

REAL WORLD DATA

Real World Data (RWD) Sharing Internationally:
Case Digital Twin (DT) in Inflammatory
Bowel Disease (IBD)

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OBJECTIVES:

Finnish patient data is impeccable in an international comparison and could be better utilised with effective data sharing. As a goal to show what is the value of data utilisation, a DT is enhanced with Finnish RWD. DT can be used for healthcare process testing, clinical analysis and more cost-effective precision medicine development. This DT is simulating an inflammatory bowel disease (IBD) patient. The burden of IBD in health care is high and the incidence and prevalence rates of IBD are increasing globally. There is no cure for IBD, and none of the currently available therapies have demonstrated clinical efficacies beyond 40 % – 60 %.

METHODS:

Collection of outcomes and treatment data has grown exponentially in IBD making it a prime candidate for artificial intelligence (AI). Takeda has developed a DT simulator using an IL-6 based mechanistic model of Crohn's disease (CD) in Japan. Additionally, Fraunhofer Institutes in Germany are presenting the first prototype using data from over 600 IBD patients. This DT is based on data from six Finnish University hospitals and accessed through FINDATA permit process. Anticipated number of patients is approx. 16 000.

RESULTS:

We can successfully use technical solutions for patient privacy in large, structured format RWD sets by synthesising the data. We have also harmonized The Finnish IBD database to the global OMOP Common Data Model (CDM) from EHDEN, allowing further data combinations internationally.

CONCLUSIONS:

The Finnish Secondary Use Act provides internationally unique centralized solution, but a federated access to a register owner's data with powerful computing environments with enough resources to use modern AI methods and which fulfil the data security requirements of Findata, is strongly needed. Only then can we have an infrastructure to share data internationally for digital solutions such as DTs. This enables more cost-effective digital solutions for research and patient care.