Resource Access: T&Cs

Terms and Conditions for Anne Rowling Clinic Resource Access Requests

1. Definition of Anne Rowling Clinic Resources

'Anne Rowling Clinic Resources' includes the following information (varies by project):

- Demographic data
- Clinical data
- Information from health and lifestyle questionnaires
- Genetic data
- Biological samples
- Medical imaging data
- Clinical and digital measures
- Contact details (will not be shared)

2. Types of request

The Anne Rowling Clinic wishes to facilitate use of its data and sample resources for the public good by the health research and clinical care communities.

Resource access to the community will be on a relatively small scale at present, and mostly restricted to existing team members or existing collaborators.

Requests for access can be made by:

- Anne Rowling Clinic researchers
- Academic and clinical collaborators: employees or students at the University of Edinburgh or another UK or international academic institution, the NHS, or in third-sector organisations such as relevant health charities
- Commercial organisations, for resources where relevant consent has been obtained

We do not consider the issue of potential overlap between research projects among external requesters.

There are several different types of resource request:

2.1 De-identified resources (default)

De-identified (aka pseudonymised) means that information directly identifying participants is removed before any data or samples are released to requestors. A unique

identifier is added to that information which can be used to link that information to the identifiable information/participant by means of a key. Requesters are not permitted to make that linkage and will not be given access to the key.

The nature of the data or samples, in particular, the fact that voice recordings and genetic information cannot be robustly de-identified or anonymised, means that the Anne Rowling Clinic classifies all de-identified data as identifiable (i.e. personal data). Specific consent for the sharing of this information has been obtained.

You will be required to comply with applicable data protection laws when processing identifiable resources.

2.2 Identifiable resources (personal data) which are not de-identified

Information which has not been de-identified that identifies participants is included, alongside data or samples released to requestors. Examples of personal information are name, date of birth, full postcode, community health index (CHI) number. This option is only available to researchers within the University of Edinburgh (and only where there is a clear requirement for identifiable resources) or to clinical professionals who require the data for a permitted activity such as a registered audit.

You will be required to comply with applicable data protection laws when processing identifiable resources.

2.3 Research information dissemination

Requests can be made for the NeuroCARE team to disseminate publicity information to participants regarding a research project.

Email dissemination is preferred. Because there is limited staff capacity to send study information by post, requesting this route might result in delays.

If you already have access to NeuroCARE we may be able to release participant contact information directly to you (see section 2.2).

Please also be aware that we may decline to disseminate information if we feel that this, combined with other participant contacts we have made, might overburden the NeuroCARE participants.

3. Review and Approval Process

Resource requests must be made using the formal procedures described in this document.

Applications must be made using the online application form, with one submission per project.

The application must contain sufficient detail about the aims of the project and the proposed use of all the resources, to justify the request.

The application must contain details of how the resources will be securely stored, with access controls and an appropriate disposal/deletion plan.

3.1 Ethical approval

If your request involves research with human participants or personal data that is not fully anonymised, ethical approval is required before data will be released. We will ask for the expiry date of the approval, and to see a copy of the ethical approval.

3.2 Anne Rowling Clinic Resource Access Team

Resource requests will be received, reviewed, approved and prioritised by the Anne Rowling Clinic Resource Access team which comprises the Anne Rowling Clinic Senior Academics, Deputy Directors and Senior Professional Services team (see Appendix A for details).

The responsibility of the Resource Access team is to review and approve or deny applications, ensuring that the following criteria are met:

- the requester is a bona fide researcher or clinical professional at a qualifying institute/organisation, and
- the proposed use of the resources:
  - is for the public good
  - is scientifically robust
  - is strategically aligned to the aims of the Anne Rowling Clinic, i.e., concerning translational and clinical research and trials relating to neurological conditions, or audits relating to clinical care of people with neurological conditions
  - does not involve research on animals (this contravenes the funding conditions of the Clinic)
  - does not bring the Anne Rowling Clinic into disrepute
  - respects participant confidentiality
- required ethics/governance permissions have been obtained
- the proposed use of the resources has the necessary funding in place

For requests that do not meet the above criteria, we will contact you to further discuss your request and give you the opportunity to make revisions.

For more details on reasons an application may be declined, see Appendix B.

3.2.1 Number of approvals required

Requests must be approved by two members of the Resource Access Team, including the most relevant Senior Academic of the Resource Access Team (or their nominated alternative in case of absence).

3.3 Additional considerations for biological samples

Biological samples collected from people with neurological conditions are finite and precious. Additional checks will be made to ensure that samples are used for projects that

maximise the amount of data obtained from available samples. Therefore, to avoid delay in approval, applicants should ensure to provide sufficient detail in their applications:

- The assay test platform should have proven quality assurance measures in place.
- The methodology should include measures to ensure the quality of any remaining sample is not jeopardised so that the sample can be utilised for assays which are able to use freeze-thawed samples.
- The volume requested is reasonable and does not seriously deplete the resource.
- The work proposed is within the scope of the consents obtained for the specific samples

3.4 Procedures prior to release of resources

All applicants must confirm on the online application form that they have read and agree to abide by these Terms and Conditions.

3.4.1 Research Information Dissemination requests

No additional documentation is required.

3.4.2 Research requests from University of Edinburgh

The Principal Investigator of the requesting research team must sign a Researcher Responsibility Agreement, which is valid for one year from the date of signature and may cover multiple approved applications within that period.

3.4.3 UK/EU academic research requests (not University of Edinburgh)

The Provider Institution and Recipient Institution/Organization must sign the UK/EU Data and Materials Transfer Agreement (DMTA) before resources are released. The UK/EU DMTA will apply for 12 months from the data of signature and may cover multiple approved applications within that period.

3.4.4 International academic research requests

For international applications, we follow University of Edinburgh policy. Applications from countries that are covered by the UK GDPR adequacy regulations (ico.org.uk/for-organisations/uk-gdpr-guidance-and-resources/international-transfers/international-transfers-a-guide/) will sign the UK/EU DMTA. All other countries must submit a Data Protection Impact Assessment and sign an international (non-UK/EU) DMTA.

3.4.5 Research requests from commercial organisations

For commercial applications, a bespoke contract will be entered into. Reputational and financial due diligence will be undertaken on all companies.

3.4.6 Non-research requests, such as for clinical audits or reports

If the request is for identifiable or de-identified data that will be used for a registered audit, or compiled for a report, but not subject to research, the applicant will be required to enter into the Permitted Activities UK DMTA.

3.5 Amendments to resource requests

An amendment to your original proposal must be requested if any of the following changes during the course of your approved project:

- Significant change or extension of scope
- Change in start or end date
- Change in ethical approval status
- Additional researchers accessing the data
- Change in institution, location, or addition of institution(s)
- Change in funding status such that the proposed project can no longer be undertaken
- Any additional data/samples required

3.6 Re-use of data

Applicants must not re-use the data or samples for a new or extended purpose. Please submit a new resource access request for any subsequent uses of the resources.

3.7 Onward sharing of resources

Applicants must not share the resources to any third-party without further discussion and agreement. This includes sharing with established collaborators, and uploading data to repositories.

4. Cost

At present, there is no cost for data access by academic researchers. For sample access, we may charge a nominal cost to cover shipping, depending on the scope of the request.

Commercial organisations will be charged on a cost recovery basis plus overheads. This cost will vary depending on the types of resources requested and the amount of time required to facilitate your request. VAT and overheads will be charged where applicable, according to University of Edinburgh policy.

Resources will not be provided until the relevant paperwork is completed and an invoice has been settled or a purchase order number is received by our finance department.

5. Timeline for providing resources

Our standard timeline for providing resources is 1 month from completion/signature of the Researcher Responsibility Agreement or DMTA, as applicable.

If you require the resources sooner than this, then please specify the reason in your application form.

We will aim to meet legitimate requests wherever possible (e.g. required for conference abstract submission, grant milestones), but cannot guarantee this as it depends how many high-priority requests are currently awaiting processing, and the complexity of your request. We therefore advise early submission of requests where possible, giving a long lead time.

If you wish to enquire about the progress of your request, please contact ARRNC.resource.access@ed.ac.uk.

6. Transfer of Resources

Data and/or an index relating to samples will be shared in a password protected file via the University of Edinburgh file-hosting service, DataSync, with the password being shared separately.

Please confirm safe receipt of resources, including a listing of what has been received, by emailing ARRNC.resource.access@ed.ac.uk

7. Resource Management

All applications must include information on how the resources will be managed.

Data must be stored in a secure network, at a standard that would be reasonably expected for the storage of valuable and proprietary sensitive/confidential data. Data should not be stored on a standalone machine. Cloud and online storage is permitted provided that only authorised individuals can access the data and appropriate security measures are in place.

Data should be stored with technical access controls that restrict access to only the people who are listed in the application.

Data must not be shared directly or indirectly with unauthorised individuals or unauthorised third parties.

Participant-level data must not be shared, stored or uploaded (directly or indirectly) to web-based or other repositories accessible by unauthorised individuals or unauthorised third parties.

Data should be fully deleted and biological samples should be destroyed when analyses are complete.

For biological samples, Anne Rowling Clinic researchers should log usage comprehensively on FreezerPro. If you wish to use residual samples for experiment optimisation or pilot studies, please specify this in your request form. Otherwise, residual samples should be logged back into FreezerPro.

The applicant and their institution/organisation will be fully responsible for the resources once received.

We might not be able to approve future resource requests if the researcher does not adhere to the above stipulations.

8. Outputs: publications, presentations and reports

8.1 Approval of research outputs

You must not name or identify (directly or indirectly) any patients/participants in publications or presentations.

If your request involves identifiable data (personal data), any resulting research outputs should be approved by the Anne Rowling Clinic Resource Access team before submission. Please send a copy of the draft research output to ARRNC.resource.access@ed.ac.uk as early as possible and allow thirty (30) days for approval.

8.2 Authorship

You should include as authors all Anne Rowling Clinic staff or students, or project team consortium members, who meet the International Committee of Medical Journal Editors (ICMJE) criteria, at www.icmje.org/recommendations/browse/roles-and-responsibilities/defining-the-role-of-authors-and-contributors.html.

Specifically, individuals who have made a substantial scientific contribution to the conception, acquisition, derivation, analysis or interpretation of the resources being used (ICMJE criterion 1) should be given the opportunity to draft and/or review manuscripts before submission, approve the manuscript, and be accountable for relevant aspects of the work (ICMJE criteria 2-4, respectively). Individuals who meet all 4 criteria should be included as authors.

We will inform you of the individuals who meet ICMJE criterion 1 (name, email address, description of contribution) upon approval of your resource access request. Please contact these individuals with your draft manuscript, and allow 1 month for review/approval.

8.3 Acknowledgements

In addition to the authorship requirements detailed in clause 8.2, please add an acknowledgement as follows:

For NeuroCARE

> "[Resources – describe what you received] were obtained from the NeuroCARE platform that is hosted and funded by the Anne Rowling Regenerative Neurology Clinic, University of Edinburgh. We thank the NeuroCARE participants and the members of the NeuroCARE Consortium (listed at edin.ac/4ePeDl3) for their contributions to this study."

For clinical data from CARE-MND being used for Permitted Activities (non-research), e.g. audit or charity reports

> "Data was obtained from the CARE-MND platform that is hosted and funded by the Anne Rowling Regenerative Neurology Clinic, University of Edinburgh. We thank

the members of the CARE-MND Consortium (listed at edin.ac/4ePeDl3) for their contributions."

For FutureMS

> "[Resources – describe what you received] were obtained from the FutureMS study that is hosted by the Anne Rowling Regenerative Neurology Clinic, University of Edinburgh, and funded by the Anne Rowling Clinic and Scottish Government. We thank the FutureMS participants and the members of the FutureMS Consortium (listed at edin.ac/4ePeDl3) for their contributions to this study."

8.4 Reporting of outputs

Please inform us on ARRNC.resource.access@ed.ac.uk if any work involving Anne Rowling Clinic resources is accepted for publication (including published meetings and abstracts and other reports), and send us a copy of the accepted output.

We may discuss with you about plans for dissemination via press releases, websites and social media.

9. Intellectual Property (IP)

Provisions for IP arrangements with researchers outwith the University of Edinburgh will be specified in the DMTA.

10. Document version and review history

Version	Date	Written/edited by	Key changes made
V1	September 2026	Rebecca Devon, Judith Newton, Christine Weaver, Jessica Gill, Rozanna Meijboom, Graham Ayres	Initial version

Appendix A

Anne Rowling Clinic Resource Access team

Senior Academics

- Prof Siddharthan Chandran
- Dr Peter Foley
- Dr Patrick Kearns
- Dr Niall MacDougall
- Prof Suvankar Pal
- Dr Bhuvaneish Selvaraj
- Prof Adam Waldman

Deputy Directors and Senior Professional Services team

- Judy Newton
- Dr Rebecca Devon
- Christine Weaver
- Dr Rozanna Meijboom

Clinical Database Team

- Jessica Gill
- Tia Cainer

Administrator

- Dianne Beaton

Appendix B

Reasons for declining a resource request

Reasons include, but are not limited to the following:

- Lack of availability of data/samples
- Applicant not being a bona fide researcher, clinician or having an appropriate role at a relevant organisation
- The proposed resource use is not currently viable due to lack of funding
- The scope of the proposed resource use: requested resources should be relevant to and justified by the research investigation, audit or report
- The proposed work, in the view of the Anne Rowling Clinic Resource Access team, risks bringing the Anne Rowling Clinic into disrepute
- The proposed work risks disclosure of identifiable information relating to any individual participant (e.g. the sample size is too small)
- The proposed outputs of the project are outside the scope of participants' consent, or the relevant ethical approval, or funders' terms and conditions, or the University of Edinburgh's policies and procedures.
- The proposed work overlaps significantly with ongoing research by the Anne Rowling Clinic team.
- Biological samples are a finite resource and therefore need to meet the criteria
- Data/sample storage plan deemed to be inadequate
- The Applicant has previously failed to comply with the Terms and Conditions, including if the Applicant has not returned a notification of receipt.