



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 access to and re-use of health data collected by clinical centres in different EU Member States with the objective of advancing research on rare cancers. The challenge is building a new tool to overcome technical barriers to such access and re-use, while at the same time complying with EU regulations on personal data protection.

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

The IDEA4RC consortium is led by the **National Cancer Institute of Milan (INT)**, based in Italy, and comprises 25 partners across Europe with a wide range of expertise. Among them, there are 11 clinical centres based in eight European countries which will test the platform. They belong to EURACAN, the European Reference Network for rare adult solid cancers. The project will thus be able to draw on the experience of the more than one hundred highly specialised cancer centres affiliated to EURACAN as well as that of other European Reference Networks.

IDEA4RC will focus on two among the 12 families in which rare cancers are **grouped**: soft tissue **sarcomas**, and **head and neck cancers**. Once in operation, the platform developed by IDEA4RC could be extended to other rare cancers.

Why would rare cancers particularly benefit from cross-border data access and re-use?

The rarity of these cancers limits the development of new knowledge about them 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. They are very heterogeneous and each one of them is found in less than 6 persons per 100'000 each year. Some of them can be extremely rare, being diagnosed in less than one person per million each year.

As a consequence, each clinical centre in Europe receives very few patients with the same type of rare tumour, and this data alone is not enough to gather new and robust evidence on these diseases. However, building large and diverse datasets to advance scientific research requires the involvement of several clinical centres across Europe, and this is why it is such a complex undertaking.

Why do we need IDEA4RC?

Currently, in order to re-use health data collected by clinical centres across Europe, researchers must overcome multiple barriers. The obstacles to face are both technical, such as different and incompatible data formats or IT infrastructures, and legal, mainly due to the uneven interpretation of the current General Data Protection Regulation (GDPR) by Member States.

These limitations slow down research and delay the availability of better care.

The EU is 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 funding 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, IDEA4RC will pioneer the area of rare cancers.

How will rare cancers patients benefit from IDEA4RC?

In the long run, IDEA4RC aims to improve the quality of care that rare cancer patients receive by expanding knowledge about these diseases. It will do so by offering researchers a quicker and safer way to understand which high-quality data are available to answer their research questions. It will also provide clinicians with further evidence to be considered in the decision-making process.

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

The platform will be accessible to all researchers investigating rare cancers, even those outside the EURACAN network, provided they have an organisation backing them.

How can you contribute to IDEA4RC?

IDEA4RC is currently developing its governance model, that is the governing bodies, rules, and procedures for accessing and managing the federated ecosystem after the end of the project. The discussion on these topics would greatly benefit from the perspective of patients.

Additionally, you can contribute to the development of a data altruism tool within the IDEA4RC platform, through which patients can voluntarily donate their data.

The future of IDEA4RC strongly depends on how the debate on personal data protection unfolds at the European level, and how the newly approved regulation on the EHDS will be implemented across Member States. Therefore, we warmly invite you to follow both the development of the project and the debate on data protection. Your support is essential in raising awareness about the importance of facilitating the cross-border access and re-use of data for scientific research.

Moreover, we would like to hear more about your expectations and concerns as a patient representative, in order to shape the design and the development of the project in a co-creation approach. This is why we are creating a **Community of Interest**, a diverse group of stakeholders with whom we wish to engage in an open and ongoing dialogue. By joining our community, you will stay up to date with IDEA4RC's progress and will have the opportunity to express your view on specific aspects.

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.

Useful materials about IDEA4RC and health data re-use

A video introduction to the project is available at the following link:

<https://www.youtube.com/watch?v=BHBscXdcexc>

You can find a summary of the results by the project at the following link:

<https://www.idea4rc.eu/category/results/>

A general presentation of the scope of the project was included in the OECI magazine. You can access it at the following link:

https://oeci.eu/Attachments/OECI_Magazine_2-2022.pdf

If you want to know more about the current legislation on the re-use of health data for scientific research, you can read an interview with one of IDEA4RC researchers at the following link:

<https://www.idea4rc.eu/2024/04/24/eu-legal-landscape-on-health-data-sharing-and-re-use-interview-with-vasiliki-tsiompanidou/>

