

DELIVERABLE NO. 3.6 – SOCIO-ECONOMIC IMPACT OF STROKE SEQUELAE

WP3 Analysis and benchmarking of stroke healthcare pathways

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This deliverable consists of a review of literature on the socioeconomic impact of stroke sequelae. It provides a list of dimensions to be taken into account for the evaluation of the social and economic impact of stroke, as well as an overview of the key dimensions that remain more affected for stroke sequelae.

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ABBREVIATIONS AND ACRONYMS

ERDF	European Regional Development Fund
ICTUSnet	“Excellence R&D network towards the successful development and implementation of innovative models of stroke care strategies”
Interreg	European Territorial Co-operation
Sudoe	Southwestern Europe
REA	Rapid Evidence Assessment
EU	European Union
WHO	World Health Organisation
ESO	European Stroke Organisation
SAFE	Stroke Alliance For Europe
ADL	Activities of Daily Living
FMAS	Fugl-Meyer Assessment
BI	Barthel Index

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EXECUTIVE SUMMARY

ICTUSnet is a project funded by the European Regional Development Fund (ERDF) through the Interreg Sudoe Program, which supports the development of south-west Europe regions by financing transnational projects. ICTUSnet has the mission to create a network of collaboration between different regions of southern Europe formed by patients and professionals from different areas related to stroke and, at the same time, to create research infrastructures that incorporate innovative data analysis technologies to improve stroke care systems and subsequently reduce the impact of the disease on the population. The present deliverable is part of WP3 “Analysis and benchmarking of stroke healthcare pathways” of the ICTUSnet project, which during the course of the project has analysed and compared of the different regional stroke care models, along all stages of the continuum of care (prevention, acute care and rehabilitation).

The overall objective of deliverable 3.6 is to find out what is the socioeconomic impact of stroke sequelae, and more specifically, to identify what is the impact of stroke on (I) the physical activity of stroke patients, (II) the economy of stroke patients, (III) the quality of life (QoL) of stroke patients, (IV) the quality of life (QoL) of stroke patients caregivers, and also to shed light on what is the cost of stroke-disability to healthcare institutions, and in particular in Spain, France and Portugal. In addition, it provides a list of insights on which are the different dimensions to be taken into account when discussing socioeconomic impact of stroke. The methodology used includes a Rapid Evidence Assessment, a research methodology that provides an overview of existing research on a topic and a synthesis of the evidence provided by studies to answer a research question.

1. Introduction

The present deliverable provides an overview of the main dimensions affected by stroke sequelae, together with a framework to evaluate its impacts. The socioeconomic impact of stroke is considerable, with an annual cost in Europe of 57 billion euro in 2017 (Luengo-Fernandez, 2019). Moreover, there are significant variations in the quality of stroke care in Europe. According to the 2016 Global Burden of Diseases, Injuries, and Risk Factors study, there were substantial differences in the burden from stroke across Europe as measured by disability-adjusted life years (DALYs). Stroke ranked first among neurological disorders in terms of age-standardised DALYs in central and eastern Europe, and second in western Europe. Not surprisingly, the socioeconomic impact of stroke is high and is increasing over time (Luengo-Fernandez, 2019).

One of the main challenges towards the successful analysis of the impact of stroke sequelae is that there is a lack of unified data about stroke and stroke outcomes. Thus, Europe-wide comparisons of stroke and stroke care are vital to help each country prevent stroke and provide better care and support for everyone affected by stroke. The present deliverable is based on global and EU-level scientific evidence, and therefore it provides a general overview of the socioeconomic impact of stroke sequelae. However, in order to have a better understanding of the burden of stroke on the ICTUSnet territories (Spain, France and Portugal), it is important to note how healthcare systems are deployed in each country, including an overview of the incidence of stroke on these territories.

With a population of 46,777,373 inhabitants, Spain counts with a decentralised public health system which is free at the point of use. Health budget is distributed at a regional level, and it covers acute and post-acute (rehabilitation and convalescence) care. In Catalonia, social care is separate from health care, as funding comes from municipalities. It is to be noted that the Catalan government has run a Stroke Programme since 2004. Spain has an average of 46.2 strokes 100,000 inhabitants annually, and the case fatality of ischaemic stroke is 10.2 per 100 discharges (Stevens, 2017).

France has a total population of 63,601,002 inhabitants and counts with a national health insurance (national insurance contributions) that covers all medical expenditure. The National Stroke Plan gave additional funding for patients treated in a stroke unit. In France, regional health agencies have a supervisory role with special responsibility for coordination between medical and social services. In addition, telemedicine is well developed in several French regions. France has an average of 46.7 strokes 100,000 inhabitants annually, and the case fatality of ischaemic stroke is 8.5 per 100 discharges (Stevens, 2017).

Lastly, with a population of 10,617,999, Portugal counts with a National health service, financed mainly through taxation, providing public provision of most primary care and hospital care. One-fifth to a quarter of the Portuguese population has voluntary additional health insurance. Portugal has an average of 75.4 strokes 100,000 inhabitants annually, and there are 15,577 deaths due to stroke every year (Stevens, 2017).

2. Methodology

2.1. Objective

Stroke has been reported to have a considerable socio-economic impact worldwide and is the leading cause of the Western world disabilities. In line with the objectives of the ICTUSnet project, the present deliverable builds on a literature review, with the aim of fully capturing the socioeconomic impact of stroke-related disabilities on stroke patients and caregivers. Besides that, it provides a framework to evaluate the socioeconomic impact of stroke for each of the dimensions identified, which are further explained on the following section.

2.2. Review of academic literature

On Deliverable 3.5 *Comparative analysis of resources available for the follow up and rehabilitation of stroke patients*, a scoping review of academic literature was conducted, and 79 articles were screened¹. The exercise resulted on a set of 324 indicators used in the evaluation of stroke rehabilitation and follow-up. After a comprehensive review, a list of 55 dimensions to be taken into account when assessing the socioeconomic impact of stroke were identified (see the full list on Annex 6.1). Subsequently, five dimensions were identified on the severity of stroke sequelae and the progression of recovery, and its impact on stroke patients and caregivers, namely;

- **Physical sequelae**, including motor impairment, cognitive impairments or communication problems.
- **Economic consequences**, including impossibility/delay to return to work or need to reduce the working time/responsibilities.
- **Quality of life sequelae**, including patients' mental health-related quality of life, depression or level of social participation.
- **Caregivers sequelae**, including burden, emotional problems or reduction of working hours.
- **Use and cost of rehabilitation services**, including the economic resources invested on sequelae services.

The identification of these five dimensions informed the second stage of the analysis methodology, described on the following section.

2.3. Rapid Evidence Assessment

In order to collect the most relevant evidence on the topic, a Rapid Evidence Assessment (REA) was conducted. According to the Rapid Evidence Assessment Toolkit index (2013), a REA is a research methodology that provides an overview of existing research on a topic and a synthesis of the evidence provided by studies to answer a research question. Thus, REA lies between literature reviews and systematic reviews in terms of rigour of assessment and are designed to be transparent and to minimise bias (Collins, 2015). The rationale for choosing

¹ Full methodology and report is available at www.ictusnet-sudoe.eu

this evidence review methodology lies in the fact that it can most readily be used to understand the impact either of a ‘pressure’ or a policy intervention without going too much into the details (Collins, 2015).

Additionally, REAs provide a general understanding of the volume and characteristics of evidence available on a certain topic and make it more accessible for further scrutiny, if required. Hence, REAs allow questions to be answered by maximising use of the existing evidence base, whilst also providing a clear picture of the adequacy of that evidence (Collins, 2015). The full methodological approach is described on Table 1, and further explained below.

Table 1. Rapid Evidence Assessment methodological approach

<p>Stage 1. Protocol development</p> <ul style="list-style-type: none"> ▪ Identify the research questions ▪ Determine search terms and strategy to develop the initial pool of literature and sources to be searched ▪ Define inclusion and exclusion criteria for studies (including time period and geographic area) and basic criteria against which documents will be selected (strength of evidence, relevance and level of academic) ▪ Set up information management processes, including bibliographic software to ensure clear recording of identified literature
<p>Stage 2. Identification and selection of the relevant sources</p> <ul style="list-style-type: none"> ▪ Develop the initial pool of literature ▪ Review titles and abstracts against inclusion/exclusion criteria ▪ Implement a snowballing approach by reviewing bibliographies of the identified literature for further sources
<p>Stage 3. Data extraction</p> <ul style="list-style-type: none"> ▪ Review literature, identifying the relevant content, depending from the sub-task that needs to be fed, and assessing these against basic feasibility criteria ▪ Extract, record and collate the relevant measures and associated contextual and background information where available using a standardised reporting tool
<p>Stage 4. Data analysis</p> <ul style="list-style-type: none"> ▪ Analyse the results to understand themes and trends and inform selection of stakeholders to be involved in primary data collection activities ▪ Synthetise and report the main findings of the review

Source: Author’s elaboration

As explained on section 2.1, the objective of this study is to shed light on the socioeconomic impact of stroke-related disability both on stroke patients and caregivers. After conducting the review of academic literature and identifying the five dimensions of study, the following overall and specific research questions were established (see Table 2).

Table 2 Research questions

<p>Overall research question</p> <ul style="list-style-type: none"> ▪ What is the socioeconomic impact of stroke?
<p>Specific research questions</p> <ul style="list-style-type: none"> ▪ What is the impact of stroke on <ul style="list-style-type: none"> the physical activity of stroke patients? the economy of stroke patients? the quality of life (QoL) of stroke patients? the quality of life (QoL) of stroke patients caregivers? ▪ What is the cost of stroke-disability to healthcare institutions?

Source: author's elaboration

The search terms are the key words and phrases selected to be used in the databases (PubMed, Scopus and Google Scholar) to identify relevant sources and documents that inform the abovementioned research questions. The set of terms and search strings used for the present study are listed on Table 3.

Table 3 Terms used to conduct the REA

Research questions	Terms
What is the impact of stroke on the physical activity of stroke patients?	stroke AND sequelae OR limitations OR restrictions OR disability OR handicap OR disorders OR deficits OR impairment OR function OR independence OR morbidity OR consequences OR problems AND Indicators OR evaluation OR impact OR effect OR assessment AND motor impairment OR cognitive impairment OR communication problem OR ICF OR International Classification of Functioning OR upper limb OR arm function OR spasticity OR speech impairment OR language impairment OR swallowing impairment OR vision impairment OR fatigue
What is the impact of stroke on the economy of stroke patients?	stroke AND sequelae OR limitations OR restrictions OR disability OR handicap OR disorders OR deficits OR impairment OR function OR independence OR morbidity OR consequences OR problems AND Indicators OR evaluation OR impact OR effect OR assessment AND costs OR burden OR economic OR financial OR productivity OR earnings OR income OR work OR employment OR return to work OR work re-entry OR payment OR handicapped worker
What is the impact of stroke on the quality of life (QoL) of stroke patients?	stroke AND sequelae OR limitations OR restrictions OR disability OR handicap OR disorders OR deficits OR impairment OR function OR independence OR morbidity OR consequences OR problems AND Indicators OR evaluation OR impact OR effect OR assessment AND mental health OR quality of life OR QoL OR depression OR socialization OR Disability Adjusted Life Years OR DALY OR social participation OR social relations
What is the impact of stroke on the quality of life (QoL) of stroke patients caregivers?	stroke AND caregiver OR carer AND indicators OR evaluation OR impact OR effect OR assessment AND emotional problems OR burden OR work OR depression OR quality of life OR QoL OR mental health OR informal care/unpaid care
What is the cost of stroke-disability to healthcare institutions?	stroke AND sequelae OR limitations OR restrictions OR disability OR handicap OR disorders OR deficits OR impairment OR function OR independence OR morbidity OR consequences OR problems indicators OR evaluation OR impact OR effect OR assessment AND economy OR policy OR healthcare system OR public health

Source: author's elaboration

REAs are carried out more speedily than systematic reviews but they are not less rigorous when it comes to determining conceptual boundaries. Thus, the inclusion criteria for the present study involved (I) publications that fed the research questions guiding the present study, (II) documents that were published after 2010, (III) systematic reviews or studies conducted at an EU level, and that (IV) were available in English. Exclusion criteria was applied to publications that did not inform our focus of study directly or did not provide robust evidence on the topic. The REA involved the identification of core literature, to subsequently conduct a snowballing exercise. The snowballing research technique involved reviewing bibliographies of most relevant literature to identify further relevant literature.

In order to manage records and data throughout the review, track of the records identified were kept for each search string and data base using an importation of citation feature usually available for the databases. Records were kept for all articles by retrieving references and recording them in an excel file. All articles that qualified for inclusion on the basis of title and abstract screening against the inclusion criteria were loaded to Mendeley.

In order to structure the review of the documents, and to ensure all relevant data to answer the research questions is captured in a consistent and comparable way, a data extraction template was used to capture information from reviewed full texts. This tool, which consists in a Excel Spreadsheet, will be structured around the objectives for the rapid evidence assessment and will include sections specifically tailored to a thorough investigation of relevant topical areas and a section on the main characteristics of the reviewed source. The template will feed directly into the synthesis process of available evidence. The data for each source will include the information reported on Table 4.

Table 4 Data extraction template (Analysis grid)

Narrative synthesis summary data	
1	Study details (author, year, title, source)
2	Dimension
3	Abstract
4	Country
5	Relevance
6	Full reference

Source: author's elaboration

Summary data for all relevant literature to be reported was closely linked with the initial aims and research questions guiding this rapid evidence assessment. The use of the data extraction template ensured the REA remained focused, and that information from diverse sources was collated in a manner to facilitate clear comparison across the literature and identify emerging themes. The free text structure of the template means that information relevant to the objectives can be added whether this relates to a specific practice or intervention (e.g. an evaluation report) or a general overview (such as a foresight study).

The research team conducted an assessment of the quality of qualitative and quantitative evidence and a deep understanding of limitations and strengths, and therefore making informed judgements about the extent to which the findings and data can be relied upon in answering the research questions. To this end, a critical review of all the literature selected of the final review was conducted. This type of review aims at evaluating the strengths and weaknesses of the previous work conducted based in the new approach to the study.

The criteria for selecting key literature were based on the analysis of the topic tackled as well as on the relevance of the publication. After agreeing on the core literature, additional literature was collected by performing snowballing and by screening the results by title and by abstract against the inclusion criteria. Items that did not meet the inclusion criteria were discarded.

3. Socio-economic impact of stroke sequelae

3.1. Physical sequelae

Stroke is one of the most impactful diseases in the world. In fact, the WHO reports that stroke is the leading cause of acquired disability, the second leading cause of dementia and the second leading cause of death. Besides that, stroke is considered a major cause of epilepsy, falls and depression (Schnitzler, 2017). According to the ESO & SAFE (2018), among the different disabilities that stroke survivors may suffer, 30% of them will be linked to communication, while 50% will be related to cognition issues and 50-85% to motor function impairments. Certainly, while there are several impairments caused by stroke, motor impairment is the most widely recognized, restricting function in muscle movement or mobility (Langhorne, 2011).

Stroke survivors are commonly reported to experience a wide range of negative physical and mental consequences (Stevens, 2017). These are often long-lasting and can have a large impact on the lives of patients and their families. Many stroke patients have problems with mobility, fatigue, speech, memory and/ or emotions among others and need support from one or more therapy areas (such as physiotherapy, speech therapy, occupational therapy and/or psychology). After 15 years, two-thirds (63%) of survivors are living with disability, nearly two in five (39%) have depression and over a quarter (30%) have cognitive impairment. Furthermore, stroke patients are much more likely than people who have not had a stroke to be living with another illness. **Thus, small percentage of stroke patients are independent in basic activities of daily living (ADL), while a majority will have to rely on human assistance for ADLs like feeding, self-care and mobility.** Nevertheless, the situation has improved over the past years.

While the interdisciplinary character of stroke rehabilitation is paramount, the availability of specific, up-to-date, and professional evidence-based guidelines for the physical therapy profession is crucial for making adequate evidence-based clinical decisions. Veerbeek (2014) studied stroke rehabilitation interventions in the domain of physical therapies, identifying different categories, namely; interventions related to gait and mobility-related functions and activities, including novel methods focusing on efficient resource use, such as circuit class training and caregiver-mediated exercises; interventions related to arm-hand activities; interventions related to activities of daily living; interventions related to physical fitness.

According to Richards (2015) **one of the main challenges towards physical recovery relate to impairment, activity and participation to generate strong evidence**, which hinder the uptake of best-practice recommendations. That is because research efforts are challenged by many factors, including difficulties in patient recruitment and small sample sizes, the heterogeneity of impairments after stroke and the complexity of their interactions with factors affecting recovery and the limited collaboration between scientists, clinicians, patients and their carers, community stroke organizations, and industry (Richards, 2015).

3.2. Economic consequences

Stroke also entails indirect economic costs related to the impact of sequelae on the work productivity of stroke patients (Doucet, 2012). Although the incidence of stroke increases with age, this affliction also affects adults of working age since a quarter of stroke victims are under the age of 65 and about 15% of the patients are under 55 years old (Doucet, 2012). The return to work rates range from 14 to 73% and the post-stroke time interval to work re-entry also varies. An analysis of systematic reviews conducted by Doucet (2012) identifies the different factors that are likely to influence the return to work rate. These include demographic factors (such as age and gender), medical parameters (such as the type and site of the stroke and the type and gravity of the sequelae) and social factors (such as the educational level and the socio-professional category). However, the true impact of these factors on the return to work is subject to debate. Furthermore, the question arises as to the role of the occupational physician and the organizations that seek to promote work re-entry for brain-damaged people.

Vocational rehabilitation programs are in some cases available for stroke patients, which help them return to or remain in work or volunteering. For patients who are deemed unable to return to work, health care teams should assist patients with completing temporary disability forms or long-term disability forms (Belagaje, 2017). In fact, Rozon (2015) found that depression was significantly higher in patients unable to return to work compared to those who returned to work.

Employment provides stroke patients with financial independence and full integration into society, and also improvement in self-esteem and confidence. Clinicians often concentrate on the severity of physical and cognitive impairments when considering a patient's ability to return to work. However, studies have demonstrated that other factors, such as younger age, educational level, level of skill, and pre-stroke professional status, appear to be strong influencers of a patient's ability to return to work. In line with these results, Terrill (2018) found that patients from lower socioeconomic backgrounds and in unskilled work were less likely to return to work successfully after a mild stroke, even though further research is needed to understand the reasons for this finding.

In fact, the association between socioeconomic status and stroke incidence, survival, mortality, and other outcomes has been studied by several authors. **Evidence shows a strong association for mortality and incidence of stroke, with high rates of stroke in low socioeconomic groups being a consistent finding.** According to Cox (2006), low socioeconomic groups also have lower survival and greater stroke severity than high socioeconomic groups, although there is less evidence for this association. The authors state that the mechanisms through which socioeconomic status affects stroke risk and outcomes are unclear, although some studies report that differences in risk-factor prevalence could account for some of the variation. We discuss the implications of these findings and make recommendations for future research. Studies using prospective population-based methods

with improved control for confounding factors are needed to confirm or refute these associations.

3.3. Quality of life sequelae

The long-term effects of a stroke affect the quality of life of community-dwelling stroke survivors and their ability to participate in life roles. Jørgensen (1995) found in a large cohort in Denmark that functional recovery, assessed with the Barthel Index, attained a plateau within 12.5 weeks from stroke onset in 95% of the patients. More recently, Verheyden (2008) reported that the most striking improvement, as measured by serial clinical measures (FMA and the BI) occurred between 1 week and 1 month after stroke onset with median improvements of 16% for FMA and 30% for BI. Further significant, but smaller improvements, occurred between 1 and 3 months poststroke. The study reflected that 50% of the patients had no further improvement or deterioration 1 month after the stroke occurred, and that there were no significant changes between 3 and 6 months after stroke (Richards, 2015). The literature reflects a nihilistic view about what clinically relevant changes are possible after the early post-stroke phase. However, Ward (2019) reported that with intensive upper limb rehabilitation, chronic stroke patients can change by clinically important differences in measures of impairment and activity. Crucially, clinical gains continued during the 6-month follow-up period.

As explained on previous sections, a significant number of stroke survivors have disabling motor, cognitive, or language deficits. **Dysphagia**, which can be life-threatening, affects about 55% of stroke victims, while **impairments of cognition** occur in 25–65% of subjects, depending on when evaluated. Furthermore, 40% of stroke survivors suffer of **excessive fatigue**, 20–50% have pain. Many have **mood and sleep disorders** and suffer from **anxiety and apathy** which affect recovery and participation. On some occasions, stroke patients lack “**walking competency**” a term used to describe a level of walking ability that allows an individual to successfully navigate in their community.

Depression is also increasingly recognized as a common sequela of stroke affecting Quality of Life. The prevalence of clinically diagnosed post-stroke depression ranges from 20% to 40%, and it is likely underdiagnosed. Depression symptoms include fatigue, reduced motivation, loss of confidence, and attention and concentration difficulties, which limit the benefits of rehabilitation and can even counteract them (Belagaje, 2017). Poststroke depression (PSD) is a common complication that occurs in approximately one-third of stroke survivors. PSD is characterized by symptoms consistent with depression, including low mood, anhedonia, changes in appetite, concentration, decreased energy, and change in sleep (Terrill, 2018). In addition, Tessier (2012) explains that stroke survivors find it difficult to go back to their previous leisure activities, as well as to start new ones, which can lead to depression and feelings of exclusion from social life.

According to Belagaje (2017), **stroke survivors are often restricted in their driving ability** because of hemiparesis, visual field, cognitive, and coordination deficits, and post-stroke seizures. A clearance to return to driving should involve both a medical clearance and a

functional assessment clearance. However, more complex aspects of driving, such as planning, motor coordination, and reaction times, are difficult to ascertain in the office. The authors suggest that a formal driving assessment could be helpful to evaluate these skills and could be conducted on a driving simulator or by in-car evaluation by a specialist assessor.

As we can see, stroke sequelae and its consequences on the quality of life have been assessed on different studies, however, there is not much evidence on post-stroke sequelae in the population of patients living at home and having been managed in stroke units (Broussy, 2019). In order to tackle the high variability of results found on stroke sequelae studies Broussy (2019) conducted a multidimensional approach to assess the frequency and type of deficiencies with a focus on their daily-life consequences in a cohort of patients who are living at home 1 year after stroke having been managed in stroke units in France. Results show that pain and fatigue represented the main persistent symptoms, while cognitive and neuropsychiatric disabilities were observed in about 20% of the population. In addition, despite an overall good functional outcome, patients who were independent in their daily-life activities had multidomain impairment in participation and a lower level of quality of life scores compared to the general population at the same age range in France (Broussy, 2019). Thus, **results suggested that the rate of “invisible handicap” was persistent across patients independently from stroke severity.** Interestingly, a high rate of invisible deficiencies identified in the study was observed despite an initial acute management of these patients in a stroke unit, that should have ensured optimal outcomes. Despite real improvement in the access to stroke units in Europe, about 4% to 50% of stroke patients are not admitted to stroke units. Thus, the rate of invisible handicap in this population might be even higher than in the analysed cohort, and highlight the need to build dedicated workflow for all stroke patients to improve their outcome (Broussy, 2019).

3.4. Caregivers sequelae

Informal caregivers are crucial for the ability of survivors to recover and adapt to life after stroke. However, this substantial commitment has been reported to restrict caregiver’s personal freedom and affect quality of life and well-being. In fact, depression prevalence ranges from 30% to 52% for caregivers. On a study conducted by Sennfalt (2019), survivor dependency was shown to be a key factor associated with poor outcomes for caregivers. That is, over half of caregivers to completely dependent survivors reported poor psychological well-being. Results especially emphasized the needs of this group where 41.1% of survivors could not be left unattended for more than 1 hour at a time and 23.7% of caregivers reported unmet needs of caregiver support.

In addition, another dimension of study is the amount of time that caregivers allocate to stroke patients. **Caregiver assistance might amount to, on average, about 9 to 17 h per week in the first year after stroke** (Sennfalt, 2019). Persson (2017) measured the time spent providing support to dependent survivors of stroke, which was subdivided into two components, namely: (I) practical support, resulting in 35 hours per week and (II) being available, which

resulted in 66.5 h per week, which sheds light to the underestimated activities undertaken besides actively providing assistance.

As for the costs associated to caregivers, **the estimated economic burden of informal caregiving per stroke survivor during the first year ranged from €3,100 to €7,600** (Persson, 2017). However, the quantity or cost of informal support has only been estimated in a short-term perspective and based on activities in daily life. Persson (2017) conducted a study in Sweden to identify and quantify the amount of support provided by spouses to their midlife stroke surviving partner 7 years after stroke onset, as well as and to estimate the annual long-term cost of the spouses' informal support. Results showed that the estimated hours per day of support provided by spouses of independent and dependent stroke survivors were 0.63 and 14.51 hours per day, respectively. The estimated annual cost of informal support provided for dependent stroke survivors was 25,127€ and for independent stroke survivor 991€. It is to be noticed that, the fact results were expressed in EUR (€) hinders a comprehensive understanding of real cost across countries. Thus, in order to properly analyse the level of life across countries, the amount of costs should be expressed in relative indicators.

On its study, Mackenzie (2012) identified positive experiences of caregivers, who are unpaid carers not statutory, looking after stroke survivors by systematically reviewing published quantitative and qualitative studies. Results showed that caregivers are able to identify what they value providing a more positive and balanced view of caregiving experiences other than just negative aspects. In addition, positive aspects of coping are associated with positive experiences. Finally, offering training to caregivers of a cognitive and behavioural nature, which includes a focus on positive experiences, may be beneficial and needs further consideration.

On another front, the Royal College of Physicians (2015) highlight that **information and training for stroke survivors and their caregivers can provide an understanding and allow patients to be involved in making decisions regarding their treatment options**. Some of the information that could be provided to patients are the patient versions of national and local guidelines/standards, the available Social Services and local Community Care arrangements, information about information relating to the Department of Work and Pensions, information on stroke, Secondary prevention advice and information about patient organisations.

3.5. Use and cost of stroke disability to healthcare institutions

The economic impact of stroke is high and is increasing over time. According to the latest report published by the Stroke Alliance for Europe in 2017, the total cost of stroke in 2015 was calculated as 45€ billion in the EU, while on the latest study by Luengo-Fernandez (2019) this cost was 57 billion euro, being the four most populous countries – Germany, France, Italy and the UK – which accounted for 63% (38 billion euro) of all costs. In 2015, 44% (20€ billion) was used for direct health care costs. Within these direct health care costs, 72% were for in-hospital care and 7% for drugs. In the EU, these costs per capita vary widely, from 132€ in Finland to 7€ in Bulgaria.

In the ICTUSnet countries, the healthcare cost of stroke varies considerably, with 27€ per capita (1,244.8€ million overall) in Spain, 30€ per capita (1,973.2€ million overall) in France and 15€ per capita (159.7€ million overall) in Portugal. This is an interesting finding, given that the incidence estimate in Portugal (75.4 strokes per 100,000 inhabitants) is higher than in France (46.2 strokes per 100,000 inhabitants) and Spain (46,2 strokes per 100,000 inhabitants).

However, the crude incidence rate of stroke included in Stevens (2017) demonstrates that **there is no association between national per-capita spending and the national rate of new strokes**. As for the overall health expenditure spent on stroke, it also varies between European countries, although the proportions vary less between countries than the stroke-specific expenditure per capita. Thus, the amount of money spent on stroke depends on the significantly different overall national healthcare budgets, but also on varying allocations within that budget.

According to Stevens (2017), **most studies measuring the cost of stroke only look at direct health care costs**, which underestimates the total cost of stroke since it does not take into account non-health care costs including informal care (the opportunity cost of unpaid care provided by family or friends), or productivity lost due to death or disability. In fact, informal care costs alone were estimated at 15.9€ billion or 35% of the total cost of stroke in the EU in 2015. Productivity losses were estimated to be 5.4€ billion or 12% for losses due to death and 4€ billion or 9%, for losses due to morbidity.

In line with this, Matchar (2015) modelled long-term post-stroke resource using the Survey of Health, Ageing and Retirement in Europe (SHARE) with data from 2004-2007. They categorized countries into 3 geographical regions, namely: Northern (Sweden, Denmark, and Ireland), Central (Austria, Germany, The Netherlands, France, Switzerland, Belgium, Czech Republic, and Poland), and Southern (Spain, Italy, and Greece). The study took into account the number of hospital days, hours of paid home nursing, hours of paid home help and unpaid home caregiving hours (informal help from family members or other informal caregivers). Results showed that **post-stroke resource use was strongly associated with ADL limitations**.

After accounting for the probability of service use and its intensity, Matchar (2015) found that **greater functional dependence would require a considerable increase in consumption of poststroke resource across all health services analyzed**. Compared with those without any limitations, those with severe ADL limitations spent, on average, 1.45 more days in the hospital, used 14.86 more hours of paid home nursing, and required 100 more hours of informal help per month. The predicted number of hours for paid home nursing and paid home help was similar among individuals with moderate and severe ADL limitations. In addition, they found that greater age only significantly affects the utilization of paid home help and informal care, while as for the gender, results showed that women used significantly less paid home nursing, paid home help, and informal help.

Among those with ADL limitations, Matchar (2015) observed relevant regional differences in informal help utilization. That is, **Southern Europeans tend to use home-based service**

(unpaid and paid) more readily than inpatient service than Northern and Central Europeans.

Thus, the study enforced the North–South gradient of family dynamics in Europe; the Scandinavian countries generally have the least traditional family structure, whereas the Southern European countries present the culture of strong family responsibilities, for instance, where family members are expected to supply caregiving, with the other continental countries lying somewhere in between.

When analysing the cost of stroke in the different Member States and especially the ICTUSnet regions one faces difficulties to directly compare the estimates to other cost analyses due to a variety of methods used, definition of cost components included and patient population considered. Direct comparison of overall cost estimates across studies conducted in different countries is inevitably influenced by the country specific unit costs used for the evaluation of resources. Thus, a more meaningful and informative comparison can be done with physical units of resources used and relative weight of different cost categories (Fattore, 2012).

The economic burden of stroke is borne by society as a whole via tax payments and insurance contributions, but significantly also by the individual stroke survivors and their families and friends. On the report of the Stroke Alliance for Europe (Stevens, 2017), it is stated that the number of strokes and the number of stroke survivors is expected to increase over the coming decades. Thus, economic impact of stroke will need more attention with regards to effective health care planning and resource allocation as well as the financial burden borne by stroke survivors and their family and friends.

To conclude, on a new publication by Luengo-Fernandez (2020) makes a prediction of the costs of stroke in 2030, 2035 and 2040 by estimating the future incidence and prevalence of stroke. The projected number of stroke was projected to rise from 9 million in 2017 to 11 million in 2030 (+21%), 11.5 million in 2035 (+29%) and 12 million in 2040 (+12%), while the number of people suffering a stroke for the first time was predicted to increase from 1,5 million in 2017 to 1.8 million in 2030 (+23%), 1.9 million in 2035 (+32%) and 2 million in 2040 (+41%). The study estimated that the overall costs of stroke per citizen would rise by 25€ in 2030, by 33€ in 2035 and by 42€ in 2040. Given that health and social care systems already suffer from the burden caused by the costs from stroke care, European countries should implement interventions and policies that try to mitigate these cost increases. According to Luego-Fernandez (2020), this should be done while also maximising the health outcomes and quality of life of stroke patients.

4. Conclusions

Stroke is the leading cause of acquired disability, the second leading cause of dementia and the second leading cause of death. Thus, stroke survivors are commonly reported to experience a wide range of negative physical and mental consequences. As a consequence, only a small percentage of stroke patients are independent in basic activities of daily living (ADL), while a majority will have to rely on human assistance for ADLs like feeding, self-care and mobility. One of the main barriers towards evidence collection for the improvement of physical recovery includes difficulties in patient recruitment and small sample sizes, the heterogeneity of impairments after stroke and the complexity of their interactions.

In addition, stroke also entails indirect economic costs related to the impact of sequelae on the work productivity of stroke patients. It has been reported that employment provides stroke patients with financial independence and full integration into society, and also improvement in self-esteem and confidence. In addition, socioeconomic status matters during stroke recovery, as low socioeconomic groups also have lower survival and greater stroke severity than high socioeconomic groups.

All these physical and occupational burdens affect the quality of life of stroke survivors and their ability to participate in life roles, as a significant number of stroke survivors have disabling motor, cognitive, or language deficits. Depression is also increasingly recognized as a common sequelae of stroke, which has a direct impact on patient's lives. Thus, rehabilitation strategies focused on participation should be developed to break the vicious circle of social isolation and improve quality of life.

Stroke sequelae also impacts caregivers, representing a relevant amount of time which on average is from 9 to 17 hours per week in the first year after stroke. In addition, the estimated economic burden of informal caregiving per stroke survivor during the first year ranges from €3,100 to €7,600. In order to reduce the burden, information and training for stroke survivors and their caregivers can provide an understanding and allow patients to be involved in making decisions regarding their treatment options. Also, caregivers' experiences (both positive and negative) should be taken into account by clinicians when supporting them.

The present document has shown the great social and economic impact of stroke. Given the latest new medical and technological advances in healthcare, it is important to mention the need to identify and implement eHealth interventions that have been proven to be cost-effective through robust evidence. The use of these new technologies could decrease the burden of stroke in all the dimensions described under this report. Thus, innovative interventions/devices in the field of stroke care could go through a cost-effective analysis to test their scalability and, if positive, reduce the burden worldwide. These types of analyses

can be done through MAFEIP², a web-based tool that estimates health and economic outcomes of a large variety of ICT-enabled social and health interventions.

Lastly, the use and cost of stroke disability is high among healthcare institutions, and it is increasing over time. In the ICTUSnet countries, the healthcare cost of stroke varies considerably, with 27€ per capita (1,244.8€ million overall) in Spain, 30€ per capita (1,973.2€ million overall) in France and 15€ per capita (159.7€ million overall) in Portugal. Given the estimated increase in the cost of stroke in Europe (Luengo-Fernandez, 2020), SAFE recommends European countries to adopt and implement national stroke plans, to invest in stroke prevention, service provision and research, as well as accurately collect comparable data.

As for the latter, in order to reduce the burden of stroke sequelae, it is crucial to make accurate comparisons between different countries, populations and health systems. To do so, it is of utmost relevance to achieve agreed and coordinated Europe-wide data collection methodologies, that enable the assessment of care quality along the whole stroke pathway. In this regard, the list of dimensions included on the Annexes of the present document could be a valuable tool, which can guide decision makers on the type of data that could be included on electronic health records, to better measure the socioeconomic burden of stroke across healthcare systems.

² Monitoring and Assessment Framework for the European Innovation Partnership on Active and Healthy Ageing (MAFEIP). Available at: <https://www.mafeip.eu/>

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6. Annexes

6.1. List of dimensions

	Dimension	Sub-dimension
1	Physical sequelae	International Classification of Functioning, Disability and Health (ICF). Values for stroke survivors (when leaving acute care; after a specific period: 1 month, 6 months, 1 year, 5 years, etc.)
2	Physical sequelae	Stroke severity computed using the National Institutes of Health Stroke Scale (NIHSS)
3	Physical sequelae	Stroke severity computed using the Canadian Neurological Stroke Scale (CNSS)
4	Physical sequelae	Stroke severity computed on the basis of functional independence measure (FIM) scores
5	Physical sequelae	Stroke severity computed on the basis of the AlphaFIM (an abbreviated 6-item version of the 18-item FIM instrument)
6	Physical sequelae	Système de mesure d'autonomie fonctionnelle (SMAF) as a measure of functional independence
7	Physical sequelae	Fugl-Meyer Assessment Scale (FMAS)
8	Physical sequelae	Barthel Index (BI)
9	Physical sequelae	SAFE score (shoulder abduction finger extension, range 0–10) to predict the potential for upper limb recovery in individual patients
10	Physical sequelae	Modified Rankin Scale (mRS)
11	Physical sequelae	Berg scale
12	Physical sequelae	Motor Index Score (MIS)
13	Physical sequelae	Trunk control test
14	Physical sequelae	ADL scale to assess patients' autonomy or disabilities
15	Physical sequelae	IADL (Instrumental. Activities of Daily Living)
16	Physical sequelae	SOFMER scale to assess patients' autonomy or disabilities
17	Physical sequelae	AGGIR scale to assess patients' autonomy or disabilities

18	Physical sequelae	Glasgow Coma Score (CGS)
19	Physical sequelae	Charlson score of co-morbidities
20	Physical sequelae	Orpington Prognostic Scale (OPS)
21	Physical sequelae	Scandinavian Stroke Scale (SSS)
22	Physical sequelae	Score of physical dependency (dressing, displacement and locomotion, eating, incontinence)
23	Physical sequelae	Gait speed
24	Physical sequelae	% of patients who suffer loss of arm function
25	Physical sequelae	% of patients who suffer spasticity
26	Physical sequelae	% of patients with motor impairment
27	Physical sequelae	% of patients with speech and language impairments/ communication problems
28	Physical sequelae	% of patients with swallowing impairments
29	Physical sequelae	% of patients with vision impairments
30	Physical sequelae	% of patients with cognitive impairments
31	Physical sequelae	% of patients with post-stroke fatigue
32	Economic consequences	% of patients who were employed before the stroke that do not return to work
33	Economic consequences	Average time to work re-entry
34	Economic consequences	Income loss from stroke- related morbidity (e.g. annual number of certified days off work from stroke * mean daily earnings)
35	Economic consequences	Direct income payments that stroke survivors receive related to stroke morbidity
36	Economic consequences	% of patients who return to work but in different conditions (e.g. a permanent change of job or employer, reduction of working hours, the survivor is officially accredited as a handicapped worker)
37	QoL sequelae	DALYs

38	QoL sequelae	Quality-Adjusted Life Year (QALY)
39	QoL sequelae	Health-related quality of Life
40	QoL sequelae	Patients' Mental Health-related quality of Life
41	QoL sequelae	Frenchay activities index (FAI)
42	QoL sequelae	Satisfaction With Life Scale (SWLS) (for patients)
43	QoL sequelae	% of patients who suffer depression
44	QoL sequelae	Level of social participation of stroke patients
45	QoL sequelae	Score of psychic dependency (behaviour and social relations, communication)
46	Caregivers sequelae	% of caregivers who have emotional problems after one year of caring for a stroke victim
47	Caregivers sequelae	% of informal caregivers (relatives) who are experiencing an important burden
48	Caregivers sequelae	% of informal caregivers who return to work (or % who need to leave their job/reduce their working hours)
49	Caregivers sequelae	Satisfaction With Life Scale (SWLS) (for caregivers)
50	Caregivers sequelae	Daily Caregiving Diary (DCD)
51	Caregivers sequelae	Carers' Assessment of Satisfactions Index (CASI)
52	Caregivers sequelae	Carers 'Assessment of Managing Index (CAMI)
53	Caregivers sequelae	% of caregivers who suffer depression
54	Caregivers sequelae	caregivers' Health-related quality of Life
55	Caregivers sequelae	caregivers' Mental Health-related quality of Life
56	Use and cost of rehabilitation services	Average amount of direct therapy received from each rehabilitation discipline each day (Min/Day)
57	Use and cost of rehabilitation services	Hours of rehabilitation therapy per week
58	Use and cost of rehabilitation services	Average total hours of therapy (average number of weeks * sessions per week * length of session in minutes). Calculated for each type of therapy (physical, occupational, speech) and for each setting (primary care, community day hospital,

		residential rehabilitation, outpatient rehabilitation, nursing home, community team rehabilitation, community stroke team)
59	Use and cost of rehabilitation services	Total cost of in-patient rehabilitation care
60	Use and cost of rehabilitation services	Annual hospital beds for stroke rehabilitation spent in the region
61	Use and cost of rehabilitation services	Days spent in a rehabilitative care facility (i.e. in-patient care)
62	Use and cost of rehabilitation services	Days spent in a long-term care facility or nursing home / Cost of stay in a nursing home/residential home/sheltered home (mean length of stay in days & unit cost per week)
63	Use and cost of rehabilitation services	National Average Hours of Physiotherapy for Stroke Survivors in a nursing home (the same but for occupation therapy and speech and language therapy)
64	Use and cost of rehabilitation services	National Average Hours of Physiotherapy for Stroke Survivors in outpatient rehabilitation (non-acute) (the same but for occupation therapy and speech and language therapy)
65	Use and cost of rehabilitation services	hours of paid home nursing
66	Use and cost of rehabilitation services	hours of paid home help/ use of paid home help * national mean hourly wage rate
67	Use and cost of rehabilitation services	unpaid home caregiving hours (+ converted to money, e.g. Using the hourly gross cost of social care)/ use of unpaid home care * hourly wage for over 65 years of age, unemployed or economically inactive carers
68	Use and cost of rehabilitation services	Cost of providing community services for stroke survivors
69	Use and cost of rehabilitation services	Number of meals on wheels received by stroke patients discharged home at 90 days
70	Use and cost of rehabilitation services	Number of medical consultations
71	Use and cost of rehabilitation services	Number of follow-up visits with a neurologist

72	Use and cost of rehabilitation services	Number of visits with a GP/ visits * unit cost
73	Use and cost of rehabilitation services	Number of physical therapy sessions /visits with a physiotherapist (* unit cost)
74	Use and cost of rehabilitation services	Visits with an occupational therapist * unit cost
75	Use and cost of rehabilitation services	Number of speech therapy sessions/visits with a speech therapist (* unit cost)
76	Use and cost of rehabilitation services	Number of visits with a nurse
77	Use and cost of rehabilitation services	Cost of drug consumption (Antihypertensive, Antithrombotic, antidepressant, etc.)