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PRESS RELEASE

IDEA4RC: a new EU funded project to create an innovative data ecosystem to facilitate the sharing and re-use of rare cancers data

One out of four cancers diagnosed each year in Europe is a rare cancer.

Research on rare cancers would greatly benefit from the analysis of large and diverse data sets, which is currently hampered by lack of interoperability among clinical centers and personal data protection requirements.

IDEA4RC is a newly funded Horizon Europe project that aims at developing an IT infrastructure to facilitate the re-use of rare cancers data across clinical centers in different EU member countries. It will be tested on 11 Expert Centres of EURCAN, the European reference network for rare adult solid cancers.

Milan, 3 October 2023. IDEA4RC is one of the five projects financed in 2022 by the Horizon Europe framework program under the topic 'Innovative tools for the use and re-use of health data'. Its objective is to develop an IT infrastructure to facilitate the re-use of rare cancers data across clinical centers in different EU member countries. Its final aim is to improve research on rare cancers.

The consortium involves 11 Expert centers of EURACAN, the European Reference Network on rare adult solid cancers, located in 8 EU countries. They represent the ideal testbed for IDEA4RC. The EU supports this project with nearly €8.2 million in funding over 4 years, starting 1 September 2022.

Every year in Europe 650'000 people receive a rare cancer diagnosis. Taken together they represent nearly 25% of all cancer diagnoses in the continent. Still, every single rare cancer suffers from lack of large and diverse data sets whose analysis could shed light on the disease course, identify new diagnostic and prognostic factors and assess treatments effectiveness.

The possibility to access and analyze large and diverse health data sets, not only those on rare cancers, is currently impaired for a number of reasons. First, the lack of interoperability among the databases maintained by different hospitals and other data sources (cancer registries, administrative data set etc). Secondly, the General Data Protection Regulation (GDPR) approved in 2016 introduced several requirements to process personal data.

IDEA4RC aims at overcoming these obstacles developing a data ecosystem which implements data protection and privacy by design and by default as required by the GDPR and that also satisfies the FAIR principles of scientific data management (Findability, Accessibility, Interoperability, and Reusability).



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To do this IDEA4RC will follow a federated learning approach, that allows to analyze multiple data sets without moving them from their original location by using an iterative procedure. Each data set will be processed locally inside a so-called *secure processing environment*, which allows to implement the principles of data protection by design and by default.

IDEA4RC will also take up another challenge, that of developing Natural Language Processing (NLP) models to extract information from the clinicians notes and medical reports. It will do this in the several different languages spoken by the clinical centers involved in the project.

Researchers will be the primary users of the IDEA4RC ecosystem, but in order for the platform to be successful, it is crucial that the needs and point of views of all stakeholders involved in its development, deployment, and exploitation, are heard and taken into account. For this reason, along the entire course of the project, a team of social scientists will conduct interviews and organize workshops to collect the values and expectations that all the actors have towards IDEA4RC. This is a challenge, since the project puts together subjects with a wide range of expertise: researchers, clinicians, software developers, data scientists and data managers, data protection officers and patients' advocacy groups.

The ecosystem will be tested through pilot projects deployed in the 11 clinical centers belonging to the consortium and based in 8 EU member countries. The projects will focus on two of the rare cancer families, head and neck tumors and sarcomas.

The consortium

IDEA4RC is led by the Fondazione IRCCS Istituto Nazionale dei Tumori, based in Milan, Italy, which already played a central role in several projects about rare cancers epidemiology and research. The IDEA4RC consortium comprises 25 partners from across Europe, which includes 11 clinical centers, 10 groups from universities and industries with technical expertise in software development and data science for the health sector, legal experts from the European Centre for Certification and Privacy (ECCP), social scientists from the University of Utrecht, and one team from the Digital Institute For Cancer Outcomes Research (DigICORe) which will foster the uptake of the IDEA4RC platform by other clinical centers after the end of the project.

At the end of September 2022, project coordinator Dr. Annalisa Trama (Istituto Nazionale Tumori) hosted the kick-off meeting in Milan. The consortium met again in Venice in April 2023 to discuss the first advancements of the project.

Contacts

To know more about the IDEA4RC, please visit the website <https://www.idea4rc.eu/>, follow us on Twitter ([@idea4rc](https://twitter.com/idea4rc)) and LinkedIn ([IDEA4RC](https://www.linkedin.com/company/idea4rc)), and subscribe to our [newsletter](#).

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