The Paradox of Precision Medicine

Challenges and approaches to solutions at Oslo University Hospital

Elin Hallan Naderi[1], Elisabeth Ross[2]
[1]Department of Oncology, Oslo University Hospital
[2]Department of Technology and e-Health, Oslo University Hospital

Background

Technology allowing the description of a cancer disease in ever greater molecular detail is developing rapidly. This enables an increasing degree of treatment tailoring, aiming for improved tumour effect with less toxicity for cancer patients, but this development also generates new challenges [1].

When a cancer case can be described not only by its organ of origin, but also by the genetic changes present in the tumour, more and smaller cancer subgroups arise (Figure 1). A scenario where all cancers are rare cancers is on the horizon and this drives innovation in research methods.

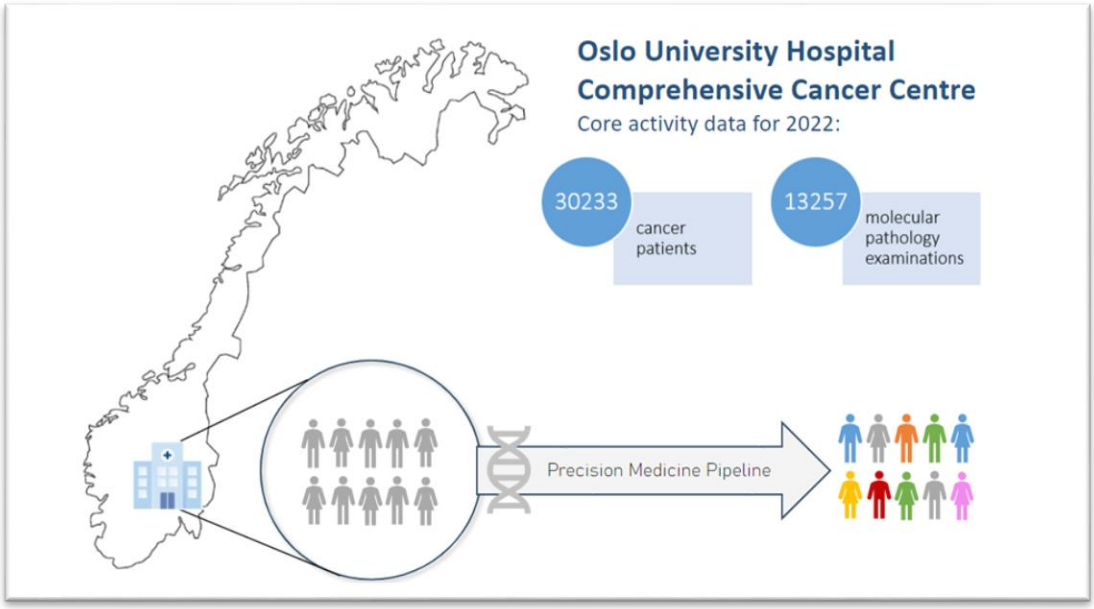

Figure 1: Precision medicine classifies patients in subgroups with a common biological disease basis

To be able to conduct research on patient cohorts of sufficient size, even large cancer centres like Oslo University Hospital (OUH) depend on international collaboration. Until recently, this kind of collaboration has depended on manual identification of the patient cohort and extraction of their data from various EHR systems, transformation of the data to a common, predetermined format, and the transfer of these data to a common, external server for analysis. This implies a significant amount of manual work, does not guarantee comparability, and could entail privacy concerns.

Methods

Oncologists and data scientists at OUH are currently collaborating with other European cancer centres to establish a learning health system for provisioning of sufficient data for research whilst preserving patient privacy. The collaboration has emerged from a pilot project, DigiONE [2], to automate quality control and research across European hospitals. Each centre will structure real world data from their EHR systems to the common data model OMOP CDM. By ensuring exchange of

only anonymous and aggregated data, research and quality control both across the network and in each hospital is facilitated while the individual patient data remains stored at the respective hospitals.

At OUH, the DigiONE project is built on interdisciplinary capabilities including oncology, pathology, technology, data science and coding. This was made possible through a close cooperation between the divisions of (1) Cancer Medicine and (2) Technology and Innovation, building on established and well-functioning structures from an existing project to build a key cancer data dashboard retrieving its information from an in-house clinical data warehouse (CDW) [3]. The DigiONE pilot has expanded these collaborative efforts, enabling systematic learning and advancement of knowledge from all patients, not only the 10-15 % of patients enrolled in clinical trials.

Results

OUH's participation in the DigiONE pilot is in line with the hospital's goal of being a leading international centre for research in technology-based medicine. It also adheres to the regional technology strategy by establishing necessary infrastructure and technology to support personalised medicine, as well as contributing to the ongoing national project to increase structuring of data in the EHR. Incorporating these structured variables and other essential cancer variables into the CDW, and thereby improving the hospital's basis for ongoing quality control, are processes accelerated by the DigiONE project.

Access to the wide range of OHDSI tools to support data-analytics use cases on patient data gives OUH a better opportunity to learn from these data, and to further develop existing CDW functionalities, e.g. its data delivery infrastructure [4].

From early on in the DigiONE project, through the outreach to other Norwegian institutions harmonising their data to OMOP, OUH benefitted from the shared experiences of what was initially an informal forum for OMOP in Norway. In 2023, OUH took part in the establishment of a new national node in the European chapter of OHDSI alongside the Cancer Registry of Norway, the University of Oslo and the Directorate for e-Health. The Norwegian node's collaboration with Finland's FinOMOP has already led to the provisioning of procedure mappings as well as other collaborative initiatives.

In parallel with the technical development, oncologists at OUH and colleagues from the DigiONE network have developed three clinical protocols of which two are currently being conducted and the third will be initiated later this year. Well in advance of the study results, the project has attracted considerable international attention, as demonstrated by a publication in the renowned journal Nature Medicine [5]. This underscores the interest in secondary use of patient data for continuous learning from current clinical practice. 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 (Figure 2).

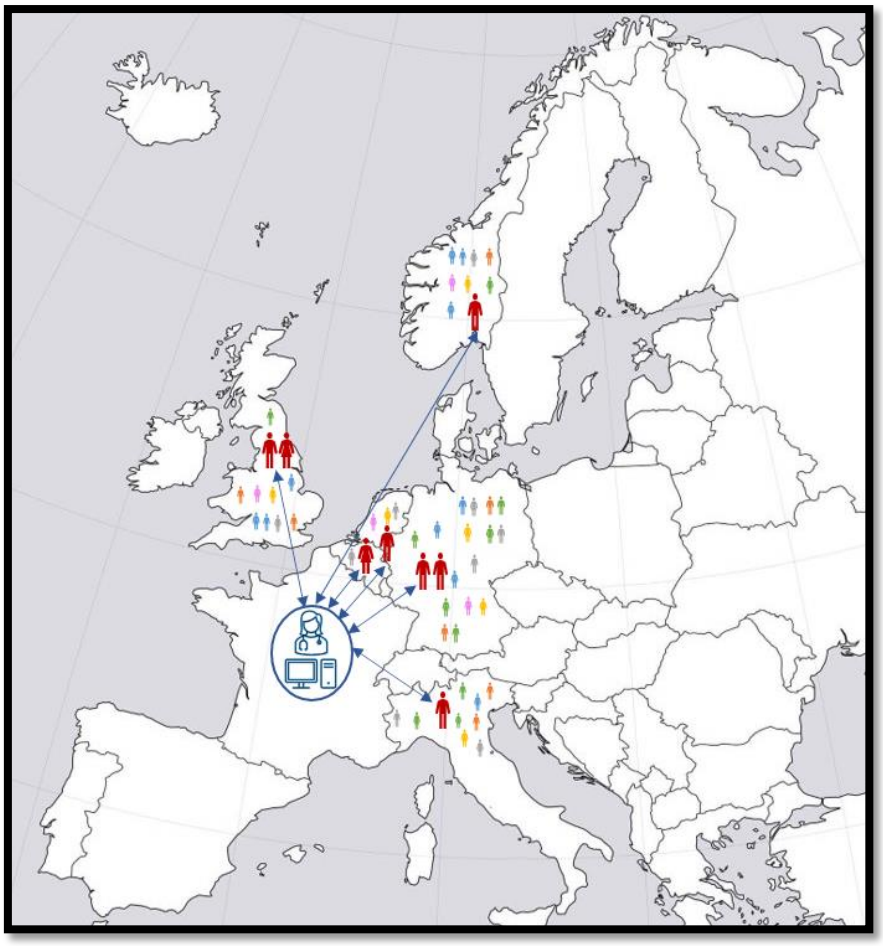

Figure 2. Data federation enables privacy-preserving learning from cancer patients across Europe

Conclusion

The engagement in DIGICORE's DigiONE pilot has paved the way for more structured cancer data in the EHR and an expansion of the CDW variable set and functionality. The project has promoted synergies with other OMOP initiatives nationally and internationally contributing to the establishment of a national OMOP node and collaboration with the FinOMOP.

The initiative and resources for the DigiONE pilot originated from the cancer research network DIGICORE, and the current variable selection and clinical protocols in cancer benchmarking of the DigiONE network reflect this. However, the challenge arising from the possibility to describe disease in ever increasing detail, creating small diagnostic sub-groups receiving tailored treatment, is not cancer specific. The establishment of a hospital infrastructure for data collection, standardisation, and federation between sites would therefore be beneficial across medical specialities. We are currently in the process of investigating an expansion of our activity to include the Department of Cardiology, and our aim is that other departments will soon follow.

References

1. Von Hoff DD, Han H. The Role of Precision Medicine in the Diagnosis and Treatment of Patients with Rare Cancers I. Cancer Treatment and Research; 178. Switzerland: Switzerland: Springer International Publishing AG; 2019. s. 81-108.

2. DIGICORE. DigiONE - Digital Infrastructure for ONcology in Europe building a European federated digital research network. DIGICORE. [Internet] 2023. https://digicore-cancer.eu/projects/5
3. Simonsen, MCA. OUS lanserer nytt verktøy for arbeid med kreftdata. Dagens medisin. [Internet] 2022. https://www.dagensmedisin.no/kreft-oslo-universitetssykehus-ous/ous-lanserer-nytt-verktoy-for-arbeid-med-kreftdata/126897
4. Bouissou, O et al (2024). Expanding the OUH Clinical Data Warehouse data delivery infrastructure with OMOP CDM and OHDSI tools. Abstract submitted for the OHDSI Europe Symposium 2024.
5. Mahon P et al. Nat Med. 2024 Feb;30(2):334-337.