



NILS-RSU

NORTHERN IRELAND LONGITUDINAL STUDY
RESEARCH SUPPORT UNIT

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Northern Ireland Longitudinal Study: A Guide to Completing the NILS/NIMS Application Form

NILS Working Paper 2.1

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NILS Research Support Unit



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1. Introduction

The Northern Ireland Longitudinal Study (NILS) and the Northern Ireland Mortality Study (NIMS) have been available since 2006 and are innovative research resources which allow for the exploration of health and socio-demographic characteristics of the Northern Ireland population. Please refer to [NILS Working Paper 1.0: The Northern Ireland Longitudinal Study – An Introduction](#) and the [NILS Cohort Profile](#) for more detail on the structure of the NILS and NIMS databases and available variables.

The NILS also offers a unique opportunity to link to administrative datasets (using one-way encryption methodology to ensure confidentiality) for specially defined one-off studies through the Distinct Linkage Project (DLP) process. These are subject to additional legal and ethical scrutiny and privacy protection protocols. Examples of successful linkages thus far include NILS and cancer screening, cancer registration, prescribing and dental services data. The success of these projects has increased the interest from the research community in the use of service provider data in the NILS environment.

All researchers wishing to access NILS/NIMS data must go through a project approvals process to gain access to a NILS/NIMS project dataset which requires the completion of a NILS NIMS Application Form.

The NILS-Research Support Unit (RSU) is committed to assisting researchers at all stages of the approvals process to provide advice and ensure minimum delays. All types of applications are welcome but in order to gain approval it is strongly recommended that potential researchers complete clear and well-designed research proposals and follow the guidance provided in this document.

2. The NILS Application Process

2.1. Formulating Your Research Proposal

Researchers should contact the RSU to discuss whether their research question of interest can be explored using the NILS/NIMS databases. The RSU is happy to provide feedback by email or telephone or to facilitate a meeting to discuss the feasibility of a potential NILS project.

If a researcher intends submitting a Distinct Linkage Project (DLP) they should also meet with RSU to discuss the feasibility of the proposed project.

In the event that a project is considered complex a meeting will be arranged between the researcher, a member of RSU and a member of Data Integration and Linkage (DIAL) team. The guidelines which indicate when a project may be deemed complex are:

- Does the proposed project intend to create novel linkages i.e. that have not been performed for previous NILS projects?
- Does the proposed project intend to use novel manipulation, methodology or technology that requires DIAL involvement for its implementation?

At the meeting RSU will take the lead with DIAL involved in the discussion where it relates to the proposed linkage and data processing. A note of the meeting will be recorded by RSU and all further contact will be between the researcher and RSU.

Researchers must then begin completion of the NILS/NIMS Application Form.

2.2. Agreement in Principal from Data Supplier (DLP only)

Researchers should contact the Data Custodian (of the data that they propose is linked to the NILS/NIMS) to get agreement in principal that they would sign the Data Transfer Agreement should the project become finalised. A letter of support from the Data Supplier is required to be included with the Final Application.

2.3. Completion of NILS/NIMS Project Application Form

Section A1: Application Details

- Study Title: the longitudinal aspect of the project should be included.



- b. Start/End Dates: projects must have realistic start and end dates which should include an additional timeframe for optimism bias: these can only be amended at a later stage in exceptional circumstances. In the case of a DLP Project, this end date is final and no extension can be granted unless agreed with the external data supplier in exceptional circumstances.

- c. Chief Investigator/Applicants: access to the research dataset and outputs will be restricted to named project team members on the application form. Should further researchers need access to the NILS project or any of the intermediate outputs, this can be achieved through a project modification.

Section A2: Background and Aims of the Study

- a. Project Summary/Abstract: this should be a concise overview of the project: a structured abstract with a clear overall aim, followed by specific research objectives, is preferred – this will be included on the RSU website after the project has been approved.
- b. Relevance of the Research Proposal to NILS: the project should: have a longitudinal aspect, illustrate how the NILS is uniquely placed to contribute to the study and indicate the researcher's understanding of how the NILS might help answer the research question. There is a hyperlink provided within the Application Form at this section, which will direct you to the Research Approvals Group (RAG) guidance paper on this topic. The researcher must also state their knowledge of the research that has been undertaken in their field of research and how their study aims improve understanding.
- c. Relevance of the Research Project to Health and Social Care (HSC) research and support for the development/delivery of public policy: the project should provide clear evidence of the value to HSC-related research and specific policies (this is based on the [World Health Organization's 'social determinants of health'](#) model which broadly defines health as a state of complete physical, mental and social well-being). The project should also provide specific information on how the project will support the development or delivery of public policy, public service or serve the public good. There is a hyperlink provided within the Application Form at this section, which will direct you to the RAG guidance paper on this topic.
- d. Prior Experience of Researcher: the researcher should demonstrate their experience or understanding of using longitudinal data or other potentially disclosive microdata. For any DLP application this section should also demonstrate their experience of using the **new data to be linked**.
- e. Planned Publication and Dissemination of Findings: the researcher should consider who the stakeholders are for dissemination (including local Northern Ireland policy-makers, national and international audiences). Key stakeholders should be named and researchers should also refer to policy documents, service frameworks or strategies that are relevant. Researchers need to emphasise both the benefits of their research for policy, and the direct implications for public health, as the NILS database is a publicly-funded research resource. Dr Elizabeth Mitchell¹ is the initial contact for researchers to approach for assistance in identifying appropriate policy representatives within the Department of Health, Social Services and Public Safety (DHSSPS) for NILS applications.

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Version 1.0

Section B1: Specifying Extract

- a. Dataset to be used: the researcher should specify whether their project intends to use the NILS or the NIMS. The NIMS dataset is of use in projects looking at mortality, especially those looking at rare causes of death, as it contains 100% of the enumerated population at the relevant Census. If a NILS project relies upon knowing whether there has been a death within a NILS members' household, it may be possible to link the NIMS deaths to the NILS data, but sufficient justification would need to be provided by the researcher for this to occur.
- b. Study Population: The NILS core sample is based on demographic data from the Northern Ireland Health Card Registration system which can then be linked to Census returns, administrative data from various sources (such as births and deaths) and area-based contextual data.

Researchers need to clarify if they want to base their project on core NILS sample members from April 2001 onwards or just those with a Census link (it is recommended that researchers use all core NILS members to have the most representative sample group: this also enables analysis of the differences between those members with and without a Census link).

Researchers may also request an extract of the population at a certain time period: for example, requesting sample members from 2007 to 2010. It is also possible to request variables to assess the current status of a NILS member and so identify whether they are live, dead or have left the study within the duration of a project timescale.

Researchers may also want to consider excluding those in communal establishments from their study population (this includes residents in psychiatric hospital/home, general or other hospital, residential care home, nursing home, other medical or care homes, hostels for the homeless or prison). See Box 1.1 below for example descriptions of study populations.



Box 1.1: Examples of study populations

Description of the population selected for the study

(e.g.: all male NILS members aged 16 – 64 who have been live members of the NILS from 2001 – 2010, with 2001 Census links where possible)

<i>Core NILS members:</i>	<i>All people who were live in 2001</i> <i>All NILS members who have ever been live</i> <i>All NILS members who have ever been live between 2001 and 2010</i>
<i>Specific Gender:</i>	<i>Females</i> <i>Males</i>
<i>Age Groups:</i>	<i>Children aged under 10 at 2001</i> <i>People aged 15-44 between 2001 and 2010</i> <i>Adults over 40 at 2010</i>
<i>2001 Census enumerated only:</i>	<i>All records and a Census link for those who have one</i> <i>Only those with a Census link</i> <i>Only those with both a 2001 and 2011 Census link</i>
<i>Other: e.g. entered study in 2003</i>	<i>Who entered the study in 2003</i> <i>Who had a baby between 1997 and 2009</i> <i>Who moved within NI between 2001 and 2005</i> <i>Who have died since 2001</i>

- c. Estimated Sample Size: Projects must outline the size of the study sample (including any population subgroups of specific interest) by providing numerical estimates of the sample size. Samples of less than 500 individuals will be considered in detail by NILS support staff. Given the NILS/NIMS disclosure safeguards, research on such small samples are unlikely to be approved. Sample size estimates should be referenced/sourced. See Box 1.2 as an example below. There is a hyperlink provided within the Application Form at this section, which will direct you to the RAG guidance paper on this topic.

Box 1.2: Example of a sample size breakdown for analysis of the characteristics of people living in Neighbourhood Renewal Areas (NRA) in Northern Ireland who move address using the NILS database:

- i. the record population: all people living in NRAs in Northern Ireland at 2008 = 275,354
 - ii. NILS sample (c.28% of population) = c.77,000 members living in NRAs
- the event population: based on an estimated 8% of the population who move each year) = c.6,167 movers per year who live in NRAs

d. NILS Core datasets:

- i. Census data: Census data is available for the 1981, 1991, 2001 and 2011 Censuses. The data includes all the information received from the Census form, although specific justification would be needed for specific restricted variables.
 - ii. Vital events data: The Vital events data includes all data available on births and deaths. The death data links includes the cause of death information which would be of use in any mortality based study. The NILS attempt to link all births to the baby, the father and the mother. This means that research can be done on any of those three individuals. These vital events allow you to specify a time period for updates, however you can request to have all dates available if that is required.
 - iii. Other NILS data: This includes migration data which is received from the bi-annual NILS downloads from BSO. Again, data may be specified for a specific time period if required.
- e. Variables Required: researchers must list in detail all NILS variables that are required: details of each variable can be found in the NILS Data Dictionary. **Only variables that will be included in the finalised dataset should be included here.** Please refer to the following section for issues to take into consideration when assessing which variables to include.

Researchers must ensure that all restricted variables and/or others not discussed in the project description sections are justified for inclusion, for example, “SOA (i.e. Super Output Area geographic indicator) is required to determine area factors that relate to ...”.

The expectation is that the researchers should specify all the variables required at the outset in the initial application. However, variables new to the project can be added at a later date where sufficient justification is provided. In the case of a DLP there can be no amendments to add extra variables without having another Data Transfer Agreement being signed and gaining ethical approval for the amended application, delaying the project significantly.

- f. Derived Variables: researchers can request that RSU/NILS-Core process restricted/confidential or detailed variables before use. These can be used for example to assign a NILS member's current age or household Capital Value, re-categorise all causes of deaths or create a summary of all address changes to a NILS member.

Researchers must list all NILS/NIMS input variables required for derived variables in the section provided, for example XUPRN may be requested to create Capital Value as a derived value: however, any restricted/confidential variables will not be made available to the researcher in the finalised dataset. Requests for derived variables should be justified and explained fully including any calculations and category outputs.

- g. **Additional Information:** researchers may wish to have external data attached to their extract using variables that would not be normally available, for example linking data to specific event dates to identify flu epidemic. Researchers must clearly outline any requirements they may have in relation to attaching external data to their NILS data extract.

Researchers can routinely attach area-based data sources to their project dataset as standard at Super Output Area (SOA) or above, for example the [NI Multiple Deprivation Measures for 2005 and 2010](#). No further details are required about which area-based dataset need to be linked.

Section C1: Linking Individual Level Data (DLP only)

- a) **Describe the individual level data:** Researchers must describe the new individual level data that they propose is linked. This description should include information on the current Data Custodian and the data collection methodology.
- b) **Discuss the requirement for Individual level data:** Researchers should use this section to discuss the benefits of linking individual based data rather than area based data. This section should specifically relate to the Abstract outlined in Section A of the application form- detailing how linkage of additional individual level data would contribute to the achievement of the overall aims and objectives of the project.
- c) **Feasibility of linkage:** Researchers should describe how feasibility of the linkage has been explored. It should describe the suitability (for linkage at individual level) of the data in terms of coverage (of Health and Social Care Number) and data quality.
- d) **One Way Encryption Methodology:** The researcher must use this section to confirm that it is appropriate for the data described to be linked using the One Way Encryption Methodology. If the linkage of this dataset requires any deviations from the methodology described, the researcher must use this section to describe the preferred linkage methodology and why it would be preferable.
- e) **Legal Basis:** The researcher should use this section to provide an account of any discussion that has taken place regarding the legal framework for using the data in this way. In this section, the researcher should also state that the proposed project has the support of the Data Custodian. A formal letter of support should be requested from the Data Custodian and attached to the application.

2.4. NILS Variables: Issues for Consideration

Researchers should take into consideration:

- a. The use of area-based variables: data extracts can be supplemented by linking the Super Output Area (SOA) level geographical indicator, data from the Land and Property Services Northern Ireland properties database (based on the capital value of houses and property attributes) and urban/rural settlement classifications that are available in the NILS database. This data can be added to NILS members' current addresses (from the health card system) or addresses at any particular time point since 2001 (including their Census addresses). It should be noted that because low geographical levels may lead to low numbers of observations, they will require special attention in relation to issues of disclosure control and confidentiality. The area-based variables required must be listed in the variables table.
- b. The use of basic demographic variables: gender, age, time of death (month and year) and location variables are available for all NILS members (whether or not they have a Census link) from the Health Card Registration system. This source provides more comprehensive coverage than the Census data for NILS sample members. Failure to utilise this data from the Health Card Registration system may make NILS RAG approval of applications less likely.
- c. The use of Census variables: these are available from Person (individual level) and Household (household-level) tables in the NILS database. Researchers interested in household analysis may use the NILS anonymised household identifiers to test for variations within and between households. The Census data of people within the same household as a NILS member can be used for detailed household relationships/characteristics analysis as Census information is available for all members of households with at least one NILS member.

Researchers should assess how useful some Census variables will be, for example requesting the 'ethnicity' variable as there are very small numbers of 'non-White' individuals recorded in the 2001 Census in Northern Ireland.

Researchers can also make use of summary Census variables, for example include the variable which indicates a sample member's highest level of educational attainment rather than the separate educational variables which list each qualification held by an individual.

- d. The use of vital events variables: births and deaths data are registered by the General Registrar Office (GRO) and are published a year after registration, for example 2009 deaths will normally be finalised, quality assured and released to DIAL for matching by the end of 2010. There is normally a lag between the occurrence and registration of a vital event – this lag is often one/two months after a birth but can

extend over a much longer period of time in the event of deaths that are registered only after an inquest has concluded. It is recommended that researchers use date of occurrence, rather than registration, for the most accurate representation of events data. However this will mean that numbers for the most recent year do not include events occurring towards the end of the year but registered in the following year.

In relation to births data: researchers can request data on new members born into the NILS sample and births to existing NILS members (both mothers and fathers) – it is important to distinguish between using information on new NILS members added to the sample to estimate populations and using births to NILS members as contextual information.

- e. Address/migration data variables: researchers can obtain an indicator to flag people who move address, obtain a summative total of address changes, determine a NILS member's location at a certain point or points in time or access the origin and destination of a single migration move (this includes internal migration, immigrants, emigration and information on people who have re-entered Northern Ireland). There are two types of migration data (1) the continually updated Health Card Registration system address changes and (2) those who change address one year prior to Census - derived from Census data.

Box 1.3: Example of variables required to identify location of a NILS member at a certain time point

Table: Address_History: to show address changes and locations at a point in time

Variables:

1. Source - this will give information on which download date an address change occurred and is used to assign the SOA for a particular time-point in the study, for example each sample member's address in 2005.
2. TYPE - this will be used to identify all movements that are due to actual Address Changes (AC = Address Change)
3. Current_Flag - this will determine if an address at a certain time point is the current address for panel member.
4. SOA2001 - this will be used to assign an SOA classification for every address

Box 1.4: Example of variables required to look at migration events (including origin and destination of move)

Table: Migration_Events: to look at the origin and destinations of moves

Variables:

1. DateMoved – date of migration event
2. ChangeType - different migration types (AC = Address Change / IM = Immigrant ...)



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- 3. OUT_OF_SOA2001 – SOA person moved out of
- 4. INTO_SOA2001 – SOA person moved into
- 5. ORDER – order of migration event

2.5. Submitting Applications & Next Steps

- a. Researchers must submit completed applications to RSU who will pass it to the NILS Research Approvals Group (NILS RAG) for consideration.
- b. The NILS RAG will meet bi-monthly to consider applications for approval. NILS RAG will consider applications based on [15 criteria](#) (with an additional 3 criteria for Distinct Linkage Projects) which will determine if the project is approved. The NILS RAG assesses whether projects should be approved and may provide some advice on how projects could be improved or stipulate changes to be made.
- c. Researchers will be contacted by the RSU as to the outcome of their submission and will be advised to liaise with the RSU to discuss next steps.
- d. Researchers will have the right to appeal any decisions in relation to their application to the NILS Steering Group. All decisions taken in relation to unsuccessful applications will be fully documented.
- e. If a NILS/NIMS project is approved, all NILS Agreements must be signed by all project team members.
- f. The RSU will then generate a project specific dataset based on the details supplied in the application form. Agreed external data can also be linked at this point.

2.6. Office of Research Ethics Committees Northern Ireland (ORECNI) Database Amendment (DLP only)

- a. Once the DLP is approved, the ORECNI amendment to database application has been processed and the Privacy Advisory Committee has been informed all NILS Agreement and Policy Forms (licenses, security and disclosure) must be signed by the Chief Investigator and all other project team members.
- b. This form will be sent to NILS-RSU who will upload this onto the ORECNI website. Please note that NILS-RSU may amend the application on the researcher's behalf. Once uploaded NILS-RSU will arrange for the application to be printed and signed by the Registrar General and forwarded to ORECNI.
- c. The application will be reviewed by a Research Ethics Committee (REC) panel and the decision notified to RSU. The RSU will notify the researcher accordingly.

2.7. Next Steps (DLP only)

- a. The researcher should complete an electronic version of a “Notification of Substantial Amendment” form which will be supplied by RSU.
- b. The Project dataset will be prepared in conjunction with the Data supplier. Only variables listed in the Application Form (and agreed by ORECNI) will be provided.
- c. The researcher should conduct initial analyses to ensure that there are no errors and that the extract is as expected.
- d. The Data Transfer Agreement is drafted using the application as an annex to specify the exact data to be transferred. This includes a copy of the legislation that permits the transfer of data to the NILS/NISRA and must be signed by a senior person on behalf of the Data Custodian.

3. Further Information

NILS Research Support Unit

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