

ADRCNI011 - Access & Application to ADRC–NI Data

The ADRC-NI will work with the research team to develop projects ensuring the five key safety principles of the ADRN are upheld, namely, safe data; safe projects that benefit us all; safe setting; safe outputs and safe people.

All researchers wishing to access data through the ADRN must go through an approvals process: this includes the completion of an ADRN Application Form. The Support Team can guide you through the process, details given below.

Step 1: Formulate your research proposal

Researchers should contact the ADRC–NI to discuss whether their research question of interest can be explored using the ADRN Framework. The ADRC–NI is happy to provide feedback by email, telephone or to facilitate a meeting to discuss the feasibility of their potential project.

Details of all potentially accessible datasets are available from the ADRC-NI Data Prospectus.

Note: where the data being sought by the researcher involves UK data, the researcher should contact the ADS in order to advance their project.

To help the ADRC-NI support team to give the best advice, researchers should provide a short summary of their proposed research to the ADRC–NI (rsu.nisra@dfpni.gov.uk) and must clearly outline the data that they require for their project and any linkage that may be required. If the researcher wishes to utilise unit level data that they are the data controller for they must include the details of this including the appropriate legislative gateways.

Proposals will be subject to an initial assessment by the Support Team in order to determine their suitability as an ADRN project. This assessment will be based on the following criteria:

- the project is for non-commercial research purposes;
- the project has demonstrable potential public benefit;
- there is a demonstrable value from using unit level administrative data to answer the research question;
- the project would not be more appropriately served by other existing services (e.g. Farr Institute of Health Informatics Research, UK Data Service Secure Lab, Longitudinal Studies, HMRC Data Lab). Specifically in Northern Ireland researchers would need to consider the [Honest Broker Service \(HBS\)](#), the [Northern Ireland Longitudinal Study \(NILS\)](#) and the [Northern Ireland Mortality Study \(NIMS\)](#);
- the project does not constitute normal operational functions undertaken by government;

Researchers will also be advised whether they meet the following eligibility criteria:

- Each researcher must be a 'fit and proper person' i.e.
 - a. They must be capable of carrying out the research either independently or under the direction of an appropriate supervisor or lead investigator;
 - b. They must have completed the ADRN Accreditation Training before commencement of the project.

Projects involving datasets where there is no agreement in principle are unlikely to be feasible in the immediate future. Such projects will be prioritised accordingly and the feasibility report that is submitted to the Approvals Panel will indicate that the project is not feasible at this stage.

Step 2: Develop project and complete an application form

Proposed research that will involve linkage between NI specific administrative datasets should be developed by setting up a project specific group meeting. This will be arranged and facilitated by the ADRC-NI support team and will involve the research team, the ADRC-NI support team, the Trusted Third Party (TTP), and the respective data controllers. The project specific group meeting can, if required, convene throughout the course of the project. The group would aim to discuss:

- Agreement in principle on project feasibility in terms of data availability, access arrangements, timescales and privacy issues, highlighting any potential limitations;
- Linkage process, in particular coverage of linkage fields;
- Determine need for future meetings and/or communication pathways for further enquiries.

Researchers should contact the ADRC-NI for further information and to arrange an initial meeting.

Researchers must then complete an ADRN Project Application Form. For those researchers who have not already been granted accredited researcher status they will also need to complete the ADRN Researcher Application Forms. These will include details about the researchers involved, a project description, research aims, datasets and variables to be included and dissemination/publicity strategies. Detailed guidance notes for completing the ADRN application forms are available in the ADRN Project Application guidance notes and ADRN Researcher Application guidance notes.

Each project will require ethical approval from a relevant ethics body – the ADRC-NI support team can assist with this process.

Step 3: Submit to ADRN Approvals Panel (AP)

The Research team submits the completed ADRN Project Application Form to help.adrn@essex.ac.uk. The ADRC-NI Support Team will then prepare the Privacy Impact Assessment report and Feasibility report and ensure it is submitted for the AP. The ADRC-NI will indicate if they have any concerns surrounding feasibility or privacy issues based on the completed application which has been submitted.

The Approvals Panel assesses the scientific merit; public benefit; feasibility; ethical concerns; and privacy issues and will decide whether projects should be approved. They may provide some advice on how projects could be improved and/ or stipulate changes to be made. Further information on [The Approvals Panel](#) can be found on the ADRN website.

The ADRC-NI deadlines for submission to the APs are outlined in the Approval Panel Dates document.

The researchers will be informed of the outcome of the AP decision in a timely manner. Researchers will have the right to appeal any decisions in relation to their application. All decisions taken in relation to unsuccessful applications will be fully documented.

Step 4: Complete relevant agreements

If an ADRN project is approved, all relevant ADRN Agreements (including the terms of use and breaches policy) must be signed by the Chief Investigator and all other research applicants.

An Institutional Signatory will also be required by a representative(s) for the organisation(s) with ultimate responsibility for research team members. Further details are provided with the ADRN Researcher Application Form.

Researchers will be required to become ADRN accredited researchers, have completed the ADRN training and if attending the secure environment researchers will be required to have BPSS security clearance. The support team can assist with these processes.

Step 5: Complete Data sharing agreements

Data sharing agreements will be developed by NISRA and the data controllers taking account of the data requirements specified by the researchers in their project application form.

Step 6: Dataset creation & Access

ADRC–NI will ensure that all agreements are in place before a de-identified research dataset is created. This will ensure that all issues such as ethics have been covered.

Working with the data controllers and the TTP, the ADRC–NI will generate a project specific dataset based on the details supplied in the application form. This de-identified research dataset will only be made available to project team members named on the application form and who have signed the licence agreements.

Step 7: Analysis

All primary data analysis will be carried out within the ADRC–NI secure environment. Researchers accessing data within NISRA's secure environment will be supervised at all times by the NISRA support team. The support team will also be available for help and advice.

In some circumstances, arrangements can be made to run analyses remotely: in this case the researchers provide code by email to the NISRA support team (rsu.nisra@dfpni.gov.uk) and statistical disclosure policy surrounding outputs will still apply. The data analysis software packages that are currently available are: SPSS, STATA, MLWin, R and Microsoft Office.

Outputs from these analyses will be assessed for statistical disclosure before being released from the secure environment (via email) by the ADRC-NI support team.

Step 8: Accessing outputs

Intermediate Outputs: outputs which are used solely by the research team for the purposes of discussion of results and writing up results outside of the secure environment and not to be shared beyond the named researchers on the project application form

Outputs from analyses will ONLY be released from the secure environment (via the organisation email on the application form) once the necessary disclosure assessment has been conducted and it has been concluded that it is safe to do so. These outputs will be cleared by the NISRA support team in accordance with the ADRC-NI Disclosure Control Procedure.

Current ADRC-NI guidelines stipulate that a frequency of 10 is the minimum count permissible in any outputs which is to be removed from NISRA's premises under the organisation's data management policy. Intermediate outputs cannot be shared with any other individual(s) or organisation(s) not named on the approved ADRN application and licence agreements. Current guidelines allow a maximum of 5 working days for clearance of all intermediate outputs.

Final Outputs: outputs which can be disseminated beyond the research team and are considered to be safe from disclosure risk. Examples of final outputs are working papers, reports or journal articles intended for publication, presentations or abstracts.

To disseminate ADRN results beyond the named project team (named in the application form and licence agreements) you must obtain clearance from the ADRC-NI. These will be circulated to the Data Custodians to ensure they are prepared for any publicity or media activity that may arise. This clearance reduces the risk of disclosure and ensures that the ADRC-NI and data are properly described, the data have been used appropriately and the approved acknowledgement is used.

Current ADRC-NI guidelines allow a maximum of 20 working days for clearance of all final outputs, with the exception of conference/journal abstracts, for which 5 working days are required.

Researchers must notify the ADRC-NI when a presentation/publication has been delivered or published as a list of all ADRC-NI related presentations and publications is made available on the ADRN website as part of our commitment to transparency and public engagement. Researchers must engage with the ADRC-NI Public Engagement and Communications Officer (PECO) will help produce a project summary which will be published on the ADRN website.

The research team will also be asked to contribute details of outputs to the ResearchFish reporting system.

Step 9: Project completion and Data deletion

When a project has been completed, data will be deleted under the terms set out in the data sharing agreement. At this point contributions to the ADRC-NI metadata or code repositories from the project will be collated. The ADRC-NI Public Engagement and Communications Officer (PECO) will engage with the researcher to help produce a two page lay summary which will be published on the ADRN website.



Document Management

Access Limitations:	None
Maintainer:	Linda Keys
Document Identifier:	ADRCNI011
Replaces:	
Review period (months):	6 months
Is related to:	ADRCNI007, 008, 009, 010

Version History

Version	Notes	Last Amended
	SLWG Operations Group	24/02/2015
00.01	Created by Linda Keys, Date	20/11/2014