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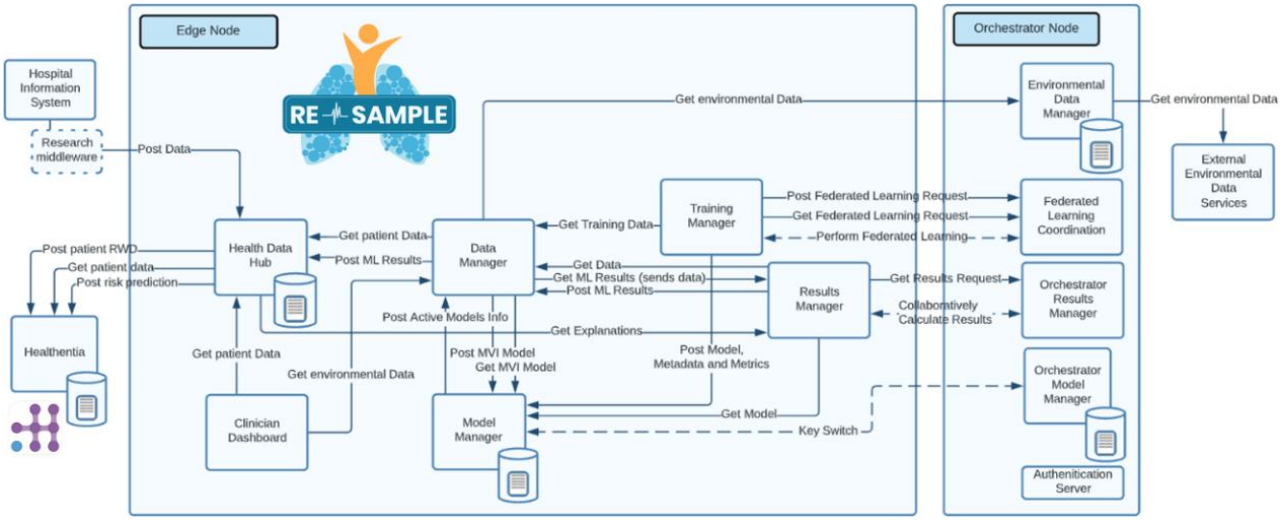
RE-SAMPLE

Newsletter N.3, April 2022

Dear reader,
For this third edition, the RE-SAMPLE project has moved forward! We will present you one of our consortium members, introduce 2 new concepts, tell you all about our last Consortium meeting! You will also discover the first presentation of our "Meet our PhD students"!

RE-SAMPLE Platform Architecture



The RE-SAMPLE project proposes the development of a technological platform for prediction of adverse events and providing better treatment to COPD patients. The platform allows the collection of the enrolled patients´ data for analysis. The system architecture has been designed following the “Privacy by Design” principle, emphasizing and putting great effort into the security of the system and protection of the clinical data handled.

Based on an ”edge computing architecture”, each participating hospital joins the system as an independent node that processes its own clinical data, keeping it under its control without the need to abandon its facilities and existing protection. Only the trained models, not containing any personal data, are transferred between the different nodes with the help of an orchestrator node.

The anonymized clinical data of the patients are added to the system from different sources, both from the hospital itself and from both the mobile application and web portal (Healthentia), through which patients provide real-world data (by providing daily information through responses to the questionnaires, physical activity data and other events). Other sources of data are also included in the analysis, such as meteorological or air quality data, with the aim of providing predictions of potential exacerbations as well as suggestions for intervention through aggregation.

Moreover, the architecture design makes the edge nodes as isolated as possible, being the ones in charge of any connection with the outside of the hospital and managing any data transfer. The edge node installed in the hospital contains the Health Data Hub (a clinical data repository under the HL7 FHIR standard) to aggregate the data used by the Machine Learning components for training and

producing the clinical models. In addition, a dashboard will allow clinicians to visualize the results and intervention suggestions for the patient, as well as to interact with the models for triggering new predictions on demand. As soon as new data is ingested, the data is used for further training the models, making them more robust and accurate.

Each of the components that make up the platform is implemented independently and interacts with each other through microservices (the current trend and appropriate for this type of platform), defining interfaces, avoiding coupling, and allowing its securitization through the most advanced current security standards.

Once the overall operation of the system and its functionalities have been verified, the RE-SAMPLE platform will be clinically validated in three pilot sites, in order to demonstrate the effectiveness of the machine learning algorithms in assisting clinicians and guiding patients in their own treatment.

Citizen Science and RE-SAMPLE

RE-SAMPLE applies a Citizen Science approach for inclusive design and evaluation, but what is Citizen Science?
Citizen Science projects actively involve members of the general public who have no formal training in the field of research. Especially in the fields of natural history, environmental sciences, ecology and astronomy, citizens have contributed, for example, by observations and data collection. How, when and how much citizens are involved may differ in the project. Citizens can *contribute* by collecting and/or analysing data; *collaborate* with scientists in the project by interpreting and/or disseminating results; or *co-create* when working together across the whole research project. Sometimes, citizens themselves lead the project and are in charge (also called 'extreme citizen science').

Involving members of the public in research aims to democratize the scientific research process and acknowledges that citizens themselves are experts in their own right.

For example, in the health and medical domain, patients are the experts when it comes to living with a certain condition on a daily basis. It is therefore important that patients and professionals work together and combine their expertise to address complex problems and develop meaningful solutions.This has been acknowledged also in other participatory approaches in the past (for example, patient and public involvement, participatory action research, human-centred design).
The availability of technology (for example, smartphones, smartwatches, tablets) has made data collection quite easy nowadays. RE-SAMPLE also depends on the collection of health data in the real world to support patients and healthcare professionals when it comes to the management of COPD in combination with other chronic conditions. In the last year, we have been working closely together with patients and healthcare professionals in Estonia, Italy and The Netherlands to understand what kind of data should be collected and how. This way we want to make sure that we are collecting the right data in a way that is feasible for patients and useful for supporting COPD self-management and decision-making. The collaboration with patients and healthcare professionals will continue throughout the project to shape RE-SAMPLE together so that it addresses their needs and preferences in COPD care

Presentation of
STICHTING MEDISCH SPECTRUM TWENTE (MST)

Medisch Spectrum Twente (MST) is a large not-for-profit teaching hospital situated in the Twente Region in the eastern part of the Netherlands. It has 1070 licensed beds on various locations and 250 medical staff members. In The Netherlands, MST is one of the largest hospital organizations, with many supra-regional specialties such as acute care centre for traumatology, cardiac surgery, radiotherapy, neurosurgery and AIDS-treatment.

The department of Pulmonary Medicine at MST is in charge of the RE-SAMPLE project with a research team consisting of PhD student Charlotte Bucsán, supervisors and clinical epidemiologists Job van der Palen, Marjolein Brusse-Keizer, and Anke Lenferink, pulmonary physician Wendy van Beurden, the pulmonary medicine research office, and ICT specialists Björn Geerdink and Tom Soer. This research team has considerable experience in COPD self-management intervention research and research on biomarkers for COPD mortality and morbidity, predictors on adherence to inhalers and action plans, with international connections in this field.

In RE-SAMPLE, they bring multi-dimensional and domain-crossing medical-scientific information from substantial databases related to COPD and Complex Chronic Conditions (CCCs), including information from existing clinical studies, as well as the possibility to add new real-world data (RWD) and assessments of interventions in the clinical and daily life of patients with CCCs. In addition, MST brings expertise on the methodology and evaluation of clinical study data.

In RE-SAMPLE, this will help to create a RWD monitoring ecosystem, to evaluate real-time personalised prediction models for the prognostics of multimorbid exacerbations of CCCs, and to provide adaptive interventions that empower patients with CCCs in self-care.

MST has three main tasks in RE-SAMPLE:

- Observational cohort for RWD collection (WP5)
- Clinical scientific overview predictors exacerbations (WP2)
- Phenotyping of patients with COPD and CCCs (WP6)

Latest news

RE-SAMPLE Consortium Meeting

On 23 and 24 March 2022, the RE-SAMPLE Consortium met on the 12th month of the project to discuss advancements of the last 12 months and to dive into the next six months. The project was introduced to the Advisory Board in presence of the whole consortium. Two workshops also took place: one on end-users involvement and the second on developing the virtual companionship programme.

This consortium meeting was also the occasion to learn more about each member of the project! It ends stating that RE-SAMPLE members:

- Are mainly dog people!
- Prefer going to the beach for holidays
- Need coffee in a consortium meeting
- Would rather do some sport activities
- Prefer Italian cuisine for the next RE-SAMPLE meeting!

The next consortium will take place in September!

Meet our PhD students: Charlotte

Hello everyone! My name is Charlotte Bucsán and I am one of the PhD students working on the RE-SAMPLE project. I am based at the department of Pulmonary Medicine in Medisch Spectrum Twente (MST) , Enschede, The Netherlands. MST is one of the three clinical sites conducting the RE-SAMPLE prospective observational cohort study. During the cohort study, we want to discover which parameters, variables and tools are most suitable to predict disease progression and exacerbations in Chronic Obstructive Pulmonary Disease (COPD) patients that also have other chronic diseases. The main focus of my PhD project is the setup, execution and analysis of the cohort study.

I find it fascinating to work with the actual people who are suffering from these diseases. The conversations about the impact of their conditions on their life emphasize the importance of this project and give me extra energy and motivation to power through my research. We collect a combination of clinical and real world data in the cohort study. For example, we perform pulmonary function tests, measure blood biomarkers and take validated questionnaires. This cohort study is very unique as the set of parameters, variables and tools for the data collection are not yet fixed and will have two updates in the first year, based on citizen-design sessions and findings from literature.

As the RE-SAMPLE consortium consists of such a diverse group of people, I had the opportunity to work with people I would have otherwise never met. I find it interesting to see how we all have a different view on the problem and how to solve it. The international nature of this project is a big bonus for me, I hope that we are soon able to visit each other for consortium meetings and meet everyone in person.

Do you want to know more about RE-SAMPLE activities? Click here!

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