



Dementias
Platform^{UK}
Medical Research Council

Data Portal user guide series



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Guide 2.

Access cohort data

The Data Portal guide series

This guide is part of a series which takes you from choosing your data to downloading findings.

1. Identify: a video guide explaining how to use the data discovery tools to select the right cohort data.

2. Apply: this downloadable guide explains how to apply for data and submit a strong DPUK research proposal.

3. Analysis: a video guide explaining how to set up an account and access your virtual desktop.

Aims and objectives

The aim of this guide is to explain how researchers can apply to access DPUK cohort data using the [DPUK Data Portal application form](#).

There are three steps to take before you can access your cohort data. You will need to:

- I. apply for specific cohort data and submit a research proposal
- II. sign and return the DPUK Data Access Agreement when your study has been approved
- III. set up your account and access the virtual desktop with data.

Applicants

Who is assisting you in your project?

- Collaborators can assist with different aspects throughout your project lifecycle.
- Collaborators may include statisticians, knowledge mentors or a project manager.
- You may benefit from collaborations beyond your own institution. Cross-institutional or collaborative projects may contribute an additional aspect to your work, and this can strengthen future grant applications.

Public benefit paragraph

Consider the benefits to the general public and wider audience.

- Who will this benefit and why?
- Why is this important?
- How does it build on what is already known?
- Can it impact at policy level?
- Are there ways to engage the public in the research or findings?

Data requested

Be guided by your research question but not restricted.

- Use the Data Discovery tools to identify the appropriate cohorts.
- Use journal papers and online dictionaries where information is not detailed adequately, or contact a member of the DPUK team.
- Avoid applying for ALL data because:
 - you risk having your application rejected (lack of focus);
 - you may end up with redundant data;
 - focusing on relevant variables assists with data processing and analysis.

Scientific context section I

Study overview

- Summarise your proposal in plain language, aimed at a non-English speaking audience.
- Avoid use of scientific or subject-specific advanced terminology if possible.
- Write out acronyms on first use.
- Avoid use of references – leave these for the scientific rationale section.
- Finish your paragraph with the aim and objectives.

Scientific context section II

Scientific rationale

- Limited use of citations may be used; please provide a reference list.
- Consider existing work and how your research contributes.
- Limited use of scientific and technical terminology is acceptable.
- Acronyms should be written out in full where not already used.
- Finish section with a clear objective, aim and research question.
- Mentioning limitations, and how they will be addressed, can be included.

Scientific context section III

Analysis plan

- Extensive detail (eg journal methods length) is not required.
- A clear understanding of the required analyses is necessary (eg longitudinal research question = longitudinal analysis).
- Show progression of analytical thought.
- Avoid detailing statistical procedures you do not intend to use, or have no expertise in, unless you are including a statistician as a collaborator (if so, state this in your proposal).

Scientific context section IV

Ethical approval

- Your application will be returned if you leave this section blank.
- Ethical approval is already in place for existing cohort data – it is good to state this. This displays your awareness of ethical procedures.
- If you are applying for re-contact studies, additional ethical procedures will apply (please see DPUK recontact policy: www.dementiasplatform.uk/policies).

Scientific context section V

Keywords

- Decide on 3-6 keywords which define your research.
- These will be used to search proposals.
- Proposals will be returned if this section is not complete.

Fail-fast criteria

DPUK Fail-Fast criteria have been created to streamline the review process and give clarity on submission overviews. In order for studies to have the highest possible chance of approval, applicants must clearly state whether they believe that their study adequately conforms to the below fail-fast criteria:

- Is the study in the public interest?
- Does the study maintain non-identifiability of cohort participants?
- Does the study have a clear scientific rationale?
- Does the study have an appropriate analysis plan?
- Does the study satisfy non-conflict of scientific interest?

If there is a conflict of interest please justify in the comment box below

- A quick check guide to ensure high quality completion.
- This provides a chance for cohort owners to swiftly assess whether your application is complete.
- Fast feedback from cohort owners.

General proposal writing guidance

- Use plain language
- Limit sentences to one key point
- Be careful with dual meaning words, eg drugs, diet
- Avoid high technicality if it is not making a relevant point
- Consider acronyms or shorter terms for repeated use
- Limit citations and provide reference list if used
- Use short paragraphs
- Keep within word count guide

The DPUK Data Access Agreement

Approved study

When the review panel has approved your application you will receive an email asking you to agree to the terms and conditions of the [DPUK Data Access Agreement](#)

This governs use and security of DPUK data within the Data Portal.

The agreement gives the data providers confidence that their data remains secure and that research is aligned with your proposal, while you are accessing the information you need to advance our understanding of dementia.

Setting up a Data Portal account

When the DPUK support team has processed your signed **Data Access Agreement**, they will email to let you know that your data is available and provide instructions on how to access to the [Data Portal virtual desktop](#).

The email will provide a user-specific QR code so you can set up your smartphone/tablet authenticator for the first stage of login. This app generates a one-time passcode you will need each time you login.

You will also be asked to set up your password – you will use your password and the one-time passcode each time you login. When you set your password, the dialog box asks if you want to ‘reset’ your password – choose this option.

The secure login system has created a password for you which you are now choosing to change.

Once you’ve logged into to your virtual desktop, your research can begin.



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www.dementiasplatform.uk/guides