

About ICTUSnet

ICTUSnet is a project that wants to improve the health care and quality of life of people having a stroke. 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, covering an area of 20 million inhabitants. At the same time, ICTUSnet aims 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.

To obtain this, the partners have structured the tasks to be performed in 8 work packages:

- WP1: REGIONAL REGISTRIES AND INTEGRATED PLATFORM
- WP2: ARTIFICIAL INTELIGENCE TOOLS (TEXT & IMAGING)
- WP3: ANALYSIS & BENCHMARKING OF STROKE HEALTHCARE PATHWAYS
- WP4: KNOWLEDGE TRANSFER TO HEALTH POLICIES
- WP5: KNOWLEDGE EXCHANGE, COLLABORATION & MUTUAL LEARNING
- WP T1: PROJECT MANAGEMENT
- WP T2: COMMUNICATION
- WP T3: EVALUATION

ICTUSnet is planned for 3 years (April 2018 - March 2021)

What will be done in WP1: Regional Registries and Integrated Platform

Objectives

In WP1, we seek to newly develop, improve or adapt pre-existing regional registries that include prospective, high quality data of patients hospitalized with an acute stroke. All these registries should share some common information to lately allow comparison of performance in different settings and health care systems. Thus, for instance, regions participating in WP1 have agreed to collect specific data about a subtype of patients with ischaemic stroke that are treated with a recently approved intervention (mechanical thrombectomy). Another relevant goal of WP1 is the development of a central platform that will exchange stroke data, knowledge and good practices. In particular, comparison of performance across regions involved in ICTUSnet based on a series of agreed indicators will provide the opportunity to produce interactive maps regarding the situation of stroke care in the south-western European regions, exchange knowledge and learn from each other. Finally yet importantly, at the end of the project, we aim at opening the platform for whatever other regions that are interested in fitting a quality improvement initiative such as ours. To make the latter possible, we will develop guidelines that facilitate other regions join the platform.

The northern region of Portugal, Occitan, and different northern regions in Spain are involved in WP1, and represented by different institutions and organisations.

Tasks

To achieve the specific objectives of WPI we need to: 1) define a minimum common set of data to include in each regional stroke registry. 2) Review the ethical and legal requirements that we need to consider at each region when transferring and sharing health data in a centralised platform. 3) Define the technical aspects and interoperability requirements that will guide the automatic processing and transferring of data. 4) Develop new decentralised stroke registries that are preferably embedded in the electronic health records. 5) Develop the so-called ICTUSnet central platform to store all deliverables and products resulting from the ICTUSnet consortium. 6) Define and provide business intelligence tools that visually analyse and compare the data, including interactive maps.

Deliverables

- E1.1.1 – Glossary of variables
- E1.2.1 – Instruction book for the exchange of health data within the ICTUSnet project
- E1.3.1 – ICTUSnet interoperability framework
- E1.3.2 – Functional and non-functional analyses of all decentralised registries
- E1.3.3 – Functional and non-functional analyses of the central platform
- E1.4.1 – Source coding and executables of the decentralised registries
- E1.4.2 – Decentralised registries test documents
- E1.4.3 – Installation and Users' guidelines of the decentralised registries
- E1.5.1 – Installation and Users' guidelines of the ICTUSnet central platform
- E1.5.2 – Source coding and executables of the ICTUSnet central platform
- E1.5.3 – Guidelines for New Users of the ICTUSnet central platform
- E1.6.1 – Report on the current situation of stroke care in the ICTUSnet regions
- E1.6.2 – Interactive maps

Products

The fundamental products of ICTUSnet WPI are: 1) the **region-wide stroke registries** containing a minimum set of data to understand the process of care and outcomes of patients with ischaemic strokes undergoing endovascular procedures (i.e. mechanical thrombectomy). To ensure interoperability between the different regional registries and the ICTUSnet central registry, we will produce an interoperability protocol with information about the catalogues and standards to be used. 2) The **ICTUSnet central platform** that will allow storage of deliverables and products resulting from the ICTUSnet consortium. It will also provide an interactive visual interface with visual analytics tools to benchmark KPIs agreed by consensus across regions. 3) **Interactive maps** to visualise performance and outcomes of each ICTUSnet region. Hot spots alerts will too be mapped. 4) **Guidelines for the capitalisation** of ICTUSnet main outcomes and adhesion of new territories to the platform.



In summary, WP1 seeks to collect region-wide information about patients with stroke to subsequently share it in a central platform. The final goal is to improve quality of stroke care through periodic assessment of quality metrics and feedback to stroke agents.

