MY WAY
A EUROPEAN COLLABORATIVE AND INNOVATIVE PARTNERSHIP TO PROMOTE PHYSICAL ACTIVITY AFTER STROKE EVENT

INTELLECTUAL OUTPUT 1
Analysis of the local contexts/Report

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1. SUMMARY

Background

In the European Union (EU), stroke is the second most common cause of death and a leading cause of adult disability. [1] It affects ≈1.1 million inhabitants of Europe every year [2] and causes 440 000 deaths[3]. In 2017, there were 1.12 million incident strokes in the European Union, 9.53 million stroke survivors, 0.46 million deaths, and 7.06 million disability-adjusted life years lost because of stroke.

Future projection of the burden of stroke is therefore valuable for medium- and long-term planning and organization of stroke services and prevention activities. Absolute burden of stroke was increasing and is expected to continue to increase over the next 30 years in most EU countries, particularly in Eastern states. With an estimated 27% increase in the number of people surviving a stroke in Europe, there is an imperative to make greater efforts to prevent stroke[4].

Although the contemporary medicine improved the survival rates, there are increasing numbers of people living with the consequences of stroke, which disrupt quality of life and ability to work effects of stroke. For those, who survived the incidence of stroke, timely and long-term rehabilitation is required.

The goals of rehabilitation are to optimize how the person functions after a stroke and the level of independence, and to achieve the best possible quality of life after rehabilitation. Even though stroke is a burden across all Europe, there are wide disparities in provision between countries and the inequalities within countries with stroke and its consequences for the individual and society, and in stroke rehabilitation framework. For many countries, there is a lack of unified data about stroke and stroke outcomes. Identification and understanding of the general framework and Europe-wide comparisons of stroke and stroke care and long-term rehabilitation are fundamental and vital to help each country provide better care and support for everyone, to return people to the labour market, and to ensure the need for quality of life and independence.

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[1] Wilkins E., Wilson L., Wickramasinghe K, Bhatnagar P, Leal J, Luengo-Fernandez R, Burns R, Rayner M, Townsend N. European Cardiovascular Disease Statistics 2017. Brussels: European Heart Network; 2017

[2] Béjot Y, Bailly H, Durier J, Giroud M. Epidemiology of stroke in Europe and trends for the 21st century. Presse Med. 2016; 45(12 pt 2):e391–e398. doi: 10.1016/j.lpm.2016.10.003

[3] OECD. Mortality from heart disease and stroke. In: Health at a Glance: Europe 2016: State of Health in the EU Cycle. Paris: OECD Publishing; 2016

[4] Wafa H.A., Wolfe C.D.A., Emmett E., Roth G.A., Johnson C.O., Wang Y. Burden of Stroke in Europe. Thirty-Year Projections of Incidence, Prevalence, Deaths, and Disability-Adjusted Life Years. Stroke. 2020;51:2418–2427

It is known that:

- Ten percent of stroke survivors recover almost completely.
- One-quarter percent recover with minor impairments.
- Forty percent experience moderate to severe impairments
- Another 10 percent require care in a nursing home or other long-term care facility[5].

The long-term goal of rehabilitation is to help the stroke survivor become as independent as possible. The chosen rehabilitation options include a subacute care unit, a rehabilitation unit in the hospital with inpatient therapy, a rehabilitation hospital with individualized inpatient therapy, a long-term care facility that provides therapy and skilled nursing care, returning home with outpatient therapy, and home therapy and often depends on the severity of the stroke[6].

Methodology

The report is based on the analysis of the local contexts. It was carried as follows: a search strategy and plan were developed with some "search terms" (stroke, cerebrovascular accident, CVA, cerebral infarct/infarction +/- country or region name + keyword or combination of keywords of interest of respective chapter; epidemiology; prevention; acute treatment; rehabilitation and long-term support; etc.) identified. The sources for information were peer-reviewed journal articles, their reference lists, 'Grey literature' such as government/health authority/stroke organization policies and guidelines, key papers known to research team and ESO, WHO, OECD, European Observatory on Health Systems and Policies, national professional and patient organizations' websites, etc.

In addition, partners completed a matrix that was created to insert all the gathered information about their local contexts to make them comparable, where possible.

[5] https://www.stroke.org/en/life-after-stroke/stroke-rehab/rehab-therapy-after-a-stroke

[6] Winstein C.J. Guidelines for Adult Stroke Rehabilitation and Recovery. Stroke. 2016;47:e98–e169

KEY FINDINGS

Epidemiological data

Despite major improvements in primary prevention and acute treatment over the last decades, stroke is still a devastating disease. At the beginning of the 21st century, the age-standardized incidence of stroke in Europe ranged from 95 to 290/100,000 per year, with one-month case-fatality rates ranging from 13 to 35%.

Approximately 1.1 million inhabitants of Europe suffered a stroke each year, and ischemic stroke accounted for approximately 80% of cases. Although global stroke incidence is declining, rates observed in young adults are on the rise, thus suggesting a need for strategies to improve prevention. In addition, because of the ageing population, the absolute number of stroke is expected to dramatically increase in coming years: by 2025, 1.5 million European people will suffer a stroke each year. Given this, urgent development of resources for post-stroke therapeutic strategies, is needed[7].

Another problem is problems in statistics concerning stroke event. Both the Burden of Stroke in Europe Report and our research had many gaps in datasheets. Stroke registries are available in very few countries across the Europe. However, RES-Q (Registry of Stroke Care Quality) to identify specific gaps and needs in health care delivery at a national, regional and hospital level. Again, this registry faces a gap as well because it was initially targeted at primarily at Central and Eastern Europe, and just a few Western European countries provide the data.

Primary prevention

Primary prevention of stroke is part of both primary healthcare and public health. Stroke prevention, which involves both pharmacological and non-pharmacological interventions, targets many of the same risk factors as those involved in other cardiovascular diseases (CVDs) and other NCDs.

Thus, primary prevention of stroke has two integral components, which can be implemented at different levels. First, measures to promote a healthy lifestyle, such as smoking cessation, diet, increase physical activity and reducing alcohol intake, can be implemented at the individual patient level. Second, improvements in socioeconomic and educational status require action at governmental and societal level.

Primary prevention can be delivered at the individual, community, and population levels. Public health interventions targeting highly prevalent risk factors that do not require pharmacological intervention, encouraging a healthy lifestyle, should be implemented at several levels; such interventions may include legislative changes, media campaigns, labelling of food and educational and preventive measures in schools, workplaces and the community. Although there is only limited high-quality evidence for a direct effect on the incidence of stroke and CVD, initiatives such as building cycle lanes, guiding people to stairs, serving healthy food in public places, smoking bans, decreasing the amount of salt and sugar in processed

7 Béjot Y, Bailly H, Durier J, Giroud M. Epidemiology of stroke in Europe and trends for the 21st century. Presse Med. 2016;45(12 Pt 2):e391-e398. doi:10.1016/j.lpm.2016.10.003

food and soft drinks, health education and public health campaigns to increase awareness of modifiable stroke risk factors are sensible public health interventions and should be pursued[8].

Rehabilitation

Rehabilitation of stroke across European countries today is quite diverse. Geographic distribution of the different rehabilitation centres is homogeneous only in small countries (e.g. Czech Republic, Lithuania), and big countries face the nonhomogeneous distribution. The wide differences between regions or urban/rural areas can be seen as well.

Public or private facilities - assessment, treatment, monitoring, physical therapy facilities for inpatients after stroke are provided in different countries. In addition, the departments of hospitals or private clinics provide rehabilitation therapy programmes that are mainly focused on physical therapy, pool therapy, and speech therapy. These programmes are mainly focused to outpatients. Patients with less severe deficits undergo stroke rehabilitation usually as outpatients.

One more issue needs a discussion. Some countries do not have a national rehabilitation program, nor are the national stroke rehabilitation guidelines available. This may lead to uneven possibilities to stroke survivors. Even though countries may use foreign guidelines, they are not possible in national languages what may be a barrier for some people to use those for the long-term rehabilitation.

Interdisciplinary/inter-professional teams in rehabilitation facilities

Long-term stroke rehabilitation should involve interdisciplinary teams working together to maximize the individual's recovery[9] [10]. Ideally, rehabilitation services are delivered by a multidisciplinary team of healthcare providers with training in neurology, rehabilitation nursing, occupational therapy (OT), physical therapy (PT), sports medicine specialists, and speech and language therapy (SLT). Such teams are directed under the leadership of physicians trained in physical medicine and rehabilitation (physiatrist) or by neurologists who have specialized training or board certification in rehabilitation medicine. Other health professionals who play an essential role in the process include social workers, psychologists, psychiatrists, and counsellors[11].

The quality of integrated stroke care depends on smooth team functioning [12]. Various professional groups, which are involved in stroke rehabilitation, express highly positive professional interest in

[8] Norrving, B., Barrick, J., Davalos, A., Dichgans, M., Cordonnier, C., Guekht, A., Kutluk, K., Mikulik, R., Wardlaw, J., Richard, E., Nabavi, D., Molina, C., Bath, P. M., Stibrant Sunnerhagen, K., Rudd, A., Drummond, A., Planas, A., & Caso, V. (2018). Action Plan for Stroke in Europe 2018-2030. *European stroke journal*, *3*(4), 309–336. https://doi.org/10.1177/2396987318808719

[9] New national recommendations expand the concept of stroke rehabilitation. The Heart and Stroke Foundation., 2013

[10] Clarke DJ, Forster A. Improving post-stroke recovery: the role of the multidisciplinary health care team. *J Multidiscip Healthc*. 2015;8:433-442. Published 2015 Sep 22. doi:10.2147/JMDH.S68764

[11] Miller EL, Murray L, Richards L, Zorowitz RD, Bakas T, Clark P, Billinger SA; on behalf of the American Heart Association Council on Cardiovascular Nursing and the Stroke Council. Comprehensive overview of nursing and interdisciplinary rehabilitation care of the stroke patient: a scientific statement from the American Heart Association. Stroke. 2010; *41*:2402–2448. doi: 10.1161/STR.0b013e3181e7512b.

[12] Cramm, J. M., & Nieboer, A. P. (2011). Professionals' views on interprofessional stroke team functioning. *International journal of integrated care*, *11*, e081. https://doi.org/10.5334/ijic.657

reorganised stroke rehabilitation concerning patients, professional practice and inter-sectoral relations; individual professional and collective inter-professional interests strongly coincided[13].

Patients' associations

Even the research highlights the advantages of involving patients and patients' associations / organizations in making decisions on stroke rehabilitation, mainly long-term rehabilitation as it appears to be associated with meeting their health services needs[14], patients' associations are involved in stroke rehabilitation only in few European countries. However, voluntary organisations support local patients and families with life after stroke.

Unmet needs

The major unmet needs in the stroke rehabilitation field are:

Financial: not enough physical therapy professionals, lack of occupational therapists, all the modalities of physical therapy not available in every centre.

Facilities: distribution of facilities is not homogeneous through the countries, rehabilitation possibilities not comprehensive in every facility, facilities are not equally available (e.g. for patients in remote and rural areas).

Cultural: a still present fatalistic attitude about stroke treatment in the general population (e.g. a widespread thinking in the general population that the deficit after a stroke cannot be improved).

Others (but extremely important in case of long-term rehabilitation): long waiting lists for stroke patients, non-comprehensive, lack of a long term rehabilitation plan, no continuous physical therapy after an acute rehabilitation, no recommendations about long term physical activity, etc.

[13] Burau, V., Carstensen, K., Lou, S., & Kuhlmann, E. (2017). Professional groups driving change toward patient-centred care: interprofessional working in stroke rehabilitation in Denmark. *BMC health services research*, *17*(1), 662. https://doi.org/10.1186/s12913-017-2603-7

[14] Kristensen HK, Tistad M, Koch Lv, Ytterberg C. The Importance of Patient Involvement in Stroke Rehabilitation. *PLoS One*. 2016;11(6):e0157149. Published 2016 Jun 10. doi:10.1371/journal.pone.0157149

2. INTRODUCTION

Background

According to a report from the Global Burden of Disease (GBD) 2016 Lifetime Risk of Stroke Collaborators, the estimated global lifetime risk of stroke in 2016 for those aged 25 years or older was 24.9%, an increased from 22.8% in 1990. Additionally, the prevalence of stroke is expected to increase even more[15]. 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[16].

Although the contemporary medicine improved the survival rates, there are increasing numbers of people living with the effects of stroke. For those, who survived the incidence of stroke, rehabilitation is required. The goals of rehabilitation are to optimize how the person functions after a stroke and the level of independence, and to achieve the best possible quality of life[17].

Nevertheless, it is stated that for stroke survivors the real battle begins after they have been discharged from the hospital. The bio- psycho- social burden on any society (family unit), if they are not properly prepared or organised, can very quickly become devastating. Thus, the burden for the healthcare system, families and society is increasing even more.

Even though stroke is a burden across all Europe, there are wide disparities in provision between countries and the inequalities within countries[18]. Even though for many countries, there is truly little information on the rehabilitation therapies that stroke survivors receive[19], it is agreed that physical activity during long-term stroke rehabilitation is beneficial[20] [21].

However, research and investigation are needed to determine optimal prescription of physical activities for effective rehabilitation in stroke[22] Identification and understanding of the general framework and Europe-wide comparisons of stroke and stroke care are fundamental and vital to help each country provide better care and support for everyone.

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15 GBD 2016 Lifetime Risk of Stroke Collaborators, Feigin VL, Nguyen G, et al. Global, Regional, and Country-Specific Lifetime Risks of Stroke, 1990 and 2016. *N Engl J Med*. 2018;379(25):2429-2437. doi:10.1056/NEJMoa1804492

16 SAFE. The burden of stroke in Europe. Report.

17 https://www.ninds.nih.gov/Disorders/Patient-Caregiver-Education/Fact-Sheets/Post-Stroke-Rehabilitation-Fact-Sheet

18 SAFE. The burden of stroke in Europe. Report.

19 SAFE. The burden of stroke in Europe. Report.

20 Dobkin BH, Dorsch A. New evidence for therapies in stroke rehabilitation. *Curr Atheroscler Rep*. 2013;15(6):331. doi:10.1007/s11883-013-0331-y

21 Tibaek S (2018) The Role of Physiotherapy in the Rehabilitation of Stroke Patients with Lower Urinary Tract Symptoms. J Phys Med 1(1):32-40

22 https://www.ncbi.nlm.nih.gov/pmc/articles/PMC3263535/

Background of the project

MY WAY project has been funded by the ERASMUS+ SPORT programme whose main aims are:

- Tackle cross-border threats to the integrity of sport, such as doping, match fixing and violence, as well as all kinds of intolerance and discrimination.
- Promote and support good governance in sport and dual careers of athletes.
- Promote voluntary activities in sport, together with social inclusion, equal opportunities, and awareness of the importance of health-enhancing physical activity, through increased participation in, and equal access to sport for all.

MY WAY involves various organizations and actors in and outside sport (rehabilitation centres, health science faculty, social and cultural associations, professional educators' groups) from Croatia, Czech Republic, Greece, Italy, and Lithuania.
Partners have been chosen from different European countries to provide a truly supranational approach to the project, including countries from a wide geographic area in the EU. Involved partners will also bring different cultural experiences to the project, which will be considered and analysed in the project data. Finally, all partners already have a commitment to the field of stroke.

The project has the aim to develop, implement and transfer innovative practices related to physical activity enhancing health in frail individuals, such as post-stroke patients.

MY WAY has been structured in different work packages.

WP1: Management and Coordination. This activity concerns the overall management and coordination of the project including the quality management activities, budget control, time management, and risk/conflicts management.

WP2: Dissemination and exploitation. Dissemination is a continuous process throughout the project's lifetime, with a focus on ensuring that the target group is implicated in the project's development from an early stage.

WP3: Analysis of the local contexts. 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 provide better care and support for everyone. This activity is based on the study of literature in each participating country and on the completion of a questionnaire. It will be fundamental to identify and allow the understanding of the general framework of the topics taken into consideration.

WP4: Identification of good practices. Each partner identifies good practices in the project field, exploring in its country promoting and inhibiting factors of physical activity in stroke patients through an analysis of successful and unsuccessful local experiences and based on a wide literature review of international publication databases to imagine for the different European local contexts cost-effective and applicable solutions.

WP5: Definition of Golden rules for physical activity in European stroke patients. Based on the results of the analysis of the local context, identification of good practices, the project partners prepare the framework of a document summarizing their Golden rules for physical activity in European stroke patients.

WP6: Organization of a train the trainers course for health care professionals and physical activity professionals and national replications of the course. Based on the results of the analysis of the local context, identification of good practices and the definition of Golden rules for physical activity in European stroke patients, the educational activities will be implemented. The Train the Trainers (TtT) methodology will be used to implement educational activities through the organization of a training course Master for healthcare and sports professionals working in the selected countries.

To know more about the project, please, visits
www.myway-project.eu

Background of the report

This report has been developed in the framework of **WP3: Analysis of the local contexts.**

It presents the study of the fundamental texts in each participating country concerning Post Stroke Rehabilitation (epidemiology of the disease, stroke rehabilitation path, facilities description, national health system scenario) is presented in order to identify the general framework of the topics taken into consideration. The report is based on the analysis of the local contexts. It was carried as follows:

1. **A search strategy and plan were developed.** Some "search terms" were identified:

- 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 ischemic 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, physical activity, sport

Date range: 2010 and later - but extended to include material published prior to 2010 when information for a country was otherwise lacking.

2. **The resources were identified.** Partners identified some "Sources" that can be useful:

- 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 organization policies and guidelines, etc.
- Key papers known to research team and ESO, WHO, OECD, European Observatory on Health Systems and Policies, national professional and patient organizations' websites, etc.

3. **Data and information collection and evaluation**

Partners completed a matrix that was created to insert all the gathered information about their local contexts to make them comparable, where possible (the questionnaire is available in attachment).
The questions were designed to acquire information on the national situation. Aggregate annual data were requested for items that can be quantified. Predefined answer categories (yes; no; not applicable/unknown) were provided for most qualitative data such as information on adherence to specific items. Information in free text format was solicited for those questions which could not be amenable to the predefined answer categories, for explanatory comments or for reporting on recent developments.
This questionnaire was developed to obtain information and perspectives on stroke care in each EU country, additional to information obtained through the literature review process.

Stroke

In 2017, 1.5 million people were diagnosed with stroke, 9 million were living with stroke and 0.4 million died because of stroke in 32 European countries[23].

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. Nevertheless, some of this variation is also due to the different criteria and methods used to collect the data. Despite this, some trends do emerge. 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. Large variations in incidence are also seen within countries (e.g. Italy, Spain, Sweden, and UK). Possible explanations for these large inter-

[23] Luengo-Fernandez R. et al. Economic burden of stroke across Europe: A population-based cost analysis. European Stroke Journal 2020, Vol. 5(1) 17–25.

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[24].

Despite major improvements in primary prevention and acute treatment over the last decades, stroke is still a devastating disease. At the beginning of the 21st century, the age-standardized incidence of stroke in Europe ranged from 95 to 290/100,000 per year, with one-month case-fatality rates ranging from 13 to 35%. Approximately 1.1 million inhabitants of Europe suffered a stroke each year, and ischemic stroke accounted for approximately 80% of cases. Although global stroke incidence is declining, rates observed in young adults are on the rise, thus suggesting a need for strategies to improve prevention. In addition, because of the ageing population, the absolute number of strokes is expected to dramatically increase in coming years: by 2025, 1.5 million European people will suffer a stroke each year.

Beyond vital prognosis, stroke patients are also at increased risk of poor outcome within the first year of the event including re-hospitalization (33%), recurrent event (7% to 13%), dementia (7% to 23%) mild cognitive disorder (35% to 47%), depression (30% to 50%), and fatigue (35% to 92%), all of them contributing to affect health related quality of life[25]. The lifetime risk of stroke recurrence among people with stroke is ≈30%, and the risk of either nonstroke vascular death or myocardial infarction is ≈2%/y [26] . Given these observations, an urgent development of acute care provision, as well as resources for post-stroke therapeutic strategies, is needed[27].

Stroke Rehabilitation

A high societal burden and a considerable increase in stroke-related disability was globally observed over the last 3 decades and is expected to continue implying a major challenge for societies around the word. Structured multidisciplinary stroke rehabilitation reduces stroke-related disability both in older and younger stroke survivors of either gender and independent of stroke severity. In addition, there is rapidly increasing evidence to support the clinical effectiveness of specific stroke rehabilitation interventions[28].

Stroke rehabilitation requires a sustained and coordinated effort from a large team, including the patient and his or her goals, family and friends, other caregivers (e.g., personal care attendants), physicians, nurses, physical and occupational therapists, speech-language pathologists, recreation therapists, psychologists,

[24] Stroke Alliance for Europe. The burden of stroke in Europe. 2020. King's College London.

[25] Béjot Y. et al. Epidemiology of stroke in Europe and trends for the 21st century. La Presse Médicale Sous presse. Epreuves corrigées par l'auteur. 2016. Doi : 10.1016/j.lpm.2016.10.003

[26] Touzé E, Varenne O, Chatellier G, Peyrard S, Rothwell PM, Mas JL. Risk of myocardial infarction and vascular death after transient ischemic attack and ischemic stroke: a systematic review and meta-analysis. Stroke. 2005;36:2748–2755. doi: 10.1161/01.STR.0000190118.02275.33

[27] Béjot Y. et al. Epidemiology of stroke in Europe and trends for the 21st century. La Presse Médicale Sous presse. Epreuves corrigées par l'auteur. 2016. Doi : 10.1016/j.lpm.2016.10.003

[28] Platz Th. Evidence-Based Guidelines and Clinical Pathways in Stroke Rehabilitation—An International Perspective. Frontiers in Neurology. 2019; 10: 200.

nutritionists, social workers, and others. Communication and coordination among these team members are paramount in maximizing the effectiveness and efficiency of rehabilitation and underlie this entire guideline. Without communication and coordination, isolated efforts to rehabilitate the stroke survivor are unlikely to achieve their full potential[29].

As systems of care evolve in response to healthcare reform efforts, post-acute care and rehabilitation are often considered a costly area of care to be trimmed but without recognition of their clinical impact and ability to reduce the risk of downstream medical morbidity resulting from immobility, depression, loss of autonomy, and reduced functional independence. The provision of comprehensive rehabilitation programs with adequate resources, dose, and duration is an essential aspect of stroke care and should be a priority in these redesigned efforts[30].

Evidence shows that neurological and functional recovery occurs in both the acute and chronic phases post stroke. Rehabilitation has been shown to be most beneficial when started early, although recovery of stroke-related impairments is still possible even years later. Stroke recovery is influenced by a variety of intrinsic and extrinsic factors that influence the likelihood and degree of neurological reorganization. The effects of early initiated rehabilitation, increased therapy intensity, and enriched environments on stroke recovery are of particular interest[31].

Effective stroke rehabilitation is characterized by an interdisciplinary team working cohesively and closely to provide a comprehensive program for each patient. These programs vary in the types of therapies provided as well as their intensity, frequency, and duration. While the benefits of a stroke rehabilitation service may seem obvious, determining the impact of this treatment was difficult, due to problems with study design and methodology (lack of randomization, inappropriate control group selection, failure to blind assessors, difficulty in controlling for all possible confounders) and difficulties inherent to stroke rehabilitation (controlling for spontaneous neurological recovery, daily fluctuation in individual function, and difficulties in measuring functional outcomes). Despite these difficulties, earlier comparative studies demonstrated patients cared for by specialized stroke rehabilitation teams had lower one-year mortality, achieved greater gains in activities of daily living by discharge, and were less likely to be in a nursing home at follow-up[32].

Very few information are available about long-term physical activity. Physical activity is a cornerstone of risk-reducing interventions for treating stroke. Moreover, exercise can improve the quality of life among stroke survivors by strengthening muscles and improving mobility. In addition, physical exercises are associated with

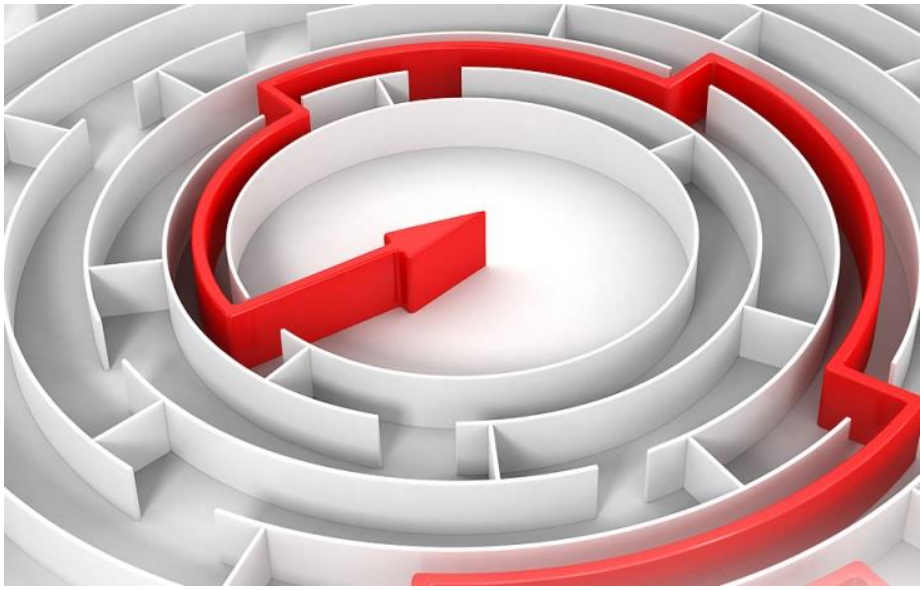
[29] Winstein C.J. Guidelines for Adult Stroke Rehabilitation and Recovery. Stroke. 2016;47:e98–e169

[30] Winstein C.J. Guidelines for Adult Stroke Rehabilitation and Recovery. Stroke. 2016;47:e98–e169

[31] Teasell R., Husein N. Background Concepts in Stroke Rehabilitation. In: Evidence-Based Review of Stroke Rehabilitation. 2018. Heart and Stroke Foundation.

[32] Teasell R. et al. The efficacy of stroke rehabilitation. In: Evidence-Based Review of Stroke Rehabilitation. 2018. Heart and Stroke Foundation.

improved cardiovascular risk factors including reduced blood pressure. Studies suggested that physical activity is likely to reduce the risk of recurrent stroke. However, physical activity after stroke is low, thus strategies are needed to promote and maintain physical activity in stroke survivors[33].



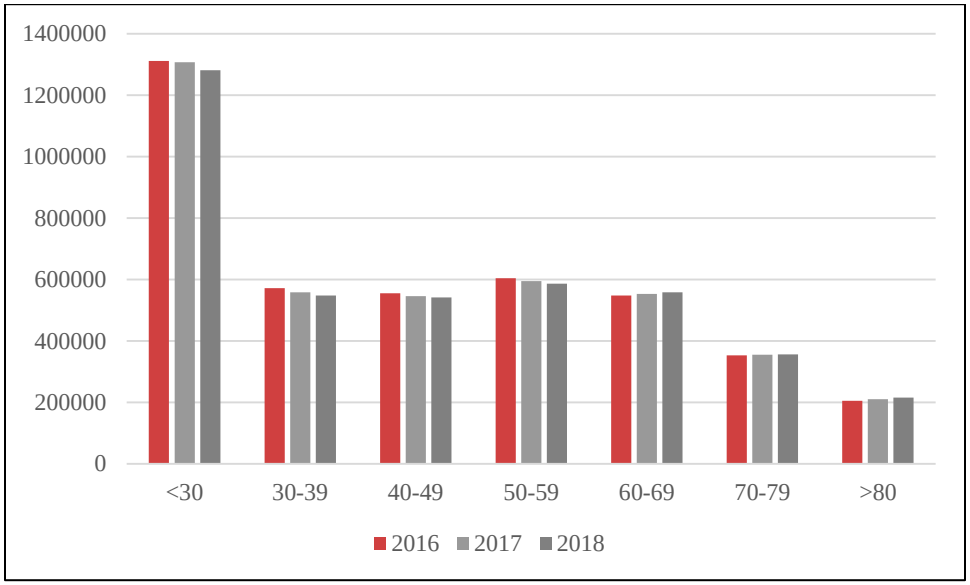
[33] Matthew J. Field, Nick Gebruers, Thavapriya Shanmuga Sundaram, Sarah Nicholson, Gillian Mead, "Physical Activity after Stroke: A Systematic Review and Meta-Analysis", International Scholarly Research Notices, vol. 2013, Article ID 464176, 13 pages, 2013. https://doi.org/10.1155/2013/464176

3. OVERVIEW ON THE EPIDEMIOLOGY OF STROKE IN THE PARTICIPATING COUNTRIES

Although stroke is a significant global health concern, validated, comprehensive stroke epidemiology data, and long-term trends are unavailable for many countries[34].

CROATIA

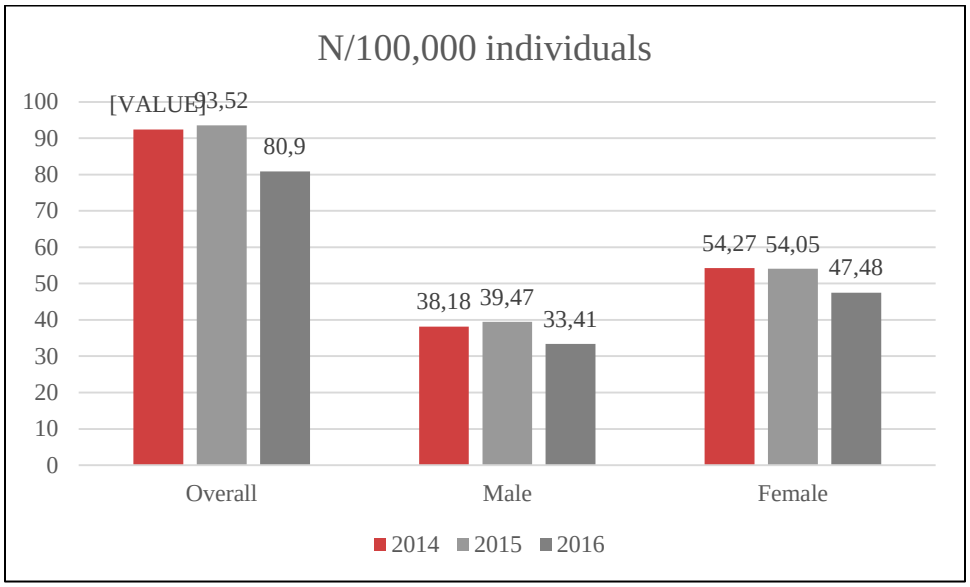
Around 4 million people live in Croatia, with a male/female average ratio 48.3% / 51.7%. This is the age distribution in the year 2016-2018:



[34] V.L.Feigin, M.H. Forouzanfar, R. Krishnamurthi, *et al.* Global and regional burden of stroke during 1990-2010: findings from the Global Burden of Disease Study 2010. Lancet, 383 (2014), pp. 245-255

The incidence of stroke varied about 150 per 100.000 inhabitants the year 2016-2019[35] [36]. The data on percentage on male/female and the age at stroke event is not available.

The mortality rate is slightly decreasing but remains high with the higher rate in females[37].



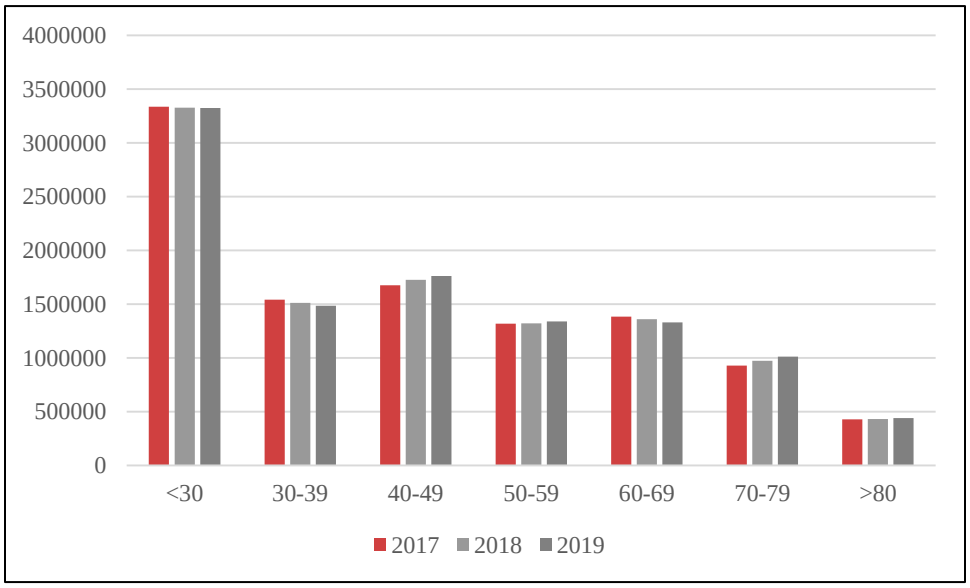
[35] GBD 2016 Stroke Collaborators. Global, regional, and national burden of stroke, 1990-2016: a systematic analysis for the Global Burden of Disease Study 2016. *Lancet Neurol*. 2019;18(5):439-458. doi:10.1016/S1474-4422(19)30034-1

[36] Krishnamurthi RV, Ikeda T, Feigin VL. Global, Regional and Country-Specific Burden of Ischaemic Stroke, Intracerebral Haemorrhage and Subarachnoid Haemorrhage: A Systematic Analysis of the Global Burden of Disease Study 2017. *Neuroepidemiology*. 2020;54(2):171-179. doi:10.1159/000506396

[37] Croatian Institute of Public Health, Croatian Health Statistics Yearbook 2018

CZECH REPUBLIC

Around 10 million people live in Czech Republic, with a male/female average ratio 49.25%/50.75%. This is the age distribution in the year 2017-2019:

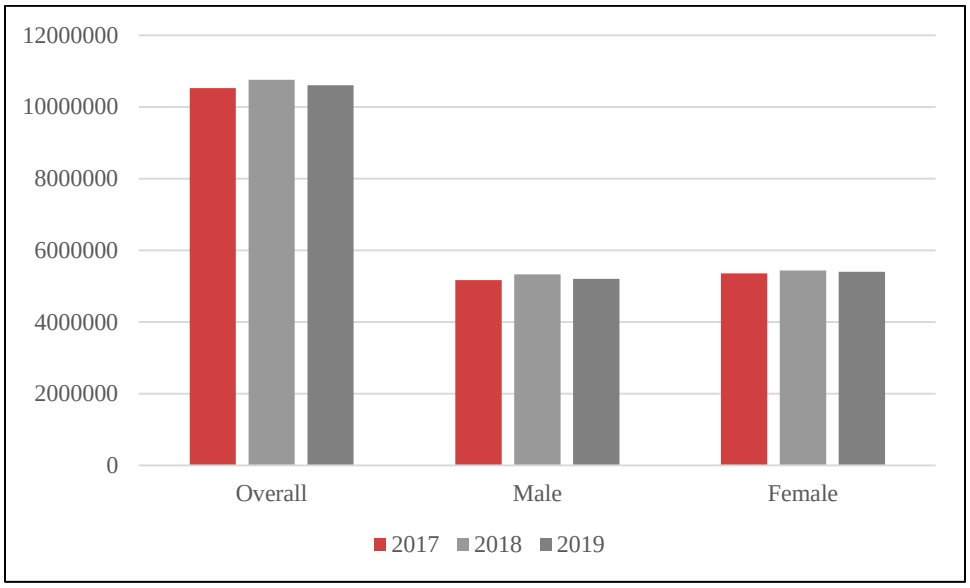


The incidence of stroke varied about 282 per 100 000 inhabitants in 2017 (the latest available data), and the male/female percentage among patients with stroke was 50.27 / 49.73.

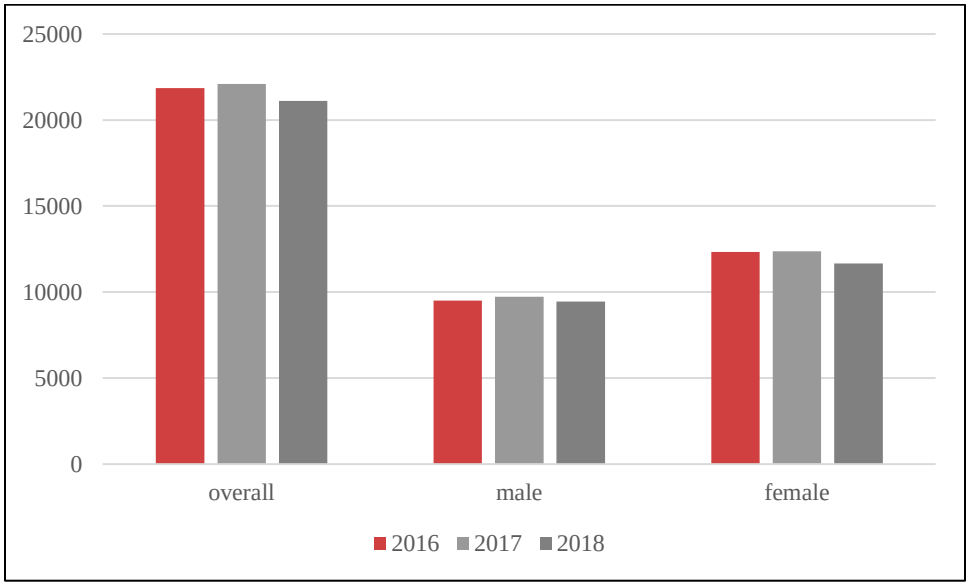
The mortality rate is slightly decreasing but remains high with the higher rate in females (~58%).

GREECE

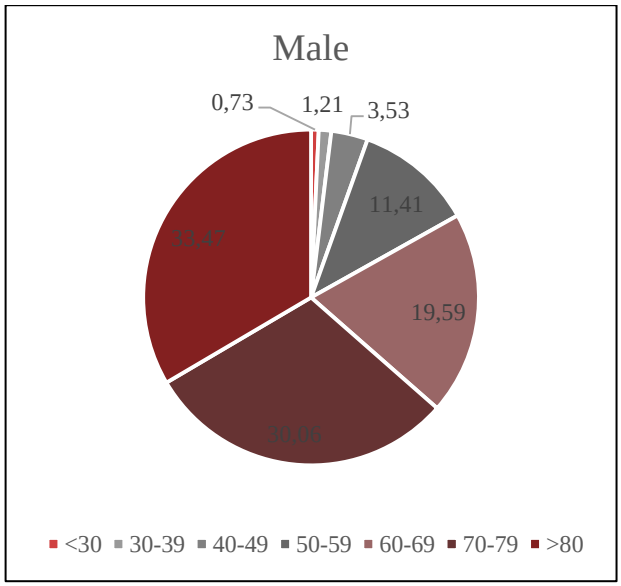
Around 10.5 million people live in Greece, with a male/female average ratio 49% / 51%. This is the age distribution in the year 2017-2019:

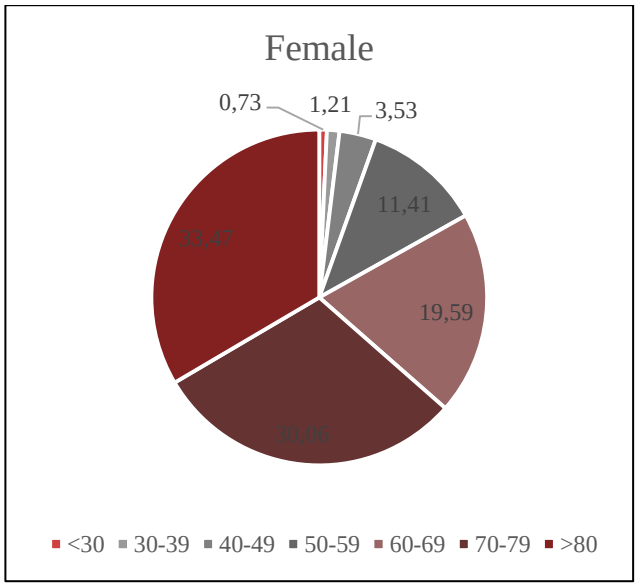


The incidence of stroke in Greece is among the highest in the western countries, and unfortunately, only few survive. The incidence of stroke varied about 330 per 100.000 inhabitants the year 2017-2019 with the higher male percentage.



It is important to emphasize that the patients' age at diagnosis is getting older, e.g. 70 years in 2017, 75 years in 2018, and 77 years in 2019. The distribution (percentage) of stroke by the age groups in 2017 is shown below.



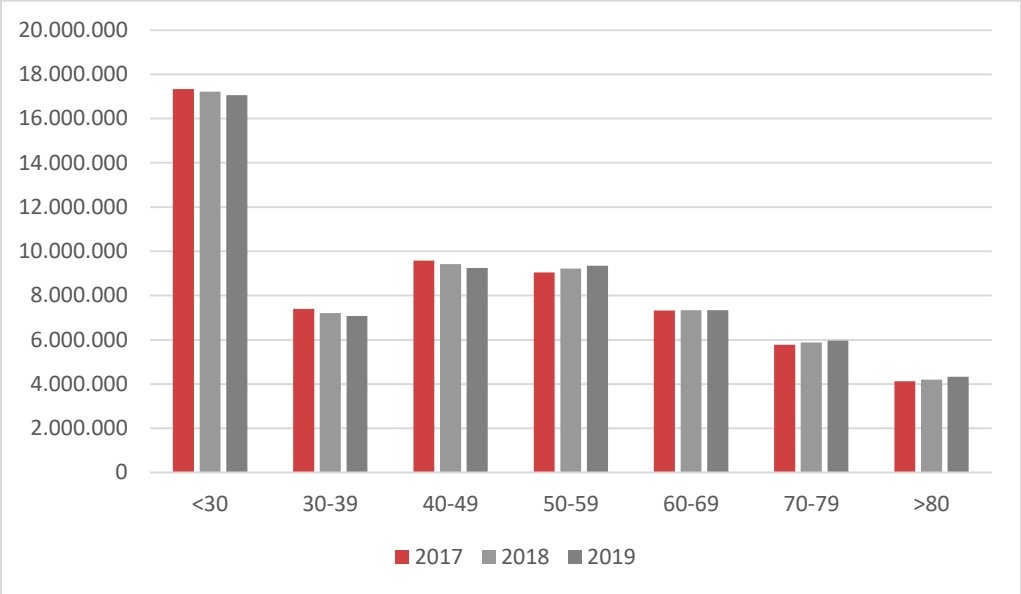


The mortality rate is about 140 per 100 000 inhabitants during the recent years.

ITALY

Around 60 million people live in Italy, with a male/female average ratio 49% / 51%.

Italy is a very old country with the 22.9% of the population over 65 years.



The incidence of stroke in Italy range from 144 to 293 /100.000 per year (year 2010-2019). In addition, the male/female percentage vary about 60/40%.

The information available is of 75% of stroke events occurring in people aged > 65.

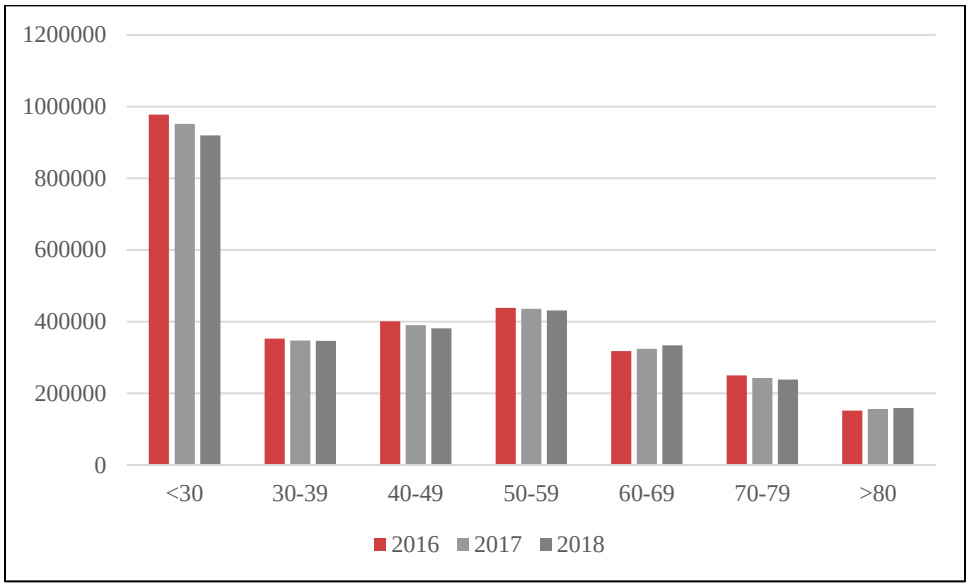
The rate of the primary stroke events range 115-234/100.000/year (year 2013-2019). While the rate of the stroke re-events (secondary, tertiary) range 30- 60/100.000/year.

About 60-120 patients/year are no more able to live on their own and need to be hospitalized in nurseries.

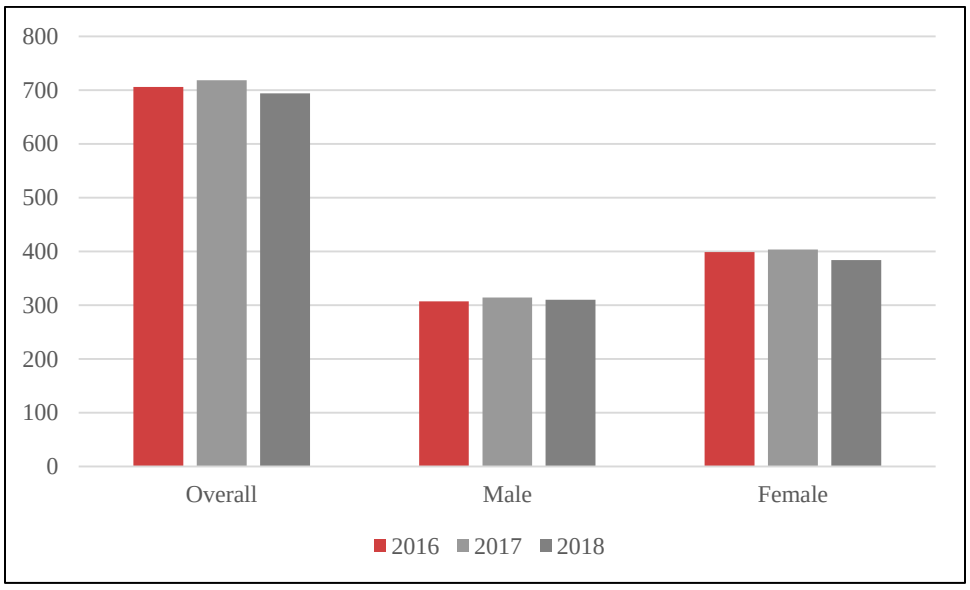
The mortality rate for stroke in Italy range 30-60/100.000/year.

LITHUANIA

Almost 3 million people live in Lithuania, with a male/female average ratio 46% / 54%. This is the age distribution in the year 2016-2018:

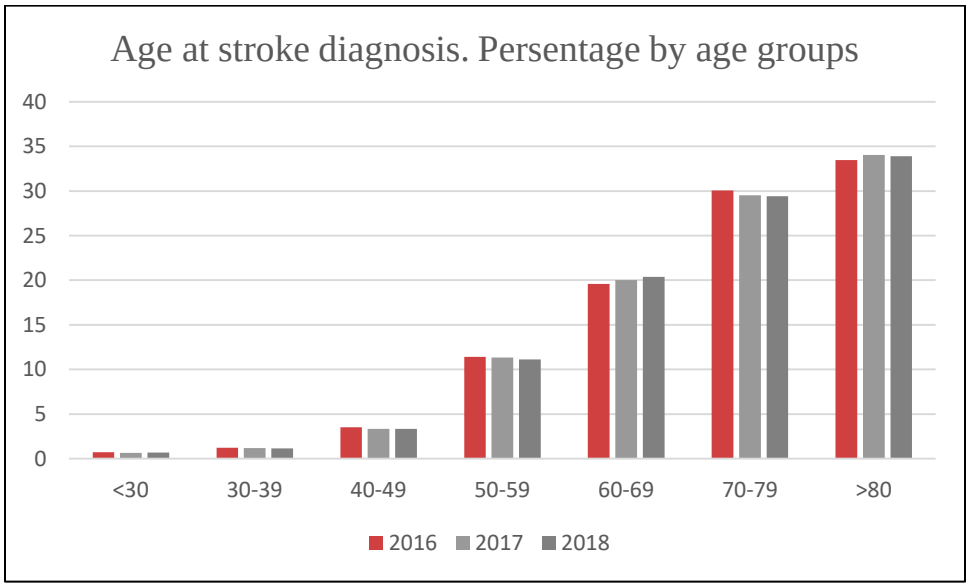


The incidence of stroke in Lithuania range about 700 /100.000 per year (year 2016-2018). In addition, the male/female percentage vary about 44/56%.



About 80% of stroke events occurring in people aged > 60. However, the mortality rate is decreasing over the last few years in Lithuania:

- 120.4 / 100 000 in 2016
- 115.5 / 100 000 in 2017
- 109.4 / 100 000 in 2018



4. OVERVIEW ON THE NATIONAL HEALTH SYSTEMS IN THE PARTICIPATING COUNTRIES

CROATIA

Croatia has a National Health System that is funded by public and is organized at Central and Regional levels.

The standard of health care in the Croatian National Health System is generally satisfactory, but the quality of health services is not homogeneously available, it is more available in cities and towns, and the standard of health services in remote and peripheral areas and islands is limited.

Health care services within Primary health care (PHC) in Croatia are provided in primary health centers, emergency medical services and pharmacies. Each municipality has a primary health center providing PHC services to patients through a network of general medical examinations provided by GPs. In rural and remote areas of Croatia, primary health centers are under the supervision of hospitals for the provision of specialist outpatient care, although there are restrictions on the provision of hospital health care and maternity care.

Private healthcare institutions are also present in the Croatian healthcare system.
Hospitals in the Republic of Croatia are categorized into four categories: national hospitals, county hospitals of regional significance, county hospitals and local hospitals.

Primary level health care is provided through the following activities: general / family medicine, patronage nurses (home health care), nursing home care, dental health care, etc.

Secondary level health care includes specialist - consultant health care and hospital health care.

Tertiary level health care involves performance of the most complex forms of specialist-consultant healthcare and hospital healthcare[38].

The National Health system in Croatia has an organized electronic database called CEZIH (Central Health Care Information System in Croatia) with health patients' data. General practice/family medicine offices, paediatric offices, gynaecological offices, dentist offices, pharmacies, primary health care laboratories, school medicine offices, out-of-hospital specialist-conciliar health care and information system of the Croatian Institute for Health Insurance are connected to CEZIH.

[38] Croatian Health Insurance Fund. Available at https://www.hzzo.hr/en/zdravstveni-sustav-rh/opis-zdravstvenog-sustava/

All of the listed participants in the system send data into the central database in real time and receive advanced reports on operation of the health care system from that database.
E-prescription has been introduced in 2011, complete national coverage was achieved, and a significant step was made towards “paperless office”. Since 2011, a full national coverage of e-referral has been achieved in biochemical laboratory. In Croatia, by implementing the electronic information exchange mechanisms (e-prescription, e-referral, notes after each examination in primary health care, sick leave report, and four messages to Croatian National Institute of Public Health: “Pompidou” form, reports of malignant neoplasms, reports of infectious diseases, and unwanted side effects related to mandatory immunization). An important part of such data is a medical treatment history.

Hospital IT system is present in public hospitals, as well. However, there is no mutual IT connection among hospitals, nor is there a unique set of data monitored and sent, and there is no reporting system that would include hospital data as well. There is no mutual IT connection between hospitals and primary care centers (e.g. GPs).
In Croatia, there is also telemedicine service, i.e. medical services provided from a distance through information and communication technologies, currently provided at the primary, secondary and tertiary level of health care[39].
However, there is no National Stroke registry available in Croatia.

CZECH REPUBLIC

Czech Republic has a National Health System that is funded by co-payment.

The National Health system is organized at central level. The Czech health care system is based on a compulsory statutory insurance model, with fee-for-service care funded by compulsory membership of a health insurance fund (often employment-related insurance plans). It is a system with virtually universal coverage and a broad range of benefits.

However, the organized electronic database with health patients’ data is not developed yet. The healthcare sector in the Czech Republic is limited by patient´s data and healthcare providers unavailability, the absence of education and financial reasons The ICT use is generally underdeveloped. Although many plans to implement national e-health capacities exist, they have not been yet realized.

The only exception is the electronical sick leave registry "eNeschopenka" and electronic recipes, which were introduced in 2018. The electronic health care is currently taking place at the local level. In a number of hospitals and facilities, all patient data is now digitized, and eHealth pilot projects are being implemented. The insurance companies might have their own databases, but it is not publicly available and centrally organized. Thus, National Stroke registry is not available as well.

39 World Health Organization. Available at https://www.who.int/goe/policies/countries/hrv/en/

GREECE

Greece has a National Health System that is organized at central level and is funded by public.

Greece's health care system is a mixed system comprising elements from both the public and private sectors.

In the public sector, a National Health Service type of system coexists with a social health insurance (SHI) model. In 2011, the National Organization for the Provision of Health Services (EOPYY) was established. It acts as the sole purchaser of health care services for patients covered by the publicly financed National Health System (NHS) (known as ESY).

Since 1987, the Hellenic Emergency Medical Services (EMS) is handled by EKAB and is entirely funded by the Greek government. EMS is managed via 12 EKAB stations in the major Greek cities. EKAB is accessible throughout the country firstly by the European emergency phone number "112" as well as by the national emergency number "166".

The Greek NHS consists of 201 rural and 3 urban primary healthcare centers, 1.478 positions in rural medicine and many outpatient departments in 140 public hospitals. It is striking that Greece has one of the highest number of physicians (6.17 physicians per 1000 people, in 2013) in the world. Primary health centers are composed of 1.787 full-time salaried doctors, mainly general practitioners (GPs) and approximately 2.414 other health professionals. The in-hospital EMS settings use triage systems to prioritize incoming patients rapidly. The emergency cases are sorted into surgical or medical emergencies and appropriately treated by specialists.

The private sector includes profit-making hospitals, diagnostic centers and independent practices. A large part of the private sector enters contracts with EOPYY, providing mainly primary/ambulatory care for the ESY. After 2010, the role of voluntary initiatives, nongovernmental organizations (NGOs) and informal health care networks increased significantly. This was mainly a response to meeting the needs of the large portion of the population that lost insurance coverage and access to public health care, primarily through prolonged unemployment or other inability to pay contributions. Coverage was restored through remedial legislation in 2016.

The Ministry of Health is responsible for the planning and regulation of the ESY and EOPYY. In 2004, regional health and welfare authorities were established and renamed as regional health authorities (YPEs) in 2004. These entities were intended to carry out extensive health care planning, organization and provision. In 2014, legislation formally transferred all public primary care facilities, health centers and rural surgeries to the jurisdiction of the YPEs with primary care coordination roles, in order to create a more integrated, two-tier

primary care system with a gate-keeping role.

National Health system in Greece has organized electronic databases with health patients' data:

- Electronic Governance of Social Insurance - http://www.idika.gr/
- Health Atlas https://healthatlas.gov.gr/#!/

However, a National Stroke registry is not available.

ITALY

Italy has a National Health System that is organized at and funded by public.

The National Health System has been created in 1978, inspired by the 32nd article of the Italian Constitution. The SSN (Servizio Sanitario Nazionale) is comprehensive of all function and healthcare activities, managed by regional health organization, by the nation central institution and by the Italian State. The National Health system in Italy is organized at regional level. Healthcare is provided to all citizens. The SSN is funded mostly by the taxation, and only for some services by a co-payment.

According to the modification of the Italian Constitution, Title V, starting from 2001, Italian Regions got the power to make choices in management of Health and assistance, based on a general indication provided by the National Health Government. The consequences of this devolution are huge differences in services provided to citizens, in quality of assistance and in balance between public and private participation to the health expenses. National Health system in Italy has an organized electronic database with health patients' data, however, not in all the regions and for all the pathologies. In addition, National Stroke registry is available in Italy, but not every region collects data.

LITHUANIA

Lithuania has a National Health System that is funded by public and is organized on three levels: central, regional, and local.

The main objectives of the health system are improving population health as well as access to and quality of health-care services. The focus is being shifted from treatment towards prevention and healthy lifestyles.

The high rates of mortality amenable to timely and effective health care interventions in Lithuania are mainly due to extremely high death rates from ischaemic heart disease and stroke. One of the most recent reforms to improve effectiveness in hospital services is to standardise care pathways with more centralised treatment for acute diagnoses. To this end, six stroke and five cardiology centres have been established regionally, to which the most severe cases are directed[40].

National Health system in Lithuania has an organized electronic database with health patients' data.

[40] OECD and World Health Organization. State of Health in the EU Lithuania Country Health Profile 2017.

The implementation of the Lithuanian electronic health system is coordinated and supervised by the Ministry of Health. The regulations of the state electronic health services and cooperation infrastructure information system are approved, and the managers are appointed by the Government.

In the system, the doctors can provide, and the patients can view the health data provided by the doctor:

- Diagnoses,
- Treatment information,
- Electronic prescriptions,
- Laboratory test submissions and responses,
- Referrals for consultations,
- Medical images,
- Information about vaccinations,
- Health certificates.

The pharmacists use the system to dispense medicines prescribed electronically.

A National Stroke registry is available in Lithuania as well. The Lithuanian Institute of Hygiene provides annual statistics on stroke cases in Lithuania.

5. OVERVIEW ON STROKE REHABILITATION PATH IN THE PARTICIPATING COUNTRIES

The Helsingborg Declaration, and its slogan “Stroke Unit for all” published in 1995, aimed to improve stroke management throughout European countries through a more uniform availability of current stroke care standards for all patient subgroups, regardless of age, gender or stroke severity. The declaration sought to reduce mortality below 20% and achieve greater independence for more than 70% of stroke survivors within 3 months[41].

In 2006, the second edition of the Consensus Conference of Helsingborg was held. Co-sponsored by the WHO Regional Office for Europe, the second Helsingborg Declaration set new targets for stroke management and care: “continuum of care from organized stroke units in the acute phase to appropriate rehabilitation and secondary prevention measures”. The specific goals for 2015 were that >85% of patients should survive the first month after stroke (5% more than the target for 2005), that 70% of survivors should be independent at 3 months (similar to the 2005 target), and that all patients with acute stroke, potentially eligible for acute- specific treatment, should be transferred to hospitals with adequate capacity and expertise to administer such treatment[42].

Nevertheless, there is a wide difference in stroke care in European Countries, conditioning the performance in stroke management[43].

[41] Limburg M. Treatment of stroke in Europe: the Helsingborg Declaration *Ned Tijdschr Geneeskd* 1997; 22 (14) : 568-571

[42] Norrving B.International Society of Internal Medicine; European Stroke Council; International Stroke Society; WHO Regional Office for European The 2006 Helsingborg Consensus Conference on European Stroke Strategies: Summary of conference proceedings and background to the 2nd Helsingborg Declaration *Int J Stroke* 2007; 2: 139-143

[43] Arnao V. et al. How is stroke care organized in Europe. La Presse Médicale. 2016. 45(12); e399-e408. Doi: 10.1016/j.lpm.2016.10.004

CROATIA

The data on the time that elapses between the stroke event and the start of rehabilitation is not available. However, the case of the University Hospital Sveti Duh can be taken as an example: rehabilitation there starts within one day of admission, except when the admission has been on Friday, rehabilitation starts on the next Monday (physiotherapists are not on call during weekends).

The average length of hospitalization (between the event and the discharge) in patients who undergo stroke is 8 days.
75 % of patients are prescribed to continue rehabilitation after the discharge from the hospital[44].

After the discharge, the rehabilitation take place in hospitals, i.e. special hospitals for medical rehabilitation, or out of hospital – primary health centers, and private polyclinics.

Croatian Stroke Society states that “For stroke survivors the real battle begins after they have been discharged from the hospital. The bio- psycho- social burden on any society (family unit), if they are not properly prepared or organised, can very quickly become devastating”. In addition, the root to a great percentage of the imperfections within the healthcare system lies in the lack of logistical coordination within the system itself.

Once the stroke survivor is released from the hospital, the stroke survivor and their primary caregiver are given very little if any information regarding post hospital recovery procedures and care options.

The information given is most often very superficial and lacks a realistic picture of what awaits the stroke survivor and their primary caregiver in the immediate and distant future.

The need for some form of standardized criteria regarding recovery, care options as well as an insight into patient rights for stroke survivors and their primary caregivers is thoroughly needed so that the stroke survivor as well as their primary caregiver may successfully navigate and reach their desired destination, which is the recovery from the burden of stroke.
To achieve these goals a firm foundation must be put in place in which an alliance of all parties involved in the stroke survivors’ rehabilitation and recovery can come together in order to maximize a successful post stroke outcome.

Without complete collaboration and cooperation (within all branches of health care, social services, patient advocate groups, and the stroke survivors’ primary caregiver) no true recovery from the burden of stroke can fully be achieved. This continuous burden not only inhibits all aspects of the stroke survivors’ life but also directly influences the lives of their family members and society as a whole[45].

[44] RES-Q (Registry of Stroke Care Quality)

[45] Stroke Allinace for Europe. Life After Stroke: Stroke Survivors’ needs across Europe. 2019.

CZECH REPUBLIC

28.513 hospitalized patients for cerebral infarction (I63 according to ICD International Classification of Diseases and Related Health Problems) and 1.821 hospitalized patients for stroke, not specified as haemorrhage or infarction (I64 according to ICD) received in Czech Republic in 2017.

The start of rehabilitation depends on the hospital. However, it is commonly 1 or 2 days between the stroke event and the start of rehabilitation in hospital. 10.4 days for cerebral infarction and 19.9 for stroke is the average length of hospitalization (between the event and the discharge).
Rehabilitation usually starts in the stroke unit or neurology unit. After discharge from the hospital, outpatient rehabilitation follows in specialized centers. Follow-up treatment is provided optimally in the patient's home environment, with outpatient care by a general practitioner, specialists, non-medical health professionals and social institutions.

Neurologist, internist, cardiologist, psychiatrist, psychologist, rehabilitation doctor, speech therapist, neurosurgeon, interventional radiologist, rehabilitation workers (physiotherapist, occupational therapist), general nurses and social workers can take part in professional patient care.
Patient care is an interprofessional issue, including the cooperation of an internist, rehabilitation workers, a speech therapist, a psychologist and other specialized workers.

The team usually consists of a doctor, physiotherapist, occupational therapist, psychologist, speech therapist, special pedagogue, nurse, nutritionist and social worker.

The possibilities of further rehabilitation for stroke patients include ergodiagnostics and work rehabilitation, assistance services, counseling, outpatient professional centers and organizations focused directly on the stroke rehabilitation.

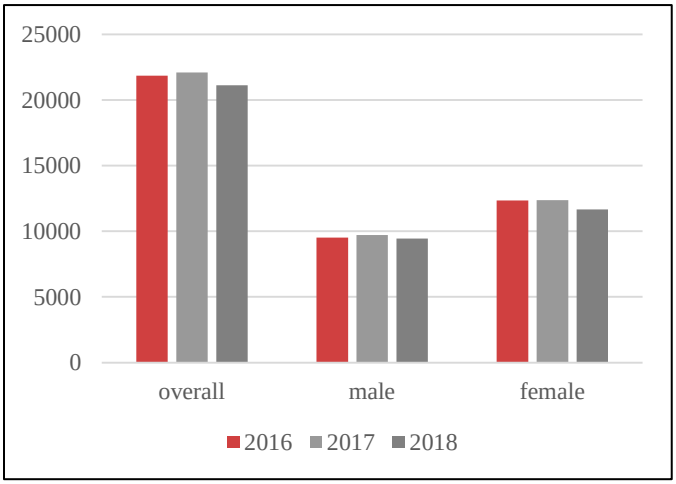
Czech organization for rehabilitation of stroke victims emphasizes that the need for more clubs for stroke victims, for stroke carers, more encouragement in terms of mutual communications, music, creative activities is the issue that needs special attention.

The people affected by stroke can produce these activities partly on their own, but they need necessarily organizational as well as logistic support. The organization for rehabilitation of stroke victims provides counselling, provides courses, activates clubs throughout the country, but its reach is by far insufficient.
Many healthy, retired people, who could actively contribute to the care of those less happy in their physical health state, ignore the needs of stroke individuals and thereby their eventual personal pleasure of making good deeds. It is stressed that patient organizations should be more proactive in sharing knowledge and encouraging people in those activities. Self-supporting groups could be conceived and put in life[46].

[46] Stroke Allinace for Europe. Life After Stroke: Stroke Survivors' needs across Europe. 2019.

GREECE

33 – 40 thousand patients are hospitalized yearly for stroke (2017-2019).
5-7 days elapses between the event and the start of rehabilitation in hospital. 10 days is the average length of hospitalization (between the event and the discharge) in patients who undergo stroke.
After the discharge, the rehabilitation take place in hospitals and out of hospital. The percentage of in-patient and out-patient rehabilitation is shown below.



However, in Greece, there is a very low number of stroke units and high regional discrepancy, including no central policy on emergency services or ambulance staff training. There is a very small number of comprehensive stroke centers, despite introduction of “stroke unit beds” within some coronary/cardiovascular units. This may lead to the high number of patients who drop out from rehabilitation program (5000 in year 2017).

Most patients pay for (costly) rehabilitation services after discharge, as there are time/session limits on national health provision in rehabilitation centers which are mostly private. A stroke survivor can be hospitalized in a rehabilitation center for the first six months after the stroke with insurance coverage of the main cost. For an outpatient stroke survivor there is coverage for physiotherapy program for 10 times/month for the first six months. In addition, voluntary organisations support local patients and families with life after stroke.

Hellenic Alliance/action for Stroke aims to make an effort both to inform and educate the public about prevention, early diagnosis and treatment of a stroke and to the health policy makers in order to achieve improvement of health services for the treatment, care and rehabilitation of the patient with stroke at the national level.

Communication and cooperation between members, coming from the scientific field, and members, coming from the field of stroke survivors, is emphasized in order to update and exchange views, knowledge and experience which is the best possible ways to treat, restore and help improve or maintain quality of life not only for the stroke survivor but the family at large.

The support and promotion of scientific research on issues related to strokes, aiming at better prevention, rehabilitation and reduction of consequences and social costs is highlighted[47].

[47] Stroke Allinace for Europe. Life After Stroke: Stroke Survivors’ needs across Europe. 2019.

ITALY

Italy does not have a stroke prevention program/strategy.

There are national clinical guidelines for high management blood pressure, cholesterol, atrial fibrillation and TIA.

There is no national stroke prevention strategy, but only a few regional programs. Stroke patients are admitted to general medicine, neurology, geriatrics, and stroke units.

Currently there are 130 stroke units in Italy.

There are wide differences between northern and southern Italy. There are some telemedicine experiences at the regional level, for example in the Veneto and Emilia-Romagna regions. The guidelines of the Italian Stroke Organization (as well as the protocols and regional strategies) include rehabilitation; a few weeks after discharge patients are checked by the general practitioner. Post-acute rehabilitative paths are foreseen for in-patients as well as for outpatients, mostly depending on residual disability, despite a lack of national protocols / paths between acute / rehabilitative care and primary care.

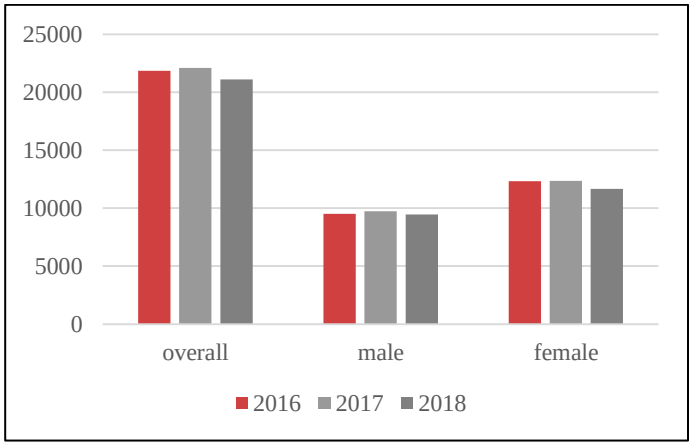
The number of hospitalized patients for stroke is not available.

The average length of hospitalization (between the event and the discharge) in patients who undergo stroke is 14 days (2018). Still the number of days between the event and the start of rehabilitation in hospital my vary from 7 to 45 days. 80% of patients are prescribed to continue rehabilitation after the discharge from the hospital.

After the discharge, the rehabilitation may take place in the hospitals, out of hospital, or in the training facilities.

LITHUANIA

More than 20 thousand hospitalized patients for stroke received yearly during the last few years[48] (see picture below).



The average length of hospitalization (between the event and the discharge) in patients who undergo stroke is 25 days. Rehabilitation is started immediately in the hospital according to the nature of the lesion and the severity of the condition.

[48] Sveikatos statistinių duomenų portalas. Užregistruotų susirgimų skaičius pagal diagnozių grupes (pagal TLK I64 - insultas). Higienos institutas. 2016-2017-2018. Retrieved from:<https://stat.hi.lt/default.aspx?report_id=169>

After the discharge, the rehabilitation take place in the hospitals, training facilities, rehabilitation hospitals, and rehabilitation centers.

After the discharge from hospital, about 10% of all patients take part in rehabilitation as the outpatients and 90% as the inpatients[49].

The data on the number of the patients dropped out from rehabilitation program is not available.

[49] Lithuanian Institute of Hygiene, 2020.

6. OVERVIEW ON STROKE REHABILITATION FRAMEWORK IN THE PARTICIPATING COUNTRIES

CROATIA

Special hospitals for medical rehabilitation offer rehabilitation programs for both inpatients and outpatients. Additionally, physiatrists and physical therapy offices within primary health centers, speech therapy offices, and private practices within primary health centers creates the facilities for outpatients.

Stroke patients mostly undergo rehabilitation in special hospitals for medical rehabilitation. Patients with motor deficit (with an ICD diagnostic code G81) are entitled to undergo treatment in a special hospital for medical rehabilitation directly after acute stroke treatment and are usually transferred from the acute hospital to the rehabilitation hospital by ambulance transportation, covered by national health insurance.

Patient with non-motor deficits are placed on a waiting list and undergo rehabilitation within weeks or months from the acute event. If a patient is not eligible for treatment in a special hospital for medical rehabilitation or is not able to participate in physical therapy as an outpatient, but is entitled to stroke rehabilitation, he can obtain an in-home physical therapy service, 5 days per week.

Patients with less severe deficits undergo stroke rehabilitation usually as outpatients.

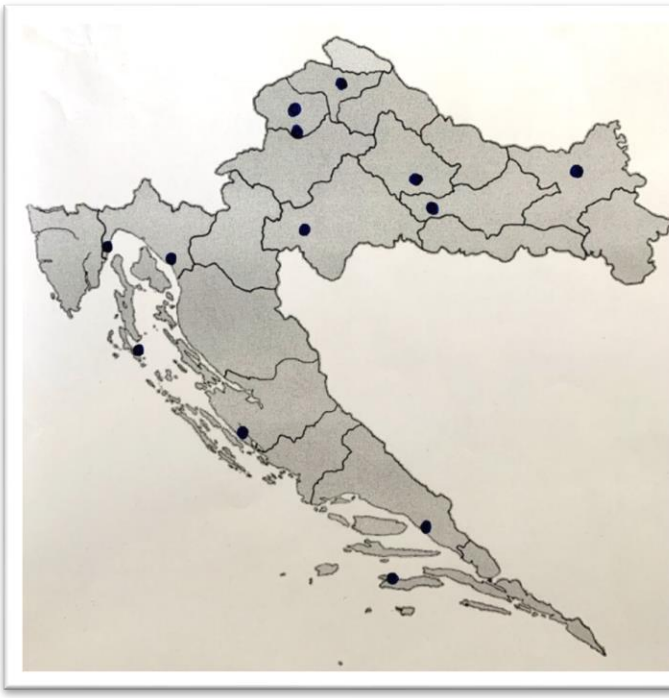
Stroke rehabilitations is covered by the national health insurance. There are thirteen public special hospitals for stroke patients' rehabilitation in Croatia. Patient can undergo rehabilitation as inpatients or as outpatients in every special hospital for stroke rehabilitation. The same hospitals offer private rehabilitation, also.

An example of a standard daily stroke rehabilitation procedure (depending on the deficit) in a special hospital for medical rehabilitation include: neuromuscular re-education - Bobath 45minute, manual massage 20 min, individual hydrogymnastics 30 min + underwater massage 10 min in Hubbard tub, + 2 physical therapy procedures (depending on the neurological deficit), psychologist treatment, speech therapist treatment, occupational therapy 30 min.

Robotic neurorehabilitation is not covered by the national health insurance.

There are four private polyclinics offering robotic neurorehabilitation: two in the capital city – Zagreb, one in the south of the country (Dubrovnik) and one in the eastern part of the country (Bizovacke toplice).

The geographic distribution of rehabilitation is non-homogeneous (see the map). All the special hospitals for medical rehabilitation in Croatia are located in small municipalities and cities with up to 11.000 inhabitants.



Picture 1. Map of public rehabilitation centers for stroke patients in Croatia

€ 85 /per day covered by the national health insurance is the average total price of the complete cycle of out-of- hospital rehabilitation in the public sector for outpatients[50].

The public special hospitals for medical rehabilitation offer private rehabilitation programs, as well. The cost for the private program is the same as the public one, but it is not paid by the national health insurance, but by the patient himself.

[50] Croatian Health Insurance Fund https://www.hzzo.hr/hzzo-za-partnere/sifrarnici-hzzo-a/

Different professionals are involved in the rehabilitation centers:

- Physicians
- Neurologist
- Physiatrist
- Internal medicine specialist
- Cardiologist
- Orthopedic – traumatologist – some centers
- Urologist – some centers
- Radiologists
- Medical laboratory specialists
- Nurses
- Physiotherapists
- Psychologists – some centers
- Occupational therapists – some centers
- Speech therapists – some centers

Professionals are educated at the university level. Stroke rehabilitation topics are a part of the 'Physical and Rehabilitation Medicine' course of Medical Schools in Croatia, including lectures, seminars, and practicums.

Lectures about the pathophysiology of the diseases of the nervous system and disorders of the motor system in stroke, clinical presentation of stroke, description of diagnostical procedures and therapeutic possibilities in stroke, learn to track changes in the clinical presentation during the course of the treatment, to learn to communicate with the patient to increase the quality of treatment.

Postgraduate courses, Doctoral Studies (individualized kinesiotherapy, neurofacilitation, training in neurorehabilitation).

Graduate study of Speech and Language Pathology, Graduate study of Educational Rehabilitation, Postgraduate courses at the Faculty of Education and Rehabilitation Sciences, Postgraduate courses at Sport Science Schools, Graduate and Postgraduate studies at Medical Schools and Study Programme of Physiotherapy.

Although Croatia does not have a national rehabilitation program, there are national stroke rehabilitation guidelines available in the country[51].
Patients associations are not directly involved in the rehabilitation process, but as a mediators and consultants about stroke rehabilitation possibilities.

The major unmet needs in the stroke rehabilitation field in Croatia:
Financial: not enough physical therapy professionals, lack of occupational therapists, all the modalities of physical therapy not available in every center.

Facilities: distribution of facilities is not homogeneous through the country, rehabilitation possibilities not comprehensive in every facility, facilities are not equally available (e.g. for patients in remote and rural areas).

Cultural: a still present fatalistic attitude about stroke treatment in the general population (e.g. a widespread thinking in the general population that the deficit after a stroke cannot be improved).

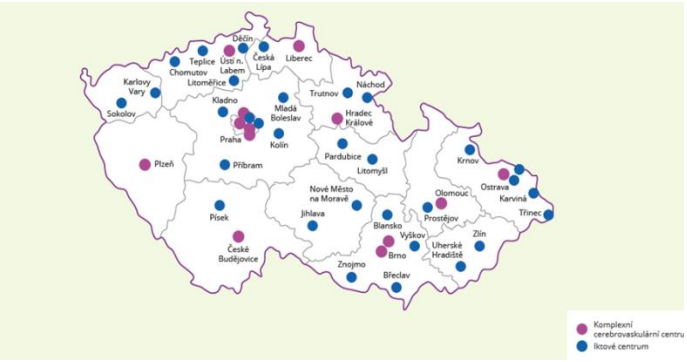
Others: long waiting lists for stroke patients without a motor deficit, non-comprehensive rehabilitation (e.g. lack of speech therapists in some rehabilitation centers), lack of a long term rehabilitation plan, no continuous physical therapy after an acute rehabilitation, no recommendations about long term physical activity.

[51] Schnurrer-Luke-Vrbanić T, V. Avancini-Dobrović V, Bakran Ž, Kadojić D. Rehabilitation guidelines for stroke survivors. Fizikalna i rehabilitacijska medicina, vol.27, br. 3-4, str. 237-269, 2015. [Online]. Dostupno na: https://hrcak.srce.hr/163304. [Citirano: 11.05.2020.]

CZECH REPUBLIC

There are a variety of the in-patient facilities of stroke rehabilitation in Czech Republic, those are: Complex Cerebrovascular Centers, Stroke Centers, Acute Stroke Units, Clinics of Rehabilitation and Physical Medicine, Rehabilitation Institutes, Medical Centers, Aftercare Clinics. And the facilities for outpatients are Clinic of Rehabilitation Medicine, Outpatient Rehabilitation, Specialized Centers, Rehabilitation Associations, Health Resorts, and Home Care.

Geographic distribution of the different rehabilitation centers is homogeneous (see the map below).



Picture 2. Map of public Complex cerebrovascular Centres and Stroke Centres in Czech Republic

Physicians, neurologist, nurses, physiotherapists, occupational therapists, and speech therapists are involved in the rehabilitation process. The aim of Czech Republic is to develop a system of comprehensive rehabilitation. In many centers work interprofessional team, but there are also facilities, where only a few professionals are involved.

Czech Republic does not have a national rehabilitation program, but the “Clinical Guidelines for the Diagnostics and Treatment of Patients with Ischemic Stroke and Transitory Ischemic Attack” were declared in 2012 and updated in the “Clinical Guidelines for the Diagnostics and Treatment of Patients with Ischemic Stroke and Transitory Ischemic Attack -Version 2016.

In addition, the patients’ associations are involved in stroke rehabilitation.

Stroke rehabilitation topics are part of Rehabilitation Medicine study programmes. Students participate 1 week of this subject in the 5 year of studies.

Stroke rehabilitation topics are part of more school subjects (First Aid, Basics of Clinical Medicine, Physiotherapeutic Propaedeutic, Physical Education and Sports for the Disabled, Physical Therapy, Occupational Therapy, Neurology and Pathology, Internal Medicine and Special Methods in Physiotherapy). However, stroke rehabilitation topics are not a part of Sport Science Schools Program.

There are courses or masters dedicated to stroke rehabilitation topics in Czech Republic.

The major unmet needs in the stroke rehabilitation field in Czech Republic are financial, facilitation, and the gaps in legal framework.

GREECE

Stroke care in Greece today is diverse, usually based on an arbitrary patient age limit of 65 years whereby patients with suspected stroke entering the hospital's Emergency Department are routinely assigned to ordinary neurological (patient age <65) or medical wards (patient age >65). Public or private facilities - assessment, treatment, monitoring, physical therapy facilities for inpatients after stroke are provided in Greece. Departments of hospitals or private clinics - rehabilitation therapy program is mainly focused on physical therapy, pool therapy, and speech therapy are provided for outpatients.

Stroke care in Greece is routinely assigned to ordinary neurologic or medical wards. There are 3 different types of settings where a patient with stroke can be admitted to a Greek state hospital. These include a medical ward (MW), a neurology ward (NW), and a specialized stroke bay (SB). The SB is a designated area for stroke care (a small stroke unit) attached to a neurology or medical ward.

These bays have a capacity of 3–6 beds and serve as an integrated part of the corresponding ward where a specific neurologist or internist may have a specialized training (usually from abroad) or special interest in stroke care. The staffing ratio is approximately 8 to 10 patients to each nurse on all of the MWs and NWs, and the ratio is 6:1 on the SB unit.

Treatment in the SB may include thrombolysis and close monitoring. Hence, the vast majority of patients are still admitted to ordinary neurology or medical wards. Yet, even the city inhabitants themselves are not guaranteed access to specialized stroke services due to the unique Greek centralized hospital rotation system whereby pairs of hospitals are on call for consecutive 24-hours periods.

This has been a result of a long-standing centralized infrastructure of the Greek health care system in combination with an imbalance of tertiary versus primary care, only to be made worse due to long-standing recession.

In this context, a unique-to-Greece rotation system for hospital emergencies evolved, whereby hospitals take turns to be on 24-hour duty for new admissions, while the rest of the city hospitals' Accident & Emergencies departments are idle, offering continuing care for in-patients.

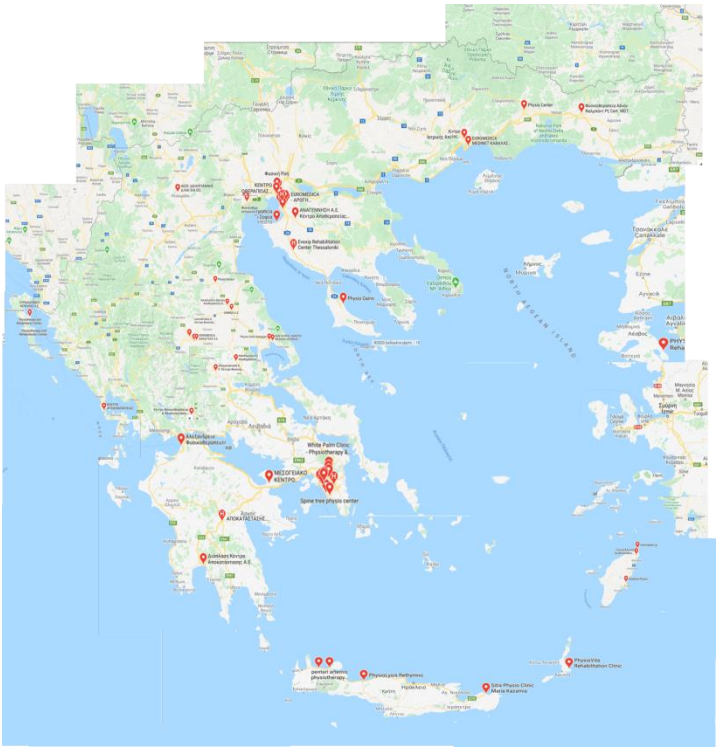
This arrangement creates numerous logistic problems as a hospital may have to face pressure on bed availability and other resources, resulting often in early discharges in order to free beds in anticipation of an influx with the next rotation on-call period.

Even, worse, it might be that none of the SBs is on call and therefore access to specialized stroke treatment is impossible for that particular period.

Thus, although there is some basic stroke infrastructure in Greece, central policies which define ward allocation by age in combination with the rotation system for hospital admission seriously obstructs seamless patient-oriented care.

Greek Rehabilitation Centers are mainly private (19 private vs 5 public) modern health structures with medical and nursing units, specialized medical and rehabilitation equipment, and experienced staff (Physiotherapists, Ergotherapists, Speech therapists, Neuropsychologists, Psychopathologists - Clinical psychologists, Social workers, etc.)

The geographic distribution of the different rehabilitation centers is non-homogeneous (see the map below).



Picture 3. Map of public rehabilitation centers for stroke patients in Greece

Greece has variations in stroke unit care between different regions. Urban areas are usually better provided for than rural areas.

The three smaller cities (Alexandroupoli, Ioannina, and Larissa,) offer advanced stroke care which may be accessed 24/7, whereas in the capital (Athens) and co-capital (Thessaloniki), access to this care is limited due to the hospital rotation process.

Thus, in essence, the “Greek oxymoron” here can be described as follows: regional stroke centers serving a total population of >350,000, offer specialized stroke services 24/7, but the two main cities of a combined population >5 m, that is, half of the country’s total population (11 m), do not meet these standards as despite excellent services in situ, access is restricted due to the centralized hospital rotation system policy in place. Moreover, it should be noted that the rest of the country, accounting for the other half of the population, is essentially left without sophisticated stroke services.

Concerning rehabilitation, the Greek healthcare system allows the uses of a private rehabilitation center. Patients with private or public insurance are fully reimbursed for the cost of all rehabilitation therapy sessions (maximum 80 sessions per year) from the National Health Insurances. Most patients pay for rehabilitation services after discharge, as there are time/session limits on national health provision in rehabilitation centers which are mostly private.

A stroke survivor can be hospitalized in a rehabilitation center for the first six months after the stroke with insurance coverage of the main cost. For an outpatient stroke survivor, there is coverage for physiotherapy program for 10 times/month for the first six months. After rehabilitation, patients' health is improved by 67.05%, has no improvement by 9.25% and is deteriorated by 23.7%.

The average total price of the complete cycle of out-of- hospital rehabilitation in the public sector for outpatients is 6,000 euros.
The average total price of the complete cycle of out-of- hospital rehabilitation in the private sector for outpatients is 14,000 euros.

Physicians, Neurologist, Physiatrist, Internal medicine specialist, Cardiologist, Orthopedic, Nurses, Physiotherapists, Occupational therapists, and Speech therapists are involved in the rehabilitation centers.

However, Greece does not have a national rehabilitation program, nor the national stroke rehabilitation guidelines are available.

Most neurology departments and rehabilitation centers use local protocols based on AHA (American Heart Association) and ASA (American Stroke Association) guidelines. Moreover, patients' associations are not involved in stroke rehabilitation.

However, voluntary organisations support local patients and families with life after stroke.

Stroke rehabilitation topics are a part of the studies at the Medicine School at Aristotle University of Thessaloniki, Faculty of Medicine University of Thessaly, and Department of medicine Democritus University of Thrace.

All departments of Physiotherapy in Greece provide topics concerning stroke rehabilitation. Stroke rehabilitation topics are a part of Sport Science Schools Program as the courses concerning therapeutic exercise and quality of life in chronic diseases. There is a master program entitled "Strokes" in the Department of Medicine Democritus University of Thrace.

The major unmet needs in the stroke rehabilitation field are financial and the poor facilities.

ITALY

Inpatients facilities in Italy are divided into:

- Post-acute units (so called code 56) for standard post-acute rehabilitations.
- Severe post-acute TBI units (so-called code 75) for patients requiring special cares due to the severity of stroke sequelae.
- Rehabilitative long-term care (so-called cod 60) for patients who need rehabilitation together with additional medical diagnosis/ treatments.

Rehabilitative day-hospital, physiotherapy structures, and home delivered rehabilitation are provided for the outpatient rehabilitation. The geographic distribution of the different rehabilitation centers is non homogeneous:

the most part of Neurorehabilitation centers are currently located in the North/North-West Regions (Piemonte, Lombardia, Emilia-Romagna), with a North-South gradient of distribution.

Picture 4. Map of public rehabilitation centers for stroke patients in Italy

Physicians, Neurologists, Physiatrists, Internal medicine specialists, Cardiologists, Orthopedic specialists, as well as Nurses, Physiotherapists, Psychologists, Occupational therapists, and Speech therapists are involved in the rehabilitation centers.

Each region has a regional rehabilitation program following national general rules. National stroke rehabilitation guidelines are available in Italy, national clinical guidelines (SPREAD) have been published by the Italian Stroke Organization (ISO).

In addition, patients' associations are involved in stroke rehabilitation as well.
Stroke rehabilitation topics are a part of Medicine School at the Universities, particularly as regards post-acute phase.

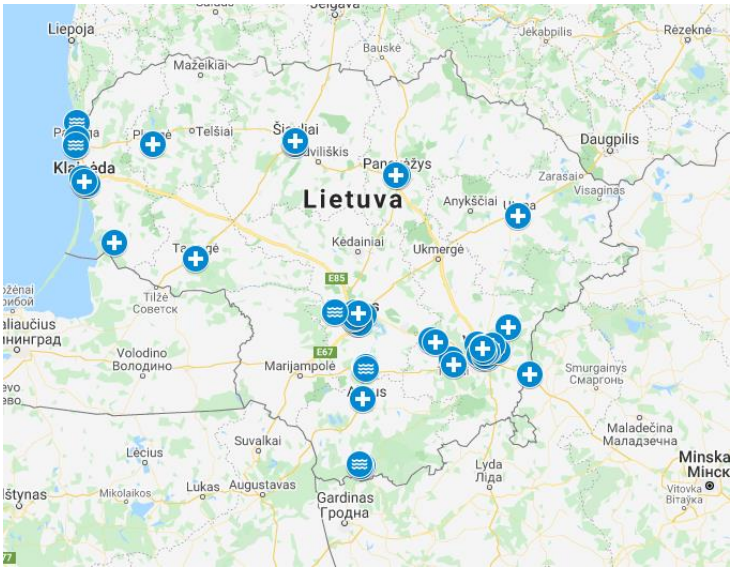
Stroke rehabilitation topics are a part of Physiotherapist Schools Program, particularly as regards therapeutic exercise.

There are as well courses or masters dedicated to stroke rehabilitation topics.

Financial, facilities, and cultural needs are the major unmet needs in the stroke rehabilitation field in Italy.

LITHUANIA

There are various inpatient and outpatient rehabilitation facilities for stroke rehabilitation in Lithuania. They are distributed nonhomogeneously (see map below) and concentrated in big cities.



Picture 5. Map of public rehabilitation centers for stroke patients in Lithuania

The average total price of the complete cycle of out-of- hospital rehabilitation depends on the patient's condition:

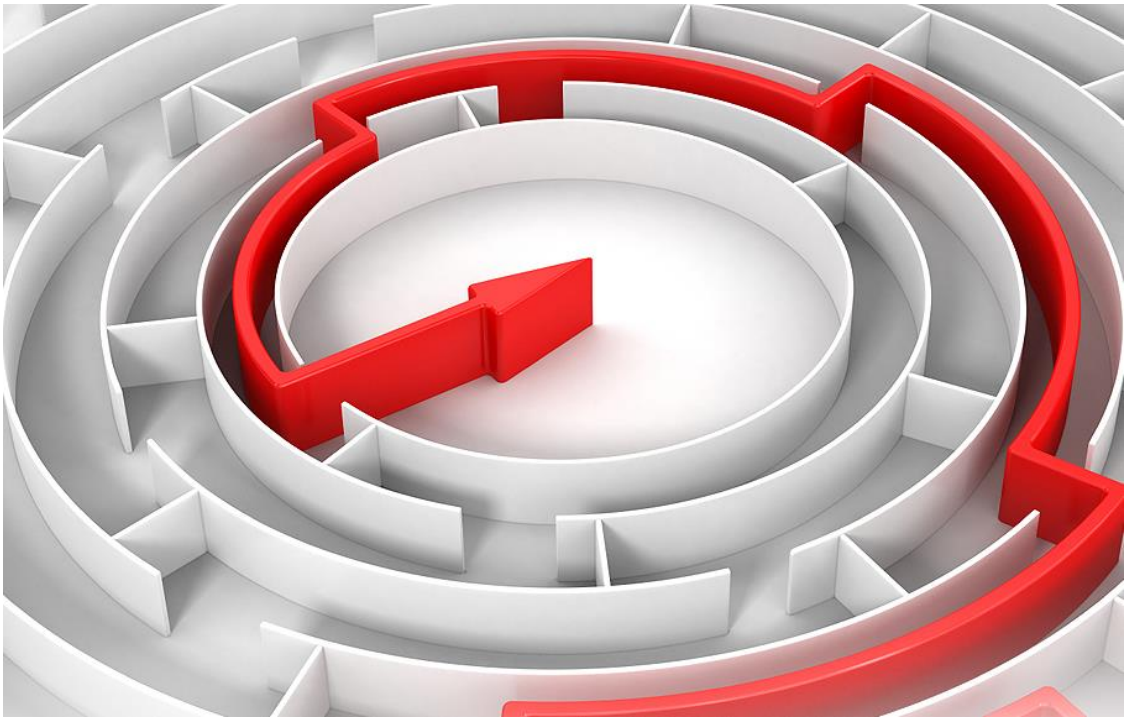
- Complicated condition 3000 euros.
- Moderate condition 1500 euros.
- Uncomplicated condition 1000 euros.

Physicians, Neurologists, Physiatrists, Internal medicine specialists, Sports Medicine specialists, Physiotherapists, Psychologists, Occupational therapists, and Logo therapists are involved in the stroke rehabilitation. If necessary, other specialists (cardiologist, nutritionist, orthopaedist, etc.) can be included in the team.

Lithuania has a national rehabilitation program. There are national stroke rehabilitation guidelines available, and patients' associations are involved in stroke rehabilitation.

Medical universities teach rehabilitation and contemporary methods of rehabilitation. Stroke rehabilitation topics are a part of Physiotherapist Schools Program. In addition, there are study practices in the hospitals and rehabilitation centres on stroke topics.

The courses and masters are dedicated to stroke rehabilitation topics. E.g., Stroke association is implementing various courses and conferences, workshops in neurology are organized regularly.
Financial issues and poor facilities are the major unmet needs in the stroke rehabilitation field.



7. OVERVIEW

Global stroke burden analysis shows that although stroke incidence, prevalence, mortality, and disability-adjusted life-years rates tend to decline from 1990 to 2013, the overall stroke burden in terms of absolute number of people affected by, or who remained disabled from, stroke has increased across the globe in both men and women of all ages.

In 2013, stroke was the second most common cause of deaths (11.8% of all deaths [95% UI, 10.9–13.0%]), after ischemic heart disease (14.8% of all deaths [95% UI, 13.4– 15.8]), and the third most common cause of disability (4.5% of DALYs from all cause [95% UI, 4.1–5.2]) after ischemic heart disease (6.1% [95% UI, 5.5–6.8]).

Although stroke mortality and DALYs rates have declined from 142/100,000 persons/year (95% UI, 129–154) and 2431/100,000 persons/year (95% UI, 2224–2631), respectively, in 1990 to 110/100,000 persons/year (95% UI, 102–122) and 1807 persons/year (95% UI, 1667–1992), in 2013, the absolute number of people who died from stroke, remained disabled from stroke (as measured by DALYs), affected by stroke (as measured by incidence of new strokes), or survived stroke has increased statistically significant (1.4- to 1.8-folds for IS and 1.2- to 1.9-folds for HS).

There were almost 25.7 million stroke survivors (71% with IS), 6.5 million deaths from stroke (51% died from IS), 113 million DALYs due to stroke (58% due to IS), and 10.3 million new strokes (67% IS). The proportional contribution of stroke-related DALYs and deaths due to stroke compared with all diseases also increased from 1990 (3.5% [95% UI, 3.1–4.0] and 9.7% [95% UI, 8.5–10.7], respectively) to 2013 (4.6% [95% UI, 4.0–5.3] and 11.8% [95% UI, 10.5–13.3], respectively).

However, there was a diverging trend in developed and developing countries with a significant increase in DALYs and deaths in developing countries (from 0.9 [95% UI, 0.8–1.0] and 2.1 [95% UI, 1.9–2.4] for DALYs and 3.0 [95% UI, 2.6–3.4] and 5.2 [95% UI, 4.6– 5.8] for deaths in 1990 to 1.7 [95% UI, 1.3–1.9], 2.8 [95% UI, 2.5–3.3] for DALYs and 5.2 [95% UI, 4.2–5.7], 6.4 [95% UI 5.8–7.5] for IS and HS deaths, respectively, in 2013)[52] [53].

[52] The burden of stroke in Europe. Report. 2020. https://www.safestroke.eu/wp-content/uploads/2020/06/The-Burden-Of-Stroke-In-Europe-Report-Main-Document_ENG_All-references.pdf

[53] Béjot Y., Bailly H., Durier J., Giroud M. Epidemiology of stroke in Europe and trends for the 21st century,La Presse Médicale, 2016, 45(12) 2, e391-e398, doi: 10.1016/j.lpm.2016.10.003.

Indeed, over the last two decades the establishment of Stroke Units (SU) and a greater adherence to European stroke guidelines have led to significant decreases for all patients, regardless of age, sex and race for both rates of death and disability[54].

Nevertheless, 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.

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. Therefore, 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.

Despite over thirty years of evidence, 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.

The report states that there is no single EU register of stroke-related indicators. There are also no statistics on primary and recurrent strokes.

Epidemiology

The study involved countries with different general populations: from the smallest in Lithuania to the largest in Italy. Comparing the results of the countries participating in the study, the highest incidence of stroke is in Lithuania, the lowest - in Croatia. In all countries, except Lithuania, men are more likely to be ill. Assessing the mortality rates of the countries, the highest mortality was in Lithuania, and a decreasing trend is observed in all countries

Health system

Health care is funded by public insurance with the option of private insurance or a premium out of pocket. E-health opportunities are not fully developed, cooperation between countries in the primary and specialized services sector is insufficient; and health inequalities are observed with a worse stroke management situation in the periphery. Croatia and Greece do not have a national stroke registry. Unfortunately, there is a lack of specific information on funding models to compare and evaluate stroke prevention, treatment, and rehabilitation options.

[54] Arnao V., Popovic N., Caso V. How is stroke care organised in Europe? La Presse Médicale, 2016, 45(12), e399-e408. Doi: 10.1016/j.lpm.2016.10.004.

Rehabilitation path

Assessing the start of the provision of rehabilitation services, the health-friendly situation is in Lithuania, the Czech Republic and Croatia, where rehabilitation starts from the first day of the stroke.

The situation in Italy is changing, as postponing the start of rehabilitation for more than a month reduces the patient's chances of regaining full mobility and service functions.
The shortest hospitalization time is in Croatia and the longest in Lithuania. Rehabilitation in the post-stroke period is applied in the majority of 70-80% of patients.

Countries have different options depending on the severity of the situation and the patient's preference: rehabilitation wards in hospitals, specialized rehabilitation centers, resorts, outpatient rehabilitation in outpatient clinics or private centers.

There are opportunities to provide rehabilitation services in the patient's home as well. Unfortunately, some countries do not have a rehabilitation strategy and adequate logistics and coordination. There are significant inequalities in access to rehabilitation services in Greece.

There is not enough data to compare logistics routes in different countries.

Too many stroke survivors have to wait too long to get an assessment of their rehabilitation needs and to actually receive physical 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.

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.

It is known from previous research that rehabilitation received by European stroke patients differs.

Variations between countries, but particularly also between different areas within countries, are large. Rural and remote areas often have poor access.

The type and quality of therapies that patients can access often depend on where they live.
Care is especially diverse in Greece.

Countries have inpatient and outpatient rehabilitation facilities, specialized centres depending on the severity of the condition.

The most homogeneous distribution of rehabilitation centres is in the Czech Republic.

Most rehabilitation is covered by health insurance.

Of the reporting countries, Greece has the largest funding, followed by annual sessions for rehabilitation.
The main focus and funds on rehabilitation are given in the first half of the year after the event, and multidisciplinary services are provided, with a strong focus on physical therapy.

Only Greece provides data on the effectiveness of rehabilitation. Some countries have rehabilitation guidelines, but there are no clear post-stroke rehabilitation programs or algorithms; Greece uses the US AHA / ASA guidelines.

Italy and Lithuania also include patient associations in rehabilitation programs.

The data provided lack specific information on the application of physical activity to long-term rehabilitation.
The data show that countries lack post-stroke rehabilitation strategies and tactics. It would be useful to pool the research and knowledge of scientists and prepare an exercise based long-term rehabilitation programme.

Unmet countries' needs

All countries agreed that the greatest unmet needs are financial, i.e. not enough physical therapy professionals and the lack of human resources due to underfunding.

Bad distribution and poor service in some facilities. There is a perception in part of the public that the deficit after a stroke cannot be improved and that the patients themselves do not make the effort.

Other (not categorized) needs are very important as well. Long waiting lists for stroke patients without a motor deficit, non-comprehensive rehabilitation (e.g. lack of speech therapists in some rehabilitation centres), lack of a long-term rehabilitation plan, no continuous physical therapy after an acute rehabilitation, no recommendations about long-term physical activity are the preconditions of poor rehabilitation. Gaps in legal rehabilitation framework need to be completed as well.

8. CONCLUSIONS

There is a lack of standardized indicators of stroke prevalence, prevention, treatment, and rehabilitation. There is very little information on the rehabilitation therapies that stroke survivors receive, especially once they have left the hospital. Few countries audit rehabilitation services, and there are inconsistencies in the standards used to measure adherence to guidelines, the effectiveness of rehabilitation measures is not assessed.

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 with a stronger focus on physical activity. Unmet needs need to be taken into account in order to achieve better survival, quality of life and faster return of a person to the labour market.

9. ANNEXES

Questionnaire completed by each project partner

INDICATIONS FOR THE STUDY OF LITERATURE

Before starting to complete the questionnaire, please, read accurately the following recommendation.

This activity will aim to study the fundamental texts in each participating country concerning Post Stroke Rehabilitation (epidemiology of the disease, stroke rehabilitation path, facilities description, national health system scenario) in order to identify the general framework of the topics taken into consideration.

Please, at the end of the document, once completed it, add a reference list, with the sources you selected as most representative, to complete your history of the research.

For the reference list please follow this order:

- for journals' papers (as minimum): author(s), title, journal year of publication, pages.
- for books: author(s), title, publisher, publication place, year of publication.
- for reports or documents from Institutional sites: Institution, title, publishing, journal (if applicable,) year of publication, and/or URL (if applicable).

An endnote data file with html links or pdf files should be provided.

Once completed the questionnaire for the analysis of the local context, with all the information collected with the study of the literature, if you think some important information is missing and hard to gather with this questionnaire, you can add a short report (maximum 1 or 2 pages, at the end of the questionnaire and before the reference list) with all the key aspects of your country, regarding:

- National Health System organization /structure or
- stroke rehabilitation national regulations, or
- stroke rehabilitation national guidelines, or
- Advocacy organizations,
- etc.

Search strategy:

Study of the literature (scientific journals, grey literature, national reports, etc.) related to each participating Member State to identify the topics of My Way (epidemiology of the disease, rehabilitation path, facilities description, national health system scenario) and allow the understanding of the general framework of the project.

Publications from year 2010 are allowed.

Resources proposed:

- Databases (PubMed, Scopus, Google Scholar, Mendeley, Zotero, Researchgate, etc.)
- Organisations (WHO Europe, ESO, OECD, European Observatory on Health Systems and Policies, national organisations).

ASSUMPTIONS

For comparability between countries, please report data of the **last 3 years available**.

HISTORY OF THE RESEARCH

Sources selected	
Numbers of items recalled	
Numbers of items selected	
Main reason for inclusion	
Numbers of items excluded	
Main reason for exclusion	

SECTION 1: EPIDEMIOLOGICAL DATA

1. Epidemiological data are collected at:

National level

Regional level (please specify_____)

Local level (please specify_____)

2. How many people live in your country?

N (year ____) =

Male/Female % =

≤30 =

30-40 =

40-50 =

50-60 =

60-70 =

70-80 =

≥80=

N (year ____) =

Male/Female % =

≤30 =

30-40 =

40-50 =

50-60 =

60-70 =

70-80 =

≥80=

N (year ____) =

Male/Female % =

≤30 =

30-40 =

40-50 =

50-60 =

60-70 =

70-80 =

≥80=

3. What’s the incidence of stroke in your country?

N/100.000 (year ____) =

N/100.000 (year ____) =

N/100.000 (year ____) =

4. Among patients with stroke, what’s the Male/Female percentage?

(year ____) Male % = Female % =

(year ____) Male % = Female % =

(year ____) Male % = Female % =

5. What is the age at diagnosis (if available)? Percentage by age groups

(year ____)

	Male	Female
<30		
30-39		
40-49		
50-59		
60-69		
70-79		
≥80		

(year ____)

	Male	Female
<30		
30-39		
40-49		
50-59		
60-69		
70-79		
≥80		

(year ____)

	Male	Female
<30		
30-39		
40-49		
50-59		
60-69		
70-79		
≥80		

6. Wat is the rate of the primary stroke events?

N/100.000 (year ____) =

(if available)

N/100.000 males =

N/100.000 females =

N/100.000 (year ____) =

(if available)

N/100.000 males =

N/100.000 females =

N/100.000 (year ____) =

(if available)

N/100.000 males =

N/100.000 females =

7. Wat is the rate of the stroke re-events (secondary, tertiary)?

N/100.000 (year ____) =

(if available)

N/100.000 males =

N/100.000 females =

N/100.000 (year ____) =

(if available)

N/100.000 males =

N/100.000 females =

N/100.000 (year ____) =

(if available)

N/100.000 males =

N/100.000 females =

8. How many patients active working have to retire after stroke?

N/100.000 (year ____) =

(if available)

N/100.000 males =

N/100.000 females =

N/100.000 (year ____) =

(if available)

N/100.000 males =

N/100.000 females =

N/100.000 (year ____) =

(if available)

N/100.000 males =

N/100.000 females =

9. How many patients are no more able to live on their own and need to be hospitalized in nurseries?

N/100.000 (year ____) =

(if available)

N/100.000 males =

N/100.000 females =

N/100.000 (year ____) =

(if available)

N/100.000 males =

N/100.000 females =

N/100.000 (year ____) =

(if available)

N/100.000 males =

N/100.000 females =

10. What is the mortality rate for stroke in your country?

N/100.000 (year ____) =

(if available)

N/100.000 males =

N/100.000 females =

N/100.000 (year ____) =

(if available)

N/100.000 males =

N/100.000 females =

N/100.000 (year ____) =

(if available)

N/100.000 males =

N/100.000 females =

SECTION 2 NATIONAL HEALTH SYSTEM

1. Does your country have a National Health System?

yes

no

unknown

not applicable please specify _____

2. The National Health system in your country is funded by:

Public

Private

Co-payment

3. The National Health system in your country is organized at:

Central level

Regional level (please specify_____)

Local level (please specify_____)

4. Does the National Health system in your country have an organized electronic database with health patients' data?

yes (if the case, add any comments)

_____

_____

no

unknown

not applicable - please specify _____

5. Is a National Stroke registry available in your country?

yes (if the case, add any comments)

_____

_____

no

unknown

not applicable - please specify _____

6. Please provide a brief description of the National Health System in your country:

_____
_

_____
_

_____
_

SECTION 3 STROKE REHABILITATION PATH

1. How many hospitalized patients for stroke received?

N (year ____) =

(if available)

Male % = Female % =

N (year ____) =

(if available)

Male % = Female % =

N (year ____) =

(if available)

Male % = Female % =

2. How much time elapses between the event and the start of rehabilitation in hospital? Before the discharge?

dd (year ____) =

dd (year ____) =

dd (year ____) =

3. What is the average length of hospitalization (between the event and the discharge) in patients who undergo stroke?

dd (year ____) =

dd (year ____) =

dd (year ____) =

4. How many patients are prescribed to continue rehabilitation after the discharge from the hospital?

% (year ____) =

(if available)

Male % = Female % =

% (year ____) =

(if available)

Male % = Female % =

% (year ____) =

(if available)

Male % = Female % =

5. After the discharge, does the rehabilitation take place in (More than one option possible - check all that apply):

Hospitals

Out of hospital

Training facilities

unknown

not applicable please specify

_____

6. After the discharge from hospital, how many patients in percentage take part in rehabilitation as inpatients and how many as outpatients?

(year ____)

In-patients %= Out-patients%=

(year ____)

In-patients %= Out-patients%=

(year ____)

In-patients %= Out-patients%=

7. What is the rate of adherence to rehabilitation programs in people invited to participate in rehabilitation ?

% (year ____) =

(if available)

Male % = Female % =

% (year ____) =

(if available)

Male % = Female % =

% (year ____) =

(if available)

Male % = Female % =

8. How many patients drop out from rehabilitation program?

N (year ____) =

(if available)

Male % = Female % =

N (year ____) =

(if available)

Male % = Female % =

N (year ____) =

(if available)

Male % = Female % =

9. How many patients who undergo rehabilitation pursue individual physical activity after the rehabilitation?

% (year ____) =

(if available)

Male % = Female % =

% (year ____) =

(if available)

Male % = Female % =

% (year ____) =

(if available)

Male % = Female % =

SECTION 4 REHABILITATION FRAMEWORK

1. Is it possible to identify facilities for inpatients and facilities for outpatients?

Yes

If yes:

facilities for inpatients

_____

facilities for outpatients

_____

No

If available, please provide a complete description of all the rehabilitation centers in your country

_____
_____

_____
_____

2. How is the geographic distribution related to your country? (If available, enclose a map pointing out the different rehabilitation centers).

Homogeneous

Non homogeneous

Very few centers

N.A.

3. How is the public/private rate? Public %= Private %=

4. How is the rural/urban rate? Rural %= %=Urban

5. What is the average total price of the complete cycle of out-of- hospital rehabilitation in the public sector for outpatients?

€ _____

6. What is the average total price of the complete cycle of out-of- hospital rehabilitation in the private sector for outpatients?

€ _____

7. Which professionals are involved in the rehabilitation centers? (More than one option possible – check all that apply):

Physicians

- Neurologist
- Physiatrist
- Internal medicine specialist
- Sports Medicine specialist
- Cardiologist
- Orthopedic

- Others _____

Nurses

Physiotherapists

Psychologists

Occupational therapists

Speech therapists

Sport scientists

Trainers

Others _____

8. Does your country have a national rehabilitation program?

yes

no

unknown

not applicable please specify

_____

_____

9. Are national stroke rehabilitation guidelines available in your country?

yes

no

unknown

not applicable please specify

_____

_____

10. Are patients associations involved in stroke rehabilitation in your country?

yes

no

unknown

not applicable please specify

_____

_____

11. Are stroke rehabilitation topics a part of Medicine School at the University?

yes (if the case, add any comments)

_____

no

unknown

not applicable - please specify

_____

_____

_____

12. Are stroke rehabilitation topics a part of Physiotherapist Schools Program?

yes (if the case, add any comments)

_____

no

unknown

not applicable - please specify

_____

13. Are stroke rehabilitation topics a part of Sport Science Schools Program?

yes (if the case, add any comments)

_____

no

unknown

not applicable - please specify

_____

14. Are there in your countries courses or masters dedicated to stroke rehabilitation topics?

yes (if the case, add any comments)

_____

no

unknown

not applicable - please specify

_____

15. What do you think are the major unmet needs in the stroke rehabilitation field in your country? (More than one option possible - check all that apply):

Financial

Facilities

Cultural

Others (please specify) _____

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