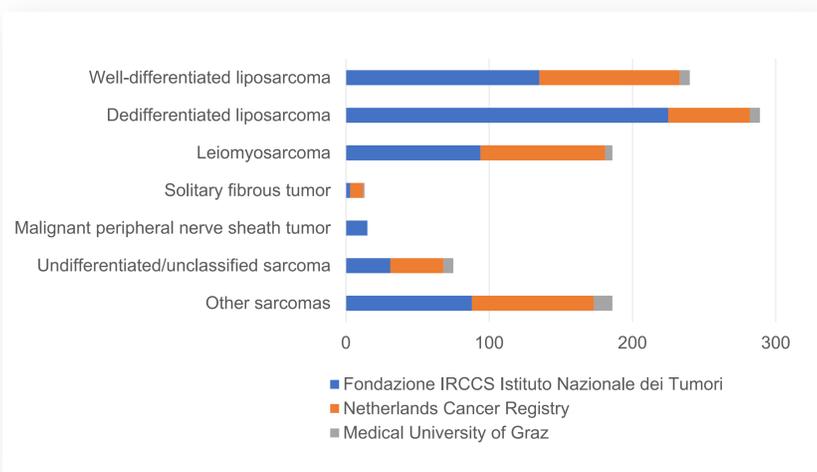


Power in numbers: overcoming the scarcity of rare cancer data by harmonizing European sarcoma registries

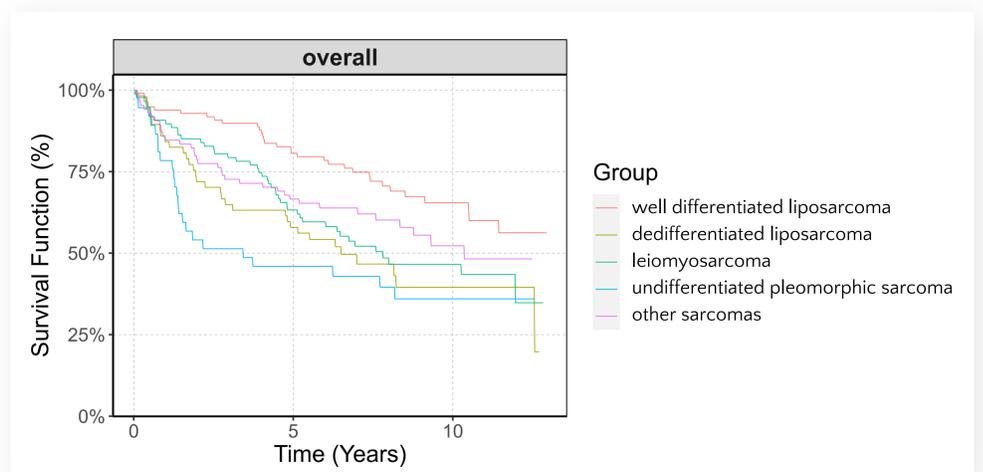
Standardizing European sarcoma registry data to the OMOP Common Data Model: the retroperitoneal sarcoma use case

Background: Research in rare cancers is hampered by low patient numbers, dispersed clinical data and tumor samples, and a limited number of experts per rare cancer diagnosis. The ERN EURACAN (European Reference Network for Rare Adult Solid Cancers) was established to bring together data and knowledge of European Healthcare professionals.

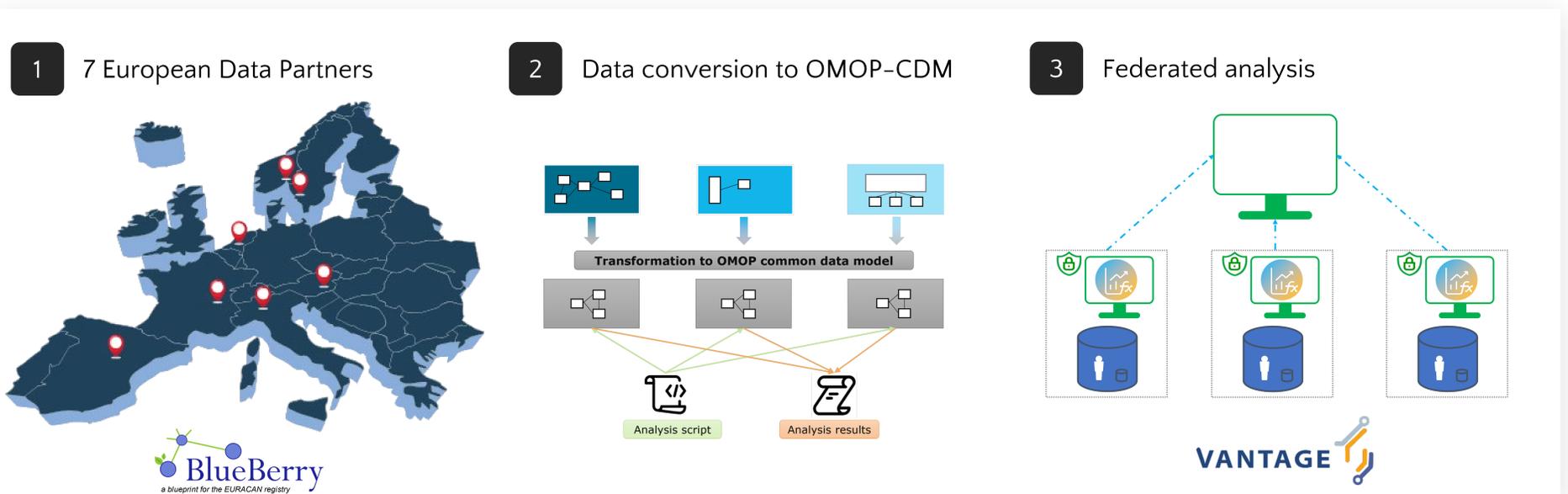
Result 1: # patients of each of the retroperitoneal sarcoma types in each registry



Result 2: Examples of survival curves generated with the CohortSurvival package.



Methods



Limitation: Conversion of each of the data sources to the OMOP-CDM and setting up a node for federated analysis requires a lot of technical expertise. The OHDSI tools have a steep learning curve.

