



Newsletter #1

Hello,

This is the first issue of the IDEA4RC newsletter. IDEA4RC is an EU-funded project that aims to develop a smart ecosystem to facilitate the collective re-use for research purposes of rare cancer data gathered by different clinical centres across the EU.

The project is led by the Istituto Nazionale dei Tumori di Milano and involves 25 partners from all over Europe with a wide range of expertise. The platform will be tested with pilot projects in 11 expert centres of EURACAN, the EU reference network on rare adult solid cancers, which are part of the IDEA4RC consortium.

By subscribing to this newsletter you will be receiving bi-monthly updates on the project's advancements. If you want to invite your friends to subscribe, send them [this link](#).

Introducing IDEA4RC

Every year in Europe 650'000 people receive a rare cancer diagnosis, nearly 25% of all cancer diagnoses. However, there are nearly 200 different rare cancers, each of which is found in less than 6 persons per 100'000 each year. Research on diagnosis and treatments needs large and diverse datasets, that are however difficult to built because this would require different clinical centers across Europe to share their data.

Currently these efforts are hampered by the lack of interoperability among clinical centers and by the privacy requirements imposed on personal data by the General Data Protection Regulation (GDPR).

IDEA4RC plans to facilitate the sharing and exploitation of rare cancers data for research purposes by developing a new IT infrastructure that implements **data protection and privacy by design and by default** required by EU regulations and complies with the **FAIR principles** of scientific data management: Findability, Accessibility, Interoperability and Reusability.

The **ultimate goal is to increase the knowledge on rare cancers**: gather new evidence on the natural history of the diseases, find new factors that influence prognosis and treatment response, assess treatments effectiveness, monitor quality of care.

The project will focus on two among the 12 families in which rare cancers are grouped: **soft tissue sarcomas** and **head and neck cancers**.

Soft tissue sarcomas can affect muscles, fat, blood vessels, nerves, tendons and linings of the joints. The most frequent sites are the arms and legs and the trunk and abdomen (nearly 1 diagnosis per 100'000 persons each year).

Head and neck cancers usually begin in the squamous cells that line the mucosal surfaces of the head and neck. The most affected sites are the larynx and bottom part of the pharynx, the oropharynx and the lips (between 1 and 5 diagnoses per 100'000 persons each year).

The IDEA4RC ecosystem will try to overcome the obstacles that hinder the re-use of clinical data following a **federated learning approach**. It 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*, thus facilitating the compliance with GDPR.

IDEA4RC will also address another challenge, that of developing **Natural Language Processing** (NLP) models to extract information from clinicians notes and medical reports. It will do so in the different languages spoken by the clinical centers involved in the project. You can find a [scheme](#) of the high-level structure of the IDEA4RC ecosystem on our website.

IDEA4RC will develop the data ecosystem **taking into account the incentives and obstacles that different stakeholders** have in sharing and re-using health data, from healthcare professionals to researchers, clinicians and patients. It will do so thanks to a Responsible Research and Innovation approach which will involve and engage the different actors through dedicated co-creation workshops.

IDEA4RC consortium is **led by the Fondazione IRCCS Istituto Nazionale dei Tumori**, based in Milan, Italy, and comprises **25 partners from across Europe**. These include:

- ▶ 11 Expert centers of EURACAN, the European Reference Network on rare adult solid cancers, located in 8 European countries. They represent the ideal testbed for IDEA4RC.

- ▶ 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 which will ensure that the values of all the actors involved in the ecosystem are considered along its conception and development.
- ▶ 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.

Explore the [consortium map](#) on our website.

IDEA4RC made its first public appearance in December 2022 in the magazine of the Organisation of European Cancer Institutes (OECI). You can read the article in the OECI magazine [here](#).

Meetings, results and updates

IDEA4RC kick-off meeting was held in Milan on 28 September 2022 at the Istituto Nazionale dei Tumori. "Our objective is to create value from data", the project coordinator Annalisa Trama stated. Read more about the [kick-off meeting](#) on our website.

IDEA4RC consortium met for the second time on 19 and 20 April 2023 in Venice. The meeting was organized within the 2nd Privacy Symposium. [Read more](#) about the second consortium meeting on our website. The first co-creation workshop was held on 20 April 2023 in Venice during the second consortium meeting. [Here](#) you can read more about it and look at some photos.

IDEA4RC delivered its **first results**. Here is a selection of the most interesting deliverables produced so far.

- ▶ Rare cancer pilots selection ([D8.1](#)).
- ▶ Stakeholder Engagement Plan ([D10.2](#)).
- ▶ Plan for communication, dissemination and exploitation activities ([D11.1](#)).

You can read short summaries of all the results [here](#) on our website.

Finally, [here](#) you can find a list of past and upcoming conferences where IDEA4RC has or will be presented.

Sent by [IDEA4RC Project](#)



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