"Studyathons" can catalyse rapid progress in OMOP-enabled oncology research: insights from DigiONE I3

Background

Studyathons are a promising model for scaling federated health research in Europe. This poster shares lessons learned and practical guidance for future implementations.

DigiONE I3 ("DIGItal Infrastructure for Oncology in Europe") is a co-funded project by the European Commission that aims to create a federated European digital real world evidence research network. Over 15 hospitals are involved from 9 countries in Europe, with support from private sector and non-profit partners. The programme started in late 2023.

As part of the programme, a number of "proof of concept" studies have been running to test and demonstrate the ability of the network (and other committed organisations) to deliver analytic outputs using federated analysis across OMOP-configured nodes in hospital sites. For two of these studies, one in non-small cell lung cancer (NSCLC) and one in metastatic breast cancer (mBC), a "studyathon" approach is being utilised. A "studyathon" is similar to a "hackathon" and brings together multi-disciplinary experts from across hospital sites and other supporting partners for a multi-day in-person event with the aim to establish the foundations, rules, and algorithms for the participating datasets based on the protocol for the study.
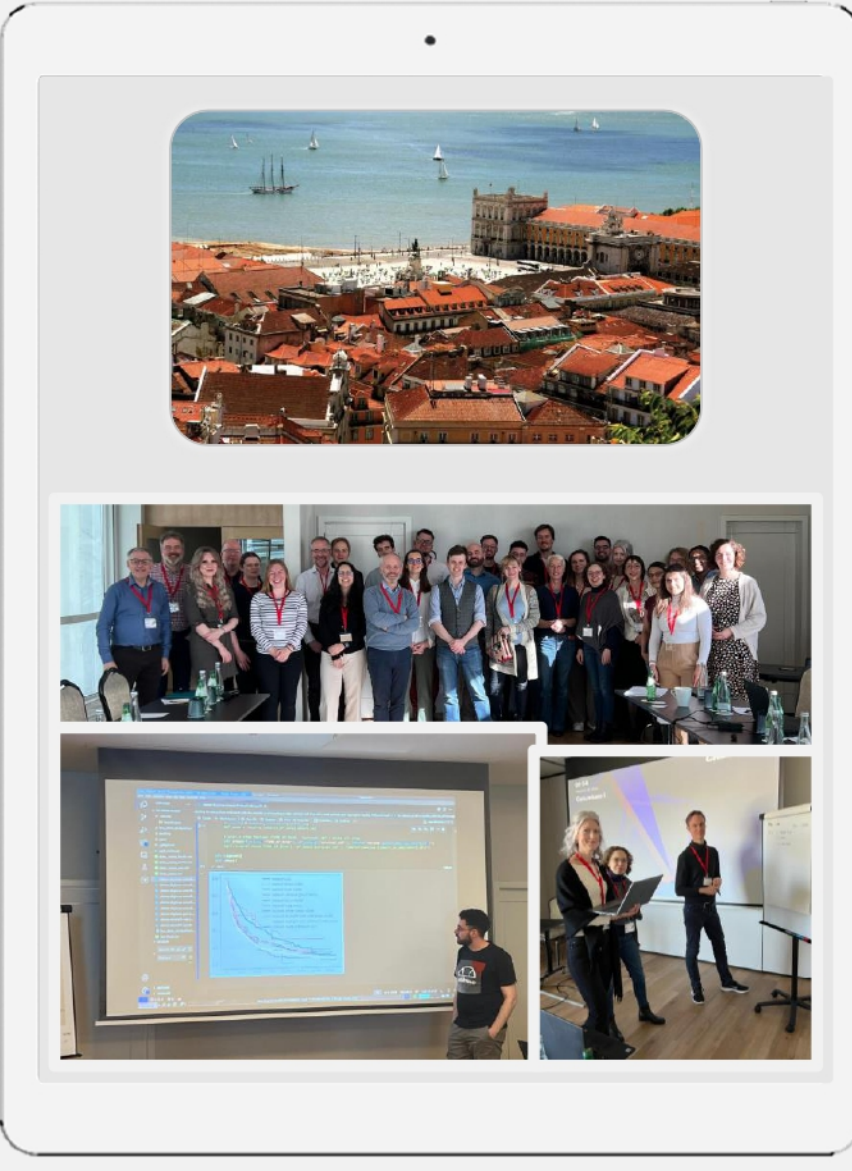
As part of the preparation for these studyathons, DigiONE has drawn on experience of similar programmes, for example the PIONEER programme (https://prostate-pioneer.eu/). Consideration has also been given to the academic literature on the subject, which indicates that there is increasing use of "hackathons" and "studyathons" (Falk, et al., 2024) although their impact is not always well understood (Schulten & Chounta, 2023). Specifically, interest in this approach for health research is increasing, and OHDSI/ OMOP are important enablers of this (Hughes, *et al.*, 2022).

Methods

Studyathon 1: Lisbon, February–March 2024

- Research focus: patient characteristics and treatment patterns for patients with **metastatic non-small cell lung cancer**.
- 5 days
- 40 attendees from all participating sites (and observers)
- 3 working groups:
  - Phenotyping (identifying cohort)
  - Treatment (identifying treatments received, and develop line of therapy algorithm)
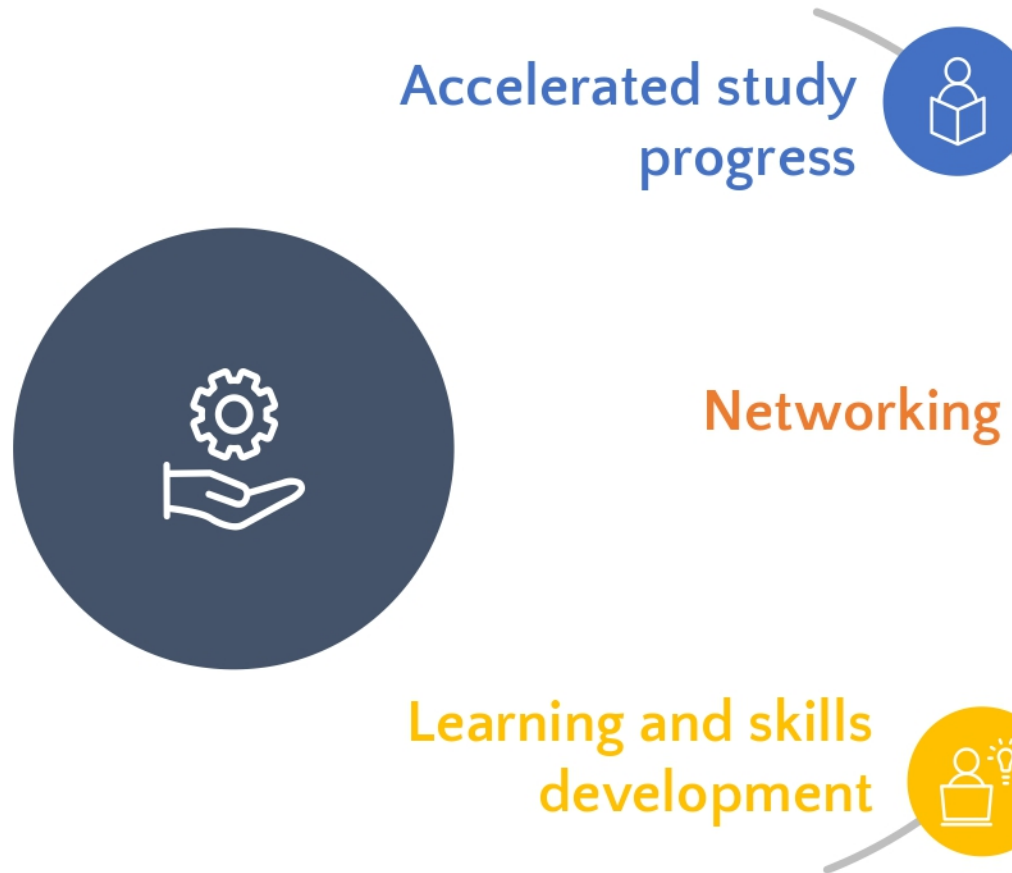 - Outcomes (developing federated analysis approach and generate KM curves)

Studyathon 2: Brussels, April 2025

- Research focus: disease natural history and outcomes in HR+/ HER2– **metastatic breast cancer**
- 3 days
- 25 attendees from all participating sites (and observers)
- 3 working groups:
  - Phenotyping (identifying cohort)
  - Flat file (extracting data into a flat file for federated analysis)
  - Federated analysis (generating analytic approaches and code for analysis)
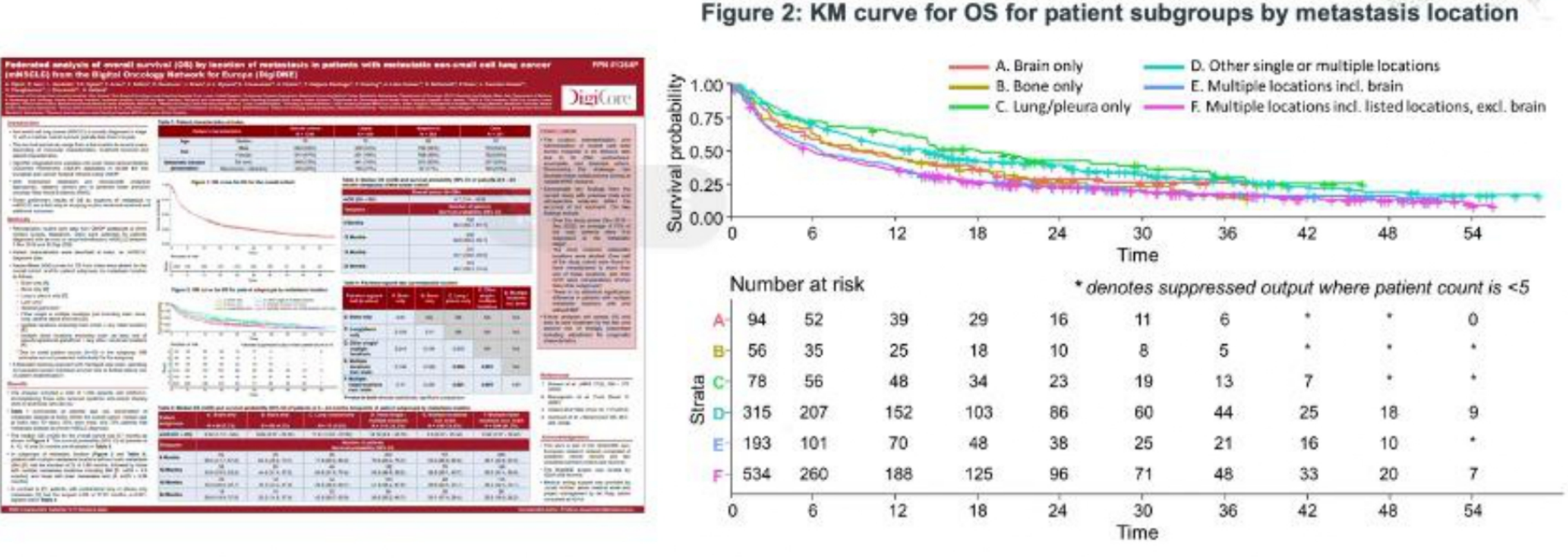

Summary of learnings

Figure 1: There are clear benefits to a studyathon approach

Accelerated study progress
- Rapid and **efficient debugging** of OMOP databases
- **Fast iteration loops** to solve problems
- Quick resolution of **clinical questions**
- **Early results** for sense checking and interpretation

Networking
- Developing new **professional relationships**
- Broadening **international networks**
- Brainstorming new **collaboration topics**

Learning and skills development
- Expert **coaching**
- On-the-job **practice**
- Peer **learning**

Figure 2: success can be improved by considering a number of factors

Planning
- **Advance planning** begins > 3 months out
- Clear **structure of working groups**, and assigned technical and facilitator leads
- **Flexibility** in planning
- Clear **onboarding processes**
- **On-site re-planning** day by day to respond to progress/ challenges

Technology
- **OMOP** instances in place
- **Federation** solutions

Skill mix
- **Clinical insight** – critical for guidance and interpretation
- **ATLAS/ R** coding
- **Statistical expertise**
- **Prior studyathon experience** (for working group leads, where possible)

Clear goal
- **Target outputs** for studyathon (e.g., particular protocol objective/sub-obj)
- **Target date** for analytic outputs
- **Publication/conference submission** identified and agreed in advance

Examples of studyathon outputs

First results at ESMO 2024 showed we can get to K-M curves on unconsented EU data by site of meta-stasis (both technically challenging*)
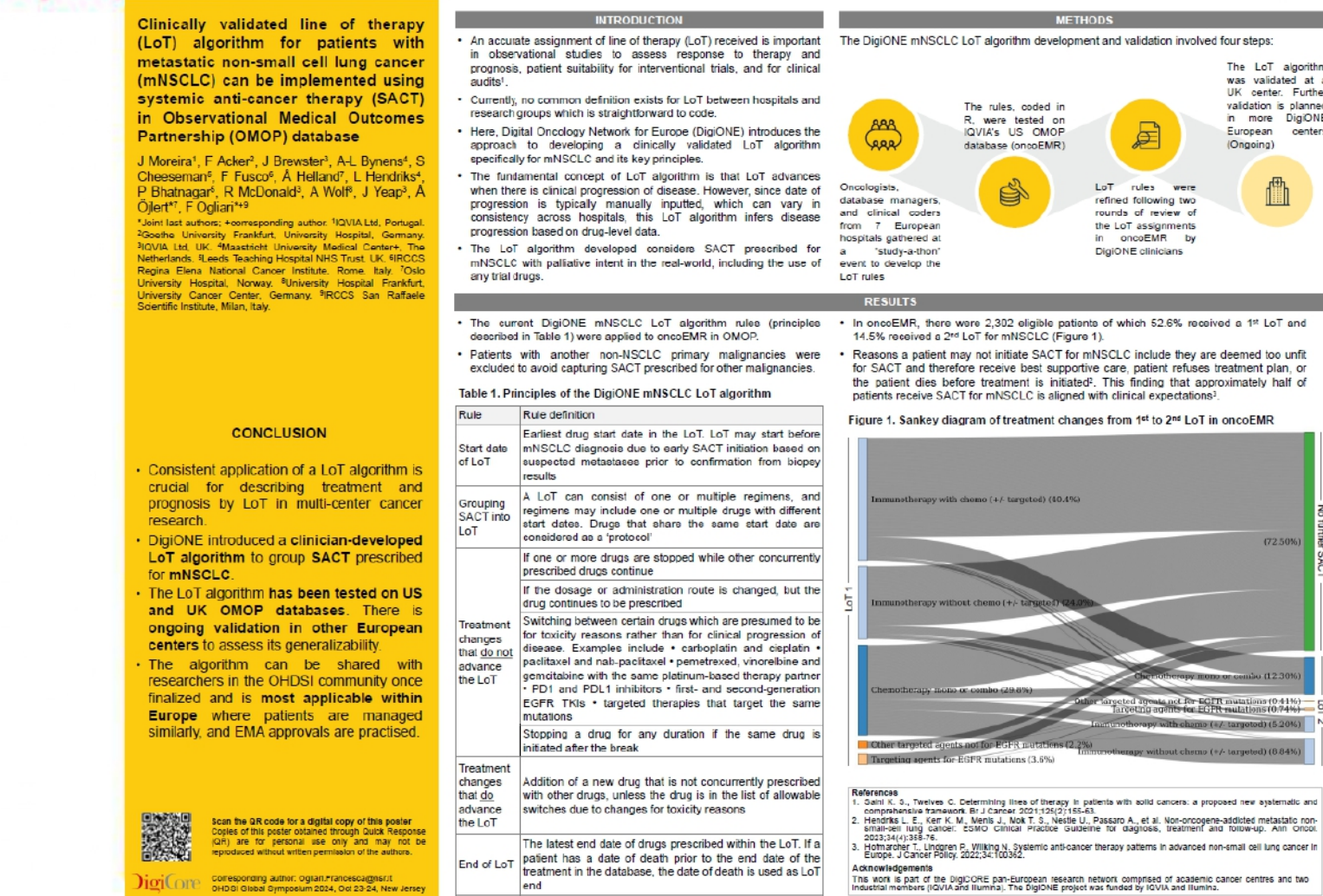

Figure 2: KM curve for OS for patient subgroups by metastasis location

Clinically validated LoT algorithm was presented at OHDSI Global Symposium 2024

- Standardized for EMA approvals and per ESMO guidelines
- Based on rules on systemic anti-cancer treatment (SACT) only (no PD dates)
- Tested and validated in oncoEMR dataset

Limitations

Only two studyathons have been conducted so far as part of the DigiONE studies, both in solid tumours, with a third one planned in 2026. Additional studyathons in new tumour types will help further refine these learnings

Neither studyathon involved patients or patient advocates "on site" – this might provide additional benefits in terms of directing the work and understanding the relevance of the findings

Future research should continue to consider the benefits and success factors of studyathons. In particular, it would be of significant value to have a systematic means of capturing learnings from these kind of events in a healthcare and OMOP context.

References

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Co-funded by the European Union

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