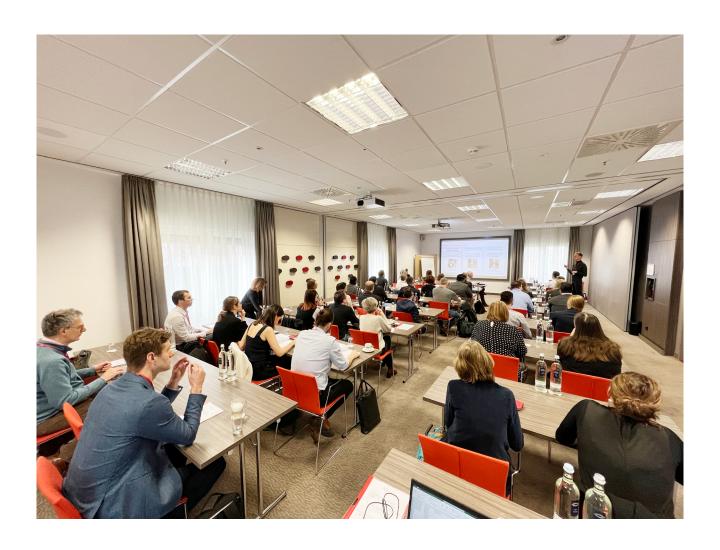# The Frankfurt DigiONE Meeting Report

The first DigiONE meeting in Frankfurt

The first meeting, including participants from all 6 DigiONE hospitals, took place in Frankfurt in March 2023. The meeting had 3 key objectives:

     1) to catalyse a European digital care quality improvement community,

     2) to co-develop a portfolio of exciting research concepts, and

     3) to start the detailed data normalisation planning.

Objective 1: Catalyse a European digital care quality improvement community

There were 55 attendees in total including representatives from 10 hospitals. These 10 hospitals include the 6 DigiONE hospitals plus the Regina Elena National Cancer Institute in Italy, Tartu University Hospital in Estonia, Tays/Tampere University Hospital in Finland, and Trinity St James Cancer Institute in Ireland. The meeting was attended by individuals belonging to various disciplines, including those with clinical, scientific, IT, and project management roles. This is rather unusual and a strength of DigiONE to have IT, data managers, and clinicians in the same meetings working together towards a scientific research interest.

Objective 2: Co-develop a portfolio of exciting research concepts

The goal of the DigiONE network is to fill evidence gaps in multimodal cancer care with transformative real-world evidence. It is up to the research teams at the 6 hospitals to decide which research questions they want to address in the next 12 months. To develop a list of research ideas, there were sessions on subjects such as 'comparative health systems research', 'research opportunities using routine blood data', 'impact of Covid-19 on cancer care', 'predictive biomarkers', and 'comparative effectiveness'.

Members of the network presented real-world data studies they had been a part of, including the rationale for key design considerations and complexities with data normalisation. This included the Ovarian Real World International Consortium's (ORWIC) study[1] discussed by Prof Geoff Hall from Leeds Teaching Hospital which is an example of the type of natural history study that DigiONE may conduct in other indications. The attendees also heard from four research teams that have ongoing studies as part of the IDEAL4RWE Leadership Training Programme, which is an initiative within DIGICORE to provide training and funding for researchers <45 years old to build the skills necessary to lead multi-site real-world data studies.

Out of the sessions there was a long list of research ideas ranging from simple studies with few data items which can be conducted pan-cancer to test our data quality to more complicated studies which require extensive information per patient on narrower cohorts such as natural history and comparative effectiveness studies. Such analyses will also provide international benchmarking on care quality. The research ideas will be prioritised by individuals from the 6 DigiONE hospitals to be developed into protocols. IQVIA will provide support by making available the services of a medical writing team to develop protocols, and plan to develop 5 to 10 real-world research protocols in 2023. The protocols the DigiONE network proceed with will be based on feasibility in terms of clinical interest, approval by hospital ethics committees, availability of data, and sufficient number of patients for informative outputs.

Objective 3: Start the detailed data normalisation planning

Retrospective research typically involves a substantial amount of manual retype from medical notes at the hospital to an eCRF, given that many key baseline clinical characterisation data items (such as history of comorbidities and other cancer diagnoses, disease stage at diagnosis, performance status) and outcomes data items (such as response to treatment) are not in a structured format that can be automatically extracted. One of the key objectives of DigiONE is to test the use of NLP with the aim of increasing data completeness and reducing the manual effort for hospital staff conducting research. Given the hospitals do not want to have to wait for multi-site data harmonisation and testing of technology such as NLP to be complete to begin research, there may be studies conducted earlier during the 12-month pilot that can run using manual curation for data not in a structured format.

Sessions such as 'Cancer OMOP Normalisation' were carried out by the Observational Medical Outcomes Partnership (OMOP) team from IQVIA, including discussing how to convert local data into a common data format so that the 'data means the same thing' across the network. The DigiONE network intend to conduct analysis using the privacy conserving federated analysis approach, which allows reporting of outputs from multiple hospitals without pooling patient-level data and only needing to share aggregate outputs outside the hospital.

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[1] Cheeseman S, Levick B, Sopwith W, Fenton H, Nam EJ, Kim D, Lim S, Martin E, Frenel JS, Bocquet F, Kubelac P. Ovarian Real-World International Consortium (ORWIC): A multicentre, real-world analysis of epithelial ovarian cancer treatment and outcomes.

DigiCore

Network building over beer

The molecular biologist James Watson once said: "At lunch Francis [Crick] winged into the Eagle [pub] to tell everyone within hearing distance that we had found the secret of life [DNA]". Watson and Crick joked that most of their innovation was done at the Eagle pub near their laboratory in Cambridge.

At the DigiONE meeting in Frankfurt, ample time was given in the agenda to catalyse international collaboration outside of formal sessions. On the first night, most attendees sat with colleagues from their hospitals, however by the second night most tables had individuals from three or more hospitals.