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Intelligent Data Ecosystem for Rare Cancers

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IDEA4RC has received funding from the European Union's Horizon Europe research and innovation programme under grant agreement no 101057048

What is it about?

- IDEA4RC is a newly funded Horizon Europe project led by Istituto Nazionale dei Tumori (Milan, Italy).
- The project will stretch over the course of the next four years (September 2022 - September 2026)
- Its objective is

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

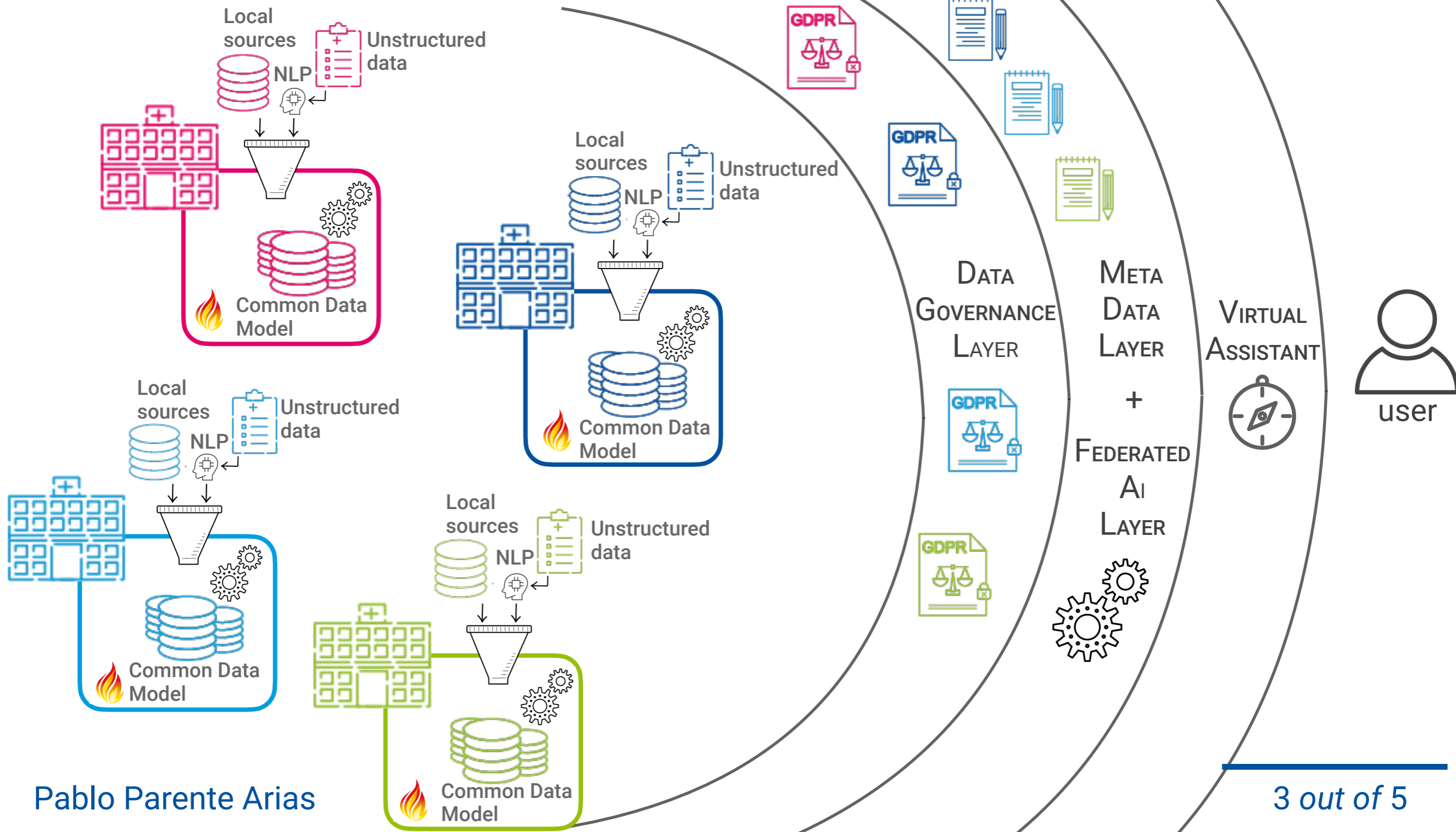
Why do we need such an ecosystem?

- 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.
- Analysing **large and diverse datasets** collected by different clinical centers and countries would greatly advance the knowledge on rare cancers.
- Current hurdles include:
 - lack of interoperability,**
 - compliance with **EU data protection requirements** when sharing health data.

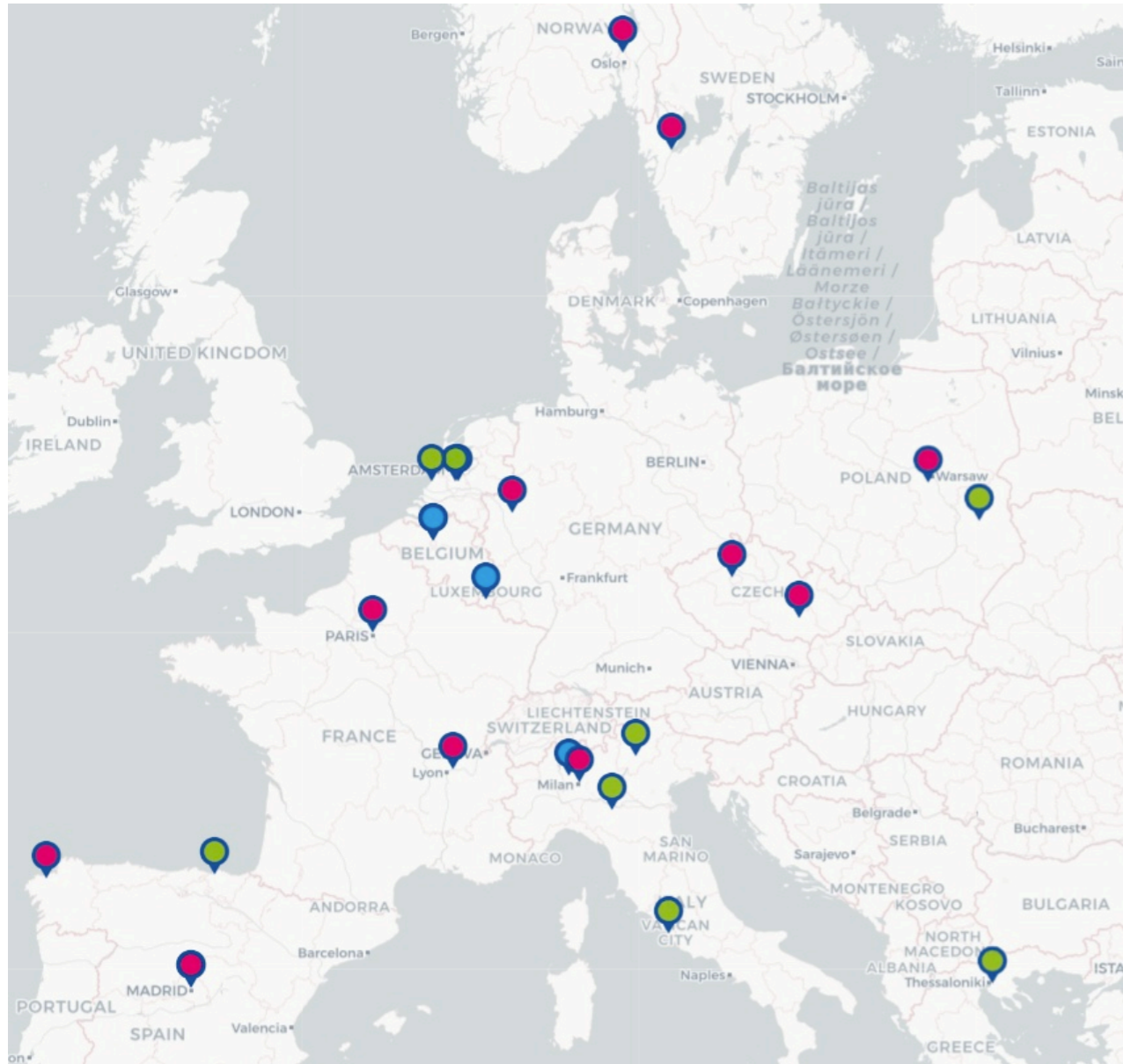
The principles

- IDEA4RC plans to develop 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 ecosystem will be tested on pilot projects involving **11 centers of excellence of the EURACAN network** (EUropean reference network for Rare Adult solid CANcers) partners of the project.

The ecosystem



The consortium

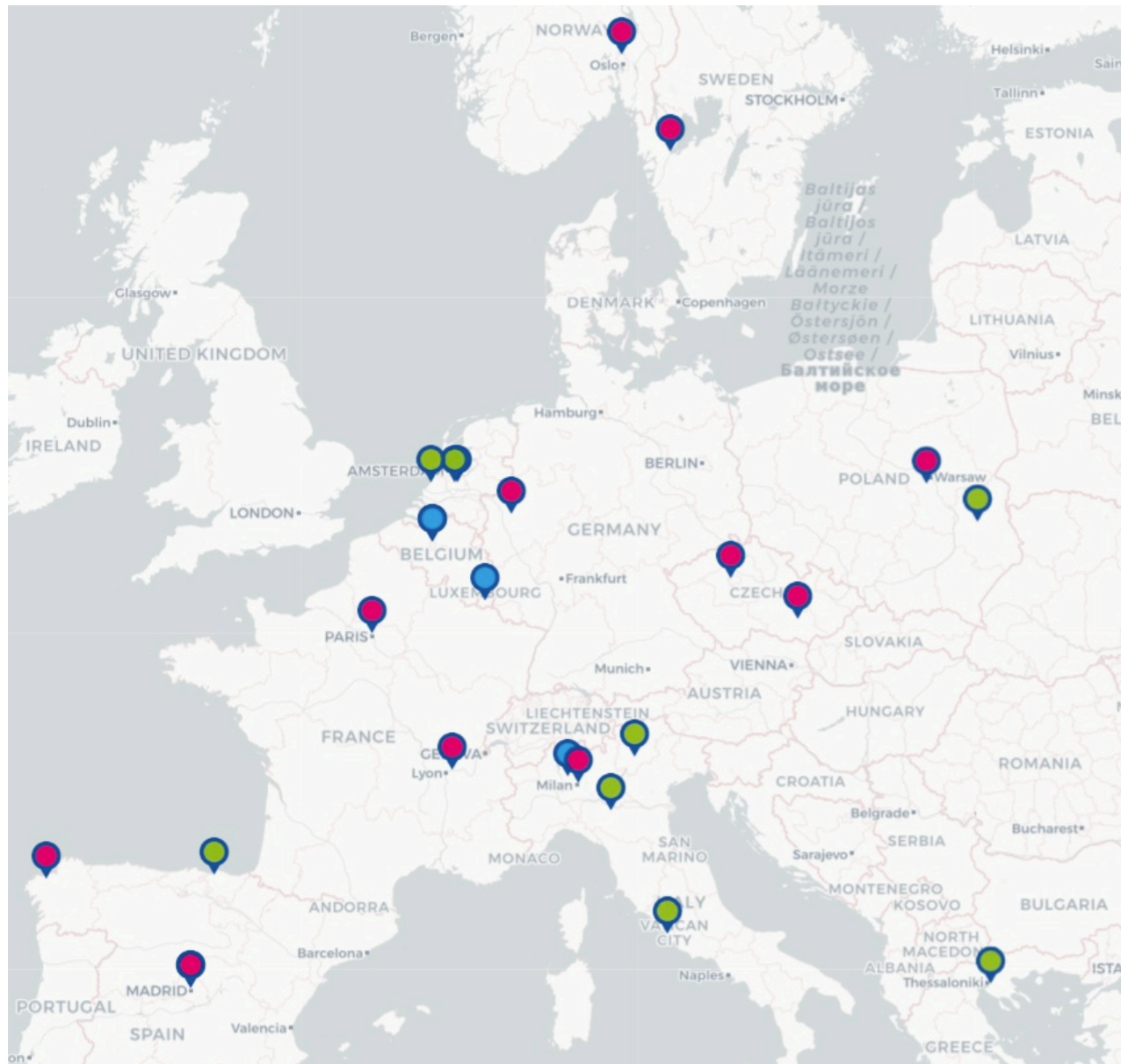


25 partners with a wide range of expertise

11 clinical centres in **8 countries**

led by **Istituto Nazionale dei Tumori** (Milan, Italy)

The consortium



Clinical centers

Istituto Nazionale dei Tumori (Italy)

Assistance Publique Hôpitaux de Paris

Centre Leon Bernard (France)

Fundación Profesor Novoa Santos

Instituto Investigación Sanitaria de la Fundación Jiménez Díaz (Spain)

Västra Götalandsregionen (Sweden)

Narodowy Instytut Onkologii im. Marii Skłodowskiej-Curie (Poland)

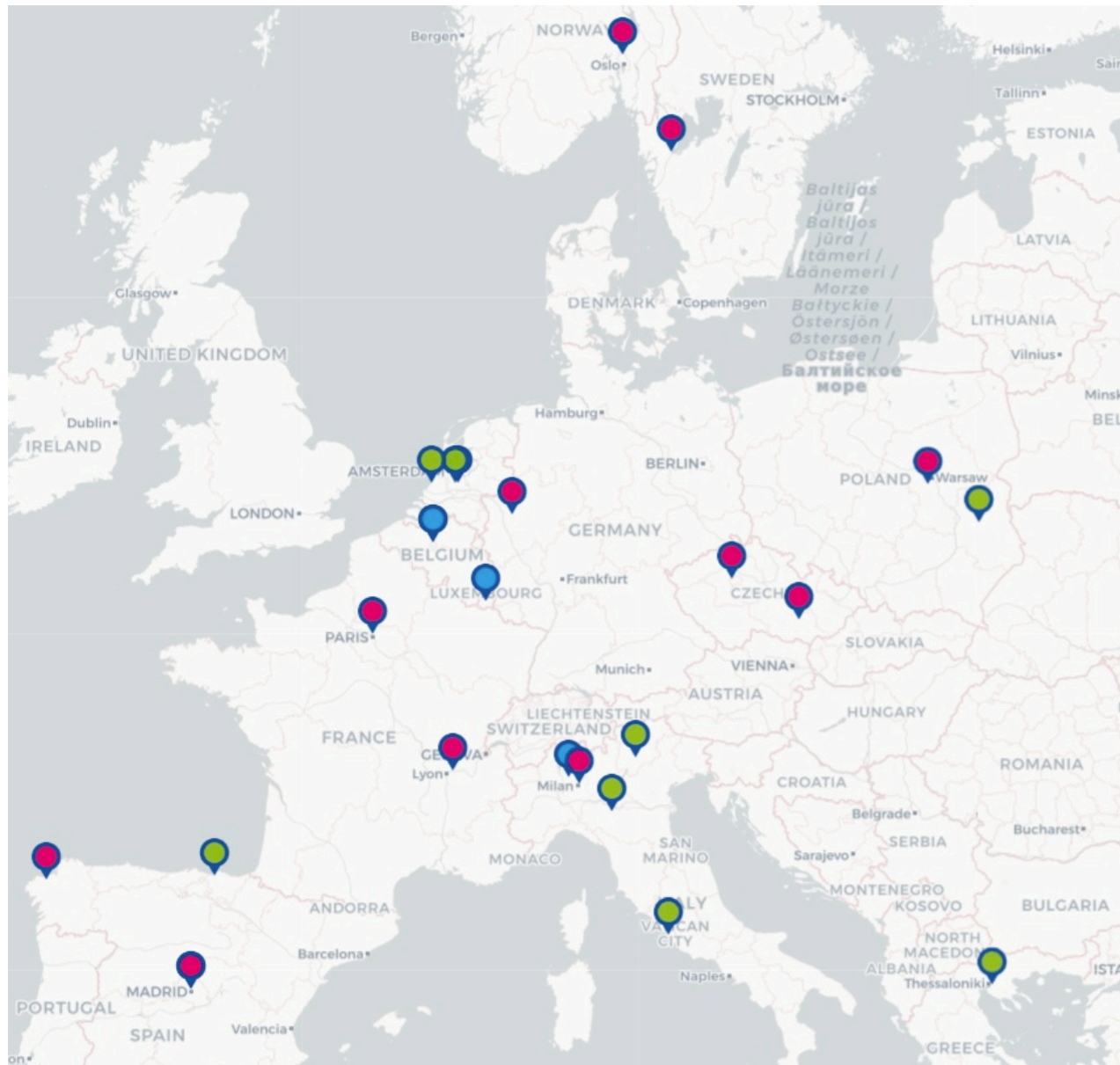
Fakultní nemocnice v Motole

Masarykův onkologický ústav (Czech Republic)

Oslo universitetssykehus (Norway)

Universitätsklinikum Essen (Germany)

The consortium



Technical partners

Universidad de Deusto
Universidad Politécnica de Madrid (Spain)
MultiMed Engineers
Engineering S.p.A.
Fondazione Bruno Kessler (Italy)
HL7 - Europe (Belgium)
Centre for Research and Technology-
Hellas (Greece)
Toegepast Natuurwetenschappelijk
Onderzoek
Integraal Kankercentrum Nederland
(Netherlands)
CliniNote (Poland)

The consortium



Ethics, legal, communication

- Utrecht University (Netherlands)
- European Centre for Certification and Privacy (Luxembourg)
- DIGital Institute for Cancer Outcomes REsearch (Belgium)
- Inferenze (Italy)

First steps

- We are defining the **general features of the ecosystem architecture** starting from the current data management practices in the clinical centres and the needs of researchers and clinicians
- We are working on **metadata taxonomy, specification and design**, taking into consideration FAIR principles of scientific data management
- In April we will have the next consortium meeting and IDEA4RC will be presented during the 2nd Privacy Symposium in Venice (where the first co-creation workshop will take place)



Thank you

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more details at <https://cordis.europa.eu/project/id/101057048>

