



NILS-RSU

NORTHERN IRELAND LONGITUDINAL STUDY
RESEARCH SUPPORT UNIT

Northern Ireland Longitudinal Study Research Support Unit Mid-Year Report 2024/25

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NISRA

Northern Ireland
Statistics and Research Agency
Gníomhaireacht Thuaisceart Éireann
um Staitisticí agus Taighde



Queen's University
Belfast



Economic
and Social
Research Council

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1. Background

The Northern Ireland Longitudinal Study (NILS) has been formally available to researchers since the end of 2006. It comprises two major data linkage studies: the NILS and the Northern Ireland Mortality Study (NIMS). The NILS and NIMS are designed for statistics and research purposes only and are managed by NISRA under Census legislation. The data are de-identified at the point of use; access is only from within a strictly controlled secure environment and governed by protocols and procedures to ensure data confidentiality.

The NILS is a large-scale, representative data-linkage study created by linking data from the Northern Ireland Health Card Registration System (Business Services Organisation) to the 1981, 1991, 2001, 2011 and 2021 Census returns and to administrative data from other sources. These include vital events registered with the General Register Office for Northern Ireland (such as births, deaths and marriages) and the Health Card Registration System migration events data. The result is a 40 year plus longitudinal data set which is regularly being updated. In addition to this rich resource, there is also the potential to link further Health and Social care data via Distinct Linkage Projects (DLPs).

The NIMS is a large-scale data linkage study that links the 1991, 2001, 2011 and 2021 Census returns for the whole of the enumerated population (approximately 1.87 million individuals) to subsequently registered mortality data from the General Register Office (GRO). While larger than NILS, it is more limited in scope, focusing only on the linkage of mortality data. The NIMS dataset is recommended to researchers whose primary interest is in mortality in Northern Ireland.

The NILS and NIMS are powerful research resources which allow exploration of health and socio-demographic characteristics. The data is of interest to a diverse variety of researchers and policy-makers UK-wide and can be used in areas such as equality analyses, demographic trends, mortality studies, the impact of policies and the planning of services.

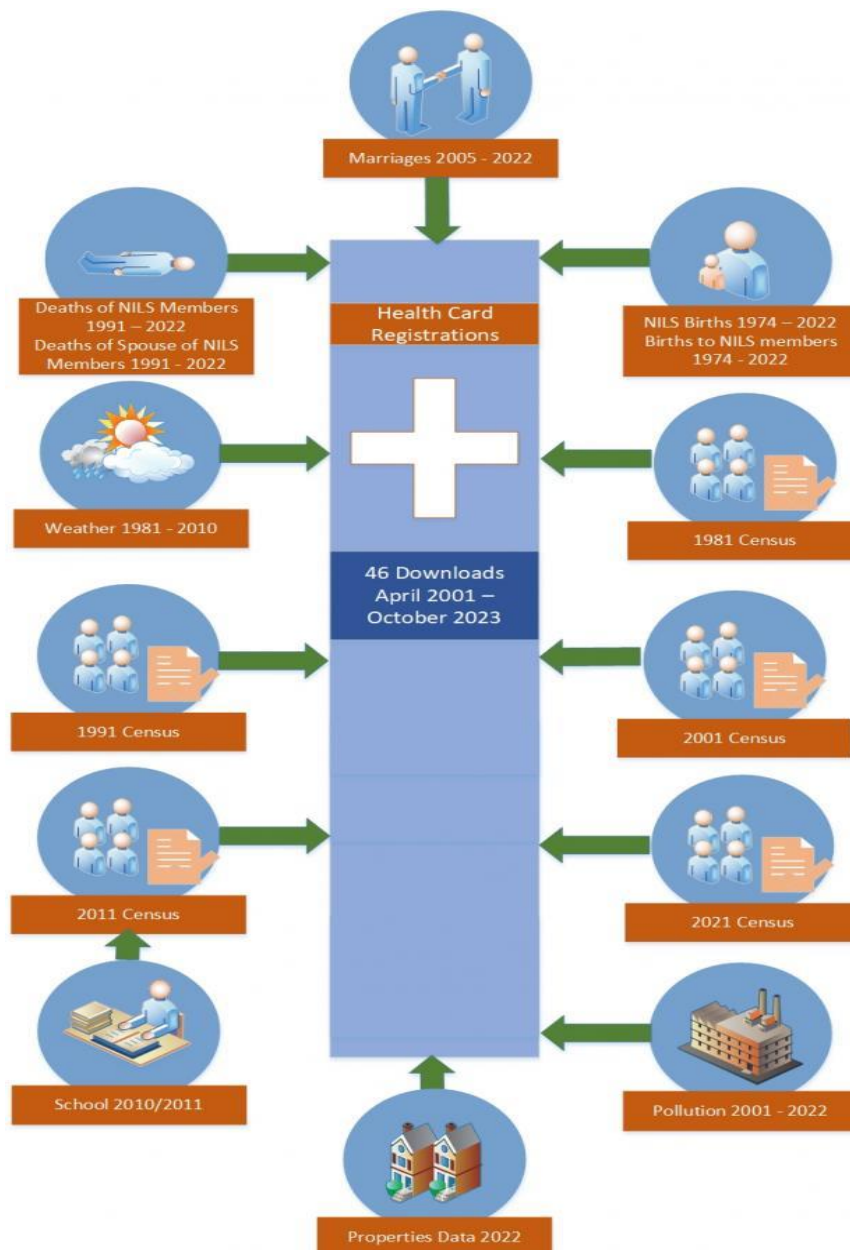
The NISRA Research Support Unit (RSU) is the support unit for the NILS and the ADRNI. Both functions are funded by the Economic and Social Research Council (ESRC) and are similar in nature.

This mid-year report describes the work of the RSU relating to the NILS from 1 April 2024 to 30 September 2024.

2. Current NILS Data Structure

The latest NILS database was released in April 2024. This was the first NILS release to include data from the 2021 Census. This release includes October 2023 data from the NI Health Card Registration System, Census data from 1981, 1991, 2001, 2011 and 2021, GRO Births data from 1974 to December 2022, GRO Deaths data from 1991 until December 2022, Marriages data from January 2005 to December 2022, Properties data based on July 2022 LPS and Oct 2023 Pointer data, Weather data from 1981 to December 2010, Pollution data from 2001 to December 2022 and School enrolment data for 2010/11. The NILS updates will be completed annually. The current structure of the NILS data is shown below.

Figure 1: NILS Data Structure



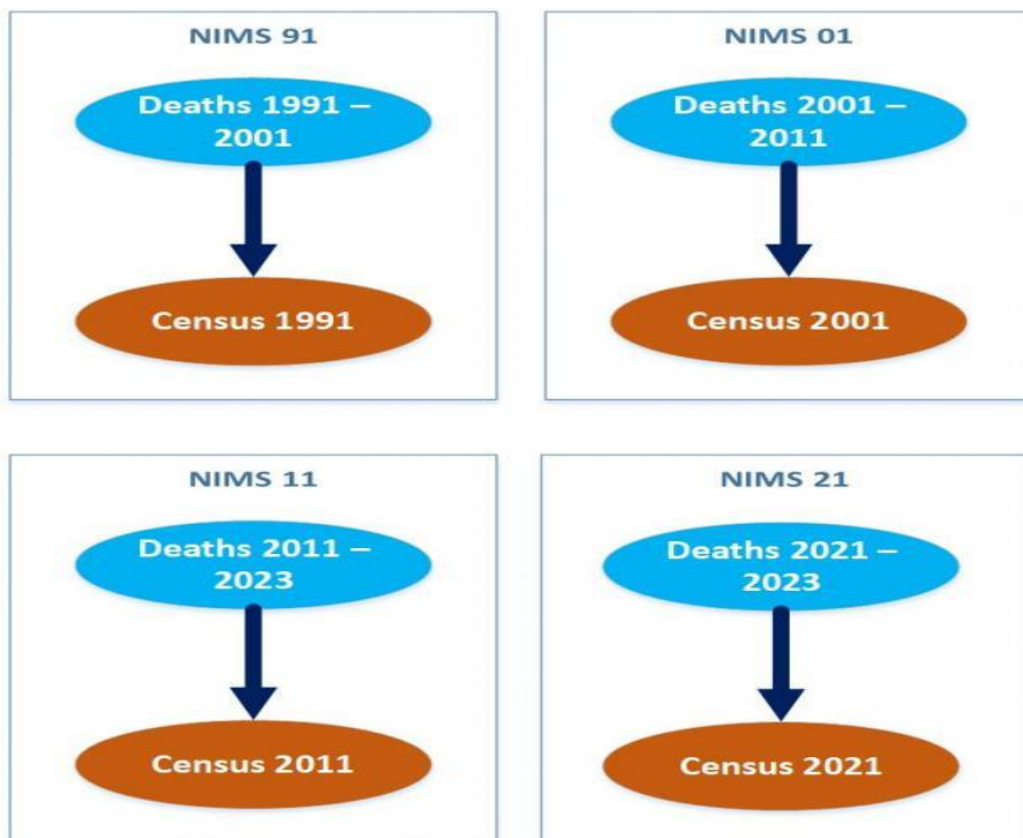
3. Current NIMS Data Structure

The NIMS21 database was created in May 2024 and includes GRO Deaths data from 2021 to June 2023 linked to 2021 Census data, and Properties data based on July 2022 LPS and Oct 2023 Pointer data. The NIMS21 database was subsequently updated in September 2024 to include GRO deaths from 2021 to December 2023 linked to 2021 Census data and Properties data based on July 2022 LPS and Apr 2024 Pointer data.

Resulting from the Covid pandemic, the 2011 NIMS study was extended and will remain active for an additional 4 years linking deaths up to the end of 2025. The latest NIMS11 database (released September 2024) includes GRO Deaths data from 2011 to December 2023 linked to 2011 Census data, and Properties data based on July 2022 LPS and Apr 2024 Pointer data.

The NIMS death updates will be completed biannually.

Figure 2: NIMS Data Structure



4. Data Release Schedule

An updated NIMS 2011 database is planned for release in January 2025 to include deaths data up to June 2024. Following this, an updated NIMS11 database will be released biannually to enable timely research on the Covid pandemic until 2025.

The NIMS 2021 database update is also planned for release in January 2025 to include mortality data until June 2024 linked to 2021 Census data. This will be completed biannually going forward.

The annual NISLS data release is planned for Q1 2025. It will include October 2024 data from the NI Health Card Registration System, Census data from 1981, 1991, 2001, 2011 and 2021, Births, Deaths, and Marriage's data until December 2023, School enrolment data for 2010/11, Weather data from 1981-2010, Pollution data from 2001-2023, plus updated Properties data.

It should be noted that the data release timetable is dependent on when data providers transfer data to RSU. RSU will endeavour to let users know as soon as possible if there are any issues with a scheduled release.

5. NISRA Secure Environment

RSU staff continue to attend the NISRA secure environment, located in Colby House, each week (on a staff rota system) to maintain infrastructure, create project specific data extracts, clear outputs and supervise researchers

Within the NISRA secure environment, there are 15 research stations available for use. All research stations are equipped with software packages such as SPSS, STATA and R.

The NISRA secure environment is open to researchers between 10am-4pm Tuesday-Friday. Researchers should contact RSU to book a time slot to visit the secure environment.

6. Researcher Access to NILS

All researchers who wish to access de-identified micro-data within the NISRA secure environment, via NILS or ADR Northern Ireland, must undergo the ONS Accredited Researcher process prior to the commencement of an approved research project. The researcher must apply for Research Accreditation using the ONS online Research Accreditation Service. This process includes the completion of a Safe Researcher training course. The researcher must also agree to their inclusion in a list of all Accredited Researchers published on the UK Statistics Authority website.

7. Ethical Approval of NILS Database

The current ethical approval of the NILS database will remain in place until 7 April 2027.

RSU submitted the NILS Research Database Annual Progress Report to the Office for Research Ethics Committees Northern Ireland (ORECNI) in May 2024. This report detailed the NILS projects approved, distinct linkage projects that obtained additional ethical approval and all final outputs produced between 8 April 2023 and 7 April 2024.

The annual report for 2024/25 will be submitted to ORECNI in April 2025.

8. NILS Governance

NILS-RSU continues to organise and attend the NILS Research Approvals Group (RAG) meetings and provide an induction to any new RAG members. RAG meetings were held in June 2024 and September 2024.

The exclusion of health bodies in the DEA resulted in ADR-NI health research using primary healthcare data being permitted through the NILS environment. Therefore, the RAG has been reviewing both ADR-NI and NILS applications.

Between 1 April 2024 and 30 September 2024, two new project applications (including one distinct linkage project) were approved by the NILS RAG. Distinct linkage projects require external datasets to be linked to the NILS, and as such require additional data access agreements to be written and signed by the relevant parties before data transfer can proceed.

The NILS RAG reviewed twelve project modifications (9 were subsequently approved) and, in accordance with the RSU Modification Policy, a further 3 project modifications were approved by RSU.

9. Upcoming Dates

NILS Research Approvals Group

Future NILS RAG meeting dates and the corresponding deadline dates for the submission of a project application or modification are listed below:

NILS RAG Deadline Dates	NILS RAG Meeting Dates 2024
30 October 2024	27 November 2024
9 January 2025	6 February 2025
13 March 2025	10 April 2025

Researchers must ensure that RSU have seen an initial draft of a project application ahead of the deadline date in order that feedback and comments can be provided in advance of the RAG meeting. RSU have introduced project subgroup meetings between the research teams, RSU and the data providers prior to RAG to streamline the application process. These meetings provide a platform for any issues or queries to be discussed and resolved more efficiently and make the RAG review of projects more straightforward.

10. NILS Developments

NILS 2021

The NILS 2021 database was formally launched as part of the UKLS conference in Queen's University Belfast in April 2024. The NILS database now contains 2021 Census data thus extending research data coverage to 40 years and significantly enhancing the continued relevance and value of the NILS data for demographic, health and socio-economic research

The approach taken to variable development for Census 2021 has enabled many pre-defined aggregations to be included, which should assist researchers when selecting the relevant detail for their topics of interest rather than having to define aggregations from base variables.

Metadata

In summer 2023 the NISRA TechLab completed the project to create a new version of the NILS metadata. The solution, using R-Bookdown software, provides the user with a more interactive means of searching the metadata and now includes frequencies for some variables. RSU have since employed the same solution to create metadata for the Northern Ireland Mortality Study (NIMS), the Earnings and Employees Study (EES) 2011 and the Education Outcomes Linkage (EOL) 2018/19 datasets. RSU will continue to create further metadata within the branch, such as the NILS 2021, to the same standards.

RSU have worked alongside MetadataWorks to create an online NISRA Metadata Catalogue.

[MDX Browser > Search](#)

This catalogue should make it easier for users to understand and explore the breadth of data available within the RSU. The NILS dataset has been added to the catalogue and contains essential information such as access provision, contact details, spatial and temporal information, and structural data, inclusive of selected frequencies. This makes NISRA the first research centre in the UK to include frequencies on the MetadataWorks website. Work is currently underway to include the 2021 NILS to the structural metadata.

Variable Review

Following a consultation process with users, Census branch, and GRO, a list of vital events variables for addition to the NILS/NIMS was agreed. These were added to NILS/NIMS when updated in April 2024 for 2022 vital events and will be updated annually moving forward. RSU

plan to include these within the NILS and NIMS data when completing the NILS annual update. The next update in Q1 2025 should include these variables along with the existing vital events variables until December 2023. Accompanying metadata on these new variables will be made available online.

Synthetic Data

Researchers using the NILS can apply for a project specific univariate synthetic dataset to facilitate the remote writing of code without needing access to the real data and the secure environment. Since April 2024 RSU have received one new request for synthetic data.

RSU are currently sitting on an Economic and Social Research Council Synthetic Data Working Group seeking to identify the characteristics of synthetic data that make it useful to researchers and exploring synthetic data characteristics that make it acceptable to data owners and the public.

Remote access

RSU have been working alongside Census Office to investigate a remote access offering for the NILS via the ONS SRS (or IDS). The current NILS dataset is being reviewed to determine a version that is suitable for remote access. NISRA is progressing work internally in the first instance. However, NISRA intends to work with key NILS stakeholders in advance of taking any decisions that could impact on research capability.

11. NILS-RSU Online

The NILS website (www.nils.ac.uk) has undergone a design refresh to include a new learning resources section as well as a new dedicated Census 2021 page.

The Census 2021 page will be updated regularly with details of the NILS 2021 project and accompanying series of events to showcase the data and celebrate all the work involved in this important linkage.

Complementary to this, the NILS page under the Research Support section of the NISRA website (www.nisra.gov.uk/support/research-support) now includes further information on NILS 2021 and NIMS 2021. Reports from the Alpha and Beta testing phases of the NILS 2021

project have been published here as well as a data dictionary for NILS/NIMS 2021 to outline the data available in the 2021 Census tables.

A research section of the website illustrates the vast range of research areas that have been undertaken by NILS projects and how they have contributed to evidence-based policy.

The NILS-RSU X (previously Twitter) account currently has 440 followers and will be used to share information with users and to publicise and promote the NILS and NILS events more widely.

12. Promotional/Dissemination Activities

- We have developed a social media strategy in collaboration with the other UK LS's in order to complement and increase traffic to the new website.
- We continue to work with researchers to produce case studies of high public interest projects to be showcased on the website.
- We have submitted the recommissioning bid for NILS funding during the 2025-2030 period to the Economic Social and Research Council. We received initial feedback from five reviewers which was largely positive and categorised as good, very good, two excellent and exceptional. We have submitted our response to any queries and comments and expect to receive the outcome in January 2025.
- We had a summer NILS intern working with us from Geography at QUB who completed a programme in data analysis using the NILS over June and August. Her project has received significant interest from Fermanagh and Omagh District Council and further analysis has been requested. The project has also extended to include a qualitative aspect, and we will present results to stakeholders.
- We had NILS presentations at ICPG in Belfast (July 2024), BSPS in Bath (September 2024) and IDPLN in Chicago (September 2024).
- We attended consultations and data forums representing NILS in Sept and Oct on Census 2021 outputs, All Party Group on Administrative Data for Public Good and Population Research UK.
- We have been awarded two studentships from Dept. Economy to use NILS data in projects on intergenerational deprivation and graduate mobility in NI. These will be supervised by Ian and Estelle and will be advertised at the beginning of 2025.

13. RSU Metrics 1 April 2024 – 30 September 2024

The following metrics are for the period 1 April 2024 – 30 September 2024.

Table 1: NISRA Secure Environment Bookings

Number of distinct bookings for secure environment	175
Number of distinct researchers who have booked into secure environment	18

Table 2: Project Totals on 30 September 2024

	NILS/NIMS Projects	ADR Projects in the NILS Environment
Number of Projects	102/42	19
Number of Active Projects	10	5
Number of Completed Projects	109	10
Number of Pending Projects	4	3
Number of Distinct Linkage Projects (Includes active and pending)	5	7

Table 3: Approved/Completed Projects

	NILS/NIMS Projects	ADR Projects in the NILS Environment
Number of projects approved	2	0
Number of projects completed	2	4

Table 4: Projects Approved April 24 – September 25

Project Number	Data	Project Title	Organisation	Project Summary
NILS 143	NILS	Assessing inequalities in health, wellbeing, and social participation outcomes for young carers in the UK	St George's University London	This project aims to investigate the long-term prospects of young carers across the UK in terms of health, wellbeing and social participation, and whether gender, socioeconomic and ethnic inequalities are present. This will be addressed using 3 UK-wide longitudinal studies – the

				ONS Longitudinal Study (ONS-LS), the Scottish Longitudinal Study (SLS) and the Northern Ireland Longitudinal Study (NILS). By using the E-dataSHIELD method we can combine estimates from all three studies without physically combining them.
NILS 144	NILS	The household context of unpaid caring in Northern Ireland: an administrative data study of household burden, health and labor market outcomes, and mortality among the NI caring population.	Ulster University	This study will examine the household context in which unpaid caring takes place in NI, as well as developing a novel index that can be used to determine levels of household burden from caring responsibilities. It will look at the association between carer status and a range of health, education, and employment outcomes while statistically adjusting for the influence of household burden levels (as measured by the novel index that we wish to develop).

Table 5: Outputs and Modifications

	NILS/NIMS Projects	ADR Projects in the NILS Environment
Number of Project Modifications	9	3
Number of Final Outputs	22	14
Number of Intermediate Output Requests/Files	39/49	27/133

Table 6: Number of Project Modifications by Type

Modification Type	NILS/NIMS Projects	ADR Projects in the NILS Environment
Additional Variables added	2	0
Extension to end date	2	2
Additional data added	2	0
Other	2	1
Researcher added to project	1	0
TOTAL	9	3

Table 7: Number of Final Outputs by Type

Output Type	NILS/NIMS Projects	ADR Projects in the NILS Environment
Article	1	2
Abstract	2	0
Presentation	10	9
Other	7	0
Poster	1	0
Paper	1	2
Thesis	0	1
TOTAL	22	14

Table 8a: Number of NILS/NIMS Intermediate Output Requests/Files by Project

NILS Project	Requests	Files
066	25	31
122	8	11
125	3	3
129	1	1
138	1	1
139	1	2
TOTAL	39	49

Table 8b: Number of ADR in the NILS Environment Intermediate Output Requests/Files by Project

Project Number	Requests	Files
248n	1	8
250n	21	66
255n	2	2
260n	3	57
TOTAL	27	133

14. RSU Contact Details

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