



# NILS-RSU

NORTHERN IRELAND LONGITUDINAL STUDY  
RESEARCH SUPPORT UNIT

## Northern Ireland Longitudinal Study Research Support Unit Annual Report 2023/24

April 2024



**NISRA**

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



Queen's University  
Belfast



Economic  
and Social  
Research Council

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## 1. Background

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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 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.

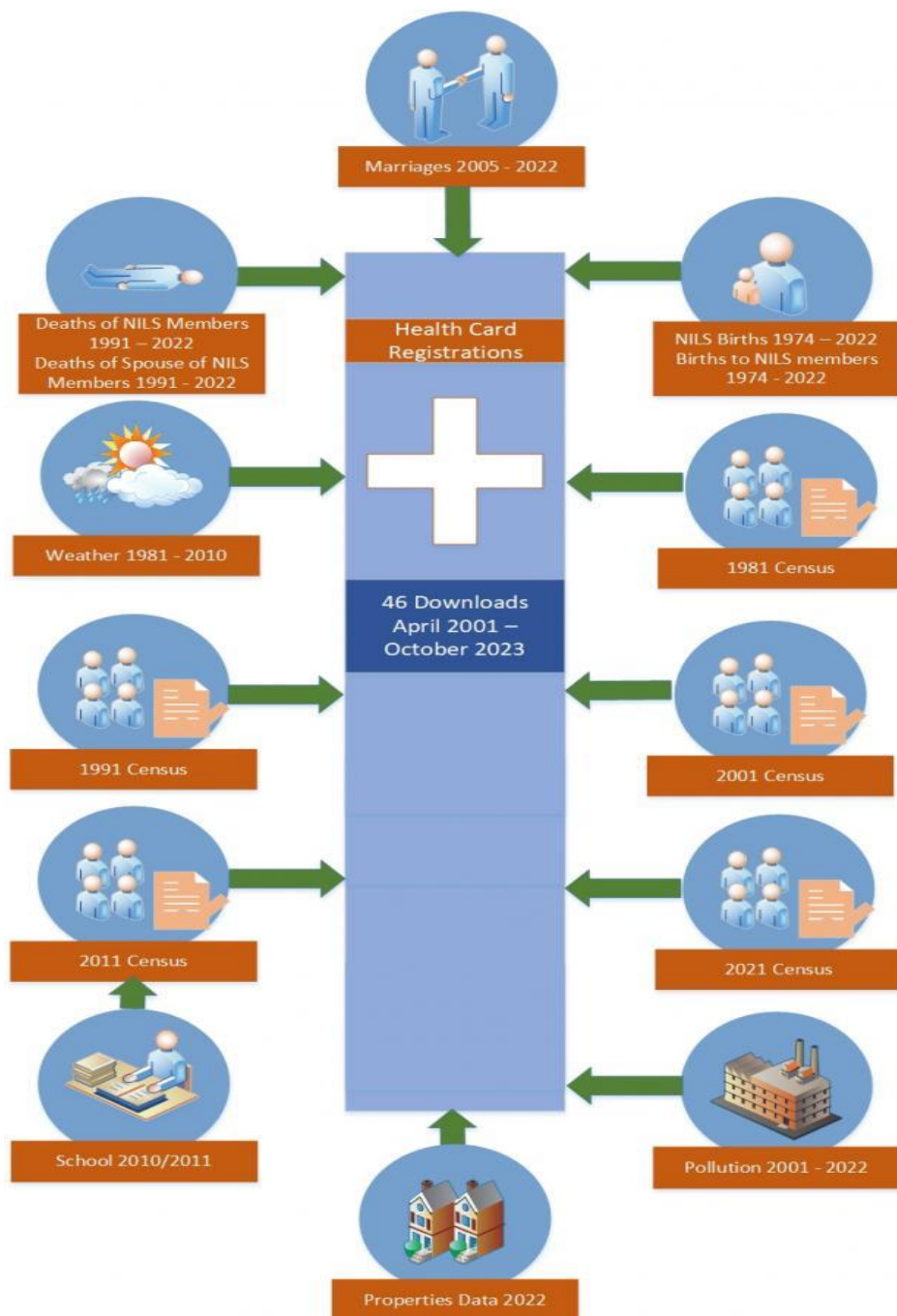
The NISRA Research Support Unit (RSU) is the support unit for the NILS and the ADRNI. Both functions are funded by the Economic and Social Research Council (ESRC) and are similar in nature.

This annual report describes the work of the RSU relating to the NILS from 1 April 2023 to 31 March 2024.

## 2. Current NILS Data Structure

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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 updated to October 2022, Weather data from 1981 to December 2010, Pollution data from 2001 to December 2022 and School enrolment data for 2010/11. The current structure of the NILS data is shown below.



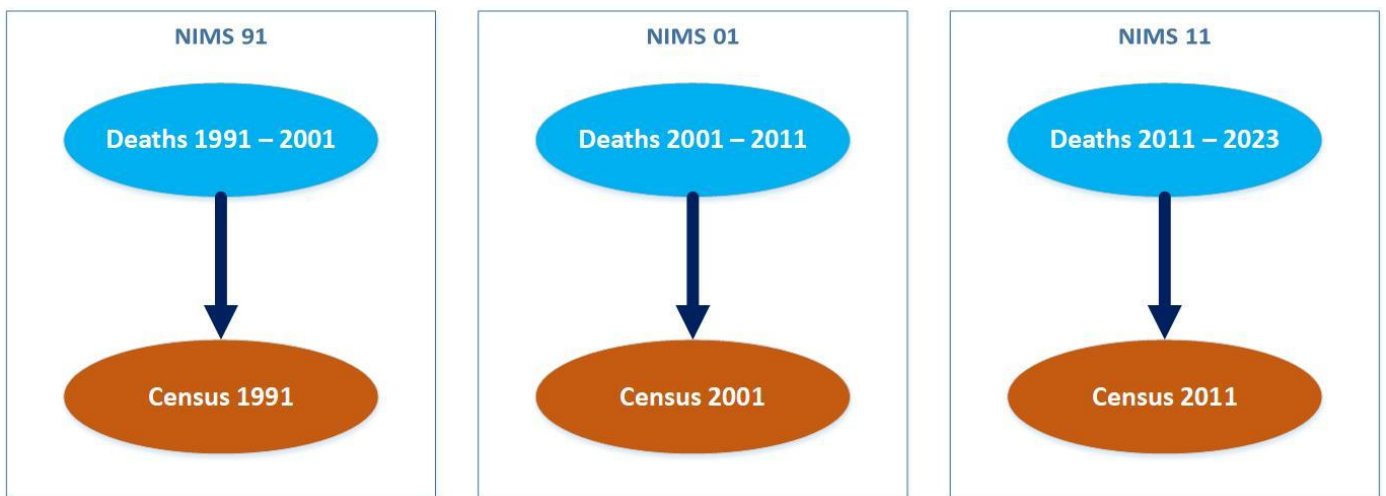
### 3. Current NIMS Data Structure

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The latest NIMS database (released November 2023) includes GRO Deaths data from 2011 to June 2023 linked to 2011 Census data, and Properties data until to December 2022.

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 2021

The creation of a NIMS 2021 database, to include Census 2021 data linked to subsequently registered mortality data, is due to be released in May 2024.

### 4. Data Release Schedule

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An updated NIMS 2011 database is planned for release in July 2024 to include deaths data up to December 2023. Following this, an updated NIMS11 database will be released biannually to enable timely research on the Covid pandemic until 2025.

A newly created NIMS 2021 database, to include Census 2021 data linked to subsequently registered mortality data, is planned for release in May 2024.

The next NILS 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 Marriages data to 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**

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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 10-4.30pm. Researchers should contact RSU to book a time slot to visit the secure environment.

## **6. Researcher Access to NILS**

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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

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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.

The annual report for 2023/24 will be submitted to ORECNI in May 2024.

## 8. NILS Governance

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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, September and December 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 31 March 2024, five 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 five project modifications and, in accordance with the RSU Modification Policy, a further 16 project modifications were approved by RSU.

RSU have been trialling a new process of completing project subgroup meetings with data providers and researchers ahead of RAG meetings. This means that project applications will have been reviewed significantly by data providers and researchers ahead of the RAG meeting and should help to make the RAG review of projects more straightforward.

## 9. Upcoming Dates

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### 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:

<b>NILS RAG Deadline Dates 2024</b>	<b>NILS RAG Meeting Dates 2024</b>
23 May	6 June

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.

## 10. NILS Developments

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### User Survey

The UKcenLS-NILS User Survey was launched on the 19 May 2023 and ran for two weeks. Due to the small number of responses, at present the report will not be released due to potential disclosure issues. Responses were received from Post-Doc/Researchers and Lecturers/Senior Lecturers/Readers/Professors. In summary, recommendations for improving the NILS website included an online secure room booking system and an online application form. The main area of research from the NILS users was neighbourhood/geographic differences. The research areas of interest were linkages to health data, fertility and family structure, migration, mental health and health science. The biggest challenges noted is the lack of remote access and a slow application process. RSU received a rating of 4.43 out of 5 for the service provided to NILS users.

### 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 Census 2021 data is added to the NILS, 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.

### 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.

Over the course of this year, RSU have worked 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. As of May 2024, the Metadata contains essential information such as access provision, contact details, spatial and temporal information etc. By June 2024, it is intended that structural data, inclusive of selected frequencies, will be accessible by prospective researchers. This will make NISRA the first research centre in the UK to include frequencies on the MetaDataWorks website.

### NILS 2021

In summer 2023, RSU began work on the Northern Ireland Longitudinal Study (NILS) 2021 project. The aim of this project was to update the current NILS database with 2021 Census data extracts. This would extend research data coverage to 40 years thus significantly enhancing the continued relevance and value of the NILS data for demographic, health and socio-economic research.

For the NILS 2021 project, the Census 2021 event was added to the NILS members and the household information was enhanced to refine the list of householders related to the NILS members, thus bringing the NILS database up to date.

## NILS 2021 Alpha Testing

The addition of the 2021 Census data to the NILS was completed in September 2023. The NILS 2021 database was extensively tested before being released to the research community. The first testing stage, the Alpha Test phase, was carried out by RSU staff. Alpha testing of the NILS 2021 database was carried out by NILS-RSU staff in September and October 2023.

During this Alpha testing phase, a range of data quality checks were performed by RSU to determine whether the database was 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. A report summarising the Alpha testing process will be made available on the NILS section of the NISRA website.

## NILS 2021 Beta Testing

To meet user demand for quick general access to the Census 2021 link, a streamlined and focussed Beta testing process was adopted for this Census round. In contrast to the process carried out for the 2011 link, an open call for Beta projects was not made, rather experienced research teams drawn from the NILS research community and NISRA were approached to take part in the Beta testing. These methodological projects assessed key aspects of the data in short clearly defined projects with the ambition of beta testing being completed within a two-month period.

It was agreed that all projects should test the linkage of the Census 2021 data to the NILS, while specific projects would test the novel features of Census 2021 such as the new Super Data Zone output geography and newly available variables (e.g. sexual orientation). Transitions between Census 2011 and Census 2021 and the linkage of vital events would also be examined.

Project specific data extracts were released to all five Beta research teams on 9 October 2023. The data was available for a nine-week period wherein researchers were encouraged to make use of the Issues Log to feedback any issues/enhancements/suggestions/questions they had.

Following feedback of the Beta test application process 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 have proven to save a lot of time in preparing a project application for RAG.

An informal NILS 2021 soft launch event, open to NILS-RSU, NILS data providers, NILS RAG members and researchers, was held in QUB on 13 December 2023. RSU provided a summary of the NILS 2021 project so far, including the Alpha and Beta testing phases, the project application process and plans for future updates. The event allowed for discussion of any issues logged in the Beta testing phase and gave the research teams a platform to share preliminary results and to make suggestions on potential improvements.

Given the results of the Beta testing and the progress against the items logged it was agreed at the NILS soft launch event to recommend the release of the NILS 2021 database to the wider research community.

Further work was then undertaken to resolve outstanding issues found in the Alpha and Beta testing phases and to add routine updates and additional vital events data to the NILS 2021 database. The NILS 2021 database will be formally launched as part of the UKLS conference in Queen's University Belfast in April 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 for addition to the NILS/NIMS was agreed. These have been added to NILS/NIMS for 2022 vital events onwards. Accompanying metadata on these new variables has also been created and 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 2023 RSU have received one new request for synthetic data.

An online synthetic data resource is due to be published online. 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.

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 to investigate a remote access offering for the NILS via the ONS SRS (or IDS) during 23/24. This item will be discussed at the NILS Steering group in June 2024.

## **11. NILS-RSU Online**

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The NILS website is now housed under a new academic domain ([www.nils.ac.uk](http://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.

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](http://www.nisra.gov.uk/support/research-support)) now includes further information on NILS 2021. Reports from the Alpha and Beta testing phases of the NILS 2021 project will be published here as well as guidance documents for researchers to outline the additional data available in the NILS 2021 database.

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 445 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**

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- 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 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 is part of the learning resources and informs 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 presented on the NILS at the 2023 Society for Longitudinal and Lifecourse Studies (SLLS) International conference in Munich in October 2023.
- We hosted a session of the 2023 Research Methods e-Festival which took place online between 7-9 November 2023 and discussed the use of all three UK Longitudinal Studies.
- Together with NISRA and PHA, NILS co-hosted a half-day event on 21 November 2023 called 'Data-Driven Resilience: Shaping Northern Ireland's Future Post-Covid' bringing together analysts, policy makers and academics to consider the need for an integrated data and research strategy in NI. This received positive feedback and we are considering how we can implement the actions arising from those sessions.
- A pre-launch event was held on 15 December 2023 to showcase the preliminary findings and feedback from the NILS 2021 beta testing process. The report from this was made available to the NILS Steering Group for approval.
- We have submitted the mid-term report to the Economic Social and Research Council and have received feedback which we will take forward in the new NILS grant.
- 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 two interactive workshops.
- We have a new summer NILS intern working with us from Geography at QUB who will complete a programme in data analysis using the NILS over June and August.

- We have had abstracts from the NILS accepted for presentation to ICPG in Belfast (July 2024), BSPS in Bath (September 2024) and IDPLN in Chicago (September 2024).

### 13. RSU Metrics 1 April 2023 – 31 March 2024

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The following metrics are for the period 1 April 2023 – 31 March 2024.

Table 1: NISRA Secure Environment Bookings

Number of distinct bookings for secure environment	461
Number of distinct researchers who have booked into secure environment	30

Table 2: Project Totals on 31 March 2024

	NILS/NIMS Projects	ADR Projects in the NILS Environment
Number of Projects	103/42	19
Number of Active Projects	15	9
Number of Completed Projects	109	6
Number of Pending Projects	5	3
Number of Distinct Linkage Projects (Includes active and pending projects)	5	11

Table 3: Approved/Completed Projects

	NILS/NIMS Projects	ADR Projects in the NILS Environment
Number of projects approved	6	0
Number of projects completed	4	1

Table 4: Projects Approved 23-24

Project Number	Data	Project Title	Organisation	Project Summary
NILS 136	NILS	Complex identities in Northern Ireland, 2011-21	QUB/NISRA	This project explores the relationships between changes in self-reported religious, national, and passport identity between 2011 and 2021. It also analyses the new 2021 question on sexual

				orientation and how non-straight identities are related to hybrid national identities and religious secularisation.
NILS 137	NILS	Health transitions and inequalities from 2011 to 2021	QUB	This project will investigate health inequalities and transitions in Northern Ireland. The first main aim is to characterize the distribution of health status across the population in 2021 and to evaluate any changes since 2011. The second main aim is to estimate individual-level health transitions between 2011 and 2021, with a focus on inequalities by population subgroup.
NILS 138	NILS	Labour market participation and health: contrasting early-life onset disabilities to those acquired in adulthood	NISRA/QUB	This proposal aims to comprehensively examine participation of disabled people in the labour market, examining potential changes in their experiences over time.
NILS 139	NIMS	An examination of health inequalities in Northern Ireland	QUB	This study will examine the health and wellbeing of the Northern Ireland population based on their responses to the self-reported health questions and examine risk and protective factors associated with being a member of a so-called "hard to reach" group.
NILS 140	NILS linked with NICR data	Inequalities in breast cancer presentation, treatment and outcomes in Northern Ireland	QUB	The main research questions are: (1) Does presentation, treatment and outcome differ in breast cancer patients from lower socio-economic backgrounds? (2) Does presentation, treatment and outcome differ in breast cancer patients with disabilities, who are from minority ethnic groups or who are migrants?
NILS 141	NILS	How conflict and peace affect fertility behaviour and infant health: A case study of the Troubles in Northern Ireland	Universitat de Barcelona	This research aims to explore the interplay between peace agreements and the end of frequent violence and fertility decisions as well as infant health outcomes.

Table 5: Outputs and Modifications

	NILS/NIMS Projects	ADR Projects in the NILS Environment
Number of Project Modifications	11	10
Number of Final Outputs	25	18
Number of Intermediate Output Requests/Files	70/134	82/456

Table 6: Number of Project Modifications by Type

Modification Type	NILS/NIMS Projects	ADR Projects in the NILS Environment
Additional Variables added	1	2
Extension to end date	8	4
Additional data added	1	1
Researcher added to project	1	3
<b>TOTAL</b>	<b>11</b>	<b>10</b>

Table 7: Number of Final Outputs by Type

Output Type	NILS/NIMS Projects	ADR Projects in the NILS Environment
Article	1	5
Abstract	5	5
Presentation	9	5
Other	9	1
Poster	1	0
Paper	0	1
Research/Policy Brief	0	1
<b>TOTAL</b>	<b>25</b>	<b>18</b>



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

NILS Project	Requests	Files
066	44	60
081	3	4
106	1	15
122	1	1
126	5	23
129	9	11
901	1	2
903	5	17
905	1	1
<b>TOTAL</b>	<b>70</b>	<b>134</b>

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

Project Number	Requests	Files
245n	1	6
248n	19	98
250n	32	267
255n	20	58
260n	10	27
<b>TOTAL</b>	<b>82</b>	<b>456</b>

## 14. RSU Contact Details

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