**External Data Request Process**

The School of Medicine has an established virtual committee, the Data Custodian and Academic Proposals (DCAP) Committee, to deal with all external requests for data from School projects.

**Contact e-mail:** medicine.datasharing@keele.ac.uk

**Membership**:

Kelvin Jordan (Chair)

James Bailey (Data Registrar)

Martyn Lewis

Clare Jinks

Danielle van der Windt

Gillian Lancaster

Jonathan Hill

Jo Smith

Julius Sim

Kika Konstantinou

Kate Dunn

Krysia Dziedzic

Lorna Clarson

Milica Bucknall

Martin Thomas

Tom Shepherd

**Roles of DCAP**

The roles of the DCAP are to:

* discuss and review external data requests
  + this will include, but may not be limited to, consideration of i) the ethics and other approvals and consent agreements in place for project(s) concerned, ii) feasibility of analysis proposed, iii) potential duplication of research question(s) or analysis within the School, iv) strength and appropriateness of team, v) how data will be stored, vi) dissemination plan
* decide on approval, need for further information / amendments, or rejection
* confirm which data should be released
* maintain a register of all requests
* audit approved requests
* monitor and review at regular intervals the request process and DCAP membership.

**Process for requesting data**

1. The external researcher who wants data from a School of Medicine project should first contact a School staff member who is willing to be the “internal link” for the external data request. The internal link will normally be associated with the project(s) involved in the request.

2. The internal link consults with the PI(s) of the projects from which data is requested and with relevant research leads in order to determine any duplication of research questions and data analysis, and assess whether there are any ethical or consent issues.

3. The external researcher, with help from the internal link, completes the standard external data request form specifying the study aims, methods and exactly which variables are required.

4. The internal link emails the completed data request form(s), the CV of the lead external researcher, and a document outlining the design of the proposed investigation to the registrar at

[medicine.datasharing@keele.ac.uk](mailto:medicine.datasharing@keele.ac.uk) , cc’ing the relevant project(s) PI and data custodian.

5. The registrar registers the data request in the data request log.

6. The registrar circulates the request by email to three members of the DCAP who are not part of the relevant project team or external data request team, cc’ing the PI and data custodian if they are not members of DCAP, with a 2 week deadline for return of comments.

7. After the given deadline, the registrar will allow a week extension and send a reminder email.

8. If there is no response from 1 or more reviewers, or disagreement between reviewers, up to 2 further reviewers will be asked to review the request.

9. The DCAP Chair will collate the feedback, make the final decision on the request based on the views of the DCAP, and feedback decision to the internal link.

DECISION OPTIONS

1. FULL APPROVAL - Whilst comments or suggestions may be raised, these are minor and no amendments necessary, all requested data can be released:

a) the internal link sends via email the final form signed by the external researcher and PI(s) of the project(s) from which the data are requested to the DCAP registrar.

b) the DCAP chair signs on behalf of DCAP to signify approval for the data to be shared.

c) the form is then passed on to the relevant Data Custodian(s) to organise the datasets associated with the request.

d) the Data Custodian(s) sends the datasets to the lead external researcher including data dictionary, with the external researcher using an approved method (as shown below), recommended by Keele University Information and Digital Services [here](https://keeleacuk.sharepoint.com/sites/IDS-O365/SitePages/Sharing-with-Externals-on-O365.aspx?CT=1637941695530&OR=OWA-NT&CID=d158dd38-e77a-9258-b6b2-259297cd9913). The optimal method should be decided by Data Custodian, internal link and external researcher:

* Password protected zip file placed in a project specific folder of the Data Custodian’s Keele OneDrive, access to the folder provided to the recipient only. The password to unlock the file to be either communicated through in a separate email, Microsoft Teams chat or verbally (i.e. Teams meeting). Data to be deleted from Data Custodian’s OneDrive folder once external researcher has confirmed they have copied data onto their secure password-protected server.
* Password protected zip file sent through the files function of Microsoft Teams chat, with the password to unlock the file either communicated in a separate email, Microsoft Teams chat or verbally.
* Set up a restricted channel in a study specific Microsoft Team only accessible by the Data Custodian and External researcher. Place the data within the files section of this channel and delete once confirmation external researcher has confirmed they have copied data onto their secure password-protected server.

e) the Data Custodian(s) signs the form and passes to the registrar, to allow for appropriate filing and inclusion on the external data request repository.

1. PARTIAL APPROVAL - part of the request is approved and/or part of the data can be released:
2. the internal link discusses with the external researcher whether they wish to go ahead for the approved part of the project:
   * If yes, the data request form should be amended using track changes to delete the part of the project not approved and the revised copy of the form signed by the external researcher and the PI(s) of the project(s) from which the data are requested passed to the DCAP registrar. The process described under FULL APPROVAL parts b) to e) are then undertaken
   * If no, a note is added by the registrar that data is no longer required and the request is appropriately filed and included on the external data request repository.
3. FURTHER INFORMATION OR AMENDMENTS REQUIRED
4. the DCAP chair will inform the internal link and clearly state what is required.
5. the internal link will then work with the external researcher and submit the necessary information and amendments.
6. this will go through a second stage of review by DCAP with the same reviewers (with 2 week deadline for comments).
7. REJECTED
8. the DCAP chair will inform the internal link to explain the DCAP’s decision and discuss potential alternatives.
9. the DCAP chair signs off the form and passes to the registrar for appropriate filing and inclusion on the external data request repository.