

Achieving federated analysis through partnership

Federated data analysis, or the analysis of healthcare information across multiple datasets, has become increasingly important in medical research. Access to this data can help practitioners better understand the root causes of a disease, shape medical research and ultimately provide novel therapies and better care for patients. But the field is complex, requiring collaboration among many partners.

At the NIHR Nottingham Biomedical Research Centre, an infrastructure between the University of Nottingham and Nottingham University Hospitals NHS Trust - in the UK, we have pioneered a method of public-private working that has been the ideal solution towards facilitating the federated discovery and analysis of data. This includes real-world data, which is information about a patient's health and/or the delivery of healthcare without having to share or move data.

What started as an initial national project connecting biobanks across the UK has evolved into an exemplary demonstration of cross-sector collaboration with Zurich-based BC Platforms AG, a specialist in real-world data solutions, including data access and analysis. The initial project began in 2014. This led to a formal partnership with BC Platforms in 2017. On 12 December 2024, this project was extended to include new platforms and tools.

The initial project involved setting up a tissue directory and coordination centre to minimise duplication and waste in human tissue sample collection. This was the UK's first pan-disease tissue directory consisting of metadata provided by each biobank, enabling researchers around the world to search for samples at different centres across the UK. As the directory was developed solely on metadata, it became apparent that the search could create false positive results, as the metadata was only a high-level description of what was available. This could create the false impression that a biobank had a particular sample of interest.

The challenge was to develop a more robust system that could provide a much richer search on real-world data without having a central database. We saw a need to be able to perform collaborative federated discovery and analysis of data. While we thoroughly understood the problem, we lacked the technical experience in the federated data and analysis capabilities required to develop the solution.

This led to the 2017 engagement with BC Platforms, who we realised could help solve our biobank challenges. We agreed on a joint R&D programme to co-develop access to the company's software application programming interfaces (APIs). This access allowed us to use open interfaces and adapt the components as needed. Our initial collaboration led to new infrastructure using these APIs that found applications in UK-wide initiatives, such as CO-CONNECT, during the COVID-19 pandemic¹. Our understanding is that the success of this infrastructure has helped shift the dynamic in the UK in terms of how health data is viewed from 'why would we' to 'how can we' undertake federated data discovery – a significant progression.

Eventually, our co-developed infrastructure was adopted by Health Data Research (HDR) UK to form its Cohort Discovery tool in 2021, enabling health researchers to

discover research-specific population cohorts. The partnership between our team at the university and BC Platforms has been pivotal in accelerating the progress we have made in becoming a core player in the digital ecosystem. Currently we are jointly developing open-source software, including a tool called 'Bunny,' that gives data partners globally the opportunity to be part of federated networks utilising and contributing to open-source software, whilst still benefitting from the power of a global platform such as BC | RQUEST.

A UK patient's access to clinical trials so often comes down to a 'postcode lottery,' where regions traditionally lacking digital infrastructure and funding are, unfortunately, overlooked. To address this, we have leaned on our experience to integrate the hospital Trust into national research initiatives. This meant adapting national solutions to the local context, which has coincided with the Trust's five-year data strategy, aiming to allow every eligible patient in the greater Nottingham area to have the chance to partake in clinical studies where they meet the necessary criteria.

Patients often describe joining clinical trials as a 'lucky break,' however as an organisation, we now have the real-world data to know exactly whether these patients are eligible. Until now, this link has been missing. Our challenge in making the Trust recruitment-ready was to connect existing internal databases to national platforms. It was crucial to ensure that Trust data could be found, was interoperable and reusable. The potential was enormous as patients would be exposed to treatment options that otherwise would be unavailable.

Through the collaboration between our teams, the Trust has gained access to the technology underpinned by BC Platforms, enabling it to participate in a greater number of international real-world evidence projects and clinical trials. As a research-active National Health Service Trust, this collaboration will proactively help enable patients' right to be involved in research. Our three-way public-private partnership incorporates both technology development and implementation. We also understand that in the industry, our partnership is a unique arrangement as we have unprecedented development access to BC Platforms' APIs. The extension of our partnership in December 2024 provides data-sharing platforms and tools facilitating data sharing, security, and advanced analyses, including trusted research environments, and includes the Trust as an official partner.

Reference:

1. Jefferson E, Milligan G, Johnston J, et al. The Challenges and Lessons Learned Building a New UK Infrastructure for Finding and Accessing Population-Wide COVID-19 Data for Research and Public Health Analysis: The CO-CONNECT Project. *J Med Internet Res* 2024;26:e50235. DOI: 10.2196/50235.

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