Short Guide to eDRIS



eDRIS Overview

The eDRIS team offer assistance with applications to the Public Benefit and Privacy Panel for Health and Social Care (PBPP); help identifying other necessary permissions; advice on the availability and quality of national datasets; help with the transfer and linkage of data; support for National Safe Haven access and can carry out bespoke analyses on your behalf.

eDRIS team work closely with the PBPP to assist in the quick and efficient scrutiny of applications by the panel members but are separate from the PBPP team.

Triage

After first contacting eDRIS, you will be asked to complete an enquiry form to provide a brief description and requirements for your proposal to enable eDRIS to confirm that it is suitable for eDRIS to support or redirect you to a more suitable service. On completion of the returned enquiry form, you will be assigned a reference number which you should quote in all future correspondence with eDRIS. Due to the high volume of enquiries eDRIS receive this will help us process your enquiry more efficiently.

At the enquiry stage we can provide an initial quote for our services which includes data provisioning, linkage and national safe haven support. Your quote will be subject to change if the work starts in a different financial year or there are any changes from your initial requirements.

During triage you may also be signposted to external data providers if you have enquired about this, or if the data you require is not available via Public Health Scotland. As not all data is within our control, we recommend researchers establish relationships with other data providers as early as possible so all parties are aware of the project before submitting for approvals. eDRIS can often provide contact information or make introductions to facilitate the development of a working relationship between all parties involved in a project. Note that other data providers may also charge for their services.

For your study to be assigned an eDRIS Research Co-ordinator (RC), you will be asked to draft your 1st PBPP application. On receipt of your application, your study will be added to the Research Coordinator (RC) waiting list. The team's workload is regularly reviewed to ensure that new studies are allocated as quickly as possible to a RC.

Research Coordinator (RC)

The RC will be your main contact throughout the duration of your study. RCs work in collaboration with researchers on specific projects. RC work includes:

- Assisting researchers in working up a data specification & data flow diagram to define the data sets. data variables, data processing and data linkage prior to seeking permission to help all data controllers involved to make an informed decision
- Reviewing your PBPP application prior to submission
- Identifying other permissions if required
- Coordinating data provision, including linkage
- National Safe Haven support

Once your application is finalised, they will submit your application to the Public Benefit and Privacy Panel for Health and Social Care (PBPP) on your behalf. In the case of proposals which also require Stats-PBPP permission for Scottish Government data, the RC will review the application and submit on behalf of researchers to Stats-PBPP.

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Public Benefit and Privacy Panel for Health and Social Care (PBPP)

The PBPP is a patient advocacy panel which scrutinises applications for access to NHS Scotland health data for non-direct care. Its role is to ensure that applicants have thought through the public benefit and privacy implications of the proposal.

Further information on PBPP approval process is available from their website, and in the eDRIS Summary Guide to PBPP.

Approval granted

For applications considered by Tier 1 PBPP you should expect to have a decision within 3 working days of the meeting, not including time you may take to respond to any queries. Where further scrutiny is appropriate applications can be referred to Tier2 (Out of Committee, Full Sitting Committee). Other data controllers have their own processes and timescales for informing applicants of their decisions.

If you do not require the eDRIS team to provide data to you, carry out linkage on your data, or host your data in the National Safe Haven, then granting of PBPP approval is the final step in eDRIS involvement with your study.

eDRIS Analyst Allocation

When a study requesting national health data has secured all the required permissions, and any other necessary documents (cohort files etc) are received, it is added to the queue for an analyst to be allocated. As with RC allocations, studies are allocated to analysts on a first come first served basis – when your study is at the front of the queue it will be allocated to an analyst as capacity allows.

Data extraction and linkage

Once the study is assigned to an analyst they begin work on extracting and linking the data. Studies are usually invoiced once the data extract is almost complete, and data will not be released if confirmation of payment (usually a purchase order) has not been received. For studies using the National Safe Haven, all individuals requiring access will complete a eDRIS User Agreement.

Data release and analysis

When the data have been extracted and linked, the datasets are checked and authorised to make sure that only approved data are released. Datasets are then transferred to researchers using a secure file transfer tool, or uploaded to a Safe Haven for researchers to access there. Studies in the National Safe Haven continue to be supported by the RC who assists with access, upload of supplementary files such as previously written syntax or lookup tables, and carries out statistical disclosure control on output. A guide is available to prepare for disclosure control. It contains the guiding principles that you should follow prior to making a request for files.

The eDRIS team ask that you acknowledge the use of our service and the National Safe Haven in any publications/presentations where appropriate.

Study Archival & Closure

Once a study reaches its end date, PBPP will request an end of study report. Studies in the National Safe Haven are archived for a requested time period after analysis is complete, and finally deleted once the archival period is over. Time in the archive can be extended and study data will not be deleted without written confirmation from the researcher.

More information on the eDRIS service is available on our website and advice on accessing administrative data can be found in the Scottish Centre for Administrative Data Research (SCADR) handbook.