Collaborative efforts confront challenges of rare cancers through privacy-preserving data sharing

The Paradox of Precision Medicine
Challenges and approaches to solutions at Oslo University Hospital (OUH)

Background: Current technological development allows the increasingly detailed description of a cancer disease, and this enables a high degree of treatment tailoring. The small subgroups that arise even in large hospitals create challenges for research and call for international collaborations through innovation in research methods.

Background: Precision medicine classifies patients in subgroups with a common biological disease basis

Methods
OUH collaborates with other European cancer centres to establish a learning health system to provision sufficient data whilst preserving patient privacy. The collaboration emerges from the DigiONE project to automate quality control and research across European hospitals through use of OHDSI tools. Building on interdisciplinary capabilities, the project enables systematic learning from all patients.

Results
OUH's participation in the DigiONE pilot adheres to the regional technology strategy by establishing necessary infrastructure and technology to support personalised medicine. It also contributes to the ongoing national project to increase structuring of data in the EHR. Through structuring of data, use of the OMOP CDM and solutions for federated analyses, benchmarking within and across hospitals in Europe as well as comparison of real-world practice with international guidelines is achievable while retaining control over individual level patient data at each participating site.

Result: Data federation enables privacy-preserving learning from cancer patients across Europe

Transferability: The challenge arising from the possibility to describe disease in ever increasing detail is not cancer specific. The establishment of a hospital infrastructure for data collection, standardisation, and federation between sites would be beneficial across medical specialties.