Northern Ireland Longitudinal Study Research Support Unit Mid-Year Report 2023/24

October 2023

Contents

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 and 2011 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 30 year plus longitudinal data set which is regularly being updated. In addition to this rich resource, there is also the potential to link further Heath and Social care data via Distinct Linkage Projects (DLPs).

The NIMS is a large-scale data linkage study that links the 1991, 2001 and 2011 Census returns for the whole of the enumerated population (approximately 1.6 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.
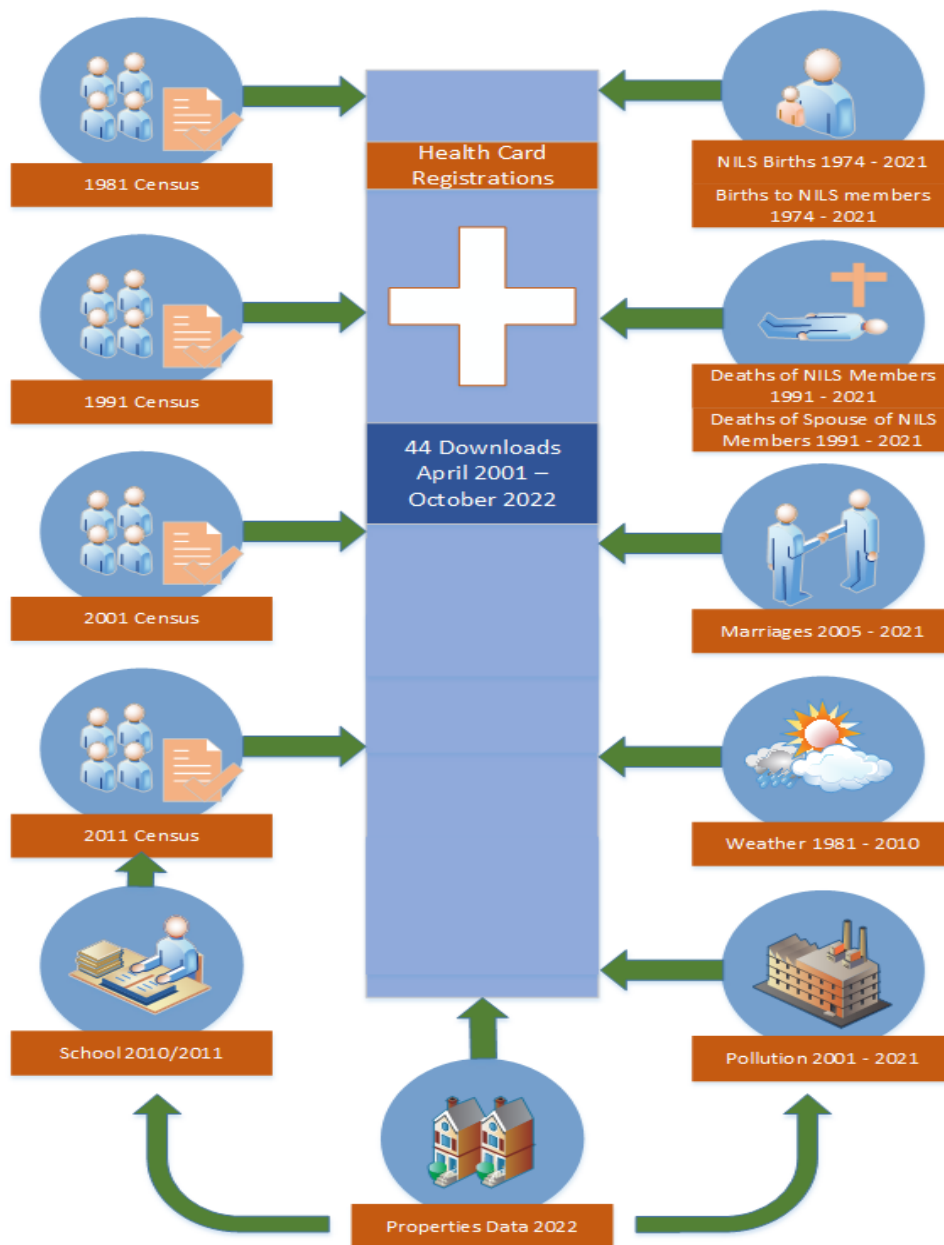
The NISRA Research Support Unit (RSU) is the support unit for the NILS and the ADRNI. Both functions are funded by the Economic and Social Research Council (ESRC) and are similar in nature.

This annual report describes the work of the RSU relating to the NILS from 1 April 2023 to 30 September 2023.

2. Current NILS Data Structure

The latest NILS data release was completed in May 2023. This release includes October 2022 data from the NI Health Card Registration System, Census data from 1981, 1991, 2001 and 2011, GRO Births data from 1974 to December 2021, GRO Deaths data from 1991 until December 2021, Marriages data from January 2005 to December 2021, Properties data updated to October 2022, Weather data from 1981 to December 2010, Pollution data from 2001 to December 2021 and School enrolment data for 2010/11. The current structure of the NILS data is shown below.
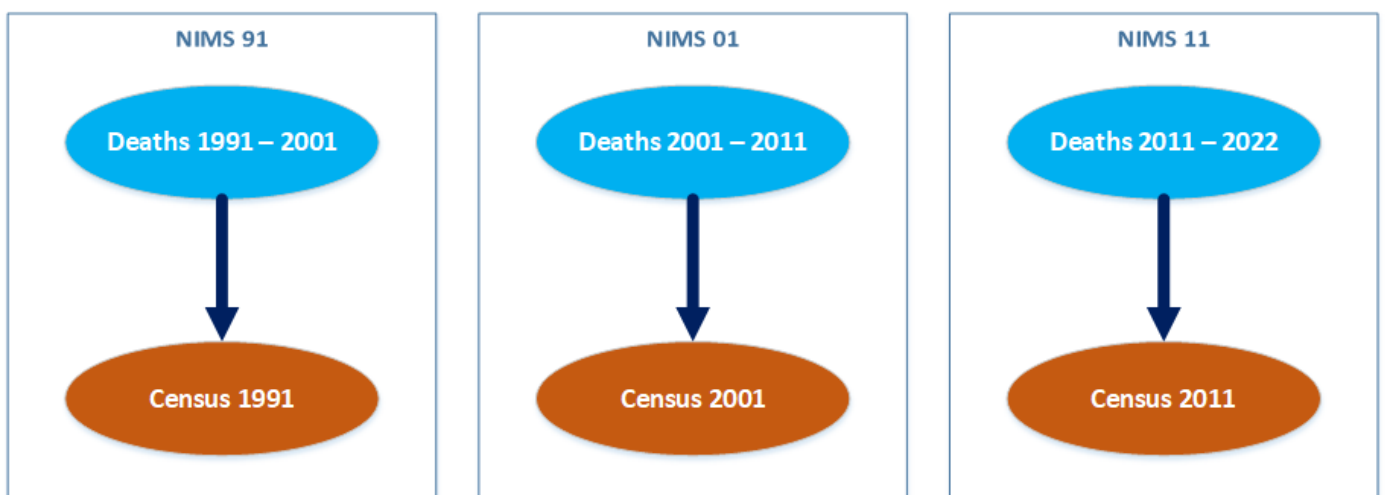
Figure 1: NILS Data Structure

3. Current NIMS Data Structure

The latest NIMS database (released June 2023) includes GRO Deaths data from 2011 to December 2022 linked to 2011 Census data, Weather data from 1981 to December 2010 and Pollution data from 2001 to December 2021.

Given the ongoing Covid pandemic, the 2011 NIMS study has been extended and will remain active for an additional 4 years linking deaths up to the end of 2025. The NIMS death updates will be completed biannually.

Figure 2: NIMS Data Structure

NIMS 91	NIMS 01	NIMS 11
Deaths 1991 – 2001	Deaths 2001 – 2011	Deaths 2011 – 2022
↓	↓	↓
Census 1991	Census 2001	Census 2011

4. Data Release Schedule

An updated NIMS database is planned for release in November 2023 to include deaths data up to March 2023. Following this, an updated NIMS database will be released biannually to enable timely research on the Covid pandemic.

The next NILS data release is planned for Q1 2024. This release will be the first to include 2021 Census data. It will also include October 2023 data from the NI Health Card Registration System, Census data from 1981, 1991, 2001 and 2011, Births, deaths and marriages data to December 2022, School enrolment data for 2010/11, 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. 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.

6. 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 April 2023. This report detailed the NILS projects approved, distinct linkage projects that obtained additional ethical approval and all final outputs produced between 8 April 2022 and 7 April 2023.

7. 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. A RAG meeting was held in June 2023. In the period between June and September 2023 any project modifications requiring approval from RAG were managed via correspondence.

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 have been reviewing both ADR-NI and NILS applications.

Between 1 April 2023 and 30 September 2023, 1 new project application was submitted for review to the NILS RAG, the NILS RAG reviewed 4 project modifications and a further 7 project modifications were approved by RSU.

8. NILS Developments

NILS 2021

The addition of the 2021 Census data to the NILS has been completed and the NILS 2021 database has been tested by RSU. During this Alpha testing phase, a range of data quality checks were performed by RSU to determine whether the database is fit for use by researchers. RSU worked with the data providers to highlight any issues found with the data and used the evidence gathered to inform the decision on when to proceed to the Beta testing phase.

To meet user demand for quick access to Census 2021 data, a beta testing process that differs from that carried out for the 2011 Census linkage has been planned. Beta test projects have been developed with a small group of invited experienced users of the NILS. These methodological projects will assess key aspects of the data in short clearly defined projects with the ambition of beta testing being completed within a two-month period.

The creation of the data extracts for these Beta test projects has been completed. The Beta testing phase will begin on 9 October 2023 with plans to complete by late November. Plans are in place to hold a NILS 2021 soft launch event at Queen's University Belfast on 13 December 2023 to present high level findings from the Beta testing phase. Pending feedback from the testers, a full data release is planned with all researchers being able to apply for access to the NILS 2021 data from early 2024.

Variable Review

In consultation with the Administrative Research Unit, RSU considered the addition of further vital events variables to the NILS/NIMS databases. Following a consultation process with users, Census branch and GRO, a list of variables that have been approved for addition to the NILS/NIMS has been agreed. These will be added for 2022 vital events onwards. Accompanying metadata on these new variables will also be created.

NIMS 2021

The creation of a NIMS 2021 database, to include Census 2021 data linked to subsequently registered mortality data, is due to commence in late 2023.

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 are also working alongside MetadataWorks to create an online NISRA Metadata Catalogue. This should make it easier for users to understand and explore the breadth of data available within the RSU.

Development of NILS Project Accreditation Tool

In April 2022, the NILS Research Approvals Group (RAG) discussed the potential of using a Project Accreditation Tool, similar to the UKSA Project Accreditation Tool, to allow research project applications to be accredited at the official level, providing projects meet certain criteria. This would result in potential changes to the RAG approval process that could see the committee move towards a correspondence-based approval process for routine projects with future RAG meetings reserved for projects that are more novel. The potential advantages of this as we move towards Census 2021, which is likely to see a surge in project applications, were explored.

The use of the NILS PAT is still being explored and continues to be piloted for all proposed project applications at RAG meetings. To date, the NILS PAT has been well received and is producing results in alignment with RAG decisions.

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 2022 RSU have received no new requests for synthetic data.

An online synthetic data resource is due to be published online very soon. The synthetic data will be accompanied by a series of online resources including tutorials on how to use it. These tutorials should allow users to optimise their time within the secure environment by focusing on the actual analysis and should provide a valuable training resource for capacity building.

9. NISRA Secure Environment

RSU staff have continued to attend Colby House each week (on a staff rota system) in order to maintain infrastructure, to create project specific data extracts, to clear outputs and to supervise researchers. RSU also continues to facilitate access to the ONS Secure Research Service within the NISRA secure environment. Researchers should contact RSU to book a time slot to visit the secure room.

10.   NILS-RSU Online

The NILS website is now housed under a new academic domain (www.nils.ac.uk). The site has also undergone a design refresh to include a new learning resources section as well as a new dedicated Census 2021 page which will be updated regularly with details of the testing process, outcomes, 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) has continually been updated to ensure information for researchers is kept up to date. This includes information on the currently available data, project application deadline dates and updated user forms.

The NILS-RSU X (previously Twitter) account currently has 444 followers and will be used to share information with users and to publicise and promote the NILS and NILS events more widely.

11.   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 and will work with them to create a brief video synopsis.

- We have commissioned three new explainer videos. The first is a general introduction to the NILS which is already on the website. The second is a more informative video on the technicalities of joining datasets which will help explain the new Census linkage and the third will be part of the learning resources and inform users of the 'dos and don'ts' of the secure environment.

- We have begun to create and develop a guidance document for Distinct Linkage Projects which will include a template for an ORECNI application.

- We have plans to present on the NILS at the 2023 Society for Longitudinal and Lifecourse Studies (SLLS) International conference in Munich in October 2023.

- We have submitted the mid-term report to the Economic Social and Research Council and will likely have a more in-depth discussion scheduled in December on the challenges and opportunities.

- Together with NISRA and PHA, NILS is co-hosting a half-day event on 21 November 2023 called 'Data-Driven Resilience: Shaping Northern Ireland's Future Post-Covid' bring together analysts, policy makers and academics to consider the need for an integrated data and research strategy in NI.

- We have plans to attend sessions of the 2023 Research Methods e-Festival taking place online between 7-9 November 2023 and will co-host a session on using the UKLS's.

- Planning is well underway for the UKLS 24 Conference which is due to be held in Belfast on 16-17 April 2024. The programme will include exciting sessions on the new Census 2021 linkage with results from the beta testing teams, an expert panel on the future of longitudinal studies and population statistics and hearing from our colleagues in the ROI. There will also be a choice of interactive workshops.

12.   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 2023	NILS RAG Meeting Dates 2023
23 November	7 December

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 from RSU in advance of the RAG meeting.

13.   RSU Metrics 1 April 2023 – 30 September 2023

The following metrics are for the period 1 April 2023 – 30 September 2023.

Table 1: NISRA Secure Environment Bookings

Number of distinct bookings for secure environment	225
Number of distinct researchers who have booked into secure environment	22

Table 2: Project Totals at 30 September 2023

	NILS/NIMS Projects	ADR Projects in the NILS Environment
Number of Projects	92/41	19
Number of Active Projects	10	9
Number of Completed Projects	108	6
Number of Pending Projects	2	3
Number of Distinct Linkage Projects (Includes active and pending projects)	3	12

Table 3: Approved/Completed Projects

	NILS/NIMS Projects	ADR Projects in the NILS Environment
Number of projects approved	1	0
Number of projects completed	2	1

Table 4: Outputs and Modifications

	NILS/NIMS Projects	ADR Projects in the NILS Environment
Number of Project Modifications	5	6
Number of Final Outputs	7	7
Number of Intermediate Output Requests/Files	34/76	48/345

Table 5: Number of Project Modifications by Type

Modification Type	NILS/NIMS Projects	ADR Projects in the NILS Environment
Additional Variables added	0	1
Extension to end date	5	3
Additional data added	0	1
Researcher added to project	0	1
TOTAL	**5**	**6**

Table 6: Number of Final Outputs by Type

Output Type	NILS/NIMS Projects	ADR Projects in the NILS Environment
Article	0	1
Abstract	1	1
Presentation	3	4
Other	3	1
TOTAL	**7**	**7**

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Table 7a: Number of NILS/NIMS Intermediate Output Requests/Files by Project

NILS Project	Requests	Files
066	26	35
106	1	15
126	5	23
129	2	3
TOTAL	**34**	**76**

Table 7b: Number of ADR in the NILS Environment Intermediate Output Requests/Files by Project

Project Number	Requests	Files
245n	1	6
248n	11	62
250n	17	221
255n	10	34
260n	9	22
TOTAL	**48**	**345**

14.   RSU Contact Details

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