S·A·F·E

Stroke Alliance For Europe

THE STROKE PATIENT VOICE IN EUROPE

THE BURDEN OF STROKE IN EUROPE

Report

King's College London

for the

Stroke Alliance for Europe (SAFE)

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CONTENTS

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Foreword

Across Europe over the last two decades there has been a welcome reduction in the proportion of people having a stroke (when taking age into account). And people's chance of recovering from their stroke has greatly improved. Europe boasts some of the best stroke care in the world, has pioneered important developments in the prevention and treatment of stroke, has an active stroke research community and has patient advocacy organisations in almost every country.

But, despite this progress, the numbers of strokes are set to rise because the proportion of Europeans over 70 is increasing. The projections in this report indicate that between 2015 and 2035, overall there will be a 34% increase in total number of stroke events in the EU from 613,148 in 2015 to 819,771 in 2035. Stroke prevention should, therefore, be a high priority. Despite most European countries having guidelines for risk factors such as high blood pressure and atrial fibrillation, there is significant under-treatment. And well below half of all people treated for high blood pressure, for example, are actually on enough medication to get their blood pressure below the desired target level.

While death rates from stroke have been falling over the last twenty years, your chance of dying from a stroke varies greatly according to where in Europe you live. Currently, rates of deaths from stroke in different countries range from 30 per 100,000 of the population to 170 per 100,000 of the population. Falling death rates due to better and quicker treatment mean that there will be more people surviving their strokes and living with the consequences. So the estimated total cost of stroke in Europe (healthcare and non-healthcare costs) of an estimated 45 billion euros in 2015 is set to rise.

When it comes to stroke care, the inequalities across the continent are apparent. For example, in some European countries we are concerned about how effective public education campaigns to encourage an emergency response to stroke are. But in many places across Europe emergency services specialised in stroke simply do not exist. Thrombolysis (clot-busting treatment) rates vary from less than 1% of patients to 16%.

Despite over thirty years of evidence showing the difference stroke units make, only about 30% of patients receive stroke unit care across Europe. The proportion of people who get treated on a stroke unit varies from less than 10% to over 80%, depending on where you live. Existing European Stroke Organisation guidelines are not consistently applied and a continent-wide, evidence-based system of specialist stroke care is yet to be realised.

Access to rehabilitation and long-term support is also a significant issue in many parts of Europe. Provision of rehabilitation is not widely monitored in many parts of Europe and even where there are audits, people often receive therapies during only brief periods of each day in hospital. In several countries there is very limited access to therapies once people are at home. There are no outpatient therapy services in two out of every five EU countries.

SAFE commissioned the Burden of Stroke study to show each EU country where it stands in terms of the stroke burden and how well it is meeting the need for acute and follow-up care, including examples of good practice. The research findings for this report have led SAFE to generate a number of action points for EU policy makers, national health service representatives and stroke support organisations.

SAFE is a non-profit-making organisation that represents a range of stroke patient groups from across Europe whose mutual goal is to drive stroke prevention and care up the European and national political agendas, prevent the incidence of stroke through education and support stroke care and patient centred research. SAFE aims to raise awareness of the major impact stroke has on individuals and on the health and economy of Europe.

Jon Barrick, SAFE President

INTRODUCTION

Background

Stroke is a brain attack, affecting 17 million people worldwide each year. It is the second most common cause of death[1] and a leading cause of adult physical disability[2].

Stroke survivors can experience a wide range of outcomes that are long-lasting, including problems with mobility, vision, speech and memory; personality changes; fatigue; and depression[3, 4].

SAFE commissioned King's College London to produce a white paper describing the burden of stroke globally for publication in 2007. At the time of writing that report, there was no up to date, comprehensive assessment of the numbers of people having stroke, dying from stroke or living with disability as a result of stroke in most European Union countries. Since then, a large global and regional study of these numbers has been undertaken as part of the Global Burden of Diseases, Injuries, and Risk Factors Study[5]. The present study uses the most recent available data to describe stroke epidemiology, prevention and care across the EU.

Scope of the study and methods

In order to frame the study and enable comparisons across countries and regions, SAFE required the inclusion of a number of indicators of stroke care quality. There are potentially many such indicators that could have been included; to keep the study manageable in the available time, a shortlist of 12 indicators was chosen (Appendix 2.1) in discussion with colleagues at King's College London and SAFE to reference different parts of the stroke care 'pathway', from prevention to long-term care and support.

Information on these indicators and the epidemiology of stroke in each country was gathered through reviewing the scientific literature and by consulting with stroke researchers, clinicians and stroke support organisation representatives.

Structure of the report

The report is structured to reflect the stroke care pathway, and focuses on the 12 stroke care quality indicators. Each chapter starts with a brief, accessible introduction to the content.

Chapter 1 describes variations across Europe in the number of people who have strokes, and explains some of the key terminology and data sources. It estimates the future epidemiological picture for stroke in Europe.

Chapter 2 focuses on stroke prevention. It considers the provision of educational campaigns for the public, and describes how well (or inadequately) important stroke risk factors are being managed at population level.

Chapter 3 focuses on stroke as a medical emergency. It summarises evidence from different European countries of the level of public awareness of acute stroke symptoms, the existence of relevant training for healthcare professionals, and the impact of pre-hospital notification systems.

Chapter 4 describes the availability of organised acute stroke care, i.e. stroke unit care, and delivery of thrombolysis. It highlights the significant variation in availability and standardisation of stroke unit care across Europe, and explores some of the barriers to delivering thrombolysis.

Chapter 5 summarises the available data on hospital-based and community rehabilitation in the different countries, and longer term support for stroke survivors and their families from statutory and voluntary agencies.

The Recommendations section consolidates a number of action points proposed by SAFE board members, based on the evidence in this report and prioritised according to the advocacy interests of SAFE's member organisations.

A summary of stroke epidemiology and data on the 12 stroke care quality indicators is provided for each EU and SAFE member country in a separate publication (see www.strokeeurope.eu).

RECOMMENDATIONS

SAFE's call to action to EU policy makers

The inequalities in stroke risk and stroke provision across Europe revealed in this report should be of great concern to European policy makers, especially as we predict a 34% rise in the number of people having strokes by 2035. SAFE wants a Europe where everyone has the opportunity to prevent a stroke, and those who do have a stroke get treated as quickly as possible in a stroke unit; get the assessment and rehabilitation they need to maximise their recovery; and get the long term support they need to regain as much independence as possible. And we are concerned that the lack of unified data on stroke events and outcomes in Europe is a barrier to comparing stroke care both within and between different healthcare systems and, therefore, to improving stroke care.

SAFE believes that each EU member state should have a national stroke strategy actively supported and sponsored by Government that covers the whole stroke pathway to include awareness, prevention, diagnosis, treatment, transfer of care, specialist rehabilitation and reassessment, long-term care and support, social integration and participation in community life and end-of-life care. Representatives from the wide range of professionals who support people with stroke, people who have had a stroke, carers and voluntary associations should all be involved in creating such strategies.

Therefore, SAFE calls on EU policy-makers (Commission, Parliament, Council) to:

Facilitate coordinated, Europe-wide data collection. In particular, the European Commission and the Joint Research Centre should support and promote the use of a robust Europe-wide stroke register including instruments to assess needs for prevention and care as well as the quality of care along the whole stroke pathway.

Incorporate the stroke indicators used in this report (e.g. blood pressure management, door-to-needle time, coordinated discharge and post-discharge rehabilitation assessment) in the EU's work on the evaluation of the performance of health systems, as they are good measures to assess the efficiency of care organisation and delivery in member states.

Support, together with Member States, a Joint Action on stroke, in the framework of the EU Health Programme. The Joint Action should focus on addressing the following topics: 1) data collection, 2) prevention, 3) promotion and implementation of national stroke strategies, and 4) performance assessment. Stroke Support Organisations (SSOs) should be actively involved in the Joint Action, and their crucial role throughout the stroke pathway, and in policy formation, should be enshrined in the national stroke strategies.

Support research into patient-reported experience, outcome measures and quality of life across Europe. This is linked to the need for more research on long-term management and support so that best practice and the effectiveness and cost-effectiveness of different models can be identified. SAFE believes strongly that patients and patient organisations/ SSOs should be actively involved in these studies as participants and co-researchers and that building the capacity for their participation is also vital.

What needs to change

The evidence in this report highlights improvements that are needed across the whole stroke care pathway. The wide disparities in provision between countries and the inequalities within countries found in this report should be of concern to all European policy makers as well as to national Governments and health planners.

The burden of stroke

There is a lack of unified data about stroke and stroke outcomes. Europe-wide comparisons of stroke and stroke care are vital to help each country prevent stroke and provide better care and support for everyone affected by stroke. To make accurate comparisons between different countries, populations and health systems we need agreed and coordinated Europe-wide data collection. Therefore, European policy-makers, in particular the European Commission and the Joint Research Centre, should support and promote the use of a robust Europe-wide stroke register to assess quality of care along the whole stroke pathway.

The number of people having a stroke and the number of people living with the long-term effects of stroke will rise in the coming decades. Effective health care planning and adequate resource allocation across Europe is needed to deal with this, taking into account that the financial burden of stroke is to a large extent borne by stroke survivors themselves and their families.

There are limitations to the current research evidence from the perspective of European stroke survivors (for example, it is largely based on small studies from mostly Western European countries). This research should be conducted more widely throughout Europe, and consolidated findings should be used to influence patient care. SAFE believes that these studies should actively involve stroke survivors and patient organisations.

Preventing stroke

A more systematic, evidence-based approach to public education across the EU is required to improve knowledge of the modifiable risk factors for stroke, i.e. an awareness that those risk factors significantly increase the risk of stroke but can be treated in most cases. Joining forces with public education efforts in relation to the other cardiovascular diseases could create a more powerful message and greater impact.

Current educational campaigns should be assessed for their effectiveness. Our understanding needs to go beyond measuring public knowledge and awareness to look at the extent to which they positively influence public behaviour over time. We should build on what works and make sure public education is both effective and cost effective. Innovative campaigning methods (such as: the use of social media, apps; collaborative campaigns in co-operation with other medical specialties; risk factor education in schools; and risk-factor checks in places such as workplaces or pharmacies) should be assessed.

Across Europe we need rapid and concerted action to prevent stroke and, especially, improvement in the detection and treatment of high blood pressure (hypertension) and atrial fibrillation (AF, an abnormal heart rhythm with rapid and irregular beating). Medical professionals and patients must both be involved through shared decision-making, in order to increase adherence to existing guidelines, and compliance with prescribed medications and frequent blood pressure checks.

Improvement in the diagnosis and management of AF is needed including systematic approaches to identifying and monitoring AF. The effectiveness and cost-effectiveness of AF screening policies of at-risk populations should be assessed in the respective health contexts of each country, as do new developments such as devices and apps for detecting AF, self-monitoring of INR, and new anti-coagulation therapies. A more systematic approach to monitoring guideline adherence (e.g. national or large regional audits), and possibly incentivising this adherence might improve treatment rates.

Timely assessment of suspected TIA patients in specialist clinics should be widely available.

Stroke as a medical emergency

SAFE calls for continuous and sustained awareness-raising campaigns across Europe so that more people understand stroke symptoms and treat stroke as a medical emergency. These should be included in national stroke strategies, financially supported by Governments and should include stroke survivors in their planning and implementation.

We need to know which public education campaigns across Europe have worked best, and why, so that success can be replicated. Systematic assessment of public health campaigns undertaken across Europe is required to prove their effectiveness and improve their impact. More collaborative working with voluntary sector organisations might improve the impact of campaigns.

There should be a more systematic approach towards training healthcare professionals, using evidence-based methods and on-going assessment of its implementation and effectiveness.

There is a need to improve emergency pathways in some centres in order to reduce Door-To-Needle times. Strategies will depend on the respective national, regional, and local health infrastructure.

Acute care

There are still far too few people across Europe being treated in dedicated stroke units with stroke specialist, multidisciplinary staff. Efforts are required, especially in Eastern European countries, but also many Western European areas, to increase the availability of stroke unit care and personnel specialised in stroke care.

Improvement plans should prioritise the consistent implementation of key elements of organised stroke unit care, as laid out in European Stroke Organisation (ESO) and national guidelines.

Comparisons of stroke unit care between European countries are difficult. Standardised, Europe-wide assessment criteria for stroke unit care would encourage international benchmarking and could drive quality improvement.

Thrombolysis is still under-performed across all of Europe. Structural changes to acute stroke care within the respective national and local context could help to improve thrombolysis rates and patient outcomes.

Thrombectomy is currently unavailable to the majority of European stroke patients. Organisational changes are required with hospital networks and regional referral centres in order to facilitate the implementation of thrombectomy across Europe and to make it more widely available.

Rehabilitation and long term support

Too many stroke survivors have to wait too long to get an assessment of their rehabilitation needs and to actually receive therapy. Across Europe the aim should be for multi-disciplinary assessments to take place on the stroke unit, and for rehabilitation to start as soon as someone is medically stable.

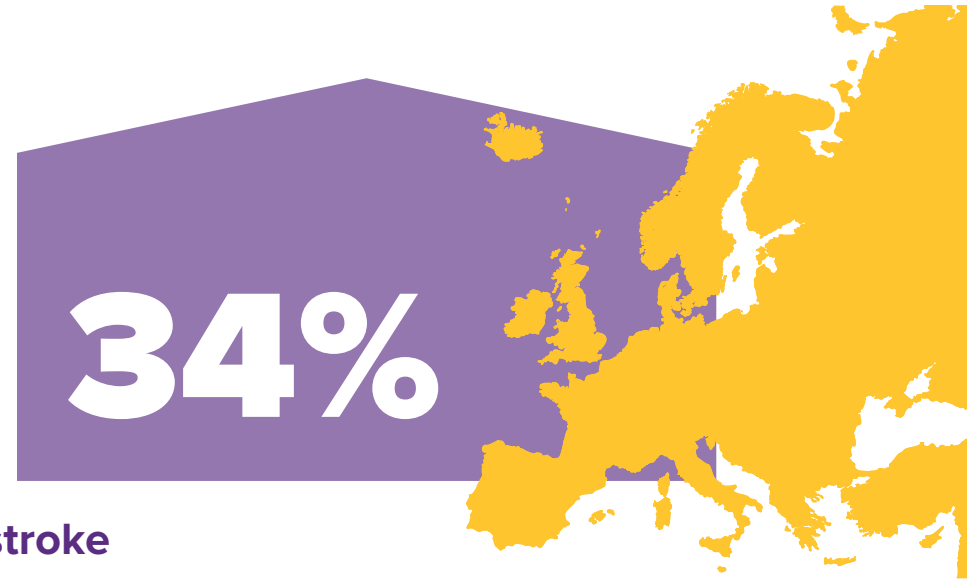
Access to rehabilitation therapy must be improved. There is a particular lack of occupational, speech and psychological therapy across Europe.

Too many stroke survivors leave hospital without on-going rehabilitation being in place. This is of particular concern for Early Supported Discharge (ESD) schemes. The evidence is clear that the effectiveness of ESD schemes relies upon access to rehabilitation at the same intensity as would have been provided on the stroke unit.

Ongoing, long-term support and follow up is inadequate in many parts of Europe. We call for national systems to be developed to ensure stroke survivors' needs are reviewed and followed up.

Countries should set targets for secondary prevention, screening for depression, and for psychological and social support.

EXECUTIVE SUMMARY



The burden of stroke

The rate of new strokes and stroke deaths, when adjusting for age, has decreased over the last two decades in all European countries. Decreasing rates of new strokes are generally attributed to **successful prevention strategies,** e.g. hypertension control and smoking cessation. On average, improvements have been larger in Western European countries - increasing the already existing difference between East and West.

However, due to the ageing of the European population and the strong association between stroke risk and age, the numbers of people having a stroke continues to rise. Using data from the Global Burden of Disease study 2015, and demographic projections obtained from Eurostat (statistical office of the EU), a 34% increase in total number of stroke events in the EU between 2015 and 2035 is predicted.

Together with the welcome improvement in survival rates, there are **increasing numbers of people living with the effects of stroke**, needing specialist supportive care and rehabilitation, resulting in a growing burden of stroke on families, societies and health care systems.

In 2015, direct healthcare costs alone added up to €20 billion in the EU, while indirect costs of stroke due to the opportunity cost of informal care by family and friends and lost productivity caused by morbidity or death were estimated to be another €25 billion. Reducing the incidence of stroke and the likelihood of long-term disability will help to bring down these costs[6, 7].

Preventing stroke

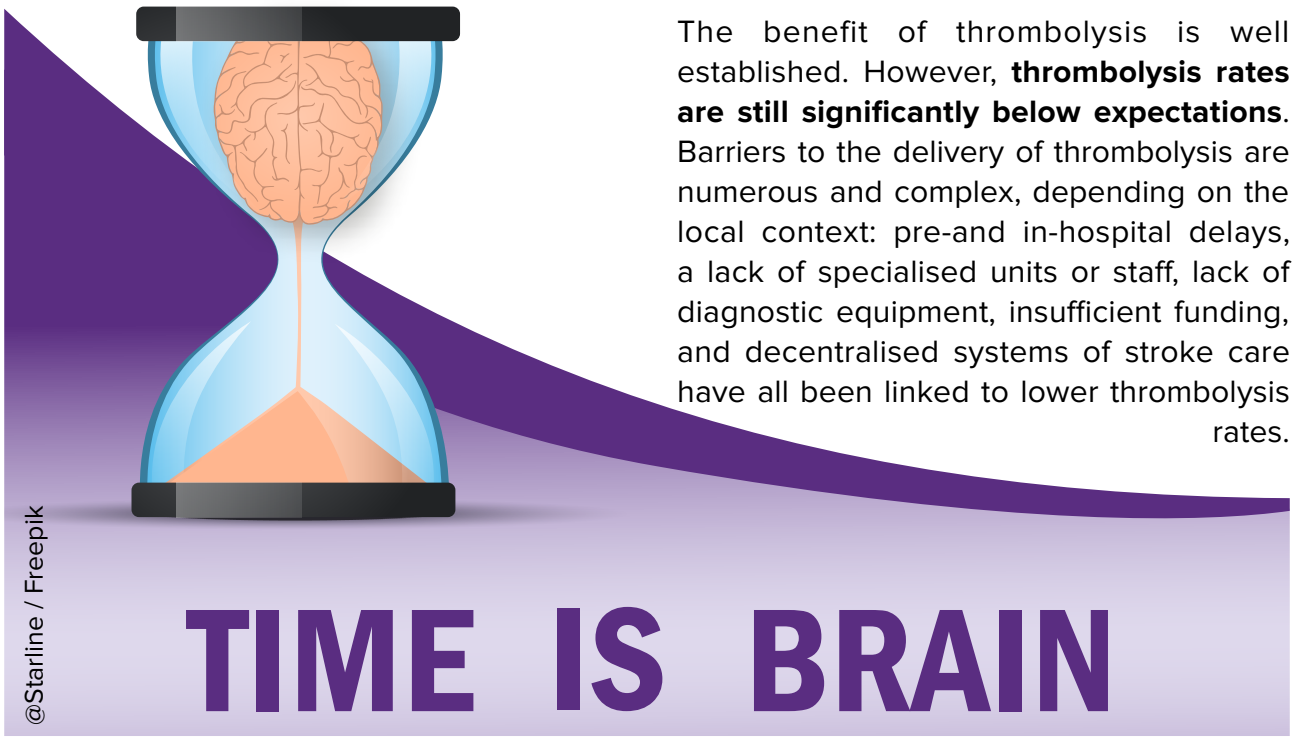
Stroke is preventable, but **public knowledge about the risk factors for stroke is low**. The impact of educational campaigns aiming to change behaviour is largely short-lived.

The proportion of the population with one or more risk factors for stroke is significant. **High blood pressure, the most important risk factor for stroke, is significantly under-treated**. The proportion of people with known high blood pressure who achieve adequate blood pressure control is well below half. Atrial fibrillation (AF, an abnormal heart rhythm with rapid and irregular beating), another important risk factor, is often not diagnosed until after a stroke event, or not treated according to widely available, national, evidence-based guidelines.

Emergency care

In stroke care, "time is brain": patients with suspected stroke need to be admitted to hospital wherever possible, assessed and treated as appropriate within a few hours, to improve their outcomes. However, **public awareness of stroke as a medical emergency is poor**. An international European study showed that about one in five people could not identify any stroke symptoms and o**nly about half would call an ambulance**. Many educational campaigns are being undertaken, but most are not systematically evaluated for their impact.

Similarly, in most European countries there is no evidence that training of medical staff involved in emergency stroke care is implemented and monitored systematically. **Many regions have improved their pre- and in-hospital emergency care pathways**. There is an opportunity to learn from these experiences and try to replicate them elsewhere.



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Stroke Units

Improvements in survival have been made particularly since the implementation of **stroke units and thrombolysis (clot-busting)** treatment. There have been significant increases in the number and quality of stroke units in Europe. However, despite their inclusion in European and national guidelines, it is estimated that **only about 30% of European stroke patients receive stroke unit care**. Variations between countries, but particularly also between different areas within countries, are large. Rural and remote areas often have poor access.

In order to improve the quality of care received in stroke units, internationally agreed standards of stroke unit care based on evidence and expert opinion have been developed. A **system of official accreditation** has been introduced on a European level, and also national level in several countries, but uptake is very variable as it is mostly voluntary.

The benefit of thrombolysis is well established. However, **thrombolysis rates are still significantly below expectations**. Barriers to the delivery of thrombolysis are numerous and complex, depending on the local context: pre-and in-hospital delays, a lack of specialised units or staff, lack of diagnostic equipment, insufficient funding, and decentralised systems of stroke care have all been linked to lower thrombolysis rates.

Rehabilitation and supporting longer-term needs

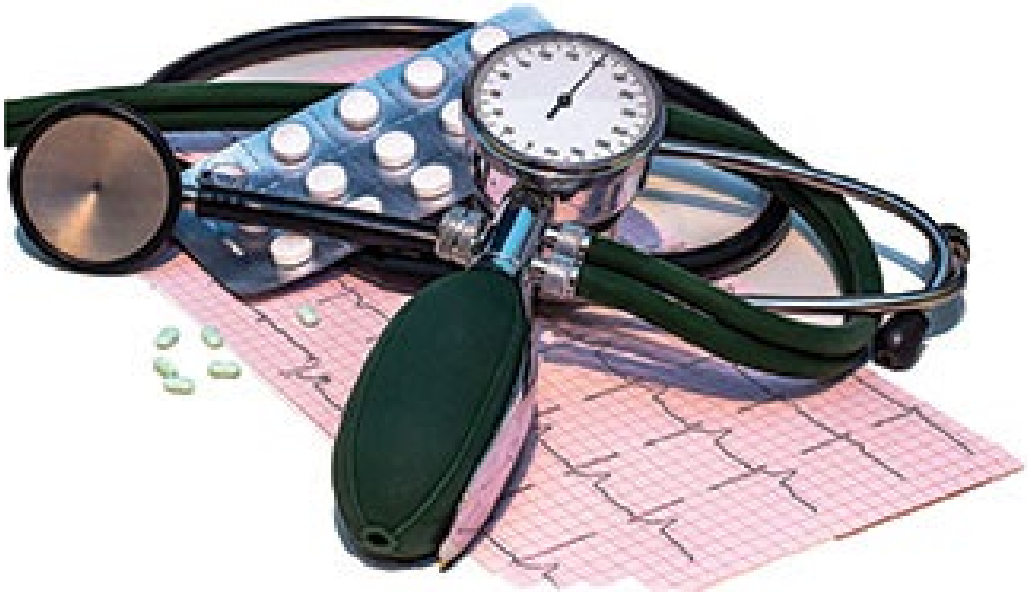
For many countries, **there is very little information on the rehabilitation therapies that stroke survivors receive**, especially once they have left hospital. Few countries audit rehabilitation services, and there are inconsistencies in the standards used to measure adherence to guidelines across Europe.

The type and quality of therapies that patients can access often depend on where they live. For example, specialist rehabilitation may only be available in large urban areas. Occupational therapy and psychological support are either very limited or not available at all to stroke patients in several countries. **Patients can experience long delays in starting rehabilitation** because of a lack of capacity in rehabilitation centres or in the community.

Once patients have been discharged from acute care, **access to further rehabilitation is also very variable between and within countries**. In around two in five EU countries, outpatient therapies are not generally available. Only a small minority of EU countries have local arrangements to offer stroke survivors a follow-up review with a therapist or doctor, and again, actual practice can vary substantially within a country.

Health insurers and national health authorities rarely offer support with adjusting to life after stroke, such as programmes to support people who want to return to work. In the last 5-10 years most European countries have cut funding of some services that support disabled people, such as training that helps people return to work.

Stroke support organisations (SSOs) exist at a national level in nearly all EU countries. They aim to offer practical, emotional and advocacy support for stroke survivors and their families and, often, promote stroke prevention awareness and action. There is a need for more information on the reach and impact of SSOs.



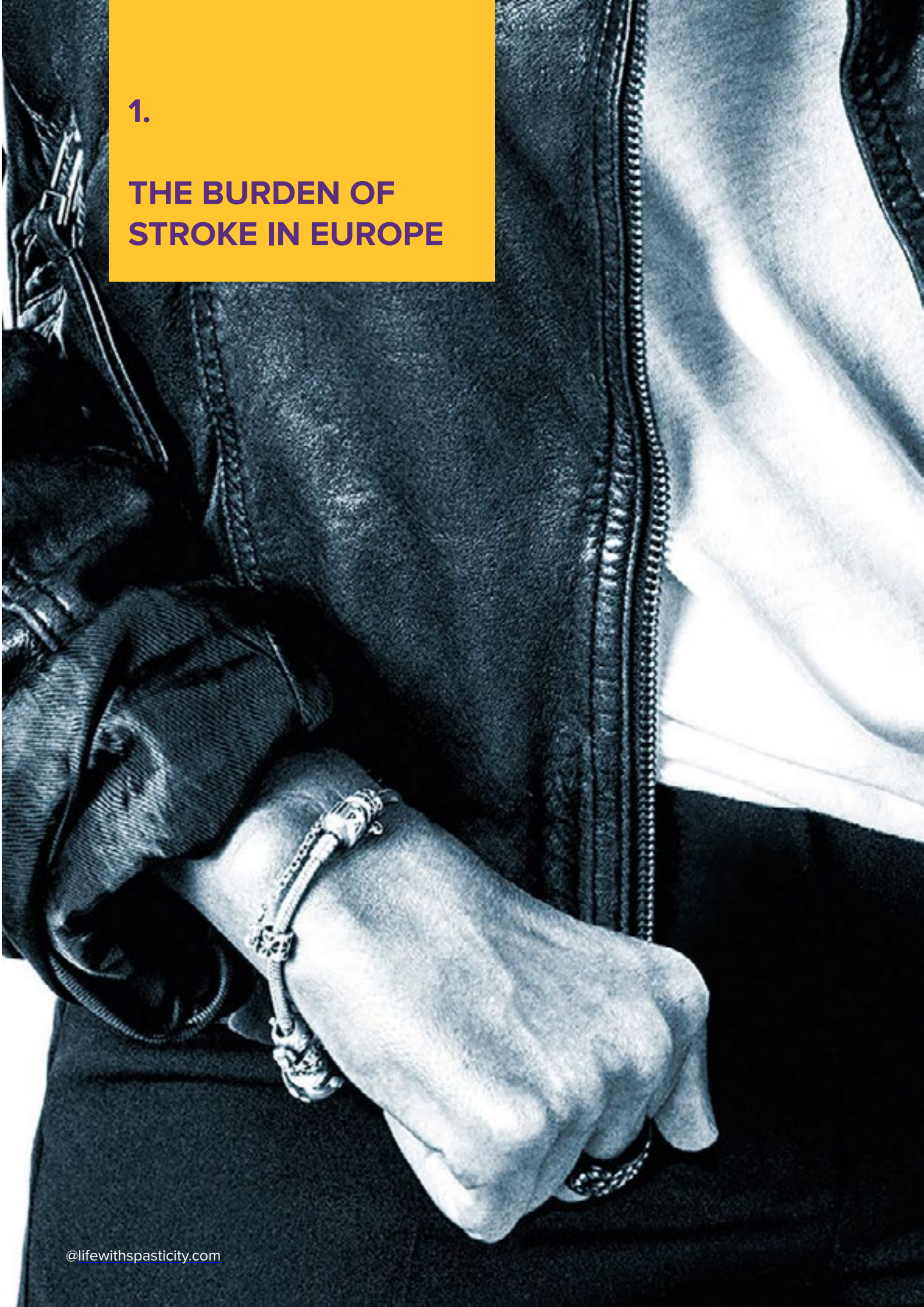
Indicators

In order to frame the study and enable comparisons across countries and regions these indicators were chosen in discussion with colleagues at King's College London and SAFE to reference different parts of the stroke care 'pathway', from prevention to follow-up care and support.

Indicator	Report section
1. Campaigns to encourage healthy lifestyles (e.g. blood pressure and cholesterol awareness and monitoring)	2.1
2. Blood pressure is checked regularly and treated according to guideline	2.2
3. Adults with atrial fibrillation at increased risk of stroke are treated appropriately with anticoagulants	2.3
4. Public campaigns and professional education emphasise that stroke is a medical emergency	3.1 and 3.2
5. Emergency services (ambulance) staff are trained to screen patients for suspected stroke/TIA and arrange immediate transfer to hospital	3.2
6. In-hospital services offer organised stroke care (stroke unit care)	4.1
7. Patients are assessed for thrombolysis and receive it (if clinically indicated) as soon as possible after the start of stroke symptoms	4.2
8. Patients with suspected TIA are urgently assessed for subsequent stroke risk	2.4
9. Patients are assessed for rehabilitation needs within the first three days after admission and provided with rehabilitation by multidisciplinary staff on the basis of need	5.3
10. Early discharge from acute care (to inpatient rehabilitation unit or to community) is supported for medically stable patients with mild or moderate impairment	5.4
11. Patients are offered a review after the stroke for assessment of medical and rehabilitation needs	5.5
12. Patients and their family/carers have access to practical and emotional support	5.7

1.

THE BURDEN OF STROKE IN EUROPE



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This section outlines the number of strokes, deaths from stroke, and people living with stroke across Europe. It includes predictions about what the burden of stroke will be in 2035 and looks at the financial and societal cost of stroke.

"While I was having a shower I suddenly felt like something had exploded in my head. I was not able to speak any more and I felt like the right side of my body had disappeared."

(Female stroke survivor, Netherlands)

1.1 What is being measured?

It is important that we have reliable information about the number of people across Europe who have a stroke and what happens to them. What services and support do they get? To what extent do they recover? How well are health and social services doing and how do we improve outcomes? What is the economic impact of stroke on individuals and also on society? What resources are needed to make sure everyone who has a stroke gets the help they need?

The way that information about stroke is gathered varies widely across Europe and there are pros and cons about different sets of information. National stroke registers and audits (e.g. in Austria, Denmark, Finland, Germany, Hungary, Ireland, Israel, Poland, Sweden, UK)[8] are a rich source of information but generally only pick up hospitalised patients. So, for example, while 85% of cases are picked up in this way in Finland, Sweden and Denmark; in Poland less than 40% of stroke patients are included.

Example from Estonia: Three stroke audits have been initiated by the Estonian Health Insurance Fund in 2003, 2010 and 2013 aiming to analyse acute stroke management in Estonia. Approximately one percent of all annual stroke cases have been randomly selected from all (18) hospitals. 5 experts using a unified protocol have reviewed medical documents. Neurologists from the Estonian L. Puusepp Society of Neurologists and Neurosurgeons have conducted the audits. Feedback has been given to all health care providers and the results have been published in the national medical journal "Eesti Arst".[9]

Population based registers, looking only at a smaller geographical area, overcome this problem by including reports from general practitioners (GPs) and outpatient departments, for example, and also have the advantage of providing the potential to measure the longer term outcomes of stroke survivors.

For this report, various types of data have been used. Most studies differ in their epidemiological and statistical methods, so comparing between them has to be done carefully. This report aims to present the most comparable data from different countries in order to show trends across Europe.

The most common measures used are:

Incidence – the number of new strokes.

The incidence of stroke depends on risk factors that can't be changed, such as age, and risk factors that are modifiable, such as high blood pressure or smoking. The number of people having a stroke is, therefore, influenced by prevention measures.

Mortality – the number of people who die as a result of their stroke.

This is linked to how severe someone's stroke is, but also to the quality of stroke care, particularly acute stroke care. Measuring "case fatality" (the number of stroke deaths within a month of having the stroke), is strongly linked to the provision of emergency and acute stroke care.

Prevalence – the number of stroke survivors in the population.

The number of stroke survivors captures stroke as a long-term condition and points to the level of rehabilitation needs that should be met.

Disability Adjusted Life Years lost (DALYs lost):

combines morbidity (the number of years lived with a certain level of disability) and mortality, thereby estimating the number of healthy life-years lost in a population due to an illness. It is useful for measuring the long-term societal burden of stroke.

So, what do the data show?

1.2 Incidence – how many people have a stroke?

There is great variation in the reported number of strokes as a proportion of the population between different studies. Some of the variation is due to real differences in stroke incidence between different countries and regions. But some of this variation is also due to the different criteria and methods used to collect the data. Despite this some trends do emerge.

Table 1 shows that there are major differences in stroke incidence rates across Europe. Some of the highest rates are in Eastern and Northern Europe (Croatia, Estonia, Lithuania, Sweden); and some of the lowest are in Western and Southern European countries (France, Italy, Spain).

This is similar to findings from the European Registers of Stroke project[10]. Large variations in incidence are also seen within countries (e.g. Italy, Spain, Sweden, UK).

Possible explanations for these large inter- and intra-country differences include different risk factor profiles (e.g. high blood pressure or cholesterol, smoking, diet, alcohol, exercise), socio-economic and environmental factors (air pollution, deprivation), but also standards of and access to healthcare, leading to different levels of risk factor control, and of acute and long term care.

"I never had before thought about that disease; I had no way of [knowing], nobody in the family had ever had a stroke. I thought everything was fine, and I was relatively young. I was 47."

(Female stroke survivor, Austria)

Table 1: Annual incidence rates of first-ever stroke since 2000 reported by population-based registers in European/SAFE countries, ranked by magnitude of incidence

Country / Region or town	Study period	Incidence rate standardised to the population of	
Sweden / Orebro[11]	1999-2000	254	Europe
Lithuania / Kaunas[10]	2004-2006	239 ♂, 159 ♀	Europe
Croatia / north-west area[12]	2007-2009	224	Europe
Portugal / Porto[13]	2009-2011	203	Portugal
Estonia / Tartu[14]	2001-2003	188	Europe
Portugal / Porto[15]	1998-2000	181	Europe
Iceland[16]	2007-2008	177	England & Wales
UK / Oxford[17]	2002-2004	162	England & Wales
Italy / Sicily[18]	1999-2000	154	Europe
Italy / Puglia[19]	2001-2002	150	Europe
UK / South London[20]	2007-2010	150	England & Wales
Spain / multi-centre[21]	2006	147	Europe
Germany / Ludwigshafen[22]	2006-2007	146	Europe
Sweden / Lund-Orup[23]	2001-2002	144	Europe
Poland / Warsaw[10]	2005	147 ♂, 126 ♀	Europe
Poland / Zabrze[24]	2006-2006	131	Europe
Italy / Valley d'Aosta[25]	2004-2005	126	Europe
Germany / Erlangen[26]	2009-2010	127 ♂, 117 ♀	Europe
Ireland / North Dublin[27]	2006	118	World
Spain / Menorca[10]	2004-2006	116 ♂, 66 ♀	Europe
UK / Scotland[28]	1998-2000	110	World

Table 1: continued

Country / Region or town	Study period	Incidence rate standardised to the population of	
France / Dijon[29]	2000-2006	107	Europe
Italy / Udine[30]	2007-2009	104	Europe
Italy / Siesto Fiorentino[10]	2004-2006	101 ♂, 63 ♀	Europe
France / Brest[31]	2010	84	World
Italy / Valley d'Aosta[32]	2004-2008	80	World

Measuring stroke incidence or fatality over time can help to evaluate the impact of changes in prevention and acute care. For example, in Portugal falling incidence rates and improved stroke outcomes in two register periods correlated with changes in national stroke prevention and treatment strategies[13] (Table 2). Stroke fatality declined in Zagreb (Croatia) after the introduction of stroke unit care[33] (Table 3).

Table 2 shows that overall there has been a significant reduction in the age standardised rate of stokes since 1980. This trend has been noted for high-income countries in other studies. Population-based registers reported an average decrease in stroke incidence of 42% in those countries (from 163/100,000 in 1970-9 to 94/100,000 in 2000-8, standardised to the world population), compared to a 52% increase in low and middle-income countries[34]. The assumption is that the fall is due to implementing successful risk reduction programs such as tobacco control and managing hypertension.

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Table 2: Annual incidence and case fatality rates (at 1 month) in population-based registers in Europe, ranked by falling, stable, or rising incidence rates

Country /Region or town	Population standardised to	Study period	Incidence rate per 100,000, or trend	Case fatality
Portugal / Porto[13]	Portugal	1998-2000	261	
		2009-2011	203	
UK / Oxford[35]	England & Wales	1981-1984	227	17.8%
		2002-2004	162	17.2%
UK / London[20]	England & Wales	1995-1998	247	25.4% *(not published)*
		2007-2010	150	14.0% *(not published)*
Germany / Erlangen[26]	Europe	1995-1996	176 ♂, 130 ♀	
		2009-2010	127 ♂, 117 ♀	
Estonia / Tartu[36, 37]	Europe	1991-1993	230	30%
		2001-2003	188	26%
Finland / Turku[38]		1982-1992	Trend -1.8%	Trend: -3.8% ♂, -4.5% ♀
Italy / Valley d'Aosta[25, 32]	Europe	1989	177	31%
	World	2004-2005	126	19%
		2004-2008	100	16%
Lithuania / Kaunas[39]		1986-2012	Flat trend in first-ever strokes, increase in recurrences	Trend for ischaemic stroke: -4.0% ♂, -6.0% ♀
Denmark / Fredericksberg[40]	World	1972-1974	85	
		1989-1990	106	

Table 2: continued

Country /Region or town	Population standardised to	Study period	Incidence rate per 100,000, or trend	Case fatality
France / Dijon[29, 41]	Europe	1985-1989	81	17.8%
		2000-2006	107	10.0% (2000-2004)
Sweden / Lund-Orup[23]	Europe	1983-1985	134	15.4%
		1993-1995	158	15.4%
		2001-2002	144	14.3%
Poland / Warsaw[42]	Europe	1991-1992	111	43%
		2005	129	14.9%

Some long-running stroke registers have reported increasing incidence rates. Better diagnosis and case ascertainment due to the increasing use of radiological scans are possible explanations as well as still insufficient prevention efforts[39].

1.3 Case fatality – how many deaths are caused by stroke?

Case fatality, the mortality due to stroke within the first month, is an important measure of the severity of stroke and, importantly, acute care.

Table 2 and 3 show wide variations in stroke fatality between countries as well as within countries e.g. between hospitalised and non-hospitalised patients (Ukraine[43]) or urban and rural populations (Bulgaria[44], Portugal[15]). Comparisons are limited because some of the reported rates date further back than others or refer to slightly different stroke patient populations.

Table 3: Case fatality rates reported in European studies, ranked by magnitude of fatality rate

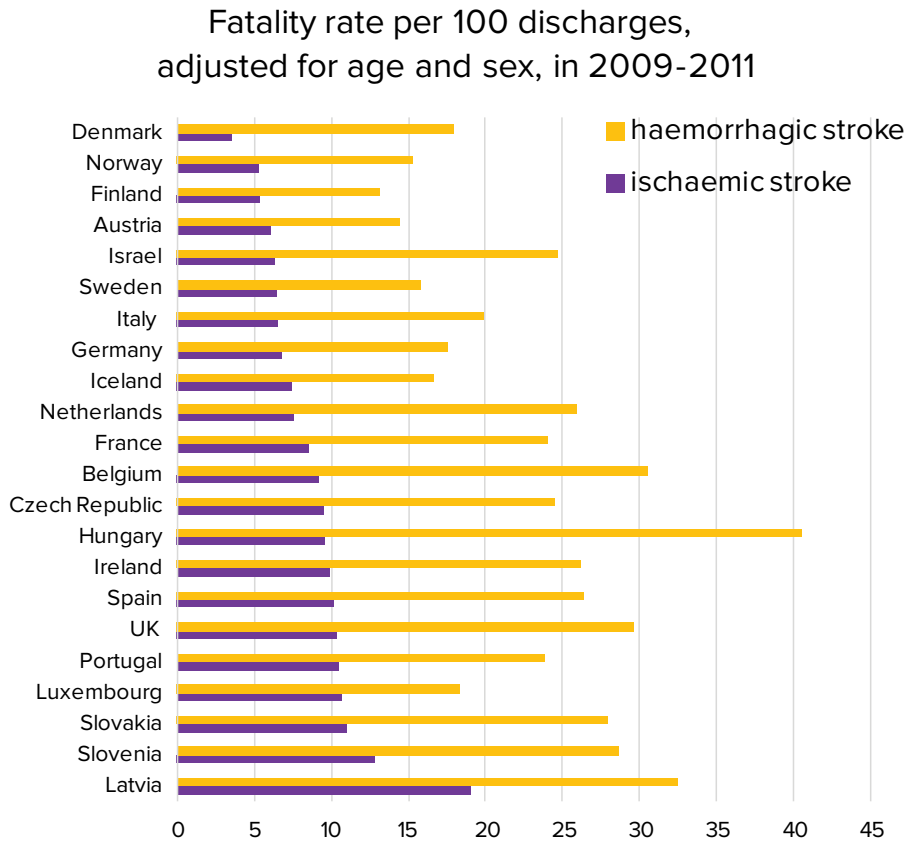
Country / Region or town	Study period	Case fatality rate
Bulgaria / Varna[44]	2000-2001	35% (aged 45-85, 48% for rural population)
UK / East Lancashire[45]	1995	34%
Italy / Belluno[46]	1992-1993	33%
Greece / Arcadia[47]	1993-1995	27%
Estonia / Tartu[14]	2001-2003	26%
Italy / Sicily[18]	1999-2000	24%
Italy / Vibo Valentia[48]	1996	24%
Croatia / North-West[12]	2007-2009	24%
Ukraine / Uzhgorod[43]	1999-2000	23% (15% hospitalised, 37% non-hospitalised)
Ireland / North Dublin[27]	2005-2006	21%
Italy / Udine[30]	2007-2009	21%
Germany / Erlangen	1994-1996	19.%
Norway / Innherred[49]	1994-1996	19%
Sweden / Orebro[11]	1999-2000	19%
Poland / Zabrze[24]	2005-2006	18%

Table 3: continued

Country / Region or town	Study period	Case fatality rate
Italy / Puglia[19]	2001-2002	18%
Iceland / Reykjavik[50]	1996-1997	17% (hospitalised only)
Hungary, Romania, Ukraine / Mures-Uzhgorod-Debrecen[51]	Not reported	16% ♂, 17% ♀ (hospitalised only)
UK / Scotland[28]	1998-2000	16%
Hungary / Debrecen[52]	1994-2006	15% (hospitalised only)
Portugal / Porto[15]	1998-2000	15% in rural areas, 16.9% in urban areas
Sweden / national audit[53]	2010	14% (hospitalised only, 84-92% hospitalised rate)
Finland / national audit[54]	1999-2007	14% (hospitalised only, 95-98% hospitalised rate)
UK / national audit[55]	2015/16	14% (hospitalised only)
Germany / Ludwigshafen[22]	2006-2007	14%
Croatia / Zagreb[33]	2001-2006	13%, was 20.% in 1995-2000 (hospitalised only, before and after introduction of stroke units)

The Organisation for Economic Co-operation and Development (OECD) (http://stats.oecd.org,[56]) released hospital-based case fatality rates for several European countries. Figure 1 shows those fatality rates stratified by stroke subtype. These rates are generally lower than those listed in table 2 and 3, which could be due to referring to data from more recent years, but also to only including hospitalised patients. Although not many Eastern European countries are included in this dataset, an East-West difference seems to emerge.

Figure 1: Case fatality rates per 100 discharges (adults ≥45 years, age- and sex-adjusted, 2009-11)



Over the last few years, stroke fatality rates have generally improved, as reported in hospital-based and population-based studies (Table 2 and 3,[56]). This could be due to people having less severe strokes; better risk factor control; and also as a result of earlier and more intensive acute treatment. There are significant inequalities in fatality rates across Europe and SAFE member countries. The vast majority of fatality rates reported from population-based registers are significantly higher than the target set in the Helsingborg 2006 declaration[57], which states that by 2015 85% of stroke patients should survive the first month. More up-to-date rates are needed from population-based registers to compare the current situation against the Helsingborg target.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1.4 Prevalence – how many people are living with the consequences of stroke?

Stroke prevalence rates describe the number of people in a society with potential rehabilitation and secondary prevention needs due to their stroke. Prevalence studies are relatively rare compared to incidence studies and rely on door-to-door surveys or survey questionnaires with widely varying cooperation rates. Table 4 lists prevalence studies in Europe published since 2000.

Table 4: European prevalence studies

Country	Study period	Method of case ascertainment	Stroke prevalence estimate
Croatia[58]	2005	Door-to-door survey	2.0%
Finland[54]	2008	National stroke database	1.5%
Germany[59]	2001	Population survey questionnaire	4.5% (aged ≥50 years)
Italy[60]	2004	Questionnaire & medical records	1.5%
Italy[61]	2001	Door-to-door survey	8.2% ♂, 5.1% ♀ (aged ≥65 years)
Netherlands[62]	2000	GP data	0.8% (estimate: 0.9% in 2020)
Slovenia[63]	2001	National survey	0.9% (aged 25-64 years)
Spain / Madrid[64]	1994	Screening questionnaire & neurological assessment	3.4%
Spain[65]	1991-2002	Door-to-door survey	6.4% (aged ≥70 years)
Sweden[66]	Not clear	Hospital data & self-reports	18.8% (aged ≥85 years)
UK[67]	1995-1996	GP data	0.9%

Together with an ageing population and improving survival rates[68-72] the number of stroke survivors in Europe is rising[62]. This represents an increasing challenge for those trying to meet long term needs of stroke survivors, impacting on health and social care providers and their funders, as well as on families and other informal care givers.

1.5 Disability-adjusted Life Years Lost

The concept of DALYs lost was developed as a combined measure of mortality (years of life lost) and morbidity (years lived with disability). It captures the burden of a long-term health condition, ranging from mild ill health to premature death, in a single, summary metric on a national or regional level, for example useful for estimating the societal cost of stroke (healthcare cost, formal and informal care costs, productivity lost). Country-level DALY estimates are very rare, as the data necessary for calculation are difficult to collect and significant estimations are needed. One recent study estimated that cerebrovascular disease generated 1,113 DALYs per 100,000 in Spain in 2008, but points out the significant variations in result depending on different estimates[73]. DALYs lost is widely used for international comparisons in the Global Burden of Disease study (Chapter 1.5).

"I got the privileged service from the insurance; they wanted me to come back to work, so they invested in me. And this is today's problem; they don't do it any longer [i.e. invest in rehabilitation], and that is why I am fighting for the patients, because I received such good help and I am now really in a good shape."

(Female stroke survivor, Austria)

1.6 The Global Burden of Disease (GBD) Study

To overcome the problem of poor comparability between studies, the GBD study, a global research programme involving hundreds of experts worldwide, has developed statistical methods (multi-state models implemented in the software program DisMod III) to model and calculate age-specific estimates of incidence, prevalence, mortality, and DALYs lost. While the study relies on some assumptions to deal with incomplete or low quality data, the estimates from GBD are widely used in stroke publications.

The latest edition was published as Global Burden of Disease Study 2015 (GBD 2015)[74] (data available at: http://ghdx.healthdata.org/gbd-2015).

"The challenges [for stroke survivors and families in Greece] are day to day living .... But also, it is becoming a viable member of society again and I think that's important worldwide, not only in [my country] Greece."

(Stroke clinician and stroke support organisation volunteer, Greece)

Figure 2 shows GBD 2015 national estimates for incidence, prevalence, mortality and DALYs lost in 1995 and 2015.

Figure 2: Number of new strokes and stroke survivors per 100,000 inhabitants in 1995 and 2015 (age- and sex-standardised to the world standard population, GBD 2015)

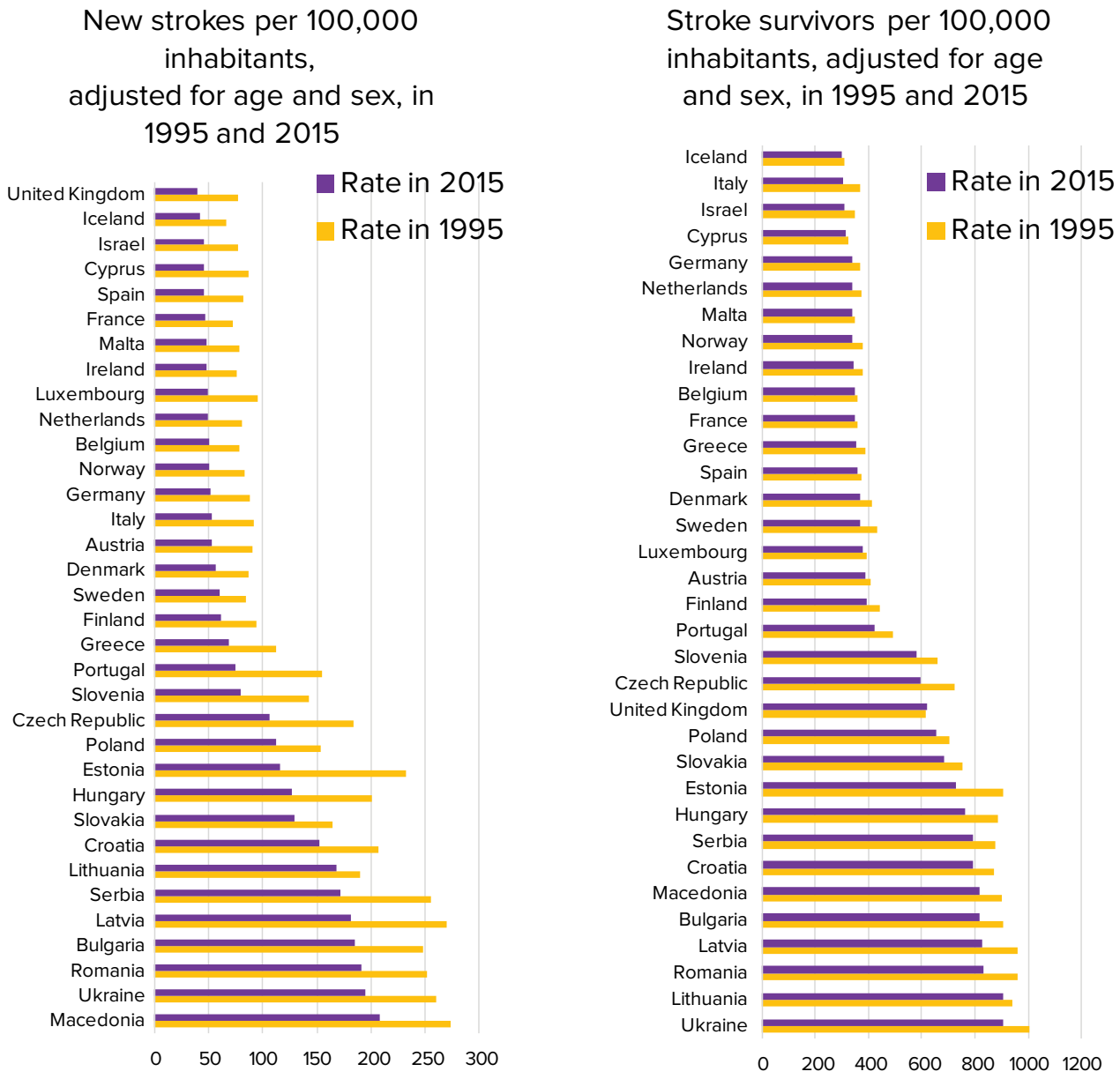
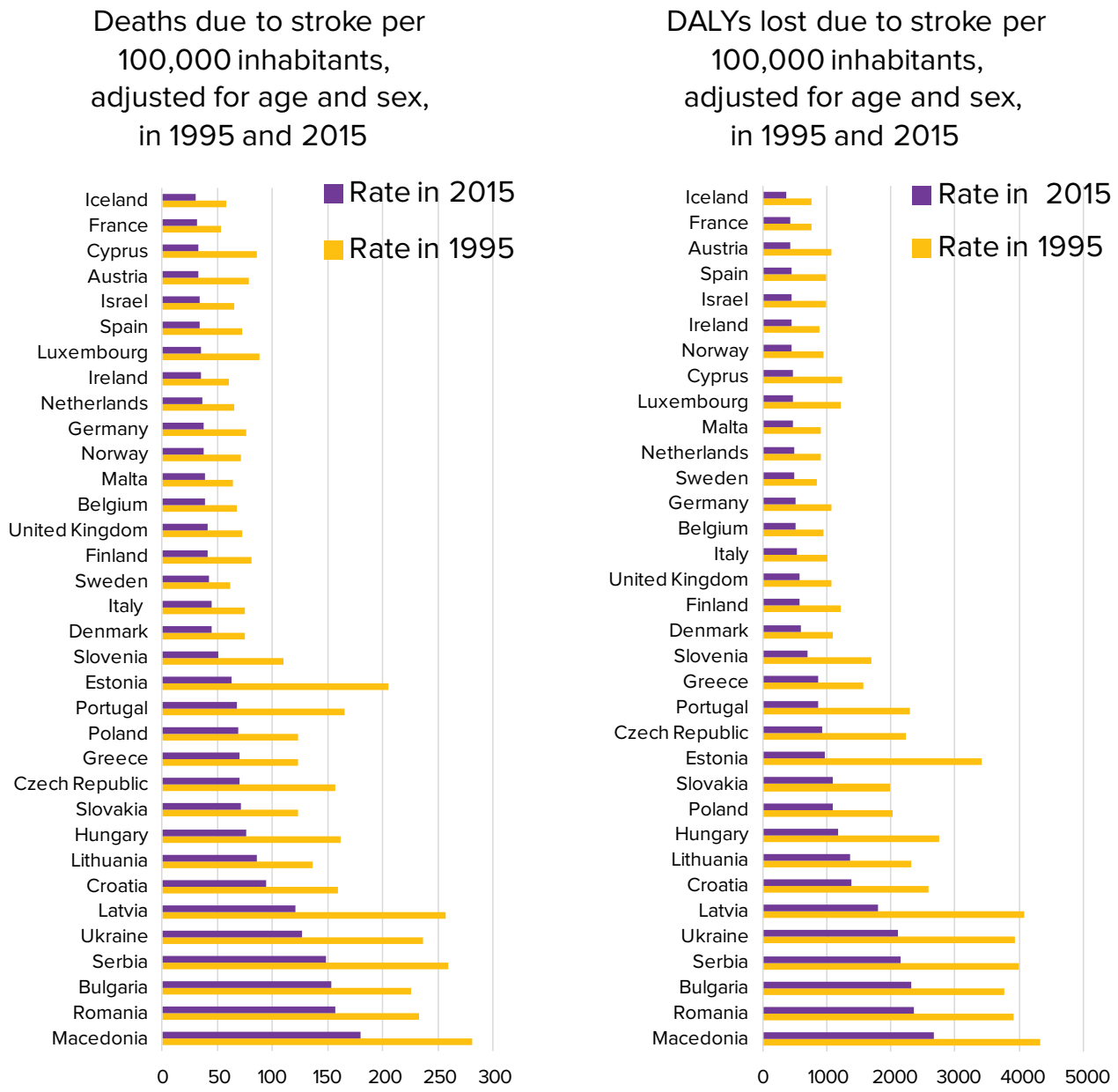


Figure 2: Number of deaths due to stroke, and DALYs lost per 100,000 inhabitants in 1995 and 2015 (age- and sex-standardised to the world standard population, GBD 2015)



The GBD study shows large inequalities in the rate of strokes and mortality due to stroke across Europe, with higher rates and poorer outcomes being consistently found in Eastern European compared to Western European countries.

Across Europe the age-standardised rates of strokes, deaths from strokes, and people living with disability as a result of stroke have gone down. But relative improvements have been larger in Western European countries than in Eastern European countries.

The latest Eurostat (statistical office of the EU) cardiovascular disease statistics add further evidence (data extracted October 2016, http://ec.europa.eu/eurostat). The Eurostat stroke mortality figures show that the highest standardised death rates for stroke were reported for Bulgaria, Romania, Serbia, Latvia, Lithuania, Croatia, Hungary, and Slovakia, while the lowest rates were reported for France, Spain, Luxembourg, Austria, and Belgium. Mortality rates in Bulgaria (highest rate) were almost seven times as high as those recorded for France (lowest rate).

However, there are currently no Europe-wide standardised, nationally collected data on stroke, leading to a significant level of uncertainty due to poor or missing data in many parts of Europe, as seen by the widely differing estimates derived from population-based registers, hospital data sets, or GBD. For example, for the UK there is a large discrepancy between the number of strokes estimated for 2015 in the GBD study (43,000) and estimates based on the national stroke audit (110,000)[75]. This illustrates that estimates of the burden of stroke on a country level, comparisons between countries and healthcare systems, and future projections all have significant caveats at present.

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1.7 What do we predict about the future burden of stroke in Europe?

The evidence shows that age-standardised incidence rates for stroke are falling. This is welcome, **but this trend is outweighed by an ageing population**. Improved survival rates from stroke mean there will be more people living with stroke as a long-term condition.

Models estimating future stroke burden usually combine national demographic projections with estimated incidence and survival rates, sometimes covering a best case and worst case scenario. Based on these methods, a 36% increase in the number of stroke events was predicted for the European Union combined with Iceland, Norway, and Switzerland between 2000 (1.1 million) and 2025 (1.5 million)[76]. Only a few studies have calculated future stroke burden on a country-level, but they are all predicting a significant increase (Table 5).

Table 5: European studies estimating the future burden of stroke

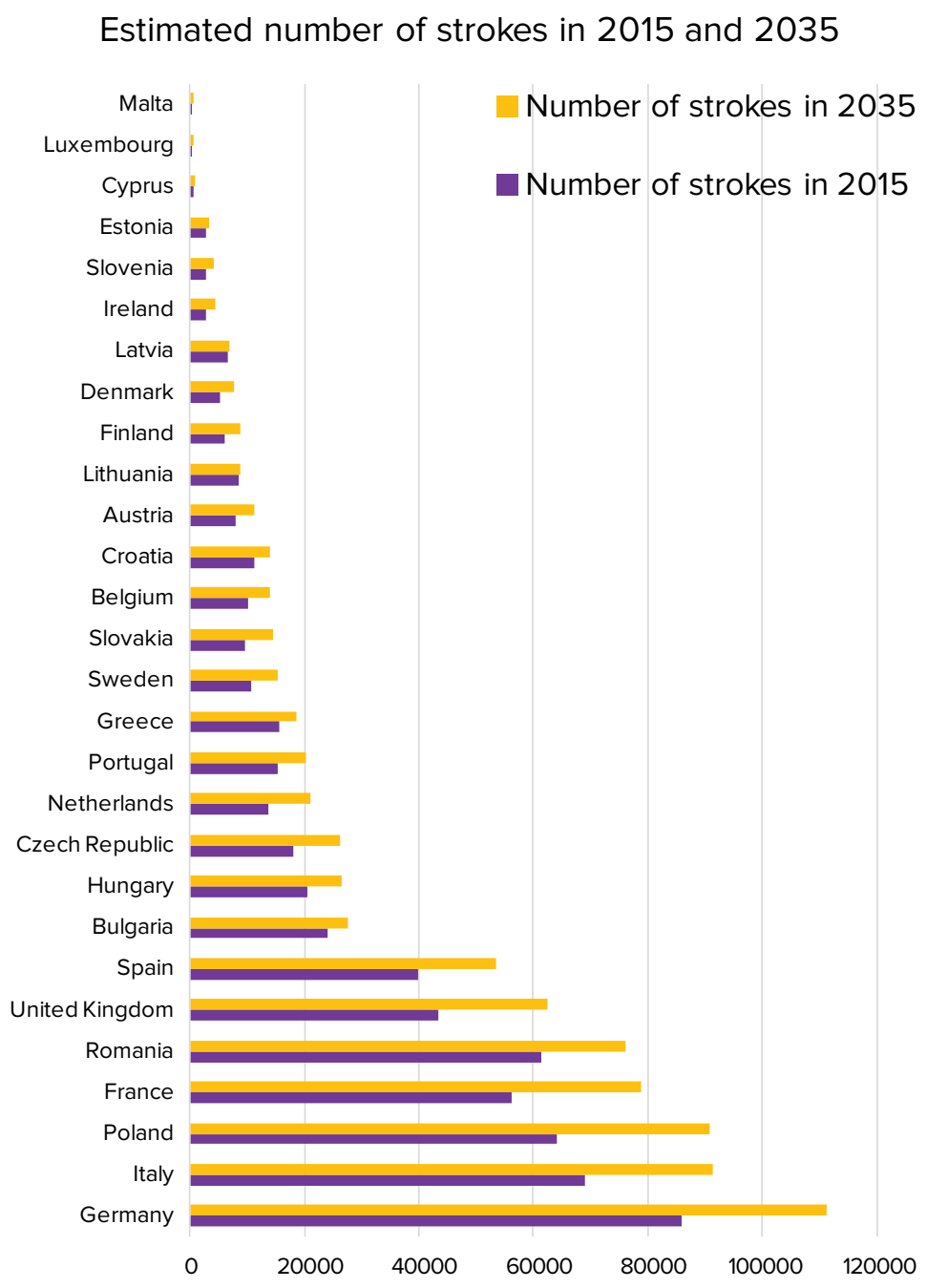
Country	Projection period	Estimate
Netherlands[62]	2000 - 2020	Incidence: +17% Prevalence: +16% Potential Years of Life Lost: +30%
Finland[77]	2000 - 2030	Number of strokes nationally assuming • Stable incidence rates: +75% • Incidence rates continue to decline: +5%
Germany / Hesse[78]	2005-2050	Number of strokes regionally assuming stable incidence rate: +68%
Ireland[79]	2007 - 2021	Number of strokes nationally assuming stable incidence rate: +58%
Sweden[23]	2001/2 - 2050	Number of stroke cases nationally assuming • Stable incidence rates: +59% • Rates decreasing 2% every 5 years: +33% • Rates increasing 2% every 5 years: +91%
Italy[80]	1991-2016	Number of strokes nationally assuming stable incidence rate: +22%
UK[81]	1983 - 2023	Number of strokes nationally assuming stable incidence rate: +30%

For this report, we have calculated epidemiological projections for all EU countries for 2025 and 2035 using the most recent age and sex-specific GBD incidence, prevalence, death, and DALY-rates. These rates were applied to the demographic projections for each country (broken down by age and sex) obtained from Eurostat to obtain projected absolute numbers. Again, we want to emphasise that a significant level of uncertainty is attached to all country-level estimates. However, as percentage change over time in our model depends purely on changes in the demographic make-up, those percentage changes should be more reliable than absolute figures.

Using GBD incidence rates, between 2015 and 2035, there will be a 34% increase in total number of stroke events in the EU from 613,148 in 2015 to 819,771 in 2035.

This is consistent with the expectation that the ageing of the population will outweigh the drop in age-standardised incidence rates (figure 3). The largest percentage increase will be seen in Luxembourg (78%) and largest absolute increase in Poland (26,807) (Figure 3). Our projections for the percentage change in stroke events and DALYs lost 2015-2035 can be found for each country in the separate report named "Overview of stroke burden and care in each EU and SAFE member country, SAFE, 2017".

Figure 3: Estimated number of strokes in 2015 and 2035 in EU countries



The number of stroke survivors in the EU will rise from 3,718,785 in 2015 to 4,631,050 in 2035, an increase of almost one million or 25%.

The largest increase will be in Luxembourg (72%) and the largest absolute number increase in the UK (193,861).

3,718,785

4,631,050

There will be a 45% increase in the number of stroke deaths from 532,321 in 2015 to 770,038 in 2035.

This ranges from a 10% increase in Lithuania to 101% increase in Malta, with Germany having the largest absolute increase of 29,243.

45%

more deaths

Overall there will be a 32% increase in DALYs lost from 2015 to 2035 (609,721 to 861,878).

The largest percentage increase is expected in Malta (63%) with almost no change in Lithuania (1%). The UK will have the largest absolute increase of DALYs from 609,721 in 2015 to 861,878 in 2035.

32%

more DALYs lost

1.8 The financial and social burden of stroke

In the EU, the total cost of stroke in 2015 was calculated as €45 billion[82]. 44% of this amount, i.e. €20 billion, was caused by direct health care costs. 72% of direct health care costs were for in-hospital care and 7% for drugs. Figure 4 shows the direct health care costs of stroke per capita in 2015. For comparison, the crude incidence rate of stroke in 2015 (GBD 2015) is included in figure 4 and demonstrates that there is no association between national per-capita spending and the national rate of new strokes.

Direct health care cost per capita varied widely across the EU, from €132 in Finland to €7 in Bulgaria, or by a factor of 19. The overall health expenditure also varies between European countries[83] and the proportions of overall health expenditure spent on stroke varied less between countries than the stroke-specific expenditure per capita: Finland and Hungary spent 4% of their total healthcare expenditure on stroke, while Denmark spent less than 1%. The amount of money spent on stroke therefore depends on the significantly different overall national healthcare budgets, but also on varying allocations within that budget.

Most studies measuring the cost of stroke only look at direct health care costs. This hugely underestimates the total cost of stroke because it does not take into account non-health care costs including informal care (the opportunity cost of unpaid care provided by family or friends), or productivity lost due to death or disability.

Informal care costs alone were estimated at €15.9 billion or 35% of the total cost of stroke in the EU in 2015. Productivity losses were estimated to be €5.4 billion or 12% for losses due to death and €4.0 billion or 9%, for losses due to morbidity.

The economic burden of stroke is borne by society as a whole via tax payments and insurance contributions, but significantly also by the individual stroke survivors and their families and friends. Figure 4 shows non-health care costs of stroke for EU countries in 2015, again in comparison with GBD estimates of stroke prevalence, i.e. the number of stroke survivors, in 2015.

As the number of strokes and the number of stroke survivors is expected to increase over the coming decades, the economic impact of stroke will need more attention with regards to effective health care planning and resource allocation[84] as well as the financial burden borne by stroke survivors and their family and friends.

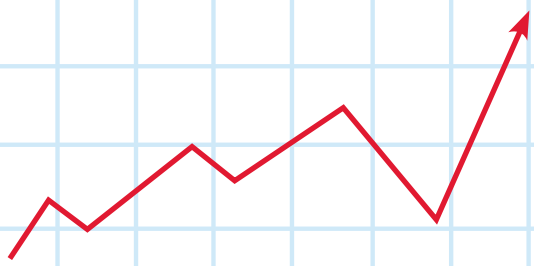
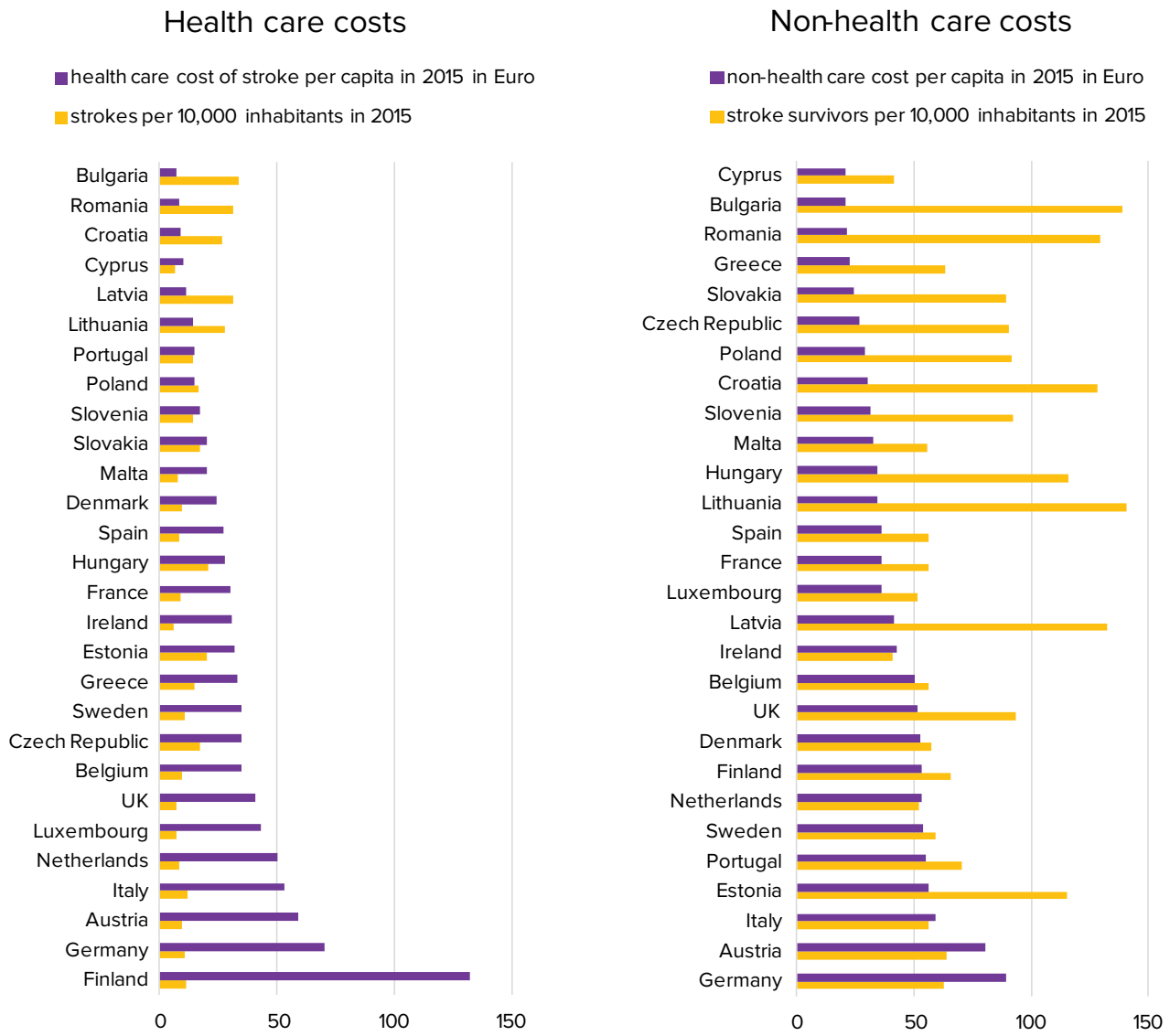


Figure 4: Health care and non-health care costs of stroke per capita in 2015 in Euro and crude incidence and prevalence of stroke per 10,000 inhabitants in 2015 (GBD 2015)



As well as the economic impact of stroke, stroke survivors commonly experience a wide range of negative physical and mental consequences. These are often long-lasting and can have a large impact on the lives of patients and their families. Impaired mobility, vision, speech, depression, and cognitive impairments such as memory problems, personality changes, and fatigue are typical[3].

By their nature, the impacts of these impairments are complex and hard to quantify. There should be more research into patient-reported experience and outcome measures, and quality of life studies. SAFE believes that patients, carers, and patient organisations/SSOs should be actively involved in these studies as participants and co-researchers.

"My GP was the best, she was fantastic. [But] when it came to the real crunch of it, that big part down the line, I spoke to her and she hadn't got a clue[about longer term support]. It's like thinking, how do you educate the medical profession to better understand about the whole person's needs? Because it all focuses around 'treat them in the hospital, rehabilitation, get them out into the community, six weeks' support ... and then you're on your own.' "

(Male stroke survivor, UK)

"There are a lot of things that I cannot do that I did before. I was fond of skiing – I cannot do that. I cannot ride a bicycle because I have no balance, and things like that. You miss it, but after some time you get used to it. It's a new life; you have to adjust to what you can do."

(Male stroke survivor, Norway)

1.9 Recommendations - The Burden of Stroke

There is a lack of unified data about stroke and stroke outcomes. Europe-wide comparisons of stroke and stroke care are vital to help each country prevent stroke and provide better care and support for everyone affected by stroke. To make accurate comparisons between different countries, populations and health systems we need agreed and coordinated Europe-wide data collection. Therefore, European policy-makers, in particular the European Commission and the Joint Research Centre, should support and promote the use of a robust Europe-wide stroke register to assess quality of care along the whole stroke pathway.

The number of people having a stroke and the number of people living with the long-term effects of stroke will rise in the coming decades. Effective health care planning and adequate resource allocation across Europe is needed to deal with this, taking into account that the financial burden of stroke is to a large extent borne by stroke survivors themselves and their families.

There are limitations to the current research evidence from the perspective of European stroke survivors (for example, it is largely based on small studies from mostly Western European countries). This research should be conducted more widely throughout Europe, and consolidated findings should be used to influence patient care. SAFE believes that these studies should actively involve stroke survivors and patient organisations.

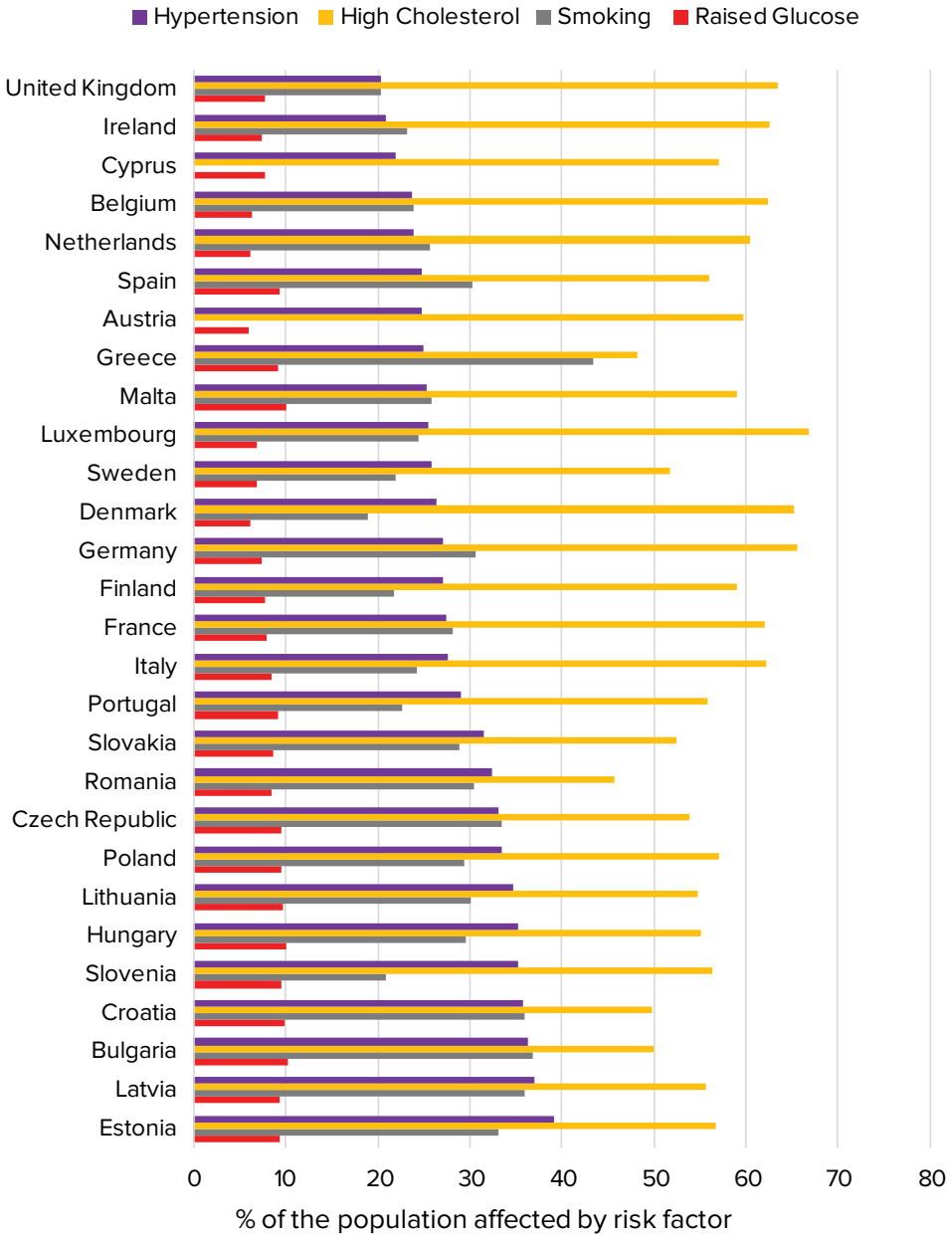
Despite public education campaigns, public knowledge about the risk factors for stroke is too low. Perhaps as a result, high blood pressure and atrial fibrillation (AF, an abnormal heart rhythm with rapid and irregular beating) are often not treated or not appropriately treated. This section outlines what is being done across Europe to tackle two important, modifiable risk factors for stroke.

Stroke is preventable.

Ten modifiable risk factors account for around 90% of all strokes[85]. The most important are high blood pressure, high cholesterol, smoking, obesity/diet, atrial fibrillation, and diabetes.

The proportion of the population estimated to have one or more stroke risk factors is high and varies significantly between countries (Figure 5[86])

Figure 5: Percentage of the population in European and SAFE member countries affected by some of the major vascular risk factors, ranked by the prevalence of hypertension



"I suffered a cerebral venous thrombosis in 2011 (I was 34 years old)...I was a journalist, editor of a weekly magazine...I did not have the time nor patience to practise sport...In addition to stress and sedentary lifestyle, also the use of oral contraceptives contributed – in the opinion of doctors - to my stroke"

(Female stroke survivor in 2011, Portugal)

2.

STROKE PREVENTION IN EUROPE

2.1 Campaigns to encourage healthy lifestyles and risk factor awareness (indicator 1)

Even though stroke is preventable, **knowledge of the risk factors is poor** (Bulgaria[87], Croatia[88], Denmark[89], Estonia[90], Germany[91], Greece[92], Ireland[93], Sweden[94]).

High blood pressure (hypertension) is the most commonly known risk factor. In a Greek study 66% named hypertension as a risk factor for stroke, but only 44% recognised smoking and 34% obesity as a risk factor[92]. In a Danish study, only few subjects recognised smoking or diabetes mellitus as major risk factors[89]. Importantly, only a small proportion of patients with risk factors consider themselves as being at high risk[88, 92].

Most countries have undertaken regional or national educational campaigns aimed at raising awareness of stroke risk factors and healthy lifestyles using a multi-media approach. These campaigns are often combined with campaigns to increase public knowledge of stroke symptoms and the appropriate response.

Events are held across most of Europe in connection with World Stroke Day (www.worldstrokecampaign.org) including multi-media campaigns; public lectures; and events/information stalls in public spaces like hospitals, shopping malls, or libraries (e.g. free pop-up blood pressure measurement points). These events are often organised by the regional or national SSOs.

Other examples are the Czech HOBIT Programme which aims to increase school children's knowledge of stroke risk factors and symptoms (www.projekthobit.cz, Chapter 3.1), the Belgian annual "Heart Rhythm Week" with free screening in hospitals and activities to raise awareness around atrial fibrillation[95], or the Finnish blood pressure campaign.

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Example from Finland: The Finnish Brain Association ran a national blood pressure campaign, which was awarded a World Stroke Organisation prize in WSO prize winner 2016. The campaign used radio, social media, a website and digi-screens in trams and metros. The radio campaign reached 2.85 million Finns. 121 pop-up measurement points were set up and, 6,002 people's blood pressure was measured.

Although many campaigns have been undertaken, very few have been evaluated systematically. The few campaigns that have been assessed showed varied success with regards to improved risk factor knowledge (Czech Republic: no effect[96], Germany: improved knowledge[91]) or, even more importantly, behaviour change[97].

2.2 Hypertension (indicator 2)

Hypertension **is the most important risk factor for stroke**[85]. Despite this, national data of blood pressure levels or blood pressure control is not systematically collected in most European countries. The accuracy of existing figures is dependent on access to diagnostic testing and monitoring which varies from country to country.

According to WHO estimates (Figure 5), high blood pressure affects 20% of the population in Israel rising up to 39% in Estonia. As observed in previous studies[98], there is generally a higher prevalence in Eastern European countries.

Eurostat (Cardiovascular disease statistics, data extracted October 2016, provided by European Health Interview Survey (EHIS), 2006-10) found a similar East-West gradient.

The highest percentage of self-reported hypertension (adults aged ≥15 years) was recorded in Hungary (32%), Bulgaria (30%), Latvia (29%), Germany (29%), and Lithuania (28%), whereas the lowest shares were recorded in Norway (13%), France (14%), Sweden (16%), the United Kingdom (16%), and the Benelux countries (all below 17%). A significant age-gradient was observed for hypertension with 52% of those aged over 75 years being affected, ranging from 36% in Belgium to 73% in Bulgaria. Hypertension is significantly more common in stroke patients than in the general population (Appendix 1, Table 1). There are again significant variations between countries and studies. Prevalence rates for hypertension ranged from 54% in Spanish and Italian studies to 87% in a Croatian study.

Stroke guidelines issued by the European Stroke Organisation in 2008 include primary prevention measures, such as regular checks of blood pressure, blood glucose, and cholesterol, as well as advocating a healthy lifestyle with regards to smoking, alcohol, physical activity, and diet.

The vast majority of European countries have developed national guidelines for the primary and secondary prevention of stroke covering all or most of those risk factors.

Some countries have developed secondary prevention, but no primary prevention guidelines (e.g. Czech Republic[9]), or have national guidelines that cover only some risk factors, while local guidelines cover other aspects (e.g. Greece and Malta: no national hypertension guideline[9]). There are very few countries that have no national or local guideline covering hypertension, e.g. Latvia[9].

Despite the wide availability of guidelines, there is **significant under-treatment.**

Figure 6 shows the percentage of the population reporting the use of antihypertensives in 15 European countries in 2008 according to Eurostat data (http://appsso.eurostat.ec.europa.eu) together with the estimated percentage of the population affected by high blood pressure[86]. Clearly, there is a considerable issue of under-treatment. In several other European studies, low treatment rates of hypertension have been observed, but with some improvements since 2000 (Table 6).

Figure 6: Population affected by hypertension (WHO data) and **self-reported use of antihypertensives** (Eurostat 2008 data, ranked by the relative gap between hypertension and the use of antihypertensives

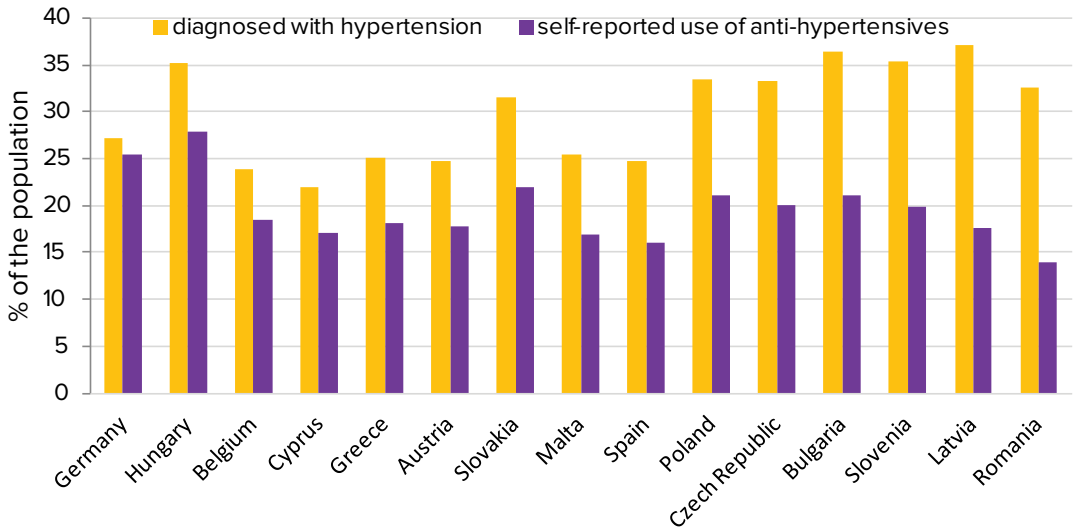


Table 6: Percentage of hypertensive patients taking antihypertensives (primary prevention)

	Country	% - year	Further details; other studies
General population	**Portugal**	39% - 2003	national sample, control rate 11%[99]
	Spain	59% - 2008-10	national sample[100]
	Italy	64% - 2013-4	national sample[101]
	Germany	55% - 1998 72% - 2008/11	multi-centre[102]; significant regional differences[103]
Pre-stroke	**Estonia**	58% - 2001-3	Tartu stroke register[14]
	Poland	78% - 1995/9 91% - 2010/13	Warsaw stroke register[104]
	UK	55% - 2007-10	South London Stroke Register[105]; significant increase in patients prior to and in the year after stroke (UK primary care database 1999-2008)[106]

Even more important than treatment rates are control rates. What proportion of people are getting treatment that is enough to lower blood pressure to recommended levels? Low control rates have been reported from many European countries. Two large international studies using primary care data, the EUROASPIRE primary care surveys[107] and the EURIKA study[108] consistently showed low control rates in hypertensive patients between 48% in Greece and 28% in Romania (Figure 7). Similarly, several national or local studies reported low control rates in treated patients between 33% (Greece) and 72% (Germany) (Table 7).

Figure 7: Proportion of hypertensive patients with controlled blood pressure
(<140/90mmHg, EURIKA: proportion of all hypertensive patients (treatment rates >90%), EURASPIRE: proportion of treated patients)

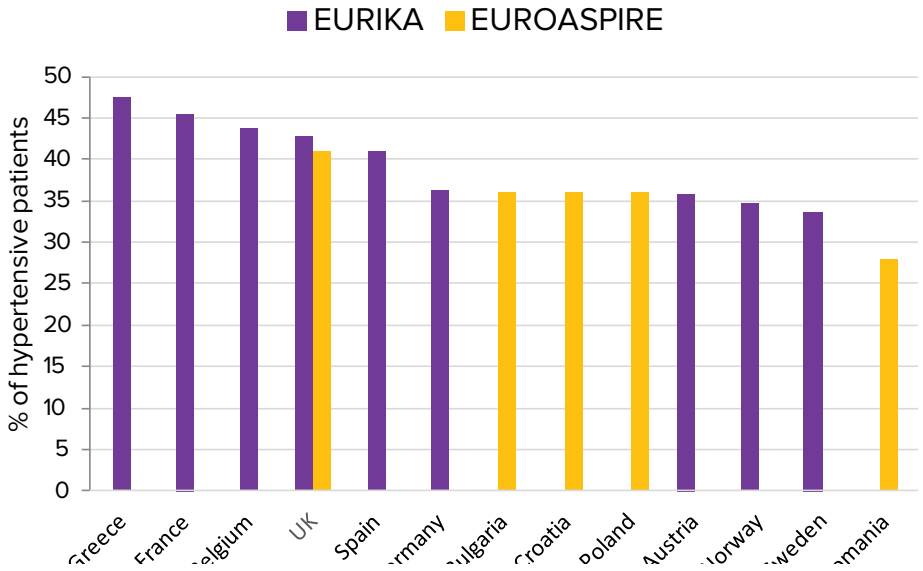
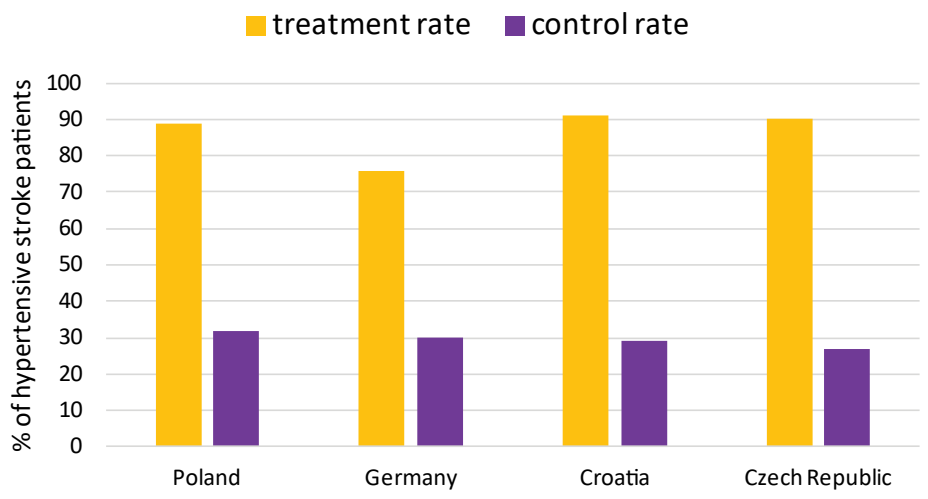


Table 7: Proportion of hypertensive patients with controlled blood pressure (Control rate)

Country	Control rate
Austria [109]	41% of treated, and adherent patients
Spain[100]	43% of treated patients, 25% of hypertensive patients 2008/10 (16% in 2000/1)
Italy[101]	58% of treated patients in 2013/14, 33% in 2000 to 2011
Italy[110]	47% of treated patients
Greece[111]	33% of treated patients (51% of hypertensive patients were treated)
Germany[112]	72% of treated patients in 2008/11, 42% in 1998
Portugal[113]	37% of hypertensive patients in 2008/9
Iceland[114]	27% of hypertensive patients in Icelandic GP database

Low control rates for hypertension are also found among people who have had a stroke (i.e. secondary prevention). Figure 8 presents data from the stroke-specific module of the EUROASPIRE study (2006-8 data[115]), showing control rates of 32% or less in those with known hypertension in four European countries. An Irish stroke population study (6 months after ischaemic stroke), modelled on the EUROASPIRE protocol, found uncontrolled blood pressure in 63% of patients[116].

Figure 8: The percentage of hypertensive stroke patients treated with antihypertensives (treatment rate) and of those achieving adequate hypertension control (control rate)



Measuring how many people get treatment does not accurately reflect how many people's high blood pressure is being controlled. Blood pressure control is a relevant measure that needs to be encouraged in future studies.

It is clear that existing guidelines are not being implemented well in every day clinical practice; there are poor treatment rates for hypertension across Europe and even worse hypertension control rates, although several studies do report some improvement over the last decade.

Across Europe primary and secondary prevention strategies are not working well enough to control hypertension, the biggest risk factor for stroke.

2.3 Atrial fibrillation (indicator 3)

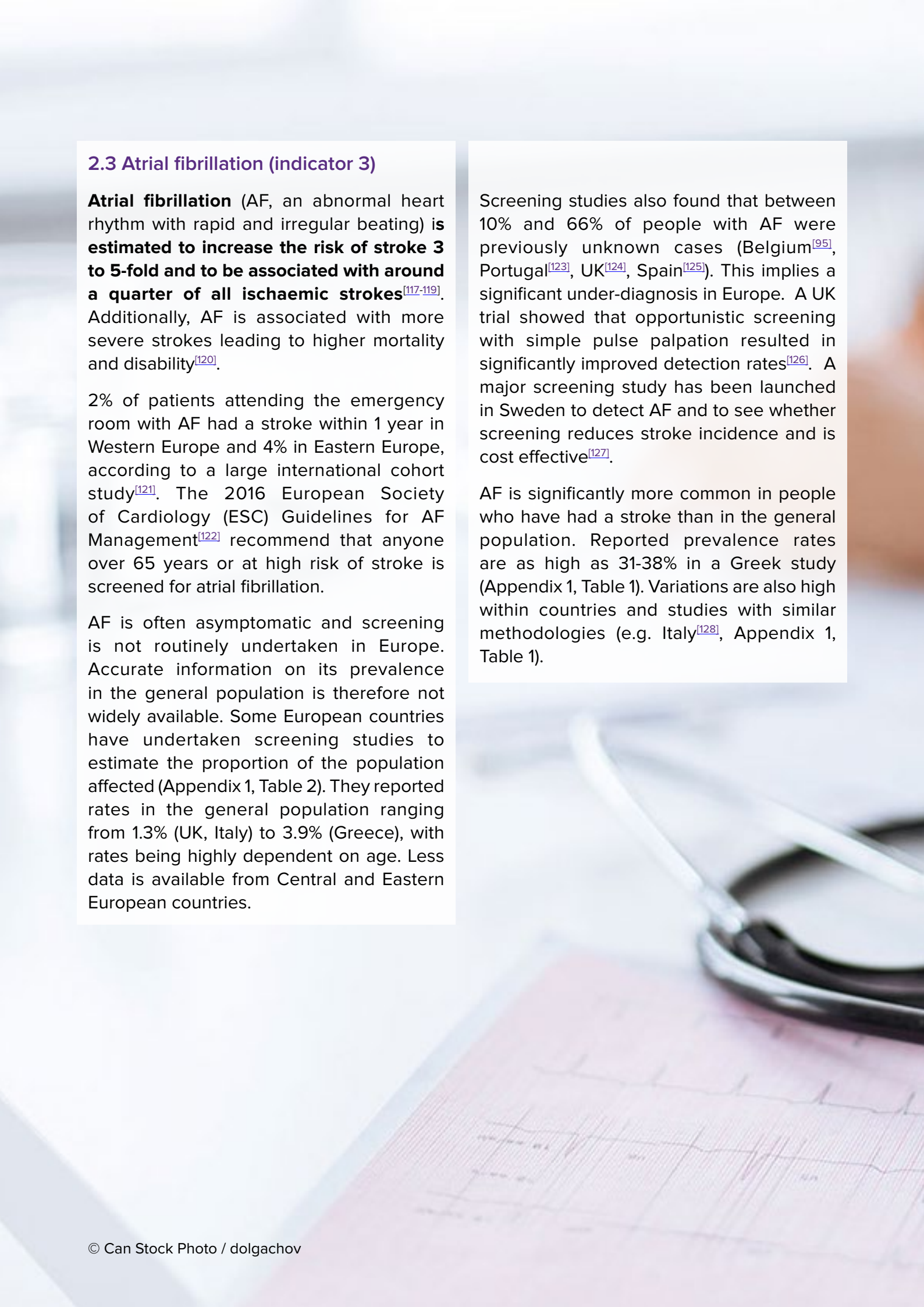
Atrial fibrillation (AF, an abnormal heart rhythm with rapid and irregular beating) i**s estimated to increase the risk of stroke 3 to 5-fold and to be associated with around a quarter of all ischaemic strokes**[117-119]. Additionally, AF is associated with more severe strokes leading to higher mortality and disability[120].

2% of patients attending the emergency room with AF had a stroke within 1 year in Western Europe and 4% in Eastern Europe, according to a large international cohort study[121]. The 2016 European Society of Cardiology (ESC) Guidelines for AF Management[122] recommend that anyone over 65 years or at high risk of stroke is screened for atrial fibrillation.

AF is often asymptomatic and screening is not routinely undertaken in Europe. Accurate information on its prevalence in the general population is therefore not widely available. Some European countries have undertaken screening studies to estimate the proportion of the population affected (Appendix 1, Table 2). They reported rates in the general population ranging from 1.3% (UK, Italy) to 3.9% (Greece), with rates being highly dependent on age. Less data is available from Central and Eastern European countries.

Screening studies also found that between 10% and 66% of people with AF were previously unknown cases (Belgium[95], Portugal[123], UK[124], Spain[125]). This implies a significant under-diagnosis in Europe. A UK trial showed that opportunistic screening with simple pulse palpation resulted in significantly improved detection rates[126]. A major screening study has been launched in Sweden to detect AF and to see whether screening reduces stroke incidence and is cost effective[127].

AF is significantly more common in people who have had a stroke than in the general population. Reported prevalence rates are as high as 31-38% in a Greek study (Appendix 1, Table 1). Variations are also high within countries and studies with similar methodologies (e.g. Italy[128], Appendix 1, Table 1).



AF is often only diagnosed after someone has had a stroke: studies from Ireland[129], Iceland[16], Croatia[130] and Norway[131] reported that between a quarter to over half of AF diagnoses known after stroke were unknown before. A recent meta-analysis also reported that 24% of stroke patients are newly diagnosed with AF after their stroke[132]. These reports again suggest a significant under-diagnosis of AF in the general population. Better detection rates of AF could lead to improved primary prevention.

Due to Europe's ageing population and AF's strong association with age (0.7% in those aged 55-59 vs. 17.8% in those aged ≥85 years,[133]), the prevalence of AF is expected to rise. Using data from the community-based Rotterdam Study and population projections from Eurostat, it was estimated that the **number of adults over 55 with AF will more than double between 2010 and 2060 from 8.8 million to 17.9 million**[117]. An Icelandic study projected the prevalence of AF to rise from 1.9% in 2008 to 3.5% in 2050[134].

In the UK, the number of AF related ischaemic strokes has trebled in the last 25 years in adults over 80 years and is predicted to treble again by 2050, with AF-related embolic events costing the UK around £374 million per year[135].

AF is therefore an important part of European[136, 137] and most national stroke guidelines, both for primary and secondary prevention. However, some European countries have not developed national guidelines covering AF treatment in relation to stroke primary prevention (Czech Republic, Greece, Latvia, Estonia,[9])

The ESC Guideline recommends treating AF patients following a structured risk assessment with oral anticoagulants for those with high risk scores[136]. Several recent, international European studies have assessed treatments rates of AF patients with oral anticoagulants (Table 8).

Table 8: International oral anticoagulants treatment studies

Study	Countries included and treatment rates*
PREFER-AF study[138]	2012: France: 90%, Germany, Austria, Switzerland: 87%, Italy: 72%, Spain: 88%, UK: 78%, CHA2DS2-VASc score: score≥2: 86%, score=0: 63%
EORP-AF study[139, 140]	2012/13: Western Europe (Belgium, Denmark, Netherlands, Norway): 72%, Eastern Europe (Poland, Romania): 74.7%, Southern Europe (Greece, Italy): 76%, CHA2DS2-VASc>=2: East (93%, South: 95%, West 81%)
BALKAN-AF survey[141]	2014/15: Bulgaria: 73%, Croatia: 84%, Romania: 76%, Serbia: 79%. High treatment rates but poorly related to CHA2DS2 -VASc score: score≥2 74%, score=0 57%
Euro Heart Survey[142]	2003/4: 67% of eligible patients compared to 40-50% of low risk patients (according to CHA2DS2-score)
GARFIELD-AF Registry[143]	Global register, including Poland, Finland, Norway, Sweden, UK, Denmark, France, Germany, Netherlands, Belgium, Austria, Italy, Spain, Czech Republic, Hungary: overuse of OAC in low risk, underuse in high risk patients
RE-LY Atrial Fibrillation Registry[144]	International study, AF patients attending ER: CHA2DS2-Vasc score≥2: 63% in Western Europe, <40% in Eastern Europe, proportion of INR values between 2.0 and 3.0: 67% in Western Europe, 59% in Eastern Europe
Gloria-AF[145]	Global register, including Austria, Belgium, Bulgaria, Croatia, Czech Republic, Denmark, Estonia, France, Germany, Greece, Ireland, Italy, Latvia, Netherlands, Norway, Poland, Portugal, Romania, Slovenia, Spain, Sweden, Switzerland, UK: High treatment rates (90%), but over-use in low risk patients

*The CHA2DS2-VASc-score is a validated risk stratification scoring system, including congestive heart failure, hypertension, age, diabetes mellitus, stroke/TIA/ thromboembolism, vascular disease, and sex.

Generally, these studies found relatively high oral anticoagulant treatment rates, but treatment was often not in accordance with the guidelines and patients' specific risk profiles. Under-use of oral anticoagulants in elderly patients[146] or those with high risk scores and over-use in those with low risk scores was observed.

Also, the majority of these studies recruited patients registered with cardiologists (PREFER-AF, EORP-AF, BALKAN-AF, Euro Heart Survey, Gloria-AF). So the generally high treatment rates might not be representative for patients in primary care.

Several smaller studies, particularly those using primary care data or data from screening studies, discovered much lower rates (Table 9). These figures might be more representative of real-life AF anticoagulant treatment. Again, a mismatch between treatment and patients' risk scores was observed, showing poor adherence to guidelines.

Table 9: Oral anticoagulant treatment rates in national/regional studies

Country	Oral anticoagulant treatment rates
Denmark	66%, with 76% treated according to guideline (2011 primary care data)[147]; 67% in 2015 for newly diagnosed AF patients (was 40-50% in 2010)[148]
Germany	71% treated according to guideline (2004-6 data)[149]
Greece	41% of eligible AF patients on oral anticoagulants, 34% on antiplatelets, 25% no therapy (screening study, rural Greece)[150]; >55% of intermediate risk and 67% of high risk AF patient not on oral anticoagulants[151]
Italy	84% at time of diagnosis (2% had low CHA2DS2-VASc score), but only 30% 2 years after diagnosis (2009-11 data, primary care)[152])
Poland	41% of eligible AF patients on oral anticoagulants (2006/10 data, cardiology/ internal medicine/ neurology wards)[153]
Spain	24% of AF pat >60 years with CHA2DS2-VASc≥2 not on oral anticoagulants, female gender, older age, cognitive impairment related to lower rates[154]
Sweden	53% of eligible AF patients on oral anticoagulants (2005-10 data)[155]
UK	53%, with 8% of very high risk patients no treatment, 38% of low risk patients on oral anticoagulants, lower treatment rates in elderly (2003 primary care data[156]

Some studies have investigated oral anticoagulant treatment rates for AF in a stroke population (Table 10). Before stroke, rates were found to be very low. After stroke, rates were slightly higher, but still low and varied significantly between studies and countries. Older age was a significant predictor of lower treatment rates[157]. There is a trend towards higher treatment rates in more recent studies.

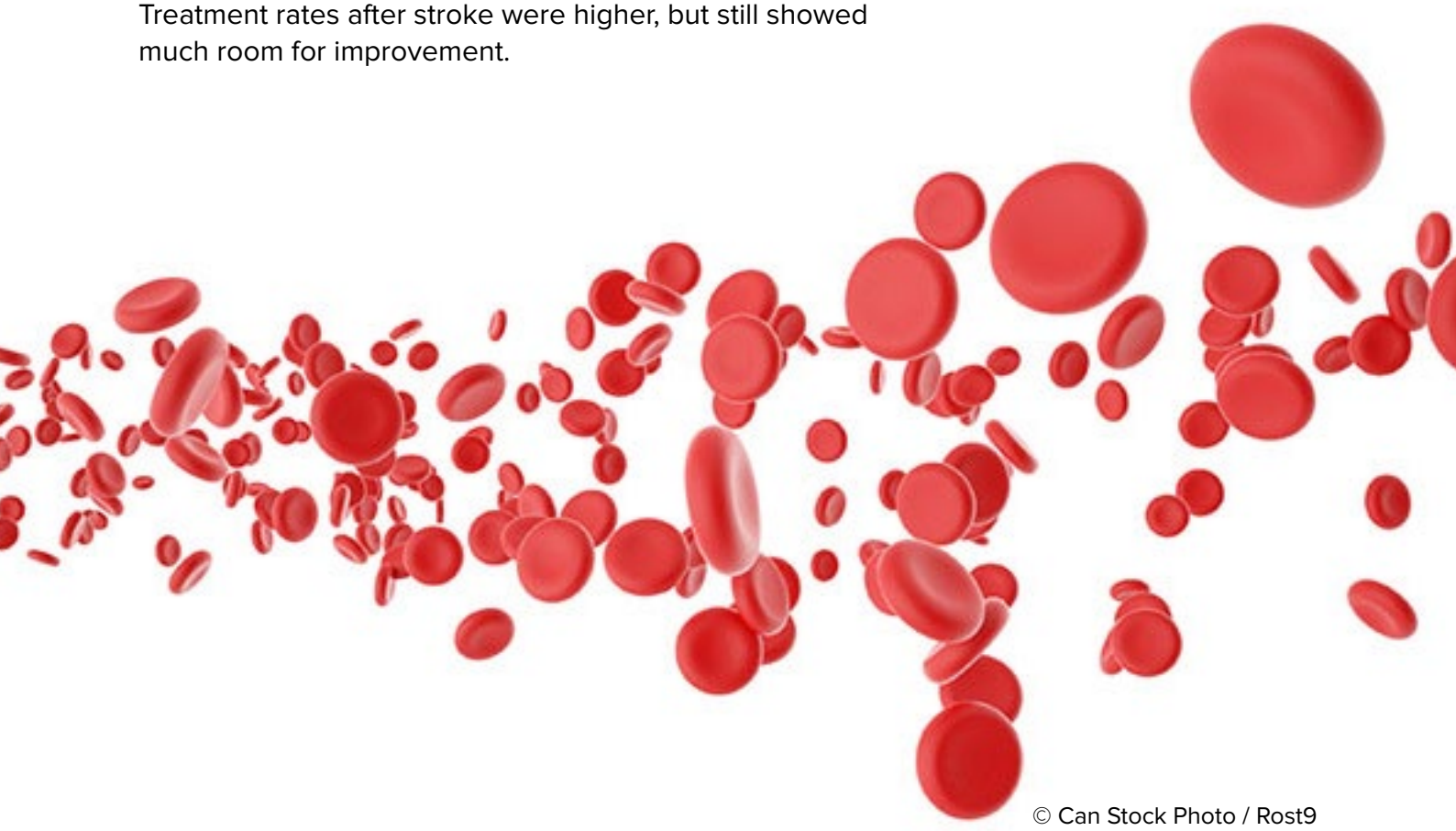
Table 10: Anticoagulation rates in AF patients before and after stroke (primary and secondary prevention)

	Country	Rate	
Before stroke	**Austria**	16%	patients diagnosed with AF prior to or at admission, 1999/2000 stroke register data[158]
	Finland	55%	patients with CHA2DS2-VASc-score ≥2, 49% in 2003 rising to 65% in 2012[159]
	Ireland	39%	2015[129]
	Poland	40%	in 2010/3, compared to 6% in 1995/9[104]
	Sweden	16%	known AF, prior to ischaemic stroke, 2005-10 stroke register data[160]
	UK	23% 25% 46%	in 2011, compared to 12% in 1995[105] poor correlation with CHA2DS2-Vasc score (1999-2008 primary care data[106] those in AF on admission[161]
After stroke	**Austria**	33%	at discharge in 1999/2000[158]
	France	91%	2004-6, local stroke register data[162]
	Germany	55%	2008/9 national audit data[163]
	Ireland	84%	6 months after ischaemic stroke, 2011 data[116]
	Italy	74%	2004-6, local stroke register data[162]
	Lithuania	37%	2004-6, local stroke register data[162]
	Poland	21% 22%	2008/9 national audit data[163] 2004-6, local stroke register data[162]
	Spain	59% 23%	pat with embolic infarction in 2009[164] 2004-6, local stroke register data[162]
	Sweden	63% / 9% 35% 37%	in 18-64 / in>85a, 2005 data[157] within the first 3 months after stroke, 2005-10, national stroke register data[160] 2008/9 national audit data[163]
	UK	34% 40%	2008/9 national audit data[163] 2007-2012 local stroke register data; was 18% in 2004-6[162]

The spread of novel oral anticoagulants (NOAC) (now known as non-vitamin K antagonist oral anti-coagulation) will overcome some obstacles to the use of traditional oral anticoagulants (the need for frequent monitoring, for example), and might improve treatment rates. However, their uptake has been reported to be slow[138]: use of NOAC in Italy: <1%, UK: 4%, France: 6%, Spain: 11%, Germany: 12%. The National Health Service in England reported that most areas had a NOAC uptake below 20% of oral anticoagulants with wide variations (4% to 69%)[165]. In Poland, 19% of anticoagulated AF patients discharged from cardiology were using NOAC[166]. More encouragingly, a German study of four tertiary stroke centres reported that half of ischaemic stroke patients discharged with anticoagulation were prescribed NOAC[167] and recent European data from GLORIA-AF show that 52.3% of all oral anticoagulant prescriptions for newly diagnosed AF patients were NOACs[145]. A recent Danish study found 73% of all prescribed oral anticoagulants being NOAC in 2015[148].

In conclusion, the prevalence of AF is expected to rise significantly over the next few decades due to an ageing population and there is evidence of severe under-diagnosis. Anticoagulation rates reported from large surveys using specialist cardiology set-ups are encouraging but studies using primary care data show much lower treatment rates, particularly in the older age group[156, 157]. Retrospective analyses of treatment rates in AF patients prior to stroke are lower still (16-39%). Adherence to available treatment guidelines and the recommended use of risk stratification is still insufficient[168].

Treatment rates after stroke were higher, but still showed much room for improvement.



2.4 Transient ischaemic attack (TIA) (indicator 8)

TIA is known as a mini-stroke and defined as a focal neurological deficit lasting less than 24 hours caused by a focal, temporary cerebral ischaemia. Its main significance lies in the increased risk of subsequent stroke. A recent large international study found a 5% risk of stroke within one year of TIA[169]. An Italian study found a 6% and 11% risk of stroke within the first 7 and 90 days of TIA respectively[170]. Other studies also reported a particularly high risk in the first few days after TIA[171, 172]. Studies calculating the 90-day stroke risk for patients having been urgently assessed after TIA found much lower risks of subsequent stroke[173, 174].

Example from Croatia: "There is only one TIA Centre in Croatia providing best outpatient medical care within 24 hours (diagnostics and therapy) for low risk TIA or mild stroke patients[...] It has full access to all diagnostics (neuroimaging, cardiology, ultrasound, biochemistry) with the limitation of not being available on weekends so far. Other hospitals either admit TIA patients to general neurological wards or discharge them home for further workup".[9]

Urgent assessment and starting of stroke prevention treatment is, therefore, essential to lower the very substantial risk of subsequent stroke.

There is little epidemiological data regarding the number of TIA events per population. Incidence of TIA in Europe was reported as 0.5-2.4 and 0.1-1.1 in men and women aged 55-64, rising to 3.0-7.2 and 2.2-8.1 in those aged 75-84[175]. Age-adjusted incidence rate was reported as 73 per 100,000 in Sweden[176], 25 in Italy (Udine)[170], and 29 in Spain[21]. Crude incidence was 101 per 100,000 in Croatia[177]. The proportion of the population which has experienced a TIA in the past was estimated at 0.5% in the UK[67], 1.3% in Spain[64], and 1.4% in Croatia[58].

In most European countries national stroke guidelines cover TIA management (Austria, Belgium, Bulgaria, Czech Republic, Finland, France, Ireland, Italy, Latvia, Luxembourg, Malta, Germany, Hungary, Sweden, Spain, and UK), while some countries use local guidelines (Croatia, Greece, and Slovakia).[9, 178]

Several European countries have to some extent a dedicated system for the care of people with TIA (immediate or same day evaluation of patients by a stroke specialist): Belgium[9], Croatia (one outpatient centre only[9]), Czech Republic, Denmark, France[179], Germany, Italy, Ireland, Israel, Portugal, Serbia, Slovakia, Slovenia[9] Spain, UK[169]). Several countries lack specialised outpatient services and TIA patients are usually admitted for diagnostic tests (Austria, Estonia, Slovakia[9]). However, there is no information available for several European countries and the extent, availability, and population coverage of the services in the countries listed above is largely unclear.

Example from Slovakia: "There is no chance for patients with TIA to pass all recommended examinations (ultrasound of carotid arteries, ECG, Holter monitoring, echocardiography, etc.) in short time (sometimes it could last 3 months). That is why they are admitted to hospital, where they pass most of these examinations in a few days (it depends on the hospital how many days) and most of them are discharged from hospital with secondary prevention".[9]

2.5 Recommendations - Preventing stroke

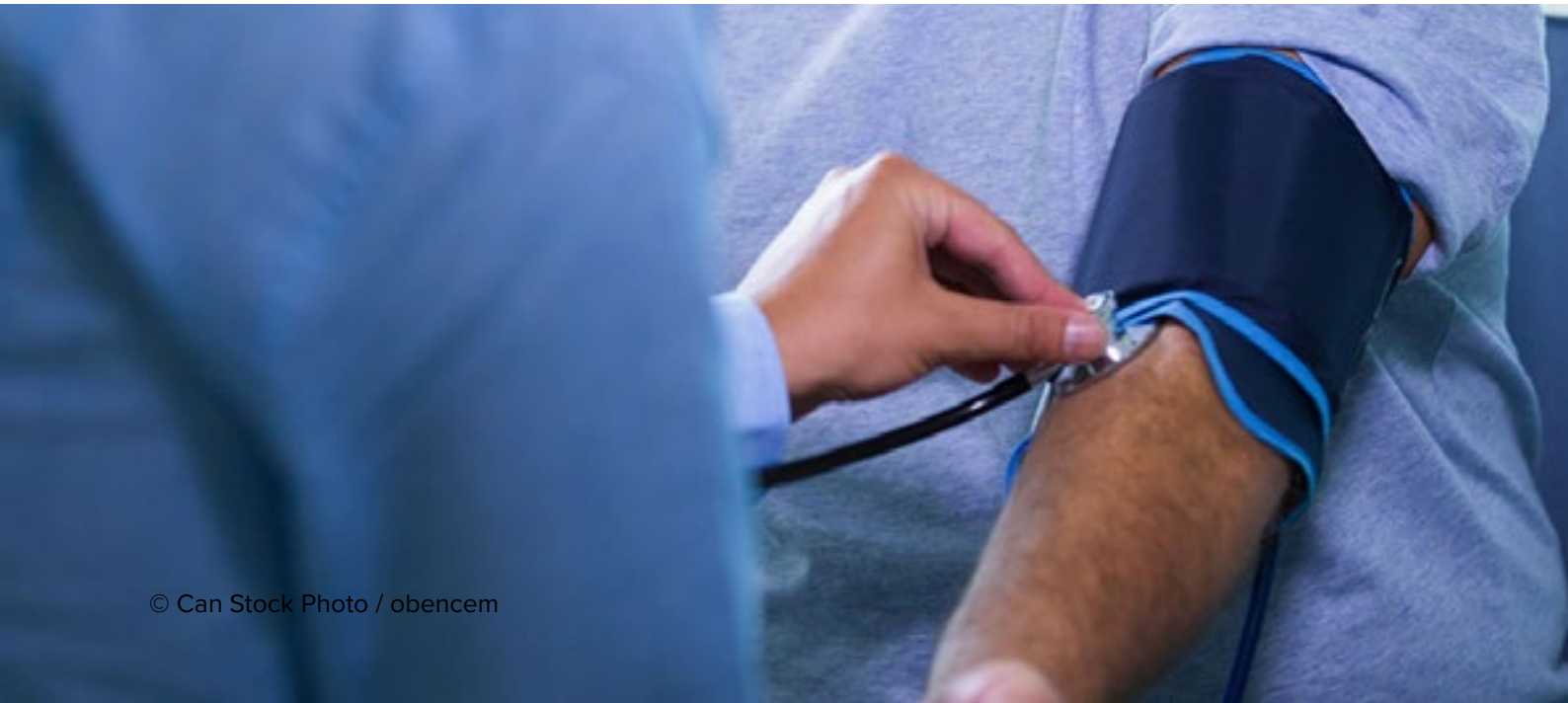
A more systematic, evidence-based approach to public education across the EU is required to improve knowledge of the modifiable risk factors for stroke, i.e. an awareness that these factors significantly increase a person's risk of stroke, but in most cases can be treated. Joining forces with public education efforts in relation to the other cardiovascular diseases could create a more powerful message and greater impact.

Current educational campaigns should be assessed for their effectiveness. Our understanding needs to go beyond measuring public knowledge and awareness to look at the extent to which they positively influence public behaviour over time. We should build on what works and make sure public education is both effective and cost effective. Innovative campaigning methods (such as: the use of social media, apps; collaborative campaigns in co-operation with other medical specialties; risk factor education in schools; and risk-factor checks in places such as workplaces or pharmacies) should be assessed.

Across Europe we need rapid and concerted action to prevent stroke and, especially, improvement in the detection and treatment of high blood pressure (hypertension) and atrial fibrillation (an abnormal heart rhythm with rapid and irregular beating). Medical professionals and patients must both be involved through shared decision-making, in order to increase adherence to existing guidelines, compliance with prescribed medications, and regular blood pressure checks.

Improvement in the diagnosis and management of AF is needed including systematic approaches to identifying and monitoring AF. The effectiveness and cost-effectiveness of AF screening policies of at-risk populations should be assessed in the respective health contexts of each country, as do new developments such as devices and apps for detecting AF, self-monitoring of INR, and new anti-coagulation therapies. A more systematic approach to monitoring guideline adherence (e.g. national or large regional audits), and possibly incentivising this adherence might improve treatment rates.

Timely assessment of suspected TIA patients in specialist clinics should be widely available.



3.

STROKE AS A MEDICAL EMERGENCY

Lack of public knowledge about stroke symptoms and that stroke is an emergency is an important cause of delays in people getting emergency stroke care. Once in the hospital, there are large variations across Europe in how quickly people are treated by stroke specialists. This section looks at what efforts are being made to avoid delays in people getting specialist treatment.

The quicker stroke treatment can be started the better – the concept "time is brain" encapsulates the fact that stroke should be treated as a medical emergency in order to improve outcomes and avoid deaths from stroke. Minimising the time between the onset of a stroke and treatment involves many people:

- a person having a stroke (or someone with them) needs to recognise the symptoms and call an ambulance;
- paramedics need to screen for stroke and take the person directly to the best place for specialist stroke treatment;
- hospitals need to have clinical pathways that minimise delay (immediate access to CT scanning, for example).

Avoidable delays have been identified at all of these levels across several European countries, including those with highly organised stroke services[180] (Germany[181], Greece[182], Italy[183], Finland[184]). These delays are an important reason for thrombolysis still being under-performed in most of Europe[185-187].

3.1 Public knowledge of stroke as an emergency (indicator 4)

Public knowledge of stroke symptoms and awareness that stroke is a medical emergency and a treatable condition is poor. Nearly one in five people (19%) were unable to identify any stroke symptom, according to a large survey covering Austria, France, Germany, Italy, the Netherlands, Poland, Russia, Spain, and the UK. Of the 14 symptoms presented, no one symptom was recognised by more than half of the respondents. **Only 51% would call an ambulance when someone has a stroke**[188].

Numerous country-level or regional studies from across all of Europe support these findings of poor stroke symptom knowledge (Bulgaria[189], Croatia[88], Czech Republic[96, 190], Denmark[89], Estonia[90], France[191], Germany[91], Greece[92], Ireland[192], Italy[193], Lithuania[194], Portugal[195], Spain[196], Sweden[197], UK[198]). Two studies found a higher level of education related to higher awareness[90, 197]). There was no difference between urban and rural populations in a Croatian study[88]). Men were found to have poorer knowledge of stroke symptoms than women[89].

Poor public awareness is a common cause of pre-hospital delays. An Italian study found underestimation of symptoms to be responsible for 49% of late admissions to their stroke unit[199]. A Dutch study found that, for their patients, most of the pre-hospital delay was due to patients delaying contacting emergency services. That study estimated that 24% of stroke patients could receive thrombolysis if delays were avoided, compared to 7% actually receiving treatment[187].

The European Stroke Organisation (ESO) guidelines recommend awareness raising programs and most countries have undertaken public campaigns to improve the public knowledge of stroke symptoms and the appropriate response.

One of the best known national campaigns is the award-winning Act FAST public health campaign launched by the Department of Health in the UK in 2009, including mass media advertisements aimed at the general population as well as primary care physicians.

This campaign subsequently served as a template for similar campaigns in other European countries (Austria, Belgium, Ireland, Macedonia, Malta, Serbia, Slovenia, and Spain). Many European countries have introduced awareness-raising activities around a national Stroke Awareness Day, often linked to World Stroke Day (http://www.worldstrokecampaign.org).

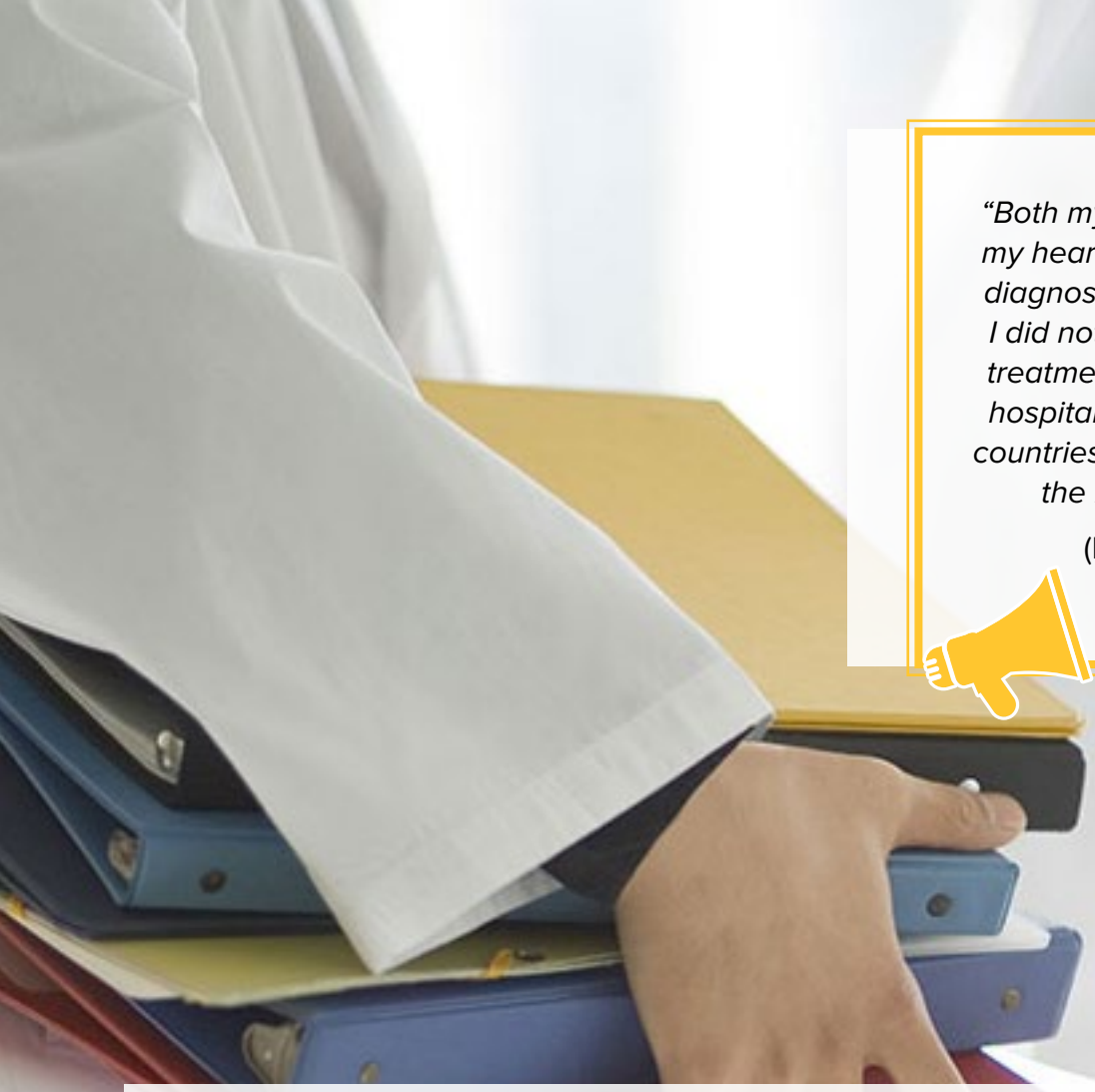
Example from Czech Republic: HOBIT Programme:

"We have initiated and conducted the HOBIT program (acronym for HOdina Blologie pro živoT) to increase the response to stroke and heart attack symptoms in school children. HOBIT 1 started in 2009 and finished in July 2015 and confirmed excellent feasibility and sufficient efficacy of the innovative web-based multimedia education program for children. We now propose a population-based intervention (HOBIT 2), which will educate[...] also their adult relatives. The intervention tool will be the existing e-learning programme customised for adults. Efficacy will be tested by randomizing adult into target group (education + testing) and control group (testing). HOBIT 2 will result in a scientifically proven educational platform and communication strategy that can be applicable nation-wide".[9]

There is little research that measures the impact of these campaigns. Some studies use a reduction of pre-hospital delays as a proxy for the campaign's impact. Evaluating the UK Act FAST campaign, a marked improvement in early presentation was seen, coinciding with the start of the campaign, as well as increased awareness of stroke symptoms[200, 201].

The Irish FAST campaign showed an initial impact on emergency department attendance of stroke patients, but these effects were not sustained in the long term[202]. While some found improvements in stroke symptom awareness following their campaign[91, 203, 204], others had negative results[96].

Overall, evaluation of public awareness programs tends to be poor and often doesn't include their impact on people's behaviour[205]. However, literature reviews on the effectiveness of stroke educational campaigns, including some European studies, generally found the potential to improve knowledge and change behaviour[205, 206]. There is therefore a need to systematically assess the public health campaigns undertaken across Europe, in order to prove their respective effectiveness and improve their impact accordingly.



"Both my brain stroke and my heart attack were only diagnosed two days later. I did not receive the right treatment in two different hospitals, in two different countries [Luxembourg and the Netherlands]"

(Female stroke survivor)

3.2 Professional education concerning stroke as an emergency (indicators 4 and 5)

Healthcare professionals who have not had specific stroke training (ambulance and emergency staff, as well as general hospital staff and primary care physicians) can contribute to delays and therefore the current ESO guidelines recommend educational programmes for professionals. There is some evidence from most European countries that professionals are being educated to some extent with regards to stroke as a medical emergency. However, evidence is mainly anecdotal, relating to individual events, or national stroke guideline recommendations are being used as evidence.

Few studies into the impact of such training programmes exist. A German study found reduced in-hospital delays and increased thrombolysis rate following an educational program for emergency staff[207].

A Finnish trial of a new emergency medical services training programme reported a reduction in the time ambulance crews spend assessing and treating patients before transporting them to hospital after ambulance crew training[208]. Other studies describe a lack of emergency staff training (Italy: low number of emergency staff activating the stroke code[193], Lithuania: current training inadequate[194], France: suboptimal professional practices and coordination as a barrier to effective stroke care pathways[191]).

There is no clear picture across Europe about the extent, intensity or impact of training that is available or systematically provided for non-stroke specialist medical staff.

3.3 Emergency care pathways

Stroke specific training for ambulance, emergency services, and other involved medical staff is often part of a wider effort of developing and implementing new, more efficient emergency care pathways on a national or regional level. Examples of stroke care pathways introduced in Europe and their impact (if published) are listed in table 11.

Table 11: Examples of European stroke care pathways

Country	Stroke care pathway
Austria	Tyrolian stroke pathway, introduced in 2009, covering pathway from symptom onset to rehabilitation, led to less in-hospital delay (median nationwide door-to-needle time decreased from 49 min in 2010 to 44 min in 2013) and increased thrombolysis rate (from 12.9% in 2010 to 16.8% in 2013[209])
Finland	"Helsinki Model" including ambulance pre-notification of stroke team, led to less in-hospital delay[210] Re-organisation of in-hospital treatment pathway with shifting stroke care from neurologists/internist to emergency doctors, led to less in-hospital delay[211]
France	Re-organisation of regional stroke care pathway (North of France region) centralised emergency service directs patients to closest SU, direct admission to radiology department, led to increased thrombolysis rate[212]
Hungary	Lysis Alarm Program with ambulance pre-notification, led to less in-hospital delay and increased thrombolysis rate[213]
Italy	Stroke Code system: screening by ambulance and pre-notification of hospital, impact: increased thrombolysis rate[214], still only 20% of stroke pat arrive with code[193]
Portugal	Via verde do AVC, describes pre- and in-hospital pathways, implemented in 2005, no improvement in stroke mortality rates[215], but higher thrombolysis rates with activated stroke code[216]
Spain	Stroke Code system, higher thrombolysis rate in Barcelona hospital[217-219]
UK	Stroke screening by ambulance using validated tools such as FAST and pre-notification and transport to hospital with acute specialist stroke services[220]

Ambulance stroke screening and pre-notification of the assigned hospital are a central part of most of the pathways listed above. They were found to improve thrombolysis rates, especially when combined with educational campaigns to optimise awareness and behaviour of patients and bystanders[214].

The key measure to assess delays in hospital is how long it takes for someone to get treatment after arriving – the door-to-needle time (DNT). This measure can be used to assess how efficient in-hospital emergency pathways and protocols for stroke are.

Large inequalities in DNTs were found between countries, but particularly also between different centres within the same country. In Slovenian centres 60% of thrombolysed patients achieved DNTs under 60 min, while only 19% did in Slovakian centres[222].

Data from Croatia, the Czech Republic, Estonia, Hungary, Lithuania, Poland, Slovakia, Slovenia, and Turkey revealed large variations between centres[223]: in some centres, the chance of imaging within 25 minutes of arrival was 93% compared to 3% in other centres.

Long transport times between the place of admission and a CT scanner was the main explanation given, pointing to a need to further re-organise stroke services.

Data from the Stroke Knowledge Network Netherlands showed similar variations between hospitals, but also a general reduction in DNTs as hospital routines improved[224].

The international Safe Implementation of Thrombolysis in Stroke Registry with predominantly European data reported that patient volume was the strongest predictor of DNT times[225].

Example from Finland: The "Helsinki Model" involved several system improvements[...] at Helsinki University Central Hospital in Finland between 1998 and 2011, including ambulance pre-notification, direct triage to CT scanner transport, and administration of thrombolysis directly in the CT suite. In-hospital delays as analysed with annual median door-to-needle time were reduced from 105 minutes in 1998 to 20 minutes in 2011[210]. Those system changes were successfully replicated at The Royal Melbourne Hospital in Australia bringing DNT down to 25 minutes.[221]

Example from Italy: Stroke Program in Siena Province includes direct transfer by ambulance or helicopter with medical assistance on board, stroke code notification, mean door-to-needle time 48 minutes, thrombolysis with possible rescue thrombectomy, stroke unit care equipped with 6 semi-intensive and 10 less intensive care beds with multidisciplinary team. The Programme has received an award from the Joint Commission Italian Network in 2016[9].

3.4 Recommendations - Stroke as a medical emergency

SAFE calls for continuous and sustained awareness raising campaigns across Europe so that more people recognise stroke as a medical emergency. These should be included in national stroke strategies, financially supported by Governments and should include stroke survivors in their planning and implementation.

We need to know which public education campaigns across Europe have worked best, and why, so that success can be replicated. Systematic assessment of public health campaigns undertaken across Europe is required to prove their effectiveness and improve their impact. More collaborative working with voluntary sector organisations might improve the impact of campaigns.

There should be a more systematic approach towards training healthcare professionals, using evidence-based methods and on-going assessment of its implementation and effectiveness.

There is a need to improve emergency pathways in some centres in order to reduce Door-To-Needle times. Strategies will depend on the respective national, regional, and local health infrastructure.

Examples from Greece[9]: Case 1 (Region of Thrace): urgent transport to a rural hospital (Komotini General Hospital- onset to ER time: 35 min) – emergency department: immediate assessment by internist and CT scan, transport to University Hospital of Alexandroupolis (60Km distance): immediate assessment by the stroke team – iv. thrombolysis - transfer to stroke unit bed (available bed in cardiovascular intensive care unit) Case 2 (from Attikon University Hospital, Athens): 28-year old female with acute (onset to ER time: 125 min) right MCA infarction (NIHSS score 16 points) due to a proximal right M1MCA occlusion disclosed by TCD and CTA. The door to needle time for iv. thrombolysis was 24 min. The patient had substantial improvement (NIHSS 9 points). A second CTA disclosed a residual clot in M2MCA- transfer to the angiography suite to undergo mechanical thrombectomy. The door to groin time was 102 min. Complete recanalisation was achieved using a stent retriever (groin to recanalisation time 32 min). The patient's neurological status further improved (NIHSS-score 1)

4.

ACUTE STROKE CARE

Stroke units save lives and improve outcomes, but we don't have a Europe-wide applied standard of the essential elements of stroke unit care. Despite over thirty years of evidence showing the difference stroke units make and despite their inclusion in European and national guidelines, it is estimated that only about 30% of stroke patients receive stroke unit care across Europe. This figure masks startling inequalities between countries, and in particular the East-West divide in stroke unit provision. This section outlines the state of hospital care for stroke across Europe, including access to specialised stroke units and treatments.

4.1 Stroke unit care (indicator 6)

Stroke units – which should provide coordinated, multidisciplinary care by personnel specialised in stroke care (European Stroke Organisation) – save lives and improve outcomes. "Stroke patients who receive organised inpatient care in a stroke unit are more likely to be alive, independent, and living at home one year after the stroke"[226]. The 2nd Helsingborg Declaration stated that "all patients in Europe with stroke will have access to... stroke units in the acute phase...by 2015"[227].

Across Europe,
it is estimated that only about
30% of stroke patients
receive stroke unit care[228].

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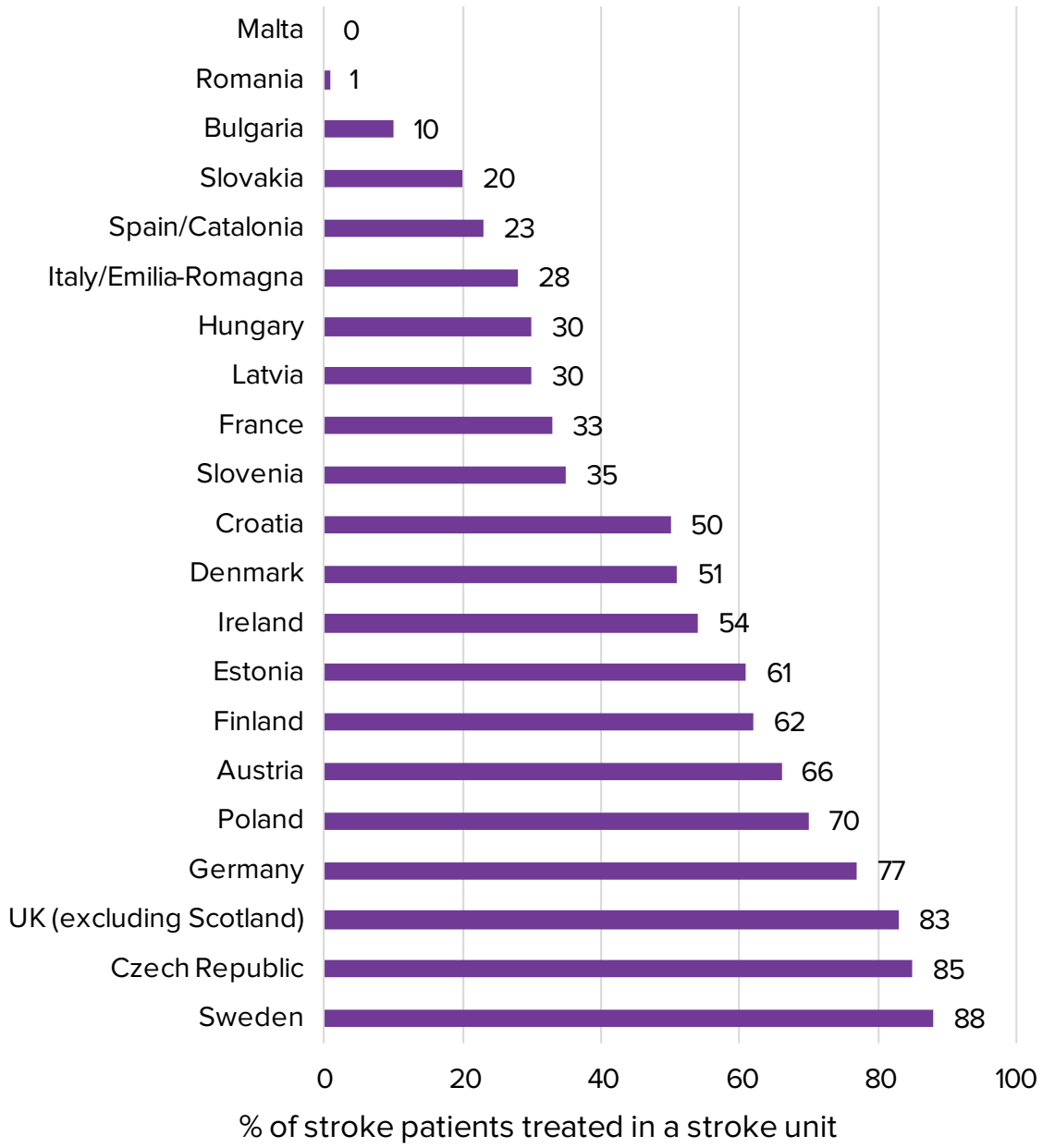
Using data from recent publications as well as information gathered through the questionnaire sent to European stroke experts[9] we found significant differences between countries in the number of stroke units and percentage of patients treated in stroke units (Figure 9) ranging from <10% in Malta, Iceland, Romania, and Ukraine to >85% in Sweden and Norway.

Lower rates of stroke unit care were generally found in Eastern Europe. However, two consecutive questionnaire-based surveys (CEESS Working Group, completed by stroke experts in the respective country) observed large variations between Central and Eastern European countries (included in Figure 9[229, 230]).

Overall, the number of stroke units and the percentage of stroke patients treated in stroke units have increased significantly since 2000. National audits in Germany, Poland, Sweden, and the UK showed a two-fold increase in the proportion of stroke patients treated in stroke units between 2004 and 2009[163]. In Spain, 39 stroke units existed in 2009 compared to 45 in 2011[231, 232], while 17% of stroke patients were treated in stroke units in 2005 compared to 23% in 2007[233].

In Finland this proportion increased by 18% between 1999 (11 stroke units) and 2007 (16 stroke units)[54, 234]. 2% of Irish stroke patients were cared for in a stroke unit in 2008 compared to 54% in 2015[129]. Also in most Eastern European countries, an increase in the percentage of patients treated in stroke units was seen in the two consecutive studies published in 2007 and 2015 (e.g. Czech Republic from 10% to 85%,[229, 230]). The number of stroke units in Poland increased from three in 1997 to 150 in 2012[235, 236].

Figure 9: Percentage of stroke patients receiving stroke unit care



References: Norway:[9], Sweden:[53], Czech Republic:[230], UK (excluding Scotland):[237], Germany:[238], Poland:[230], Austria:[239], Finland:[54], Estonia:[230], Ireland:[129], Denmark:[240], Croatia:[230], Serbia:[230], Slovenia:[230], France:[241], Latvia:[230], Hungary:[230], Italy:[242], Spain:[233], Slovakia:[230], Bulgaria:[230], Romania:[230], Iceland:[9], Malta:[243]

Many European countries report variations in stroke unit care between different regions. Urban areas are usually better provided for than rural areas, e.g. Greece with variations between major cities, rural areas, and islands[9]. In Spain, stroke units are concentrated in Madrid and Barcelona[231], and the ratio of stroke unit beds to residents was found to range from 1/74,000 to 1/1,037,000[232]. Of 130 Italian stroke units, 67% are located in Northern, 22% in Central, and only 11% in Southern Regions, which, however, contains 34% of the Italian population[244]. French data indicate that nationally 33% of stroke patients are treated in stroke units[241] compared to 51% in the Dijon Stroke Register area[162]). 73% of Finnish patients living within the catchment area of a stroke unit were treated in a stroke unit compared to 9% outside a catchment area[54]. In Austria, a stroke unit can usually be reached in less than 45 min, but some areas show travelling times of over 90min[245]. Therefore, **within-country variations might be as large, or even larger than variations between national averages** (if known).

However, comparing the published proportions of stroke unit care or number of stroke units across countries has to be done cautiously due to several limitations.

Firstly, due to the significant increase in stroke unit care over recent years, figures depend on when the data were collected.

Secondly, some studies only looked at subsets of stroke patients, e.g. those admitted to a stroke unit within a certain time of hospital arrival[240] or patients spending a certain proportion of their hospital stay in a stroke unit[162].

Thirdly, some studies use only hospitalised stroke patients as their denominator (national audits), while others give the proportion of all stroke patients in a certain area (e.g. population-based registers). In this case, the proportion of stroke unit care is highly dependent on stroke hospitalisation rates, which again vary across Europe (estimated rates: Finland 95-98%, Sweden 84-92%[54], Bulgaria 96%[189], Hungary 90%, Italy 87%, The Netherlands 60%, Scotland 62%[246]).

Some international studies have developed standardised datasets, in order to be able to compare between countries. The European Registers of Stroke (EROS) Investigators compared the proportion of stroke patients in population-based studies spending more than half of their hospital stay on a stroke unit in 2004-6 and found a proportion of 0% in Spain (Menorca), 16% in Italy (Sesto Fiorentino), 23% in Lithuania (Kaunas), 48% in Poland (Warsaw), 51% in France (Dijon), and 65% in England (London)[162]. The European Implementation Score (EIS) project, using national audit data of hospitalised stroke patients, reports stroke unit treatment rates of 91% for Poland, 84% for Sweden, 75% for Scotland, and 73% in England, Wales and Northern Ireland in 2008[163]. Again, large

differences between countries/studies could be seen.

However, definitions of what is called a "stroke unit" are not always the same and significant differences in standards of care can be found. The European Stroke Initiative (EUSI), based on expert opinion, stratified "Stroke Units" into "comprehensive stroke centres" (CSCs, equipped with interventional neuroradiology, advanced neurosurgery, 24/7 MRI) and "primary stroke centres" (PSCs, multidisciplinary team, stroke-trained nurses, 24/7 CT) and any hospital ward (AHW) admitting stroke patients routinely[247]. The European Stroke Facilities Survey, 2005, looked at the number of hospitals fulfilling CSC-, PSC-, and AHW-standards. It found large disparities between countries, with only few European hospitals providing an optimal level of care[248]. In Estonia, France, Greece, and Portugal more than three quarters of participating hospitals did not provide the minimum level of care. Countries with a large number of small hospitals treating only few stroke patients, e.g. France and Germany, performed badly in this survey.

Overall, 51% of participating European hospitals caring for 42% of stroke patients did not meet minimum standards.
Only 5% of hospitals had facilities meeting the standards of comprehensive stroke centres[248].

Much has improved over the last decade in terms of the availability and standard of stroke unit treatment, but also the quality of stroke units. Poland had no CSCs in 2003, while by 2010 nine stroke units fulfilled the CSC criteria. In 2003, most "stroke units" failed to provide care at PSC level, but by 2010 all of them did[236]. In Catalonia, a stroke network has been operating since May 2006 with 6 CSCs, 8 PSCs, and 35 Community hospitals, and those providing thrombolysis (6) are linked to their PSCs via telestroke[244]. The Czech Republic introduced a system with 11 comprehensive and 34 primary stroke centres in 2010/11[249].

The Central Denmark Region carried out a stroke care reform in 2012 involving centralisation of stroke care into two specialised centres and found increasing thrombolysis rates and reduced 30-day mortality[250].

In two UK urban areas (London and Manchester), stroke services were centralised in 2010 into a small number of hyperacute stroke units for the acute phase and general stroke units.

Example from the Czech Republic[249]:
before 2001 there was no central accreditation of stroke units; 2001-9: stroke units were accredited by scientific society; 2011: new system of 34 PSC/11 CSC, accredited by Ministry of Health and scientific societies; 2013: 12 Quality of care indicators reviewed in 6-monthly audit (compulsory); stroke unit care of stroke patients increased from 10%[229] to 85%[230];

Example from Bulgaria:
St. Marina University Hospital in Varna: 2005 course of stroke care for nurses - 2007 introduction of thrombolysis - 2011 enrolled in the SITS programme - 2015 part of QUICK program, ESO and part of ESO-East - 2016 registered for Angels Initiative, thrombolysis rate 5.8%, nationally under 1%.[9]

Patients admitted to hyperacute stroke units were shown to be significantly more likely to receive evidence-based interventions and experience better outcomes[251, 252]. Despite this, the 2014 UK national stroke audit (using a gold standard of seven stroke unit criteria) reported that the majority of UK stroke unit beds did not meet this standard[253]. So improvements made in some areas, in this case two large metropolitan areas, might not be representative of a country as a whole.

The large inequalities in quantity and quality of stroke unit care between and within European countries led to several international (Stroke Unit Trialists' Organisation, ESO) and national stroke organisations, e.g. Belgian Stroke Council, German Stroke Society, Spanish Neurological Society, issuing guidelines for the creation of stroke units using widely agreed standards based on evidence or experts consensus.

Example from the UK: Until 2010 acute stroke care in London was provided in 32 acute hospitals of very variable quality, even though each hospital had a stroke unit. From July 2010, all acute stroke patients were taken to one of 8 accredited hyperacute stroke units for the initial 2-3 days. Several hospitals were not accredited and ceased providing any stroke care at all. Length of stay has fallen by about 4 days and thrombolysis rates have risen from about 3% to about 12%.[244]

A system of official accreditation has been introduced on a European- and national level (e.g. ESO Stroke Unit and Stroke Centre Certification Platform launched in 2016). Hospitals are encouraged to apply[244, 254]. Certification is now mandatory in some countries/areas (e.g. France) and financed and organised by governmental agencies. In other countries, it remains voluntary (e.g. Germany, organised by the German Stroke Society, the German Stroke Foundation and an accredited certification institution, and paid for by the hospital). Some European countries have no system of official accreditation, e.g. Belgium, Lithuania[244], Sweden (where the national audit is a driver of care quality), or Macedonia[178]. In many European countries (Latvia, Croatia, Slovakia, Lithuania, Bulgaria, Hungary, Poland, Greece, Czech Republic, Romania, Austria, France), some hospitals have become members of the ESO Registry, setting standards of stroke unit care, but figures vary from less than 5 in Latvia and Croatia, to over 50 in France[228].

Comparisons of stroke unit care across Europe have many caveats because there is no Europe-wide standardised system of assessment. However, it is clear that stroke unit care differs widely between, and within countries in terms of both quantity and quality.

The 2015 Helsingborg goals of universal availability for every stroke patients have not been reached, in most countries by a very wide margin.

4.2 Thrombolysis (indicator 7)

The **benefit of thrombolytic therapy ("clot busting treatment") for acute ischaemic stroke has been well established** [255]. All EU member states have introduced national guidelines for the treatment of acute stroke including thrombolysis, often based on the guidelines issued by the European Stroke Organisation or the American Stroke Association. The implementation of thrombolysis across Europe since the beginning of this century has transformed acute stroke care, with stroke becoming a treatable condition. One of the main targets of most national stroke strategies is to reduce the time interval from stroke onset to diagnosis in order to increase thrombolysis rates.

Thrombolysis rates have increased in most European and SAFE member countries. Some countries with long-running national stroke audits showed a two- to four-fold increase in thrombolysis rates between 2004 and 2008, e.g. Germany: 6.0% to 9.5%, Sweden: 2.2% to 7.0%, and Poland: 0.9% to 1.2%[163]. UK thrombolysis rates have increased from 1.8% in 2008 to 12.2% in 2014[237]. Israel reported an increase from 0.4% in 2004 to 5.9% in 2010 in hospitalised stroke patients[71].

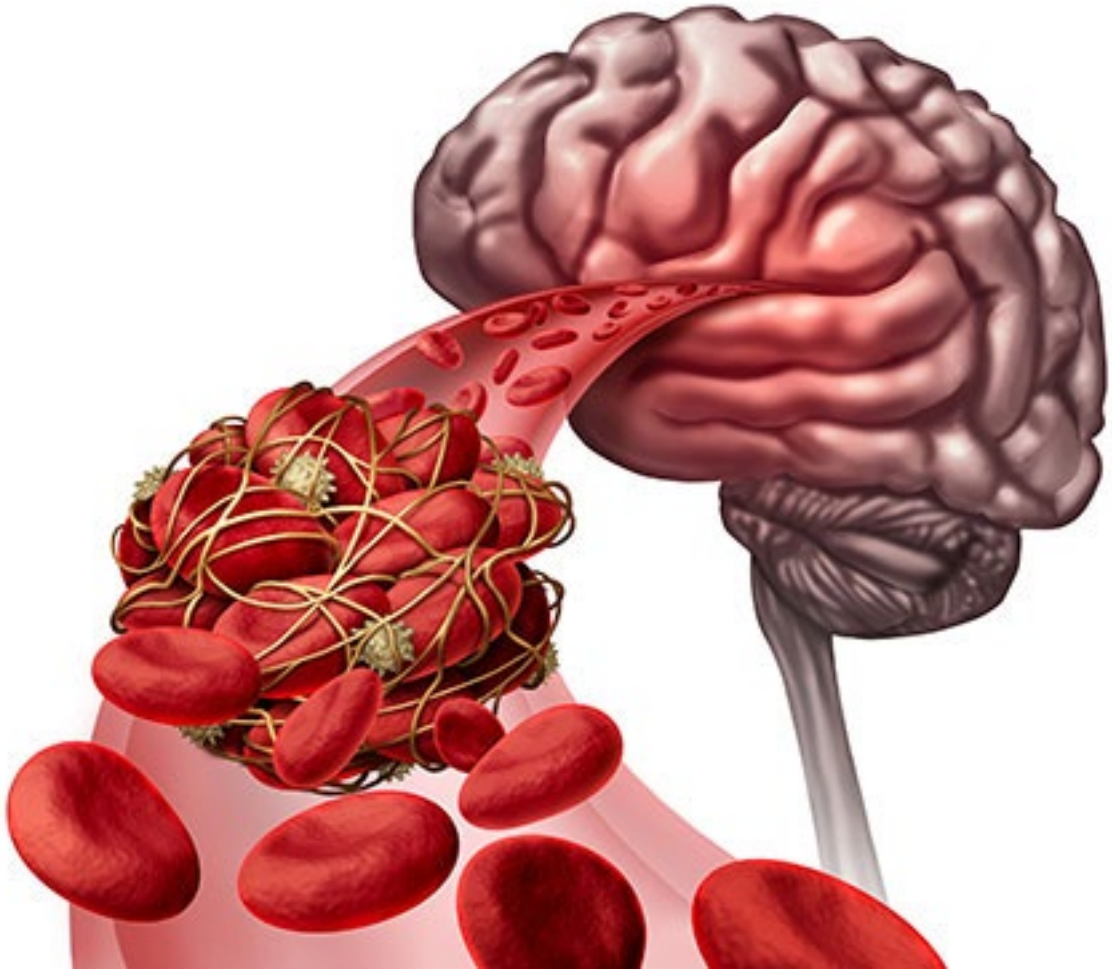
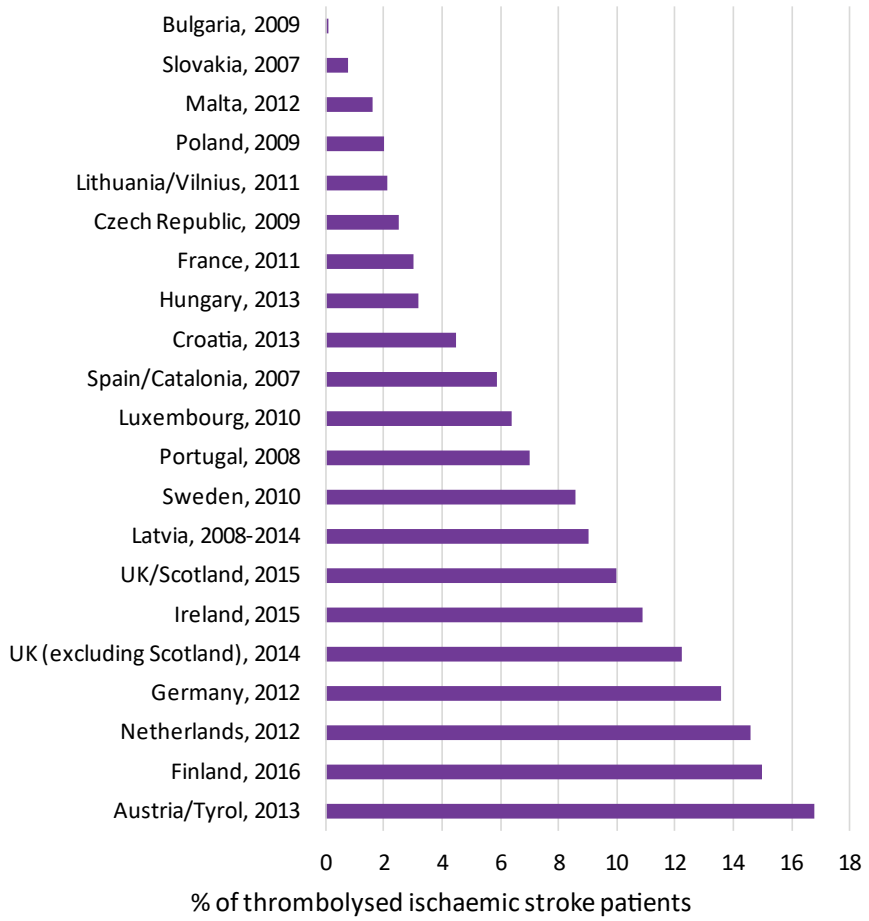


Figure 10 shows the proportion of thrombolysed ischaemic stroke patients, as reported in national or large regional audits, or published national estimates. Studies referring to individual hospitals, or stroke unit patients only (e.g. France: 16.7%[241]) were excluded. The time point of data collection is included in the figure and explains some of the variations found.

Figure 10: Thrombolysis rates in national/large regional audits or national estimates in the year indicated



References: Bulgaria:[189], Slovakia:[256], Serbia:[230], Malta:[243], Poland:[236], Lithuania:[223], Czech Republic:[257], France:[244], Hungary:[213], Croatia:[258], Spain:[233], Luxembourg:[259], Portugal:[215], Israel:[260], Sweden:[53], Latvia:[230], Norway:[261], UK/Scotland:[262], Ireland:[129], UK (excluding Scotland):[237], Germany:[163, 238], Netherlands:[224], Finland:[9], Austria:[209]

As with stroke unit care, **thrombolysis rates vary widely across Europe, but are generally lower in Eastern European countries. Variations between Eastern European countries are also large.** The 2015 CEESS Working Group Survey[230] published numbers of thrombolysis procedures undertaken in Eastern European countries between 2008 and 2014. In this 7-year period in Romania (22 million population) 205 thrombolysis procedures were undertaken and 149 in Ukraine (45 million), compared to 1572 in Estonia (1.3 million) and 3665 in Slovakia (5 million). Figure 11 presents these figures converted into average annual thrombolysis rates per 100,000 population for easier comparison.

Both Western (Germany[263,264], Netherlands[265], Spain[231], Sweden: 7-fold gradient[266]) **and Eastern European countries have found significant inequalities within their countries between different areas and particularly also between different centres/ hospitals**.

In Bulgaria, the national rate was below 1%, but has risen from 0.04% in 2006 to 0.1% in 2009, with rates being higher in urban centres[189, 267], while in Romania in 2012 thrombolysis was only available in Bucharest, the capital covering around 10% of the population[258]. In Hungary, the thrombolysis rate was 3.2% in 2013[213], again with significant differences between national rates and rates in large cities[258, 268]. One Slovakian centre reached thrombolysis rates of 15.8% against a national rate of 0.5-1%[256]. Polish studies reported thrombolysis rates of 4.2% in rural areas compared to 23.1% in urban areas[269] and centre rates varying between <3% to around 20%[236] In the Czech Republic, the thrombolysis rate was 2.5% nationally in 2009, while a group of centres (SITS registered) achieved 4.3% in 2007[270].

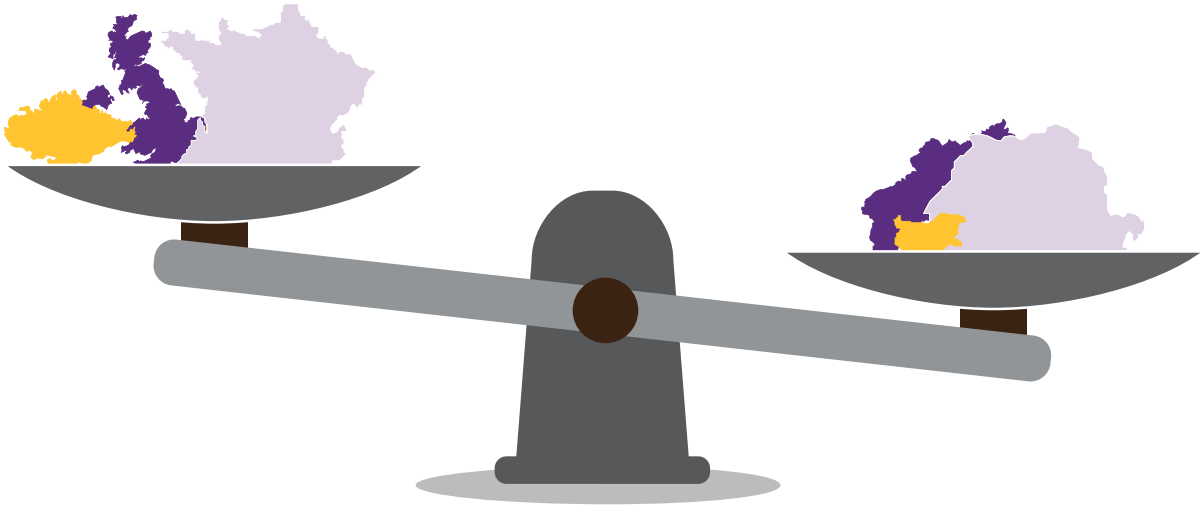
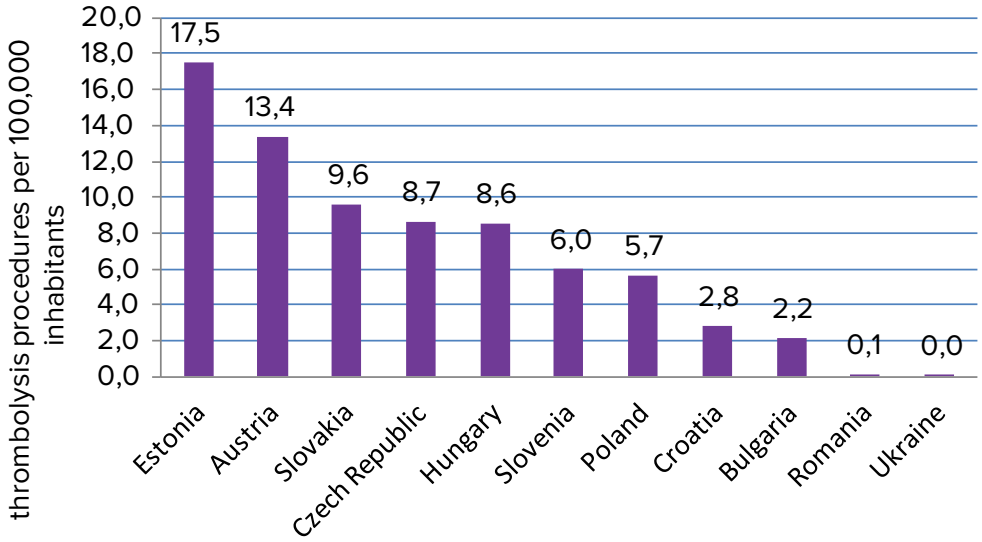


Figure 11: Average annual thrombolysis rate per 100,000 population, 2008-2014[230]



Again, comparisons between studies have limitations as different studies reporting thrombolysis rates often investigate different subgroups. Denominator populations vary between all stroke patients, all ischaemic stroke patients, hospitalised stroke patients (e.g. national audits), stroke unit patients (e.g. Austrian Stroke Unit Register), or refer to a specific region (population-based registers) or individual stroke centres only (31% in one Finnish centre in Helsinki[210], 22% in 2012 in large Dutch University hospital[271], 11% in University hospital Verona, Italy[193], 0% in two Lithuanian centres in 2006/7[272].

The 2006 Helsingborg Declaration states as a goal for 2015 that all countries aim to establish a system for the routine collection of data needed to evaluate the quality of stroke management, including patient safety issues. However, national audits are only undertaken in a small number of countries (chapter 1.1.).

Standardised, internationally agreed datasets would allow accurate international benchmarking. The Safe Implementation of Thrombolysis in Stroke (SITS) Registry, started in 1996, contains standardised data on thrombolysis procedures performed in each country, but shows significant variations between countries in terms of the percentage of centres providing data (Appendix 1, Table 3). Due to these highly variable recruitment rates SITS data is currently a poor measure of national thrombolysis rates and country-level comparisons.

The international Registry of Stroke Care Quality (RES-Q) was launched in May 2016 by ESO, targeting mainly Eastern European countries, but aiming to collate internationally agreed care quality measures.

The Safe Implementation of Thrombolysis in Stroke-Monitoring Study (SITS-MOST) includes over 160,000 stroke patients from over 70 countries, primarily those who received thrombolysis. All European countries are registered, but reporting rates vary hugely between countries, either due to low thrombolysis volumes, or poor interest in reporting data (19,826 cases from Czech Republic, 4th largest contributor to SITS), compared to 354 from France, 2002-2016,[228].

The Registry of Stroke Care Quality (RES-Q) is an important project within the European Stroke Organisation (ESO) launched in May 2016 and targeted primarily at Eastern European countries. It is a multi-national study designed to document the quality of stroke care. Standardised measurements have been agreed by an international working group[273] and include the availability of stroke units, brain imaging, vascular imaging, cardiac arrhythmia detection, thrombolytic therapy, and other factors[228].

So, due to the variations between studies, only rough indications and trends can be observed when comparing between countries. Data is more reliable when looking at trends over time within a smaller subgroup (single centre, region, hospitalised patients only). Observing trends over time is a valuable part of stroke observational studies, as they provide proof that organisational change is efficient. Additionally, monitoring performance itself helps to improve care quality[163].

Structural changes to stroke services were found to be associated with higher thrombolysis rates in European studies and supported by a recent review[274]:

- hospital pre-notification (Portugal[216]) and reduction of door-to-needle time (Netherlands[224])
- implementation of stroke unit care (Germany[275], Sweden[266]: thrombolysis 5-times more likely in stroke unit)
- centralization of stroke services (Denmark[250], UK[244]: rise in thrombolysis rate from 3 to 12%)

A further factor that has contributed to increased thrombolysis rates was the approval of the extended time window for thrombolysis from 3 to 4.5 hours by the European Medicines Agency in November 2010.

A rapid implementation into clinical practice was observed leading to an increase in thrombolysis rates from 8.6% before to 11.7% in a large hospital-based study in Germany[276]. Additionally, changes in reimbursement systems are also relevant.

In Poland, thrombolysis was initiated within the Polish National Cardiovascular Disease Prevention and Treatment Program POLKARD and was subject to reimbursement limits. Since 2009 thrombolysis is reimbursed through the National Health Fund with no reimbursement limits. Thrombolysis rates increased from 4.3% to 7.6% in a hospital based observational study[277].

"Treatment with rt-PA in ischemic stroke was introduced ... within the frame of the Polish Ministry of Health National Cardiovascular Disease Prevention and Treatment Program POLKARD. As the funds in POLKARD were limited, the number of centres and total number of patients treated with thrombolysis in each centre were limited. This resulted in an unusual situation, where legally registered treatment could not be administered to all eligible and insured patients. Beginning with 2009, thrombolytic treatment in acute stroke has been reimbursed by NFZ (National Health Fund, Narodowy Fundusz Zdrowia)... When reimbursement limits were eliminated, higher proportion of patients with acute ischemic stroke could be treated with intravenous thrombolysis ..."[277].

Despite improvements over the last decade, thrombolysis rates are still significantly below expectations in Europe.

This is particularly true for Eastern Europe, but also for Western European countries. In Germany, only 60% of eligible patients were found to have received thrombolysis in 2012[238], and 42% in Italy and Portugal[216, 278]. Under-performance was also reported from France[212] and the Netherlands (5-7% actual rate compared to 25% potential rate[187], whereas the National Stroke Audit for England, Wales and Northern Ireland concluded that 81% of eligible patients were thrombolysed in 2014[237].

Barriers to the delivery of thrombolysis are numerous and complex[279].

The most significant barriers include pre- and in-hospital delays. Within pre-hospital delays, poor public knowledge as well as inadequately trained ambulance staff has been identified as significant factor in European studies (review[180], Poland[269], Sweden, Denmark, and Norway[280], Norway[281, 282], England[283], Netherlands[187, 284, 285]). In-hospital delays were related to insufficient in-hospital routines, i.e. the existence of and adherence to specific protocols[280, 286], a lack of specialised units or staff[275, 287, 288], lack of diagnostic equipment[228], a de-centralised system of stroke care[284] and low thrombolysis numbers[223, 289]. Additionally, financial considerations are important. In 35% of Czech centres thrombolysis was found to be restricted due to financial limitations[270], and, as above, re-imbursement schemes limited thrombolysis in Poland until 2008[277].

Accordingly, improvements to the factors listed above have been suggested or found to improve thrombolysis rates further.

- Public awareness campaigns to reduce pre-hospital delay[214]
- Ambulance training and hospital pre-notification (UK[290], Norway[282], Netherlands[291])
- Use of mobile medical teams to bypass emergency room admission (France[292], Germany, review[274], review[293])
- Improved hospital services and protocols (Netherlands[291], Poland[236], review[274])
- Treatment by specialised staff / stroke units (review[274])
- Centralisation of stroke services, primary and comprehensive stroke centres to increase volumes (review[293], review[274])

Thrombectomy (mechanically removing blood clots) is currently being introduced in many European countries by including it in national stroke guidelines and implementing the necessary health care facilities in specialised centres. While there are several countries where it is not yet available at all (Bulgaria, Iceland, Macedonia[9, 178]), in most countries it is not available 24/7 or in all regions. Future effort will be required to implement a network of collaborating hospitals with regional referral centres that makes thrombectomy more widely available to patients.

In summary, thrombolysis rates have increased significantly over the last decade. However, large variations exist between and within countries. Even countries with comparatively high thrombolysis rates have room for improvement. Apart from improving public stroke knowledge, several organisational factors have been found to improve rates and merit further assessment of their effectiveness and feasibility according to the individual country's context.

Accurate international comparisons of stroke care quality, e.g. thrombolysis rates, are difficult, because of a lack of standardised, internationally agreed and widely collected quality measures. Within the EU, there are numerous stroke registers on a local, regional, national, and sometimes international level collecting varied data with different methods. International stroke registers with standardised datasets exist, e.g. SITS-MOST and RES-Q (see example), but data reporting is voluntary and therefore coverage varies significantly.

If used more extensively these registers could contribute to reliable international benchmarking, providing valuable insights into inequalities of care and the performance of different healthcare systems and helping to focus on areas where improvement is most needed.

4.3 Recommendations - Acute stroke care

There are still far too few people across Europe being treated in dedicated stroke units with stroke specialist, multidisciplinary staff. Efforts are required, especially in Eastern European countries, but also many Western European areas, to increase availability of stroke unit care and personnel specialised in stroke care.

Improvement plans should prioritise the consistent implementation of key elements of organised stroke unit care, as laid out in ESO and national guidelines.

Comparisons of stroke unit care between European countries are difficult. A Europe-wide system of standardised assessment criteria of stroke unit care would encourage international benchmarking and could drive quality improvement.

Thrombolysis is still under-performed across all of Europe. Structural changes to acute stroke care within the respective national and local context could help to improve thrombolysis rates and patient outcomes.

Thrombectomy is currently unavailable to the majority of European stroke patients. Organisational changes are required with hospital networks and regional referral centres in order to facilitate the implementation of thrombectomy across Europe and to make it more widely available.

5.

REHABILITATION AND LONGER TERM SUPPORT

Stroke survivors across Europe are waiting too long to have their immediate rehabilitation needs assessed and therapies started. In general, the rehabilitation they get is not intense enough, is too short, and often fails to address on-going issues, such as depression. Very few people get follow up reviews. In the long term, support is too often non-existent. This section looks at what rehabilitation and long-term support is available for stroke survivors across Europe.

Many stroke patients have problems with mobility, fatigue, speech, memory and/or emotions among others and need support from one or more therapy areas (such as physiotherapy, speech therapy, occupational therapy and/or psychology). These problems affect their ability to complete daily activities at home and to participate in the community: in England, Wales and Northern Ireland, over a third (40%) of stroke survivors need help with daily activities when they are discharged from hospital[294]. Patients should be assessed for these problems by therapists while they are in hospital and a rehabilitation plan should be made.

Problems related to stroke can be long-lasting. After 15 years, two-thirds (63%) of survivors are living with disability, nearly two in five (39%) have depression and over a quarter (30%) have cognitive impairment[295]. Furthermore, stroke patients are much more likely than people who have not had a stroke to be living with another illness[296].

Health and social care services need to understand and address gaps in rehabilitation and support, as inadequate rehabilitation can leave patients with disabilities that could have been avoided[297].

Stroke patients may find that health and social care services do not meet all their needs. For example, in one UK study, up to 59% of patients reported unmet clinical needs[3]. Post-stroke disability contributes significantly to long-term healthcare resource use, therefore effective rehabilitation will potentially save costs[7].

5.1 Data on rehabilitation and longer term care

In comparison with acute medical care, longer-term management and support have not been as well researched to identify best practice, or to describe what is being provided by each health system. The information presented here on provision of rehabilitation is therefore, for many countries, based on our consultation with health and research professionals and stroke support organisations, and has not been verified.

A small minority of countries regularly check what rehabilitation is being provided to patients in hospital, in at least one region[9] (Bulgaria, Catalonia, Czech Republic, Germany, Ireland, Slovakia, Sweden, UK). Audits of rehabilitation provision after discharge from acute hospital are rarer (Ireland, UK).

There are ongoing European rehabilitation studies which will provide more reliable data in the future. These include the ESO project Res-Q, which will include a performance measure on early rehabilitation assessment (led by Czech Republic,[9]); and an ongoing study on rehabilitation delivery and outcomes in the Netherlands[298].

Where data is available, it is not necessarily possible to compare rehabilitation between countries because the studies use different definitions of what rehabilitation or a particular therapy consists of, and different performance measures (e.g. timeframe, patient applicability). For instance, some audits include 'assessment for rehabilitation (physiotherapy/occupational therapy)' as a quality indicator (Catalonia, Czech Republic Germany, Ireland, Luxembourg, Slovakia, Sweden, UK) but there is inconsistency in what time period this is recorded for (e.g. within 48 hours in Catalonia, within 72 hours in UK)[299].

5.2 Rehabilitation guidelines

European stroke care guidelines make recommendations for the elements of rehabilitation, although there is not enough evidence to be certain about what exactly the therapies should consist of, how long sessions should last for and how often patients should have therapy sessions or practise themselves. For instance, ESO guidelines (2008)[300] recommend:

Early, coordinated multidisciplinary rehabilitation (on a stroke unit, for acute patients). This includes physiotherapy, occupational therapy, and communication therapy assessment (speech and language). Individual countries' national guidelines (where they exist) include similar statements.

Early discharge from stroke unit care if medically appropriate and suitable community rehabilitation is available

Early assessment of needs after discharge

Rehabilitation after discharge during the first year after stroke.

5.3 Early coordinated multidisciplinary rehabilitation (indicator 9)

Early rehabilitation improves outcomes for stroke patients[301]. Patients who get care and rehabilitation in a stroke unit (i.e. a multi-disciplinary team of medical, nursing and therapy staff who meet at least once a week) rather than on a general medical hospital ward, are less likely to die and less likely to be dependent on other people after they leave hospital[226].

However, the therapies that patients can access often depend on where in a country they live (e.g. Belgium[302], Netherlands[9], Portugal[303], UK[237]). In some countries, specialised neurology/stroke inpatient rehabilitation centres have very limited capacity or are non-existent (Bulgaria[304]; Croatia[305]; Cyprus[306]; Ireland[307], Lithuania[308], Poland[308] and Slovakia[9]).

There is wide variation across Europe in how well countries meet their targets for assessment and rehabilitation. Early multidisciplinary assessment is one example. In Sweden the national stroke audit records whether eligible patients are assessed by a multidisciplinary team within 48 hours of admission.

"I was six weeks in emergency care, nearly six months in total in hospital, and afterwards directly in rehabilitation. That means I was half a year away from home. I continued my therapies, my rehabilitation therapies over seven years...they kept me too long in the hospital because I was a private patient. I should have gone three months earlier to rehabilitation. I think that would have helped a lot."

(Female stroke survivor, Austria)

This target is met for 78% of patients[309]. In contrast, in Ireland, although two thirds of applicable patients have a physiotherapy assessment within 48 hours of admission, less than half of patients have an occupational therapy assessment in that timeframe[129].

Early multidisciplinary therapies in hospitals are meant to be standard practice across Europe but in some countries access is inadequate e.g. Austria,[9]; Finland[310]; Ireland[129] or many patients are often not treated early enough. For example, in one study in Poland about half of patients were not seen for rehabilitation within 3 months[311].

Across Europe, access to therapies other than physiotherapy can be especially poor. For example, in some countries patients do not usually get occupational therapy and/or psychological therapy.

This is the case for occupational therapy in Bulgaria[9], Croatia[9], Cyprus[306], Italy[244], and Slovakia[9]; and for psychological therapies in Bulgaria[9], Croatia[9], Czech Republic[9], Ireland[312] and the UK[161].

There is little data collected across Europe on how much therapy patients actually get. The available data suggests that patients get therapies for only brief periods of each day in hospital, due to e.g. time pressures and staff availability[313, 314].

For example, in a Netherlands study (of physiotherapists across most acute hospital stroke units) patients only had an average of 22 minutes per day of exercise therapy on weekdays[314]. In the UK during a similar time period, patients had physiotherapy on only half of the days they were in hospital, giving an average per day of stay of under 15 minutes vs a target of 27 minutes[315] (provision in the UK has on average improved since then[55]). Some evidence suggests that more formal management of therapy, for instance having defined phases of rehabilitation, can improve provision as therapists spend more time with patients and less time on nontherapeutic activities[313].

"I think that receiving psychological support, not only for myself but also for my family, since the beginning of the 'illness' would have been very positive...It was very difficult to be away from my children [while in rehabilitation centre] ... the fear of dying or being stuck in a wheelchair forever ..."

(Female stroke survivor, Portugal)

5.4 Early supported discharge (indicator 10)

There is an increasing trend to reduce the length of time that patients spend in hospital. Several countries discharge stroke survivors from hospital within 1-2 weeks (e.g. Austria, Bulgaria, Estonia, Slovakia[9]). However, rehabilitation in the community is limited in many countries and people may be discharged without follow up support.

Some countries have developed care pathways where mild to moderately affected stroke survivors are discharged when medically stable, and continue to get rehabilitation at home at a similar intensity to support on a rehabilitation unit ('early supported discharge').

One third of patients are typically eligible for early supported discharge[316]. When these early supported discharge services are well organised, patients can return home earlier and are more likely to regain independence in daily activities[316], and there is evidence of its cost-effectiveness compared with care on the general medical ward or on a stroke unit (without early supported discharge)[317].

In a few countries, early supported discharge is well established, if locally variable, and is included in national guidelines i.e. Sweden, with an average length of stay of 12 days[318], and the UK[319, 320]. In England, Wales and Northern Ireland, 81% of hospitals have a stroke skilled early supported discharge team and 35% of patients are treated by one of these teams[294, 321].

In most European countries, including in other high-income countries, early supported discharge has not been well developed. In around half of EU countries for which we have data it is non-existent or not nationally developed i.e. there have been local trials or pathways but not widespread implementation (Appendix 1, Table 4).

5.5 Follow up on rehabilitation needs after discharge from hospital (indicator 11)

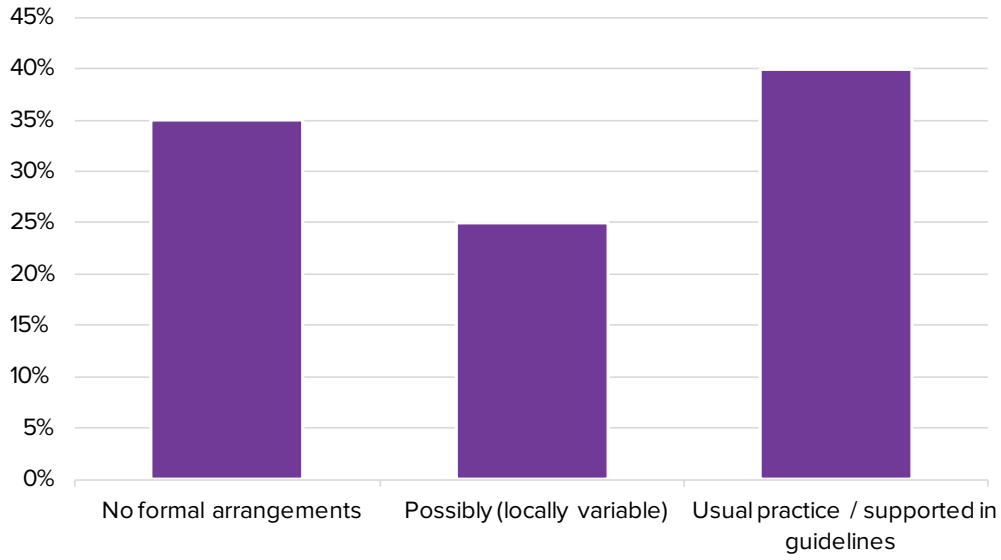
Problems related to stroke can be long lasting but questionnaire responses received by King's College London suggest that only around 2 in 5 EU member countries' guidelines recommend (or it is usual practice) that patients are offered follow-up reviews with a member of the therapy team, doctor/ consultant or stroke service after discharge from hospital or rehabilitation centre (Figure 12). In nearly 2 in 5 countries, there are no formal arrangements for reviews (no known local protocols or national guidelines), and in a quarter of countries, there are some examples of services offering reviews but the practice is not thought to be widespread.

"From that point[the stroke] it has been a slow rehabilitation. I've still got consequences; the cognitive problems I have. Travel is the worst thing in the world. Going through an airport blows my mind sometimes."

(Male stroke survivor, UK)

Follow-up reviews may be supported in guidelines but not consistently implemented: for instance, UK consensus guidelines recommend that patients are offered a structured health and social care review at 6 months and 12 months after stroke[322] but the arrangements for reviews and who delivers them (e.g. therapist, GP or multidisciplinary team) is very variable according to local funding decisions[323].

Figure 12: Availability of follow-up reviews in EU member countries as percentage of 20 countries for which information available (Appendix 1, Table 5)



5.6 Rehabilitation after discharge from hospital

Around 2 in 5 stroke survivors in the UK are discharged from hospital requiring help with activities of daily living[237]. Few countries appear to publish data on community provision of therapies. It seems that stroke rehabilitation for patients once they have been discharged from acute care is very variable between and within countries, including those with the longest histories of providing post-stroke rehabilitation. In around 2 in 5 EU countries, outpatient therapies are not generally available. In the recent past, there has been evidence of some countries reducing their outpatient stroke rehabilitation programmes.

The variation in access between and within countries is due to different organisation of stroke services, different strategic approaches, and different levels of resources.

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In some countries, formal pathways between different phases of care (acute, inpatient rehabilitation, community rehabilitation) do not exist, are incomplete, are not fully implemented, and/or vary between localities (e.g. Austria[209]; Italy[9], Latvia[9], Portugal[9], Macedonia[9], Slovakia[9]).

According to UK guidelines, hospitals should work with patients to make a plan for rehabilitation after discharge and make referrals to other services as needed[322]. There should be formalised pathways between acute care, primary care and rehabilitation services so that stroke survivors' continuing care is well organised, but in several countries links between rehabilitation and primary care, e.g. general practitioners, are weak[244]. Pathways are sometimes not fully implemented, so that despite efforts to make post-acute care more consistent, patients continue to experience different levels of access to rehabilitation (e.g. the timing of assessments after discharge from hospital, or how long they have specialist rehabilitation for)[298].

"There are a lot of things that I cannot do that I did before. I was fond of skiing – I cannot do that. I cannot ride a bicycle because I have no balance, and things like that. You miss it, but after some time you get used to it. It's a new life; you have to adjust to what you can do."

(Male stroke survivor, Norway)

In many countries, there is not enough multi-disciplinary therapy provision for stroke survivors in the community, and access varies between regions. In most countries, increasing numbers of survivors are discharged from hospital within a matter of days but they may not be able to access any or all of the therapies they need in the community, and may experience long delays.

Example of post-acute case management, East Saxony, Germany. This trial (pilot phase) placed patients on a standardised post-stroke pathway with a certified case manager. The pathway comprised patient education, quarterly check-ups for vascular risk factors and adherence to antithrombotic/anticoagulant medication in addition to usual care. Compared with usual care alone, the intervention was more successful in modifying two important stroke risk factors; intervention patients also reported higher satisfaction with their healthcare and quality of life after 12 months[324].

This can be a nationwide issue e.g. general lack of any provision of outpatient or domiciliary care in Eastern Europe even sometimes when community based rehabilitation is the subject of legislation[36, 308, 325]. There also tends to be regional and rural vs urban variation in access to community based rehabilitation, e.g. patients in some regions of Ireland[312], Portugal[326], Sweden[53] and Spain[9] do not have access to outpatient and/or domiciliary rehabilitation. Europe-wide, this is particularly true of occupational therapy (e.g. Ireland[312]; Italy[244]; Luxembourg[9]; Spain[9]) and similarly vocational rehabilitation (e.g. UK[161]) and psychological support (e.g. Ireland[312], UK[161]). Lack of capacity for rehabilitation in the community can mean stroke survivors experience longer stays in hospital or rehabilitation centres (e.g. Croatia[9]; Cyprus; Czech Republic[9]; Estonia[9]; and Ireland[129]).

"After I left the rehabilitation hospital I was sent home with a multidisciplinary team coming home to ask whether I needed help from them. I got help from an occupational therapist for my aids, as a walker, handles in the shower and a wheelchair and I went for many years to a physiotherapist to learn how to walk as steady as possible."

(Female stroke survivor, Norway)

"I stayed there [in a rehabilitation unit in the UK] for half a year with training. That was very good. It was physical training and mental training, and all the time they measured where I was in the training programme and adjusted it all the way. ... When I got home [to Norway] I didn't get any therapy. It took me about half a year before I could continue with the training, and that was bad because you should have continuous training, that is important. Because when you have a break, then you have to start at a lower level again and build yourself up, so you lose a lot of time by doing that."

(Male stroke survivor, Norway)

5.7 Practical and emotional support for stroke survivors & families (indicator 12)

Apart from medical and physical therapy needs, stroke survivors and their families may face a number of difficulties in life after stroke, including emotional or psychological problems, extra costs of living (e.g. transport, rehabilitation, medications), and difficulties with finding suitable work or returning to work and therefore loss of earnings.

5.8 Support from health insurers and health authorities

From the limited information we have identified, health insurers and national health authorities rarely offer support with adjusting to life after stroke beyond, in some cases, loans for home adaptations and aids, and financial benefits for those eligible for reasons of unemployment, sickness or disability.

Formal care services are funded less in central Europe (e.g. Austria, Germany, Netherlands, France, Belgium, Czech Republic, and Poland) and southern Europe (e.g. Spain, Italy and Greece), compared with northern Europe (e.g. Denmark, Ireland and Sweden)[7].

Independent living support for disabled people (as a result of stroke or other causes) is very wide-ranging across Europe. There has been more focus on institutional care in some of the newer EU states (e.g. Bulgaria, Lithuania, Romania, Slovenia[325]). Access to support can be complicated by disagreements between health and social care bodies over which department is responsible for providing rehabilitation, aids and so on (e.g. Sweden[327]).

"The worst thing about it at the time was that I had no understanding about stroke at all. No one had told me, "You may feel like this, you may feel like that." No one explained to my partner what it was going to be like moving forward, what the consequences might be, what they might not be."

(Male stroke survivor, UK)

"[After the stroke] I was not able to find the right words. I was not able to understand anything, and I was in slow motion. ... After my stroke I had to give up my job [as a teacher of Luxembourgish]. ... I took five years to understand people and to read short texts ... Apart from my aphasia the worst effects are chronic tiredness and insomnia."

(Female stroke survivor, Luxembourg)

"You don't want life to change, it's too hard... we could not talk about it and each of us kept our painful feelings inside. My sister was afraid of him when he looked at her... but she was only 4 and couldn't understand "why us". My father stayed along time in a training centre and after 6 months came home for good. It was very difficult, we had to rearrange the house, but worse, I did not want my friends to come to our house any more just because I was ashamed of him."

(The daughter of a male stroke survivor, France)

There is some evidence that austerity has had an impact on funding of services and financial support for disabled people, which potentially includes stroke survivors and their families[328]. Most European countries have cut funding to health care, social care and/or to non-governmental organisations in the last 5-10 years, with growing inequality between rural and urban areas in access to services.

The areas that have been negatively affected vary between countries but include: vocational rehabilitation and training and support for employers of people with disabilities; access to personal budgets; disability benefits; and help with costs e.g. transport[328].

> *"The challenges [for stroke survivors and families in Greece] are day to day living .... But also, it is becoming a viable member of society again and I think that's important worldwide, not only in [my country] Greece. In Greece you do have support, but you do have the immediate consequences of stroke which are quite devastating for everybody."*
>
> (Stroke clinician and stroke support organisation volunteer, Greece)

Some countries (Bulgaria, Greece, Poland, Romania) have abandoned programmes such as plans to move care more into the community. Some countries (Bulgaria, Greece, Italy, Hungary, Spain, Portugal and Romania) have re-emphasised that the family has the main (social) caring responsibility, before the state. Some have introduced or increased user fees for health services or medications (Hungary, Estonia, Portugal, Spain, UK), and made the criteria for accessing disability benefits or personal assistance more strict (Greece, Hungary, Ireland, Italy, Portugal, Slovenia, Slovakia, Spain, Sweden, UK)[328].

There are some examples of follow-up support being funded. Social insurance institutions in Estonia and Finland offer vocationally oriented rehabilitation; the Estonian scheme also offers peer support[9, 329]. In parts of the UK the Stroke Association is commissioned to provide 'Life after Stroke' services, including practical (communication support, return to work etc.) and emotional support.

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5.9 Support from stroke support organisations


@King's College London Stroke Research Patients and Family Group

Stroke support organisations (SSO) are usually voluntary sector (non-governmental) organisations providing practical, emotional and advocacy support for stroke survivors and their families and, often, promoting stroke prevention awareness and action. Their scope sometimes includes other conditions such as other forms of acquired brain injury or cardiovascular disease. Most EU/SAFE member states have a regional or national level SSO (in the Faroe Islands, there is a disabled people's organisation with an interest in stroke). The exceptions, as far as we are aware from our questionnaire and literature searches, are Lithuania, Malta, Romania and Slovakia.

Stroke survivors and their families can benefit from attending peer support groups, in terms of improvements to their sense of wellbeing, social isolation and practical skills[330]. Some stroke support voluntary organisations also offer opportunities for stroke survivors to continue with low intensity rehabilitation, e.g. exercise groups or communication groups. Examples from SAFE member countries include the Finland Brain Association's reablement training for patients and families[9]; and the Neeman Association rehabilitation clubs in Israel which support patients to maintain rehabilitation gains[331].

"...what I see from my organisation is that people are very lonely after they have lost these abilities [physical functions]. And maybe worse for those who lose the ability to speak, they get very lonely; they often get very depressed... The families are very, very tired. I often speak to the relatives, to the families, because they don't know what to do"

(Volunteer at support organisation for people with disabilities including as a result of stroke, Faroe Islands)

"Eventually I managed to get into a [peer support group]. Even walking through the door, in the end it took my sons to actually physically walk me through the door because I couldn't do it myself, I just couldn't face it. I didn't know why. And then when I got in there it was suddenly relief. They are my stroke family and that is what we now call – all of us, it is our stroke family."

(Male stroke survivor, UK)

5.10 Recommendations - rehabilitation and longer-term support

Too many stroke survivors have to wait too long to get an assessment of their rehabilitation needs and to actually receive therapy. Across Europe the aim should be for multi-disciplinary assessments to take place on the stroke unit, and for rehabilitation to start as soon as someone is medically stable.

Access to rehabilitation therapy must be improved. There is a particular lack of occupational, speech and psychological therapy across Europe.

Too many stroke survivors leave hospital without on-going rehabilitation being in place. This is of particular concern for Early Supported Discharge (ESD) schemes. The evidence is clear that the effectiveness of ESD schemes relies upon access to rehabilitation at the same intensity as would have been provided on the stroke unit.

Ongoing, long-term support and follow up is inadequate in many parts of Europe. We call for national systems to be developed to ensure stroke survivors' needs are reviewed and followed up.

Countries should set targets for secondary prevention, screening for depression, and for psychological and social support.

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Appendices

1. Data tables

Table 1: Risk factor prevalence in stroke patients, organised by type of source (population-based study, national hospital-based, regional hospital-based)

Source	**Country**/Region/City	Hypertension	AF	Cholesterol
Population-based registers, EROS, risk factors diagnosed pre-stroke[10, 41, 105]	**France**/Dijon	65.2	21.2	28.7
	Italy/Sesto Fiorentino	62.1	18.6	
	Lithuania/Kaunas	67.3	25.4	
	Spain/Menorca	54.0	13.2	
	UK/London	64.7	15.0	24%
	Poland/Warsaw	75.8	25.0	
Summary of Italian registers[128]	**Italy**	54-65	12-24	7-24
Population-based register[217]	**Spain**/Catalonia	68.8	18.9	
Population-based register[332]	**Spain**/Barcelona	60.6	29.3	19.4
Population-based register, ischaemic stroke[36]	**Estonia**/Tartu	61	30	
Population-based register[333]	**Greece**/Arcadia (♂, ♀)	78/85	31/38	41/46
National population-based, ischaemic stroke/ intracerebral haemorrhage[16]	**Iceland**		29/18	
National hospital-based data[129]	**Ireland**	58.6	24.3	24.5
National hospital-based data[309]	**Sweden**	58.7-65.1	28.1-28.9	

Table 1: continued

Source	**Country**/Region/City	Hypertension	AF	Cholesterol
National hospital-based data[54]	**Finland**	60	14	
National hospital-based data[238]	**Germany**	80.5	25.6	
National hospital-based data[71]	**Israel**	78.2	17.4	72.9
National hospital-based data, EuroHOPE, ischaemic stroke only[246]	**Finland**	70.9	9.1	
	Hungary	76.5	4.5	
	Italy	65.4	3.7	
	The Netherlands	77.2	2.7	
	Sweden	70.3	9.0	
Cross-sectional, multi-centre survey, EUROASPIRE III, stroke-specific module, ischaemic stroke only[115]	**Germany**	56.6		74.8
	Czech Republic	67.3		76.4
	Poland	63.6		78.0
	Croatia	64.9		72.1
Register of thrombolysed patients, SITS-EAST[223] Harsany 2014	**Croatia, Czech Republic, Estonia, Hungary, Lithuania, Poland, Slovakia, Slovenia, Turkey**	75	29	37
Hospital-based study, ischaemic stroke[334]	**Lithuania**/Vilnius (♂, ♀)		32.1/ 28.6	
Hospital-based study[52]	**Hungary**/Debrecen	81	14.1	
Hospital-based study[335]	**Malta**	73.2	9.8	
Hospital-based study[281]	**Norway**	72.1	31.0	55.9
Hospital-based study[131]	**Norway**		32	
Hospital-based study[336]	**Greece**/Athens	70.2	31.1	31.5
IS patients admitted to SU [337]	**Austria** (♂, ♀)	79.1/80.8	22.7/ 32.3	57.4/51.3
Population-based study[338]	**Denmark**		12.5	
Primary care data-base[106]	**UK**	65	11	38.7

Table 2: European AF prevalence studies

Belgium	screening study: 1.4%, 66% of cases previously unknown[95]
Denmark	2.0% in adults ≥25 years[338]
France	screening study: 0.05%/0.01% in ♂/♀ ≤50 years compared to 6.5%/5.2% in ♂/♀ ≥80[339], prevalence estimate 600,000 to 1 million[340]
Germany	5.3% of patients without previously known AF diagnosed in those with additional vascular risk factors. 3% in those with one RF, 7% in those with two risk factors[341]
Greece	screening study in adults>65 years: 5%, increasing with age[150], 3.9%[151]
Iceland	known AF: 1.9% in 2008, was 1.6% in 1998, projected 3.5% in 2050[134]
Italy	known AF: 1.3%[152]
Netherlands	overall 1.6% , but 7.7% in adults >55, 0.7% in adults 55-59 compared to 17.8% in adults >85 years[117, 133] 6% annual increase in incidence 1982-2000 and 1.4% annual increase 2000-2012[342]
Portugal	known AF: 1.29% in adults >30[343], screening study: 2.5% in adults > 40 (only 1.6% had previously known AF)[123]
Spain	4.4% in adults >40, in 10% of them AF was unknown[125], estimated prevalence 1 million, 100,000 unidentified[344], 20.1% of undiagnosed AF in population-based study of adults >60 years[154], overall prevalence 1.5%, steep rise with age: 0.05% in < 45 years, 6.3% in >75 years[345]
Sweden	known AF: 2.9%[155], known AF in adults >20: 3.2%[346]
UK	known AF 1.49%/1.29% in men/women in 2003, compared to 0.84%/0.83% in 1994 [156], estimate of total prevalence (known and unknown): 2.4% or 1.36 million people with 474,000 people being undiagnosed (Public Health England, www.ncvin.org.uk)

Table 3: SITS Registry, overall figures for EU or SAFE countries, December 2002 to November 2016[347], ranked by recruitment per 100,000 population

Country	Recruitment overall	Recruitment per 100,000 population	Thrombectomy Register	General stroke register
Estonia	2660	205.5	147	
Czech Republic	19826	185.7	595	418
Sweden	9269	97.4	363	1267
Slovenia	1482	72.3	21	
Finland	3667	67.8	334	
Slovakia	3641	67.1	281	
Italy	31349	51.7	725	1362
Lithuania	1395	48.4	126	
Denmark	2375	44.2		
Norway	2072	41.2	22	
Portugal	3844	36.2	293	
Bulgaria	2692	35.3		2180
UK	22884	34.9	363	
Croatia	1387	30.9	1	
Belgium	3073	27.9	206	413
Hungary	1926	19.1	21	
Austria	1146	14.0		
Poland	4861	12.6	68	
Spain	4138	8.8	270	
Germany	6637	8.1	73	
Macedonia	165	8.0		

Table 3: continued

Country	Recruitment overall	Recruitment per 100,000 population	Thrombectomy Register	General stroke register
Greece	468	4.0	6	
Israel	255	3.1		
Iceland	8	2.5		
Netherlands	217	1.3		
Ireland	57	1.2		
France	354	0.6		
Ukraine	27	0.1		
Cyprus	0	0.0		
Latvia	0	0.0		
Luxembourg	0	0.0		
Malta	0	0.0		
Romania	0	0.0		
Serbia	0	0.0		

Table 4: Early discharge practices in EU countries (ESD = early supported discharge)

EU Country	Typical availability of early discharge to further rehabilitation	Source
Austria	Early discharge to inpatient rehab centre	[9]
Belgium	Not generally available	[9]
Bulgaria	Not generally available	[9]
Croatia	Not generally available	[9]
Czech Republic	Not generally available	[9]
Cyprus	Not generally available	[348]
Denmark	Early discharge to inpatient rehab centre /community as appropriate *(ESD available in one region)*	[250]
Estonia	Not generally available	[9]
Finland	Early discharge to inpatient rehab centre /community as appropriate	[9]
France	Not generally available	[9]
Germany	Early discharge to inpatient rehab centre	[9]
Greece	Not generally available	[9]
Ireland	Early discharge to inpatient rehab centre /community as appropriate *(ESD available in some regions)*	[129]
Italy	Early discharge to inpatient rehab centre /community as appropriate *(ESD available in some regions)*	[349]
Latvia	Not generally available	[350]
Lithuania	Not generally available	[244]
Malta	Not generally available	[9]
Netherlands	Early discharge to inpatient rehab centre /community as appropriate *(ESD available in at least one region)*	[351]
Poland	Not generally available	[311]

Table 4: continued

EU Country	Typical availability of early discharge to further rehabilitation	Source
Portugal	Not generally available	[326]
Slovakia	Not generally available	[9]
Slovenia	Not generally available	[9]
Spain	Not generally available	[244]
Sweden	Early discharge to inpatient rehab centre /community as appropriate *(ESD available in some regions)*	[9]
UK	Early discharge to inpatient rehab centre /community as appropriate *(ESD available in majority of regions)*	[55]
Hungary **Luxembourg** **Romania**	No data found	

Table 5: Follow up review practices in EU countries. Sources:[9, 323, 352]

EU country	Follow up review practice
Austria	Possibly, depending on local practice - no specified timescale
Belgium	Possibly, depending on local practice - no specified timescale
Bulgaria	No formal arrangements for follow-up reviews *(other than e.g. SITS/ research follow ups)*
Croatia	No formal arrangements for follow-up reviews *(other than e.g. SITS/ research follow ups)*
Czech Republic	No formal arrangements for follow-up reviews *(other than e.g. SITS/ research follow ups)*
Finland	National guidelines support reviews/usual practice - 0-3 months after discharge
France	National guidelines support reviews/usual practice - >3-6 months after discharge
Germany	Possibly, depending on local practice - no specified timescale
Greece	No formal arrangements for follow-up reviews *(other than e.g. SITS/ research follow ups)*
Ireland	National guidelines support reviews/usual practice - >3-6 months after discharge
Italy	National guidelines support reviews/usual practice - 0-3 months after discharge
Latvia	No formal arrangements for follow-up reviews *(other than e.g. SITS/ research follow ups)*
Luxembourg	National guidelines support reviews/usual practice - no specified timescale
Malta	National guidelines support reviews/usual practice - no specified timescale
Netherlands	Possibly, depending on local practice - no specified timescale
Slovakia	No formal arrangements for follow-up reviews *(other than e.g. SITS/ research follow ups)*

Table 5: continued

EU country	Follow up review practice
Slovenia	No formal arrangements for follow-up reviews *(other than e.g. SITS/ research follow ups)*
Spain	Possibly, depending on local practice - no specified timescale
Sweden	National guidelines support reviews/usual practice - no specified timescale
UK	National guidelines support reviews/usual practice - >3-6 months after discharge
Cyprus **Denmark** **Estonia** **Hungary** **Lithuania** **Poland** **Portugal** **Romania**	No data found

2. Research framework and methods used in the study

2.1 Development of stroke care quality indicators

To select the 12 care quality indicators to be included in the study, stroke care guidelines and indicators developed by a number of European and international organisations were searched (including from UK Stroke Sentinel National Audit Programme (SSNAP) [353], UK National Institute for Health and Care Excellence (NICE)[320], UK Royal College of Physicians[322], American Heart/Stroke Association[354], European Stroke Organisation[300], European Implementation Score Collaboration[355], and Stroke Unit Trialists' Collaboration[226]). A long list of indicators was drawn up based on clinical relevance, likely data availability and relevance to SAFE's objectives, in consultation with colleagues experienced in stroke treatment and rehabilitation, and the final 12 indicators were selected in consultation with SAFE. These indicators have informed focused literature searching and the development of the questionnaire that King's College London (KCL) sent to country representatives.

Table 6. Selected stroke care quality indicators

Indicator	Source* (evidence base)
PRIMARY PREVENTION	
1. Campaigns to encourage healthy lifestyles (e.g. blood pressure and cholesterol awareness and monitoring)	EIS *(consensus)*
2. Blood pressure is checked regularly and treated according to guideline	AHA/ASA, NICE CG127 *(high/moderate quality evidence: observational & RCTs**, except for patients aged <40).*
3. Adults with atrial fibrillation at increased risk of stroke are treated appropriately with anticoagulants	NICE QS93 based on NICE CG180 *(high/moderate quality RCT evidence)*, ESO 2008
EMERGENCY RESPONSE	
4. Public campaigns and professional education emphasise that stroke is a medical emergency	ESO, NCG *(consensus)*
5. Emergency services *(ambulance)* staff are trained to screen patients for suspected stroke/TIA and arrange immediate transfer to hospital	ESO, NCG, NICE QS2 *(consensus)*

Table 6: continued

Indicator	Source* (evidence base)
ACUTE MANAGEMENT	
6. In-hospital services offer organised stroke care (stroke unit care)	ESO, NCG *(consensus)*
7. Patients are assessed for thrombolysis and receive it (if clinically indicated) as soon as possible after the start of stroke symptoms	ESO, NCG[ESO: within 3 hours. NCG: all patients within 3 hours if not contraindicated; between 3 and 4.5 hrs if age<80 and not contraindicated] *(high quality RCT evidence for benefit up to 4.5hrs with most benefit up to 3hrs)*
Transient Ischaemic Attack (TIA)	
8. Patients with suspected TIA are urgently assessed for subsequent stroke risk	NICE CG68[assessment within 24 hours of onset] *(consensus)*, NCG, ESO
REHABILITATION (ACUTE PHASE)	
9. Patients are assessed for rehabilitation needs within the first three days after admission and provided with rehabilitation by multidisciplinary staff on the basis of need	NCG[assessment by nursing staff + at least 1 member of rehab team within 24 hrs; all relevant members of rehab team within 72 hrs]; NICE CG162 *(consensus)*; ESO
10. Early discharge from acute care (to inpatient rehabilitation unit or to community) is supported for medically stable patients with mild or moderate impairment	ESO, NCG, NICE CG162 *(moderate evidence for reduced length of stay & equivalent outcomes)*
FOLLOW UP / POST-ACUTE REHABILITATION	
11. Patients are offered a review after the stroke for assessment of medical and rehabilitation needs	NCG, NICE QS2, NICE CG162 *(consensus on 6 month review)*
12. Patients and their family/carers have access to practical and emotional support	NCG *(consensus)*

*AHA/ASA= Guidelines for the Primary Prevention of Stroke: A Guideline for Healthcare Professionals From the American Heart Association/American Stroke Association 2014

EIS= Methods of Implementation of Evidence-Based Stroke Care in Europe, European Implementation Score Collaboration 2015

ESO= European Stroke Organisation Guidelines for Management of Ischaemic Stroke and Transient Ischaemic Attack 2008

NCG= National Clinical Guideline for Stroke 5th Edn, Royal College of Physicians 2016

NICE CG68= Stroke and transient ischaemic attack in over 16s: diagnosis and initial management Clinical guideline[CG68] National Institute for Health and Care Excellence 2008

NICE CG127= Hypertension in adults: diagnosis and management Clinical guideline[CG127] National Institute for Health and Care Excellence 2011

NICE CG162= Stroke rehabilitation in adults Clinical guideline[CG162] National Institute for Health and Care Excellence 2013

NICE CG180= Atrial fibrillation: management Clinical Guideline[CG180] National Institute for Health and Care Excellence 2014

NICE QS2= Stroke in adults Quality standard[QS2] National Institute for Health and Care Excellence 2010

NICE QS93= Atrial fibrillation Quality standard[QS93] National Institute for Health and Care Excellence 2015

**RCT = randomised controlled trial (the 'gold standard' of evidence)

2.2 Literature reviews

A review of the literature on topics in the tender document and on the stroke care quality indicators was undertaken. This aimed to establish the best-available information and data (most recent and most robust) for individual countries and regions. The search strategy is outlined below.

Search terms: Stroke, cerebrovascular accident, CVA, cerebral infarct/infarction +/- country or region name + keyword or combination of keywords of interest of respective chapter

Epidemiology: incidence, prevalence, fatality, burden, epidemiology, epidemiological, attack rates, survey, surveillance, projection, trend, audit, register/registry

Prevention: guideline, prevention, preventive, hypertension, hypertensive, blood pressure, risk factor, atrial fibrillation, AF, TIA, transient ischaemic attack, mini-stroke

Stroke awareness/ emergency care: emergency, ambulance, pre-hospital, admission, arrival, presentation, delay, symptoms, warning signs, knowledge, recognition, awareness, education

Acute treatment: stroke unit, care, treatment, thrombolysis, thrombolytic, thrombectomy, telemedicine

Rehabilitation and long-term support: discharge, early supported discharge, follow-up, physiotherapy, post-stroke, rehabilitation, support, therapy

Date range: 2007-2016. Focus on material published since the last Burden of Stroke report (2007) but extended to include material published prior to 2007 when information for a country was otherwise lacking.

Sources:

Peer-reviewed journal articles (using databases PubMed and Scopus, and searching key journals) and their reference lists
'Grey literature' such as government/health authority/stroke organisation policies and guidelines
Key papers known to research team and SAFE
Websites (ESO, WHO, OECD, European Observatory on Health Systems and Policies, national professional and patient organisations)

Language of search terms and publications: English. The literature identified was mainly in English (if an English-language translation of e.g. the webpage was available, this was used). Where key papers were identified by SAFE and were not in English, their members' help was sought to provide brief summary translations.

2.3 Questionnaire and consultation with country clinicians, researchers and support organisation representatives

A questionnaire was developed to obtain information and perspectives on stroke care in each EU country, additional to information obtained through the literature review process.

Potential respondents to KCL's questionnaire were identified through KCL's & SAFE's previous European stroke research collaborations and through relevant publications. These included epidemiologists, neurologists, rehabilitation experts and leaders of national stroke or neurology professional organisations. Those contacted were emailed the questionnaire as an attachment and were encouraged to name an alternative respondent where appropriate. Contacts who did not respond were sent email reminders.

Additionally, the research team gained information and contacts from questions sent by the Stroke Association to SAFE board members, from brief discussions with a number of clinicians and researchers attending the European Stroke Organisation Conference in Barcelona in May 2016, and from discussions with delegates at the SAFE working conference in Amsterdam in December 2016.

Not all country contacts responded to the questionnaire. No response was received from Cyprus, Denmark, Ireland, Lithuania, Poland, Portugal or Romania. No contact was identified for Ukraine.

Table 7. Respondents to King's College London's questionnaire on stroke care

Country	Respondent(s)
Austria	Dr Milan Vosko, FESO, Neurologist, Linz
Belgium	Dr Robin Lemmen, Neurologist, UZ Leuven
Bulgaria	Assoc. Prof. Dr. Silva Andonova, St. Marina University Hospital in Varna, head of the Stroke Section at the Bulgarian Society of Neurosonology and Cerebral Hemodynamics. Involved in SITS-EAST
Croatia	Dr Branko Malojcic, Dpt. of Neurology, University Hospital Center Zagreb
Czech Republic	Svatava Kalna *(with support of Veronika Svobodová)*, Study Coordinator Stroke Research Program St. Anne's University Hospital, Brno International Clinical Research Center
Estonia	Assoc Prof Janika Kõrv, neurologist, University of Tartu, Estonia
Finland	Dr Tiina Sairanen, Department of Neurology, Helsinki University Central Hospital
France	Professor Maurice Giroud, Dijon Stroke Registry, University Hospital of Dijon, University of Burgundy, responsible for the Burgundy Stroke Network. Professor Yannick Béjot, Dijon Stroke Registry, Head of the Stroke Unit, University Hospital of Dijon, University of Burgundy.
Germany	Professor Peter Heuschmann, MD, Dr Silke Wiedmann, PhD *(1)*; Professor Peter Hermanek, MD *(2)*, Professor Otto Busse, MD *(3)*. Profession/Affiliation: University of Wuerzburg Institute of Clinical Epidemiology and Biometry Wuerzburg *(1)*, Bavarian Permanent Working Party for Quality Assurance *(BAQ)*, Munich *(2)*; German Stroke Society *(3)*

Table 7: continued

Country	Respondent(s)
Greece	Dr. Konstantinos Vadikolias, MD, President of the Board of Directors of the HNS and HSCVD, member of the exec committee of the H.A.S, Hellenic Neurological Society & Hellenic Society of Cerebrovascular Diseases *(Greek Stroke Society)* with the collaboration of members of the Board of Directors and Committees of the Hellenic Alliance-Action for Stroke *(H.A.S)*, Hellenic Neurological Society *(HNS)* and Hellenic Society of Cerebrovascular Diseases *(HSCVD)* : Georgios Tsivgoulis, Associate Professor of Neurology, Attikon Hospital, University of Athens, Gen Secretary of HSCVD Hariklia Proios, PhD, CCC-SLP, Assist. Professor, Department of Educational and Social Policy, University of Macedonia, Thessaloniki Member of the exec committee of the Board of Directors of H.A.S Athina Mitsoglou, Neurologist, General Hospital of Xanthi, member of the Board of Directors of the H.A.S Dimitrios Keramefs, Member of the Board of Directors of the H.A.S Artemis Nikolaos, Emeritus Professor of Neurology, Emeritus President of the HSCVD, past President of the HNS, member of the exec committee of the H.A.S
Italy	Antonio Di Carlo, MD; Institute of Neuroscience, Italian National Research Council Domenico Inzitari, MD; NEUROFARBA Department, University of Florence
Latvia	Guna Bērziņa, Physical and Rehabilitation doctor Department of Rehabilitation, Riga Stradiņš University
Luxembourg	Prof. Dr. Dirk W. Droste, FESO, Adjunct Professor of Neurology, Westfälische Wilhelms-Universität Münster
Malta	Johanna Pizzuto, Rehabilitation Nurse, Mater Dei hospital
Slovakia	Prof. Zuzana Gdovinová, Head of Department, Department of Neurology, P.J. Safarik University Košice
Slovenia	Janja Pretnar Oblak, MD, PhD, Head of Vascular Neurology Dpt, University Medical Centre Ljubljana, Slovenia
Sweden	Kjell Asplund, Professor, MD, Department of Public Health and Clinical Medicine, Umea, Sweden

Table 8. Respondents to Stroke Association questions on stroke care

Country	SAFE / nominated respondent(s)
Austria	Manuela Messmer-Wullen, President Schlaganfall-Hilfe Österreich *(Stroke patient organisation)*
Belgium	Dr Andre Peeters, Belgian Stroke Council
Croatia	Dr Hrvoje Budincevic, Croatian Stroke Society
Finland	Paivi Seppa-Lassila, Aivoliitto *(Finnish Brain Association)* and Dr Risto O. Roine, Professor and Chairman, Division of Clinical Neurosciences Turku
Germany	Dr Markus Wagner, Stiftung Deutsche Schlaganfall-Hilfe, Vice President of SAFE
Greece	Dr. Konstantinos Vadikolias, MD, President of the Board of Directors of the HNS and HSCVD, member of the exec committee of the H.A.S, Hellenic Neurological Society & Hellenic Society of Cerebrovascular Diseases *(Greek Stroke Society)* with the collaboration of members of the Board of Directors and Committees of the Hellenic Alliance-Action for Stroke *(H.A.S)*, Hellenic Neurological Society *(HNS)* and Hellenic Society of Cerebrovascular Diseases *(HSCVD)*: Georgios Tsivgoulis, Associate Professor of Neurology, Attikon Hospital, University of Athens, Gen Secretary of HSCVD Hariklia Proios, PhD, CCC-SLP, Assist Professor, Department of Educational and Social Policy, University of Macedonia, Thessaloniki Member of the exec committee of the Board of Directors of H.A.S Athina Mitsoglou, Neurologist, General Hospital of Xanthi, member of the Board of Directors of the H.A.S
Greece (continued)	Dimitrios Keramefs, Member of the Board of Directors of the H.A.S Artemis Nikolaos, Emeritus Professor of Neurology, Emeritus President of the HSCVD, past President of the HNS, member of the exec committee of the H.A.S
Hungary	Krisztina Völgyes, National Stroke League of Hungary
Iceland	Valgerður Gunnarsdóttir, Ministry of Welfare
Israel	Sandra Levy, Neeman Association stroke support organisation
Italy	Dr Francesca R Pezzella, A.L.I.Ce Italia stroke patient organisation
Luxembourg	Chantal Keller, Bletz asbl stroke support organisation

Table 8: continued

Country	SAFE / nominated respondent(s)
Macedonia	Dr Maja Bozinovska, neurologist, president of Macedonian stroke patient organisation
Netherlands	Lineke Dijkstra, Hersenletsel *(Netherlands acquired brain injury support organisation)*
Norway	Bent Indredavik, Professor Department of Neuromedicine and Movement Science, Norwegian University of Science and Technology
Serbia	Ivan Milojevic , Serbian Stroke Association
Slovenia	Dr Janja Pretnar Oblak, Head of Vascular Neurology Dept, University Medical Centre Ljubljana
Spain (Catalonia)	Miquel Gallofré Director Stroke Programme, Health Department, Autonomous Government of Catalonia
Spain	Carmen Aleix, Federación Española de Ictus *(Spanish Stroke Federation)*
UK	Professor Anthony Rudd, National Clinical Director for Stroke, Consultant Stroke Physician, Guy's and St Thomas' NHS Foundation Trust