

ODAP Report 2022-23



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1 Summary

The ODAP has created a globally-unique research capability combining clinical data, deep phenotyping, host genome sequence, viral sequence data and clinical trial data across the four nations of the UK. ODAP-delivered research has changed the global course of the Covid-19 pandemic, and the outbreak of unexplained hepatitis in children. ODAP combines the security of an accredited trusted research environment with flexible software tools and high-performance compute power, including state-of-the-art GPU compute for machine learning and artificial intelligence applications.

The key innovation in the ODAP is the overarching ISARIC Clinical Characterisation Protocol (CCP), which enables a single set of legal agreements and regulatory approvals to apply across multiple studies, vastly decreasing the complexity of data linkage. This is known as the [ISARIC Spine](#). The Spine offers investigators access to a range of other academic and clinical data sources, creating a significant incentive for researchers to contribute data to the platform.

Access to data is at the discretion of data controllers. ODAP offers to share data controllership with any data contributor who wishes to take advantage of this service, in order to lower the barrier for access. At present, data from the [ISARIC4C](#) and [GenOMICC](#) studies is openly accessible.

2 Funding

The ODAP is funded by the Baillie Gifford Pandemic Science Hub (PSH) at the University of Edinburgh, and the University of Edinburgh City Deal for Data Driven Innovation. The set up and design was funded by UKRI (MC_PC_19025, MC_PC_19059). Funding from the National Core Studies Data and Connectivity Programme (MC_PC_20029, administered by HDR UK) supported the programme from Sept 2021 to March 2023.

3 Key Achievements

- Data ingress and linkage
- Publications
- Support for research to answer key public health questions through ISARIC4C Consortium
- Support for NCS and UKRI-funded research studies
 - (CI: Kamlesh Khunti)
 - SLICK. Studying Long-term Impact of COVID on Kids. A consortium involving investigators from Edinburgh, Oxford and Liverpool using data from ISARIC4C and GP records to ask, “Do children and young people need extra follow up care after having SARS-CoV-2 infection?” Funded by Health Data Research UK and the Alan Turing Institute. (CI: Dr Olivia Swann, University of Edinburgh)
 - 4C Readmission. Investigating using artificial intelligence as an aid to predict the risk of hospital readmission in patients with COVID-19. Funded by Health Data Research UK and the Alan Turing Institute. (CI Prof Ewen Harrison, University of Edinburgh)
 - GenOMICC GPU Compute. Providing GWAS-on-the-fly using GPU compute architecture through a web browser, to provide effortless data access to the raw genotype and whole genome sequence data generated by the GenOMICC study (CI: K Baillie)
 - Cancer COVID (CI Prof Carlo Palmieri)

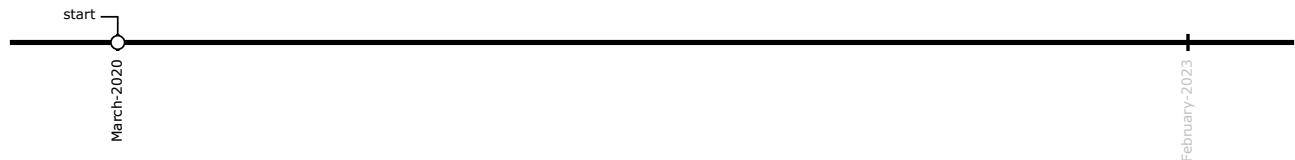


Figure 1: Timeline of data transfer and access activity

4 Problems

Fundamentally, data linkage on this scale is difficult, and the achievements of ODAP are globally unique. However there have been several key challenges in operational delivery of the ODAP. Specifically, the five-safes data access processes are not yet active. This is behind schedule.

- **Resources.** The core team were very under-resourced from the outset due to a combination of recruitment failures and prolonged sickness absence.
- **Project management.** In the current labour market, the very short-term contracts available in ODAP have not been attractive, so we were unable to recruit effective project management. The consequence has been poor coordination across the multiple delivery teams in three different branches (administration in PSH, infrastructure in Edinburgh Parallel Compute Centre (EPCC), linkage and information governance in Public Health Scotland (PHS)). This problem was identified in Sept 2021 and led to the appointment of Ewan Harrison as ODAP Director, which ended in June 2022. Subsequent attempts to provide project management support from HDR UK on two occasions in Sept 2022 and Nov 2022 were not successful.
- **Legal complexity.** The requirement for data processing agreements for each data contributor with two legal entities (UofE and PHS) led to confusion, because the core team at UofE did not have oversight of legal agreements signed by PHS with data contributors.

- **Optimism.** The development of information governance and data access processes consumed more resource than anyone expected, to the exclusion of key events such as data ingress. Competing priorities between the CI (focused on data ingress and linkage) and one funder (focussed on data access processes) led to confusion and misdirection of the admin team.
- **Information governance expertise.** The core project team are lacking in data governance expertise, leading to an excessive dependence on overstretched institutional legal teams in UofE and PHS.

4.1 Recommendations

- **Project management & information governance (IG).** Appoint a dedicated director for the project, with high-level expertise in information governance and the capability to think creatively about solutions to IG challenges. This has not been possible due to the absence of sufficient long-term resource.

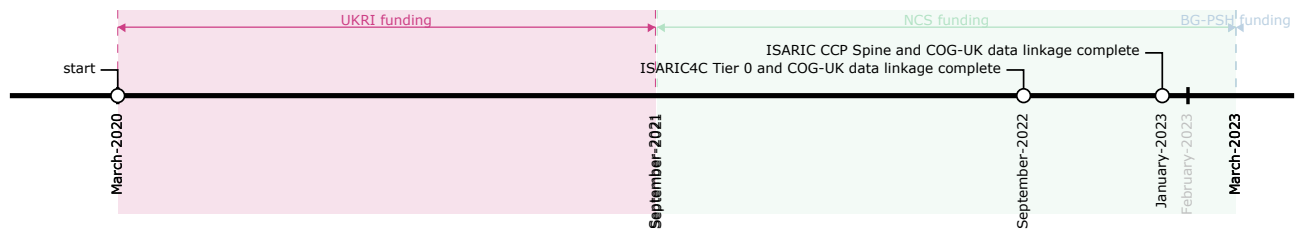


Figure 2: Timeline of data transfer and access activity

Plans:

[ppie2] startdate:nov22 enddate:jan23 [dagc2] dependency: ppie2