DELIVERABLE NO. 5.5 – TRANSFER PLANS BASED ON THE RESULTS OF THE REGIONAL TRANSFER GROUPS

WP3 Analysis and benchmarking of stroke healthcare pathways

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This deliverable provides insight on the challenges on establishing sustainable stroke care monitoring in each region (A.3.4) and provides recommendations on potential solutions to overcome such challenges and propose transferability plans on best practices to improve the stroke care process in each region. It has been developed on reflections on the experience shared with participant regions while developing and coordinating the deploying the federated infrastructure enabling the discover and comparison of the stroke care process in each region and specific discussions on the implementation challenges with the representatives of each region health system during the analysis and benchmark workshops.

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EXECUTIVE SUMMARY

This deliverable provides insight on the challenges on establishing sustainable stroke care monitoring in each region and provides recommendations on potential solutions to overcome such challenges and propose transferability plans on best practices to improve the stroke care process in each region. It has been developed on reflections on the experience shared with participant regions while developing and coordinating the deployment of the federated infrastructure enabling the discover and comparison of the stroke care process in each region. Main insights for the transfer plans were extracted from the discussion on the implementation challenges with the representatives of each region health system on the analysis and benchmark workshops.

Although all regions participating in the ICTUSnet project included in their Stroke Care Plans the evaluation of the organization of care and their health outcomes, there was an agreement on the need to systematize and standardize these evaluations to, among other things, facilitate international comparison and the assessment and dissemination of their health outcomes.

Main considerations guiding the assessment of the stroke process were that,

- Innovation or improvements of the care processes should be led by the continuous assessment of health system performance and health outcomes, thus considering that stroke care demands a continuum of integrated care and rehabilitation to increase survival and reduce disability.
- Key performance indicators of the care process should be included on the stroke data management systems to enable periodic evaluation and improve efficiency. A continuous monitoring of this KPI should led to regular public reporting on the results produced by the evaluation, fostering dialogues with health authorities and within the multidisciplinary groups such as those produced during the knowledge transference workshops organized by ICTUSnet.
- Continuous assessment of stroke care providers and processes should lead to comparisons between care providers both within and between health systems to settle benchmarks and targets within a quality-improvement program, transferring knowledge and practices aligned with the aims and objectives of the Stroke Action Plan in Europe.

Therefore, main general recommendations derived from the analysis of the challenges presented by the implementations of the stroke care process assessment are:

- The need for building and maintaining health data infrastructures supporting systematic and continuous evaluation of the stroke care activities across the whole care pathway using any available data source checking the information provided by each source from stroke registries to electronic health records or discharge reports to increase consistency, complete or improve the quality of the data.
- Enabling data anonymization and sharing between stroke registries compliant with the

GDPR and with the principles of the European Interoperability Framework, to facilitate comparison and knowledge transference.

- Enabling digital transformation and data management innovation promoting real time monitoring; thus, exploring advance data mining tools and innovative data reuse integrating technological, methodological, and analytical capabilities to care management and planning team.
- Promoting IT experts, data scientist, healthcare professionals and healthcare managers to work hand-on-hand to transform the stroke care process using the insights generated by continuous monitoring to improve health outcomes and patients' quality of life.

1. Introduction

The ICTUSnet project aims to improve the quality of stroke healthcare, including stroke care strategies. The present deliverable belongs to WP3 “analysis and benchmarking of stroke healthcare pathways”, which aims to perform an analysis and comparison of the different regional stroke care models through all the stroke care stages, including the rehabilitation phase. The project involves stroke regional plans of six regions of Spain (Aragon, Balearic Islands, Catalonia, and Navarra), France (Occitanie) and Portugal (Norte).

ICTUSnet participants to agree on criteria to select good practices mainly based on the results of the empirical assessment of the process of the acute phase stroke care and the focus on the documentation and evaluation of the implementation of any plan, program, strategy, or campaign promoted or developed within the regions tackling primary prevention, stroke awareness, follow-up, and rehabilitation, thus leading to the selection of the stroke care processes established by Navarre and Aragon as good practices from which specific elements could be though to transfer to the healthcare organization of other regions.

The following challenges and recommendations are directly based on the interaction with the participant partners while implementing the analytic pipeline supporting stroke care pathway monitoring and the subsequent discussions sustained during the transference seminars with each of the participant regions, assessing their experience during the implementation, the barriers encountered, and the appropriateness of the solutions proposed and commenting on their results.

2. Challenges to the implementation of the Stroke care process assessment

The concept of process mining is referred to data science (or statistical learning) applied to processes to provide novel insights that can be used to identify and address performance or compliance issues. Process mining turns event data into insights and actions to improve business processes.

It requires event data (activities with an associated timestamp) as input to answer process-related questions. In the ICTUSnet use case, we leverage the availability of healthcare data in regional health information systems to analyse the acute phase of the stroke care from Aragon, Balearic Islands, Catalonia, and Navarre (in Spain) and Norte ARS (in Portugal).

The main aim of the process mining is to produce an empirical model of the processes in place when no formal description of the process can be obtained by other approaches. The empirical process is discovered from the individual-level or case-level data in the first step, named “Process Discovery”.

This empirical process enables conformance checking and performance assessment both by

comparison with the expected process and performance or by comparison with an available alternative, such as same process from another region.

As a result of the effort on providing the best available effective treatments to stroke patients, regional health systems have organized integrated healthcare assistance through multiple stroke plans, including clinical protocols considering each phase in the diagnose and treatment of a patient suspected of undergo a stroke from emergency care transportation to rehabilitation. These protocols are widely disseminated within the organizations and regularly lead by neurologist that act as coordinators of the integral assistance of those patients within a healthcare professional team involving multiple specialties and profiles and mobilizing many resources along the hospital stay and afterwards. These plans recognize the need to assess and continuously monitor the effectiveness of the interventions and the requirement for the healthcare information systems to provide a way to systematize that assessment following the principles of a learning health system in which feedback from the effectiveness of the current practice prompt improvements actions.

The main barriers encountered will implementing the Stroke care process assessment were related with the difficult to access healthcare information and available technical resources to process the existing information to produce valuable and actionable insight. Most of the barriers encountered could be classified as challenges on the interoperability of the existing healthcare systems at organisational, technological, and semantic level.

Key elements in terms of organisational interoperability were related to achieve a common understanding of the procedures and roles of each of the parties. That included the need to access and process health data; thus, facing the challenges regarding the technical deployment of the infrastructure and formalising the knowledge of the theoretical pathways of care implicitly designed within the care plans and the routine organization of healthcare in each region.

As for data access challenges, the case study was designed to get the intended outputs with a very simple data model and rather limited data requirements. Therefore, questions such as linkability of data sources, insufficient coverage or lack of relevance of the data sources, or more in depth data quality elements at variable level such as incompleteness, missingness or systematic errors have not been deemed as big challenges to deal with in this very exercise. In addition to data access and data quality barriers the need for IT and data literate personnel with technical capacities to deploy de analytical solutions within the healthcare system in some regions was perceived as a major barrier as these profiles are not traditionally included within the health care planning and are not easily available. An extra effort on supervision and capacity building was considered required to achieve transfer both the monitoring and the interpretations and translation of the insight provided by the assessment to the medical practice.

As in any cross-national comparative research, semantic (and syntactic) interoperability is the main challenge. Each of the entities composing the data model (patient, contact, event, time) are subject to threats to semantic (and syntactic) interoperability. As a matter of example, the definition of the cohort (how to define stroke and refine the strategy to select stroke patients); how specific or sensitive is the definition of ischemic or hemorrhagic stroke, the definition of episode, the identification of the care activities and where these activities are provided; and if these activities can be separate out across care providers, the uneven granularity of the timestamps, or how exiting the process is defined.

The effort made to get the common data model has implied understanding the care processes in the different nodes of the federation, agreeing on common concepts (and then, definitions) for the different attributes within entities, if there were different standards or encoding systems, building the appropriate cross-walks, transforming the variables when needed to a common format or, in the worst scenario, reaching a minimum common denominator.

Finally, apart from the barrier regarding the requirement for IT personnel, some regions had difficulties accessing or provisioning of the required IT equipment to implement the monitoring infrastructure to leverage their own healthcare data even when the proposed infrastructure requirements were considered average.

3. Recommendations

Main insights for the transfer plans derived from those challenges could be translated into the following specific recommendations in providing valuable and actionable insight to stroke care from the continuous monitoring and assessment of the effectiveness of the interventions implemented within the Stroke plans; and, eventually scaling-up of the solutions proposed in the ICTUSnet project to other European regions.

Recommendation 1: In the context of the participant regions (nodes), there is a need for Data Protection Officers (DPOs) to understand how data accessing and data management procedures will work in the context of a federated approach. Specific training programs for DPOs could be recommendable. The other way round, the continuous exchange with DPOs will make each node be aware of the local and specific requirements and anticipate the data accessing needs.

Recommendation 2: In a scaled context (Europe), there will be a need for technological solutions that ensures security- and privacy-by-design. Robust authentication and authorization systems will be needed to manage data access to only authorised users and to provide traceability information for forensic analyses in the follow up of a given user.

In the ICTUSnet project, the number of actors interacting has been confined to a few: in the Coordination Hub a technological and a domain expert, in the different regions (nodes) one or two contact persons with mixed profiles. In this very controlled case study, bilateral interaction between the Coordination Hub and participant nodes, close tutoring of the process, even online remote intervention can be used to solve queries on the deployment of the technological solutions.

Recommendation 3: In the context of a scaled up infrastructure, participating regions will require a number of profiles: domain experts (depending on the research question), data scientists, data managers and system administrators.

Recommendation 4: Orchestrating the whole distribution in more complex environments or a scale-up infrastructure will require a stepwise approach that smooths down the exchange between the Coordination Hub and the regions, while deploying an analytical pipeline that is transparent and reproducible at any step.

Recommendation 5: In the regional health systems involved, rating data curation institutions according to their procedures to get data up-to-date and high quality; agreeing on a common data quality framework; cataloguing their data sources in a way that is standard; providing information on interoperability standards and reusability; publishing clear procedures to get access to their data.

In addition to the variety of data sources is also the heterogeneity of data in their very nature (at one end, administrative data; at the other end, natural language) but also heterogeneous in the encoding systems. For example, the inclusion of new regions from other countries may have required other disease encoding systems, such as NOMESCO [15], OPCS [16], Leistsungkatalog or

ACHI. In case of using data from lab tests LOINC [19] should have been mapped out.

Recommendation 6. In the context of a scaled up infrastructure, it would be recommendable to map out and catalogue the most prevalent semantic interoperability standards. In that sense, future initiatives should link to standards developers and curators, for example, using SNOMED [20], the ontology of reference terms for medical conditions.

Recommendation 7. A pan European federated infrastructure should link with the existing research infrastructures on health data. On the one hand, to learn how they have catalogued the standards of semantic (and syntactic) interoperability. On the other hand, to provide access to their standards to the population health research community that could be interested in data models including that variety of data sources. As a matter of example, standards on biosamples, medical image or omics.

Recommendation 8. When it comes to reducing human interaction, a way forward will be developing and implementing a robust deployment protocol to automatically orchestrate the federation set up activities between the Coordination Hub and the different, detailed in the stepwise process represented in appendix 2

Recommendation 9. As a way to optimize the infrastructure resources and reduce the management overheads, it is sensible to outsource the computing or storage capabilities instead of having and maintaining high capacities in-house at the regional health system level. Solid European service providers such as, EGI, for computation capacities https://www.egi.eu, or EUDAT, for storage capacities (https://www.eudat.eu/) are primary choices for this purpose.

Recommendation 10. In monitoring and assessment infrastructures based in the analysis of health data, as that deployed in ICTUSnet, differential privacy is guaranteed as long as each node ensures differential privacy inside their own datasets. In other cases, it is always a good practice to analyse the data sets' characteristics, and enforce privacy through additional processes, like data minimisation or k-anonymization.

Finally, ICTUSnet has proved useful in providing insight to inform the medical practice and promote organizational changes in the integrated care of stroke patients. In this sense, the ICTUSnet federated analysis infrastructure can be considered a step towards more sophisticated solutions proving a reliable solution for a problem specific scenario, but the foundations may be easily extended to include more analysis pipelines that delve with other nuances of the stroke care organization and the patient experience and health care outcomes from the healthcare assistance. For example, a generalized version of the infrastructure may support fully distributed statistical algorithms and, in the final term, state-of-the-art federated learning algorithms, the current cutting-edge analysis approach when leading with huge data sets distributed across multiple locations, without having the possibility of merging them. In addition, the current client-server architecture, which relies on a Coordination Hub that agglutinates a high level of responsibility, can be moved to a peer-to-peer architecture, where all partners/Data Hubs can act as peers, having the capacity to coordinate analyses through the infrastructure. This transition

would mean the actual implementation of a global Learning Health System enabling the continuous improvement of the quality of the healthcare assistance for patients undergoing stroke and any other condition requiring assistance.