



NILS-RSU

NORTHERN IRELAND LONGITUDINAL STUDY
RESEARCH SUPPORT UNIT

Northern Ireland Longitudinal Study- Research Support Unit Annual Report 2020/21

April 2021



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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 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 Health 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.

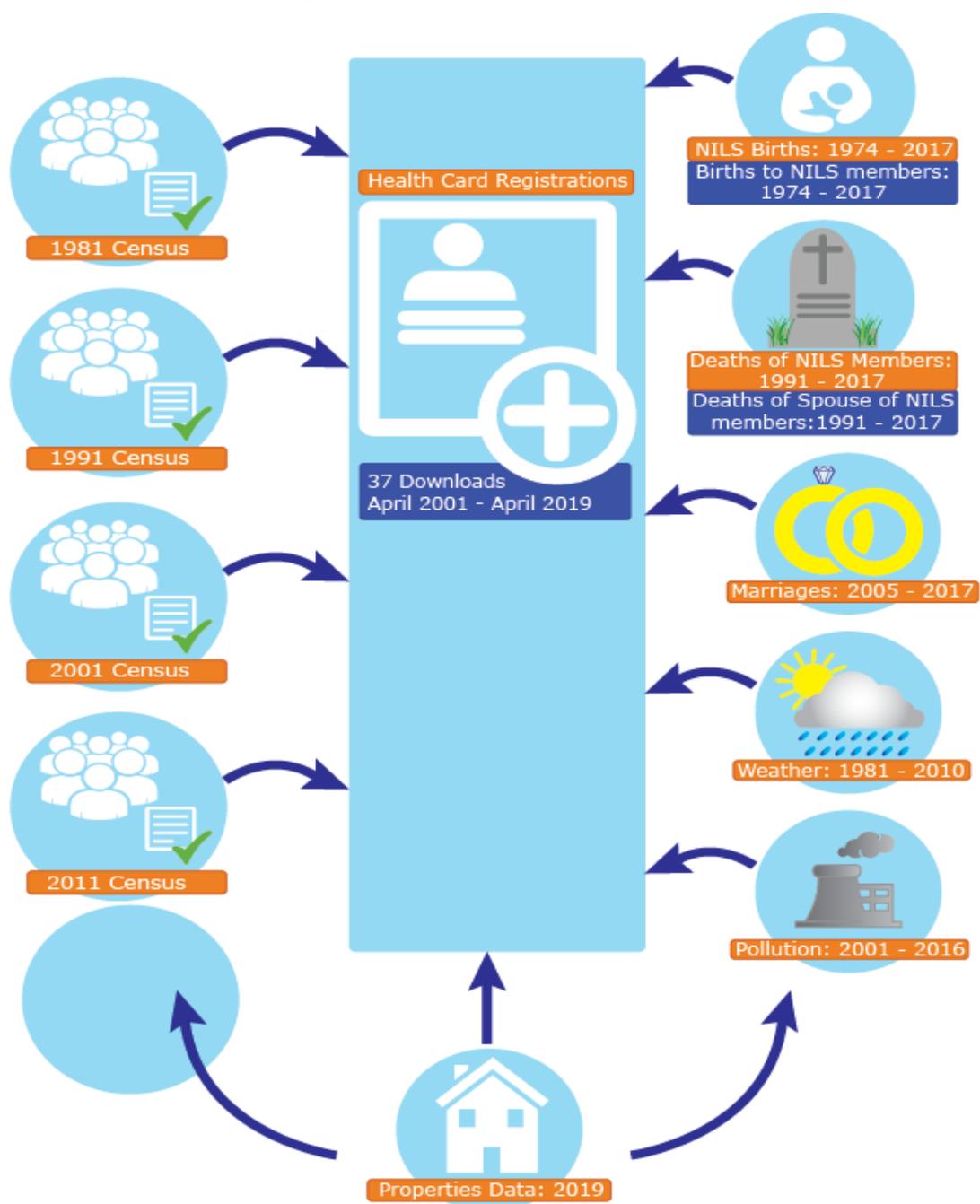
The NISRA Research Support Unit (RSU) is the support unit for the NILS and the ADRNI. Both functions are funded by the Economic and Social Research Council (ESRC) and are similar in nature.

This annual report describes the work of the RSU relating to the NILS from 1 April 2020 to 31 March 2021.

2. Current NILS Data Structure

The latest NILS/NIMS data release was completed in February 2020. This release includes April 2019 data from the NI Health Card Registration System, Census data from 1981, 1991, 2001 and 2011, GRO Births data from 1974 to December 2017, GRO Deaths data from 1991 until December 2017, Marriages data from January 2005 to December 2017, Widow(er)hood data from January 1991 to December 2017, Properties data updated to March 2019, Weather data from 1981 to December 2010, Pollution data from 2001 to December 2016 and School enrolment data for 2010/11. The current structure of the NILS data is shown below.

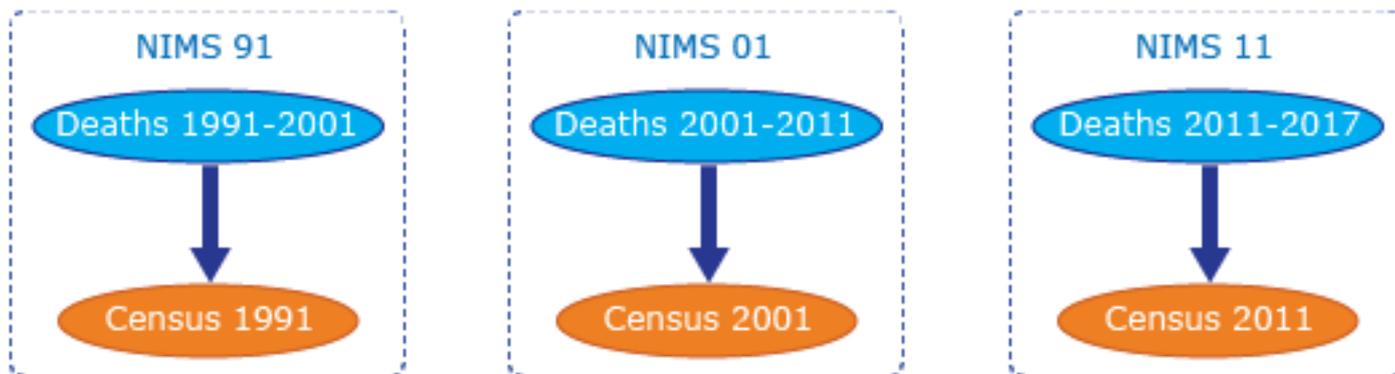
Figure 1: NILS Data Structure



3. Current NIMS Data Structure

The latest NIMS database (released February 2020) includes GRO Deaths data from 2011 to December 2017 linked to 2011 Census data, Weather data from 1981 to December 2010 and Pollution data from 2001 to December 2016.

Figure 2: NIMS Data Structure



4. Data Release Schedule

The next NIMS data release is planned for June 2021. This will include deaths data up to September 2020. The following release, to include 2020 Q4 deaths will also contain an additional Covid mentions indicator which should prove a valuable resource for upcoming research.

From June 2021, the frequency of NIMS data releases will increase from twice a year to four times a year. The NIMS data will be updated quarterly with up-to-date deaths data to enable timely research on the Covid pandemic.

The next bi-annual NILS data release is planned for July 2021. The NILS release will include October 2019 and April 2020 data from the NI Health Card Registration System and GRO births and deaths data from the Registrar General Annual Report for 2018, 2019 and 2020.

It should be noted that this 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

During 2020, there have been significant changes to the Researcher Accreditation process. It is a mandatory requirement for all researchers to attain Accredited Researcher status under the Digital Economy Act 2017. All researchers who wish to access de-identified micro-data within the NISRA secure environment, via ADR Northern Ireland or NILS, must now 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. Applications are assessed by the UK Statistics Authority's Research Accreditation Panel (RAP) which consists of independent members and representatives from governments departments and the devolved administrations.

RSU has liaised with researchers and ONS in order to ensure that the details of researchers who had previously received NISRA Approved Researcher accreditation have been transferred to the ONS system. Any researcher who wishes to access data within the NISRA secure environment must agree to their inclusion in a list of all accredited researchers published on the ONS website.

The researcher accreditation process also includes completion of Safe Researcher Training (SRT). In liaison with ONS, RSU continues to refine this training.

6. Ethical Approval of NILS Database

RSU submitted the NILS Research Database Annual Progress Report to the Office for Research Ethics Committees Northern Ireland (ORECNI) in October 2020. This report details the NILS projects approved, NILS projects that obtained additional ethical approval and the final outputs that were produced during the time period from 1 August 2019 to 31 July 2020. No further information was requested.

7. NILS-RSU Funding

The current funding cycle (commenced 2018) for the RSU was due to end in September 2020. In advance of this, a working group consisting of stakeholder representatives was set up to support the Director of the NILS RSU in informing a funding bid to the ESRC for a further 5 years. Working group meetings took place virtually in March-April 2020.

In preparing the bid, a review of the NILS RSU over the latest funding period was carried out as well as the development of a strategic plan for the NILS over the next 5 years. Additionally, a survey of users and other stakeholders was conducted to gather feedback and views on the areas of NILS development, research support and the impact of the NILS.

A bid was developed which included information on the NILS team, the continued maintenance of the secure environment and processes, wider user support and capacity building, communications and impact, external relationships with partners in QUB and beyond and management and governance. The bid for the recommissioning of the RSU for a further five years (2020-2025) was submitted to ESRC in April 2020. This received approval in June 2020.

An updated sub-contract (ending September 2025) between Queen's University Belfast and NISRA, including the planned scope of work, was agreed and signed.

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.

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.

Since April 2020, a total of 4 projects and 4 project modifications have been submitted for review to the NILS Research Approvals Group. A further 17 project modifications submitted by researchers have been approved and completed by RSU.

An annual report on all approved and completed NILS Distinct Linkage Projects in 2020 was submitted to the Privacy Advisory Committee in January 2021.

9. NILS Developments

RAG Criteria Review

RSU have carried out a review of the NILS RAG criteria used by the Research Approvals Group in assessing proposed NILS projects. The original 18 criteria have been reduced to 10 (5 criteria for RSU and 5 for RAG to consider). An assessment grid has also been developed as a means of formally recording the outcome of the RSU and RAG assessment of a project against the criteria. As a consequence of the review of the NILS RAG criteria, the NILS application form was also revised in order to ensure that the information necessary to assess each criterion was captured in the application. This involved the inclusion of additional sections to the NILS application form.

The updated criteria and the RAG assessment grid were trialed for new projects at the May and September 2020 RAG meetings. RSU presented the new project assessment process to the NILS Steering Group in November 2020 where it was agreed to be formally adopted.

Synthetic Data

In response to the restrictions on researcher access to the NISRA secure environment due to Covid-19, RSU investigated ways to facilitate researchers with progressing their projects. Within the NILS, it was agreed that researchers can apply for a *univariate synthetic* dataset. Univariate synthetic data can be created and accessed outside the secure environment. The main intended purpose of the univariate synthetic data is to facilitate remote writing of code without needing access to the real data and the secure environment. The RAG Terms of Reference and the NILS Modification Policy have been updated to reflect the provision of synthetic data and a NILS Synthetic Dataset Approvals Criteria and Synthetic Data Marking Template and Guidance have been developed. Any new projects requesting synthetic data can be approved at RAG whereas any older projects requesting synthetic data can be reviewed by correspondence by data providers. It is hoped that this product will be a valuable addition to the service offered to researchers.

10. NISRA Secure Environment

The NISRA secure environment in Colby House closed on the 16 March 2020 due to the lockdown imposed due to Covid-19. Since then RSU have regularly kept researchers up-to-date with the situation in regards to accessing the secure environment.

On 6 July, following the completion of an internal NISRA risk assessment, the secure environment reopened to staff on a limited basis. This allowed RSU staff to work on tasks that were unable to be completed from home, such as the clearance of intermediate outputs, remote running of code, the creation of data extracts, the production of data dictionaries for worked datasets and the creation of univariate project level synthetic data.

It is envisaged that there will still be restrictions in place for the foreseeable future for both researchers and staff. While access to the secure environment is only available to staff on a limited basis, RSU has sought solutions to maintaining the NILS and supporting users. RSU has acquired access to ITAC laptops for several members of staff. This allows work, such as the creation of new NILS/NIMS databases containing up-to-date data and the creation of new project-specific datasets, to be completed without needing access to the RSU network in the secure environment. This has been very successful in allowing RSU to fulfil its full role in the current restricted opening of the secure environment and in any future full or partial lockdown.

From Monday 7 September, following a further risk assessment which included the purchasing of equipment to manage the risk in the secure environment, RSU offered researchers safe but restricted access to the secure environment in Colby House. RSU produced guidelines for researchers returning to Colby House, which included on site protocols for Colby House and for the NISRA secure environment. RSU also developed a booking request system for researchers to request time slots to attend the secure environment each week. This included the introduction of a rota based seating plan to accompany other measures to reduce risk in the room. Returned access to the secure environment allowed researchers to conduct analysis, create intermediate/final outputs and submit outputs for statistical disclosure checks.

From 19 October, with the announcement of restrictions from the NI Executive, the secure environment closed again to researchers. Following on from the easing of restrictions from the NI Executive, NISRA plan on reopening the secure environment to researchers from 1st June

2021. While this will initially be on a restricted basis, it is hoped that access will increase over the summer as restrictions and guidance from the NI Executive relax.

Meanwhile, RSU staff endeavour to continue to attend Colby House in order to maintain infrastructure and to provide the same range of remote services for researchers that were put in place in July upon reopening of the secure environment to staff. Due to the actions of the RSU over summer 2020 to procure and install a comprehensive range of protective measures and equipment, RSU will be well placed to open again to researchers relatively quickly when it is deemed safe to do so.

11. NILS-RSU Online

Information for researchers continues to be added to the NILS website (www.nils-rsu-co.uk) which has undergone a fundamental redesign. The new navigation system has allowed the reorganisation of content to make navigation and gathering information easier for the user. 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) is continually being updated to ensure information for researchers is kept up-to-date.

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 456 Twitter followers.

12. Promotional/Dissemination Activities

Following the announcement of the COVID-19 pandemic and the subsequent imposed restrictions, we have had to revise our programme of engagement for this year. 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 recent re-design on the 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.

- An online workshop was hosted in June 2020 to provide researchers with advice on "Writing a successful NILS Application". This workshop was attended by 16 participants from across the UK and included a mixture of academics and statistical agency staff. A modified version of the workshop is also available on the NILS website for reference.
- We are working with researchers to produce case studies of high public interest projects which will be showcased on the site, together with a brief video synopsis.
- We were invited to present a summary of the NILS as a resource for examining Section 75 data at the Equality Commission launch on 20th January 2021. This was attended by 350 participants and made available as a resource on the Equality Commission website.
- We gained ESRC Impact Acceleration funding for an "Effective Briefs for Policymakers" workshop hosted by Bulletin (a strategic communications consultancy). This was held on 27th January 2021. In addition, the funding will also be used to hire a Research Assistant for 6 months starting from 1st June 2021. This position will be specifically to enhance policy impact from the NILS and will involve scanning for evidence calls, compiling policy briefs and synthesising existing NILS evidence.
- We are in the process of recording and editing a series of online resources for NILS users including a tutorial on the data formats and linkages provided for approved projects. This tutorial should allow users to optimise their reduced time within the secure setting focusing on the actual analysis.
- In response to participant feedback from a previous course, we have planned for two additional online courses on data linkage projects and how NILS data can be used to look at the impact of COVID-19.
- We are developing a seminar in collaboration with ARK to bring together NILS stakeholders to explore the use of NILS in relation to a specific research theme. The date has been provisionally set as 19th September 2021 but this will be confirmed together with the theme in the upcoming months.
- We are working with the other UK longitudinal studies to host an online conference in spring 2021.

13. 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 shown below:

NILS RAG Deadline Dates 2021	NILS RAG Meeting Dates 2021
25 May	8 June
7 September	21 September
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.

14. RSU Metrics 1 April 2020 – 31 March 2021

The following metrics are for the time period 1 April 2020 – 31 March 2021.

Table 1: NISRA Secure Environment Bookings

Number of distinct bookings for secure environment	37
Number of distinct researchers who have booked into secure environment	11

Table 2: NILS/NIMS Project Totals at 31 March 2021

Number of NILS/NIMS projects	90/39
Number of Active Projects	14
Number of Completed Projects	97
Number of Pending Projects	5
Number of Distinct Linkage Projects	18

Table 3: NILS/NIMS Projects

Number of projects approved	3
Number of projects completed	5

Table 4: Outputs and Modifications

Number of Intermediate Output Requests/Files	16/67
Number of Final Outputs	10
Number of Project Modifications	21

Table 5: Number of Final Outputs by Type

Output Type	Number
Article	3
Paper	3
Thesis	3
Other	1
TOTAL	10

Table 6: Number of NILS/NIMS Project Modifications by Type

Modification Type	Number
Additional Variables added	1
Extension to end date	17
Additional data added	1
Researcher added to project	1
Other	1
TOTAL	21

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

NILS Project	Requests	Files
066	2	2
101	2	4
102	5	14
114	3	41
120	2	2
123	2	4
TOTAL	16	67

15. RSU Contact Details

Research Support Unit
Colby House
Stranmillis Court
Belfast
BT9 5RR
028 9038 8488
rsu@nisra.gov.uk

nils-rsu.co.uk

 @NILRSU