RE-SAMPLE has received funding from the European Union's Horizon 2020 Research and Innovation Programme under Grant Agreement no 965315.

Newsletter N.10, September 2024

INTRODUCING EVIDEN

Atos is a global leader in digital transformation, and European number one in cybersecurity, cloud and high-performance computing. Atos group provides tailored end-to-end solutions for all industries in 73 countries.

Eviden is an Atos business that brings together its digital, cloud and big data & security business lines. With almost 30 years of experience in running Research, Development and Innovation projects, we have become a well-known player in the EU context.

Our multidisciplinary and multicultural team has the skills to cover all the activities needed to run projects successfully, from scientific leadership to partnership coordination, from

BDS R&D Spain is Eviden's research and development division working towards innovation in BDS products through the results of the projects in which it participates. Committed to high quality in delivery, sustainability and cost control, our team (140 professionals in seven locations across Spain) is currently involved in 80 co-funded R&D projects.

Eviden' technical expertise was crucial in leading the definition of the platform architecture, ensuring a balance between using cutting-edge technologies and prioritizing privacy and security by design. EVIDEN also led the definition of the common data model for the project, translating extensive clinical discussions into a technologically viable result. This model facilitates the aggregation of heterogeneous data and its

development of emerging technologies to the exploitation of project outcomes, with a strong focus on dissemination, innovation adoption and commercialisation.
With a robust portfolio of patented technologies and worldwide leading positions in advanced computing, security, AI, cloud and digital platforms, it provides deep expertise for all industries in more than 47 countries. Bringing together 47,000 world-class talents, Eviden expands the possibilities of data and technology across the digital continuum, now and for generations to come. Eviden has an annual revenue of over € 5 billion.

EVIDEN
an atos business

standardization, thereby enhancing value creation.

Moreover, Eviden developed and implemented the Health Data Hub, the central component for data aggregation and storage. This implementation leveraged Eviden' expertise in clinical standards to improve data exploitation by analysts and machine learning algorithms. Eviden also collaborates closely with other technical partners, providing support and consulting services to ensure seamless integration of the platform's various components. Additionally, Eviden collaborates in defining the possibilities of opening the platform's data to the public, adhering to the strictest privacy and security requirements and developing robust data access management protocols.

Finally, Eviden is coordinating the definition of the exploitation strategy of the project.

RE-SAMPLE Consortium Meeting in Bremen

On 13 and 14 May 2024, the RE-SAMPLE partners met for a Consortium meeting hosted by DFKI in Bremen (Germany).

Owing to intense discussions and cooperation on topics ranging from usability testing to integration in daily care, and from security and privacy to the possible impacts of the project in the future, the RE-SAMPLE solution is now taking its final shape.

RE-SAMPLE project team meets the Advisory Board

On 15 May 2024, the RE-SAMPLE project had a 2nd Periodic hybrid Review Meeting with the Project Officer and two external experts invited by the European Commission. The meeting went well, and we can be really proud of our work!

The reviewers were interested and engaged, asked helpful questions aimed at further improving the application we are developing, and did not identify major failures or concerns.

The level of preparations and execution by the hosting partner DFKI and all the presenters was outstanding. We received several compliments and expect the monitoring process to be completed soon.

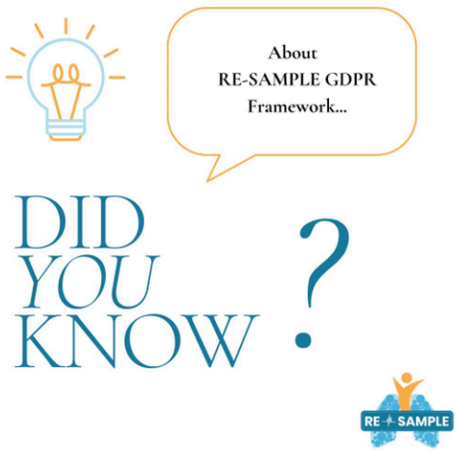
Meeting with the WARIFA project!

On 25 June2024, the RE-SAMPLE project and the WARIFA project's officers met to discuss synergies and collaboration in order to enhance awareness!

Together, we are sharing project outcomes, championing open science and creating unified strategies for future advancements, working to transform the health journey through artificial intelligence!

The WARIFA Project will develop a prototype of a combined early risk assessment tool that will provide individual citizens with personalized recommendations for the management of chronic conditions - such as cancer, cardiovascular diseases, diabetes and chronic respiratory diseases – which represent the leading causes of death for the citizens of the European Union. WARIFA will be available to individual citizens via a user-friendly interface on their smartphone.

RE-SAMPLE and the GDPR



The preservation of data in the medical sector is an essential aspect of eHealth products, and the RE-SAMPLE team works intensely to preserve privacy for the patients involved in the project and beyond.

Since the end of 2023, the RE-SAMPLE project gained much attention regarding the proposed GDPR complaint framework designed in the context of the specific project in order to assist patients with COPD to self-manage their disease through a trustworthy and privacy-preserving solution.

The GDPR framework proposed combines the security and privacy by design principles following GDPR compliance and is one of the most recent research outcomes of enforcing security and privacy by design principles in complex environments that are relying on strong AI technologies.

RE-SAMPLE researchers were invited to present their contribution in two opend events.

The first event was organised in the context of the Postgraduate Programme "Cybersecurity and AI Technologies" of the University of Piraeus, one of the most advanced programmes on cybersecurity in Greece.

The second event was organised by the Hellenic Data Protection Authority in the context of the EU Programme byDefault, which deals with the identification of the needs for data protection and privacy education and for an open knowledge source for DPOs and privacy professionals.

The GDPR framework of RE-SAMPLE was presented in both events receiving highly positive comments about its necessity and contribution in the privacy field.

Continuous end-user involvement

Roessingh Research and Development is responsible for the continuous end-user involvement within the RE-SAMPLE project. Together with the pilot sites, we carried out

several iterations to test the RE-SAMPLE solution. In the last months, we performed our last iteration in which we tested the final prototype of the RE-SAMPLE project. In the following, we will summarize our main findings.

The last usability test was performed with patients (to test the application) and healthcare professionals (to test the clinical dashboard). As can be seen in the Table below, there were several study parameters.

Study parameters	
Usability test of the application (people with COPD)	Usability test of the clinical dashboard (Healthcare professionals)
Number of usability issues • *Minor issues* • *Serious issues* • *Critical issues*	Number of usability issues • *Minor issues* • *Serious issues* • *Critical issues*
Satisfaction with the virtual coach • *Bot Usability scale*	Task metrics • *Task completion* • *Time on Task* • *Task Satisfaction* *(After Scenario questionnaire (ASQ)*
User experience • *Semi-structured interview*	User experience • *Semi-structured interview*
	Usability Benchmarking scores • *HUBBI*

The RE-SAMPLE application for patients was tested with 5 Italian participants. It appeared that there were no usability issues during the one-time testing with patients.
Participants could score their satisfaction with the virtual coach on a 5-point Likert scale (1=strongly disagree, to 5=strongly agree).
Overall, participants gave a score of 3.6, indicating the satisfaction to be above average. Results regarding user experience showed that participants were overall positive about the application, and considered it overall, as a useful tool.

The clinical dashboard was tested with 3 healthcare professionals from Estonia and 3 healthcare professionals from Italy. There were several minor issues (e.g., the shared decision-making tool was not found), some major issues (e.g., unclear where to find whether a patient has an exacerbation), and several critical issues (e.g., the risk predictions were incomprehensible). The Usability Benchmarking Score (HUBBI) showed that some aspects (e.g., interface design, guidance, and support) need improvement, and other aspects (e.g., basic system performance) are considered as okay but can be improved. Results regarding task performance, in which the time is measured to perform

certain tasks within the system, showed an average completion time of 1.5 minutes. Meaning that participants had some struggles with completing a specific task. Task satisfaction could be scored on a 7-point Likert scale (1= totally disagree, to 7=totally agree). Results showed an average score of 4.7 which can be considered relatively low. Finally, user experience revealed that in case of improvements, the clinical dashboard can be helpful.

With this last usability test, the task of continuous end-user involvement within the RE-SAMPLE project is completed. Throughout the several iterations, we aimed to collect the opinions, needs, and wishes of the potential end-users of RE-SAMPLE. The results from the iterations will be used by our technical partners to improve the RE-SAMPLE solution. Hereby, we aim to eventually develop a solution that will fit with its end-users and will create added value for both healthcare and people with COPD and Chronic Complex Conditions.

Publications

Technology-supported shared decision-making in chronic conditions: a systematic review of randomized controlled trials

On 21 March 2024, Roswita Vaseur, Eline te Braake, Tessa Beinema, Wendy Oude Nijeweme - d'Hollosy and Monique Tabak published a paper titled "Technology-supported shared decision-making in chronic conditions: A systematic review of randomized controlled trials" in Patient Education and Counseling.
Link to publication

The abstract can be read below:

Objectives

To describe the role of patients with a chronic disease, healthcare professionals (HCPs) and technology in shared decision making (SDM) and the

Results

Forty-three articles were identified and reported on 21 SDM-studies, 15 CDSS-studies, 2 studies containing both an SDM-tool and a CDSS, and 5 studies with other decision support components. SDM elements were mostly identified in SDM-tools and interactions styles were least common in the other decision support components.

Discussion

Patients within the included RCTs mainly received information from SDM-tools and occasionally CDSSs when it concerns treatment strategies. HCPs provide and clarify information using SDM-tools and

use of clinical decision support systems (CDSSs), and to evaluate the effectiveness of SDM and CDSSs interventions.

Methods

Randomized controlled studies published between 2011 and 2021 were identified and screened independently by two reviewers, followed by data extraction and analysis. SDM elements and interactive styles were identified to shape the roles of patients, HCPs and technology.

CDSSs. Technology provides interactions, which can support more active SDM. SDM-tools mostly showed evidence for positive effects on SDM outcomes, while CDSSs mostly demonstrated positive effects on clinical outcomes.

Practice implications

Technology-supported SDM has potential to optimize SDM when patients, HCPs and technology collaborate well together.

ERS Monographs

The *ERS Monograph* is the quarterly book series from the European Respiratory Society. Each Monograph covers a specific area of respiratory medicine, providing in-depth reviews that give clinicians at all levels a concise, comprehensive guide to symptoms, diagnosis and treatment.

Two recent Mongraphs can bring insights to the RE-SAMPLE project:

- 'Digital Respiratory Healthcare', released in December 2023
- 'COPD in the 21st Century' released in March 2024.

The Monographs are accessible for free for ERS members, and at a fee of 85$ per book for non-ERS members.

PhD Corner

Meet our PhD students: Dumiana Chamaon

Hello everyone,

My name is Dumiana Chamaon, I am a health scientist and PhD candidate at the Pulmonary department of Medisch Spectrum Twente in the Netherlands, one of the RE-SAMPLE project clinical partners.

A main part of my role within the RE-SAMPLE project is in managing and including participant in the cohort for Medisch Spectrum Twente.

Some of my day-to-day work is administering visits with participants, assisting participants with regards to difficulties and/ or issues in the usage of the RE-SAMPLE project products and assisting in setting up the further course of the RE-SAMPLE project in Medisch Spectrum Twente.

As a PhD candidate I will be working on topics in the field of pulmonology with the focus point being on Chronic Obstructive Pulmonary Disease (COPD), my special interests lie in the predictors of exacerbation of COPD.

With the RE-SAMPLE project I do not only want to aid in the self-management of patients with COPD and complex chronic conditions (CCC) but also contribute to the knowledge on predictors of exacerbation of COPD. Therefore I will be working on different ways to aid in the COPD management throughout the course of the RE-SAMPLE project.

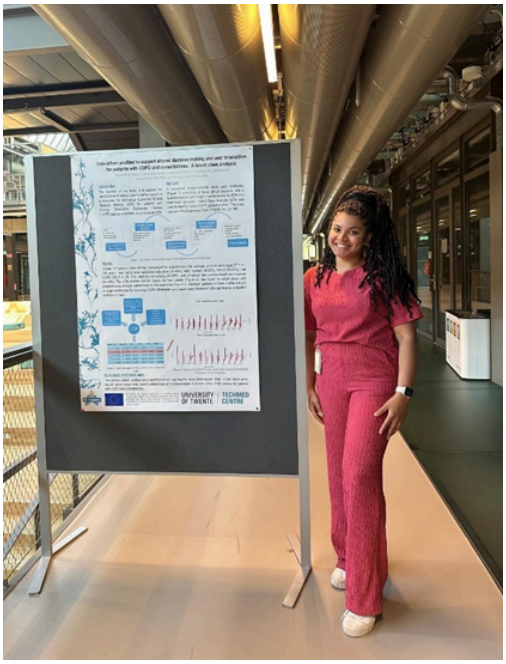
Health by Technology Conference & TechMed Day

May and June were exciting months for our PhD candidate Roswita, who conducts research on technology supported decision making.

In May, Roswita attended the Health by Technology Conference in Groningen, where she presented an eHealth application with an integrated shared decision-making process to support patients with COPD and comorbidities, as well as healthcare professionals during consultations.
Using the Creative Technology Design Process, it was concluded that the application should be further improved and will thereafter be implemented and evaluated in a larger clinical trial. It is expected that the application will enhance communication and collaboration between patients and healthcare professionals.

In June, Roswita attended the TechMed Research Day at the University of Twente, where she gave a poster presentation about data-driven profiles to support shared decision-making and user interaction for patients with COPD and comorbidities. She presented two distinct profiles identified based on a latent class analysis.
These profiles will serve as valuable input for refining the eHealth application introduced at the Health by Technology Conference. Future work will delve deeper into patient preferences and characteristics to further refine shared decision-making profiles for patients with COPD and comorbidities, potentially leading to more personalized shared decision-making within the application.

All in all, Roswita enjoyed both conferences, during which she had valuable conversations about her work and learned much from the various inspiring sessions and presentations by the keynote speakers.



Events to come

NordiCHI 2024

On 15 October 2024, some of our RE-SAMPLE partners will be presenting their Case Study "Self-management of COPD supported by eHealth: Patients' attitudes towards monitoring, risk prediction and virtual coaching" at the NordiCHI Conference in Uppsala, Sweden!

Other interesting events

The ERS International Congress 2025 will be held from 27 September to 1 October 2025 in Amsterdam, Netherlands.

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

Click here!

Sign up to receive our newsletter!

Stay in touch with RE-SAMPLE project's progresses and results by subscribing to our newsletter sent out every two months. You can unsubscribe at any moment.

Subscribe