Data Access Review Process

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1   Introduction

The Edinburgh Parallel Computing Centre hosts the following TREs:

- The National Safe Haven managed by Public Health Scotland that holds the sensitive/unconsented clinical data including from NHS data from Scotland and England

- The Flexible Compute Environment of Ultra2 that will hold cleaned clinical de-identified consented data from a number of (mainly) covid 19 research studies

The plan for accessing will be depend on where analysis will be performed:

1. Analysis using clinical / patient level data without individual patient consent:

   - Perform analysis in National Safe Haven

   - The joint data controllers (The University of Edinburgh and the Data Provider) manage access / approvals

2. Analysis using cleaned clinical de-identified consented data in the FCE either unlinked, or linked to research datasets with individual patient consent

   - Analysis performed in the FCE

   - The joint data controllers (The University of Edinburgh and the Data Provider) manage access / approvals

1.1   Purpose

To describe the end to end data access process (as per the ODAP data access review process diagram).

1.2   Start process

Details of the available dataset will be published on the ODAP website; HDR UK Innovation Gateway and/or the data provider's website. The Lead Institute (i.e. the University of Edinburgh) will ensure that appropriately trained bona fide researchers can easily access data.

1.2.1   Application:

1. Researchers can submit an initial data request via the ODAP enquiry form available on the ODAP website. The form asks for basic information such as name of researcher; title of project; datasets wish to access/use, including any linked datasets (either between research studies and/or with NHS data); public benefit in doing the research.

2. ODAP data access team will undertake a light touch triage of the submission, checking:

3. The data request is within scope of approved research types [add link to ODAP website of scope]

4. The dataset(s) required are available for analyses

5. The ODAP data access team, if deemed necessary, may propose an online meeting to discuss the data requests with the applicant.

6. ODAP data access team confirms (via email) if the submission is within/out of scope with the researcher.

7. Researcher next steps may include:

   - Recommendation to proceed to the full five safes form available via the HDR UK innovation Gateway (note: the applicant must identify the datasets first and then select the form from therein)

   - Review feedback from triage, and address any points before resubmission

1.3   Pre-approval

1. Researchers submit a full online five safes form via the HDR UK Innovation Gateway, alongside initial enquiry form.

2. ODAP data access team will undertake a light touch triage of the total submission and refer to:

   - The Project Review Panel (PRP) for full review

   - The Data Access Governance Committee (DAGC), for information (on instruction or voluntarily, members of DAGC may be asked to provide expert review). The DAGC should always have sight of data access requests even if only for information.

3. On feedback from the PRP and/or the DAGC, the ODAP data access team confirms (via email) if the submission is within/out of scope with the researcher.

4. Researcher next steps may include:

   - Recommendation for approval to access the data within ODAP

   - Review feedback from PRP and/or DAGC, and address any points before resubmission

1.4   Approval

During the approval phase there are multiple activities that take place, most of these are led and coordinated by the data access team:

Communication:

- Publicise applicants details about approved/declined projects are on the ODAP website

- Share details about approved data access, where dataset from a particular data provider is approved, with/to a pre-agreed contact/mailbox of that data provider

Data access agreement

- Contact the contracts team to complete a data access agreement

- Refer drafted DAA with the researcher for their organisational sign off

- Receives signed-off DAA from the researcher and refers to Lead Institute for sign off

- Share copy of fully executed DAA with all parties concerned

1.5   Data access

During the data access phase there are multiple activities that take place, most of these are led and coordinated by the data access team, with support from the data management team:

1.5.1   Compliance

Share with the researchers and their teams the following documents:

- Attribution and publication policy

- Data access acceptable use policy (to be developed)

- User guide to register to the ODAP

- Outputs review policy, SOP and template

1.5.2   Registration & notification

1. Approve registration to the permitted areas for approved data access

2. Researcher is notified of approved registration for data access. They have completed the process to access the data.

1.5.3 Undertake research

Researchers can undertake their research/data analyses within the ODAP.

- The ODAP data access team initiate process for data access with the data management team

1.6 Outputs

1.6.1 Review and approval:

- Researcher completes the outputs review form and returns to the ODAP data access team
- Data access team undertake initial triage of the outputs requested and may refer to the data management team for a second opinion
- Once the data access and data management team are in agreement, they can approve/reject outputs requested (giving reasons for the latter)
- Outputs agreed for release may need a third opinion of the originating data provider
- Preparation for release:
- Data management team will review figures and outputs of data analysis performed in the ODAP before they are removed from the TRE.
- Outputs are prepared for release by the data management team, with any caveats noted by the data provider or the joined approving/authorising teams

Outputs can be requested throughout the lifetime of the project approved by the project review panel/DAGC/etc.

1.7 Project closure

Project closures may be triggered in several ways, all of which are detailed out with this document. Please refer to the ODAP Project Closure Revoke Access (in development) process document for further information, including extending a project and revoking researcher access to the ODAP at the end of a project.

1.8 Publicising Research

The ODAP data access team will adhere to the publicity policy (to be developed) when publicising all research that has been produced within the platform.