*Newsletter N.8, October 2023*

Dear reader,
In this eighth edition, we will take you with us to our recent consortium meeting, share latest publications, introduce one more project partner and PhD student, and invite you to a webinar on Real-World Data in medical research!

## EUROPEAN HOSPITAL AND HEALTHCARE FEDERATION (HOPE)

HOPE mission is to promote improvements in the health of citizens and a uniformly high standard of hospital care by the European Union, fostering efficiency, effectiveness and humanity in the organisation and operations of hospital and health services.

HOPE is representing its members in the European arena covering all policies with an impact on hospitals and health services. HOPE contributes to the legislative agenda but also to the non-

HOPE, the European Hospital and Healthcare Federation, is a European

non-profit organisation, created in 1966 representing national public and private hospital and healthcare associations and hospital, health and social care services owners. With 36 organisations from the 27 Member States of the European Union, the United-Kingdom, Switzerland and the Republic of Serbia, HOPE covers almost 80% of hospital care and is also active in the healthcare and social fields.

legislative activities in particular through participation in European projects and joint actions.

Since its creation HOPE has produced comparative information on the ways healthcare systems are organised and financed. It also includes a unique annual exchange programme for health professionals, together with study tours, workshops and conferences.

In the RE-SAMPLE project, HOPE is leading Work Package 8 regarding Communication, Dissemination and Exploitation activities.

## RE-SAMPLE met in Piraeus!



On 19 and 20 September 2023, the RE-SAMPLE Consortium met in Piraeus, Greece, for its month 30 milestone!

Our consortium meetings are always the moment for fruitful discussions on the project advancements and challenges to come. This one was no exception, with a lot of constructive dialogue and teamwork to make the project's objectives a reality.

The virtual companion programme was in the spotlight, with the organisation of next months' work between clinical and technical partners.

Additional plenary sessions and workshops collecting inputs from all the partners, as well as some parallel sessions on the clinical and technical side, enriched the efficiency, consistency, and creativity of our cooperation!

We thank all participants for their terrific work, and give special thanks to our partners at UPRC for hosting us and organising a great social event! We left Greece with great memories and an amazing work plan for the following months.

## Privacy and reuse of health data

On June 19, 2023, RE-SAMPLE participated in an online roundtable about privacy and reuse of health data. More specifically, two partners of the EU Project "DataTools4Heart" (a project funded under the health cluster of the Horizon Europe, the EU's framework programme for research & innovation) have organised an online meeting on "Privacy & tech scenarios on reuse of health data: EU projects' roundtable". The aim of the event was to open a discussion, together with many other EU-funded projects, on technical and legal solutions which may enable, foster or facilitate the reuse of personal data for research purposes, also in view of the upcoming Artificial Intelligence Act, Data Act and European Health Data Space.

Prof. Christos Kalloniatis, a member of RE-SAMPLE from University of Piraeus acting also as the Data Protection Officer of the project has participated as speaker in the online meeting delivering a speech on the privacy challenges encountered in RE-SAMPLE. He presented the objectives and goals of the project in terms of security and privacy; the GDPR compliance issues and how they were overcome in RE-SAMPLE; and furthermore discussed the strategy for Open Data Usage. The latter topic stirred great interest among the participants whose questions provoked motivating a stimulating discussion at the end of the meeting.

Thus, in this meeting participants had the opportunity to share recommendations and thoughts on how the European Union can become a global leader in medical research and data-driven knowledge discovery thanks to a safe and ethical reuse of personal and health data.

EU-Funded Projects Roundtable

RE-SAMPLE Project
Privacy Challenges

19.06.2023
Prof. Christos Kalloniatis, University of Piraeus
RE-SAMPLE DPO

## PhD corner

## Meet our PhD students: Federico Mazzone

Ciao! My name is Federico, and I am a doctoral candidate originating from Italy, currently in the third year of my academic journey. I work as part of the Cybersecurity (EEMCS-SCS) group at the University of Twente, in the Netherlands.
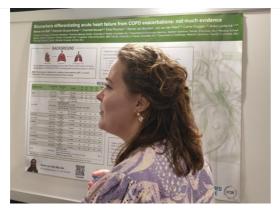
My academic background is rooted in the fields of Mathematics and Cryptography, in which I got my master's degree at the University of Trento, Italy. My research mainly focuses on designing and developing cryptographic protocols for machine learning applications. In particular, my goal is to allow multiple entities to collaboratively train models on sensitive data, without outsourcing such data.

This is particularly important in scenarios such as RE-SAMPLE, where a group of hospitals wants to train a joint model over distributed patient data. As medical records are extremely sensitive from a privacy perspective, it is of the utmost importance that potential malicious entities cannot access them directly or indirectly.

Accomplishing this task in a privacy-preserving way is not trivial. Existing solutions are either prone to known attacks, or too inefficient to be used in practice in terms of computation and communication costs. My current line of research focuses on investigating how to solve this issue and to find a compromise between these extremes.

In this very moment we are developing a framework that allows this. We theoretically proved its security, and we are extensively assessing it against state-of-the-art attacks. The results we got so far are very promising, and they make us believe we can give a valuable contribution to both the RE-SAMPLE project and to the scientific community at large!

## ERS experience

From 9 to 13 September, the annual international congress of the European Respiratory Society took place in Milan, Italy. Sanne van Dijk, one of the RE-SAMPLE PhD students, presented two posters communicating the results of her research on COPD and chronic heart failure.

**Biomarkers differentiating acute heart failure from COPD exacerbations: not much evidence**

By means of a systematic literature review, markers able to identify acute heart failure in patients with COPD were identified from existing literature. The review included 10 distinct studies. Three blood biomarkers (BNP, NT-proBNP & MR-proANP) and one ultrasound marker (inspiratory inferior vena cava diameter) showed promising results. However, the overall research quality of the included studies was low, and future research should validate the most promising markers for their diagnostic accuracy.

**Exploring patterns of COPD exacerbations and comorbid flare-ups**

Patients with COPD, chronic heart failure, anxiety, and depression were included in this study. They reported their symptoms on a daily basis during one year (comparable to the RE-SAMPLE study). These data were transformed to pattern visualisations of exacerbations of COPD and flare-ups of comorbidities on a time line of one year. Overall, the patients showed a variety of patterns, which were summarised into ten categories. In two-thirds of patients, COPD exacerbations occurred simultaneously with comorbid flare-ups. This study, therefore, stresses the importance of personalising COPD care by taking comorbid diseases into account.

These two studies are valuable to RE-SAMPLE, as we now know what (and what not) to focus on during the design of the RE-SAMPLE intervention that is soon to be offered and that will advance the personalisation of COPD and comorbid care.

## Publications

## Artificial intelligence in systematic reviews: promising when appropriately used

In July 2023, Sanne van Dijk, Marjolein Brusse-Keizer, Charlotte Bucsán, Job van

**Methods** Use of the AI tool consisted of several steps. First, the tool required

der Palen, Carine Doggen and Anke Lenferink, published a communication in the BMJ Open Journal entitled "Artificial intelligence in systematic reviews: promising when appropriately used".

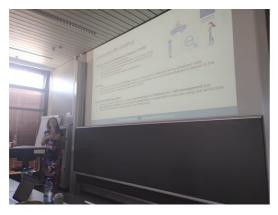[Link to publication](#)

The abstract can be read below:

**Background** Systematic reviews provide a structure overview of the available evidence in medical-scientific research. However, due to the increasing medical scientific research output, it is a time-consuming task to conduct systematic reviews. To accelerate this process, artificial intelligence (AI) can be used in the review process. In this communication paper, we suggest how to conduct a transparent and reliable systematic review using the AI tool 'ASReview' in the title and abstract screening.

training of its algorithm with several prelabelled articles prior to screening. Next, using a researcher-in-the-loop algorithm, the AI tool proposed the article with the highest possibility of being relevant. The reviewer then decided on relevancy of each article proposed. This process was continued until the stopping criterion was reached. All articles labelled relevant by the reviewer were screened on full text.

**Results** Considerations to ensure methodological quality when using AI in systematic reviews included: the choice of whether to use AI, the need of both deduplication and checking for inter-reviewer agreement, how to choose a stopping criterion and the quality of reporting. Using the tool in our review resulted in much time saved: only 23% of the articles were assessed by the reviewer.

**Conclusion** The AI tool is a promising innovation for the current systematic reviewing practice, as long as it is appropriately used and methodological quality can be assured.

## Position Paper for the "Mensch und Computer" (MuC) Conference

The workshop was titled "Partizipative und Sozialverantwortliche Technikentwicklung" (in English: Partcipatory and Socially Responsible Technology Development) and took place during the conference "Mensch und Computer" (MuC, in English: "Humans and Computers") in Rapperswil (Switzeland).

MuC is the largest conference series on human-computer interaction in Europe. The conference is organised by the German Informatics Society and German UPA (professional association of German usability and user experience professionals).

The [workshop on participatory and socially responsible technology development](#) wanted to foster the discussion around the question: "To what extent does user participation lead to socially responsible technology development?" People interested in joining the workshop were invited to submit a position paper in which they reflect on their experiences in participatory design and on questions:

- What was the structure of participation and the relationships of interests in the project? Which criteria were used to select users? Were gender and diversity aspects taken into account?

RE-SAMPLE partners from RRD Christiane Grünloh, Marian Hurmuz, Eline te Braake, and Stephanie Jansen-Kosterink wrote the following position paper for the workshop:

End-user and stakeholder participation in the European eHealth project RE-SAMPLE. Mensch und Computer 2023 - Workshopband.

DOI: [https://doi.org/10.18420/muc2023-mci-ws02-436](https://doi.org/10.18420/muc2023-mci-ws02-436). They explained it below:

In our position paper, we reflected on the end-users and stakeholders that were engaged in several different activities in the project (for example, user needs and requirements elicitation, testing of technology, creating the new service model) using different methods (for instance, interviews, surveys, workshop) and formats (online, in-person, by phone). We are very grateful for the the time that people took, to give us their input and information, on which many decisions were based.

Together with other participants, we reflected on how we could improve the level of participation of end-users and stakeholders. Given the workload of healthcare professionals and the disease burden of people living with COPD, we have to balance the level of involvement (i.e., sharing power, decisions and responsibilities) with the burden that comes with this. Given the challenges to recruit people to be involved, we often needed to take what we get. However, the people who volunteered might not be representative of the whole population of people living with COPD. An ongoing challenge therefore is to reach people who are difficult to reach, to also include their
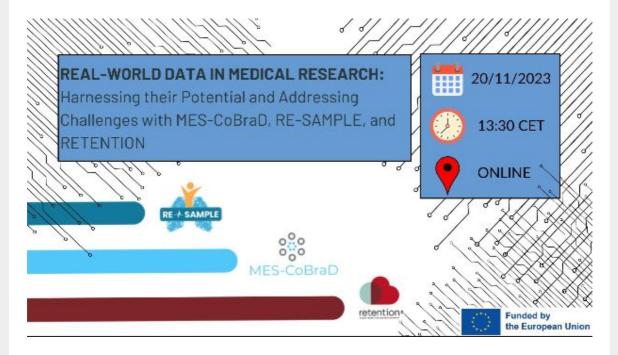
- What was the research and development process like? Who was involved in which knowledge and decision-making proceses? How much influence or decision-making power did the users have?
- What methods were used? How did they influence, enable or prevent participation and influence?
- How are the process and the project evaluated with regards to the demands of participatory design and ultimately with regard to their contribution to socially responsible technology?

perspective when developing the RE-SAMPLE virtual companion.

As we conclude in our position paper: our goal is to continuously find ways to reach all people that are affected by the technology under development and that are representative of the population - in all of our projects. Building good relationships with the stakeholders and involving them already when writing a grant proposal can help to shape the project in a way that addresses their needs and kick-start outreach activities early on. Furthermore, we believe that delivering first and asking later (e.g., by continuously sharing activities and results from ongoing studies in an accessible way) is a good way to show our commitment to stakeholder involvement. It can also illustrate what we mean by participation, to lower the barriers for people who do not have any experience yet.

## Events to come

## Joint Webinar



REAL-WORLD DATA IN MEDICAL RESEARCH: Harnessing their Potential and Addressing Challenges with MES-CoBraD, RE-SAMPLE, and RETENTION

20/11/2023

13:30 CET

ONLINE

Funded by the European Union

On 20 November, RE-SAMPLE will meet two other projects (MES-CoBraD and RETENTION) to discuss the potential of Real-World Data (RWD) in advancing medical research and healthcare. The session will bring together experts from three European research projects that utilise RWD to tackle complex medical challenges, contributing to a digital transofrmation in healthcare delivery. These expert speakers will share their respective projects, as well as addressing the challenges of collecting, anonymizing, harmonizing, and combining data.

[Sign up for the webinar!](#)

You will learn about the remarkable potential of RWD and its applications in enhancing healthcare outcomes, and gain insights into the challenges and best practices for medical research, as well as clinical practice. This event is well-suited for researchers, data scientists, and anyone interested in the evolving role of big data in medicine. Register now and be a part of this important discussion.

This event is the second in a series of webinars from MES-CoBraD, RE-SAMPLE, and RETENTION. To watch the first event, which served as an introduction to the three projects and outlines their overlapping aspects, follow [this link](#)

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# Other interesting events

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The Supporting Health by Technology Conference will be held in Groningen on 30 and 31 May 2024.

Symposium 2024 - 13th Edition

**Supporting Health by Technology**

May 30 & 31, 2024 | Groningen (NL)

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**ECSCW 2024**
June 17th-21st | Rimini, Italy

The 22nd edition of the European Conference on Computer-Supported Cooperative Work (ECSCW) will take place in Rimini, Italy from 17 to 21 June 2024.

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The ERS International Congress 2024 will be held from 7 to 11 September in Vienna.

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

**Click here!**



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