Northern Ireland Longitudinal Study Research Support Unit Annual Report 2022/23

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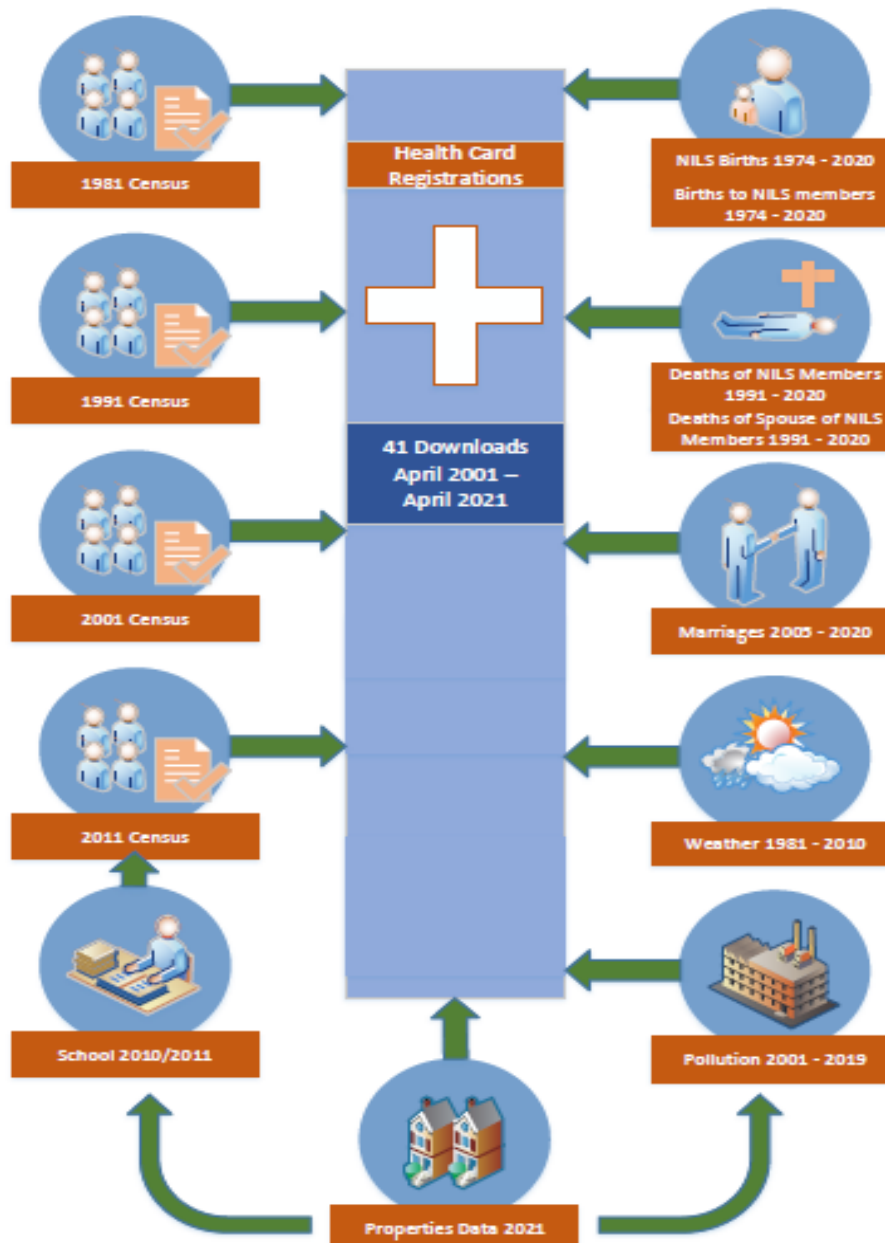
The NISRA Research Support Unit (RSU) is the support unit for the NILS and the ADRNI. Both functions are funded by the Economic and Social Research Council (ESRC) and are similar in nature.

This annual report describes the work of the RSU relating to the NILS from 1 April 2022 to 31 March 2023.

2. Current NILS Data Structure

The latest NILS data release was completed in February 2022. This release includes April 2021 data from the NI Health Card Registration System, Census data from 1981, 1991, 2001 and 2011, GRO Births data from 1974 to December 2020, GRO Deaths data from 1991 until December 2020, Marriages data from January 2005 to December 2020, Properties data updated to April 2021, Weather data from 1981 to December 2010, Pollution data from 2001 to December 2019 and School enrolment data for 2010/11. The current structure of the NILS data is shown below.
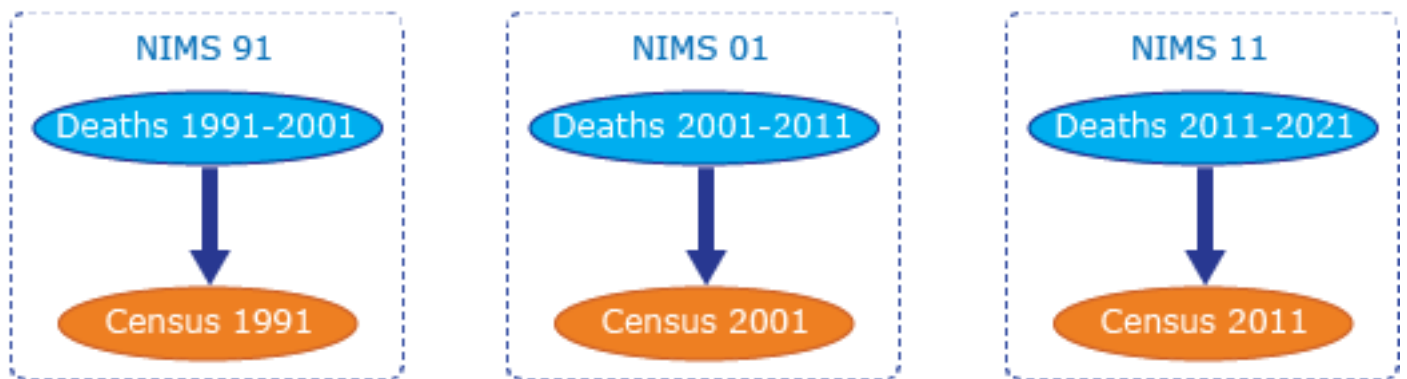
Figure 1: NILS Data Structure

3. Current NIMS Data Structure

The latest NIMS database (released February 2023) includes GRO Deaths data from 2011 to September 2022 linked to 2011 Census data, Weather data from 1981 to December 2010 and Pollution data from 2001 to December 2019.

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

4. Data Release Schedule

An updated NIMS database is planned for release in May 2023 to include deaths data up to December 2022. 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 May 2023. The NILS release will include data up to October 2022 from the NI Health Card Registration System and GRO events data from the Registrar General Annual Report up to December 2021.

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.

Discussions have begun with Census on the linkage of the 2021 Census data to the NILS. The Census release schedule proposes that work on adding the Census 2021 into the NILS will begin in mid-2023. RSU have prepared a NILS Census 2021 Linkage Process Map to detail the potential timelines involved in the different phases of the linkage process.

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 favourable ethical opinion for the NILS research database expired on 30 May 2022. In early March 2022, a fresh application to renew the opinion was submitted to ORECNI along with supporting documentation. RSU attended a meeting of the Research Ethics Committee on 29 March 2022 at which the application was reviewed. The NILS database received a favourable ethical opinion from the Research Ethics Committee on 7 April 2022. This will remain in place for a period of five years until 7 April 2027.

RSU submitted the NILS Research Database Annual Progress Report to the Office for Research Ethics Committees Northern Ireland (ORECNI) in October 2022. This report detailed the NILS projects approved, distinct linkage projects that obtained additional ethical approval and all final outputs produced between 1 August 2021 and 7 April 2022. A further report will be submitted to ORECNI in April 2023 to cover the period from 8 April 2022 to 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. RAG meetings were held in April, October and November 2022 and February 2023. In the period between April and October 2022 any project modification approvals 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 2022 and 31 March 2023, 2 new project applications were submitted for review to the NILS RAG, the NILS RAG reviewed 17 project modifications and a further 22 project modifications were approved by RSU.

8. NILS Developments

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 soon on the Research Support section of the NISRA website. This will allow users to explore the NILS variables that can be made available in project datasets and therefore optimise their analysis time within the secure environment. Metadata and other supporting material are being prepared to accompany the online synthetic data resource.

Remote access

NISRA have worked in collaboration with ONS to provide remote access using the ONS Secure Research Service (SRS) in order to increase access to NI data for researchers. The Earnings and Employees Study (EES) 2011 was made available to researchers on the ONS SRS at the

end of 2021. An evaluation of the use of the ONS SRS for this pilot project was carried out to examine the processes followed and the suitability of future datasets for hosting on the ONS SRS. The pilot project was deemed successful and the evaluation resulted in recommendations such as the roll out of remote access for other datasets on a project-by-project basis and the importance of obtaining user feedback.

Use of secondary care data in the NILS

RSU has been working alongside the Business Services Organisation (BSO) and the HSC Trusts to streamline the process for researchers accessing secondary healthcare data. In June 2022 an evaluation of the process via the pilot NILS project 'Social and Economic Determinants of Maternal Obesity' project was completed.   Following this, the NILS Process Map for Health Data was updated in line with the recommendations from the evaluation. RSU will work with the BSO and the Trusts to adopt this process for future NILS projects requiring secondary health care data.

A further project requiring the linkage of secondary healthcare data to the NILS was approved by the NILS RAG in February 2023.

Metadata

Since summer 2022 RSU has been working with the NISRA TechLab to convert the structure of the NILS and NIMS metadata within RSU to international standards. A solution is being developed by the NISRA TechLab using R-Bookdown software. As a replacement for the current static Word documentation (metadata) and Access database (data dictionary), this online solution in R should provide the user with a more interactive means of searching the metadata and sorting fields. Once completed, this project will provide RSU with the tools and skills to create further metadata within the branch to the same standards.

Suicide Review

In 2020, the Northern Ireland Statistics and Research Agency (NISRA) and Coroner's Service for Northern Ireland (CSNI) began a review into suicide deaths. They found that a number of cases were inaccurately coded and, as such, have since been re-coded by the Vital Statistics team. The NIMS database was updated in summer 2022 following the release of updated deaths data from 2018 onwards.

Cases between 2015-17 were made available to RSU in February 2023 and these have been updated in the most recent NIMS update. The RSU have assisted the Vital Statistics team in engaging with the research community on this work.

Variable Review

In consultation with the ARU, RSU have been considering the addition of further vital events variables to the NILS/NIMS databases. A proposed variable list has been drafted and RSU have consulted with users and now plan to consult further with Census branch. Once agreement is reached, these additional vital events variables will be added to the NILS/NIMS.

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.

Over the summer, RSU have developed a Process Map detailing the proposed approvals process for the use of the PAT. The process map directs the user in either reaching approval of a project application at official level or forwarding to the NILS RAG for consideration. The First Stage of the tool sets out a number of key administrative criteria that each research project application must meet. Each of these criteria must be fulfilled before continuing to the Second Stage.   The Second Stage of the tool sets out a number of project assessment criteria that help to decide whether the project in question requires the independent scrutiny of the NILS RAG before an accreditation decision can be provided.

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.

9. NISRA Secure Environment

The NISRA secure environment has remained open to staff and researchers since the start of this reporting period (April 2022). In line with the NICS Recovery Plan and as the NICS transitions into hybrid working, RSU have been working to increase the capacity with the secure environment as restrictions ease.

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.

The RSU booking request system, allowing researchers to request time slots to attend the secure environment each week, is still in use.

10.   NILS-RSU Online

Information for researchers continues to be added to the NILS website (www.nils-rsu.co.uk). A new learning resources section is currently under development on the website.

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.

Twitter has been used a number of times to share information with users and to publicise and promote the NILS and NILS events more widely. RSU is working to increase the social media presence of the NILS using National Awareness Days on Twitter to highlight related projects and publications arising from the NILS. Publicised hashtags have also been used to highlight NILS work. The NILS-RSU Twitter account now has 451 Twitter followers.

11.   Promotional/Dissemination Activities

Since the start of the COVID-19 pandemic there has been a rapid transition to working online and hosting of virtual events in every sector and within the NILS team we have also been working to develop a strong online presence. The re-design of the NILS-RSU website has provided a good platform for this move.

- We have also 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 NILS-RSU website and will work with them to create a brief video synopsis.

- We intend to launch the synthetic dataset online when we open the call for Census 2021 beta test projects. 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.

- We have commissioned two 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 and will be especially useful given the upcoming Census 2021 linkage. It is due to be finished by Easter.

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

- Members of RSU attended the International Population Data Linkage Network conference in Edinburgh on 7-9 September 2022. The theme of the conference was Data Linkage Research – informing policy and practice.

- The Director of RSU attended the UK Census Longitudinal Studies conference in Cardiff Castle on 20th September 2022. This event brought together the England and Wales, Scottish and Northern Ireland census Longitudinal Studies, to explore their research power. The programme focussed on the unique contribution of the studies to the population data landscape of the UK and how they may be used.

- We have submitted a proposal for a joint UKLS symposium session at the 2023 SLLS Annual International Conference.

- We have planned an information session to officially open the call for Census 2021 beta test projects which will be held as a hybrid event. We are pleased to return to holding in-person events as this will open more opportunities for networking and collaboration.

- We have been working on an article detailing the transformation of NILS-RSU infrastructure over the past few years in response to the report produced from the collective intelligence workshop held in 2019. This is in the final stages of edits and will be submitted to the journal 'Health Research Policy and Systems'.

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
21 March	4 April
8 June	22 June
14 September	28 September
9 November	23 November

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 2022 – 31 March 2023

The following metrics are for the period 1 April 2022 – 31 March 2023.

Table 1: NISRA Secure Environment Bookings

Number of distinct bookings for secure environment	265
Number of distinct researchers who have booked into secure environment	13

Table 2: Project Totals at 31 March 2023

	NILS/NIMS Projects	ADR Projects in the NILS Environment
Number of Projects	92/41	19
Number of Active Projects	12	12
Number of Completed Projects	106	4
Number of Pending Projects	2	3
Number of Distinct Linkage Projects (Includes active and pending projects)	2	13

Table 3: Approved/Completed Projects

	NILS/NIMS Projects	ADR Projects in the NILS Environment
Number of projects approved	1	1
Number of projects completed	5	1

Table 4: Outputs and Modifications

	NILS/NIMS Projects	ADR Projects in the NILS Environment
Number of Project Modifications	21	18
Number of Final Outputs	26	20
Number of Intermediate Output Requests/Files	71/124	82/325

Table 5: Number of Project Modifications by Type

Modification Type	NILS/NIMS Projects	ADR Projects in the NILS Environment
Additional Variables added	3	0
Extension to end date	8	8
Additional data added	3	6
Request for univariate synthetic data	0	0
Researcher added to project	3	4
Other	4	0
TOTAL	**21**	**18**

Table 6: Number of Final Outputs by Type

Output Type	NILS/NIMS Projects	ADR Projects in the NILS Environment
Article	3	1
Abstract	2	3
Research/Policy Brief	8	2
Presentation	6	7
Blog	1	0
Poster	2	0
Other	5	7
TOTAL	**27**	**20**

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

NILS Project	Requests	Files
066	36	44
126	17	54
128	3	3
129	7	7
130	8	16
TOTAL	**71**	**124**

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

Project Number	Requests	Files
245n	21	25
248n	15	100
250n	20	123
251n	1	3
255n	7	16
257n	9	15
258n	1	2
260n	8	41
TOTAL	**82**	**325**

14.   RSU Contact Details

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