



NILS-RSU

NORTHERN IRELAND LONGITUDINAL STUDY
RESEARCH SUPPORT UNIT

Northern Ireland Longitudinal Study- Research Support Unit Annual Report 2017/18

April 2018



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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 ADRC-NI. Both functions are funded by the Economic and Social Research Council (ESRC) and are similar in nature. This report describes the work of the RSU relating to the NILS from 1 April 2017 to 31 March 2018.

2. Current NILS Data Structure

A NILS/NIMS data release was completed in August 2017. This included April 2017 data from the NI Health Card Registration System.

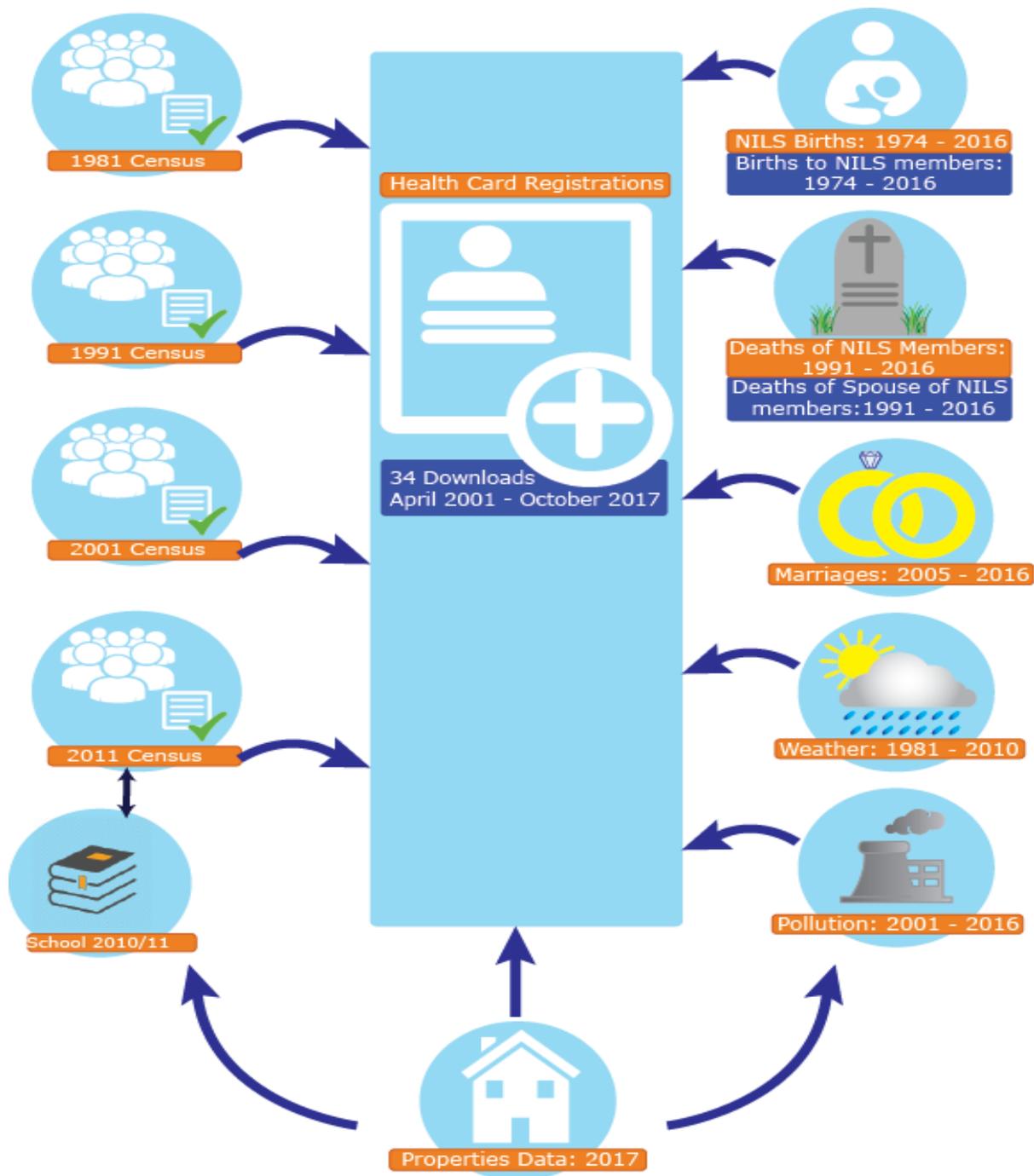
In November 2017 School enrolment data at an institutional level for 2010/11 was added to the NILS. This was drawn from the annual school census exercise carried out by the Department of Education. This School data can be linked to the Census Person 2011 table.

A further NILS data release was completed in March 2018 to include the October 2017 data from the NI Health Card Registration System and GRO data from the latest Registrar General Report.

The NILS data currently includes Health Card registration data until October 2017, Census data from 1981, 1991, 2001 and 2011, GRO Births data from 1974 to December 2016, GRO Deaths data from 1991 until December 2016, Marriages data from January 2005 to December 2016, Widow(er)hood data from January 1991 to December 2016, Properties data updated to October 2017, 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 next. An updated NILS Data Dictionary and NILS Metadata have been published on the NILS-RSU website.

Figure 1: NILS Data Structure

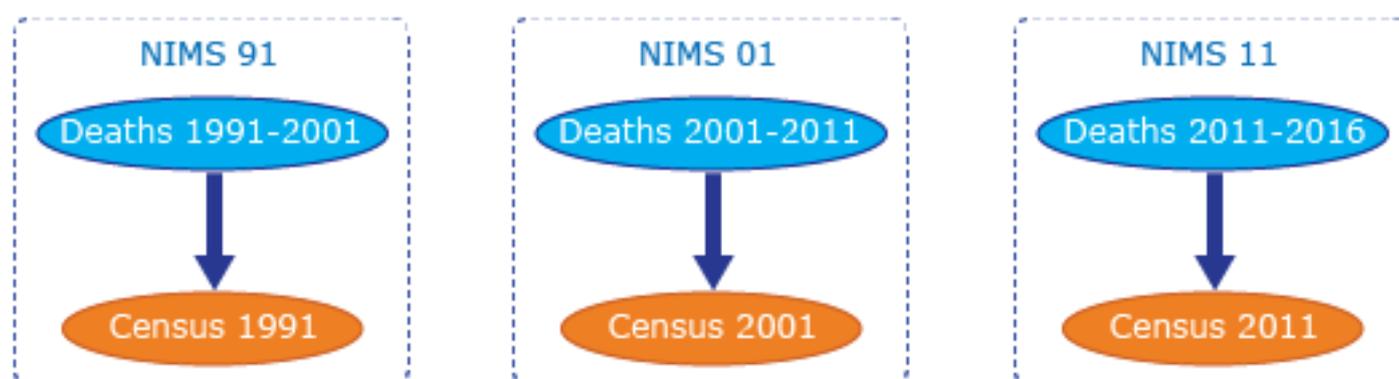


3. Current NIMS Data Structure

The latest NIMS database (released March 2018) includes GRO Deaths data from 2011 to December 2016 linked to 2011 Census data, Weather data from 1981 to December 2010 and Pollution data from 2001 to December 2016.

An up to date version of the NIMS Metadata has been published on the NILS-RSU website.

Figure 2: NIMS Data Structure



4. Data Release Schedule

The next NILS data release is planned for Quarter 2 July - September 2018. This release will include April 2018 data from the NI Health Card Registration System.

The general release pattern will continue each year with the data release in the summer (Q2) to include the April data for the same year from the NI Health Card Registration System and the data release in the New Year (Q4) to include the October data for the same year from the NI Health Card Registration System and GRO data from the latest Registrar General Report and Pollution data. Weather data is updated every 10 years (last updated April 2012). It should be noted that this timetable is dependent on the data providers transferring the data to RSU on time and 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

The NISRA Approved Researcher process continues to be managed by RSU. This process ensures that the researcher is 'fit and proper' and that they have the support of an institutional guarantor. All researchers who wish to access de-identified micro-data within the NISRA secure environment, via ADRC or NILS, must undergo this process prior to the commencement of an approved research project. Currently, 83 researchers have completed this process.

All researchers named on a project, who wish to access data within the secure environment, must complete Safe User of Research data Environments (SURE) training. Researchers who wish to gain access to project outputs in an advisory capacity, but who do not need access to data in the secure environment, must complete Safe Researcher Training (SRT). Currently, a total of 97 researchers have completed either SURE or SRT training.

RSU has liaised with the Office for National Statistics (ONS) on the changes to accredited researchers, accredited centres/staff and accredited projects in relation to the Digital Economy Act. ONS have developed a new version of training for accredited researchers. RSU has been working with ONS to refine and agree the content of the course and how it will be delivered. Going forward, RSU will plan and deliver the training sessions bimonthly in Colby House.

All researchers who wish to access data within the secure environment are also required to have Baseline Personnel Security Standard clearance. The number of researchers who have been security cleared since April 2017 is seven.

6. Ethical Approval of NILS Database

The ethical approval of the NILS database was due for renewal on the 7 August 2018. RSU completed an application for the renewal of the ethical approval and attended a meeting on 20 May 2017 at which the Research Ethics Committee reviewed the application. The NILS database received a favourable ethical opinion for a further five years until 7 August 2022.

RSU submitted the NILS Research Database Annual Progress Report to the Office for Research Ethics Committees Northern Ireland (ORECNI) in August 2017. No further information was requested.

An Annual report on NILS Distinct Linkage projects for 2017 was submitted to the Privacy Advisory Committee in January 2018.

7. NILS-RSU Funding

Further funding was secured to cover the eight month period from August 2017 until March 2018. An amendment to the Sub Contract between QUB and NISRA was agreed and signed by both parties.

In June 2017, RSU carried out an online consultation to consult NILS users and other stakeholders on the future of the NILS-RSU and the wider development of the NILS over the next five years from April 2018. The consultation was interested in gathering ideas and suggestions in the areas of NILS development, research support, research impact and future access to the NILS and other UK Longitudinal Studies. RSU published a report outlining a summary of the responses to the consultation. Views from the consultation were used to inform the NILS-RSU funding bid to the ESRC, for the 2.5 years from April 2018. NILS-RSU supported Dr Ian Shuttleworth with drafting this bid. In December 2017, the proposal was assessed through the ESRC peer review process and was recommended for funding. In April 2018, a fully executed Sub Contract between QUB and NISRA was agreed by both parties.

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. Future RAG meetings in 2018 are planned for 31 May, 25 July and 12 September.

Since April 2017, 3 projects and 11 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.

RSU has held regular meetings with the Chair of the NILS User Forum. These meetings have proved useful in keeping users informed and in addressing any issues and queries NILS users have raised. Any issues of significance are to be brought to the NILS Steering Group for discussion.

9. NILS Developments

In order to ensure RSU is compliant with the requirements of the General Data Protection Regulation (GDPR), a Privacy Impact Assessment (PIA) of the RSU network was carried out in June 2017. This resulted in the recommendation for the introduction of project specific PIAs for all NILS projects. RSU are now completing project specific PIA's to accompany each NILS Project Application for review by the NILS Research Approvals Group. This brings NILS in line with the process already in place for ADRC projects and addresses privacy concerns in the NILS governance processes.

In November 2017, the NILS synthetic data spine was published on the NILS-RSU website. This data is for general use and will allow users who are unfamiliar with longitudinal data to get a feel for the kinds of questions that can be answered by following individuals through time and observing changes in their characteristics.

Following the approval of synthetic data within ONS, the NILS Synthetic Data Working Group has prepared a paper on the utility of project specific synthetic data within the NILS/NIMS.

The recent NILS-RSU funding bid included a proposal to establish defined long-life student projects dealing with general themes in order that access to the NILS be made easier for undergraduate and postgraduate students. Students would be able to apply to sign on to a 'Student Dataset', within existing NILS protocols and processes, and work alongside an experienced NILS researcher. RAG members were consulted on this proposal in March 2018 and were content to support it provided suitable governance and security processes are agreed. Going forward, RSU have agreed to work with Dr Shuttleworth to develop a process for managing 'Student Datasets'.

10. NISRA Secure Environment

There is currently one NILS Support Officer within the secure environment. This is complemented by four further ADRC support officers who are also available for research support. Normal support for researchers through help with applications and the supervision of the RSU secure environment has been taking place. The secure environment continues to be open for researchers from 8.30am to 4.30pm (or later depending on staff availability) each day with coverage over lunchtimes.

NILS-RSU continues to supervise the Secure Research Service (SRS) data within the secure environment and is responsible for conducting a weekly test of the SRS alongside ONS staff. In addition, a live link to ADRC-W has recently been activated, which is being utilised for the conduct of an approved ADRC-W project.

11. NILS-RSU Online



The [NILS-RSU website](#) is up-to-date and is being reviewed and maintained on a frequent basis by RSU staff.

Recent additions to the website include an online resource for [GRO Births Information](#) and the [NILS List of Abstracts Report 2016/17](#).

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. The NILS-RSU Twitter account now has 363 Twitter followers.

NILS-RSU continues to ensure relevant, accurate and up to date information on NILS is included on the CALLS-Hub website. This has included the provision of information to assist with the production of a series of Thematic Guides, such as 'Using the Census Longitudinal Studies for research on health and health inequalities'.

12. Promotional/Dissemination Activities

The NILS Research Forum carries out a series of workshops and seminars to build capacity amongst existing NILS researchers and to promote the NILS to potential new users. These events have proved very popular with NILS researchers in the past and have attracted new NILS users and raised awareness about the potential of the NILS for academic research.

- In August 2017, the NILS Research Forum, alongside the Q-Step Centre in the School of Social Sciences, Education and Social Work at Queen's University Belfast, ran a three day training course in R statistical software at Queen's University Belfast.
- In March 2018, the NILS Research Forum, hosted a 1-day introductory course on Mapping Population Data using QGIS in Queen's University Belfast.

RSU continues to promote the utility of NILS amongst researchers throughout the UK and policy makers within Northern Ireland. Work is ongoing to develop materials and outreach to build on the impact of the NILS.

- In December 2017 Dr Shuttleworth gave a presentation on the NILS to staff at the Scottish Longitudinal Study in Edinburgh.
- A NILS Lunchtime seminar was held in the Department of Health on 14 March 2018. This was delivered by Orla Bateson and Dr Aideen Maguire.
- A NILS Research Showcase event, featuring work conducted using the NILS, was held in Riddel Hall on 29 March 2018. This half day event supported by the Public Engagement Office at Queen's University Belfast, was opened by Dr Shuttleworth. The aim of this event was to bring researchers and community organisations together to highlight mutual interests and promote the work and value of the NILS to the wider community.
- On 17 April 2018, Dr Shuttleworth presented on the NILS to the Research and Library Service at the NI Assembly.
- On 10 May 2018, Dr Shuttleworth presented on the NILS to the Northern Ireland Local Government Association.

13. RSU Metrics 1 April 2017 – 31 March 2018

Table 1: Researcher Metrics

Number of researchers who have been granted/renewed Approved Researcher Status	26
Number of researchers who have completed SURE/SRT Training	9
Number of researchers who have been granted/renewed BPSS Clearance	28
Number of distinct bookings for secure environment	53
Number of distinct researchers who have booked into secure environment	19

Table 2: NILS/NIMS Project Totals at 1 April 2018

Number of NILS/NIMS projects	67/36
Number of Active Projects	27
Number of Completed Projects	74
Number of Pending Projects	2
Number of Potential Projects	2
Number of Distinct Linkage Projects	18

Table 3: NILS/NIMS Projects

Number of projects approved	3
Number of NILS/NIMS projects made active	1/1
Number of projects completed	10

Table 4: NILS/NIMS Outputs and Modifications

Number of Intermediate Output Requests/Files	197/641
Number of Final Outputs	89
Number of Project Modifications	28

Table 5: Number of NILS/NIMS Final Outputs by Type

Output Type	Number
Abstract	13
Article	13
Other	12
Paper	6
Poster	4
Presentation	38
Research/Policy Brief	0
Thesis	3
TOTAL	89

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

Modification Type	Number
Additional Data added	3
Additional Variables added	6
Extension to end date	14
Researcher(s) added to project team	4
Other	1
TOTAL	28

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

NILS Project	Requests	Files
066	15	39
069	8	39
071	6	10
076	1	1
080	2	4
086	7	9
087	14	28
089	6	16
093	1	1
094	1	4
097	20	30
100	1	1
101	21	26
102	13	35
106	24	161
108	29	100
110	6	11
111	2	11
112	8	62
114	5	32
115	7	21
TOTAL	197	641

14. RSU Contact Details

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