



The Northern Ireland Longitudinal Study – An Introduction

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NILS Research Support Unit

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1. Introduction

The Northern Ireland Longitudinal Study (NILS) is a large-scale, representative, data-linkage study of c. 28% (approximately 500,000 people) of the Northern Ireland population. The NILS has been created by linking demographic data from the Northern Ireland Health Card Registration system to the 2001 Census returns and to administrative data from various sources. These include vital events registered with the General Register Office for Northern Ireland and Health Card Registration system migration events data. There also exists a second study, the Northern Ireland Mortality Study (NIMS), which is based on the 2001 Census returns for the whole enumerated population (approximately 1.6 million people) to which subsequent registered deaths are linked.

Both the NILS and the NIMS can be supplemented by linking the Land and Property Services Northern Ireland properties database data (based on the capital value of houses and property attributes), geographical indicators and contextual area characteristics such as settlement classifications¹ and deprivation measures² supplied by the Northern Ireland Statistics and Research Agency (NISRA).

The NILS and the NIMS have been available since 2006 and are innovative research resources which allow for the exploration of health and socio-demographic characteristics and, as such, can be used to provide an insight into the status of the Northern Ireland population. The NIMS is recommended for researchers or analysts whose primary interest is in mortality-related research as it allows focus on more detailed analyses of specific sub-populations and causes of death. Both studies are designed for statistics and research purposes only and are managed by NISRA under census legislation. The infrastructure is funded by the Health and Social Care Research and Development Division of the Public Health Agency (HSC R&D Division) and NISRA. The support function is funded by the Economic and Social Research Council (Census of Population Programme Award Ref: RES-357-25-001) and the Office of the First Minister and Deputy First Minister for Northern Ireland.

The NILS is very similar in design to both the Office for National Statistics Longitudinal Study (ONS-LS) for England and Wales, established in 1971, and the Scottish Longitudinal Study (SLS), made available in 2006. The three UK longitudinal studies have comparable aims in that they promote the development of our understanding of population dynamics. This also provides the potential for undertaking UK-wide longitudinal analysis in the future. However, there are some differences between NILS and both the ONS-LS and SLS which are discussed in more detail in latter sections.

1.1. Why were the NILS and NIMS set-up?

The NILS and the NIMS have been developed to allow investigation of the changing profile of population characteristics unique to Northern Ireland. For instance, Northern Ireland has traditionally had the highest rates of fertility and currently has the fastest growing and youngest population within the UK³. It is also one of the most deprived areas in the UK and, until fairly recently, has consistently had the highest rates of unemployment and long-term unemployment, and the lowest

proportions of the economically active working-age population, of any of the regions within the UK⁴. In addition, Northern Ireland experiences some of the poorest levels of health in the UK⁵. Current legislation and government policies on targeting social need, such as the Northern Ireland Anti-Poverty Strategy⁶ and monitoring and targeting tools, like the Northern Ireland Multiple Deprivation Measure², are a response to such inequalities.

Available data from cross-sectional studies, such as surveys of poverty and social exclusion, can provide good information about the condition of people at a particular point in time but they cannot provide insight into change over time. The NILS helps to address the need for information about disadvantage and inequalities across the lives of individuals and allows for changing circumstances to be investigated. This is of particular importance given the contemporary increase in social and geographical mobility. The NILS and the NIMS are designed to be multi-cohort, longitudinal studies that can fulfill a range of public policy related purposes, with sample sizes large enough to enable robust analysis of population sub-groups and of low-level geographical areas.

1.2. What are the NILS and NIMS?

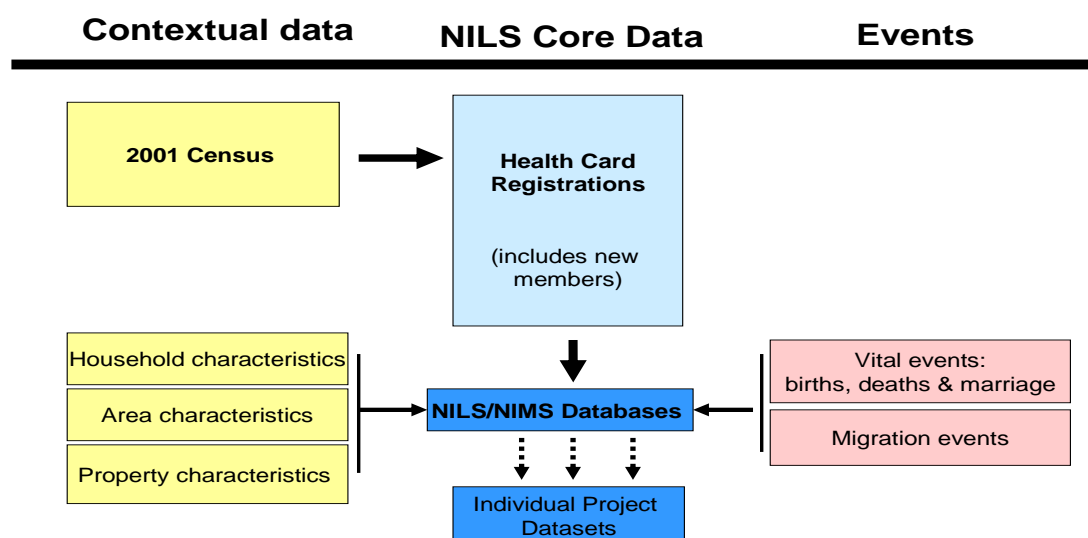
The NILS and the NIMS, like the ONS-LS and SLS, are based on collections of data from routine administrative sources such as census and registration systems. As a result, attrition rates are extremely low and linkage rates for events tend to be very high.

The NILS members provide a c. 28% representative sample of the Northern Ireland population and were initially selected from live records from the Northern Ireland Health Card Registration system on the 2001 Census Day (29 April). In contrast, the ONS-LS and SLS use census population data linked to the National Health Service Central Register to define their cohorts.

The NILS members are then matched to the 2001 Census records which include a large range of information including demographic, socio-economic, self-reported health, housing and household and family structure data. Census information is also available for all members of households with at least one NILS member. The NILS members are subsequently linked to updated migration and vital events data - see Figure 1 for the structure of the NILS database.

The NIMS comprises the population enumerated at the 2001 Census (approximately 1.6 million people), to which deaths registered to NIMS members are linked. The only linkage is to mortality records and the larger cohort size enables more robust examination of specific mortality sub-populations and of causes of death (where accumulated deaths may be too small to explore within the NILS sample).

Figure 1: Structure of the NILS



2. The Methodology

2.1. Selection of the NILS sample

The NILS sample of c. 28% of the Northern Ireland population (approximately 500,000 people), which includes c. 50% of households, is proportionately larger than those of the SLS and ONS-LS (at 5.3% and 1% of the Scottish and England & Wales populations respectively). As with the ONS-LS and the SLS, inclusion depends on an individual's day and month of birth. While the ONS-LS uses four birthdates, and the SLS is based on 20 birthdates, the NILS includes individuals on the basis of 104 birthdates (these incorporate the four birthdates that define entry to the ONS-LS, which are also included in the SLS, providing the potential for future analysis of a unified UK longitudinal sample).

The overall annual rate of population increase in Northern Ireland in recent years (from 2005-06 to 2007-08) equates to an average of 16,800 people each year⁷. The NILS is a dynamic database which is continually updated and is also increasing, by approximately 12,000 (2.3%) per year. This includes the initial cohort of NILS members from the Health Card Registration system and, in addition, all new sample members who have since joined the study (if they have since either been born in, or immigrated into, Northern Ireland and have one of the 104 NILS birthdates).

2.2. The role of the Health Card Registration system

The Health Card Registration system, owned and managed by the Health and Social Care Business Services Organisation (formerly the Central Services Agency), is a database of all people registered for health services in Northern Ireland, including those who migrate into and out of Northern Ireland. Each individual record contains the person's age, sex and home postcode, enabling counts of registered people by age and sex to be constructed for any specified geography. Health Card Registration

system data (name, date of birth, sex and address) are used as the core of the NILS sample.

The principal strength of the system for demographic analysis is that the data allow the construction of a population profile by single year of age and sex for the entire Northern Ireland population. The database can also be used to estimate migration levels (within Northern Ireland, within the UK, to and from the Republic of Ireland and with the rest of the world) via statistics on the changes accruing within the system. Some limitations can arise from employing this methodology, for example the general problem of list inflation where records continue to exist on the registration system for individuals who no longer exist in Northern Ireland.

The 2001 Census published figure of the NI population is 1,685,267. This is 83,206 lower than the 1,768,473 patients registered on the health card system in May 2001, representing an overall list inflation rate of 4.7%. The NILS live sample cohort of 508,279 represents approximately 28% of Health Card Registrations and thus includes an estimated 23,914 records of people who ought not to be on the register and therefore cannot have a 2001 Census record match.

Overall, the Health Card Registration system data are arguably a more robust source for basic demographic data for the NILS database as the census data are only captured once and in 2001 depended on accurate interpretation of electronically scanned census forms.

2.3. Data matching and linkage

NIMS

The NIMS comprises 100% of the population enumerated at the 2001 Census (1,603,641 people), to which deaths are linked from General Register Office for Northern Ireland's (GRONI) data. The overall rate of linkage between mortality data and the 2001 Census for the first five years was 94%. Non-linkage was primarily due to non-enumeration in the Census, people who came to Northern Ireland and subsequently died and to differences between the information collected on the census form and the death certificate. Further information is available on the potential biases arising from the non-linkage of census records to deaths⁸.

NILS

As NILS sample members are subsequently linked to census records, census under enumeration will have an impact on linkage rates. The 2001 Census aimed to provide essential statistical information about the total population and One Number Census methodology⁹ was employed throughout the UK to produce detailed robust estimates of underenumeration for complete coverage of the population. The people estimated as not counted were imputed to produce an adjusted total on which the final census results were based. Census imputation varies by age, gender and geographical area, for example it is thought to disproportionately affect younger adult males from deprived inner city areas¹⁰.

The number of actually enumerated people in the 2001 Census in Northern Ireland was 1,603,641 with an additional 81,626 people imputed to provide an overall total of 1,685,267. This represents an overall imputation rate of 4.6%. Within the NILS sample of 508,279 members, approximately 23,460 are estimated to have been alive and resident in the country on enumeration day, but were not counted in the 2001 Census and therefore cannot be linked to census returns.

For NILS sample members who can be linked to the 2001 Census records, and subsequent migration and vital events data, a three-stage matching process is used:

- (1) exact computer matching is undertaken which identifies all records with no discrepancies between individual characteristics;
- (2) fuzzy computer matching is performed which allows for less strict matching on those records with largely similar, but not identical, characteristics. This is verified through a process of manual clerical assessment; and
- (3) detailed manual searching takes place for those sample members whose records are not matched in the first two stages.

This matching process is outlined in more detail below.

Step 1: Identifying the sample.

The 104 birthdates, distributed across the year, were chosen to provide a c. 28% sample of the population. The sample is drawn from the Health Card Registration system data.

Step 2: Linking Census records to NILS sample members.

Demographic data from the Health Card Registration system are matched to the 2001 Census returns. Clearly, Health Card Registration data cannot be linked to a census record for those who were not enumerated.

Step 3: Linking vital events and migration data to NILS sample members.

Vital events can be linked to Health Card Registration data even if there is no census record.

- a) Births and deaths to and from the NILS sample: exact matching is undertaken linking the Health Card Registration record to the GRONI birth or death record using demographic details such as forename, surname, sex, date of birth and address.
- b) Births, stillbirths and infant deaths to NILS mothers and/or fathers: there will be no indicator on the Health Card Registration system that a mother and/or father experienced any of these events and therefore matching is undertaken using the GRONI record of such events for women (aged 15 to 49) and men (aged 12 to 80) and linking to the Health Card Registration record using demographic details as before.

- c) Marriages to NILS sample members: the Health Card Registration record is linked to the GRONI marriage record using demographic details as before.
- d) Widow(er)hoods: as there is insufficient information on a spouse recorded on the GRONI death records, the widow(er)hood data is linked by extracting the GRONI death link from the NIMS for those who were married to a NILS member at the time of the 2001 Census.
- e) Migration: data from the Health Card Registration system provides information on change of address for NILS sample members – data are generated from regular six-monthly downloads comparing current to previous address.

2.4. Data included in the NILS and the NIMS

A variety of administrative and statistical datasets are linked in the NILS and the NIMS databases. Most of the socio-economic data come from the 2001 Census returns which include a wide range of demographic, housing, employment and social variables. For the NIMS resource, census returns of those enumerated in the 2001 Census are subsequently linked to the GRONI death records. For each individual included in the NILS sample the census information recorded for other members of the household is also available.

NILS sample members are also linked to vital events data, such as births and deaths, which are available from 1997 to 2007 (births) and from 2001 to 2007 (deaths) and further possible linkages, not currently routinely linked for the same time period, include; infant deaths to NILS members, infant deaths of NILS members and stillbirths to NILS members. Marriage legislation in Northern Ireland was changed in 2004 and from this date data are available to facilitate linkage to marriages of NILS members. Marriage datasets have been linked for the period 2004 to 2006 and there is potential to link to more updated marriage data based on research demand. Widow(er)hood datasets have also been linked for the period 2001 to 2006; these linkages can also be routinely updated depending on researchers' needs.

Health Card Registration system data currently provides demographic and migration information from 2001 to 2010. This includes immigrants added to the sample, emigration of sample members, re-entry of sample members after previous emigration and migration within Northern Ireland to sample members.

The data currently included in the NILS database are described in Table 1 below. Detailed information on the variables held in the NILS is available in the Data Dictionary which can be found online at <http://www.nils-rsu.census.ac.uk>.

Table 1: Data Currently Held in the NILS

Census Data 2001	GRO Vital Events Data 1997-2007
<p>Variables include:</p> <ul style="list-style-type: none"> ▪ Age, sex and marital status ▪ Religion and community background ▪ Family, household or communal establishment type ▪ Housing, including tenure, rooms and amenities ▪ Country of birth, ethnicity ▪ Educational qualifications ▪ Economic activity, occupation and social class ▪ Migration (between 2000 and 2001) ▪ Limiting, long-term illness, self-reported general health, caregiving ▪ Travel to work <p>This data is available for NILS members and for all members of households with at least one NILS member.</p>	<ul style="list-style-type: none"> - New births into the sample - Births to sample mothers and fathers - Stillbirths to sample mothers (on demand) - Infant mortality of children of sample mothers and fathers (on demand) - Deaths of sample members 2001-2007 - Marriages 2004-2006 - Widow(er)hoods 2004-2006 <p>Variables include:</p> <ul style="list-style-type: none"> ▪ Births datasets: parents' duration of marriage, employment and occupation status, age, social class, address, age, marital status, previous births, month and year of occurrence and registration, place of birth and sex. ▪ Deaths datasets: age, address, month and year of occurrence and registration, employment status, occupation code, social class, marital status, main cause of death, place of death.
LPS Property Data 2010	Health Card Registration Data 2001-2010
<p>Capital and rating value (based on 2005 valuation exercise)</p> <p>Variables include:</p> <ul style="list-style-type: none"> ▪ Household characteristics (no. of rooms, property type, floor space, central heating) ▪ Estimated capital value 	<ul style="list-style-type: none"> - Demographic data: age, status and location - Migration events: <p>Variables include:</p> <ul style="list-style-type: none"> ▪ Immigrants added to the sample ▪ Emigration of sample members ▪ Re-entry of sample members to Northern Ireland after previous emigration ▪ Migration within Northern Ireland of sample members

Contextual and geographical indicators can also be linked to the NILS and NIMS databases including urban and rural settlement classifications¹ and deprivation rankings² and analysis can be performed at a number of geographical, such as Super Output Areas (c. 2000 population). However, because low geographical levels may

lead to low numbers of observations, they may require special attention to issues of disclosure and confidentiality.

2.5. Maintenance and vital events updates

The maintenance work on the NILS involves bi-annual event updates (in April and October), maintenance of the servers and closed network, management of the researcher secure setting and ensuring that the process of routine data back-ups is managed effectively.

GRONI vital events data and Health Card Registration migration data are downloaded to the NILS database on a six monthly basis. See Table 2 for an overview of data files downloaded and matched to the NILS database.

This equates to the following:

- Health Card Registration data: each data file is received in a raw state, downloads are created, the files are transferred to the Health Card Registration database and the linkage identifier updated with the new data. All raw text files are cleaned-up/deleted. For migration data, current address is checked with the latest version of the address referencing system, new address change records are created and administrative geographies attached.
- Vital events: data files are received from GRONI, required information identified and added to the NILS sample database.

The matching process includes the following:

- Prepare both sets of data.
- Create and run matching queries.
- Accept exact matches.
- Create screens for manual confirmation.
- Manually confirm/refute fuzzy matches.
- Create screens for manual searches.
- Clerical searching for unmatched records.
- Check for duplicates and resolve.

Table 2: Data Files Downloaded and Matched on the NILS and NIMS Databases

Data Files Downloaded and Matched

NIMS:

- Deaths to 2001 Census.

NILS:

- Health Card Registration data downloads to 2001 Census.
 - Births to Health Card Registration database.
 - Mothers who had birth event to Health Card Registration database.
 - Fathers who had birth event to Health Card Registration database.
 - Mothers who had stillbirth event to Health Card Registration database (on demand).
 - Infant deaths of babies to Health Card Registration database (on demand).
 - Mothers who had infant death event to Health Card Registration database (on demand).
 - Fathers who had infant death event to Health Card Registration database (on demand).
 - Deaths to Health Card Registration database.
 - Marriages to Health Card Registration database (on demand).
 - Widow(er)hoods to Health Card Registration database (on demand).
 - Sample members' addresses to POINTER database (assigns the Unique Property Reference Number, UPRN, to each address enabling links to the relevant Super Output Area) then to Land and Property Services properties database.
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3. Confidentiality

The NILS and NIMS are large and complex databases which include a range of personal and sensitive information about individuals as defined under the Data Protection Act.

NISRA takes extreme care to maintain the confidentiality of individual-level information. This confidentiality is protected by statute (1991 Census Confidentiality Order) and those handling individual level data must sign a census confidentiality undertaking. This requires those who handle census data to never knowingly disclose

information on individuals. Failure to adhere to these undertakings can lead to criminal prosecution under the Census (Confidentiality) (Northern Ireland) Order 1991. Therefore NISRA staff are duty bound to avoid knowingly releasing identifiable individual-level information into the public domain.

The Information Commissioner for Northern Ireland, the Office of Research Ethics Committees for Northern Ireland (ORECNI) and the Department of Health, Social Services and Public Safety Privacy Advisory Committee have all been consulted about the NILS and the NIMS. The NILS and the NIMS databases have received ethical approval from the ORECNI for all research on migration, fertility, mortality and inequalities. In order to protect individual information, and to adhere to the legislation regarding the protection of individual data, the NILS has strict controls on the storage, processing and analysis of the NILS data – see Appendix A.

4. Research Opportunities

The NILS and NIMS research resources will be of interest to a diverse variety of researchers and policy-makers UK-wide and can be used in areas such as equality analyses, population trends, mortality studies, the impact of new public health policies and the planning of services.

The availability of linked census information relating to a large sample of the population - including demographic, socio-economic, self-reported health, housing, household and family structure data - has proven a rich source of data for research. For each individual included in the sample the 2001 Census information recorded for other members of the household is also available, allowing the detail of the household context to be used. Also included are related vital events (non-census based events such as migration history and deaths and births) occurring to NILS sample members.

Data on housing attributes unique to NILS members are available from the Land and Property Services Northern Ireland properties database which also provides information on the estimated capital value of the residential properties (as part of a valuation exercise undertaken in 2005). In addition, area-level, contextual data can be also be included for analysis, for example settlement classifications¹ and deprivation rankings².

The NILS Research Support Unit (NILS-RSU) provides information and advice for potential academic and government users of NILS or NIMS. Anyone wishing to use NILS or NIMS data should contact the NILS-RSU who will help define the project, select the appropriate variables for research and assist in the completion of an application form for submission to the Research Approvals Group. Once the project has been approved, NILS-RSU will set up a user dataset and can assist with required training, analysis and interpretation of the results, information on the data, further data requests and the management of outputs by researchers.

For examples of research produced using the NILS and NIMS resources please refer to the publications section of the NILS website at: <http://www.nils-rsu.census.ac.uk>.

Links to research outputs from projects based on the ONS-LS and SLS databases are also available here.

5. Funding

Funding for the establishment and maintenance of the NILS and the NIMS databases was jointly secured in 2003 from the Department of Health, Social Services and Public Safety (DHSSPS) and the Research and Development Office of the then Health and Personal Social Services (HPSS). All funding for the development and maintenance of the NILS and NIMS now comes from the Health and Social Care Research and Development Division of the Public Health Agency (HSC R&D Division). NISRA helps to fund the NILS/NIMS project through the provision of accommodation to facilitate data processing by the NILS/NIMS Core Team and a secure data setting for researchers. NISRA also provides IT infrastructure and supports the strategic management of the project. In 2007, the HSC R&D Division, in conjunction with the Economic and Social Research Council (ESRC), provided a one-off funding opportunity for a series of research projects to utilise NILS/NIMS databases and support public health policy.

More recently, in 2009, the ESRC funded the NILS Research Support Unit (NILS-RSU) to provide a support service for the NILS and NIMS studies (see section above for more details). The NILS-RSU is now part of the ESRC-funded Census of Population Programme (Award Ref: RES-357-25-001). The Equality and Social Needs Steering Group of the Office of the First Minister and Deputy First Minister for Northern Ireland (OFMDFMNI) have also committed to support the NILS-RSU to assist government researchers and to undertake exemplar public policy research on the NILS.

6. Conclusion

The NILS and NIMS databases are a remarkable resource which will underpin a wide range of academic and policy-relevant research. They are designed to allow longitudinal analysis utilising both census and linked vital events data and other data collected for routine administrative purposes. It also has the capacity to link area level contextual data.

In order to comply with the legal requirements of our principal data provider, a key aspect of the remit of the NILS and NIMS studies is to provide a resource for health-related research, for both academic and government sectors, and to support the development and/or delivery of public policy. This is reflected in the criteria used by the Research Approvals Group to assess the suitability of proposed NILS projects. The term 'health' can be interpreted in terms of the World Health Organization's definition of overall well-being¹¹ and so is fairly broad in scope.

The longitudinal nature of the NILS and NIMS databases allows the changing circumstances of sample members to be explored through time; it is particularly valuable for event history analyses. Many social science and health-related research

questions cannot be adequately addressed using cross-sectional data. The ability to consider transitions into and out of different states, as well as the opportunity to tease out age, period and cohort effects, make the NLS and NIMS particularly valuable for researchers.

As a result of Economic and Social Research Council (Census of Population Programme Award Ref: RES-357-25-001) and Northern Ireland Government funding, the NLS-RSU is available to provide support for users from government and academia. In this role the NLS-RSU can provide expert advice on proposed projects and help with undertaking the research.

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Appendix A: Controls on Storage, Processing and Analysis

- The NILS is based on individual-level data for a sample of 104 birthdates. Only the small group of NILS staff who are responsible for maintaining the NILS Processing Database know what these dates are.
- Once all initial linking and matching of the various sources is completed the dataset is anonymised, all identifying features are removed to create a Research Database. Researchers and Research Support personnel only have access to the NILS Research Database only and not the NILS Processing Database.
- Staff in the NISRA building are required to wear a security pass, bearing their photograph and personal details, at all times. Visitors wear easily identifiable passes and are required to be escorted in the building at all times. The anonymised NILS datasets, set up for research projects, are held on an isolated network which has no internet or email access. Access to the network is strictly controlled by NILS staff who assign usernames and passwords to authorised users. Access to the NILS network is available only within the NILS secure setting and the NILS processing room. Optical media are not permitted in the secure setting and portable data storage ports on all PCs used by researchers and NILS-RSU staff have been disabled. Access to both rooms is restricted via a keypad.
- The creation, maintenance and use of the NILS is overseen by the NILS Steering Group and every proposed project is considered by the NILS Research Approvals Group (RAG). Each project is assessed against 15 criteria, which determine whether access to the requested NILS data is authorized. No projects are permitted which may potentially allow individuals to be identified by deduction or inference.
- Once a project has been approved by the RAG, access to the research data is strictly controlled. Access by researchers to the full, core database is not permitted. No data are available through any of the academic data archives and individual-level raw data are not released. Instead, a subset of the data, incorporating the variables specified in the approved research application, is created for each project. The researcher can only analyse the dataset within the NILS safe-setting environment, with project-specific access and under supervision by the NILS Research Support Unit (NILS-RSU) staff.
- Researchers cannot extract information to be taken away from the secure-setting. Once a researcher has created their aggregated outputs they are checked for disclosure by the support personnel. Only outputs that pass the disclosure thresholds specified in the NILS Disclosure Control Protocol may be transferred from the secure-setting of the NISRA building. The current

disclosure rule is that no tabulated cell counts of less than 10 are permitted to be taken from the secure setting.

- Policies for staff: all staff working on the NLS database have to sign several security and confidentiality agreements. The basis for these documents is the Census (Confidentiality) (Northern Ireland) Order 1991 which makes it an offence to knowingly disclose personal information held for Census purposes. All staff are trained in disclosure control methods and data handling / protection issues.
- Policies for researchers: additional to the access controls noted above, researchers must sign and abide by a user license, outlining their adherence to the disclosure control and security policies. This license must also be signed by someone with authority from the researchers' institution.