2011	2012	2013
version	1.0		2.0	3.0	4.0	5.0		6.0			7.0			8.0		9.0	10.0	11.0	12.0	13.0
Thrombectomy or other catheter-based (endovascular) treatment for stroke																				
Notable improvement after thrombectomy																				
Cerebral haemorrhage with clinical deterioration <36 hrs after start of treatment																				
NIHSS prior to thrombectomy																				
Is the NIHSS assessment complete																				
NIHSS 24 hours after thrombectomy																				
Is the NIHSS assessment complete																				
Date of thrombectomy																				
Time of thrombectomy																				
Thrombectomy performed <u>on</u> <u>behalf</u> of another hospital																				
Hospital that performed the thrombectomy																				

Hemicraniectomy

Year	1994	1995	1996	1997	1998	1999	2000	2001	2002	2003	2004	2005	2006	2007	2008	2009	2010	2011	2012	2013
version	1.0		2.0	3.0	4.0	5.0		6.0			7.0			8.0		9.0	10.0	11.0	12.0	13.0
Hemicraniectomy for stroke																				
Date of hemicraniectomy																				
Time of hemicraniectomy																				
Hospital that performed the																				
hemicraniectomy																				

Information

Year	1994	1995	1996	1997	1998	1999	2000	2001	2002	2003	2004	2005	2006	2007	2008	2009	2010	2011	2012	2013
version	1.0		2.0	3.0	4.0	5.0		6.0			7.0			8.0		9.0	10.0	11.0	12.0	13.0
Information about																				
smoking																				
Information about																				
driving vehicles																				
Suitability as driver																				

Rehabilitation

Year	1994	1995	1996	1997	1998	1999	2000	2001	2002	2003	2004	2005	2006	2007	2008	2009	2010	2011	2012	2013
version	1.0		2.0	3.0	4.0	5.0		6.0			7.0			8.0		9.0	10.0	11.0	12.0	13.0
Examined by																				
physiotherapist																				
Received physiotherapy																				
Examined by																				
occupational therapist																				
Received occupational																				
therapy																				

Health care chain

Year	1994	1995	1996	1997	1998	1999	2000	2001	2002	2003	2004	2005	2006	2007	2008	2009	2010	2011	2012	2013
version	1.0		2.0	3.0	4.0	5.0		6.0			7.0			8.0		9.0	10.0	11.0	12.0	13.0
A Date of onset																				
Time of onset of first symptom																				
Certainty of time of onset																				
Time in hours from onset to arrival at hospital																				
Woke up with symptoms																				
Arrived by ambulance																				
Priority level 1 during transport to hospital by ambulance																				
A: Date of arrival																				
Time of arrival																				
Admitted first at another hospital for the current stroke onset																				
Date of arrival at stroke unit																				
Time of arrival at stroke unit																				
First admitted to																				
First clinical department																				
Continued care during the acute phase																				
Subsequent clinical department																				
A Date of discharge																				
Number of days at the stroke unit																				

After discharge (following A Acute management) the patient is moved to

Year	1994	1995	1996	1997	1998	1999	2000	2001	2002	2003	2004	2005	2006	2007	2008	2009	2010	2011	2012	2013
version	1.0		2.0	3.0	4.0	5.0		6.0			7.0			8.0		9.0	10.0	11.0	12.0	13.0
After discharge (following A Acute management)																				
Planned rehabilitation after discharge A																				
A Address and phone number of the place to which the patient is moved after discharge																				
B Date of admission																				
B Date of discharge																				

After discharge (following B Aftercare) the patient is moved to

Year	1994	1995	1996	1997	1998	1999	2000	2001	2002	2003	2004	2005	2006	2007	2008	2009	2010	2011	2012	2013
version	1.0		2.0	3.0	4.0	5.0		6.0			7.0			8.0		9.0	10.0	11.0	12.0	13.0
After discharge (following B Aftercare)																				
Planned rehabilitation after discharge B																				
B Address and phone number of the place to which the patient is moved following B Aftercare																				

Complications during hospital care

Year	1994	1995	1996	1997	1998	1999	2000	2001	2002	2003	2004	2005	2006	2007	2008	2009	2010	2011	2012	2013
version	1.0		2.0	3.0	4.0	5.0		6.0			7.0			8.0		9.0	10.0	11.0	12.0	13.0
Deep venous																				
thrombosis/pulmonary embolism																				
Fracture																				
Pneumonia																				

Follow-up of stroke patients

Year	1994	1995	1996	1997	1998	1999	2000	2001	2002	2003	2004	2005	2006	2007	2008	2009	2010	2011	2012	2013
version	1.0		2.0	3.0	4.0	5.0		6.0			7.0			8.0		9.0	10.0	11.0	12.0	13.0
Has a follow-up visit been																				
scheduled																				
General planning of care																				

CVS diagnosis

Year	1994	1995	1996	1997	1998	1999	2000	2001	2002	2003	2004	2005	2006	2007	2008	2009	2010	2011	2012	2013
version	1.0		2.0	3.0	4.0	5.0		6.0			7.0			8.0		9.0	10.0	11.0	12.0	13.0
CVS diagnosis																				
TIA diagnosis																				

Deceased

Year	1994	1995	1996	1997	1998	1999	2000	2001	2002	2003	2004	2005	2006	2007	2008	2009	2010	2011	2012	2013
version	1.0		2.0	3.0	4.0	5.0		6.0			7.0			8.0		9.0	10.0	11.0	12.0	13.0
Deceased																				
Postmortem performed																				

FOLLOW-UP FORM

Year	1994	1995	1996	1997	1998	1999	2000	2001	2002	2003	2004	2005	2006	2007	2008	2009	2010	2011	2012	2013
version	1.0		2.0	3.0	4.0	5.0		6.0			7.0			8.0		9.0	10.0	11.0	12.0	13.0
Personal ID number																				
Name, address, telephone																				
number																				
Reporting hospital																				
Ward/department																				
Follow-up date																				
Deceased																				

After the onset of stroke

Year	1994	1995	1996	1997	1998	1999	2000	2001	2002	2003	2004	2005	2006	2007	2008	2009	2010	2011	2012	2013
version	1.0		2.0	3.0	4.0	5.0		6.0			7.0			8.0		9.0	10.0	11.0	12.0	13.0
Staying at the time of follow-up																				
Received treatment after the first hospital care or being cared by this time in a geriatric clinic																				
Received treatment after the first hospital care or being cared by this time in a medical- or neurological clinic																				
If yes to any of this questions, was it because of a new stroke																				
Living alone																				
Mobility																				
Help toilet visit																				
Help clothes																				
Dependency on family/friends																				

Rehabilitation support

Year	1994	1995	1996	1997	1998	1999	2000	2001	2002	2003	2004	2005	2006	2007	2008	2009	2010	2011	2012	2013
version	1.0		2.0	3.0	4.0	5.0		6.0			7.0			8.0		9.0	10.0	11.0	12.0	13.0
Follow-up appointment after hospital																				
Been to a follow-up appointment or been given an appointment to see a physician again																				
Been to a follow-up appointment or been given an appointment to see a nurse again																				
Support after hospital care																				
If support – what type of support																				
Support requirements fulfilled?																				
General planning of future care after hospital																				
Have you participated in that planning																				
Did you get rehabilitation																				
Undergoing rehabilitation/training right now																				

Health

Year	1994	1995	1996	1997	1998	1999	2000	2001	2002	2003	2004	2005	2006	2007	2008	2009	2010	2011	2012	2013
version	1.0		2.0	3.0	4.0	5.0		6.0			7.0			8.0		9.0	10.0	11.0	12.0	13.0
Speech difficulties																				
Are you finding it difficult to speak ,read ,write, swallow																				
Contact with speech therapist																				
Smoking																				
Depression																				
Anti-depressants																				
Medication for high blood-																				
pressure																				
General state of health																				
Health evaluation EQ-5D																				
Fatigue																				
Pain																				
Memory problems																				

The patient's opinion of the treatment

Year	1994	1995	1996	1997	1998	1999	2000	2001	2002	2003	2004	2005	2006	2007	2008	2009	2010	2011	2012	2013
version	1.0		2.0	3.0	4.0	5.0		6.0			7.0			8.0		9.0	10.0	11.0	12.0	13.0
Satisfied with care																				
Treatment by staff																				
Private conversation with																				
physician																				
Satisfied or dissatisfied with individual conversation with																				
physician																				
Conversation with staff about																				
matters that worry you																				
Satisfied or dissatisfied with the conversation with staff																				
Information about stroke												-								
Satisfied or dissatisfied with the																				
stroke information																				
Received rehabilitation																				
Satisfied or dissatisfied with the																				
rehabilitation or the training																				
Information about support after hospital care																				
Satisfied or dissatisfied with																				
information where to turn to for																				
support or assistance after																				
discharge from hospital																				
How satisfied or dissatisfied are																				
you with the rehabilitation or																				
training at the hospital																				
How satisfied or dissatisfied are you with the rehabilitation or																				
training after you were																				
discharged from the hospital																				

Completed by

Year	1994	1995	1996	1997	1998	1999	2000	2001	2002	2003	2004	2005	2006	2007	2008	2009	2010	2011	2012	2013
version	1.0		2.0	3.0	4.0	5.0		6.0			7.0			8.0		9.0	10.0	11.0	12.0	13.0
The form was completed by																				