MRC Science Archive Data Access Committee: Annual Report 2020

MRC Science Archive

The MRC Science Archive contains research data sets from former MRC units and Institutes, as well as other documents and publications that continue to have scientific or historical value. As the scientific data held in the MRC Archive may include personal details from study participants, it is held under secure conditions and access is carefully controlled. Access to the data can be requested through application to the independent Data Access Committee (DAC) for the MRC Science Archive.

MRC Science Archive Data Access Committee

To ensure that the data in the MRC Science Archive are available for re-use in research, with appropriate controls to protect participants, in 2019 the MRC set up an independent Data Access Committee to manage access. The committee includes a Chair with expertise in Bioethics, three expert members with relevant expertise in scientific research, statistics, data science and data management, two lay representatives, and the UKRI data protection lead.

The Data Access Committee:

- considers the scientific merit and feasibility of the proposal;
- checks that access is consistent with the reasonable expectations of research participants and the original consent;
- ensures the applicant is a *bona fide*[1] research team/organisation with the appropriate skills and resources to perform the proposed analyses and safeguard the confidentiality of participants;
- assesses the resource implications of providing access;
- ensures that all legal, ethics and governance requirements have been addressed.

When a data access request is approved, a Data Sharing Agreement is drawn up between the UKRI and the research organisation that employs[2] the applicant. This specifies the data to be released, the research purpose, and the time period for access. The costs of preparing data for applicants, for example where data has been archived in the format of older historical paper records, may be charged to the applicant.

Data Access Committee Annual Report of Activity 2019-2020

This report on the activity of the DAC covers the period from the appointment of the Chair in 25 September 2019 to the 31 December 2020. (See Annex 1 for the flowchart for the data access review process).

Chair appointed: 25 September 2019

Recruitment of DAC members completed: 01 July 2020 (including 2 lay members)

Meeting frequency:

Two meetings of the full DAC were held in July and October 2020 (one preliminary meeting in 2019 involved the Chair only).

There will be three meetings of the DAC each year from January 2021 (see Annex 1 for meeting dates 2021).

---

[1] As defined in the *MRC Policy and Guidance on Sharing of Research Data from Population and Patient Studies* available at https://mrc.ukri.org/publications/browse/mrc-policy-and-guidance-on-sharing-of-research-data-from-population-and-patient-studies/

[2] In the case of students, this will be the organisation at which the student is registered.

Applications and Enquiries

Since January 2019, there have been 10 applications for access to 25 separate datasets held within the MRC Science Archive.

One application was considered at the DAC on 25 September 2019 and 9 were considered by the DAC during 2020. Six applications (for 18 datasets) involved datasets that had transferred to the MRC Science Archive after the closure of the Human Nutrition Research Unit in Cambridge.

Timeliness of review in 2019-2020 (25 datasets requested):

	Mean (range)
Period from initial enquiry to Access Application	12 weeks (1-31 weeks)
Period from Access Application to Data Access Committee review	12 weeks (1-49 weeks)
Period from Data Access Committee review to Data Sharing Agreement	7 weeks (2-11 weeks)
Period from Data Sharing Agreement to data transfer	0 weeks (0-1 weeks)

In 2019-2020, the mean time between an access application being received and reviewed by the MRC Data Access Committee was 12 weeks (range: 1 to 49 weeks). For applications that were submitted in 2020 (19 datasets), the mean time from access application to Data Access Committee review was 4 weeks (range: 1 to 13 weeks).

Outcomes of Data Access Committee review

For the 25 dataset requests in 2019-2020, the outcomes from the Data Access Committee review were:

Data Access Committee outcome	Number of datasets
Approved	3
Approved with Conditions*	19
Access refused	2
Application withdrawn	1

The condition placed on approval for 19 applications was confirmation that each main or co-applicant held an employment, honorary or visiting worker contract with one of the research organisations signing the Data Sharing Agreement for the whole period that access was required.

One application was withdrawn in 2019 as the access process was too slow.

Two applications for data were refused because the MRC could not confirm the re-use of the data was within the original consents. These datasets will continue to be held for the retention period specified in MRC's Good Research Practice guidance, in order check reproducibility of research findings if required.

There were no appeals against Data Access Committee decisions in 2019 or 2020.

Transparency

To ensure transparency in the management of the research data held within the MRC Science Archive, information about the MRC Science Archive has been placed on the MRC public webpages (https://mrc.ukri.org/research/policies-and-guidance-for-researchers/data-sharing/); these will be expanded after the transition to the UKRI website to include:
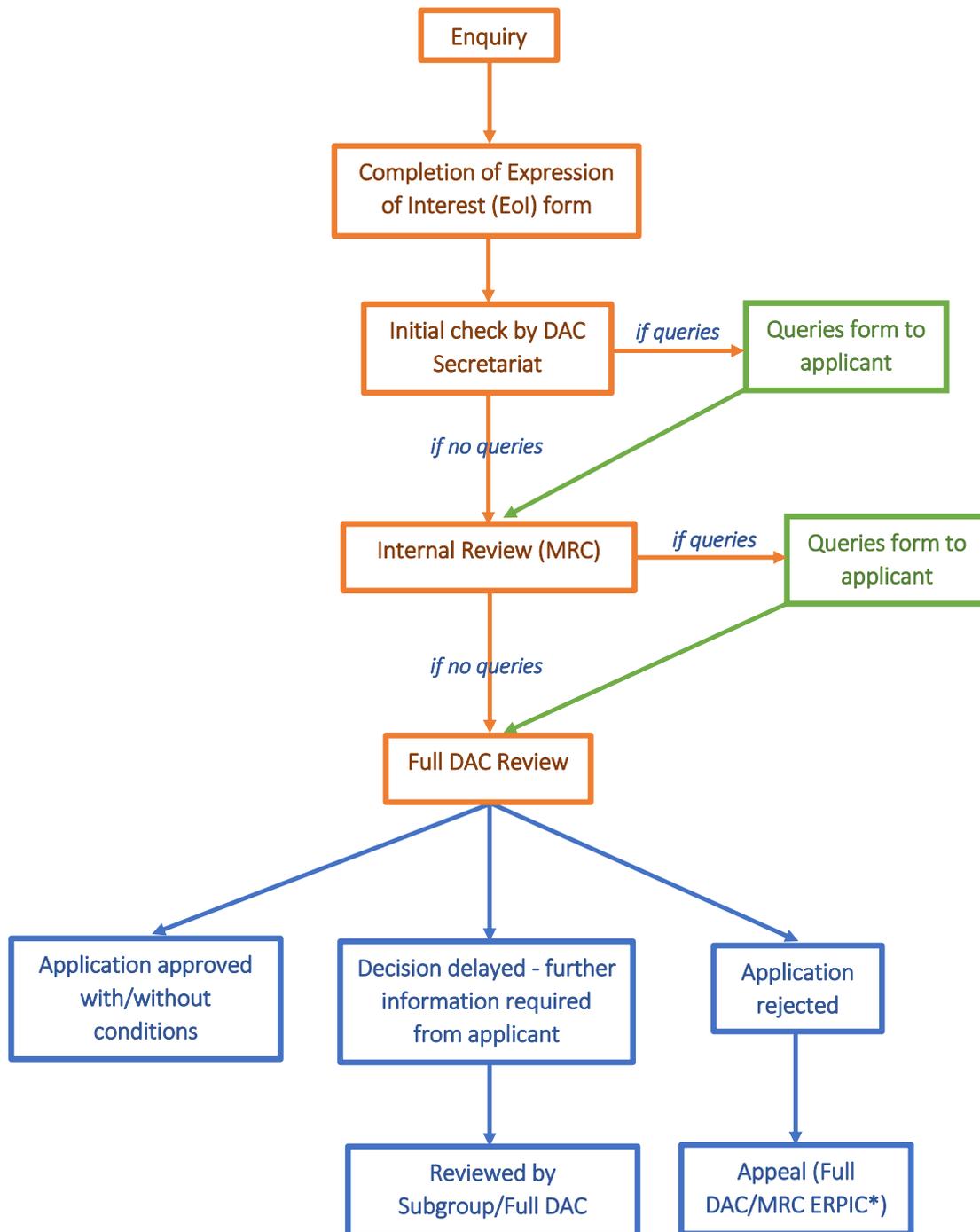- information about the members of the Data Access Committee;
- the application and appeals process;
- a public register of data access requests that have been approved and the research purposes;
- an annual report of activity.

Planned work for the coming year

In the coming year, a list of the curated datasets held in the MRC Science Archive and available for re-use will be developed.

Annex 1:

Flowchart of the Data Access Application Process

```
                          ┌─────────────────┐
                          │     Enquiry     │
                          └────────┬────────┘
                                   │
                                   ▼
                    ┌──────────────────────────┐
                    │ Completion of Expression │
                    │  of Interest (EoI) form  │
                    └────────────┬─────────────┘
                                 │
                                 ▼
                ┌──────────────────────┐  if queries  ┌──────────────────┐
                │ Initial check by DAC │─────────────▶│ Queries form to  │
                │     Secretariat      │              │    applicant     │
                └──────────┬───────────┘              └──────────────────┘
                           │ if no queries                      │
                           ▼                                    │
                ┌──────────────────────┐  if queries  ┌──────────────────┐
                │ Internal Review (MRC)│─────────────▶│ Queries form to  │
                │                      │              │    applicant     │
                └──────────┬───────────┘              └──────────────────┘
                           │ if no queries                      │
                           ▼                                    │
                ┌──────────────────────┐◀──────────────────────┘
                │   Full DAC Review    │
                └──────────────────────┘
```

Full DAC Review branches to:

- **Application approved with/without conditions**
- **Decision delayed - further information required from applicant** → **Reviewed by Subgroup/Full DAC**
- **Application rejected** → **Appeal (Full DAC/MRC ERPIC*)**

* ERPIC = Ethics Regulation and Public Involvement Committee

Data Access Committee Members

Chair: **Sarah Edwards**, Professor of Bioethics, University College London

Members: **Mary-Kate Hannah**, Data Scientist, University of Glasgow
Maurice Hoffman (public involvement representative)
David Hyett, Head of Information Governance, UKRI (Deputy Chair)
Ben Micklem, Research Support Manager, University of Oxford
Fleur North (public involvement representative)
Victoria Yorke-Edwards, Research Fellow for Trial Conduct Methodology, UCL

Meeting dates 2021

Deadline for applications	*Internal Review Group meeting date*	*Data Access Committee meeting date*
29 January 2021	09 February 2021	24 February 2021
30 April 2021	11 May 2021	07 July 2021
30 August 2021	08 September 2021	06 October 2021