EuroHOPE

Building register-based performance indicators for

STROKE

using individual-level administrative health care data

Version of August 27, 2016

BRIDGEHEALTH WP11
Integrating data sources into a comprehensive EU Information System
for Health Care Monitoring and Reporting

Contents

1. Introduction and objectives

The principal aim of the BRIDGEHealth Work Package 11 "Integrating data sources into a comprehensive EU Information System for Health Health Care Monitoring and Reporting" is to create databases to enable comparison of performance in the care of specific patient groups between countries, within countries (regions and hospitals), and over time, using patient-level administrative health care data. The specific aims are updating protocols, data processing, reporting for selected diseases/condition included in the European Health Care Outcomes, Performance and Efficiency (EuroHOPE) project. This paper updates the earlier version of the protocol for stroke (Malmivaara et al. 2013), which has been applied in several articles (Malmivaara et al. 2015, Peltola et al. 2015, Häkkinen et al. 2015) as well as in the regional indicators available in http://eurohope.info.org.

In the earlier stage of EuroHOPE, the stroke data was gathered from Finland, Hungary, Italy, Netherlands, Scotland and Sweden for the years 2006-2008. Now the data will be updated for Finland, Hungary, Italy and Sweden to cover more recent years. In addition data from Norway, Denmark and Spain (Madrid) will be collected.

The main objective of the database is to produce performance indicators at country, regional and hospital level for international benchmarking. The database enables to extend and deepen the international comparative research on the relationship between outcomes/quality and costs/resources as well as on the reasons behind the differences in outcomes and costs (Peltola et al. 2015, Häkkinen et al. 2015).

This specific protocol for international comparison for stroke describes how the EuroHOPE international comparison data is constructed is based on the data of hospital discharge registers, mortality registers, and other available administrative health care registers (such as medication use, specialty visits, etc.) (Figure 1). The protocol is used for preparing both the **national stroke databases for each country and for an international comparative stroke database,** which is produced using the national stroke databases.

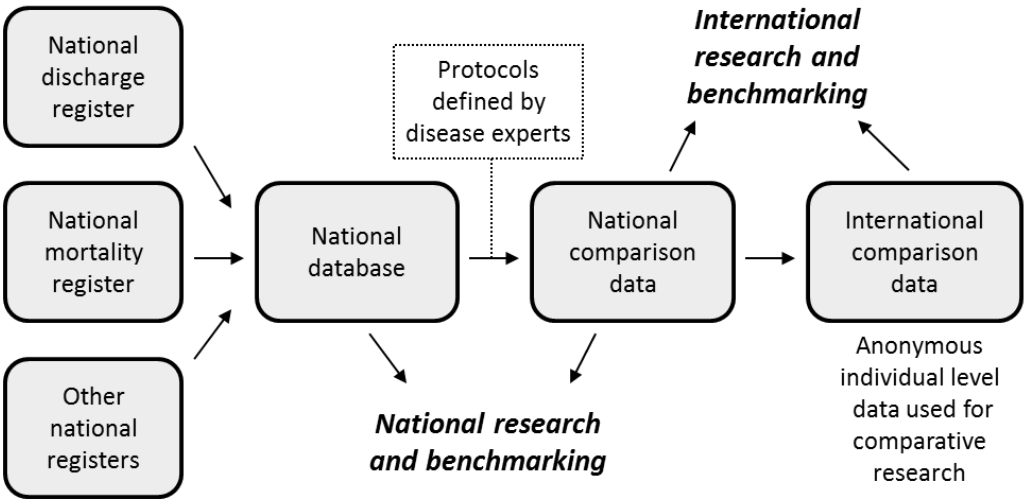

Figure 1. Schematic presentation of data flow in BridgeHEALTH WP11.

This protocol also defines how we have produced indicators on stroke at national and also regional and hospital level within countries. The indicators include basic information on patients (number of patients, demographic characteristics, co-morbidity), indicators on the content of care (use of services and procedures, costs, treatment practices, process indicators), and outcomes.

The protocol, first introduced in EuroHOPE[1], has been updated to be applied in the present project. Participants of the present project are:

- University of Southern Denmark, Odense, Denmark
- National Institute for Health and Welfare, Helsinki, Finland
- Centre for Research on Health and Social Care Management, Università Commerciale Luigi Bocconi, Milan, Italy
- Health Services Management Training Centre, Semmelweis University, Budapest, Hungary
- Instituto de Salud Carlos III (ISCIII), Madrid, Spain
- Medical Management Centre, LIME, Karolinska Institutet, Stockholm, Sweden
- Department of Health Management and Health Economics, University of Oslo, Oslo, Norway.

[1] The original discussion paper was part of the Stroke subproject of the EuroHOPE project. The following institutions in the six countries participated in the Stroke subproject: National Institute for Health and Welfare (Helsinki, Finland); Centre for Research on Health and Social Care Management, Università Commerciale Luigi Bocconi (Milan, Italy); Semmelweis University, Health Services Management Training Centre (Budapest, Hungary); National Institute of Public Health and the Environment (Bilthoven, the Netherlands); Ragnar Frisch Centre for Economic Research (Oslo, Norway); University of Edinburgh (Scotland, UK); Medical Management Centre, LIME, Karolinska Institutet (Stockholm, Sweden). The original paper was a joint work established (in alphabetical order) by Helen Banks, Eva Belicza, Anne Douglas, Peter Engelfriet, Richard Heijink, Unto Häkkinen, Antti Malmivaara, Emma Medin, Atte Meretoja, Dino Numerato, Mikko Peltola, Clas Rehnberg and Timo T. Seppälä. Antti Malmivaara was the primary author.

2. Construction of data

Definition of stroke

Stroke is defined by the WHO as "Rapidly developed clinical signs of focal (or global in case of subarachnoid haemorrhage) disturbance of cerebral function, lasting more than 24 hours or leading to death before that, with no apparent cause other than of vascular origin."

In the present study stroke includes patients discharged with the main diagnosis, in terms of the WHO International Classification of Diseases (ICD), of ischemic stroke (ICD-9 codes 433-434/ICD-10 code I63), intracerebral haemorrhage (431/I61), subarachnoid haemorrhage (430/I60), and ill-defined stroke (436/I64).

National databases

Total incidence of stroke in a given calendar year comprises of all patients admitted to hospital due to stroke and persons who have died of stroke without being admitted to hospital. Stroke may be fatal and the person may not reach a hospital. Partly the access to treatment may depend on the local health care system characteristics. In EuroHOPE we try to assess the number of persons who suffered from stroke irrespective of the access to hospital care. Persons who died of stroke without being admitted to hospital due to stroke are gathered from countries where available. The analysis of total incidence of stroke will be explored later. However, the health system's performance in treatment of stroke is assessed by analysing the persons being treated in hospital due to stroke.

In EuroHOPE, every country has established a **national stroke database** that includes patients treated in hospital due to stroke (prevalence of stroke in acute care). From national discharge registers patients that have been admitted to hospital inpatient care because of a main diagnosis of stroke were included in the national stroke database: ischemic stroke (ICD-9 codes 433-434 / ICD 10-code I63), intracerebral haemorrhage (431/I61), subarachnoid haemorrhage (430/I60), and ill-defined stroke (436/I64).

Using anonymised personal identification numbers we have linked patient information from the following sources:

- Hospital discharge registers
- Outpatient services in specialty care in hospitals
- Drug utilisation registers
- National cause-of-death registers.

National comparison database for calculating indicators

For an explanation regarding the approach used in this part of the study, please see Häkkinen et al. (2013) and Malmivaara et al. (2015).

Registry data on hospital discharges, prescription drugs and causes of death were acquired in the participating European countries. This chapter describes in detail how the 2013 cohort of the **national stroke comparison data** in EuroHOPE was created, starting from the prevalence of stroke in acute hospital care. Datasets covering other cohorts are created using the same logic. The steps in constructing the national comparison data for Finland are also shown in a flow chart in Appendix 4.

First, using hospital discharge data all patients admitted between 1st January 2013 and 31st December 2013 with a main diagnosis of one of the stroke subtypes of cerebral infarction (WHO International Classification of Diseases, 9th edition codes 433-434; 10th edition code I63), intracerebral haemorrhage (431; I61), subarachnoid haemorrhage (430; I60), or ill-defined stroke (436; I64) were identified. The hospital discharge records and all the identified patients' records in the other data sources mentioned above were gathered for the period between 1.1.2012 and 31.12.2014, i.e. for the preceding and following calendar years in addition to the cohort year data. The first stroke admission (index admission) of the year was identified as it starts the follow-up of the patient.

Patients with a stroke admission during the previous 365 days before the index admission were excluded from the 2013 cohort (stroke admission = hospital discharge record with a stroke diagnosis as the main diagnosis).

For each patient all continuous hospital treatment (the first hospital episode) starting from the first stroke admission (index admission) in 2013 was constructed by combining all consecutive hospital stays for each patient. The consecutive hospital stays need not be in the same hospital, i.e. hospital transfers are taken into account when making the first hospital episode.

In case a patient had different stroke subtype or ill-defined stroke diagnoses during the first hospital episode, the most 'severe' diagnosis was chosen to characterize the condition of the patient. For this purpose, the following hierarchy of stroke subtypes was applied (from the most to the least severe): subarachnoid haemorrhage, intracerebral haemorrhage, cerebral infarction, and ill-defined stroke. The most severe diagnosis was chosen as the stroke subtype characterizing the first hospital episode.

The included stroke patients were followed for up to 365 days from the first day (index day) of the index admission for inpatient and outpatient care in hospitals, medication purchases and vital status. In addition, the hospital discharges and use of prescribed medicines in the 365 days prior to the start of the index admission were used in assessing the presence of comorbid diseases among the patients.

In each country, patients under 18 years of age, tourists, visitors and other residents with incomplete personal identification numbers as well as patients with incomplete data on look-back and/or follow-up period of 365 days were excluded.[2]

The main analysis will be done using the patient data collected from the national discharge registers as described above. Specific information on registers in each country is provided in Appendix 1 and on country specific procedure codes in Appendix 2. Appendix 3 gives a characterization of the classification of regions used in the project. Variable definitions, together with definitions of comorbid conditions, complications and hospital hierarchy are described in a separate excel file.

3. Hospital and first hospital episode

Definition of a hospital

A hospital is a health care institution providing treatment for a number of medical conditions by specialized staff and equipment. In the present project, we speak of hospitals meaning institutions providing somatic (non-psychiatric) inpatient care for patients staying overnight (for at least one night, i.e. inpatients), and usually also health care services (diagnosis, treatment, or therapy) for patients without staying overnight (i.e. outpatients). A hospital may be a single building or a number of buildings on a campus. Also, in some countries a hospital can consist on many buildings in a certain geographical area. For example, in Finland after reorganization of Helsinki University Hospital in 2006, it includes several buildings in different municipalities in the capital area.

At hospital level analysis we have specified the definition of a hospital in order to be sure that we are comparing units with a similar structure and scope. For this end, we have formulated a definition of hospital, and a corresponding classification of different types of hospitals. We have used these definitions of hospitals in a specific variable depicting the type of care that the patient has received for each day of the follow-up daily information (during one year follow-up). In addition, we will gather more detailed information on the hospitals that have the main responsibility for the care. The more specific hospital-level information collection is to be gathered for the hospitals acting as the first hospitals in the care chain, and for the hospitals taking the responsibility of the patient in the first hospital episode (in the individual level data the hospitals are given variables named FSTHOSP and HEPHOSP, respectively). Thus, FSTHOSP is the hospital where the patient was initially admitted in. HEPHOSP is defined as the hospital that was highest in the hierarchy of hospitals which treated the patient during the first week[3].

[2] In Hungary, patients being imprisoned are excluded as their use of health care services is not included in the hospital discharge register.

[3] According to data of four countries (Häkkinen et al. 2015) about 1 % of the ischemic stroke patients were transferred to higher level hospitals within the first week of hospitalization

Definition of the first hospital episode

The total episode of care is defined as the entire treatment pathway from the beginning of the disease to the end of the treatment throughout any hospital admissions, other health service provisions or purchased medication in order to solve the health problem at hand in a specified time frame (Figure 2).

The first hospital episode covers all care given to patients as an inpatient in a hospital. Consecutive hospital discharges are included in the same hospital episode if the preceding hospital stay's discharge date is the same as the following discharge's admission date or the admission date is the next date after the preceding discharge date. If the patient is immediately transferred to a rehabilitation centre at the hospital this is included in the first hospital episode (Häkkinen et al. 2013). The first hospital episode ends when the patient is discharged to home (and is at home for at least one day), to a nursing home or to a long-term care institution, or the patient dies. The total episode of care was defined as the entire treatment pathway from the beginning of the disease (i.e. acute stage of the disease) to the end of the episode (predefined follow-up time, see below), irrespective of any organizational boundaries (Figure 2).

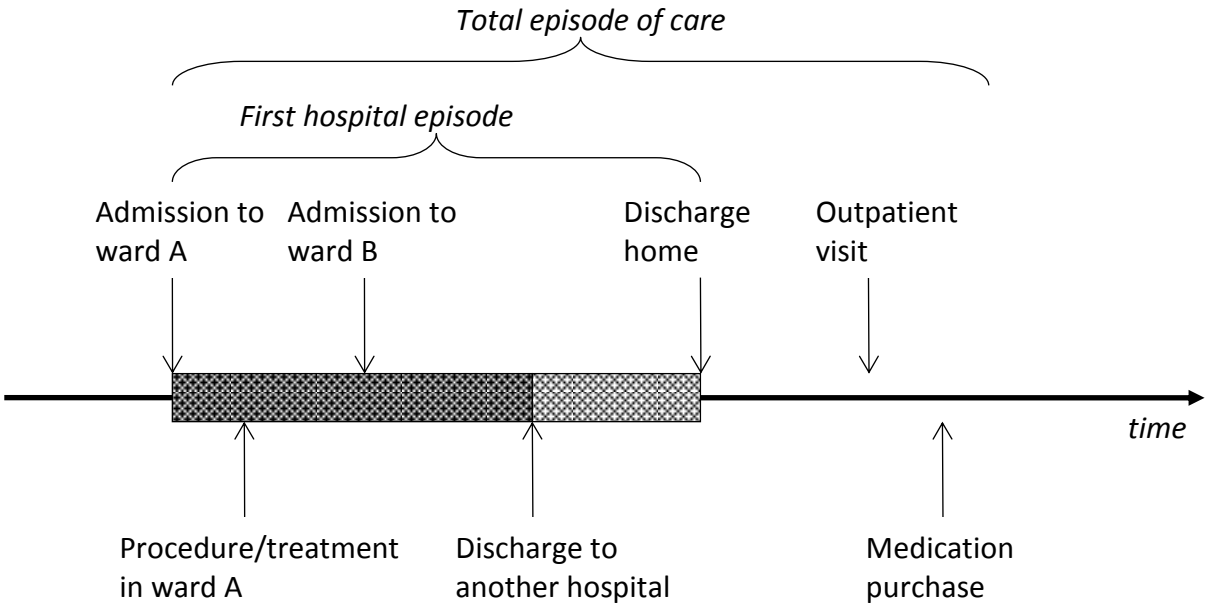

Figure 2. A schematic presentation of the follow-up of patients throughout the treatment pathway demonstrating the definitions of the first hospital episode and the total episode of care.

Rehabilitation

In some countries (e.g. in Finland) it is difficult to separate rehabilitation given in a hospital from acute care as well as to separate rehabilitation from long-term care. Some countries (e.g. Hungary) may have data on all inpatient rehabilitation. Other countries usually have data on inpatient rehabilitation given in hospitals but no data on rehabilitation given in a specialized rehabilitation centre.

We have divided the first hospital episode to acute and non-acute care. In countries where rehabilitation is included in hospital inpatient data and can be separated from acute care this is coded in a STATE variable[4]. In addition, an own class in the hospital hierarchy is given for geriatric wards of hospitals.

We will include inpatient rehabilitation and thus keep our definition of the end of an episode. In addition, in countries where rehabilitation is included in hospital inpatient data and can be separated from acute care this will be coded like mentioned earlier. In addition, an own class in the hospital hierarchy will be given for geriatric wards in hospitals.

Length of stay, acute and non-acute care

We measured the length of stay (LoS) in acute care during the first hospital episode from the index day at the start of the initial admission to the last day of acute hospital care during the period of continuous acute hospital treatment (LoS = last date in acute treatment – index date +1).

We defined acute hospital care as treatment given in a hospital's intensive care unit, stroke ward, neurological ward, or in other acute care settings (all other medical and surgical specialties). In addition, we calculated several other LoS measures including the length of the first admission, the total length of the continuous episode of care, the number of days in rehabilitation during the first continuous episode of care, and the number of days in hospital during the entire follow-up year. All LoS measures were truncated at 365 days if the length of stay was longer.

Hospital hierarchy

The daily STATE variable describes in which place or state the patient is. It is based on the idea that a patient can only be in one place in each day and that with hospital discharge data the days in institutions can be located in time. In case of overlapping admissions, the STATE variable is marked with the hospital being in the highest step of hospital hierarchy (defined by each country). In descending order, the hospitals, institutions or units in the hierarchy are university hospitals,

[4] The daily STATE variable conveys information on if a patient was, in a given day, in a hospital or not, about the type of hospital where the patient was that date, whether the main diagnosis was related to a certain disease, information about the intensity of the treatment (i.e. acute care, non-acute etc. based on information known about the ward giving the treatment). Thus, the state variables give a possibility to extract and pinpoint the days the patient spent in rehabilitation, even within the first hospital episode or any other hospital stay during the follow-up. The codes for state variables are given in a separate excel-file.

specialist hospitals, central or regional hospitals and general or local hospitals, rehabilitation, geriatric and general care, psychiatric care, and long term care.

1. University hospital

A university hospital (teaching hospital) combines hospital treatment to patients with teaching to medical students and nurses and usually it is linked to a medical school, or university. University hospital has an extensive array of specialties and services, and university hospitals are able to provide treatment to the most demanding medical conditions and are responsible for the treatment of rare and severe medical conditions in their region. University hospitals are usually tertiary referral hospitals: Tertiary care is specialized consultative health care, usually for inpatients and on referral from a primary or secondary health professional, in a facility that has personnel and facilities for advanced medical investigation and treatment, such as a tertiary referral hospital (Healy, Mckee 2002). Examples of tertiary care services are cancer management, neurosurgery, cardiac surgery, plastic surgery, treatment for severe burns, advanced neonatology services, palliative, and other complex medical and surgical interventions.

2. Specialized hospital

Types of specialized hospitals treat certain disease categories such as cardiac, oncology, or orthopedic problems, and so forth. A specialized hospital may have smaller volumes, but they are considered to have an excellent know-how in their field.

3. Central or regional hospital

A central hospital is typically the major health care facility in its region, with a fairly large numbers of beds for intensive care and many specialized facilities (for example surgery, plastic surgery, childbirth, bioassay laboratories, and so forth).

4. General/local hospital

General hospital is set up to deal with many kinds of disease and injury, and it has an emergency department to deal with immediate and urgent threats to health. These hospitals have usually only the basic specialties such as surgery, internal medicine, deliveries and gynecology, ear, nose and throat disease etc.

5. Rehabilitation

Here we include all rehabilitation given in special rehabilitation hospitals/clinics as well as all other hospitals if this can be separated from the acute care using diagnoses, procedures, DRGs, or the department level information. Thus if rehabilitation is given e.g. in a university hospital and it can be separated from the acute care, the state variable is coded to give information about this.

6. Geriatric and general care

Care given in geriatric wards and care given in general medicine departments, independent of the hospital type (any of the above accepted care).

7. Psychiatric care

Care given in psychiatric specialties, or having ICD-10 code F* as main diagnosis.

8. Long term care

All inpatient care given in nursing homes and other long-term institutions.

4. Description of indicators

The EuroHOPE project aims at constructing a number of indicators describing the performance of the health care system in treatment of stroke. With the national comparison data a number of national-, regional- and hospital-level indicators are produced. The calculation of indicators and the reporting of the data are based on a common script, executed in Stata on the national comparison data. Below in Table 1, the indicators that are published on the national- and regional-level in the EuroHOPE website in the ATLAS tool are described. The name of the indicator, a short description of the indicator, and the factors used in risk-adjustment are given in Table 1.

Table 1. EuroHOPE indicators on ischaemic stroke publicly available on www.eurohope.info.

Indicator	**Description**	**Risk-adjustment**
Number of patients	Number of patients included in the national comparison data.	
Number of patients per 100 000 inhabitants	Number of patients included in the national comparison data per 100 000 inhabitants.	
Age	Average and median age of the patients. Age in years at the start of the hospital care for stroke.	
Males	Share of males.	

Length of stay, first hospital episode	The number of days in acute hospital treatment during the first hospital episode. Consecutive hospital stays are taken into account when constructing the first hospital episode.	Age[5], sex
Length of stay, first year	The number of days in hospital treatment during 365 days after the start of the acute hospital treatment due to stroke.	Age[5], sex
7-, 30-, 90-day and 1-year mortality	The share of ischaemic stroke patients who died within the given period of time after the start of the first hospital admission because of ischaemic stroke.	Age[5], sex
Readmission in 30 days	Readmission to acute hospital care within 30 days after the end of acute care in the first hospital episode.	Age[5], sex

In addition to the indicators given in Table 1, a number of indicators are produced in EuroHOPE. The indicators can be classified as indicators related to the baseline patient characteristics, process, and outcome.

Baseline patient characteristics

In addition to the publicly reported indicators given in Table 1, a number of other indicators are produced in EuroHOPE. The indicators can be classified as indicators related to the baseline patient characteristics, process, and outcome.

As baseline patient characteristics the following information is gathered:

- Age and gender

[5] Classified: 18-39, 40-44, 45-49, 50-54, 55-59, 60-64, 65-69, 70-74, 75-79, 80-84, 85-89, 90-.

- Comorbidities (see separate file for definitions)
    - Hypertension
    - Coronary artery disease
    - Atrial fibrillation
    - Cardiac insufficiency (heart failure)
    - Diabetes mellitus
    - Atherosclerosis
    - Cancer
    - COPD and asthma
    - Dementia
    - Depression
    - Parkinson's disease
    - Mental disorders
    - Renal insufficiency (failure)
    - Alcoholism

Co-morbidities are defined from various register sources according to two different approaches:

1. based on the main and secondary diagnoses of all hospital inpatient and outpatient records during the 365 days preceding the index admission
2. based on medicine purchases and the main or secondary diagnoses of all hospital inpatient and outpatient records during the 365 days preceding the index admission.

Process indicators

The patients' first hospital episode and the whole follow-up of one year are tracked for a number of aspects that convey information about the care given to the patient. The process indicators produced in the project are the following:

- Length of stay of first hospital admission, days per patient
- Length of stay of the first hospital episode, days per patient
    - Total
    - Acute care
    - Non-acute care
    - Days per patient due to any cerebrovascular disorder
- The number of inpatient days per patient over the first year after stroke
    - Total
    - Acute care
    - Non-acute care
    - Days per patient due to any cerebrovascular disorder
- Number and share of patients with length of stay of the first hospital episode of 90 days or more
- Number and share of patients who received arteria carotis endarterectomy during the first hospital episode

- Number and share of patients who received thrombolysis during the first hospital episode
- Number and share of patients that have used drugs (outside hospitals) based on the ATC (anatomic therapeutic classification) code during the one year before and one year after hospitalisation:
    - diuretics (C03*, C07BB*, C09BA*, C09DA*)
    - beta blockers (C07*)
    - ACE-inhibitors (C09A* and C09B*)
    - AT II antagonists (C09C* and C09D*)
    - calcium blockers (C08*, C07FB*, C09BB*)
    - insulin (A10A*)
    - oral diabetes medication (A10B*)
    - statins (C10AA*)
    - clopidogrel (B01AC04)
    - dipyridamol (B01AC07 , B01AC30)
    - warfarin (B01AA03)
    - antidepressants (N06A*)
    - dementia medications (N06D*)
    - antiepileptics (N03A*)
    - Acenokumarol (B01AA07)
    - Ticlopidin (B01AC05)
    - Dabigatran (B01AE07)
    - Apixaban (B01AF02)
    - Rivaroxaban (B01AF01)

Outcome indicators

The project aims at constructing measures to be used for performance monitoring and assessing the outcomes of care given to the patients. As outcome indicators, the following measures are included:

- Mortality at 7, 30, 90, and 365 days from the index admission day
- Readmission (due to recurrence of stroke) to hospital within 30, 90 days and 365 days from the index admission
- Readmission to acute hospital care within 30 days after end of the first hospital episode
- Readmission to acute hospital care within 30 days after end of the acute hospital care in the first hospital episode
- Complications during the first hospital episode:
    - pulmonary embolism
    - acute myocardial infarction
    - phlebitis and thrombophlebitis
    - pneumonia

Adjusting for patient mix

Comparisons of health outcomes between countries need to take into account differences in the patient mix. In addition, countries may differ in the degree to which the relevant information is

recorded, the availability of patient information, or variables being very differently defined across countries. In order to the performance indicators to be comparable, the indicators have to be adjusted for confounding factors.

In EuroHOPE this problem was tried to solve by using all relevant registry data available for everyone with a specified health problem, by collecting available information on disease specific comorbidities, length of hospital stay and medication use prior to the occurrence of the health problem studied - variables potentially having an effect on health outcomes. However, this does not alleviate the problem arising from the potential existence of differences between countries in registering this information.

Three different risk-adjusted outputs are produced for each outcome:

1. adjusted for sex and age
2. adjusted for sex, age, disease-specific comorbidities based on primary and secondary diagnoses[6], the number of hospital days (LOS) the year prior to index admission
3. adjusted for sex, age, disease-specific comorbidities based on primary and secondary diagnoses and medication purchases, LOS the year prior to index admission.

Based on the experiences in the PERFECT project (Peltola et al., 2011), the observed/expected approach described by Ash et al. (2003) is used - this roughly corresponds to indirect standardization. Specifically, the method uses regression modelling for the risk adjustment. For mortality outcomes up to one year, logistic regression is used, while for the LOS outcomes, negative binomial regression is used. In each country, a common indicator-specific set of coefficients for each factor included in the risk-adjustment is used for calculation the predicted values for the outcome in question. The coefficients applied for calculating the predicted values for each outcome are based on the estimates acquired from the Finnish national comparison data covering the years 2006 to 2013. The coefficients will be updated as data from other countries is available. The method is described in greater detail in Moger and Peltola (2014).

Each country will apply a standardized, centrally-constructed Stata syntax code to the national comparison database for calculating the country and regional level indicators. The national files were processed with a common script in order to enable standardized reporting of the data from all countries with minimum workload and minimized possibility of human error in processing the data. This Stata do-file is available upon request from the researchers.

Case-mix standardisation will be used when comparing countries, regions, hospitals, or years. Variables which are considered potential prognostic factors (and thus confounders) are used for adjustment. These will be derived from primary and secondary diagnoses of previous discharge data and from data on previously prescribed medicines. We will use the following variables:

[6] Hypertension, coronary heart disease, atrial fibrillation, cardiac insufficiency, diabetes mellitus, cancer, chronic obstructive pulmonary disease and asthma, dementia, depression, Parkinson's disease

- age (in years, classified)
- gender
- comorbidity as defined in separate file (only the comorbid diseases with at least 1% prevalence in the study population in each country of the EuroHOPE partners' data in the year 2007 were included in the risk adjustment as confounding factors: atherosclerosis, renal insufficiency, mental disorders and alcoholism were not included in the risk adjustment as comorbidities)
- inpatient hospital stay days during one year prior to stroke in acute inpatient hospital care.

Levels of analysis

Indicators are produced annually at the national level by types of stroke (ischemic stroke, intracerebral haemorrhage, subarachnoid haemorrhage, and ill-defined stroke). For ischemic stroke indicators are calculated also at the regional level and at the hospital level. Regional information is based on patients' place of residence. The definitions for regions have been made in each country according to the local preferences. The definitions for a region and for a hospital are described in Appendix 3.

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Appendix 1. National registers and data sources used in National databases

To be updated: only data used in the project will be included (years, countries).

Hospital discharge register for inpatient care	
Denmark	2005-2014
Finland	2005-2014
Italy	
Hungary	2005-2015
Norway	2008-2015
Spain	
Sweden	2005-2014

Register on use of outpatient services in hospitals and/or other specialist units	
Denmark	2005-2014
Finland	2005-2014
Italy	
Hungary	2005-2015
Norway	
Spain	
Sweden	

Register on prescribed medication	
Denmark	2005-2014
Finland	2005-2014
Italy	
Hungary	2005-2015
Norway	2004-2015
Spain	
Sweden	2005-2014

Causes of death	
Denmark	2005-2013
Finland	2005-2014
Italy	
Hungary	NA (dates of death available for 2005-2015)
Norway	2004-2015
Spain	
Sweden	2005-2014

Appendix 2. Procedure codes used in countries to identify procedures in treatment of stroke

Stroke		Codes						
OPE	**Procedure**	**Denmark**	**Finland**	**Hungary**	**Italy**	**Norway**	**Spain**	**Sweden**
CEA	Thrombendarterectomy of arteries of aortic arch and branches	KPAF*	PAF*	1182				PAF10, PAF20, PAF21, PAF21, PAF22, PAF30, PAF40, PAF99
IET	Intracranial endovascular thrombolysis	KAAL10	AAL10	1171, 1172, 1173, 1177				AAL10
ANE	Ligature or endovascular occlusion of intracranial aneurysm	KAAC0*, KAAL00	AAC00, AAL00	1174, 1175				AAC00, AAL00
HAE	Evacuation of traumatic intracerebral haematoma or spontaneous intracranial haematoma	AAD15, KAAB30	AAD15, AAB30	50100				AAB30, AAD15
SHU	Shunt operations on ventricles of brain or intracerebral cysts	KAAF*	AAF*	50232				AAF00, AAF05, AAF10, AAF15, AAF20, AAF25, AAF30, AAF35, AAF40, AAF45, AAF99
CT	Computed tomography (of the brain)		AA1AD, AA1BD, AA1CD, AA1DD	34410, 34490, 34491				AA011, AA012, AA013, AA014
OTH	Other operation of nervous system	KA* (excluding codes above)	A* (excl. codes above)					A* (excl. codes above)

Appendix 3. Regions used in reporting of indicators in EuroHOPE countries

Country	Description	Number of regions	Average population size
Finland	Hospital districts and hospital regions responsible for providing specialised health care. Smallest districts combined.	19	280 000
Denmark	Administrative regions.	5	1 000 000
Hungary	19 counties and Budapest area providing self-governmental administrative duties (not health care).	20	500 000
Italy	Counties of the Friulia-Venezia Giulia autonomous region. Counties responsible for providing health care.	4	300 000
Norway	Hospital trusts responsible for providing specialist health care in their geographical areas.	20	250 000
Spain			
Sweden	Counties responsible for providing health care.	21	450 000

Appendix 4. Guidelines and steps for building the National stroke database

This example shows how the Finnish database is formed. However, there will certainly be differences in each country and thus these steps have to be modified accordingly.

1st step: screening inpatient database for patients

Screen hospital database (hospital discharges/hospital department discharges, inpatient social care), from the year 2004 onwards for records with stroke (ICD-10: I60*, I61*, I63*, I64*) as main diagnosis in all hospital stays (hospital departments).

2nd step: screening mortality register database for stroke patients treated at hospitals

Take patient IDs from the first step and gather their information on date of death and causes of death and place of death.

3st step: screening mortality register database for stroke patients not having hospital care (not possible in all countries)

Screen national mortality database from the year 2006 onwards for records with main diagnosis (ICD-10: I60*, I61*, I63*, I64*). Take patient ID and main diagnosis of death, date of death and place of death.

4th step: merge data

Merge data from steps 1, 2 and 3 together with patient id in order to create a stroke ID data that includes four elements:

i. patient ID
ii. main diagnosis of death (if available)
iii. place of death (in hospital / outside hospital)
iv. date of death
v. other reasons of patient drop out (eg. moving from the country).

5th step: **1st data set, stroke (prevalence) (1)**

Take patient IDs from the fourth step and gather their **all records** from hospital records.

6th step: 2nd data set, all patients in hospital care due to stroke (2)

Exclude all patients that have not been in hospital care in the year under consideration due to stroke.

7th step: National comparison data (3)

Make the exclusions given in section 2.

Constructing the Finnish databases

Figure A1 describes the construction of Finnish stroke data from the year 2013. Total prevalence of stroke was 15 234. Of these 868 (6 %) had not been in hospital because of stroke in 2013.

The Finnish Care Register for Health Care (FCRC) includes data from various hospitals (e.g. rehabilitation hospitals, health centers). In order to make the patients more comparable with hospital register in other countries we have excluded patients that had been only in health centers and other hospitals in departments without specialty code or whose specialty code is general medicine. This further decreased the number of patients by 2 117.

Table A1 describes development (2006-2013) of the structure of stroke data. The structure has been rather stable during time period.

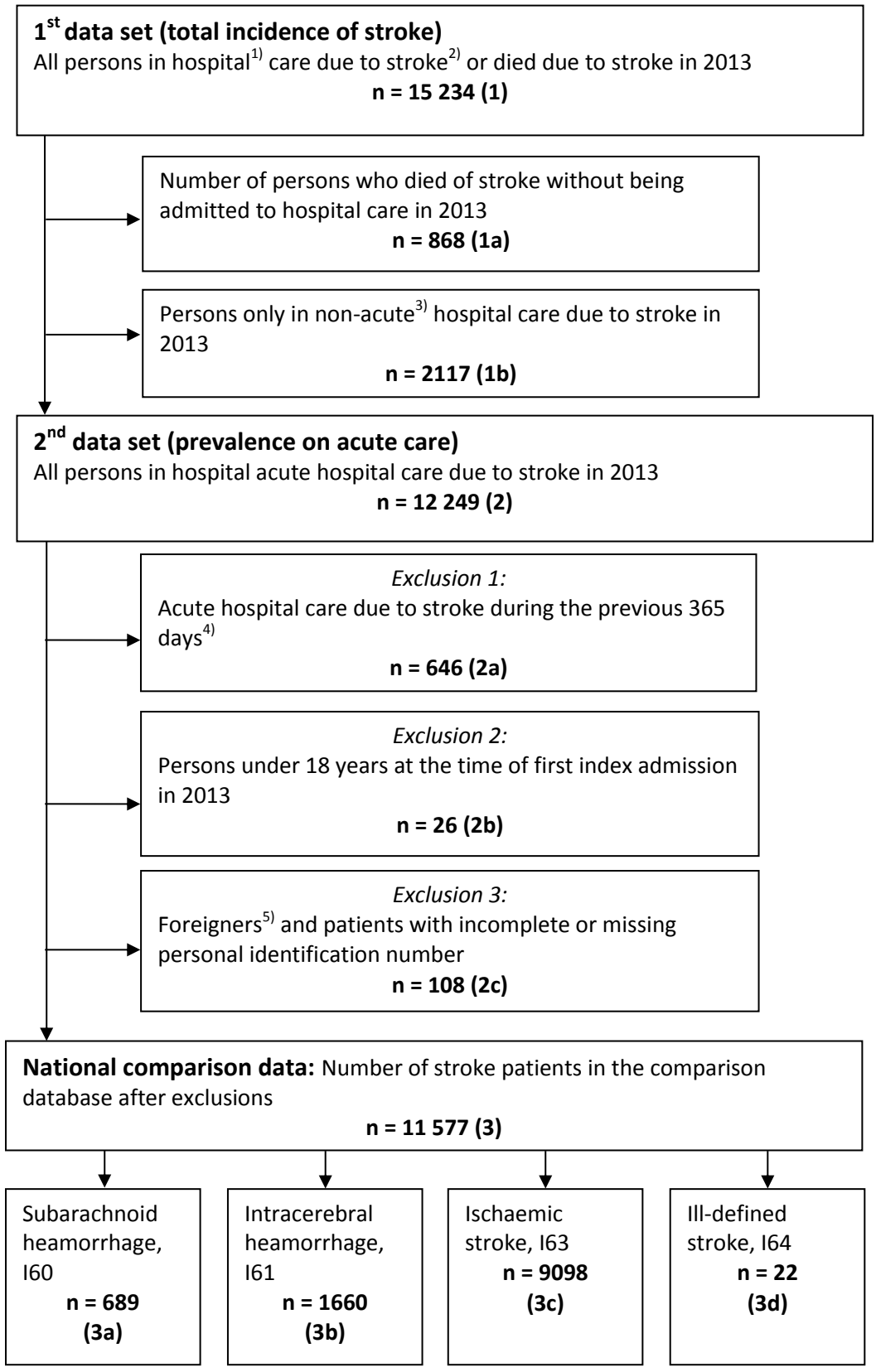
1st data set (total incidence of stroke)
All persons in hospital1) care due to stroke2) or died due to stroke in 2013
n = 15 234 (1)
Number of persons who died of stroke without being admitted to hospital care in 2013
n = 868 (1a)
Persons only in non-acute3) hospital care due to stroke in 2013
n = 2117 (1b)
2nd data set (prevalence on acute care)
All persons in hospital acute hospital care due to stroke in 2013
n = 12 249 (2)
Exclusion 1:
Acute hospital care due to stroke during the previous 365 days4)
n = 646 (2a)
Exclusion 2:
Persons under 18 years at the time of first index admission in 2013
n = 26 (2b)
Exclusion 3:
Foreigners5) and patients with incomplete or missing personal identification number
n = 108 (2c)
National comparison data: Number of stroke patients in the comparison database after exclusions
n = 11 577 (3)
Subarachnoid heamorrhage, I60
n = 689
(3a)
Intracerebral heamorrhage, I61
n = 1660
(3b)
Ischaemic stroke, I63
n = 9098
(3c)
Ill-defined stroke, I64
n = 22
(3d)

Figure A1. Creation of the Finnish comparison database for stroke in 2013

1) Hospital care is defined as inpatient hospital care only.
2) Stroke is defined according to the main diagnoses of I60, I61, I63, I64 (ICD-10).
3) Non-acute hospital care includes care given in health centres and other hospitals in departments without specialty code or specialty code is general medicine.
4) Counting starts from the first index admission in 2013.
5) In Finland all patients whose home municipality is Åland or unknown are excluded from the comparison database.

Table A1. Construction of stroke databases in Finland 2006-2013

Data	2006	2007	2008	2009	2010	2011*	2012	2013
1	**15 556**	**15 638**	**15 554**	**15 655**	**15 547**	**15 072**	**15 658**	**15 234**
1a	962	1 095	1 027	1 019	941	558	858	868
1b	2 354	2 363	2 271	2 266	2 395	2 167	2 169	2 117
2	**12 240**	**12 180**	**12 256**	**12 370**	**12 211**	**12 347**	**12 631**	**12 249**
2a	796	750	704	730	721	669	669	646
2b	23	29	24	37	31	33	38	26
2c	127	149	115	127	128	119	159	108
3	**11 400**	**11 386**	**11 523**	**11 596**	**11 456**	**11 642**	**11 921**	**11 577**
3a	847	819	823	793	786	800	691	689
3b	1 610	1 569	1 651	1 574	1 645	1 636	1 691	1 660
3c	8 792	8 817	8 907	9 072	8 859	9 065	9 370	9 098
3d	45	47	32	37	41	25	13	22

* Some deaths are missing