



**Intelligent ecosystem to improve
the governance, the sharing
and the re-use of health data for rare cancers**

An intelligent data ecosystem for rare cancers

What is IDEA4RC?

IDEA4RC is an EU funded project that aims at developing a digital infrastructure to facilitate the sharing and re-use of health data among clinical centers with the objective of advancing research on rare cancers. The challenge is building a new tool to overcome technical barriers to such sharing and re-use, while at the same time complying with EU regulations on data protection.

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.

IDEA4RC consortium is led by the **Istituto Nazionale dei Tumori**, based in Milan, Italy, and comprises 25 partners from across Europe with a wide range of expertise. Among them, there are 11 clinical centers based in eight European countries which will test the platform. They belong to **EURACAN**, the European Reference Network for rare adult solid cancers.

Why would rare cancers particularly benefit from data sharing and re-use?

The current paucity of data on rare cancers limits the development of new knowledge about these diseases and the provision of better care.

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.

Building large and diverse datasets on rare cancers thus requires the involvement of several clinical centers across Europe, and this is why it is such a complex undertaking,

IDEA4RC will focus on two among the 12 families in which rare cancers are grouped: soft tissue [sarcomas](#), and [head and neck cancers](#). They affect nearly 350 and 600 thousand people in Europe, respectively (EU28, [prevalence 2008](#)). Once in operation, the platform developed by IDEA4RC could be extended to other rare cancers.

Why do we need IDEA4RC?

Currently, researchers who want to re-use health data collected by clinical centers to deliver healthcare services, must overcome several barriers, both technical, such as different and incompatible data formats or storage technologies, and legal, that is restrictions to scientific research created by the current regulatory context.

This slows down research and delays the availability of better care and therapy options.

The EU is well aware of these issues and is trying to tackle them through a new regulation intended to set up a European Health Data Space (EHDS). At the same time, the EU is financing a series of research and innovation projects that can test, develop, and shape frameworks that could then be implemented in the EHDS. Among these initiatives, IDEARC will pioneer the area of rare cancers.

What's in it for patients?

Researchers will be the main users of the IDEA4RC platform, that will offer them a quicker and safer way to understand which data are available to answer their research questions and assess their quality. This will improve the effectiveness of clinical research and boost the development of new drugs, medical devices, therapies, that will lower the burden of rare cancers.

Patients' organizations want to make sure that through the forthcoming EHDS Regulation "the benefits of data are widely shared and used to advance scientific knowledge and improve health outcomes"¹.

¹ Joint statement on the European Health Data Space Draft Proposal, March 2023. Available at this link <https://www.eurordis.org/publications/joint-statement-on-the-european-health-data-space-draft-proposal/>

By choosing EURACAN centers as a first testbed of the data ecosystem, IDEA4RC aims at making the new knowledge widely accessible to clinicians all over Europe so that the benefits generated by this knowledge have the best chance to reach as many European citizens as possible.

How can you stay in touch with IDEA4RC?

The ultimate beneficiaries of IDEA4RC are rare cancer patients and their families. IDEA4RC therefore warmly invites you to follow both the development of the project and the parallel debate on data protection. Your support is essential in raising awareness on the current unmet patients' needs and obstacles to research on rare cancers.

By joining our Community of Interest, a group of stakeholders with whom we wish to build an open and ongoing dialogue, you will stay up-to-date with IDEA4RC's progress and will have the opportunity to shape its development by giving feedback on specific aspects. We would also like to hear from you, so we encourage you to ask questions and request insights about our project.

We publish regular updates on the project website <https://www.idea4rc.eu/> and social media profiles ([X](#) and [LinkedIn](#)). You can also [subscribe](#) to our bi-monthly newsletter.

