DELIVERABLE D4.1.1

Action Plan for ICTUSnet regions

WP 4 Knowledge Transfer to Health Policies

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Deliverable description:
This deliverable describes the methodology used in WP2 to develop the SUPERVISED CATEGORIZATION MODELS, TOPIC MODELLING AND EXTRACTION OF CLINICAL INFORMATION using deep learning techniques. The results obtained by the deep learning models are remarkable, reaching 91% F1 on average.

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ABBREVIATIONS AND ACRONYMS

ABPM	Ambulatory Blood Pressure Monitoring
ADACEN	Asociación de Daño Cerebral de Navarra
AF	Atrial Fibrillation
AIDA	Asociación Ictus de Aragón
AQuAS	Agència de Qualitat i Avaluació Sanitàries de Catalunya
ARP	Alcohol Related Problems
ARS	Agence Regional de Santé
ARSN	Administração de Saúde do Norte
AVC	Accidente Vascular Cerebral/ Accident Vasculaire Cérébral
CEPS	Centros Educativos Promotores de la Salud
CHN	Complejo Hospitalario de Navarra
CICAT	Codi Ictus Catalunya
CMBD	Conjunto Mínimo Básico de Datos
CP	Care Pathway
DICOM	Digital Imaging and Communication On Medicine
EHR	Electronic Health Record
ERDF	European Regional Development Fund
e-SIAP	Sistema de Información de Atención Primaria
ESO	European Stroke Organisation
EU	European Union
EVT	Endovascular Treatments
F.A.S.T.	Face Arms Speech Time
HCIS	Health Care Information Systems
HL	Health Level
HTA	Hypertension
HUSE	Hospital Universitario Son Espases
IACS	Instituto Aragonés de Ciencias de la Salud
ICD	International Classification of Diseases
ICPC	International Classification for Primary Care
ICTUSnet	"Excellence R&D network towards the successful development and implementation of innovative models of stroke care strategies"
IHE	Integrating the Healthcare Enterprise
Interreg	European Territorial Co-operation
IT	Information Technology
IVT	Intravenous Thrombolysis Treatment

NCD	Non Communicable Disease
PADIB	Pla d'Addiccions y Drogodependències de les Illes Balears
PAIA	Programa de Atención al Ictus de Aragón
PCH	Puesto Clínico Hospitalario
PDMAC	Pla Director de Malalties de l'Aparell Circulatori
PNNS	Programme National Nutrition Santé
PSC	Post-Stroke Checklist
REA	Rapid Evidence Assessment
REHACER	Asociación para la Rehabilitación de Accidentados Cerebrales de Baleares
RISS	Redes Integradas de Servicios de Salud
SAFE	Stroke Alliance For Europe
SAP	Stroke Action Plan
SAP-E	Stroke Action Plan for Europe
SEFAC	Sociedad Española de Farmacía Clinica, Familiar y Comunitaria
SHE-LELHA	Sociedad Española de Hipertensión Arterial - Liga Española para la lucha contra la Hipertensión Arterial
SNOMED CT	Systematised Nomenclature of Medicine – Clinical Terms)
SPAVC	Sociedade Portuguesa do Accidente Vascular Cerebral
Sudoe	Southwestern Europe
UCA	Unidades de conductas Adictivas
UPRA	Unidad de Problemas Relacionados con el Alcohol
WHO	World Health Organisation

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EXECTIVE SUMMARY

This deliverable describes the action plan proposed after a thorough review of the different deliverables reported in each of the Work Package (WP) within the ICUTSnet project. The report describes the characteristics of each region and the common points to be improved in response to weaknesses detected. In addition, it reinforces the good practices identified.

The result of this report is the formulation of relevant recommendations to stimulate the adoption of new strategies (or the renewal of existing ones) for regional and local policymakers.

1 INTRODUCTION

Nowadays in Europe, stroke is the second most common cause of death and disability. The increase in population and elderly people as a result of longer life expectancy is one of the key associated factors. In order to prevent, treat and manage stroke and significantly reduce the burden of stroke and its long-term consequences, 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.

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.

Therefore, ICTUSnet project not only intends to update the knowledge in stroke and to incorporate the advances that modified the concept and management of stroke, but also seeks to facilitate the use of this knowledge to improve efficiency, inequity and quality of health services. After analysis of the roles played by the different stakeholders involved in the project in their stroke systems of care, the present report aims to design an action plan that defines concrete steps and measures to be taken to:

1) solve problems that the data collected and analysed by ICTUSnet have highlighted;
2) transfer and adapt to other environments the good practices identified in WP3.

The ICTUSnet project involves the participation of regions coming from: Spain (Aragon, Balearic Islands, Catalonia and Navarre), Portugal (ARS-Norte) and France (Occitanie). Some available data of the 3 countries (from *Access to and delivery of acute ischaemic stroke treatments: A survey of national scientific societies and stroke experts in 44 European countries, European Stroke Journal, 2018)* are given in Tables 1 to 3:

Table 1. Absolute and relative numbers per million inhabitants. IVT: intravenous thrombolysis treatments, EVT: endovascular treatments.

Country	France	Portugal	Spain
No. of stroke units	140	25	60
Stroke units per million	2.2	2.4	1.3
Annual no. of IVT	8000	1516	5002
Annual no. of IVT per million	124.2	146.5	108.5
No. of IVT centres	140	25	59
IVT centres per million	2.2	2.4	1.3
Annual no. of EVT	4589	845	2408
Annual no. of EVT per million	71.3	81.6	52.2
No. of EVT centres	37	9	37
No. of EVT centres 24/7	-	4	35
EVT centres per million	0.6	0.9	0.8

Table 2. Relative numbers per annual incident ischaemic strokes.

Country	France	Portugal	Spain
Annual no. of incident ischaemic strokes	87.37	18.20	66.59
Stroke units per 1000 ischaemic strokes	1.6	1.4	0.9
Annual no. of IVTs per 1000 ischaemic stroke	91.6	83.3	75.1
Proportion of stroke patients with IVT (%)	9.2	8.3	7.5
IVT hospitals per 1000 ischaemic strokes	1.6	1.4	0.9
Annual no. of EVTs per 1000 ischaemic stroke	52.5	46.4	36.2
Proportion of ischaemic stroke patients with EVT (%)	5.3	4.6	3.6
EVT centres per 1000 ischaemic strokes	0.4	0.5	0.6

Table 3. Estimated number of additional stroke units and comprehensive stroke centres required to achieve three stroke units per one million inhabitants and one comprehensive stroke centre per one million inhabitants, and estimated number of additional treatments with intravenous thrombolysis and endovascular interventions if rates of 18% and 5%, respectively, are to be achieved.

Country	France	Portugal	Spain
No. of additional stroke units required	53	6	78
No. of additional comprehensive stroke centres required	27	1	9
No. of additional intravenous thrombolysis treatments per year (target rate 18%)	7727	1761	6985
No. of additional endovascular treatments per year (target rate 5%)	0	62	922

According to the data given in Deliverable 3.6, the healthcare cost of stroke within the ICTUSnet countries is shown in Table 4.

Table 4. Overall national cost and cost per capita in: France, Portugal and Spain.

Country	Overall national cost (in million €)	Cost per capita (in E)
France	1,973.2	30
Portugal	159.7	15
Spain	1,244.8	27

The Action Plan describes the characteristics of each region, according to the different aspects studied during the development of the project, and the common points to be improved in response to weaknesses detected. It also reinforces the good practices identified. The information has been extracted from WP1 and WP2 as well as from the studies performed within WP3.

The result is the formulation of recommendations to regional health authorities in the SUDOE area and to European institutions to stimulate the adoption of new strategies (or the renewal of existing strategies).

2 METHODOLOGY

The work was has been performed by Fundació Institut d'Investigació Sanitària Illes Balears (IdISBa) within WP4 led by Administração de Saúde do Norte (ARSN).

The different deliverables reported up to date have been reviewed in order to identify, extract and summarise the relevant information. The list of deliverables finally used is the following:

- D 1.1.1 Glossary of variables.
- D 1.2.1 Instruction book for the exchange of health data within ICTUSnet project.
- D 1.3.1 Technical Interoperability document.
- D 1.6.2 Interactive maps.
- D 2.3 Application for the standardization of multilingual clinical documents.
- D 3.1.1. Evaluation Framework.
- D 3.2.1 Report on health promotion campaigns and primary prevention strategies implemented in ICTUSnet regions.
- D 3.3.2. Report comparing the provision of Stroke Code across ICTUSnet regions.
- D 3.4.2. Repertoire of best practices, including guidance notes for identification.
- D 3.5. Comparative analysis of resources available for the follow up and rehabilitation of stroke patients.
- D 3.6 Socio-economic impact of stroke sequelae.
- D 5.3.2 Report on the results of the training program and the experiences of the participants.
- D 5.4.1 Toolkit from the organisations of campaigns for stroke prevention and health promotion for the citizens.

Throughout the ICTUSnet project, a conceptual framework (Deliverable 3.1.1) has been developed aligned with the Stroke Action Plan for Europe 2018-2030, SAP-E, outlined by the European Stroke Organisation (ESO) in cooperation with the Stroke Alliance for Europe (SAFE). In addition, a detailed review of different phases of stroke care has been carried out in the regions that have participated in the project (outreach campaigns, primary prevention, care in the acute phase, secondary prevention and rehabilitation) as reflected in selected deliverables. A consensus was reached on the way to record the process and result indicators for mechanical thrombectomy and interoperability between the different registries was built. The acute phase stroke care process has been analysed using process mining techniques, and a tool has been developed to analyse the discharge reports of stroke patients, to extract relevant data from them. The opinion of patients and their relatives has also been taken into account, with whom the document "Shared clinical decision-making in stroke care" has been drawn up. A systematic review of the cost of stroke in all its aspects has been carried out.

Whenever necessary, information from existing health plans and stroke documents and websites in the regions has been added.

All this has allowed the comparison between regions and, following the guidelines of the ESO and SAFE collected in the conceptual framework, establish specific recommendations for each of the regions.

We know that certain actions for the stroke care chain and good practices have been carried out in the regions, but they have not yet been published. Therefore, we have not been able to review and reflect them in the relevant documents.

Given that throughout the life of the project the regions have continued to advance, it could happen that some of the recommendations have already been carried out at the time of publication of the Action Plan.

Some of the work carried out it could not be analysed from a regional perspective, so common recommendations have been formulated for all regions.

The information of the 6 regions included within the ICTUSnet project has been divided into four categories as follows:

1. General data.
2. Primary prevention strategies, health promotion and campaigns.
    a) Health lifestyle.
    b) Stroke awareness campaigns.
3. Attention in acute phase: organisation of stroke services and management of acute stroke:
    a) Data from the web page, action times.
    b) Data from process mining.
    c) Data from text mining.
4. Follow-up and rehabilitation, secondary prevention, life after stroke.
    a) Pathways in stroke rehabilitation.
    b) Resources for stroke survivors.
    c) Follow-up of stroke survivors.
    d) Secondary prevention.

After analysing the information provided in each point, recommendations are given.

3 REGIONAL RECOMMENDATIONS

3.1 Aragon

3.1.1 General data

The general data of Aragon are provided in Table 5.

Table 5. General data of Aragon.

Category	Item	Current situation
General information	Population:	1.308.750 inhabitants
	Number of hospitals:	12
	Number of healthcare professionals:	16.659
	Health system:	Public Health System called Servicio Aragonés de Salud (SALUD).
ICT characteristics	Use of standards:	• HL7. • Developed their own data model based on 13606. • Use of ICD-10-CM to encode diagnosis (2016/01 onwards). This refers only to diagnosis and procedures registered during the hospital episode. Diagnoses at other instances of the healthcare system (i.e., Primary care or Emergency wards within the hospital) are coded using other standards (i.e., ICPC-I for primary care and ICD-9-MC for emergency ward services). • Experience in SNOMED CT to structure the EHR information.
	EHR situation:	All the hospitals have the same EHR system with an integrated data base (with integration of the Stroke registry from January 2019 onwards).
Stroke related information	Regional stroke program:	A regional Stroke code network exists from 2009 onwards (Código Ictus Aragón).
	Reference stroke hospital:	Thrombectomy treatments: Multihospital unit involving neurologist from both Hospital Universitario Miguel Servet (ESO Stroke Centre accreditation for 5 years from April 2020) and Hospital Clínico Lozano Blesa located in Hospital Miguel Servet. Fibrinolysis treatment: Performed in all Aragon hospitals. Neurological clinical service: 24x7 services by the multihospital unit at Hospital Miguel Servet.
	Number of stroke cases per year:	2500 episodes per year and 90-130 of them involving a thrombectomy treatment.
	Stroke registry:	A unique and centralised registry exists for the entire region maintained by the Aragonese Health Service and by every process team; unique visualization for the entire region with filters by hospitals.
	Stroke structured information:	They have it but it is not structured using an international controlled vocabulary.

Aragon has updated documents and web sites related to (see Annex I):

- Health Plan.
- Stroke Plan which includes all phases of cerebrovascular disease divided into clearly defined processes and sub-processes; it also contains indicators for their evaluation.
- Territorial plan for the entire region.
- Nursing care plan 2018.
- Process mining.
- Stroke Foundation of Aragon (AIDA).

Aragon counts with specific guidelines and protocols for stroke condition (including, from 2020, the Pediatric stroke care plan). By comparison with other ICTUSnet regions, it is noteworthy that Aragon region is the only one that counts with a detailed stroke plan in line with ESO and SAFE stroke plan for Europe for 2018-2030, covering all the dimensions that have been identified as relevant through an exhaustive revision of scientific literature conducted on the present project. Therefore, we consider that their Stroke Plan could be taken as a model for the development or modification of any regional stroke plan.

3.1.2 Primary prevention strategies, health promotion and campaigns

From Deliverable 3.2: COMPARATIVE STUDY OF PRIMARY PREVENTION STRATEGIES, HEALTH PROMOTION AND CAMPAIGNS.

a) Healthy lifestyle

Does the region have updated Health Programs/Plans containing healthy life / hypertension / atrial fibrillation strategies? Do they have available documents?

The Health Ministry of Aragon has launched the most updated Health Plan. There is no specific health promotion or primary prevention program on Stroke in Aragon at the population level. The Stroke Plan of Aragon (2019-2022) describes primary prevention of risk factors for cardiovascular disease, included at the Primary Care level (Hypertension, Dyslipidaemia, Diabetes, Atrial Fibrillation, etc.), with recommendations. There is a specific diabetes plan.

On the other hand, within the Aragon Health Plan 2030 (DGSP) action lines have been collected on health determinants (cardiovascular, among others) but not specifically on stroke. With the Department of Public Health, the strategy against smoking is also being worked on at the population level with an information website on the matter and a public health blog with information. The Department of Public Health, in the promotion and prevention section, works on different aspects against tobacco. There is an official website to work on different aspects of smoking cessation with publications, regulations, etc. In addition, a network of smoking cessation consultations has been created from the general health care department in primary health care centres, and smoking cessation treatments are supported by the public health system.

Do they have specific programs to address primary prevention in Stroke? Is there any specific section for evaluation?

There is no specific health promotion or primary prevention program on Stroke in Aragon at the population level. The ***Stroke Plan of Aragon (PAIA, 2019-2022)*** describes primary prevention of risk factors for cardiovascular disease, included at the Primary Care level (Hypertension, Dyslipidaemia, Diabetes, Atrial Fibrillation, etc.).

The PAIA has an evaluation chapter including the main objectives, which are: the development of a score card with the key indicators that are extracted from the electronic health record and other

sources of data (PCH, RISS, HISS, CMBD) through a Business Intelligence tool to be able to obtain prospectively and updated the main monitoring data. The indicators collected at Primary Care level are: 1. Arterial Hypertension coverage; 2. Arterial hypertension prevalence; 3. Diabetes coverage.; 4. Diabetes prevalence; 5. Obesity coverage; 6. Obesity prevalence; 7. Smoking rate of those over 15 years old; 8. Percentage of people with physical activity.

Which is the approach of the objectives regarding Healthy lifestyle campaigns?

From the Stroke Action Plan of Aragon, they are collaborating with the School of Health of Aragon in the elaboration of materials and in the participation as teachers in a course for training Expert Patients "Gánale Vida al Ictus". Aragon Stroke Association (AIDA) develops prevention, awareness and rehabilitation campaigns. Not specific information was founded in AIDA's website.

The Aragon Health Plan emphasizes the approach to lifestyles in Aragon's health, with the motto "Health in all policies" and the analysis of less favourable aspects of its regional characteristics and its population lifestyles with negative consequences for health.

Another line of work is the "Community Care Strategy". It is an initiative of the Department of Health aimed at promoting and improving the health and well-being of people in Aragon. In Primary Care, the Community Care Service includes actions on the health problems and needs of the population of each area and the attention to their inequalities. Through Community activities, the participation and capacity of people and groups to address their own problems is enhanced. This has led to the detection and registration of community assets. The asset maps, through their participatory development, are a useful tool to promote the empowerment of the population in their health and increase awareness of the health resources available in the environment, helping to create a positive approach to health and to increase the relationship between health and social professionals, and neighbours of a community.

The information regarding primary prevention strategies, health promotion and campaigns is summarized in Tables 6 and 7.

Table 6. Programs and documents related to alcohol intake, diet, physical activity and tobacco consumption in Aragon.

	ALCOHOL INTAKE		DIET		PHYSICAL ACTIVITY		TOBACCO	
	Prog	Docs	Prog	Docs	Prog	Docs	Prog	Docs
Aragon	√	√	√	√	√	√	√	√

Table 7. Existence of Ictus program, actions related to hypertension (HT) and atrial fibrillation (AF), Indicators and Evaluation in Aragon.

	Stroke programs		HT action	AF action	Indicators	Evaluation
	Available	Ambit				
Aragon	Stroke	Local	Planned	Planned	planned	Planned

b) Stroke awareness campaigns

Over the last five years, The Stroke Foundation of Aragon (AIDA), as part of its dissemination and awareness-raising acts on stroke and in addition to organising events such as setting up tents with information points, has launched awareness campaigns that consist on handing out brochures and journals with information about the disease during the International Stroke Day in different hospitals. These acts are coordinated with other entities (Spanish Federation of Stroke, Spanish Society of Neurology, MAPFRE Foundation, Freno al Ictus). These campaigns have had different themes and slogans (e.g. "Take out the superhero you have inside", "Stroke: prevent, learn, act",

"Run: every minute counts"). An awareness campaign was carried out and supported by the Department of Health in 2019 including videos and posters, and a day for the presentation was made. The description of this campaign is given in Table 8.

Table 8. Stroke awareness campaign carried out in Aragon.

	Date	Tool	Item	Number	Evaluation
Aragon	2019	Tent	F.A.S.T.	Stroke Day	No

3.1.3 Attention in acute phase: organization of stroke services and management of acute stroke

At the time of writing this document we do not have the final results of some deliverables, hence the same information is described for all regions.

a) Data from Interactive maps on thrombectomy (from Deliverable 1.6.2)

The project's web portal has been developed by AQuAS, it includes interactive maps with quality indicators in the care process during the acute phase of stroke for those patients who have received endovascular treatment in all participating regions. For this it was necessary to reach consensus on the selection of variables to be collected (see Deliverable 1.1) and establish rigorous interoperability criteria (see Deliverable 1.3).

In the interactive map, assessment can be made globally or by region. Process and outcome indicators are shown separately. A table with all regions and indicators is included to allow comparison between regions.

At the present time, it is in the validation phase and no specific regional recommendations can be drawn from it; therefore, general recommendations are given.

b) Data from the Report comparing the provision of Stroke Code across ICTUSnet regions, process mining (from Deliverable 3.3.2.)

Process mining has been led by IACS given its experience in the analysis of the acute stroke care process in the Aragon region (Construction of Empirical Care Pathways Process Models from Multiple Real-World Datasets, IEEE Journal of Biomedical and Health, 2020).

Care pathways (CPWs) are "multidisciplinary care plans that detail essential care steps for patients with specific clinical problems" and work on how to apply an existing process mining methodology to construct the empirical CPW process models in the acute stroke setting in each region.

It was decided to frame the analysis for patients admitted to a hospital with suspected stroke. Each region had a different way of recording the events associated with date and time (logs) necessary to draw the circuits followed by each patient, so that a strictly comparable result between regions has not been obtained. Therefore, only general recommendations could be given.

c) Data from Application for the standardization of multilingual clinical documents, text mining (from Deliverable 2.3)

Barcelona Supercomputing Center has described the rule-based normaliser tool used to pre-annotate the Gold Standard and analyse the structure of discharge stroke reports. The eventual deep learning normaliser, trained with the Gold Standard, is described in Deliverable 2.4; in addition, the normaliser pre-processes medical records in order to identify and standardise the different sections of the text according to a common general scheme. The mapping of the clinical information following different report models in a common scheme will favour the subsequent text mining process. The code can be found in GitHub.

In scenarios such as ICTUSnet, in which different hospitals are involved, the heterogeneity of the data to be processed is an important aspect to take into account. Clinical documents present a very high variability, as each centre uses its own templates and formats. Often, even the same centre can use different styles, formats, and templates. Therefore, it is necessary to implement clinical document normalisation process and to define interoperable document architecture. Consequently and as an objective of the project, a standardiser tool has been developed, that would facilitate the task of data mining and allow for more effective data and results comparison between hospitals using the reference archetypes suggested by the Spanish Ministry of Health.

This tool can help to extract relevant information in the acute stroke care process from hospital discharge reports when it is not possible to set up an appropriate registry.

3.1.4 Follow-up and rehabilitation plan in stroke: rehabilitation, secondary prevention, life after stroke

From Deliverable 3.5: COMPARATIVE ANALYSIS OF RESOURCES AVAILABLE FOR THE FOLLOW UP AND REHABILITATION OF STROKE PATIENTS.

a) Pathways in stroke rehabilitation

The Stroke care process included in the Aragon Stroke Plan covers the different rehabilitation needs of patients throughout their lives since the first stroke.

In Deliverable 3.5 are described the actions to carry out according to the clinical characteristic of the patients and the phase in which they are. In addition, the objectives to be met, the requirements, and the professionals involved are established. It is also settled that the rehabilitation process must be continuous from the acute phase to the subacute and chronic phases, with the appropriate intensity and duration as well as with the necessary periodic evaluations and the involvement of caregivers or family members.

b) Resources for stroke survivors

In 7 out of 8 health sectors, special beds have been established for the care of patients during the acute phase of stroke. These beds are attended cared for by a multidisciplinary professional team, with special interest and dedication to stroke, organised in Stroke Process Teams (one in each Sector). Regarding the resources, Aragon plan counts on an exhaustive list of available material resources in the stroke areas.

Therapies

According to the Aragon Stroke Regional Plan, the beginning of the rehabilitation should start as soon as possible, as long as the patient's clinical situation allows it. The type of treatment and the areas of intervention vary depending on the type of the dysfunctionalities of the patient. Communication disorders: speech therapist; Neuropsychological disorders: cognitive deficits and behavioural disorders; Motor function disorders: stroke physiotherapists; Limitation in activities of daily living: multidisciplinary team that includes occupational therapy; Spasticity: physical therapies and then consider options for oral medication and botulinum toxin infiltrations.

Quality of Life services

The Aragon Stroke Plan includes “Socio-health care and support for dependency” that is a study on the social situation of the patients, which includes the support of a social worker, to assess the capacities of the patients to go back to their previous jobs.

During the rehabilitation process, all patients hospitalised in Aragon centres receive a social report which provides information to facilitate access to adequate health and social resources.

The Aragon Stroke Plan stands out for mentioning and supporting patient associations through the guidelines. The document appoints patient associations and their key role not only in the dissemination of the disease and the needs of its members, but also in the integration and socialisation of patients and in the knowledge and management of their disease. In that sense, Aragon supports and encourages their work to be of quality and to reach as many people as possible. To this end, a list of patient associations in the regions is included.

Services for caregivers

One of the main requirements explained in the Aragon Regional Plan is that any rehabilitation treatment must include training for family and caregivers to facilitate the active participation of family members and patients in the rehabilitation process (explanatory brochures on postural treatment, transfers, etc.).

Social services and patient associations can help to maintain the level of social and leisure activities of the caregivers through advice on all social resources available and actions aimed at the reintegration and participation of people with stroke. Community activities should be evaluated as an option to help patients and caregivers in this regard.

Personnel

The PAIA defines the human resources for stroke units and the training among all the personnel involved in the stroke care processes.

With specific objectives: a) to include best practices related to stroke care, identification and patients transfer in the continuing education programmes; b) to favour the access of health personnel (doctors, nurses, occupational therapists, physiotherapists) to content and skills that improve their practices and relationships with stroke patients.

c) Follow-up of stroke survivors

Assessment

One of the main requirements explained in the Aragon Regional Plan is that any rehabilitation treatment in acute or subacute phase must have continuous evaluation. The use of objective scales makes it possible to identify problems, establish objectives, and determine the effectiveness of the interventions made. The Plan recommends evaluating aspects of mobility, language, and cognitive functioning.

Sequelae

The services related to patient sequelae follow-up are carried out fundamentally by the Primary Care Services as explained in the PAIA. The main objectives are to evaluate and treat any complication that patients may have, and to assist patients on the recovery of their functional losses. To standardise the follow-up of patients with chronic stroke sequelae and ensure access to evidence-based rehabilitation interventions, it is recommended to use the Post-Stroke Checklist (PSC). For the evaluation of daily life activities, the plan recommends to use the Barthel Index since it has been shown to be valid, reliable, and of simple application. Alternative scales are recommended such as Measure of Functional Independence which measures daily life activities, cognition, and functional communication.

d) Secondary prevention

In Aragon region, secondary prevention actions start at the acute phase, continuing during the subacute phase until the chronic phase, as detailed in the PAIA. One of the objectives of the Aragon stroke plan is to reduce the incidence of stroke by controlling risk factors, promoting lifestyle habits, and maintaining a preventive medical treatment appropriate. Now, the PAIA group has developed a stroke follow-up plan in Primary Care that includes adherence to treatment, promotion of interventions on risk factors, assessment and prevention of sequelae, and rehabilitation needs. Health outcome indicators will be drawn from this plan. The information system for post stroke follow-up is incorporated into the primary care electronic registry.

3.1.5 Recommendations

Recommendations related to healthy lifestyle habits:

The Health Ministry of Aragon should be asked to:

- Obtain and facilitate the proposed outcome indicators that are in line with those suggested by WHO, NCD, and SAP (see Deliverables 3.1 and 3.2).
- Include the risk of stroke in population campaigns that are promoted.
- Keep a coordinated work together with professionals involved and patient associations to obtain indicators, campaign assessment with evaluation of outcomes and their impact.

Recommendations related to hypertension:

The Health Ministry of Aragon should be asked to:

- Make a greater effort against hypertension, as the most important risk factor in the occurrence of stroke, to carry out campaigns on the detection of hypertension in the population at risk, to support campaigns on control and adherence to medication and risk of abandonment in patients with hypertension.
- Obtain and facilitate the proposed outcome indicators that are in line with those suggested by WHO, NCD, and SAP) (the proposed indicators are developed in Deliverables 3.1 and 3.2).
- Include the risk of stroke in population campaigns promoted on hypertension.
- Work together with professionals involved and patient associations to obtain indicators, campaign assessment, and outcomes evaluation and their impact.

Recommendations related to atrial fibrillation:

The Health Ministry of Aragon should be asked to:

- Publicise the importance of atrial fibrillation and previous detection to prevent stroke.
- Enhance screenings for detection of atrial fibrillation in the population at risk.
- Include atrial fibrillation indicators in the list of indicators collected in Primary Care.
- Support arrhythmia control campaigns through the pulse in close connection with Primary Care services and pharmacists.
- Adopt or evaluate the use of personal heart rhythm analysis devices to aid in the diagnosis of paroxysmal atrial fibrillation and their integration with health IT systems.

Recommendations related to stroke awareness campaigns:

The Health Ministry of Aragon should be asked to:

- Enhance the collaboration with scientific societies, patients' associations, professionals, and stakeholders involved to promote periodic campaigns.
- Increase the number of campaigns focused on different aspects of cerebrovascular disease.

- Evaluate the campaigns and publish and assess their results and impact.

Recommendations related to attention in the acute phase:

The Health Ministry of Aragon should be asked to:

- Review the number of stroke units in the region and adapt them to current recommendations.
- Promote the accreditation of every hospital according to ESO criteria.
- Guarantee human and material resources for early and accurate assessment of stroke patients.
- Guarantee access to a stroke unit regardless of patients' geographical location.
- Guarantee rapid access to reperfusion treatment with equity criteria.
- Review the regional stroke registry for all levels of care including emergency services.
- Develop a regularly update stroke registry maintenance plan.
- Collect the variables considered essential to develop comparable quality indicators between regions (specified in the Evaluation Framework (see Deliverable 3.1) following the SAP-E/SAFE guidelines).
- Assess the use of mobile applications to facilitate data collection.
- Maintain the plan for periodic review of process and outcome indicators for stroke patients in order to establish actions for improvement (audit).
- Keep the professionals involved informed (feedback).
- Extract information from discharge reports using the developed tool (data mining) to build the necessary quality indicators, in case of not being able to extract information from registers or until its full implementation.
- Set deadlines for updating process mining with the necessary IT tools (public and free of charge) to be able to compare processes and establish improvement actions.
- Accredit the referral stroke units.
- Develop and implement (or maintain) with the necessary frequency a stroke training plan for all professionals involved.

Recommendations related to follow up and rehabilitation of stroke patients:

The Health Ministry of Aragon should be asked to:

- Include, if not, the global rehabilitation process at all healthcare levels.
- Incorporate the entire regional rehabilitation process (of all involved centres) into the integrated health records.
- Select the process and outcome indicators according to the Evaluation Framework and the list proposed in Deliverable 3.5 to assess the entire process.
- Ensure equitable access to the continuum of stroke care, guaranteeing that at least 90% of the stroke population has access to early rehabilitation within the stroke unit.
- Address the organisation of enough stroke rehabilitation services.
- Work to provide an early supported discharge for at least 20% of the stroke population.
- Ensure that all stroke patients and their caregivers have a review of their rehabilitation and other needs reviewed every 6 months after stroke if necessary.
- Incorporate secondary prevention into the integrated health records including all healthcare levels, not solely primary/community care.
- Improve and monitor the provision of secondary prevention services as much as necessary to ensure that up to 90% of the stroke population will be seen by a stroke specialist (if needed) and will have access to secondary prevention management (investigation and treatment).
- Evaluate secondary prevention with properly indicators (see Deliverable3.5).

- Address the long-term unmet needs in life after stroke (see Deliverable 3.6 and "Shared clinical decision-making in stroke care" document).
- Set out, through the Aragon stroke plan and Stroke Foundation of Aragon, the support that will be provided to stroke survivors regardless of their place of residence and socio-economic status.

3.2 Balearic Islands

3.2.1 General data

The general data of Balearic Island are provided in Table 9.

Table 9. General data of Balearic Islands.

Category	Item	Current situation
General information	Population:	1.115.999 inhabitants
	Number of hospitals:	7
	Number of healthcare professionals:	14.289
	Health system	Public Health System called “Servei de Salut Illes Balears”.
ICT characteristics	Use of standards:	• HL7. • ICD-10 to encode diagnosis. • Experience in SNOMED CT to structure the EHR information.
	EHR situation:	There are 3 different EHR platforms in the Public Health System: Primary Care uses e-SIAP, Hospital Univesitario Son Espases (HUSE) uses Cerner-Millennium and rest of Hospitals use HCIS.
Stroke related information	Regional stroke program:	Regional stroke code. BI stroke strategy.
	Reference stroke hospital:	Thrombectomy treatments: Hospital Universitario Son Espases, Palma de Mallorca.
	Number of stroke cases per year:	700 patients (HUSE) per year: 86.6 % correspond to ischemic strokes and, in 2019, 10% of these were treated (fibrinolytic) intravenously and 20% benefited from endovascular treatment.
	Stroke registry:	They have 2 different stroke specific registries, one in HUSE and another one in Son Llàtzer Hospital. The HUSE registry is integrated and thrombectomy variables could be mapped on to SNOMED-CT.
	Stroke structured information:	In the EHR system, the entire data set considered in ICTUSnet project has been structured.

Balearic Islands has updated documents and web sites related to (see Annex I):

- Strategic Health Plan of Balearic Islands (Pla Estratègic 2016-2020).
- Balearic Islands Stroke Strategy 2017-2021.
- Recommendations for action in primary care in cerebrovascular disease 2014.
- Association of Patients with Acquired Brain Injury of the Balearic Islands (REHACER).

3.2.2 Primary prevention strategies, health promotion and campaigns

From Deliverable 3.2: COMPARATIVE STUDY OF PRIMARY PREVENTION STRATEGIES, HEALTH PROMOTION AND CAMPAIGNS.

a) Healthy lifestyle

Does the region have updated Health Programs/Plans containing healthy life / hypertension / atrial fibrillation strategies? Do they have available documents?

The Strategic Health Plan of Balearic Islands (Pla Estratègic 2016-2020, Conselleria de Salut de les Illes Balears) enhances to promote **healthy eating and active life** through various campaigns:

a) The Mediterranean flavour campaign ("Sabor Mediterrani"), where organizations get the label "Sabor Mediterrani" and the Mediterranean diet is promoted in educational and health centres as well as with the Balearic Tourism Agency within the framework of the Gastronomic Product Club to promote the project; a Mediterranean diet recipe book was finalized with the College of Nutritionist Dietitians and with the research team PREDIMED and UNESCO that was published in 2018.
b) "Healthy routes" campaign ("Rutas Saludables") to promote physical activity. Besides, the Health Promotion Service coordinates the Health Promotion Educational Centres (CEPS) Program, in collaboration with the Ministry of Education, to promote that the entire educational community adopts healthy lifestyles in a health-friendly environment.
c) The fight against **smoking** is one of the priorities established by the General Directorate of Public Health and Participation. Furthermore a series of prevention, promotion, and intervention actions in Education Centres and Primary Care Centres were developed within the collaboration between Primary Care, Specialised Care and Central Health Services, professionals and technicians from the General Directorate of Public Health and Participation Health Promotion, Disease Prevention, Drug Coordination, Environmental Health and Health Protection Department developed.
d) As part of the Addiction and Drug Addiction Plan of the Balearic Islands (PADIB), there is a program and a catalogue to address addictions mainly focused on smoking and cannabis consumption. The catalogue is divided into 5 areas of intervention (Educational, Family, Community, Leisure, and Work).
e) Regarding alcohol, there is a committee of experts on the consumption of alcohol risk and alcohol abuse disorders (Primary Care, addictive behaviours unit (UCA), unit for patients related to alcohol (UPRA), the PADIB and the Health Service). This committee prepares and disseminates information material and organises training aimed at professionals and activities to raise awareness among the population.

The Mallorca Primary Care Management has a consensual document specifically directed to stroke (Recommendations for action in primary care in cerebrovascular disease; Recomanacions d'actuació a l'atenció primària en la malaltia cerebrovascular, ISBN: 978-84-693-9758-9) that includes primary prevention recommendations about healthy lifestyles, hypertension, atrial fibrillation, and other risk factors. But this document is not updated.

Recently, primary care professionals wanted to improve the resolution capacity of their teams to monitor arterial hypertension and increase the provision of ambulatory blood pressure monitoring devices (ABPM) in order to make possible the diagnosis of arterial hypertension with outpatient techniques, as recommended today, in addition to monitoring the degree of control acquired with antihypertensive treatment. The Balearic Stroke Strategy refers to such document.

Do they have specific programs to address primary prevention in Stroke? Is there any specific section for evaluation?

This region has the *Balearic Islands Stroke Strategy 2017-2021*. The main objectives are to reduce the incidence of stroke in the Balearic Islands and to guarantee its immediate identification, approach, treatment and follow-up, following standards of quality of care that allow improving the quality of life of patients and their families. There is a specific objective related to primary prevention so-called "Reduce the incidence of TIA and / or stroke" which specifies the actions necessary to carry it out.

In general terms, it could be said that the best treatment for any disease is its prevention. In the specific case of stroke, it is estimated that 80% of them could be prevented if vascular risk factors were recognised and treated in time. The promotion of healthy environments and lifestyles, through the coordination of interventions in the health, family, educational, and community ,spheres can prevent stroke in people who have never had symptoms of cerebrovascular origin (primary prevention) or, if already first episode has happened , seek to avoid it from happening again (secondary prevention).

The document contemplates an evaluation plan to be carried out after 2021 based on the indicators of the National Health System Strategy and complemented with its own indicators which will be defined by a working group of experts to complement the assessment of the National Health System Strategy.

Which is the approach of the objectives regarding Healthy lifestyle campaigns?

The International Society of Hypertension and the World Hypertension League launched the May Measurement Month (MMM 2018) campaign with the aim of measuring the blood pressure during the month of May to the largest possible number of people over the age of 18, mainly to all those who blood pressure (BP) has not been measured in the last year. In Spain, this project is led by the Spanish Society of Family and Community Pharmacy (SEFAC) with the collaboration of several pharmacist colleges. So far, the project has the participation of more than 800 pharmacists who have registered more than 1,100 cases. In the last year edition, 190 pharmacists participated and at the end of the campaign more than 3,300 cases were registered and 25% of these had high blood pressure. In this project, in addition to measuring BP, pharmacists offer practical information on the prevention and control of hypertension as well as healthy lifestyle habits. SEFAC has been working for years to improve the preparation of community pharmacists through the impact program developed in collaboration with the Spanish Society of Hypertension-Spanish League for the fight against arterial hypertension (SEH-LELHA). This program, in which more than 1,700 community pharmacists from all over Spain are enrolled, trains them to overcome its different phases (theoretical, practical, and case registration) for the provision of BP measurement and control services and the calculation of vascular risk.

Alcohol campaigns are mainly targeted to the youth, as the recent one "We cannot keep looking elsewhere" ("No podem seguir mirant a un altre costat"). In 2018 within the framework of the World No Alcohol Day, the Mallorca Primary Care Management and the General Directorate of Public Health and Participation, through the PADIB, organised a day to raise awareness among the population about the consumption of this substance.

SEFAC led in Spain the Know your pulse campaign (from AF Association), which started in November 2018 and it is now complete. There is still no evaluation of the results of this campaign. To our knowledge, there were no specific campaigns in Balearic Islands.

The *Balearic Islands Stroke Strategy 2017-2021* has a specific objective with a description of the actions to achieve it in relation to the campaigns: "Disseminate knowledge about stroke so that the

population knows how to prevent it, how it manifests itself and how to respond to symptoms when they appear. Publicise the updated situation of stroke assistance in the Autonomous Community of the Balearic Islands".

The information regarding primary prevention strategies, health promotion and campaigns is summarised in Tables 10 and 11.

Table 10. Programs and documents related to alcohol intake, diet, physical activity, and tobacco consumption in Balearic Islands.

	ALCOHOL INTAKE		DIET		PHYSICAL ACTIVITY		TOBACCO	
	Prog	Docs	Prog	Docs	Prog	Docs	Prog	Docs
Balearic Islands	√	√	√	√	√	√	√	√

Table 11. Existence of Ictus program, actions related to HT and AF, Indicators and Evaluation in Balearic Islands.

	Stroke programs		HT action	AF action	Indicators	Evaluation
	Available	Ambit				
Balearic Islands	Stroke	Local	√	not found	planned	planned

b) Stroke awareness campaigns

Annually on International Stroke Day, a coordinated campaign is launched in Mallorca together with other entities (Spanish Federation of Stroke and Spanish Society of Neurology). These campaigns have had different themes and slogans. The Association of Patients with Acquired Brain Injury of the Balearic Islands (REHACER) has organised a "Walk for Stroke" in recent years.

On March 2019, MAPFRE Foundation, The Spanish Society of Neurology, and Freno al Ictus presented the campaign "Stroke: avoid, learn and act" to raise the general population awareness about Stroke with the support of the Balearic Island Government, the Palma Council, the Balearic Society of Neurology, and t REHACER patients' organization,. MAPFRE placed a tent for two days at Plaça Major where information regarding how to prevent, detect, and act when a person has a stroke was provided. There is no result of a formal assessment of this campaign. The description of this campaign is given in Table 12.

Table 12. Stroke awareness campaign carried out in Balearic Islands.

	Date	Tool	Item	Number	Evaluation
Balearic Islands	2019	Tent	ICTUS	2 days	No

3.2.3 Attention in acute phase: organization of stroke services and management of acute stroke

At the time of writing this document we do not have the definitive results of some deliverables, hence the same information is described for all regions.

a) Data from Interactive maps on thrombectomy (from Deliverable 1.6.2)

The project's web portal has been developed by AQuAS, it includes interactive maps with quality indicators in the care process during the acute phase of stroke for those patients who have received endovascular treatment in all participating regions. For this it was necessary to reach consensus on the selection of variables to be collected (see Deliverable 1.1) and establish rigorous interoperability criteria (see Deliverable 1.3).

On the interactive map, assessment can be done globally or by region. Process and outcome indicators are shown separately. A table with all regions and indicators is included to allow comparison between regions.

At the present time, it is in the validation phase and no specific regional recommendations can be drawn from it; therefore, general recommendations are given.

b) Data from the Report comparing the provision of Stroke code across ICTUSnet regions, process mining (from Deliverable 3.3.2.)

Process mining led by IACS given its experience in the analysis of the acute stroke care process in the Aragon region (Construction of Empirical Care Pathways Process Models from Multiple Real-World Datasets, IEEE Journal of Biomedical and Health, 2020).

Care pathways (CPWs) are "multidisciplinary care plans that detail essential care steps for patients with specific clinical problems" and work on how to apply an existing process mining methodology to construct the empirical CPW process models in the acute stroke setting in each region.

It was decided to frame the analysis for patients admitted to a hospital with suspected stroke. Each region had a different way of recording the events associated with date and time (logs) necessary to draw the circuits followed by each patient, so that a strictly comparable result between regions has not been obtained. For this reason, only general recommendations could be given.

c) Data from Application for the standardization of multilingual clinical documents, text mining (from Deliverable 2.3)

Barcelona Supercomputing Center has described the rule-based normalizer tool used to pre-annotate the Gold Standard and analyses the structure of discharge stroke reports. The eventual deep learning normaliser, trained with the Gold Standard, is described in Deliverable 2.4; in addition, the normaliser pre-processes medical records in order to identify and standardise the different sections of the text according to a common general scheme. The mapping of the clinical information following different report models in a common scheme will favour the subsequent text mining process. The code can be found in GitHub.

In scenarios such as ICTUSnet, in which different hospitals are involved, the heterogeneity of the data to be processed is an important aspect to take into account. Clinical documents present a very high variability, as each centre uses its own templates and formats. Often, even the same centre can use different styles, formats and templates. Therefore, it is necessary to implement clinical document normalisation process and to define interoperable document architecture. Consequently and as an objective of the project, a standardiser tool has been developed that would facilitate the task of data mining and allow for more effective comparison of data and results between hospitals using the reference archetypes suggested by the Spanish Ministry of Health.

This tool can help to extract relevant information in the acute stroke care process from hospital discharge reports when it is not possible to set up an appropriate registry.

3.2.4 Follow-up and rehabilitation plan in stroke: rehabilitation, secondary prevention, life after stroke

From Deliverable 3.5: COMPARATIVE ANALYSIS OF RESOURCES AVAILABLE FOR THE FOLLOW UP AND REHABILITATION OF STROKE PATIENTS.

a) Pathways in stroke rehabilitation

The Balearic Islands Stroke Strategy 2017-2021 has as main objectives to reduce the impact of stroke in the Balearic Islands region and to guarantee prompt stroke identification, treatment, and follow up. It aims to follow standards that allow improving the quality of life of patients and their families. The model explained in the Stroke Plan includes strategic lines towards the improvement of the rehabilitation process, which must be comprehensive, start early, be continuous, and provide the appropriate level of care for each patient who requires it with an: In order to achieve car continuity, the rehabilitation process involves an effective coordination between all health care devices , the social area devices, the resources integrated within the scope of the Ministry of Health, and the network of associations to get better care for affected people and their families.

The Stroke Strategy for the Balearic Islands includes 7 areas of strategic interest, for which 12 specific objectives have been identified. Altogether, it involves 56 strategic actions lines made up of 287 specific actions. Two of the specific objectives refer to rehabilitation and life after stroke: 1) to increase the percentage of people with stroke who are fully reintegrated into their personal and social life and 2) to provide care and support to the person with disability and their family, including specific actions to be developed.

In order to obtain a rather similar rehabilitation process in the region, the strategy contemplates the creation of general healthcare documents (protocols, programmes, and clinical guidelines) that include work guidelines for both assessment and treatment in the neurological areas with stroke deficits, which are typically affected by strokes.

This strategy provides an overview of the trajectory that patients follow after suffering a stroke, which should be structured for early or acute phase care, for subacute care, and for chronic phase care. After hospital discharge, patients can either return to their home with follow-up by their Primary Care team —if their health condition allows it—, or enter another medium or long stay hospital center to continue with their rehabilitation and receive the appropriate care.

The objectives described in the Balearic Islands Stroke Strategy Plan consider rehabilitation in the acute phase of stroke as a continuous process linked to the rehabilitation after hospital admission. The levels of care should include: acute care hospital, inpatient neurorehabilitation, outpatient rehabilitation in hospital, rehabilitation at home, outpatient rehabilitation in primary care, medium and long-stay rehabilitation hospital, and total or partial long-stay in residential care homes. Before discharge from hospital, the rehabilitator should evaluate the rehabilitation indication to determine the equipment or adaptations that can increase the safety and functional independence of the patient. This information should be included in the registration report.

b) Resources for stroke survivors

The Balearic Islands has two half-stay hospital centres dedicated to stroke in the subacute phase, the General Hospital, which has a programme specifically defined for stroke care, and the San Juan de Dios Hospital, which counts with neurorehabilitation for acquired brain damage, including cerebrovascular disease. Acute stroke hospitals provide rehabilitation in this period and on an outpatient basis. Stroke-specific home physiotherapy is also available.

Quality of Life services

The Strategic Plan in the Balearic Islands has a specific objective aimed at increasing the percentage of stroke patients who fully reintegrate in their personal and social life. Among other actions, the Plan encourages rehabilitation teams to have a specific stroke programme focused on the lives of stroke patients to provide social and health services and services for those who, after stroke, present

sequelae consisting of severe mobility, sensory or cognitive deficits which cover therapeutic actions or resources such as day centres, night centres or part-time care homes.

All the resources and services available aimed at improving the quality of life of stroke patients will be duly explained in a document available at the stoke units. The Plan also promotes the use of global scales of function as well as outcome measures, which include instrumental activities of daily life and advanced mobility and adapt them to the cultural and gender environment of the person.

The Balearic Islands Stroke Plan has as an objective to promote employment of people with disabilities caused by stroke. The Plan envisages supporting the organisations in the development and aid for companies that maintain employees or generate employment for people with sequelae after a stroke.

Services for caregivers

The Balearic Islands Stroke Plan defines as an objective the evaluation of the social support needs before and after hospital admission of both the patients and caregivers. The strategy aims at developing training workshops for stroke caregivers that include the necessary measures for the management of sequelae and prevention of complications.

Personnel

One of the main pillars of the Balearic Islands Stroke Strategy is to enhance the training of professionals in the public health system to adequately address the needs of stroke patients and promote a comprehensive and integrated approach to the disease.

c) Follow-up of stroke survivors

Assessment

The Balearic Islands Stroke Strategy Plan aims to evaluate the services provided by using the indicators of the National Health System Strategy together with the indicators described along the plan.

d) Secondary prevention

Two of the specific objectives of the Stroke Strategy in the Balearic Islands are to reduce the recurrence of strokes in the region, and that of vascular events in a location other than the brain after a first cerebrovascular event. To this end, the Stroke Strategy defines a series of strategic lines to be followed, such as monitoring vascular risk factors in those who have already suffered a stroke or ensuring continuity of care as a tool to reduce mortality. To follow such strategic lines, the plan foresees a series of actions related to secondary prevention, among which are the dissemination of thematic content with professionals, patients and caregivers, organization of awareness workshops for stroke survivors, and promotion of self-care.

The document “Recomanacions d’actuació a l’atenció primària en la malaltia cerebrovascular” establish secondary prevention recommendations for the most prevalent vascular risk factors.

3.2.5 Recommendations

Recommendations related to healthy lifestyle habits:

The Health Ministry of Balearic Islands should be asked to:

- Obtain and facilitate the proposed result indicators that are in line with those suggested by WHO, NCD, and SAP (see Deliverables 3.1 and 3.2).
- Include the risk of stroke in population campaigns promoted on healthy lifestyle habits.

- Work together with the professionals involved and the patients associations to obtain indicators, campaign assessment and evaluation of outcomes and their impact.

Recommendations related to hypertension:

The Health Ministry of Balearic Islands should be asked to:

- Make a greater effort against hypertension, as the most important risk factor in the occurrence of stroke; to carry out campaigns on the detection of hypertension in the population at risk; to give support to the campaigns about the control and adherence to medication and risk of abandonment in patients with hypertension.
- Obtain and facilitate the proposed outcome indicators that are in line with those suggested by WHO, NCD, and SAP (see Deliverables 3.1 and 3.2. where the proposed indicators are developed).
- Include the risk of stroke in population campaigns promoted on hypertension.
- Work together with professionals involved and patient associations to obtain indicators, campaign assessment and evaluation of outcomes and their impact.

Recommendations related to atrial fibrillation:

The Health Ministry of Balearic Islands should be asked to:

- Publicise the importance of atrial fibrillation and previous detection to prevent Stroke.
- Enhance screenings for detection of atrial fibrillation in the population at risk.
- Support arrhythmia control campaigns through the pulse in close connection with Primary Care services and pharmacists.
- Adopt or evaluate the use of personal devices that allow heart rhythm analysis to aid in the diagnosis of paroxysmal atrial fibrillation.

Recommendations related to stroke awareness campaigns:

The Health Ministry of Balearic Islands should be asked to:

- Collaborate with scientific societies, patient associations, professionals, and stakeholders to promote periodic campaigns.
- Increase the number of campaigns focused on different aspects of cerebrovascular disease.
- Evaluate the campaigns and publish and assess their results and impact.

Recommendations related to attention in the acute phase:

The Health Ministry of Balearic Islands should be asked to:

- Review the number of stroke units in the region and adapt them to current recommendations.
- Guarantee human and material resources for early and accurate assessment of stroke patients.
- Guarantee access to a stroke unit regardless of patient's geographical location.
- Guarantee rapid access to reperfusion treatment with equity criteria.
- Create a regional stroke registry for all levels of care including emergency services.
- Develop a regularly updated stroke registry maintenance plan.
- Collect the variables considered essential to develop quality indicators comparable between regions (specified in the evaluation framework following the SAP-E guidelines, see Deliverable 3.1).
- Assess the use of mobile applications to facilitate data collection.
- Develop a plan for the periodic review of the process and outcome indicators of stroke patients in order to establish improvement actions.

- Keep the professionals involved informed (feedback).
- Extract information from discharge reports using the developed tool (data mining) to build the necessary quality indicators, in case of not being able to extract information from registers or until its full implementation.
- Assess the incorporation of process mining with the necessary IT tools (public and free of charge) to be able to compare processes and establish improvement actions.
- Accredit the referral stroke units.
- Develop and implement with the necessary frequency a stroke training plan for all professionals involved.

Recommendations related to follow up and rehabilitation of stroke patients:

The Health Ministry of Balearic Islands should be asked to:

- Create a comprehensive rehabilitation plan for develop the actions described in the Balearic Islands Stroke Strategy, including all healthcare levels and the complete rehabilitation process.
- Incorporate the entire regional rehabilitation process (of all involved centres) into the integrated health records.
- Incorporate indicators (process/outcome) to assess the process.
- Ensure equitable access to the continuum of care in stroke, guaranteeing that at least 90% of the stroke population has access to early rehabilitation within the stroke unit.
- Address the organisation of enough stroke rehabilitation services.
- Analyse human and material resource needs to ensure that each patient receives the necessary rehabilitation by specialised professionals. In case of lack of these resources, provide them.
- Work to provide an early supported discharge for at least 20% of the stroke population.
- Ensure that all stroke patients and caregivers have their rehabilitation and other needs reviewed every 6 months after stroke if necessary.
- Evaluate all the processes and results of rehabilitation using the indicators proposed in the Evaluation Framework and in Deliverable 3.5.
- Incorporate secondary prevention into the integrated medical record at all healthcare levels (comprising primary/community care).
- Update and implement throughout the region the document Recommendations for action in primary care in cerebrovascular disease.
- Improve and monitor the provision of secondary prevention services as much as necessary to ensure that up to 90% of the stroke population will be seen by a stroke specialist (if needed), and will have access to secondary prevention management (investigation and treatment).
- Address the long-term unmet needs in life after stroke (see Deliverable 3.6 and "Shared clinical decision-making in stroke care" document).
- Set out, through the stroke strategy, the support that will be provided to stroke survivors regardless of their place of residence and socio-economic status.
- Evaluate secondary prevention with properly indicators (see Deliverable 3.5).

3.3 Catalonia

3.3.1 General data

The general data of Catalonia are provided in Table 13.

Table 13. General data of Catalonia.

Category	Item	Current situation
General information	Population:	7.518.913 inhabitants
	Number of hospitals:	71
	Number of healthcare professionals:	130.000
	Health system:	Public Health System called "SISCAT (Sistema sanitari integral d'utilització pública de Catalunya)".
ICT characteristics	Use of standards:	• HL7, DICOM and IHE. • ICD-9 and ICD-10 to encode diagnosis and procedures (hospital and primary care datasets, respectively). • LOINC for laboratory test. • SNOMED CT as reference terminology for the EHR.
	EHR situation:	20-30% of hospitals have the same EHR system but the remaining 80-70% use different EHR systems.
Stroke related information	Regional stroke program:	A regional Stroke program and a stroke code network exist.
	Reference stroke hospital:	27 hospitals in Catalonia are part of the so-called Stroke code network (6 Comprehensive Stroke Centres, 8 Primary stroke Centres, and 13 Community Hospitals with Telestroke).
	Number of stroke cases per year:	>13,000 episodes per year, of which just over 800 involve treatment with Mechanical Thrombectomy.
	Stroke registry:	A centralised stroke registry exists, called CICAT, but it is not integrated with the different EHR systems.
	Stroke structured information:	The information is structured in the register but not in the different EHR systems, with the exception of hospitals sharing a common HER system.

Catalonia counts with specific guidelines and protocols for stroke condition and has updated documents and web sites related to (see Annex I):

- Action Plan for Vascular Diseases 2017-2019 by Catalan Master Plan for the diseases of the Circulatory System.
- Stroke Program.
- Catalan Stroke Guidelines.
- Centralized stroke registry.
- Periodic audits with quality control.

The Fundació Ictus was created in 2007 to raise awareness of stroke among the population, promote research into the disease and provide support to people who have suffered from it.

It is noteworthy that Catalonia has a detailed stroke plan covering almost all the dimensions that have been identified as relevant in the ICTUSnet project.

3.3.2 Primary prevention strategies, health promotion and campaigns

From Deliverable 3.2: COMPARATIVE STUDY OF PRIMARY PREVENTION STRATEGIES, HEALTH PROMOTION AND CAMPAIGNS.

a) Healthy lifestyle

Does the region have updated Health Programs/Plans containing healthy life / hypertension / atrial fibrillation strategies? Do they have available documents?

In Catalonia an Integral Plan for the promotion of health through physical activity and healthy eating, known as PAAS, was prepared by the Ministry of Health in response to the increase observed in the prevalence of obesity, according to the World Strategy of the World Health Organization and the NAOS Strategy (Nutrition, Physical Activity and Prevention of Obesity) of the Spanish Agency for Consumer, Food Safety and Nutrition. Specific indicators are published periodically and specific programs related to the physical activity are developed. Legislation on this programme is also provided.

Do they have specific programs to address primary prevention in stroke? Is there any specific section for evaluation?

The ***Action Plan for Vascular Diseases 2017-2019*** - Pla Director d'ICTUS (Stroke Program) as part of Pla de Malalties de l'Aparell Circulatori (PDMAC) - aims to improve the attention to circulatory system diseases in Catalonia by rearranging resources and actions to promote health, disease prevention, early diagnosis, adequate treatment, and rehabilitation from a territorial perspective of social condition and of equitable and sustainable gender in order to reduce its impact on the health of the population.

Stroke Program deals with the stroke issues of the PDMAC. It is a comprehensive program dealing with the different steps of stroke: prevention, acute phase, rehabilitation and return to the community. Regarding prevention, the Stroke Program works together with the Public Health Agency of Catalonia and specific actions regarding AF has been undertaken. An *AF pathway* has been launched in 2017, and the goal is to detect the unknown people with arrhythmia in a different setting (pharmacies) and act consequently. Some actions have been undertaken with the Catalan Society of hypertension oriented to highlight the importance of HTA in stroke.

Which is the approach of the objectives regarding Healthy lifestyle campaigns?

The Public Health Agency of Catalonia is in charge of campaigns regarding healthy lifestyles, tobacco, alcohol, and drugs. They launch campaigns periodically regarding healthy lifestyles. These are local actions, in Catalonia, that take into account the special characteristics of local population and specifically on the topic (different targets in childhood obesity, smokers, and alcohol consumers) or age (approach to the healthy lifestyle is different in young or older people). The information regarding primary prevention strategies, health promotion and campaigns is summarised in Tables 14 and 15.

Table 14. Programs and documents related to alcohol intake, diet, physical activity and tobacco consumption in Catalonia.

	ALCOHOL INTAKE		DIET		PHYSICAL ACTIVITY		TOBACCO	
	Prog	Docs	Prog	Docs	Prog	Docs	Prog	Docs
Catalonia	not found	not found	√	√	√	√	√	√

Table 15. Existence of Ictus program, actions related to HT and AF, Indicators and Evaluation in Catalonia.

	Stroke programs		HT action	AF action	Indicators	Evaluation
	Available	Ambit				
Catalonia	Stroke	Local	Global	√	NO	NO

b) Stroke awareness campaigns

The Catalan Stroke Foundation (Fundació Ictus) launches periodically stroke awareness campaigns since 2009. In 2010 with the exhibition "Què tens al cap", the results were assessed on whether visitors remembered the messages 3 months later, in 2 cities (out of 15 visited). FAST actions (RAPID in Catalan) after stroke were launched periodically and the last campaign in 2018/19 was addressed to the children in collaboration with Angels Initiative. Related also the children, a campaign involving schools was launched, in 2016, through an interactive video game with monitors and teachers without further assessment.

Other approaches have been done, related to Atrial Fibrillation with the campaign "Pren-te el pols" Take the pulse, involving pharmacies and covering an area of more than 2 million people. Regarding disability, an action "Què ets capaç de fer" what are you able to do was performed in 2015. This action highlights the remaining capacities versus lost capacities through different activities.

The description of the stroke awareness campaign is provided in Table 16.

Table 16. Stroke awareness campaign carried out in Catalonia.

	Date	Tool	Item	Number	Evaluation
Catalonia	2018	Show	RAPID	Stroke Day	No

3.3.3 Attention in acute phase: organization of stroke services and management of acute stroke

At the time of writing this document we do not have the final results of some deliverables, hence the same information is described for all regions.

a) Data from Interactive maps on thrombectomy (from Deliverable 1.6.2)

The project's web portal has been developed by AQuAS, it includes interactive maps with quality indicators in the care process during the acute phase of stroke for those patients who have received endovascular treatment in all participating regions. For this it was necessary to reach consensus on the selection of variables to be collected (see Deliverable 1.1) and establish rigorous interoperability criteria (see Deliverable 1.3).

On the interactive map assessment can be done globally or by region. Process and outcome indicators are shown separately. A table with all regions and indicators is included to allow comparison between regions.

At the present time, it is in the validation phase and no specific regional recommendations can be drawn from it; therefore, general recommendations are given.

b) Data from the Report comparing the provision of Stroke code across ICTUSnet regions, process mining (from Deliverable 3.3.2.)

Process mining has been led by IACS given its experience in the analysis of the acute stroke care process in the Aragon region (Construction of Empirical Care Pathways Process Models from Multiple Real-World Datasets, IEEE Journal of Biomedical and Health, 2020).

Care pathways (CPWs) are "multidisciplinary care plans that detail essential care steps for patients with specific clinical problems" and this work on how to apply an existing process mining methodology to construct the empirical CPW process models in the acute stroke setting in each region.

It was decided to frame the analysis for patients admitted to a hospital with suspected stroke. Each region had a different way of recording the events associated with date and time (logs) necessary to

draw the circuits followed by each patient, so that a strictly comparable result between regions has not been obtained. Therefore, only general recommendations could be given.

c) Data from Application for the standardization of multilingual clinical documents, text mining (from Deliverable 2.3)

Barcelona Supercomputing Center has described the rule-based normaliser tool used to pre-annotate the Gold Standard and analyses the structure of discharge stroke reports. The eventual deep learning normaliser, trained with the Gold Standard, is described in Deliverable 2.4; in addition, the normaliser pre-processes medical records in order to identify and standardise the different sections of the text according to a common general scheme. The mapping of the clinical information following different report models in a common scheme will favour the subsequent text mining process. The code can be found in GitHub.

In scenarios such as ICTUSnet, in which different hospitals are involved, the heterogeneity of the data to be processed is an important aspect to take into account. Clinical documents present a very high variability, as each centre uses its own templates and formats. Often, even the same centre can use different styles, formats and templates. Therefore, it is necessary to implement clinical document normalisation process and to define interoperable document architecture. Consequently and as an objective of the project, a standardiser tool has been developed to facilitate the task of data mining and allow for more effective comparison of data and results between hospitals using the reference archetypes suggested by the Spanish Ministry of Health.

This tool can help to extract relevant information in the acute stroke care process from hospital discharge reports when it is not possible to set up an appropriate registry.

3.3.4 Follow-up and rehabilitation plans in stroke: rehabilitation, secondary prevention, life after stroke

From Deliverable 3.5: COMPARATIVE ANALYSIS OF RESOURCES AVAILABLE FOR THE FOLLOW UP AND REHABILITATION OF STROKE PATIENTS.

a) Pathways in stroke rehabilitation

Catalonia counts with a Master Plan for the diseases of the circulatory system which aims to approach these types of diseases, from promotion and prevention to rehabilitation, and to reduce the impact of these on population's health. The Master Plan has specific objectives for stroke care in Catalonia with the aim of continuing to develop rehabilitation and reinsertion actions for stroke patients. The main objectives described in the Master Plan are to analyse the demand for rehabilitation generated by stroke disease and its different levels of care, and the territorial integration of rehabilitation care. The two main activities described in the Master Plan are a) the design and implementation of integrated rehabilitation models (following the stroke guide recommendations); b) the coordination with the socio-sanitary Master Plan.

On another front, the Stroke Protocol (updated on 2018) count with a full section referring to stroke rehabilitation that starts during the acute phase and secondary prevention, including different guidelines to be followed by stroke professionals that will be treating the stroke patients. The rehabilitation actions and pathways are mainly focused on defining the type of stroke patient (age, needs for hospitalisation, previous functional status, clinical and social situation) and the derivation algorithm to high, medium or low intensity facilities depending on those features.

When the functional and medical status of the patient allows to, they should be discharged home at the earliest convenience. Depending on each patient, recovery programmes will be done either at home or at outpatient clinics.

The Stroke Protocol in Catalonia count with several basic principles for the rehabilitation processes, namely, the early start of rehabilitation from the acute phase, the adequate intensity, the continuity of the process throughout the different phases of attention, the active participation of patients and caregivers and the availability of the appropriate technology for the evaluation and treatment of disability.

b) Resources for stroke survivors

Three hospitals in Catalonia have monographic beds for stroke patients and there is an extensive network of convalescent or social health centres with different modalities of care for chronic patients. Home Care and Ambulatory rehabilitation are covered with public provision in an extended network covering the entire region in coordination with hospitals, socio-sanitary centres with primary care.

Therapies

Although the duration of the RHB program will depend on the severity of the stroke, usually the treatment lasts a few months as long as functional targets are identified. The Stroke Protocol pays special attention to specific areas of intervention for the rehabilitation treatment, and provides a series of evidence-based information on the best therapies available, selected for each patient individually.

Quality of Life services

The activity of occupational therapy in the person who has suffered a stroke aims at promoting the conservation or acquisition of the highest autonomy or independence in their environment attending to self-care, domestic, work and social activities including basic and instrumental daily life activities. The therapies are selected individually.

Services for caregivers

The Stroke Protocol involves caregivers since the very beginning of the stroke rehabilitation treatment. They receive information and formation on ergonomics and sanitary education for stroke patients' care before hospital discharge.

Personnel

The Stroke Protocol in Catalonia mentions the rehabilitation team, which assist patients with stroke sequelae, and is built on a RHB expert doctor who coordinates a multidisciplinary group of professionals (physiotherapists, nurses, occupational therapists, neuropsychologists, social workers and speech therapists) working together to achieve the objectives previously highlighted above.

The Catalan Master Plan includes the regulation of 4 working groups for the cerebral vascular disease constituted by external experts in the different fields, one of them for stroke rehabilitation and reincorporation into the community.

The Stroke Program in collaboration with the Catalan Stroke Foundation (Fundació Ictus) also includes a project for training stroke professionals, patients and caregivers.

c) Follow-up of stroke survivors

Assessment

In Catalonia, patients are assessed once they are in a stable condition. The Catalan Stroke Protocol mentions that one of the basic principles of stroke rehabilitation is to count with the appropriate technology for the evaluation and treatment of disability.

Catalonia has a strategy to audit the stroke care strategies, including the rehabilitation processes, with feedback collection of information and the active dissemination of the results through all hospitals in the region. As a consequence, the use of evidence-based best practices has improved clinical practices and hospitals have increased their rates on established quality indicators.

Sequelae

In Catalonia, the rehabilitation of the patient with stroke has the fundamental objective of treating the disability in order to achieve the maximum possible functional capacity, facilitating autonomy and reintegration in the family, social and working environment, reducing the risk of institutionalisation and secondary mortality. To this end, Catalonia has systematic information, education and support programmes for patients and caregivers prior to hospital discharge. The need for personal and environmental support products that enable the activity and safety of patients at community level must be evaluated.

d) Secondary prevention

The Catalan Stroke Guidelines take secondary prevention into account when advising professionals who need to treat patients at different stages (starting from acute phase and during rehabilitation). Guidelines are provided for several cases to prevent readmission or complications for stroke patients.

3.3.5 Recommendations

Recommendations related to healthy lifestyle habits:

The Health Ministry of Catalonia should be asked to:

- Obtain and facilitate the proposed results indicators that are in line with those suggested by WHO, NCD, and SAP (see Deliverables 3.1 and 3.2).
- Include the risk of stroke in population campaigns that are promoted.
- Work together with the Action Plan for Vascular Diseases to encourage professionals involved, and with the patient associations to obtain indicators, campaign assessment, and evaluation of outcomes and their impact.

Recommendations related to hypertension:

The Health Ministry of Catalonia should be asked to:

- Make a greater effort against hypertension, as the most important risk factor in the occurrence of stroke; to carry out campaigns on the detection of hypertension in the population at risk; to give support to the campaigns about the control and adherence to medication and risk of abandonment in patients with hypertension.
- Same recommendations as for healthy lifestyle habits.

Recommendations related to atrial fibrillation:

The Health Ministry of Catalonia should be asked to support and collaborate with the Action Plan for Vascular Diseases (Stroke Program) to:

- Publicise the importance of atrial fibrillation and previous detection to prevent Stroke.
- Enhance screenings for detection of atrial fibrillation in the population at risk.
- Include atrial fibrillation indicators in the list of indicators collected in Primary Care.
- Support arrhythmia control campaigns through the pulse in close connection with Primary Care services and pharmacists.

- Adopt or evaluate the use of personal devices that allow heart rhythm analysis to aid in the diagnosis of paroxysmal atrial fibrillation.

Recommendations related to stroke awareness campaigns:

The Health Ministry of Catalonia should be asked to:

- Support Catalan Stroke Foundation with scientific societies, patient associations, professionals, and stakeholders involved to keep periodic campaigns.
- Increase the number of campaigns focused on different aspects of the disease.
- Evaluate the campaigns and publish and assess their results and impacts.

Recommendations related to attention in the acute phase:

The Health Ministry of Catalonia should be asked to:

- Review the number of stroke units in the region and adapt them to current recommendations.
- Guarantee human and material resources for early and accurate assessment of stroke patients.
- Guarantee access to a stroke unit regardless of the patient's geographical location.
- Guarantee rapid access to reperfusion treatment with equity criteria.
- Create or revise a regional stroke registry for all levels of care including emergency services.
- Develop a a regularly updated stroke registry maintenance plan.
- Collect the variables considered essential to develop quality indicators comparable between regions (specified in the evaluation framework following the SAP-E guidelines, see Deliverable 3.1).
- Assess the use of mobile applications to facilitate data collection.
- Develop a plan for the periodic review of the process and outcome indicators of stroke patients in order to establish improved actions.
- Keep the professionals involved informed (feedback).
- Extract information from discharge reports using the developed tool (data mining) to build the necessary quality indicators, in case of not being able to extract information from registers or until its full implementation.
- Assess the incorporation of process mining with the necessary IT tools (public and free of charge) to be able to compare processes and establish improvement actions.
- Accredit the referral stroke units.
- Develop and implement (or maintain) with the necessary frequency a stroke training plan for all professionals involved.

Recommendations related to follow up and rehabilitation of stroke patients:

The Health Ministry of Catalonia should be asked to:

- Include the global rehabilitation process at all healthcare levels.
- Incorporate the entire regional rehabilitation process (of all involved centres) into the integrated health records.
- Adjust indicators (process/outcome) to assess all the process (see Deliverables 3.1 and 3.5).
- Ensure equitable access to the continuum of care in stroke, guaranteeing that at least 90% of the stroke population has access to early rehabilitation within the stroke unit.
- Address the organisation of enough stroke rehabilitation services.
- Work to provide an early supported discharge for at least 20% of the stroke population.
- Ensure that all stroke patients and caregivers have their rehabilitation and other needs reviewed every 6 months after stroke if necessary.

- Incorporate secondary prevention into the integrated medical record at all healthcare levels not only at primary/community care.
- Improve and monitor the provision of secondary prevention services as much as necessary to ensure that up to 90% of the stroke population will be seen by a stroke specialist (if needed) and will have access to secondary prevention management (investigation and treatment).
- Evaluate secondary prevention with properly indicators (see Deliverable 3.5).
- Address the long-term unmet needs in life after stroke (see Deliverable 3.6. and "Shared clinical decision-making in stroke care" document).
- Set out, through the Catalonia Stroke Plan and Stroke Foundation, the support that will be provided to stroke survivors regardless of their place of residence and socio-economic status.

3.4 Navarre

3.4.1 General data

The general data of Navarre are provided in Table 17.

Table 17. General data of Navarre.

Category	Item	Current situation
General information	Population:	643.234 inhabitants
	Number of hospitals:	3
	Number of healthcare professionals:	10.277
	Health system	Public Health System called “Servicio Navarro de Salud-Osasunbidea”.
ICT characteristics	Use of standards:	• HL7 with some products. • ICD-10 to encode diagnosis in hospital. • ICPC2 to encode diagnosis in primary attention. • Experience in SNOMED CT to structure the EHR information of allergies.
	EHR situation:	All the public hospitals have the same EHR system with an integrated data base.
Stroke related information	Regional stroke program:	A protocol “stroke code” exists.
	Reference stroke hospital:	1 public hospital with stroke unit; since 2021 with 8 beds: Complejo Hospitalario de Navarra (CHN), in Pamplona. 1 contracted health care hospital with stroke unit (4 beds): Clínica Universidad de Navarra.
	Number of stroke cases per year:	900 episodes per year: 86% correspond to ischemic strokes and in 2020 22% of these are treated pharmacological (fibrinolytic) intravenously and 9,5% benefit from thrombectomy treatments by catheterization.
	Stroke registry:	A regional stroke registry has been created since 2019.
	Stroke structured information:	The stroke information is structured in the EHR and it feeds the stroke registry database.

Navarre has updated documents and web sites related to (see Annex I):

- Navarre Health Plan 2014-2020 and their priority strategies includes:
  - Integrated prevention and care of vascular diseases.
  - Integrated approach and care of time-dependent emergencies.
  - Integrated care strategy for chronic and multi-pathological patients.
- In each of these strategies, objectives, actions, evaluation indicators, instruments and participation channels are defined.
- Guide for patients and accompanying persons of the Stroke Unit of the Neurology Service of Complejo Hospitalario de Navarra.
- Brain Injury Association of Navarre (ADACEN).
- Shared Clinical Decisions work and document.

It is noteworthy the great job carried out jointly by healthcare professionals, ADACEN, patients and families to give a voice to patients and families in the experience of a stroke and establish the relevant recommendations, which will qualify those issued in this Action Plan.

3.4.2 Primary prevention strategies, health promotion and campaigns

From Deliverable 3.2: COMPARATIVE STUDY OF PRIMARY PREVENTION STRATEGIES, HEALTH PROMOTION AND CAMPAIGNS.

a) Healthy lifestyle

Does the region have updated Health Programs/Plans containing healthy life / hypertension / atrial fibrillation strategies? Do they have available documents?

As part of Navarre Health Plan 2014-2020, the health promotion strategies are focused on self-management and healthy environment.

The specific programs in Navarre Health Plan 2014-2020 are: a) Health promotion programs for children, youth and adult (community and individualised approach); b) prevention and care of Vascular disease including primary prevention.

As part of the Health promotion program for children and youth, there are specific interventions led by Primary Care professionals (systematic assessment of healthy nutrition and obesity prevention program) or other stakeholders who are part of the community (Promotion of the Network of Health Promoting Schools, Exercise in school and obesity prevention, Interdepartmental alliances and with municipal entities for the improvement of the environments, Positive health and self-care and lifestyles, Hospitals Health Promoters- children friendly).

The Department of Health has built a specific portal web (SaludNavarra), with different interfaces (Citizens, Professionals, Corporations), to provide information regarding healthy lifestyle campaigns and tips for individuals.

The specific site for Citizens includes different tabs, such as:

- "Me cuido", where people can find information sheets regarding healthy nutrition habits, reduction of alcohol intake, and physical exercise adapted to each stage of life and proposals such as healthy rides through the CHN based on the Japanese ancestral tradition Shinrin-Yoku (Forest bathing).

- "Mi enfermedad", where there is a specific section for vascular diseases in which objectives, self-care plans, non-pharmacology treatment and links to accessible information for the general public are provided.

The tab for Professionals includes information on the Navarre Health Plan 2014-2020. This Plan is divided into different strategies/programs, including one for vascular diseases and diabetes.

On the website of the Navarre Ministry of Health, within the section of the Navarre Institute of Public Health, there is also a tab with access to publications:

- For the public: with health advices guides and featuring picture posters and brochures on twelve steps to gain health in midlife including healthy lifestyle habits.
- For professionals: where there are publications and material for educational use from the Drugs and Addictions Prevention Plan, the Tobacco Use Prevention Plan, and the Health Promotion Plan of the Navarre Institute of Public Health.

All this information is scattered throughout the websites and is not available in an aggregated form on health issues, or on stroke.

Do they have specific programs to address primary prevention in Stroke? /Is there any specific section for evaluation?

There is no specific primary prevention program focused on Stroke in Navarre. Stroke is included in vascular diseases chapter of the Navarre Health Plan 2014-2020. Within the strategy of integrated prevention and care of vascular diseases, there is a section on monitoring and evaluation of the strategy, in which a series of indicators have been defined including stroke primary prevention in people with high vascular risk, combined with indicators of other stages of stroke and other vascular diseases.

Which is the approach of the objectives regarding Healthy lifestyle campaigns?

In relation to population campaigns, the Public Health Institute of Navarre is in charge of the Stroke prevention and awareness campaigns. Specific collaborations have been made with a non-governmental organisation of the "ABC that saves lives" and through it different campaigns and actions have been carried out.

Within the framework of education in self-care of vascular diseases, the following has been developed by Navarre Public Institute of Health with the Primary Care and Heart Disease area:

- Materials: posters, brochures, guides for educational use in the setting of primary care and community interventions. Educational styles, Brief educational guide (for Primary care) and Lifestyles, Brief educational guide (for hospitals).
- Self-care training.
- Vascular Diseases, Information and Vascular Diseases, Self-Care Manual.
- School of health: school for patients with workshops about healthy habits, self-care, and living with vascular disease.

Non-specific information has been founded on evaluation or indicators based on the campaigns.

The information regarding primary prevention strategies, health promotion and campaigns is summarised in Tables 18 and 19.

Table 18. Programs and documents related to alcohol intake, diet, physical activity and tobacco consumption in Navarre.

	ALCOHOL INTAKE		DIET		PHYSICAL ACTIVITY		TOBACCO	
	Prog	Docs	Prog	Docs	Prog	Docs	Prog	Docs
Navarre	not found	not found	√	√	√	√	√	√

Table 19. Existence of Ictus program, actions related to HT and AF, Indicators and Evaluation in Navarre.

	Stroke programs		HT action	AF action	Indicators	Evaluation
	Available	Ambit				
Navarre	Vascular	Local	?	√	√	Planned

b) Stroke awareness campaigns

Information to the population has been done through short and simple messages on "how to recognize stroke", written on the sugar packets used in cafeterias (also in CHN) in a short time period. It is also planned to disseminate the information by putting it in the milk boxes.

Campaign on stroke day: The professionals of the CHN organise annually an informative campaign for the population on the day of the stroke and various activities (taking blood pressure and pulse, doppler...). Specifically, in 2017 it was intended to disseminate it and posters were prepared on how to recognise stroke and were distributed by all Health Centres of Navarre (Hospitals, Primary Care Centres ...).

In 2018, the Brain Injury Association of Navarre (ADACEN) and Mutua Navarra launched a novel campaign to detect and prevent stroke in companies (posters, infographics and videos). The initiative was developed in a first phase throughout 2018 and had the collaboration of the General Directorate of Economic and Business Policy and Labour of the Navarre Government.

There are no regular stroke awareness campaigns available on health websites.

Specific collaborations have been carried out with a non-governmental organisation of the "ABC that saves lives" and through it different campaigns and actions have been performed actions led by the Neurology department of the hospital in collaboration with ADACEN.

The description of the stroke awareness campaign carried out in 2018 is given in Table 20.

Table 20. Stroke awareness campaign carried out in Navarre.

	Date	Tool	Item	Number	Evaluation
Navarre	2018	Enterprise	ICTUS Total	Limited	?

3.4.3 Attention in acute phase: organization of stroke services and management of acute stroke

At the time of writing this document we do not have the final results of some deliverables, hence the same information is described for all regions.

a) Data from Interactive maps on thrombectomy (from Deliverable 1.6.2)

The project's web portal has been developed by AQuAS; it includes interactive maps with quality indicators in the care process during the acute phase of stroke for those patients who have received endovascular treatment in all participating regions. For this, it was necessary to reach consensus on

the selection of variables to be collected (see Deliverable 1.1) and establish rigorous interoperability criteria (see Deliverable 1.3).

In the interactive map, assessment can be made globally or by region. Process and outcome indicators are shown separately. A table with all regions and indicators is included to allow comparison between regions.

At the present time, it is in the validation phase and no specific regional recommendations can be drawn from it; therefore, general recommendations are given.

b) Data from the Report comparing the provision of Stroke code across ICTUSnet regions, process mining (from Deliverable 3.3.2.)

Process mining has been led by IACS given its experience in the analysis of the acute stroke care process in the Aragon region (Construction of Empirical Care Pathways Process Models from Multiple Real-World Datasets, IEEE Journal of Biomedical and Health, 2020).

Care pathways (CPWs) are "multidisciplinary care plans that detail essential care steps for patients with specific clinical problems" and work on how to apply an existing process mining methodology to construct the empirical CPW process models in the acute stroke setting in each region.

It was decided to frame the analysis for patients admitted to a hospital with suspected stroke. Each region had a different way of recording the events associated with date and time (logs) necessary to draw the circuits followed by each patient, so that a strictly comparable result between regions has not been obtained. Therefore, only general recommendations could be given.

c) Data from Application for the standardization of multilingual clinical documents, text mining (from Deliverable 2.3)

Barcelona Supercomputing Center has described the rule-based normalizer tool used to pre-annotate the Gold Standard and analyses the structure of discharge stroke reports. The eventual deep learning normalizer, trained with the Gold Standard, is described in Deliverable 2.4; in addition, the normaliser pre-processes medical records in order to identify and standardise the different sections of the text according to a common general scheme. The mapping of the clinical information following different report models in a common scheme will favour the subsequent text mining process. The code can be found in GitHub.

In scenarios such as ICTUSnet, in which different hospitals are involved, the heterogeneity of the data to be processed is an important aspect to take into account. Clinical documents present a very high variability, as each centre uses its own templates and formats. Often, even the same centre can use different styles, formats and templates. Therefore, it is necessary to implement clinical document normalization process and to define interoperable document architecture. Consequently and as an objective of the project, a standardiser tool was developed, that would facilitate the task of data mining and allow for more effective comparison of data and results between hospitals using the reference archetypes suggested by the Spanish Ministry of Health.

This tool can help to extract relevant information in the acute stroke care process from hospital discharge reports when it is not possible to set up an appropriate registry.

3.4.4 Follow-up and rehabilitation plan in stroke: rehabilitation, secondary prevention, life after stroke

From Deliverable 3.5: COMPARATIVE ANALYSIS OF RESOURCES AVAILABLE FOR THE FOLLOW UP AND REHABILITATION OF STROKE PATIENTS.

a) Pathways in stroke rehabilitation

We could not find information on this topic in the integrated care strategy for chronic and multi-pathological patients of Navarre. Through the interviews it has been pointed out that specific documents detailing the pathways in stroke rehabilitation do exist, but they are not officially distributed in the hospital and outpatient centres across the region.

b) Resources for stroke survivors

Quality of Life services

To improve functional capacity and quality of life of patients and caregivers is one of the main objectives described in the Navarre strategy for chronic diseases. This is intended to be achieved by undertaking a series of specific objectives like reducing the emotional impact produced by patient's condition or preventing the impact on caregivers. However, the strategy has been designed taking into account several chronical diseases, not providing concrete or specific actions for stroke patients.

Services for caregivers

The Integrated care strategy for chronic and multi-pathological patients of Navarre defines actions towards caregiver's wellness, such as caregiver needs assessment, provision of information and advice, training, telephone consultation / preferential e-mail, management of additional family support, personal and emotional support, self-help groups, promotion of volunteering, and residential respite services.

c) Follow-up of stroke survivors

Assessment

The Integrated care strategy for chronic and multi-pathological patients of Navarre includes a short set of indicators to evaluate the results that refer to all pathologies within the scope, so there are no specific indicators for stroke patients or caregivers. The indicators focus on the overall improvement of health results, technical quality, functional capacity and quality of life, patients' satisfaction, autonomy and capacity of patients, and sustainability of the healthcare system.

d) Secondary prevention

We could not find information on this topic within the integrated care strategy for chronic and multi-pathological patients of Navarre. Through the interviews it has been pointed out that specific document detailing the strategy for secondary prevention does exist, but it is not embedded to the analysed and official strategy.

3.4.5 Recommendations

Recommendations related to healthy lifestyle habits:

The Health Ministry of Navarre should be asked to:

- Obtain and facilitate the proposed outcome indicators that are in line with those suggested by WHO, NCD, and SAP (see Deliverables 3.1 and 3.2).
- Include the risk of stroke in population campaigns that are promoted.
- Improve the work together with professionals involved and patient associations to obtain indicators, campaign assessment, and evaluation of outcomes and their impact.

Recommendations related to hypertension:

The Health Ministry of Navarre should be asked to:

- Make a greater effort against hypertension, as the most important risk factor in the occurrence of stroke.
- Carry out campaigns on the detection of hypertension in the population at risk.
- Support campaigns on control and adherence to medication and those on the risk of abandonment in patients with hypertension.
- Obtain and facilitate the proposed outcomes that are in line with those suggested by WHO, NCD, an SAP (the proposed indicators are developed in Deliverables 3.1 and 3.2).
- Include the risk of stroke in population campaigns promoted on hypertension.
- Work together with professionals involved and patient associations to obtain indicators, campaign assessment, and evaluation of outcomes and their impact.

Recommendations related to atrial fibrillation:

The Health Ministry of Navarre should be asked to:

- Publicise the importance of atrial fibrillation and previous detection to prevent stroke.
- Enhance screenings for detection of atrial fibrillation in the population at risk.
- Include atrial fibrillation indicators in the list of indicators collected in Primary Care.
- Support arrhythmia control campaigns through the pulse in close connection with Primary Care services and pharmacists.
- Adopt or evaluate the use of personal devices that allow heart rhythm analysis to aid in the diagnosis of paroxysmal atrial fibrillation.

Recommendations related to stroke awareness campaigns:

The Health Ministry of Navarre should be asked to:

- Enhance the collaboration with scientific societies, patient's associations, professionals and stakeholders involved to promote periodic campaigns.
- Increase the number of campaigns focused on different aspects of cerebrovascular disease.
- Evaluate the campaigns and publish and assess their results and their impact.

Recommendations related to attention in the acute phase:

The Health Ministry of Navarre should be asked to:

- Do a specific stroke strategy plan which includes not only the emergency phase, but also the acute phase in stroke unit care and in hospital admission.
- Review the number of stroke units in the region and adapt them to current recommendations.
- Provide the resources for accreditation of the stroke unit according to ESO criteria.
- Guarantee human and material resources for early and accurate assessment of stroke patients.
- Guarantee access to a stroke unit regardless of patient's geographical location.
- Guarantee rapid access to reperfusion treatment with equity criteria.
- Create or revise the regional stroke registry with all levels of care including emergency services.
- Develop a regularly updated stroke registry maintenance plan.
- Collect the variables considered essential to develop comparable quality indicators between regions (specified in the evaluation framework following the SAP-E guidelines, see Deliverable 3.1).
- Assess the use of mobile applications to facilitate data collection.
- Develop a plan for periodic review of process and outcome indicators for stroke patients in order to establish actions for improvement.
- Keep the professionals involved informed (feedback).

- Extract information from discharge reports using the developed tool (data mining) to build the necessary quality indicators, in case of not being able to extract information from registers or until its full implementation.
- Assess the incorporation of process mining with the necessary IT tools (public and free of charge) to be able to compare processes and establish improvement actions.
- Develop and implement (or maintain) with the necessary frequency a stroke training plan for all professionals involved.

Recommendations related to follow up and rehabilitation of stroke patients:

The Health Ministry of Navarre should be asked to:

- Include the global rehabilitation process at all healthcare levels.
- Incorporate the entire regional rehabilitation process (of all involved centres) into the integrated health records.
- Adjust indicators (process/outcome) to assess all the process (see Deliverable 3.1 and 3.5).
- Ensure equitable access to the continuum of stroke care, guaranteeing that at least 90% of the stroke population has access to early rehabilitation within the stroke unit.
- Address the organisation of enough stroke rehabilitation services.
- Work to provide an early supported discharge for at least 20% of the stroke population.
- Ensure that all stroke patients and their caregivers have a review of their rehabilitation and other needs reviewed every 6 months after stroke if necessary.
- Incorporate secondary prevention into the integrated medical record including all healthcare levels, not solely primary/community care.
- Improve and monitor the provision of secondary prevention services as much as necessary to ensure that up to 90% of the stroke population will be seen by a stroke specialist, if needed, and will have access to secondary prevention management (investigation and treatment).
- Evaluate secondary prevention with properly indicators (see Deliverable 3.5).
- Address the long-term unmet needs in life after stroke (see Deliverable 3.6 and "Shared clinical decision-making in stroke care" document).
- Set out, through the Navarra stroke plan, the support that will be provided to stroke survivors regardless of their place of residence and socio-economic status.

3.5 North Region of Portugal

3.5.1 General data

The general data of the North Region of Portugal are provided in Table 21.

Table 21. General data of the North Region of Portugal.

Category	Item	Current situation
General information	Population:	3.689.000 inhabitants
	Number of hospitals:	25
	Number of healthcare professionals:	35537 in all ARSN hospitals. 31317 in ARSN 11 hospitals with stroke code and thrombolysis treatment. 16035 in ARSN 4 hospitals with endovascular treatment.
	Health system:	Public Health System called Serviço Nacional de Saúde.

ICT characteristics	Use of standards:	• HL7 V2.X in some projects and initiatives. • ICD-10 to encode diagnosis and procedures. • SNOMED CT in some projects and initiatives (not in stroke care).
	EHR situation:	All the hospitals have the same EHR system (SONHO / Sclínico) with an integrated data base, developed by the Ministry of Health of Portugal (Serviços Partilhados do Ministério da Saúde – SPMS).
Stroke related information	Regional stroke program:	yes
	Reference stroke hospital:	11 hospitals perform intravenous thrombolysis and 4 hospitals perform endovascular treatment in stroke patients.
	Number of stroke cases per year:	About 7000 stroke episodes per year: 85% correspond to ischemic strokes and about 8% of these are treated pharmacological (fibrinolytic) intravenously and 4% benefit from thrombectomy treatments by catheterization.
	Stroke registry:	In advanced preparation.
	Stroke structured information:	Not yet. The stroke information is not structured in the HER.

North Region of Portugal has updated documents and web sites related to (see Annex I):

- Planos Nacionais.
- *Portuguese Stroke Programme 2017* (Programa Nacional para as Doenças Cérebro-Cardiovasculares).
- Via Verde do AVC (stroke code).
- Acidente Vascular Cerebral (AVC): Prescrição de Medicina Física e de Reabilitação.
- Sociedade Portuguesa de Sociedade Portuguesa do Acidente Vascular Cerebral.
- PT.AVC- União de sobreviventes, familiares e amigos.

3.5.2 Primary prevention strategies, health promotion and campaigns

From Deliverable 3.2: COMPARATIVE STUDY OF PRIMARY PREVENTION STRATEGIES, HEALTH PROMOTION AND CAMPAIGNS.

a) Healthy lifestyle

Does the region have updated Health Programs/Plans containing healthy life / hypertension / atrial fibrillation strategies? Do they have available documents?

Portugal has National Plans (Planos Nacionais, PN) that address healthy diet, physical activity and tobacco use to the general population. These plans are promoted directly by the Portuguese Health Ministry (Ministério da Saúde. Direção-Geral da Saúde, DGS). Portugal was integrated in the general European policy for the control of alcohol (PLA for better individual and community health) taking into account is highest alcohol consumption and prevalence of Alcohol Related Problems (ARP) . In 1984, Portugal joined the European Technical Cooperation Program for the Prevention of ARP and adopted the European Charter on Alcohol, approved at the Paris Conference in 1995; Its dissemination has been part of the Health Promotion and Education Program integrated in the

National Plan against Alcoholism. For this purpose, the DGS published in 2001 a manual for students and health professionals, but an updated plan has not been found.

At a regional level, the latest regional health plan (2014-2016) and later extended to 2020, considered cerebrovascular diseases as one of the five main health problems of the Northern region of Portugal. Different approaches and programs were proposed to tackle health determinants, including: Tobacco-Free Schools Program; Healthy Eating in School Health Program; Trails Program and Prevention Service; Specific surveillance primary health care visits to health determinants.

Among stroke health determinants, there were specific goals for the reduction of hypertension, tobacco and alcohol consumption, obesity and physical inactivity; some of them primarily targeting children.

In fact, the regional strategic plan of the Northern Regional Health Administration (2017-2019) is aligned with the regional health plan and tackles the different health determinants for stroke, including the strengthening of primary health care (whose services are evaluated also through hypertension management). National studies have been performed on the prevalence of arterial hypertension and the law was modified to force the amount of salt in the bread to decrease. Within the context of World Hypertension Day the Portuguese Society of Hypertension as well as different Hospitals and Health Centres, among other entities, promote annually awareness actions and free health screenings for the population.

There are no official national/regional programmes for Atrial Fibrillation. However, there is an association (AFA), as part of an international charity, which provides information and support for patients with suspected or diagnosed atrial fibrillation. This association and its campaigns are supported by Stroke Alliance for Europe (SAFE). In 2017, they launched an international campaign called “Conheça a sua pulsação” (Know your pulse) at the World Heart Rhythm Week (from 5-11 June 2017).

Do they have specific programs to address primary prevention in Stroke? Is there any specific section for evaluation?

According to the *Portuguese National Cerebro-cardiovascular Programme 2017* (Programa Nacional para as Doenças Cérebro-Cardiovasculares), the strategies/programmes to address primary prevention of Stroke until 2020 are in articulation with the National Program for the Promotion of Food Healthy and the Ministry of Education (for targeting young people), with the aim of reducing salt intake in the feeding following a multilevel approach (administration -education- healthcare). Although one of the main objectives is to improve control at the Primary Health Care level of Hypertension, there are no other programmes/strategies/campaigns detailed, neither for atrial fibrillation considered in the Programa Nacional para as Doenças Cérebro- Cardiovasculares.

In the annual report of the Portuguese *National Cerebro-cardiovascular Programme 2017*, it can be found information regarding output indicators, mainly concerning mortality, hypertension and atrial fibrillation (anticoagulation) therapy and reperfusion therapies.

Both regional plans include specific goals for stroke health determinants, including hypertension, tobacco and alcohol consumption, obesity or physical inactivity, and both have a specific section for monitoring and evaluation.

Which is the approach of the objectives regarding Healthy lifestyle campaigns?

The results of the campaign “Conheça a sua pulsação (Know your pulse)” reported were structural (2017) (number of events in: hospitals, general clinics, more than 60 pharmacies, and nursing homes), but no information regarding output indicators was given.

The information regarding primary prevention strategies, health promotion and campaigns is summarised in Tables 22 and 23.

Table 22. Programs and documents related to alcohol intake, diet, physical activity and tobacco consumption in North Region of Portugal.

	ALCOHOL INTAKE		DIET		PHYSICAL ACTIVITY		TOBACCO	
	Prog	Docs	Prog	Docs	Prog	Docs	Prog	Docs
North Portugal	not found	not found	√	√	√	√	√	√

Table 23. Existence of Ictus program, actions related to HT and AF, Indicators and Evaluation in North Region of Portugal.

	Stroke programs		HT action	AF action	Indicators	Evaluation
	Available	Ambit				
North Portugal	Stroke	National	√	√	√	√

b) Stroke awareness campaigns

The most recent campaign launched in Portugal for stroke awareness was in 2015, under the moto "Viva mais, não arrisque. Eu não arrisco". It was promoted by the Portuguese Stroke Society (Sociedade Portuguesa do Accidente Vascular Cerebral, SPAVC), with a video in Vimeo platform.

In 2017, the SPAVC launched a video in YouTube about stroke, in particular the warning signs (3Fs), risk factors and preventive measures produced in the context of National Day of people with stroke, annually marked in Portugal on March 31. However, there was no evaluation of the campaigns to assess their impact. The description of this campaign is given in Table 24.

Table 24. Stroke Awareness campaign carried out in North Region of Portugal.

	Date	Tool	Item	Number	Evaluation
North Portugal	2019	Video	F.A.S.T.	Stroke Day	No

The Portuguese National Cerebro-cardiovascular Program and the ARS Norte also provide information to the general population through websites and social networks, as well as intervention in television programs, mainly around the National Day of Stroke Survival (31 March) and World Stroke Day (29 October). In addition, individual hospitals, the Portuguese Stroke Society and the Portuguese Stroke Survivals Support Association (Portugal AVC) often provide information to the population. However, the results of these various actions have not been monitored.

3.5.3 Attention in acute phase: organization of stroke services and management of acute stroke

At the time of writing this document we do not have the final results of some deliverables, hence the same information is described for all regions.

a) Data from Interactive maps on thrombectomy (from Deliverable 1.6.2)

The project's web portal has been developed by AQuAS, it includes interactive maps with quality indicators in the care process during the acute phase of stroke for those patients who have received endovascular treatment in all participating regions. For this it was necessary to reach consensus on the selection of variables to be collected (see Deliverable 1.1) and establish rigorous interoperability criteria (see Deliverable 1.3).

In the interactive map assessment can be made globally or by region. Process and outcome indicators are shown separately. A table with all regions and indicators is included to allow comparison between regions.

At the present time, it is in the validation phase and no specific regional recommendations can be drawn from it; therefore, general recommendations are given.

b) Data from the Report comparing the provision of Stroke Code across ICTUSnet regions, process mining (from Deliverable 3.3.2.)

Process mining has been led by IACS given its experience in the analysis of the acute stroke care process in the Aragon region (Construction of Empirical Care Pathways Process Models from Multiple Real-World Datasets, IEEE Journal of Biomedical and Health, 2020).

Care pathways (CPWs) are "multidisciplinary care plans that detail essential care steps for patients with specific clinical problems" and work on how to apply an existing process mining methodology to construct the empirical CPW process models in the acute stroke setting in each region.

It was decided to frame the analysis for patients admitted to a hospital with suspected stroke. Each region had a different way of recording the events associated with date and time (logs) necessary to draw the circuits followed by each patient, so that a strictly comparable result between regions has not been obtained. By that, only general recommendations could be given.

c) Data from Application for the standardization of multilingual clinical documents, text mining (from Deliverable 2.3)

Barcelona Supercomputing Center has described the rule-based normalizer tool used to pre-annotate the Gold Standard and analyses the structure of discharge stroke reports. The eventual deep learning normaliser, trained with the Gold Standard, is described in Deliverable 2.4; in addition, the normaliser pre-processes medical records in order to identify and standardise the different sections of the text according to a common general scheme. The mapping of the clinical information following different report models in a common scheme will favour the subsequent text mining process. The code can be found in GitHub.

In scenarios such as ICTUSnet, in which different hospitals are involved, the heterogeneity of the data to be processed is an important aspect to take into account. Clinical documents present a very high variability, as each centre uses its own templates and formats. Often, even the same centre can use different styles, formats and templates. Therefore, it is necessary to implement clinical document normalisation process and to define interoperable document architecture. Consequently and as an objective of the project, a standardiser tool was developed, that would facilitate the task of data mining and allow for more effective comparison of data and results between hospitals using the reference archetypes suggested by the Spanish Ministry of Health.

This tool can help to extract relevant information in the acute stroke care process from hospital discharge reports when it is not possible to set up an appropriate registry.

3.5.4 Follow-up and rehabilitation plan in stroke: rehabilitation, secondary prevention, life after stroke

From Deliverable 3.5: COMPARATIVE ANALYSIS OF RESOURCES AVAILABLE FOR THE FOLLOW UP AND REHABILITATION OF STROKE PATIENTS.

a) Pathways in stroke rehabilitation

In the North Region of Portugal, the rehabilitation process is under continuous evaluation and

executed at local, regional and national level through internal and external audits. The Department of Quality in Health and the Central Administration of Health develop and disseminate the monitoring reports. The implementation of the stroke rehabilitation plan is monitored and evaluated through two indicators, namely: a) percentage of patients with stroke diagnosis; b) rehabilitation medicine average cost.

The rehabilitation process follows the Canadian Best Practice Recommendations for Stroke Care. It starts at the acute phase, as early as possible, with an individual rehabilitation therapy plan.

Criteria are established for referral to the most appropriate resource (outpatient/inpatient, continuous care/home treatment) and for the specify treatment (intensity, differentiated interventions) related to the previous functional situation, the Barthel scale, age, and physical resistance.

The stroke trajectory in Northern Portugal also evaluates social and family factors and the environment that may affect the rehabilitation process of the patient. During the chronic sequelae phase, reassessment is done at 6 and 12 months.

b) Resources for stroke survivors

The North Region of Portugal has a rehabilitation centre and 3 hospitals including rehabilitation beds as well as multiple community centres. The rehabilitation plan does not mention any of the dimensions that fall under this category.

c) Follow-up of stroke survivors

Assessment

All patients with a therapeutic rehabilitation plan after stroke are re-evaluated by specialised hospital services during the following 6 and 12 months.

Sequelae

When assessing the post-stroke deficits and evaluating the functional status of the stroke patients, the physicians in the North of Portugal use at least one of the standardised functional assessment scales, namely Barthel Index, and functional independence measure (FIM) scale. ARSN is building a regional registry to monitor rehabilitation from an early stage, which will allow the monitoring of the follow up after three months by using the Modified Ranking Scale (mRS).

d) Secondary prevention

No detailed information. ARS-Norte lacks information regarding the pathways.

3.5.5 Recommendations

Recommendations related to healthy lifestyle habits:

The ARS-NORTE office of the Portuguese Health Ministry should be asked to:

- Obtain and facilitate the proposed outcome indicators that are in line with those suggested by WHO, NCD, and SAP (see Deliverables 3.1 and 3.2).
- Include the risk of stroke in population campaigns about healthy lifestyle habits that are promoted.
- Work together with professionals involved and patient associations to obtain indicators, campaign assessment, and evaluation of outcomes and their impact.

Recommendations related to hypertension:

The ARS-NORTE office of the Ministry of Health of Portugal should be asked to:

- Make a greater effort against hypertension, as the most important risk factor in the occurrence of stroke; to carry out campaigns on the detection of hypertension in the population at risk; to support campaigns on control and adherence to medication and risk of abandonment in patients with hypertension.
- Obtain and facilitate the proposed outcome indicators that are in line with those suggested by WHO, NCD, an SAP (see Deliverables 3.1 and 3.2, where the proposed indicators are developed).
- Include the risk of stroke in population campaigns promoted on hypertension.
- Work together with professionals involved and patient's associations to obtain indicators, campaign assessment, and evaluation of outcomes and their impact.

Recommendations related to atrial fibrillation:

The ARS-NORTE office of the Portuguese Health Ministry should be asked to:

- Publicise the importance of atrial fibrillation and previous detection to prevent Stroke.
- Enhance screenings for detection of atrial fibrillation in the population at risk.
- Support arrhythmia control campaigns through the pulse in close connection with Primary care services and pharmacists.
- Adopt or evaluate the use of personal devices that allow heart rhythm analysis to aid in the diagnosis of paroxysmal atrial fibrillation.

Recommendations related to stroke awareness campaigns:

The ARS-NORTE office of the Portuguese Health Ministry should be asked to:

- Collaborate with scientific societies, patient associations, professionals and stakeholders involved to promote periodic campaigns.
- Increase the number of campaigns focused on different aspects of cerebrovascular disease.
- Evaluate the campaigns and publish and assess their results and impact.

Recommendations related to attention in the acute phase:

The ARS-NORTE office of the Portuguese Health Ministry should be asked to:

- Review the number of stroke units in the region and adapt them to current recommendations.
- Guarantee human and material resources for early and accurate assessment of stroke patients.
- Guarantee access to a stroke unit regardless of patient's geographical location.
- Guarantee rapid access to reperfusion treatment with equity criteria.
- Create or revise the regional stroke registry for all levels of care including emergency services.
- Develop a regularly update stroke registry maintenance plan.
- Collect the variables considered essential to develop comparable quality indicators between regions (specified in the evaluation framework following the SAP-E guidelines, see Deliverable 3.1).
- Assess the use of mobile applications to facilitate data collection.
- Develop a plan for periodic review of process and outcome indicators for stroke patients in order to establish actions for improvement.
- Keep the professionals involved informed (feedback).
- Assess the incorporation of process mining with the necessary IT tools (public and free of charge) to be able to compare processes and establish improvement actions.
- Accreditation of referral stroke units.

- Develop and implement (or maintain) with the necessary frequency a stroke training plan for all professionals involved.

Recommendations related to follow up and rehabilitation of stroke patients:

The ARS-NORTE office of the Portuguese Health Ministry should be asked to:

- Update the *Stroke Physical Medicine and Rehabilitation Policy Document (2012).*
- Complete the whole rehabilitation process including all healthcare levels.
- Incorporate the entire regional rehabilitation process (of all involved centres) into the integrated health records.
- Incorporate indicators (process/outcome) to assess the process (see Deliverables 3.1 and 3.5).
- Ensure equitable access to the continuum of stroke care, guaranteeing that at least 90% of the stroke population has access to early rehabilitation within the stroke unit.
- Address the organisation of enough stroke rehabilitation services.
- Work to provide an early supported discharge for at least 20% of the stroke population.
- Ensure that all stroke patients and their caregivers have their rehabilitation and other needs reviewed every 6 months after stroke if needed, as scheduled in the *Stroke Physical Medicine and Rehabilitation Policy Document (2012).*
- Evaluate the process and results of rehabilitation using proposed indicators.
- Incorporate secondary prevention into the integrated medical record for all healthcare levels (including primary/community care).
- Improve and monitor the provision of secondary prevention services as much as necessary to ensure that up to 90% of the stroke population will be seen by a stroke specialist and will have access to secondary prevention management (investigation and treatment).
- Address the long-term unmet needs in life after stroke (see Deliverable 3.6. and "Shared clinical decision-making in stroke care" document).
- Set out, through national stroke plans, the support that will be provided to stroke survivors regardless of their place of residence and socio-economic status.
- Evaluate secondary prevention with properly indicators (see Deliverable 3.5).

3.6 Occitanie

3.6.1 General data

The general data of Occitanie are provided in Table 25.

Table 25. General data of Occitanie.

Category	Item	Current situation
General information	Population:	5.900.000 inhabitants
	Number of hospitals:	58
	Number of healthcare professionals:	XXX professionals
	Health system	Public health system called “Agence regional de santé”.
ICT characteristics	Use of standards:	• Don’t use HL7. • ICD-10 to encode diagnosis.
	EHR situation:	Montpellier and Toulouse have different EHR systems.
Stroke related	Regional stroke	National stroke plan 2010-2014.

information	program:	
	Reference stroke hospital:	• 5 TSC Thrombectomy Stroke Centre. • 15 Primary Stroke Centres. • 2 Comprehensive Stroke Centres (Centre Hospitalier Universitaire de Toulouse and Centre Hospitalier Universitaire de Montpellier).
	Number of stroke cases per year:	250 ischemic episodes per 100,000 inhabitants per year: Thrombolysis rate: 14.3%. Thrombectomy treatments: not known.
	Stroke registry:	There is a regional registry called PMSI but it contains sociodemographic data. There is an Endovascular treatment in ischemic stroke registry called ETIS. There isn't a specific regional stroke registry.
	Stroke structured information:	The stroke information is not structured in the EHR.

Occitanie has updated documents and web sites related to (see Annex I):

- Occitan Regional Health Plan.
- Occitan Stroke program is part of the Plan d'actions national « accidents vasculaires cérébraux 2010-2014.
- Via Trajectoire.

3.6.2 Primary prevention strategies, health promotion and campaigns

From Deliverable 3.2: COMPARATIVE STUDY OF PRIMARY PREVENTION STRATEGIES, HEALTH PROMOTION AND CAMPAIGNS.

a) Healthy lifestyle

Does the region have updated Health Programs/Plans containing healthy life / hypertension / atrial fibrillation strategies? Do they have available documents?

This French region is involved in national and regional plans for healthy lifestyle. The National Health Nutrition Plan created in France in 2001 provides the reference framework for food and physical activities. The "PNNS" (Programme national nutrition santé) logo is used to authenticate all the actions, measurements, messages and tools of the program. The promotion of healthy eating and regular physical activity is integrated into the National Health Strategy 2018-2022.

The "Agence Regional de Santé", ARS Occitanie, has the regional plan "Sport, Health, Well-being" (2019-2024). This responds to an inter-ministerial will between Ministries in charge of Social Affairs and Health and Sports, Youth, Popular Education and Community Life. There are several initiatives to promote physical activity through this program, like "Active Cities" and "Active Departments" labels.

In the last programs, there is a predefined evaluation, a steering committee to monitor this Program, working groups and regional technical committees to implement it. The ARS Occitanie has set up prevention programs for addictions (including alcohol), focusing primarily on young people but also on adults.

On the festive scene, actions in urban areas (downtown with bars), rave parties or student parties, including the peer-to-peer intervention approach, with young people trained have been developed. These experiences were capitalised and used in the context of the Euro 2016 football tournament (Toulouse, Montpellier and other major cities). Currently, in addition to the prevention programs developed in the region, the ARS relies on its network of actors in the medico-social system.

The National Tobacco Reduction Program (NRPP) had emblematic actions (neutral package, Tobacco Free Month, prescription authorization for new professions, notification of the characteristics of tobacco products, tobacco transparency, etc.) The Ministry of Solidarity and Health launched the national program to fight against tobacco (PNLT) for the years 2018 to 2022.

Do they have specific programs to address primary prevention in Stroke? Is there any specific section for evaluation?

The Occitan Stroke Program is part of the *Plan d'actions national « accidents vasculaires cérébraux 2010-2014* from the French Ministry of Health. The goals are to implement support channels and adapted information systems; providing information, training and reflection for professionals; promote research and ensure demographic balances.

In 2013, a group of experts of the Haute Conseil de Santé Publique elaborated the report: *Proposals for impact assessment of the National Action Plan Stroke 2010-2014.* This report describes targets and indicators. Despite this report there is no a final evaluation report regarding that Plan.

Which is the approach of the objectives regarding Healthy lifestyle campaigns?

From a National perspective, the Comité Français de *Lutte contre l'hypertension artérielle*, alongside the Féderation Française de Cardiologie and the Société Française d'Hypertension Artérielle, has launched several campaigns to raise awareness about the effects of hypertension and to promote self-measurement. As a novelty, in 2017, the Protection Sociale Des Boulangers launched a campaign against high blood pressure, initiated in partnership with the Foundation for Research on Hypertension (FRHTA).

There is a French branch of the AF Association with the same campaigns as mentioned before translated into French. The PROFIL FA campaign, conducted by general practitioners sensitised to stroke risk factors and developed in 2013 with the institutional support of Boehringer Ingelheim, was part of the 2010-2014 Stroke National Plan. Its goal was to reduce the risk of stroke by managing AF. There are no results available regarding the assessment of the campaign.

The information regarding primary prevention strategies, health promotion and campaigns is summarised in Tables 26 and 27.

Table 26. Programs and documents related to alcohol intake, diet, physical activity and tobacco consumption in Occitanie.

	ALCOHOL INTAKE		DIET		PHYSICAL ACTIVITY		TOBACCO	
	Prog	Docs	Prog	Docs	Prog	Docs	Prog	Docs
Occitanie	√	not found	√	√	√	√	√	not found

Table 27. Existence of Ictus program, actions related to HT and AF, Indicators and Evaluation in Occitanie.

	Stroke programs		HT action	AF action	Indicators	Evaluation
	Available	Ambit				
Occitanie	Stroke	National	√	√	√	√

b) Stroke awareness campaigns

From a national perspective, there has been several awareness campaigns every year during the international Stroke Day, promoted alongside the Societé Française Neuro-vasculaire, with the moto "L'AVC, nous sommes tous concernés". There is no information regarding the assessment of those campaigns.

The AVC tous concernés is a National French Stroke Association that is committed to a 2019 - 2022 multi-year action: "the AVC minibus on the roads of the regions of France - prevention of strokes to vacationers on the beaches of 4 islands", with the CNM Santé Mutual Mecanism. The first installment, in 2019, took place in Occitanie "prevention in ski resorts". The description of these campaigns is given in Table 28.

Table 28. Stroke awareness campaign carried out in Balearic Islands.

	Date	Tool	Item	Number	Evaluation
Occitanie	2018-19	Bus	F.A.S.T.	Always	?

3.6.3 Attention in acute phase: organization of stroke services and management of acute stroke

At the time of writing this document we do not have the final results of some deliverables, hence the same information is described for all regions.

a) Data from Interactive maps on thrombectomy (from Deliverable 1.6.2)

The project's web portal has been developed by AQuAS, it includes interactive maps with quality indicators in the care process during the acute phase of stroke for those patients who have received endovascular treatment in all participating regions. For this it was necessary to reach consensus on the selection of variables to be collected (see Deliverable 1.1) and establish rigorous interoperability criteria (see Deliverable 1.3).

In the interactive map assessment can be made globally or by region. Process and outcome indicators are shown separately. A table with all regions and indicators is included to allow comparison between regions.

At the present time, it is in the validation phase and no specific regional recommendations can be drawn from it; therefore, general recommendations are given.

b) Data from the Report comparing the provision of Stroke Code across ICTUSnet regions, process mining (from Deliverable 3.3.2.)

Process mining has been led by IACS given its experience in the analysis of the acute stroke care process in the Aragon region (Construction of Empirical Care Pathways Process Models from Multiple Real-World Datasets, IEEE Journal of Biomedical and Health, 2020).

Care pathways (CPWs) are "multidisciplinary care plans that detail essential care steps for patients with specific clinical problems" and work on how to apply an existing process mining methodology to construct the empirical CPW process models in the acute stroke setting in each region.

It was decided to frame the analysis for patients admitted to a hospital with suspected stroke. Each region had a different way of recording the events associated with date and time (logs) necessary to draw the circuits followed by each patient, so that a strictly comparable result between regions has not been obtained. By that, only general recommendations could be given.

c) Data from Application for the standardization of multilingual clinical documents, text mining (from Deliverable 2.3)

Barcelona Supercomputing Center has described the rule-based normalizer tool used to pre-annotate the Gold Standard and analyses the structure of discharge stroke reports. The eventual deep learning normaliser, trained with the Gold Standard, is described in Deliverable 2.4; in addition, the normaliser pre-processes medical records in order to identify and standardise the different sections of the text according to a common general scheme. The mapping of the clinical information following different report models in a common scheme will favour the subsequent text mining process. The code can be found in GitHub.

In scenarios such as ICTUSnet, in which different hospitals are involved, the heterogeneity of the data to be processed is an important aspect to take into account. Clinical documents present a very high variability, as each centre uses its own templates and formats. Often, even the same centre can use different styles, formats and templates. Therefore, it is necessary to implement clinical document normalisation process and to define interoperable document architecture. Consequently and as an objective of the project, a standardiser tool was developed that would facilitate the task of data mining and allow for more effective comparison of data and results between hospitals using the reference archetypes suggested by the Spanish Ministry of Health.

This tool can help to extract relevant information in the acute stroke care process from hospital discharge reports when it is not possible to set up an appropriate registry.

3.6.4 Follow-up and rehabilitation plan in stroke: rehabilitation, secondary prevention, life after stroke

From Deliverable 3.5: COMPARATIVE ANALYSIS OF RESOURCES AVAILABLE FOR THE FOLLOW UP AND REHABILITATION OF STROKE PATIENTS.

a) Pathways in stroke rehabilitation

One of the objectives of the **Occitan regional health plan** in the domain of follow-up and rehabilitation activities (in general, not specific to stroke) is to streamline the connections within the different rehabilitation centres and between them and the health and medico-social structures. In order to aid on this, there is an application that offers personalised guidance to patients: ViaTrajectoire.

Another objective is to remove the bottlenecks in these activities by supporting the shift towards outpatient care, promoting the emergence of innovative solutions, analysing the pertinence of inpatient stays, facilitating return home, etc.

The last objective is to promote mobile teams specialised in rehabilitation and physical medicine that provide homecare, as an alternative to inpatient care in rehabilitation centres.

In Occitanie, rehabilitation starts in the neurovascular unit (UNV) when the state of the patient allows for it. Afterwards, rehabilitation continues in the specialised rehabilitation centres, in outpatient care, or at home. It indicates that access to rehabilitation centres and to specialised treatments should be facilitated. It also recommends the development of mobile rehabilitation teams and of specialised home care (in order to facilitate that the patients return home). Some of

the expected results linked to this priority are: to streamline the management of care for stroke survivors, to accelerate and coordinate patients' return home, and the coordination between representatives from the hospital and from the municipality, including also medical and paramedical professionals. It is pending to foster coordination among professionals, especially between neurologists and those responsible for follow-up.

The health strategic plan for Languedoc-Roussillon, published in 2011, included the treatment of stroke survivors as one of the focus in the domain of chronic diseases. One of the operational objectives was to organise stroke follow-up, covering the treatment in rehabilitation centres (SSR) and taking care of patients' disabilities, through re-education protocols, home help, and strategies to prevent of stroke recurrence.

The health strategic plan 2012-2017 for Midi-Pyrénées establishes the trajectory of stroke victims. In the post-stroke phase, the plan indicates that it is necessary to coordinate better the relationship between the hospital and the municipality and to ensure a follow-up consultation 3 months after stroke. When patients return home, the plan indicates that they will receive re-education therapy to prevent a second stroke and to allow them to live better with stroke sequelae.

b) Resources for stroke survivors

The regional plan indicates that the number of beds and places for follow-up and rehabilitation activities is satisfactory, but it doesn't specify the situation regarding beds for stroke rehabilitation. In 2015, the ratio was 2.1 beds and places per 1000 habitants in Occitanie, compared to 1.8 in metropolitan France. Nonetheless, the plan underlines that there are territorial differences.

Therapies

One of the expected results and impacts of the Occitan regional health plan is to promote patients' access to targeted therapies. There is a cooperation protocol for spasticity with a centralised organisation to a territorial network of rehabilitation centres specialised in diseases that affect the central nervous system. It may be the case that this organisation requires the use of telemedicine. The expected results in the next 5 years are the validation and implementation of the protocol in Occitanie region, the adherence of health professionals to the protocol, the reduction of waiting times to start the treatment of spasticity with botulinum toxin, and the increase in the number of patients following this treatment.

Quality of Life services

In France, stroke survivors can receive economic help.

Personnel

One of the priorities of the Occitan regional health plan is to support health professionals in charge of stroke, from the pre-hospitalisation phase until reinsertion. It targets several professionals, including specialists in rehabilitation, geriatricians, speech-language pathologists, occupational therapists, physiotherapists, nurses, psychologists, and social assistants.

Two of the objectives are related to the post-stroke phase: "to raise awareness among health professionals about care in adapted rehabilitation facilities, either outpatient care or inpatient care in rehabilitation centres (in French Soins de suite et de réadaptation-SSR)" and "to support and promote educational therapy projects".

c) Follow-up of stroke survivors

Assessment

One of the expected results and impacts of the Occitan regional health plan is to implement, evaluate, and follow-up post-stroke consultations involving different professionals. The plan contains one project related to this: develop consultations post-stroke involving different professionals. This consultation post-stroke should take place within the 6 months after the stroke (or maximum within the first year). It targets all patients and has the objectives to revert past complications, prevent or reduce the loss of autonomy, disabilities and social exclusion.

There are 3 types of consultations. First, the simple multi-professional consultation consists in a hospital consultation with a neurologist, a specialist in rehabilitation, or a geriatrician plus a paramedical professional. Second, the complex multi-professional consultation consists in a hospital consultation with a medical professional and at least two paramedical professionals or other non-medical professionals. Third, the consultation with a liberal professional (a neurologist, a specialist in rehabilitation or a geriatrician). The deployment and funding are taking place in Occitanie centres.

The national circular on healthcare facilities stresses the need to assure the health maintenance and surveillance of patients once they have returned home, to define programmes to support social and professional reintegration, to have a follow-up medical consultation between 2 to 6 months after the stroke (depending on the state and needs of the patients, the consultation would be with a neurologist, geriatrician, or specialist in physical medicine and rehabilitation), and to collaborate with the social services.

The Ministry of Health has regulated on the regional organisation of the multi-professional consultations post-stroke and stroke follow-up. It has insisted on the importance of formalising stroke follow-up and having multi-professional consultations. In this line, it has requested ARS (the regional health agencies) to support health centres that are in charge of conducting multi-professional consultations for stroke follow-up. The goal is to promote cooperation among stakeholders and to help acquire the appropriate skills. The ministry provides a list of items that should be considered during this consultation.

d) Secondary prevention

Some of the expected results and impacts of the Occitan regional health plan are to implement therapeutic education programs targeting patients; avoid recurrent stroke and readmissions to hospital due to complications; and to reduce disabilities and promote return to work. The plan underlines that the therapeutic education of patients' needs an improvement.

The French national circular on healthcare facilities emphasises the importance of therapeutic education, which includes the treatment of the disabilities post-stroke and secondary prevention. This secondary prevention aims to avoid another stroke by controlling the neuro-cardio-vascular risks, especially the arterial hypertension. Having a multi-professional follow-up consultation has as goal to ensure a better secondary prevention.

3.6.5 Recommendations

Recommendations related to healthy lifestyle habits:

The ARS Occitanie office of French Minister of Solidarity and Health should be asked to:

- Obtain and facilitate the proposed outcome indicators that are in line with those suggested by WHO, NCD, and SAP (see Deliverables 3.1 and 3.2).
- Include the risk of stroke in population about campaigns that are promoted.
- Work together with relevant scientific associations, professionals involved and patient associations to obtain indicators, campaign assessment, and evaluation of outcomes and their impact.

Recommendations related to hypertension:

The ARS Occitanie office of French Minister of Solidarity and Health should be asked to:

- Make a greater effort against hypertension, as the most important risk factor in the occurrence of stroke, to carry out more campaigns on the detection of hypertension in the population at risk, to support campaigns on the control and adherence to medication and risk of abandonment in patients with hypertension.
- Obtain and facilitate the proposed outcome indicators that are in line with those suggested by WHO, NCD, and SAP (see Deliverables 3.1 and 3.2).
- Include the risk of stroke in population promoted campaigns.
- Work together with relevant scientific associations, professionals involved and with the patient associations to obtain indicators, campaign assessment, and outcome evaluation of s and their impact.

Recommendations related to atrial fibrillation:

The French Minister of Solidarity and Health with ARS Occitanie should be asked to support and collaborate with the Occitane Stroke program to:

- Publicise the importance of atrial fibrillation and previous detection to prevent Stroke.
- Enhance screenings for detection of atrial fibrillation in the population at risk.
- Include atrial fibrillation indicators in the list of indicators collected in Primary Care.
- Support arrhythmia control campaigns through the pulse in close connection with Primary Care services and pharmacists.

Recommendations related to stroke awareness campaigns:

The ARS Occitanie office of French Minister of Solidarity and Health should be asked to support and collaborate with the Occitanie Stroke program to:

- Collaborate with scientific societies, patient associations, professionals, and stakeholders involved keeping periodic campaigns.
- Increase the number of campaigns focused in different aspects of the disease.
- Evaluate the campaigns and publish and assess their results and impacts.

Recommendations related to attention in the acute phase:

The ARS Occitanie office of French Minister of Solidarity and Health should be asked to:

- Review the number of stroke units in the region and adapt them to current recommendations.
- Guarantee human and material resources for early and accurate assessment of stroke patients.
- Guarantee access to a stroke unit regardless of patient's geographical location.
- Guarantee rapid access to reperfusion treatment with equity criteria.
- Create or revise a regional stroke registry, including all levels of care including emergency services.
- Develop a regularly updated stroke registry maintenance plan.
- Collect the variables considered essential to develop comparable quality indicators between regions (specified in the evaluation framework following the SAP-E guidelines, see Deliverable 3.1).
- Assess the use of mobile applications to facilitate data collection.
- Develop a plan for periodic review of process and outcome indicators for stroke patients in order to establish actions for improvement.

- Keep the professionals involved informed (feedback).
- Assess the incorporation of process mining with the necessary IT tools (public and free of charge) to be able to compare processes and establish improvement actions.
- Accredit the referral stroke units.
- Develop and implement (or maintain) with the necessary frequency a stroke training plan for all professionals involved.

Recommendations related to follow up and rehabilitation of stroke patients:

The ARS Occitanie office of French Minister of Solidarity and Health should be asked to:

- Include life after stroke in the Occitanie Stroke program.
- Include the entire rehabilitation stroke process at all healthcare levels.
- Incorporate the entire regional rehabilitation process (of all involved centres) into the integrated health records.
- Adjust indicators (process/outcome) to assess all the process (see Deliverables 3.1. and 3.5).
- Ensure equitable access to the continuum of stroke care in, guaranteeing that at least 90% of the stroke population has access to early rehabilitation within the stroke unit.
- Address the organisation of enough stroke rehabilitation services.
- Work to provide an early supported discharge for at least 20% of the stroke population.
- Ensure that all stroke patients and their caregivers have their rehabilitation and other needs review ed every 6 months after stroke if necessary.
- Incorporate secondary prevention into the integrated medical record including all healthcare levels not only primary/community care.
- Improve and monitor the provision of secondary prevention services as much as necessary to ensure up to 90% of the stroke population will be seen by a stroke specialist and will have access to secondary prevention management (investigation and treatment).
- Address the long-term unmet needs in life after stroke (see Deliverable 3.6 and "Shared clinical decision-making in stroke care" document).
- Set out, through the Occitanie stroke plan, the support that will be provided to stroke survivors and caregivers regardless of their place of residence and socio-economic status.
- Evaluate secondary prevention with properly indicators (see Deliverable 3.5).

4 TRANSVERSAL ISSUES

a) Variables for the ICTUSnet registry (E1.1) and Technical interoperability (E1.3)

One of the cornerstones of the ICTUSnet project is the shared registry between the different regions. This work has been leaded by AQuAS. The variable selection process is described in Deliverable 1.1; the document shows the consensus reached after the second ICTUSnet meeting held in Montpellier (September, 2018). It includes a list of variables that seek to obtain the information necessary to work out a series of indicators/metrics to be displayed on an interactive map to allow comparison between ICTUSnet regions and to enable improvement actions to be taken.

The variables to be recorded, the cohort of patients, and the process and outcomes indicators/metrics have been defined.

The ICTUSnet registry includes those variables related to reperfusion therapy. The cohort of interest is composed of those patients with acute ischemic stroke (AIS) who underwent endovascular treatment (EVT) and, primary or bridging procedures. As bridging procedures include cases that receive fibrinolysis (IVT) prior to EVT, IVT procedure related variables were also collected, but only in those selected cases.

The article "*Multisociety Consensus Quality Improvement Revised Consensus Statement for Endovascular Therapy of Acute Ischemic Stroke" (Journal of Vascular and Interventional Radiology, 2018, Vol. 29)* has been used as a guide in the selection and definition of variables and indicators of the EVT to facilitate the determination of quality standards through their comparison between different centres.

These indicators/metrics have been used not only in the comparative maps (webpage) but also in WP 3 to evaluate EVT in the assessment of the acute phase of the stroke patient.

The interoperability framework (Deliverable 1.3) tackles the semantic and technical aspects of the central ICTUSNet registry and aims to help the different stakeholders involved in the development of stroke registries, mainly those related with endovascular procedures, to follow international recommendations (SNOMED-CT) and technical aspects once they consider to be part of the ICTUSnet network.

In this document, there are also brief descriptions of the stroke epidemiology and some aspects that have been taken into account for every region to develop their stroke registry. The deliverable also contains a table with the list of variables that are part of the ICTUSnet registry, with their corresponding definition, SNOMED-CT code, values and labels to prepare a csv files ready to be interoperable with the central registry.

b) Consortium agreement, collaboration agreements and legal issues.

During the life of the project, it has been necessary to draw up agreements, both at a global level between all the project partners (Consortium Agreement) and at a particular level between specific institutions or companies for singular collaborations (Collaboration Agreements) to transfer data and reports or to redistribute the project funds.

The purpose of the Consortium Agreement was to specify with respect to the Project the relationship among the Beneficiaries, in particular, regarding the organisation of the work, the management of the Project, and the rights and obligations of the Beneficiaries concerning inter alia liability, access rights, and dispute resolution.

ICTUSnet project aims to foster the development of stroke registries in different south-western European regions. Data from these regional registries have been incorporated in the ICTUSnet central repository to allow interregional benchmarking and stroke care quality assessment.

Deliverable 1.2 (E1.2.1 - Handbook for use and exchange of health records within the ICTUSnet framework. Manuel d'utilisation et échange des données de registres de santé dans le cadre du projet ICTUSnet) describes legal and regulatory requirements in each country to set up all the regional registries of the ICTUSnet project, and good practices to collect and transfer in secured the data to ICTUSnet registry. The collection and the transfer of the anonymised data within the project has been governed by agreement between partners.

As previously explained, specific Collaboration agreements have been drawn up between partners and other involved institutions, like the Collaboration agreement between AQuAS, IdISBa and HUSE for the transfer of anonymised data; the agreement established the purpose, duration and extension of the agreement, the transfer of data, the type of data, the obligations of the partners, and the applicable legislation and jurisdiction.

c) Evaluation framework

It has been developed an Evaluation framework that aims to guide different stakeholders related to stroke care in multiple levels in the assessment of their national/regional stroke plans.

As the aim of ICTUSnet project is to be aligned with the Stroke Action Plan for Europe 2018-2030 of European Stroke Organization and Stroke Alliance for Europe, the main targets and indicators have been based on the aforementioned document, besides other well-recognized health/stroke care institutions publications, such as the World Health Organization, the Stroke Alliance for Europe, and the World Stroke Organization.

This deliverable has been structured into three main sections: 1) evaluation framework for primary prevention and awareness campaigns in stroke; 2) organisation of stroke services and management of acute stroke; 3) follow-up and rehabilitation. Each main section is at the same time divided into different sections (Overview, Purpose, Audience, Structure, Background, Methodology and Definition of the specific selected strategies, their targets, and indicators) to tackle specific aspects concerning the different settings of the stroke care.

d) Shared Clinical Decisions

In clinical practice, patients, families, and healthcare professionals continually face situations in which they must make decisions with varying levels of uncertainty, whether in relation to diagnostic or therapeutic procedures.

Shared decision-making allows both the professional and the patient to participate jointly in health decisions, after considering the range of available options. Joint assessment of the advantages and disadvantages of every alternative takes into account the individual characteristics, values, preferences, and circumstances of each person. This model favours a more active role by the patient in the disease process and marks a change in the relationship between the patient and healthcare workers.

The research discussed on the ICTUSnet workshop attempts to analyse at what stage the Shared Clinical Decision-Making model is found within the stroke care process in the community of Navarre, assessing current limitations or tools needed to establish it. It also seeks to provide a space for reflection to identify unmet needs or suggest possible improvements in the different stages of the integrated stroke care process.

This work has been carried out jointly by the Neurology Service of Complejo Hospitalario de Navarre (CHN), Navarrabiomed (Biomedical Research Centre of the Government of Navarre), and Navarre Brain Damage Association (ADACEN), framed within ICTUSnet project, whose mission is to create a collaborative network between different southern European regions, made up of patients and professionals from different areas related to stroke care.

e) Costs

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. The Deliverable 3.6 shows the analysis and comparison of the different regional stroke care models, along all stages of the continuum of care (prevention, acute care and rehabilitation) with the overall objective of finding 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.

This document shows the great social and economic impact of stroke and the need to identify and implement interventions that have been proven to be cost-effective through robust evidence. The use of new technologies could decrease the burden of stroke in all the dimensions described under this report. The cost of stroke disability is high among healthcare institutions and it is increasing over time. Therefore, 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.

Lastly, 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 upmost relevance to achieve agreed and coordinated Europe-wide data collection methodologies, which enable the assessment of care quality along the whole stroke pathway. In this regard, the list of dimensions included on the Annexes of Deliverable 3.6 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.

f) Formation

This document analyses the existing professional training on stroke in the different regions participating in the ICTUSnet project on the basis of a survey carried out in the different regions, preceded by a brief analysis of training at the European level that may be of interest to stroke professionals.

g) Toolkit for stroke day campaign

The Stroke Foundation of Catalonia in collaboration with stroke patient associations and partners in the ICTUSnet regions have developed a toolkit aimed at developing a common campaign for Stroke Day in 2021.

h) Common recommendations for all ICTUSnet regions

The Ministries of Health in all regions are requested to:

- Build or complete the regional registry for all stroke patients (not only patients receiving endovascular treatment) with the characteristics established in the project.
- Elaborate for each registry the glossary of variables with their definitions, following the SAP-E criteria; for reperfusion treatment use the variables selected in the ICTUSnet project.
- Guarantee the interoperability of the registries to be able to construct comparable indicators between centres, regions or countries.
- Code or establish automated mappings to SNOMED-CT.
- Design user-friendly registries with intuitive interface and sufficient integrations so that professionals do not duplicate their work.
- Evaluate the use of PPPs to speed up and facilitate the completion of registries.
- Establish user-friendly systems for data anonymization that follow European and country-specific legal guidelines.
- Foresee that in order to share data or registries, collaboration agreements must be previously drawn up between all the partners involved.
- Use the document for the selection of indicators and their respective definitions to evaluate actions in health promotion, primary prevention, acute care, secondary prevention, rehabilitation, and life after stroke, given the exhaustive analysis carried out in the Evaluation Framework (see Deliverable 3.1) and SAP-E.
- Incorporate the perspective of the patient, family or caregiver throughout the entire process, collecting indicators considered of value by them.
- Include not only direct but also indirect cost measures throughout the care process. This requires adapting the health and social records of the entire stroke process, including life after stroke, to confirm the lifetime costs of the person who has suffered a stroke (see Deliverable 3.6).
- Complete or improve the training programs using a standard methodology and the minimum contents suggested in Deliverable 5.3.2.
- Use the campaign toolkit for Stroke Day 2021' campaign.

5 CONCLUSIONS

The work developed throughout the ICTUSnet Project has proven that cooperative work between different regions is possible, despite the existing differences.

The project has made possible to develop or improve stroke registries and to enhance their usefulness in the description and evaluation of processes and health outcomes.

It has been shown that it is feasible to achieve consensus in the definition of variables and indicators and to use an interoperable language, and, in addition, a common platform has been used to make comparisons between ICTUSnet regions. However, there have been difficulties related to the different legislations, the level of computerisation of medical records, and the human and material resources available.

It has become clear that stroke care must start before it happens, with specific information campaigns for stroke, including its risk factors and the best preventive measures, and continuing with excellent care in the acute phase, avoiding mortality and disability. It must encompass all life after stroke to ensure the best quality of life for the patient and his or her family, including the early and complete rehabilitation process.

Taking into account the regional characteristics, specific recommendations aligned with those established by the Stroke Action Plan for Europe 2018-2030 have been settled within the project.

The ICTUSnet project has been considered a good practice by the SAP-E.

6 ANNEXES

6.1 Annex I

This Annex provides information regarding the different plan, website, and campaigns on Stroke and items related to from every ICTUSnet region as well as from International Organisations:

Europe Stroke Organisation

- Stroke Action Plan for Europe: https://actionplan.eso-stroke.org/

Stroke Alliance For Europe (SAFE):

- The Burden of Stroke in Europe Main Report: https://www.safestroke.eu/wp-content/uploads/2020/06/The-Burden-Of-Stroke-In-Europe-Report-Main-Document_ENG_All-references.pdf
- The Burden of Stroke in Europe – Country by Country Overview: https://www.safestroke.eu/wp-content/uploads/2020/06/The_Burden_of_Stroke_in_Europe_Report_-_Appendix.pdf
- The Burden of Stroke in Europe Report – Challenges for Policy Makers: https://www.safestroke.eu/wp-content/uploads/2020/06/The_Burden_of_Stroke_in_Europe_-_Challenges_for_policy_makers.pdf

ICTUSnet project

- ICTUSnet website: https://ictusnet-sudoe.eu/es/

European Commission

- European Commission Health Programmes: https://webgate.ec.europa.eu/dyna/bp-portal/

Institute for Health

- Institute for Health Metrics website: http://www.healthdata.org/

Aragon

- Aragon Health Plan 2030: http://plansaludaragon.es/wp-content/uploads/2018/09/Plan-de-Salud-FINAL-EDITADO.pdf
- Stroke strategy website: https://www.aragon.es/-/estrategia-de-ictus
- Update of the Stroke Plan of Aragon (2019-2022): https://www.aragon.es/documents/20127/674325/Programa_Ictus_actualizacion2019.pdf/f164a068-544a-0248-af0d-ca2a2f7c5624

- Nursing stroke care plan: https://www.aragon.es/documents/20127/47341647/Plan_cui_enfer_ICTUS_2018.pdf/88758129-ca3b-207d-469f-0a01a01ce30d?t=1615207568265
- Pediatric stroke care plan: https://www.aragon.es/documents/20127/47341647/Atenci%C3%B3n+al+Ictus+Pediatrico+en+Arag%C3%B3n.+Octubre+2020.pdf/4c375d5a-9453-2a9b-3763-2862c2d7aca5?t=1603180361740
- Stroke Foundation of Aragon (AIDA) website: https://www.ictusdearagon.es/
- Strategy against smoking website: https://www.aragon.es/-/dejar-de-fumar-2

Balearic Island

- Strategic Health Plan of Balearic Islands (Pla Estratègic 2016-2020): http://www.caib.es/sites/salut/f/257421
- Balearic Islands Stroke Strategy 2017-2021: https://www.caib.es/sites/planificaciosanitaria/f/236583
- Association of Patients with Acquired Brain Injury of the Balearic Islands (REHACER) website: https://rehacerbaleares.com/
- e-Health Promotion Educational Centres (CEPS) Program: http://e-alvac.caib.es/index.html
- "We cannot keep looking elsewhere" Alcohol campaign website: https://www.alcohol-info.es/en/home

Catalonia:

- Catalonia Heatlh Plan (2016-2020): https://salutweb.gencat.cat/web/.content/_departament/pla-de-salut/Pla-de-salut-2016-2020/documents/health-plan-catalonia_2016_2020.pdf
- Action Plan for Vascular Diseases 2017-2019 by Catalan Master Plan for the diseases of the Circulatory System: https://salutweb.gencat.cat/web/.content/_ambits-actuacio/Linies-dactuacio/Estrategies-de-salut/Aparell-circulatori/Documentacio/pdmac_2017_2019.pdf
- Catalan Stroke Guidelines: https://portal.guiasalud.es/wp-content/uploads/2019/01/GPC_466_Ictus_AP_Lain_Entr_compl_en.pdf
- Centralized stroke registry website: https://aquas.gencat.cat/ca/ambits/real-world-data-lab/registre-cicat
- Fundació Ictus website: https://www.fundacioictus.com/ca
- Comprehensive plan for health promotion through physical activity and healthy eating (PAAS) website: https://salutpublica.gencat.cat/ca/sobre_lagencia/Plans-estrategics/PAAS/

- Specific indicators: http://salutpublica.gencat.cat/web/.content/minisite/aspcat/sobre_lagencia/Plans_estrategics/PAAS/indicadors_paas/INFOGRAFIA-2019.pdf
- Specific program on physical activity website: http://salutpublica.gencat.cat/ca/ambits/promocio_salut/activitat_fisica/
- Specific program on healthy foods website: http://salutpublica.gencat.cat/ca/ambits/promocio_salut/alimentacio_saludable/
- Legislation: http://salutpublica.gencat.cat/ca/sobre_lagencia/Plans-strategics/PAAS/Impactelegislatiu/
- "Qué tens al cap" campaign (2010): https://www.youtube.com/watch?v=1Qc92eB6BKc
- Second RAPID campaign (2011): http://www.elpuntavui.cat/article/469346-un-de-cada-cinc-infarts-cerebrals-apareix-abans-dels-65-anys.html
- "Qué ets capaç de fer" campaign (2015): https://www.youtube.com/watch?v=KaqOHWrdqM0
- Take your pulse campaign (2017): https://canalsalut.gencat.cat/ca/actualitat/campanyes/campanya-pren-te-el-pols/

Navarre

- Navarre Health Plan 2014-2020: http://www.navarra.es/NR/rdonlyres/21DDBA10-A8D3-4541-B404-7A48827D3CFF/303761/PLANDESALUD20142020versionfinalParlamento.pdf
- Integrated care strategy for chronic and multi-pathological patients of Navarra: https://www.navarra.es/NR/rdonlyres/51981DF4-7AF3-4BAC-8AFF-321448406951/421221/4CaminandoMETASInglesNAVEGABLE.pdf
- An adaptation of the Manual for the Navarra health website: http://www.navarra.es/home_es/Temas/Portal+de+la+Salud/Ciudadania/Mi+enfermedad/Enfermedades+vasculares/
- Guide for patients and accompanying persons of the Stroke Unit: http://www.navarra.es/NR/rdonlyres/98C98EE6-4A1A-446D-B657-9C03B3785239/466582/FASESENELPROCESODEICTUS.pdf
- Brain Injury Association of Navarra (ADACEN) website: https://www.adacen.org/
- Detect and prevent stroke in companies campaign (2018): https://cermin.org/adacen-mutua-navarra-impulsan-una-campana-deteccion-prevencion-del-ictus-la-empresa/

North Region of Portugal

- Regional Health Plan (2014-2016): http://www.arsnorte.minsaude.pt/wp-content/uploads/sites/3/2019/10/PlanoRegionalSaudeNorte_2014_2016.pdf

- Strategical regional plan for the Northern Regional Health Administration (2017- 2019): http://www.arsnorte.min-saude.pt/wpcontent/uploads/sites/3/2018/01/Plano_Estrategico_ARSN_2017-2019.pdf
- Programa Nacional para as Doenças Cérebro-Cardiovasculares 2017: https://www.dgs.pt/portal-da-estatistica-da-saude/diretorio-de-informacao/diretorio-de-informacao/por-serie-882061-pdf.aspx?v=%3d%3dDwAAAB%2bLCAAAAAAABAArySzItzVUy81MsTU1MDAFAHzFEfkPAAAA
- Via Verde do AVC (stroke code) website: https://nocs.pt/via-verde-do-acidente-vascular-cerebral-no-adulto/
- National studies on arterial hypertension: http://www.insa.min-saude.pt/artigo-prevalencia-de-hipertensao-arterial-em-portugal-resultados-do-primeiro-inquerito-nacional-com-exame-fisico-insef-2015/
- Portuguese HYpertension and SAlt Study (PHYSA): https://www.sphta.org.pt/files/physastudy_20150506_2.pdf
- Healthy diet website: http://www.alimentacaosaudavel.dgs.pt/
- Physical activity: https://www.dgs.pt/programa-nacional-para-apromocao-da-atvidade-fisica/ficheiros-externos-pnpaf/recur_ferramentasab-pdf.aspx
- Tobacco Use: https://www.dgs.pt/programa-nacional-para-a-prevencao-e-controlo-do-tabagismo/quer-deixar-de-fumar.aspx
- Acidente Vascular Cerebral (AVC): Prescrição de Medicina Física e de Reabilitação website: https://nocs.pt/avc-mfr/
- Sociedade Portuguesa de AVC – SPAVC: https://www.spavc.org/
- PT.AVC - União de Sobreviventes, Familiares e Amigos website: https://www.portugalavc.pt/
- Associação de Fibrilação Atrial website: http://www.heartrhythmalliance.org/afa/pt
- "Viva mais, não arrisque. Eu não arrisco" campaign: https://vimeo.com/140960752
- Stroke video launched by SPAV at National Day of people with stroke on 31st March 2017: https://www.youtube.com/watch?v=mYHd82qWH20

Occitanie

- National Health Strategie 2018-2022: https://solidarites-sante.gouv.fr/IMG/pdf/dossier_sns_2017_vdef.pdf
- Regional plan "Sport, Health, Well-being" (2019-2024): https://www.occitanie.ars.sante.fr/system/files/2019-03/PRSSBE_OCCITANIE2019.pdf

- National program to fight against tobacco (PNLT) (2018-2022): https://solidarites-sante.gouv.fr/IMG/pdf/180702-pnlt_def.pdf
- Occitane Stroke program as part of the Plan d'actions national « accidents vasculaires cérébraux 2010-2014: https://www.cnsa.fr/documentation/plan_actions_avc_-_17avr2010.pdf
- Via Trajectoire website: https://trajectoire.sante-ra.fr/Trajectoire/
- Awareness campaigns on 2018 International Stroke Day: https://www.accidentvasculairecerebral.fr/
- AVC tous concernés Association website: http://www.jemarche-avc.fr/