DELIVERABLE D4.2.1

ROADMAP shared with public authorities for ICTUSnet regions

WP 4 Knowledge Transfer to Health Policies

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Deliverable description:
This deliverable is part of WP4, "Knowledge Transfer to Health Policies", with the aim of constructing a roadmap with the main steps needed to improve effectiveness, equity and quality of integrated stroke care plans, in order to influence the policies of ICTUSnet regions and other parts of the SUDOE area of Europe

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EXECUTIVE SUMMARY

The present deliverable is part of the fourth ICTUSnet Work Package named “Knowledge Transfer to Health Policies”, which aims to transfer the acquired knowledge from the different project´s work plans to all relevant decision-making stakeholders and, in a co-creation process, develop measures to improve the effectiveness, equity and quality of integrated stroke care plans in european regions. This deliverable seeks to reach a consensus about what are the main steps needed to achieve this purpose, aligning with the ESO action plan for Stroke in Europe 2018-2030, and construct a roadmap in order to influence the policies of ICTUSnet regions and other parts of the SUDOE area of Europe.

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I. BACKGROUND

1. THE CHALLENGE OF STROKE

The rate of new strokes and stroke deaths, when adjusting for age, has decreased over the last two decades in European countries. Decreasing rates of new strokes are generally attributed to successful prevention strategies. However, due to the ageing of the European population and the strong association between stroke risk and age, the numbers of people having a stroke continues to rise.

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Using data from the Global Burden of Disease study 2015, and demographic projections obtained from Eurostat (statistical office of the EU), **a 34% increase in total number of stroke events in the EU between 2015 and 2035 is predicted**.

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

In 2015, direct healthcare costs alone added up to €20 billion in the EU, while indirect costs of stroke due to the opportunity cost of informal care by family and friends and lost productivity caused by morbidity or death were estimated to be another €25 billion.

Reducing the incidence of stroke and the likelihood of long-term disability is therefore a major need in Europe and an urgent issue to be addressed. In order to achieve this, the different actors involved have to work together.

Integrated stroke care is a challenge that involves different categories of stakeholders with different interests, perspectives and influences on innovation of circuits of care and on improvement of quality of care.

2. CONCEPTUAL FRAMEWORK : WHAT IS NEEDED TO BE DONE TO IMPROVE STROKE PATIENT CARE IN EUROPE

The Stroke Alliance for Europe (SAFE) commissioned in 2018 the study and report named **“Burden of stroke in Europe” (**available at https://strokeeurope.eu) to King’s College of London in order to show each EU country where it stands compared to others in terms of the stroke burden and how well it is meeting the need for acute and follow-up care, including examples of good practice.

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

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In this report, **12 indicators were chosen** in order to frame the study and enable comparisons across countries and regions.

As a conclusion, SAFE included in the report a section named **"SAFE Calls On EU Policy-Makers (Comission, Parliament, Council)"** with 4 main recommendations;

- Facilitate **coordinated, Europe-wide data collection**. Promote the use of a robust Europe-wide stroke register including instruments to assess needs for prevention and care as well as the quality of care along the whole stroke pathway.
- Incorporate the **stroke indicators** used in this report in the EU's work on the evaluation of the performance of health systems.
- Support a **Joint Action on stroke**, in the framework of the EU Health Programme. The Joint Action should focus on addressing the following topics: 1) data collection, 2) prevention, 3) promotion and implementation of national stroke strategies, and 4) performance assessment. Stroke Support Organisations (SSOs) should be actively involved in the Joint Action, and their crucial role throughout the stroke pathway, and in policy formation, should be enshrined in the national stroke strategies.
- Support **research into patient-reported experience, outcome measures and quality of life** across Europe. There is a need for more research on long-term management and support so that best practice and the effectiveness and cost-effectiveness of different models can be identified. Patients and **patient organisations/ SSOs should be actively involved** in these studies as participants and co-researchers and building the capacity for their participation is also vital.

Simultaneously, the European Stroke Organisation (ESO) in cooperation with SAFE prepared a **Stroke Action Plan for Europe** (**SAP-E**, avalaible at https://actionplan.eso-stroke.org), **for the years 2018 to 2030.** The SAP-E identified **four over-arching targets** for the implementation of evidence-based preventive actions and stroke services to 2030:

- To reduce the absolute number of strokes in Europe by 10%
- To treat 90 % or more of all patients with stroke in Europe in a dedicated stroke unit as the first level of care.
- To have national plans for stroke encompassing the entire chain of care from primary prevention to life after stroke.

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- To fully implement national strategies for multisector public health interventions to promote and facilitate a healthy lifestyle, and reduce environmental (including air pollution), socioeconomic and educational factors that increase the risk of stroke

In order to achieve these four overarching targets, the scientific publication (European Stroke Journal 2018, Vol. 3(4) 309–336) provides a basic road map for the implementation of evidence-based preventive actions and stroke services to 2030.

The SAP-E includes **8 domains with specific targets** identified in each one;

- Primary prevention
- Organization of stroke services
- Management of acute stroke
- Secondary prevention
- Rehabilitation
- Evaluation of quality and outcomes
- Life after a stroke
- Prioritised research areas

To monitor and facilitate change, a **common European dataset of 12 Key Performance Indicators** (https://actionplan.eso-stroke.org/key-performance-indicators) has been recently established, that allows analyzing the current state and progress across the entire chain of stroke care.

3. ICTUSNET; THE PROJECT. A PROOF OF CONCEPT OF WHAT IS NEEDED TO BE DONE

ICTUSnet is a project funded by the European Regional Development Fund (ERDF) through the Interreg Sudoe Program. It represents regions of the Southwest of Europe (Aragon, Balearic Islands, Catalonia, Navarra, Occitania and North of Portugal), covering a population of approx. 20 million people.

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The project has three main specific objectives:

1. **Innovation in data technology:** Use of innovative data technologies (real life data) available to extract and analyze information and enable cross-regional comparisons and decision making in the stroke care process
2. **Strategy:** Deep analysis of collected information and healthcare regional strategies in order to plan measures to enhance effectivity, promote evaluation procedures and reduce impact on stroke consequences.
3. **International collaboration:** Foster international and regional cooperation by exchanging good practices and lessons learned, peer learning and joint problem solving.

Since its beginning in 2018, ICTUSnet is pursuing several **work plans (WP**, https://ictusnet-sudoe.eu/en/project/workplan) with different activities of which several **deliverables (D.)** have been produced; these activities and deliverables are a proof of concept of the pursuit of objectives set out in the SAP-E.

Furthermore, the ICTUSnet project aims to **incorporate advances and facilitate the transfer, adapt and use of this knowledge by stakeholders and decision-makers of other European regions**, to improve efficiency, inequity and quality of their own health services. It seeks to make recommendations to both regional and national health authorities in the SUDOE area, but also to European institutions, to stimulate the adoption of new strategies (or the renewal of existing ones), taking into account all the information and experience carried out.

For this purpose, one of the **Work Package (WP4)** aims to transfer the acquired knowledge obtained to all relevant decision-making stakeholders. ARSN, as a regional authority, leads this WP favouring the participation of all actors and also a consensual approach between all the beneficiaries and the associated partners. It involves two deliverables:

A. An **Action Plan (D.4.1) for the improvement of stroke care on the ICTUSnet regions**. The Action Plan describes the analysis of each region and the common points to all of them. The result is the formulation of recommendations to each participants' regional and national health authorities in order to:
   - overcome weaknesses and solve problems that the data collected and analysed have highlighted
   - reinforces the good practices identified

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B. A **Roadmap for European health authorities and policy makers** in order to influence the policies of the ICTUSnet regions and other parts of the SUDOE area of Europe

4. VALUE-BASED AND PATIENT-CENTERED HEALTH CARE

Ictus net aims to contribute to the shift towards a value-based healthcare; this is a healthcare delivery model in which providers, including hospitals and physicians, are evaluated based on patients' health outcomes. Under value-based care agreements, providers can be also paid for the level of patients' health improvement, in an evidence-based way. In other words, the "value" in this model is derived from **measuring health outcomes** against the cost of delivering the outcomes.

This healthcare delivery model stress **a team-oriented approach** to patient care and sharing of patient data so that care is coordinated and outcomes can be measured easily. It also involves addressing care processes **along the entire care pathway; Continuum of care with integrated primary, specialty, and acute care** relies on the **sharing of data among all providers**; electronic medical records (EMRs) and data mining in order to reduce redundant care and associated costs. Doctors, hospitals, and other healthcare providers have to work as a networked team to deliver the best possible coordinated care at the lowest possible cost.

In this conception of value, **patient-centeredness is one important quality measure**.
Most definitions of **patient-centered care** have several common elements that require a shift in the way health systems and facilities are designed and managed, and the way care is delivered:

- The health care system's mission, vision, values, leadership, and quality-improvement drivers are aligned to patient-centered goals.
- Care is collaborative, coordinated, and accessible. The right care is provided at the right time and the right place.
- Care focuses on physical comfort as well as emotional well-being.
- Patient and family preferences, values, cultural traditions, and socioeconomic conditions are respected.

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- The presence of family members in the care setting is encouraged and facilitated.
- Information is shared fully and in a timely manner so that patients and their family members can make informed decisions.

Therefore, the primary goal and benefit **is to improve individual health outcomes** although population outcomes may also improve. Not only do patients benefit, but providers and health care systems benefit as well, through:

- Improved satisfaction scores among patients and their families.
- Enhanced reputation of providers among health care consumers.
- Better morale and productivity among clinicians and ancillary staff.
- Improved resource allocation.
- Reduced expenses and increased financial margins throughout the continuum of care.

II. KEY ACTIONS IMPLEMENTED WITHIN THE ICTUSNET PROJECT

Throughout the ICTUSnet project, there have been many actions that have yielded deliverables, proposals and good practices;

Within the **Work Package 3 "Analysis and benchmarking of stroke healthcare pathway**s" the following can be highlighted:

- A **conceptual framework** (Deliverable D 3.1) to evaluate the different levels of the stroke care delivered in each region, aligned with SAP-E.
- A **detailed review of every regional stroke care plan**, differentiating the stages of the patient care process (outreach campaigns, primary prevention, acute care, secondary prevention and rehabilitation) reflected in selected deliverables (D 3.2.1, D 3.3.2, D 3.5).
- **Indicators and metrics** selected and proposed to evaluate each stage and allow comparisons and quality audit.

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- **Innovative uses of real world data on stroke;** the acute phase stroke care process has been analyzed using process mining techniques, led by the Health Science Institute of Aragon (IACS). They have worked on how to apply an existing process mining methodology to construct the empirical CPW process models in the acute stroke setting in each region. Care pathways (CPWs) are multidisciplinary care plans that detail essential care steps for patients with specific clinical problems. Available at *Process mining software in the acute phase of stroke* in the ICTUSNET platform- professional area
- A systematic **review of the cost of stroke in all its aspects** ; the deliverable 3.6 shows the analysis and comparison of the different regional stroke care models, along all stages of the continuum of care with the overall objective of finding out what is the socioeconomic impact of stroke sequelae on the stroke patients and their caregivers. It also sheds light on what is the cost of stroke-disability to healthcare institutions in the ICTUSnet countries, and provides a list of insights on which are the different dimensions to be taken into account when discussing socioeconomic impact of stroke.

Within **the Work Package 1 "Regional registries and integrated platform"** several remarkable results have been achieved;

- **Regional Stroke Registries and centralised ICTUSnet registry**

  ICTUSnet project aimed to foster the **development of stroke registries in every region**, and then to share some anonymised data from these regional registries and incorporate them in the **ICTUSnet central repository**, to allow interregional benchmarking and stroke care quality assessment. One of the cornerstones of the ICTUSnet project is this shared registry between the different regions.

  Deliverable 1.2.1 describes **legal and regulatory requirements** in each country to set up the regional registries, and good practices to collect and transfer in secured the data to ICTUSnet central registry. **Collaboration agreements** between partners and other involved institutions have been carried out establishing the purpose, duration and extension of the agreement, the purpose of the transfer of data, the type of data, the obligations of the partners, and the applicable legislation and jurisdiction

  Previously, it was necessary to reach consensus on the selection of variables and indicators to be collected (D 1.1) and establish rigorous interoperability criterion. The

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interoperability framework (D 1.3) tackles the semantic and technical aspects of the central ICTUSNet registry and aims to help different stakeholders involved in the development of stroke registries, to follow international recommendations (SNOMED-CT) and to address the technical aspects needed to be part of the shared ICTUSnet registry.

- **The ICTUSnet's platform (*http://platform.ictusnet-sudoe.eu*) has been developed** by the Catalan Agency for Health Quality and Evaluation (AQuAS), including **a professionals' area,** where they can find;
  - **Interactive maps** with quality indicators and outcome metrics of the care process of patients who had undergone endovascular treatment since September 2019, allowing comparison between regions. It is the result of the shared ICTUSnet registry.
  - **Direct access to text and imaging artificial intelligence tools**

  The portalweb also includes **a section for general public and patients** with information of interest and links to other helpful websites as well as information on patient organizations.

During the life of the project, it has been necessary to draw up **agreements at a global level between all the project partners (Consortium Agreement)** concerning the organisation of the work between them, the management of the Project and the rights and obligations of the Beneficiaries concerning inter alia liability, access rights and dispute resolution.

Development and evaluation of an automatic service that supports human experts in extracting relevant information from stroke patients' discharge reports was one of the objectives of Work Package 2 "Artificial intelligence tools". To do so, the Barcelona Supercomputing Center used deep learning and knowledge transfer techniques. They first used deep neural networks to generate a medical language and adapted it to their specific task in a supervised manner using the previously annotated Gold Standard. The annotation guidelines can be found in deliverable D 2.5 The code for the pre-annotation pipeline is dockerised and freely available in the Docker Hub repository (https://hub.docker.com/r/bsctemu/ictusnet) to ease its deployment and distribution. The results of the deep learning models are very good, demonstrating that the use of language technologies are a great help in complex clinical information extraction tasks. More details can be found in the deliverables D 2.4 and D 2.3.

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In the framework of **Work Package 5 "knowledge exchange, collaboration and mutual learning",** during the project´s lifetime **five thematic workshops have been held,** in order to create debate on relevant topics related to stroke healthcare;

1. Design, planning, implementation and assessment of stroke plans (IdisBa, Palma Mallorca April 2019)
2. Current and future challenges of endovascular stroke treatment (CHUT, Nice, September 2019)
3. Shared clinical decision-making in stroke (Navarrabiomed, online October 2020)
4. Innovative uses of real world data on stroke (IACS and BSC, online February 2021)
5. The future of stroke care in Europe (ARSN, online may 2021)

- For the 3rd thematic workshop, some research was carried out beforehand in the region of Navarre, jointly between professionals from the Neurology Service of the hospital, Navarrabiomed and ADACEN (Navarre Brain Damage Association, a non-profit organization that works with patients and family members). Four **multidisciplinary focus groups** (patients, families, professionals, other stakeholders) were held, in order to analyze at what stage the **Shared Clinical Decision-Making model** was found within the stroke healthcare in Navarre, and to provide a space for reflection to identify unmet needs or suggest possible improvements in the different stages of the stroke chain of care. A **final document** describing the work was drafted to help other regions do the same, as well as the main conclusions and recommendations to be followed. In addition, a **video** was recorded showing up the experience, and an **outline guide for patients with infographics** describing the common stages along the whole stroke pathway and what to expect at each one.

Also within Work Package 5 the Stroke Foundation of Catalonia (Fundació Ictus) have designed;

- **A toolkit for planning, conducting and evaluating stroke prevention and awareness campaigns on stroke** intended for professionals who collaborate and develop such activities.
- A document that compiles **existing professional training in the different regions participating in the ICTUSnet project and recommendations for their implementation,** which may be of interest to stroke professionals.

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It is noteworthy that the **global pandemic of covid 19 emerged in the middle of the project's duration**. This had a major impact on the progress of this ambitious and complex project, forcing a concentration of most of the health resources in the regions (and therefore delaying the ICTUSnet activities), and changing the format of the meetings and networking that involved face-to-face work.

III. OBJECTIVES :

The objectives of the Roadmap are:

1. **Summarize the main recommendations** from the ICTUSnet Action Plan and lessons learned from the ICTUSnet partners and leaders throughout the execution of the project.

2. **Align these recommendations with value-based and patient-centered care**, giving priority to those that contribute most to this approach.

3. **Propose key actions common to all regions** for the improvement of stroke care in the short, medium and long term, aligned with the ESO Action Plan (SAP-E) and the recommendations of the SAFE report.

4. **Address and disseminate the final recommendations** to call on health authorities and key stakeholders

IV. METHODOLOGY:

The work was performed by Navarrabiomed-FMS with the active participation of the Brain Damaged persons' Association in Navarra, ADACEN, in the framework of ICTUSnet Work Package 4 led by ASRN.

Different documentation has been reviewed in order to identify, extract and summarise recommendations:

- ICTUSnet Action Plan with focus on recommendations (E 4.1.1).
- Scientific publication and updated official SAP-E website.

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- SAFE report "The impact of stroke in Europe".
- Document of the 3rd thematic workshop on patient-centered medicine and shared decisions in the stroke care process, section “identification opportunities and recommendations for priority strategies”.

Whenever necessary, information from other deliverables has been added.

We selected **the requirements that the recommendations had to comply with**, namely:

1. General for all regions
2. Grouped into two areas:
   - Recommendations on transversal issues: data management and sharing, evaluation and measure of healthcare outcomes, team networking, innovation and research
   - Recommendations by stage of the stroke care process: Primary prevention and educational campaigns, Stroke as a medical emergency, Stroke units, Rehabilitation and long-term support, Secondary prevention
3. Drawn from a consensus among ICTUSnet partners

The **5th ICTUSnet workshop “Future of stroke care in Europe”** with relevant speakers that are involved in Stroke care organisation was used as inspiration, and guided the first choice set; we **selected a list of 11 take home messages** in order to structure the recommendations and present them to health authorities and strokecare organisations in a meaningful way.

Finally, **a list of 10 final recommendations was elaborated and agreed upon by all partners**, and a separate summary document with the help of infographics, in poster format, was designed for dissemination.

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V. MAIN ICTUSNET RECOMMENDATIONS FOR HEALTH AUTHORITIES

V.1 RECOMMENDATIONS ON TRANSVERSAL ISSUES:

➢ *STROKE SHOULD BE A HEALTH PRIORITY; IT NEEDS GOVERNMENT'S INVOLVEMENT AND EUROPEAN CONSENSUS*

1. **Face the challenge of Stroke as a health priority** not only to invest resources, but to promote efficiency, specially on long-term management and supportive care of the increasing numbers of people living with the effects of stroke
2. **Take into account the complexity of Stroke chain of care;** it is one of the diseases that involve most different actors and institutions and it is mandatory that they get organized.
3. Policies that are promoted at European level will have more guarantees of implementation than others; **the Stroke Action Plan for Europe is an opportunity** for European countries to move forward and step in the right direction
4. **ICTUSnet tools and products can be used** as a European best practice to join in

➢ *STROKE NEEDS AN INTEGRATED ORGANISATIONAL AND COLLABORATIVE STRATEGY ENCOMPASSING THE ENTIRE CHAIN OF CARE*

1. **Have a strategy: national and regional stroke plans** aligned with the Stroke Action Plan for Europe
2. **Support a joint action with all the actors involved, including Stroke Support Organisations**
3. **Address quality of care along the whole stroke pathway** from primary prevention to life after stroke.
4. **Promote integrated care**

➢ *STROKE REQUIRES A PERSON-CENTERED MODEL OF CARE*

1. Incorporate the **perspective of the patient and family**
    - Collect valid indicators considered of value by them
    - Agree on health states and concepts of quality of life.

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2. Promote the **model of shared clinical decisions and active participation** of patients and caregivers throughout the whole process.
3. **Improve information and provide positive and effective communication** with patients and/or caregivers throughout the whole stroke pathway
4. Promote actions that contribute to a **greater humanisation** of health care.
5. Provide **training for professional teams** to promote this model of care.
   Enable an active role for **Stroke patients' associations** in the Regional Stroke Plan and build the capacity for their participation

➢ *STROKECARE NEEDS DATA MANAGEMENT- SYSTEMATIC AND STANDARDISED COLLECTION OF STROKE DATA*

1. **Build, update or maintain a regional/national Stroke Registry** that covers **the whole pathway of stroke care** including emergency services and stages beyond hospital (follow up, rehabilitation, secondary prevention).
2. **Facilitate data collection:** Design user-friendly web based data collection formularies or mobile PPPs, with intuitive interface and sufficient integrations with applications used in day-to-day basis so that professionals do not duplicate their work.
3. **Implement standards; define the cohort and core items to be monitored and construct indicators;** use those selected in the ICTUSnet project and aligned with SAP-E.
4. Develop a **maintenance plan** with regular updates for the stroke registry to guarantee quality of data
5. Code or establish automated mappings to **interoperable codes in order to share and collect disaggregated data** with other regional or national stroke registries. Promote **SNOMED-CT codes** and **join ICTUSnet project centralized registry**
6. Establish **systems for data anonymisation** that follow European and country-specific legal guidelines.
7. Take into account that in order to share data or registries, **collaboration agreements** must be previously drawn up between all the partners involved.
8. Promote **collection and comparison of aggregated stroke data across Europe**
9. In case of no registry available or as a complementary way of managing data, use **discharge reports** from stroke patients using the **ICTUSnet developed tool for text mining**.

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➢ *STROKECARE ORGANISATIONS NEEDS TO EVALUATE, AUDIT AND DISSEMINATE HEALTH OUTCOMES AND RESULTS TO IMPROVE*

1. Choose **Key Performance Indicators (KPI) and health care outcomes at each stage of the stroke care pathway** as objective tools for evaluations; use those selected in the ICTUSnet project and aligned with SAP-E, WHO, NCDs.
2. Evaluate periodically the **effectiveness of prevention and awareness campaigns,** in order to determine the extent to which they positively influence public behavior, assess cost-effectiveness and determine sustainability over time.
3. Evaluate periodically **stroke treatment** in order to close gaps between practices and evidence based guidelines; not only for reperfusion therapies, but also rehabilitation treatments and secondary prevention. Use **targets and benchmarks** for evaluation in a **quality-improvement program,** with **specific actions** aimed at improving.
4. Evaluate the **economic and social impact of stroke,** including not only direct but also indirect cost measures throughout the care process.
5. **Incentivize** professionals for audits and **set deadlines.**
6. Openly disseminate the results and give feedback to the professionals involved with **easy-to-use open, visual BI tools and newsletters.**

➢ *STROKE NEEDS INNOVATION AND RESEARCH IN MANAGEMENT AND CARE*

1. Innovate in data management

- Enable **digital transformation**
- Promote **automatized data collection from population-based registries and real time data monitoring**
- Explore **advanced analytics process mining** for decision-making
- Explore **artificial intelligence tools**
- Promote the **design and use of user-friendly PPPs** to foster a culture of data registration

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2. Innovate in models of care

- Promote **multidisciplinary stroke teams and evaluation comittees** with independent functionality and administrative support
- **Incentivise** professionals to the provision of **high-value care and integrated care**
- Enable **coordination and effective communication** between levels of healthcare

3. Innovate in communication and dissemination of knowledge

- Use **open BI tools to disseminate health outcomes** in a transparent way.
- Have a **communication team** in place to disseminate new and updated protocols to all involved professionals in a timely manner.
- **Have a teaching team; train new professionals** and enable them to update their knowledge of stroke in their working time.
- Use **social media** and information based on safe places on the **internet, PPPs.**
- Use **visual thinking and infographics**
- **Differentiate information** for the general public from that for patients and care providers
- Take into account the different **social idiosyncrasies and languages of each target group.**

4. Innovate in social support to brain damaged patients

- Enable **coordination between social and health care in stroke**
- Promote **multidisciplinary synergistic approach to help patients in life after the stroke** with active participation of patients 'associations, community based organizations, NGO and social resources in the patient's area of residence.
- Promote **innovative social inclusion and support projects** aimed at patients with stroke-related disabilities
- **Empower community strategies** and encourage participation

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5. **Support specially research**

- **On long-term management and support** and **patient-reported experience** so that best practice and the effectiveness and cost-effectiveness of different models can be identified. Patients and patient organisations/ SSOs should be actively involved in these studies as participants and co-researchers
- **Into outcome measures and quality of life across Europe**

V.2 RECOMMENDATIONS BY STAGE OF THE HEALTH STROKE CARE PROCESS:

➢ *STROKE IS PREVENTABLE AND HAVE DISTINCTIVE RISK FACTORS*

1. **Improve knowledge of the modifiable risk factors for stroke; carry out stroke prevention campaigns**

- **Continuous, sustained over time** and impact **periodically evaluated** with indicators previously selected
- Aimed at **changing behaviors** towards practices that protect against stroke, with positive messages.
- Included in national/regional strategies and led by **Public Health Departments.**
- **Oriented and adapted to different population** groups and community settings (work, school, family, elderly population).
- Presenting stroke as a preventable illness; **highlight the main preventable risk factors** and the possibility of controlling them.
- Using **innovative communication tools**

2. **Promote the development of healthy lifestyles as stroke preventive**

- Carry out information campaigns on healthy eating and physical exercise as factors preventing the risk of stroke.
- Develop specific actions aimed at **active ageing**
- **Alcohol, smoking and drugs:** carry out campaigns aimed at the entire population, linking these habits also to the risk of stroke

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3. **Improve prevention and control of the main stroke risk factors**

a. **High blood pressure (Hypertension)**

- Measure both treatment and control indicators
- Include the risk of stroke in population-based campaigns on hypertension that are promoted

b. **Atrial Fibrillation**

- Raise awareness of the importance of AF and its pre-detection.
- Improve the diagnosis of AF including **systematic strategies to identify it**
- Support pulse arrhythmia monitoring campaigns with primary care and pharmacies and the use of new technologies.

4. **Promote and facilitate collaboration between healthcare, health management and public health professionals, with patient associations and scientific societies** for the planning, implementation and evaluation of prevention campaigns carried out on a regular basis.

5. **Use the ICTUSNET campaign toolkit**

➢ *STROKE IS A TIME-DEPENDENT TREATABLE EMERGENCY*

1. **Carry out stroke awareness-raising campaigns**

- **Continuous,** sustained over time and **systematically evaluated**
- Included in national/regional strategies and led by **Public Health Departments**
- In **collaboration** with patient and their associations, voluntary sector organisations and scientific societies to improve their impact
- **Oriented and adapted to different population** groups and community settings (work, school, family, elderly population)
- Using **innovative communication tools**
- Use the **ICTUSNET campaign toolkit**

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2. **Improve emergency pathways for stroke patients**

- Consider Stroke as a **time-dependent medical emergency** and guarantee rapid access to reperfusion treatment with equity criteria.
- Guarantee **human and material resources** for early and accurate assessment of stroke patients, including mobile applications to facilitate data collection
- Have a regional multidisciplinary **Stroke Code work team** with the mission to build, update and systematically evaluate the **Regional Stroke Code system** for the immediate care of patients before and after the arrival to the appropriate referral hospital, depending on local health infrastructure
    - with **algorithms** of management and referral criteria to health care facilities
    - with **targets** to reduce times to reperfusion therapies
- **Include emergency level of care in the regional stroke registry** in order to measure indicators selected to assess quality of care.
- Have a systematic, periodic approach towards **training healthcare professionals** involved

3. **Improve reperfusion therapies rates and outcomes and report the results**

- Guarantee **organisational changes** needed to create hospital networks and regional referral centers in order to facilitate the availability of thrombectomy for ischemic stroke Guarantee access to recanalisation therapies to at least 95% of eligible patients
- Achieve **intravenous thrombolysis (IVT) rates above 15% and endovascular treatment (EVT) above 5%**
- Close gaps between **evidence-based clinical guidelines** for stroke treatment and practice
- **Define a clear plan for monitoring and audit IVT and EVT onset-to-treatment times** and keep them updated in the stroke registry, to allow comparisons and audit quality of care.
- **Audit outcomes** in order to control morbidity and cost effectiveness (also in terms of quality of life) of these therapies

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- Use ICTUSnet **targets and benchmarks for IVT and EVT indicators**, based on multisociety consensus and ESO guidelines
- **Keep the professionals informed** with periodic newsletters (Give them feedback to their effort).

4. **Increase the availability of Stroke Unit and stroke-trained proffesionals**

- Review the **number of Stroke Units and stroke unit beds** in the region and adapt them to recommendations according to current reference population and regional stroke incidence.
- Guarantee **equal access to a comprehensive stroke unit** regardless of the patient's geographical location.
- **Audit and accreditate the regional Stroke Units** according standardised criteria set out by ESO.
- Have a systematic, periodic approach towards **training healthcare professionals** involved.

➢ ***STROKE DEMANDS A CONTINUUM OF INTEGRATED CARE AND A REHABILITATION PROCESS; DISABILITY CAN BE REDUCED***

1. **Ensure early access to multidisciplinary rehabilitation treatment.**

- Ensure at least 90% of people have access to early rehabilitation **during hospital admission**
- Conduct **multidisciplinary assessments** in the first days post stroke including dysphagia and speech therapy needs
- Initiate multidisciplinary rehabilitation **as soon as the patient is medically stable**.

2. **Improve the rehabilitation process.**

- Create or update **a comprehensive rehabilitation plan for stroke patients, included in the Regional Stroke Plan,** with pathway algorithms and criteria for elegibiliity of each one: intensive rehabilitation, outpatient rehabilitation programmes, inpatient facilities, long term care facilities, maintenance therapy.

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- Guarantee **on-going rehabilitation** treatment after early discharge. Avoid gaps of care
- Guarantee **equitable access** to rehabilitation regardless of the patient´s place of residence and socio-economic status.
- Address the organisation of enough stroke rehabilitation services
- Analyse human and material resource needs to rehabilitation by **multidisciplinary, coordinated, trained teams.** Provide them
- Enable **complementary outpatient rehabilitation approaches** like community-based, home rehabilitation and tele-rehabilitation technologies.
- Incorporate the patient´s rehabilitation plan and evolution into the **integrated medical record** in a structured and trackeable way

3. Incorporate **Key Performance Indicators (KPIs) of the rehabilitation process** from the list proposed in deliverable E3.5 **to the stroke registries**. Analyze them periodically in order to adecuate and improve the process

4. **Ensure an adequate follow up after discharge**

- Have a **specific section in the Regional Stroke Regional Plan that structures and organizes care after hospital discharge**, with the aim of continuum of care throughout the whole pathway, with integrated levels of care and structured by objectives.
- Establish in the discharge protocol the **professional of reference** for follow-up (stroke team and/or primary care staff).
- Establish criteria and pathway algorithms for types of outpatient rehabilitation, inpatient rehabilitation facilities, long term care facilities or nursing homes
- Enable a **liaison nurse** between primary and specialized care in selected cases
- Ensure all stroke patients and caregivers have **periodic reviews** especially in the first months, with focus on adherence to secondary prevention, rehabilitation plans, symptoms that have emerged and adaptation to the new reality.
- Update and create a **specific accessible protocol for primary health and social care** of stroke patients at this stage
- Enable **user-friendly tools** to facilitate information exchange, integrated care with **shared medical records between levels of care**

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5. **Involve patients and caregivers**

- Promote personalised rehabilitation **plans shared with the patient** and caregivers, tailored to their needs and personal priorities.
- Implement information, guidance and programmes for patients and caregivers to encourage **participation** in the rehabilitation process and support
- Actively involve **Stroke Support Organizations and patients´associations** in the Regional Stroke Plan

➢ *RECURRENT STROKE IS PREVENTABLE*

1. **Reduce the recurrence of stroke**

- Have a **specific section in the Regional Stroke Regional Plan that structures and organizes secondary prevention in stroke**, with the aim of **evidence-based treatment**
- Establish necessary **updated diagnostic workup protocols** in order to set the cause of the stroke
- Monitor and establish **periodic risk factors control** recommended in clinical guidelines and updated protocols with specifics goals to achieve
- Close gaps between evidence-based clinical guidelines for secondary stroke prevention and practice
- Encourage and monitor **adherence** to prescribed treatments and healthy habits
- Promote personalised secondary prevention **plans shared with the patient**, according to his/her risk factor profile ad taking into account their needs and personal priorities
- Incorporate secondary prevention into the **integrated medical record**

2. **Incorporate secondary stroke prevention KPIs and data in the stroke registries**

- Incorporate some KPIs of the secondary stroke prevention from the list proposed in deliverable E3.5
- Analyze them periodically in order to adecuate and improve secondary stroke prevention

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➢ *LIFE AFTER A STROKE DOES CONTINUE. STROKE SURVIVORS HAVE SPECIFIC HEALTH AND SOCIAL NEEDS*

1. Have a **specific section in the Regional Stroke Regional Plan that addresses life after a stroke, long-term support for stroke survivors and social impact of stroke**

- **Continue secondary prevention** plans according to guidelines
- Continue integrated care with an essential role of **primary care**
- Enable **maintenance rehabilitation in the local setting**
- Guarantee **social support** according to the degree of disability and regardless of the place of residence and socio-economic status
- Promote the **integration of stroke survivors into the community**; innovate, and look for synergistic collaboration with social resources and local facilities
- Support physical and psychological health of **caregivers**

2. **Promote an active role for Stroke Support Organizations and Patients´ Associations**

- Promote **support and educational groups**, family respite services, in coordination with community resources
- **Formalise the involvement of stroke survivors and their caregivers** in identifying problems and solutions to improve patient support.

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VI. CONSENSUS ICTUSNET FINAL RECOMMENDATIONS

A consensus was achieved within ICTUSnet partners on the final summarized messages, its order of importance and actions to be highlighted in each message, which were the following:

ICTUSNET ROADMAP TO IMPROVE STROKE CARE IN SOUTHWESTERN EUROPEAN REGIONS. Statements on stroke and main recommendations for health authorities

1. STROKE SHOULD BE A HEALTH PRIORITY; IT NEEDS GOVERNMENT'S INVOLVEMENT AND EUROPEAN CONSENSUS

- **Tackle the challenge of stroke** not only to invest resources on prevention and treatment of stroke, but to **promote effective and efficient care** for the increasing number of stroke survivors with sequelae
- Use the **European Stroke Action Plan** as a reference for the development of actions and measures in the right direction and together ***https://actionplan.eso-stroke.org***
- **ICTUSnet tools and products** should be used as European best practices; avalaible at ICTUSnet platform ***http://platform.ictusnet-sudoe.eu***

2. STROKE NEEDS AN INTEGRATED ORGANISATIONAL AND COLLABORATIVE STRATEGY ENCOMPASSING THE ENTIRE CHAIN OF CARE

- National and regional stroke plans should have **a whole strategy from primary prevention to life after stroke,** with an integrated, multidisciplinary and synergetic approach
- **Cooperation** should be encouraged across stakeholder groups including representatives from public health, health management, emergency, primary, specialised healthcare and social care organisations, and patients' associations.

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3. STROKE REQUIRES A PERSON-CENTERED MODEL OF CARE

- Incorporate the **patient's perspective** in the evaluation of outcomes and quality of life
- Promote the model of **shared clinical decisions, effective communication and active participation** of patients and caregivers throughout the whole process Watch the video "Together in Strokecare "*https://youtu.be/uX2sfVsa0ak*
- Provide **training for professional teams** to promote this model of care

4. STROKE IS PREVENTABLE AND HAVE DISTINCTIVE RISK FACTORS

- **Improve population's knowledge** on the modifiable risk factors for stroke; carry out **regular prevention campaigns**
- Promote the development of **healthy lifestyles and obesity prevention** as stroke preventive
- Improve **prevention and control of hypertension and detection of atrial fibrillation**
- Reduce the recurrence of stroke. Have a **secondary prevention strategy** in the Regional Stroke Plan with the aim of updated, evidence-based causative treatment. **Encourage and monitor adherence** to prescribed treatments and healthy habits
- Incorporate **secondary prevention Key Performance Indicators** in the stroke registries and analyze them periodically in order to evaluate and improve

5. STROKE IS A TIME-DEPENDENT TREATABLE EMERGENCY

- **Improve population's knowledge** on stroke signs and symptoms and how to react. **Stroke awareness campaigns** should be conducted regularly
- **Improve emergency pathways** for stroke patients and ensure equity; have a **regional multidisciplinary Stroke Code Team** in the region with the mission to update and evaluate them periodically
- **Improve rates, times and outcomes of reperfusion therapies** and communicate results
- Increase the **availability of Stroke Units and stroke-trained professionals**.

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6. STROKE DEMANDS A CONTINUUM OF INTEGRATED CARE AND A REHABILITATION PROCESS; DISABILITY CAN BE REDUCED

- Avoid gaps in care; have a strategy in the Regional Stroke Regional Plan for care **after hospital discharge,** with the aim of **continuum of integrated care throughout the whole pathway,** structured by objectives.
- Have a **comprehensive rehabilitation plan** included in the Regional Stroke Plan. Ensure early access to multidisciplinary rehabilitation treatment and guarantee accessible, equitable, on-going rehabilitation treatment after discharge. Establish criteria and pathway algorithms for types of updated, evidence-based neurorehabilitation. Promote personalised rehabilitation plans shared with the patient and caregivers
- Incorporate **Key Performance Indicators** to the stroke registries in order to **periodically evaluate and improve the rehabilitation process efficiency**
- **Actively involve patients and caregivers,** stroke Support Organizations and patients ´associations in this phase

7. LIFE AFTER A STROKE DOES CONTINUE. STROKE SURVIVORS HAVE SPECIFIC HEALTH AND SOCIAL NEEDS

- Have a **specific section in the Regional Stroke Regional Plan that addresses life after a stroke**, long-term health and social support for stroke survivors
- Continue **secondary prevention** plans according to guidelines
- Enable **maintenance rehabilitation** in the local setting
- Promote the **integration of stroke survivors** into the community
- Promote **support and educational groups** including caregivers' needs
- Promote an **active role for Stroke Support Organizations and Patients´ Associations** in coordination with **community resources.**

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8. STROKECARE NEEDS DATA MANAGEMENT- SYSTEMATIC AND STANDARDISED COLLECTION OF STROKE DATA

- Build, develop and maintain **data infrastructures that support systematic approach, data-centric stroke care assessment across the whole care pathway**. To this end, use any available data source, from stroke registries to electronic health care records or discharge reports, compliant with the principles of the European Framework of Interoperability.
  Watch the video about ICTUSnet work *https://youtu.be/6WoIO1iG7x0*
- Enable **data anonymisation and sharing with other stroke registries**. ICTUSnet project centralized registry and the use of its identified standards are particularly recommended for the acute phase. Report available at *http://platform.ictusnet-sudoe.eu/red-ictusnet/informe-tratamiento-de-reperfusion-e-indicadores/*

9. STROKECARE ORGANISATIONS NEEDS TO EVALUATE, AUDIT AND DISSEMINATE HEALTH OUTCOMES AND RESULTS TO IMPROVE

- Promote **stroke care continuous assessment and sound comparisons** of care providers, within and between health systems. Settle **targets and benchmarks for evaluation of the whole stroke care pathway in a quality-improvement program**. **Indicators identified in the ICTUSnet project** should be used, aligned with Stroke Action Plan in Europe
- Promote **regular public reporting of the results** produced in the evaluation of stroke care and, out of this, **foster dialogues** with health authorities and within the multidisciplinary working group
- The **economic and social impact of stroke** should also be regularly assessed, including measures of indirect costs throughout the care process

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10. STROKE NEEDS INNOVATION AND RESEARCH IN MANAGEMENT AND CARE

- **Data management** seeks innovation. Enable digital transformation, promote real time data monitoring, explore advanced data mining tools and innovate in data reuse.
- **Models of strokecare** should be innovative: incentivise and enable stroke professionals to provide **integrated, patient-centered care**
- **Communication and dissemination of knowledge** should include innovative strategies
- **Social innovation** is needed to improve support for patients with acquired brain injury
- **Research on care based in patient-reported experience**, specially on long-term care should be encouraged to identify best practices and efficient models of care from a broad perspective.

VIII. ADDENDUM: ICTUSNET ROADMAP POSTER FOR DISSEMINATION

See addendum named “ICTUSNET ROADMAP DISSEMINATION POSTER”

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