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| C:\Users\1526026\Desktop\RSU\Logos\RSU Logos\NILS logos\Powerpoint logos\NILS 2.jpg | NILS/NIMS APPLICATION FORM |

#### The Northern Ireland Statistics and Research Agency (NISRA) is responsible for the Northern Ireland Longitudinal Study (NILS) and the Northern Ireland Mortality Study (NIMS).

**Please refer to the NILS-RSU website for the** [**Research Approvals Group Applications Criteria**](http://www.qub.ac.uk/research-centres/NILSResearchSupportUnit/FileStore/Filetoupload,427895,en.DOCX) **which are used to assess a research proposal.**

**PART A: USER AND STUDY DETAILS**

**SECTION A1 APPLICATION DETAILS**

**Study Title**

This should be a brief informative summary of the research proposal.

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**Proposed Start Date** (DD/MM/YY)

**Proposed End Date** (DD/MM/YY)

*Please ensure that you propose a realistic end date. This can only be amended at a later stage in exceptional circumstances.*

**Contact Details of the Chief Researcher**

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| --- | --- |
| Title |  |
| Name |  |
| Position |  |
| Organisation |  |
| Institutional Address |  |
| Telephone |  |
| Email Address |  |
| Date of last Safe Researcher Training (SRT) |  |
| Date of last Approved Researcher Status (ARS) |  |

**Contact Details of Other Researcher(s)**

Please provide details of all other researchers on the project team.

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| Name | Organisation | Email Address | Date of last SRT | Date of last ARS |
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| **I agree to protect the confidentiality of the NILS/NIMS data.**  **I will follow all the** [**‘Dos and Don’ts’**](http://www.qub.ac.uk/research-centres/NILSResearchSupportUnit/FileStore/Filetoupload,536512,en.DOCX) **as published by the NILS team.**  **I will read and sign the NILS Licence Agreement, NILS Disclosure Control Policy and NILS Security Policy upon approval of this application.**  **Signature: Date:**    (electronic signatures accepted here) |

**Please ensure that all named researchers provide their signature above.**

**SECTION A2 BACKGROUND AND AIMS OF THE STUDY**

**Project Summary/Abstract**

This will be published on the NILS-RSU website if the research proposal is approved (circa 250 words). [See current projects](http://www.qub.ac.uk/research-centres/NILSResearchSupportUnit/Projects/Current/)

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**Relevance of Research Proposal to NILS/NIMS**

Please provide evidence of the longitudinal aspect to the research and explain how the NILS/NIMS data is uniquely placed to contribute to the study.

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Please provide a brief summary of what is known to date about your chosen topic and how the proposed research would contribute.

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**Relevance of Research Proposal to Health & Social Care**

Please indicate how the research proposal relates to Health & Social Care research.

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Please indicate how the research may support the development/delivery of public policy, public service delivery or serve the public good. Please reference any local or national policies where possible.

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**Prior Experience of Researcher**

Please provide detail of your experience or understanding of using longitudinal data and of handling potentially disclosive microdata.

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**Planned Publication and Dissemination of Findings**

Please provide detail on the relevant stakeholders for the research.

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|  | Health bodies such as Department of Health (DoH), Public Health Agency, Health and Social Care Board, Department of Health (England); please specify: |
|  | Other Government Department; please specify: |
|  | Research Council, Charitable Foundation; please specify: |
|  | NISRA; please specify: |
|  | Other; please specify: |

Indicate how you plan to publicise and disseminate the findings of the study.

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|  | Refereed journals  *We aim to publish the findings in a refereed academic journal in the field of health/economics*. |
|  | Report for Government Department, Research Councils or other sponsors  *Economic and Social Research Council (research funder) will be notified of the findings.* |
|  | Internal NISRA reports  *The results could be published via NILS Research Briefs (but not prior to journal publications)* |
|  | Presentations (conferences, workshops, seminars)  *We will seek to present findings at economics and/or health conferences* |
|  | Other; please specify: |

# *You will be required to periodically provide updates on any policy relevance, impact or dissemination activities. This will be throughout the life of the project and for a period afterwards.*

# PART B: SPECIFYING DATA EXTRACT

**SECTION B1 STUDY POPULATION**

**Dataset to be Used** (please select). NILS NIMS

**Study Population**

Please provide a description of the population selected for the study specifying as much detail as possible. Please consider gender, age group, timeframe and the link to Census data.

For example, all male NILS members aged between 15-44 enumerated at the 2001 Census and/or the 2011 Census.

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**Estimated Sample Size**

Please include details of the size of the sample and any subgroups that may be the focus of any analysis. Alternatively provide power calculations. Where possible, please include references for your estimates and please show the calculations used to generate your final sample size.

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**Requested Datasets**

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| **Census Data** |  |  |  |  |
| 1981  1991 |  |  |  |  |
| 2001 |  |  |  |  |
| 2011 |  |  |  |  |
|  |  |  |  |  |
| **Vital Events Data** | |  | **Event Dates** | (please specify if require latest available) | |
| Deaths | |  | from | to |
| Deaths of household members | |  | from | to |
| Births of NILS Members | |  | from | to |
| Births to NILS Mothers | |  | from | to |
| Births to NILS Fathers | |  | from | to |
| Marriages |  |  | from | to |
| **Migration data**  **(NILS only)** | |  |  |  |
| Internal Migration | |  | from | to |
| Immigration/Re-entrants | |  | from | to |
| Emigration | |  | from | to |

**Variables Required**

Please complete this section using the NILS Data Dictionary and, if necessary, in consultation with the NILS-RSU. Please add more rows as necessary.

Please note this dataset can only be updated at a later stage through a project modification form. [Weblink to data dictionary](http://www.qub.ac.uk/research-centres/NILSResearchSupportUnit/Variables/). Please note there is a Microsoft Access version of the Data Dictionary that allows the creation of a variable list which can be inserted below.

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| Table Name | Variable Name | Justification for Inclusion  (necessary for all Restricted variables) |
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**Derived Variables**

You may need to have new variables included in your project dataset which can be generated by the NILS-RSU using existing NILS/NIMS data (including confidential or restricted variables). Please list the input variables required for the derivation and, where possible, show how the new variable will be derived.

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**Additional Information**

Please outline any requirements you may have in relation to attaching external data (other than area-based data at Super Output Area level or above) to your project dataset.

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**SECTION C1 LINKING INDIVIDUAL LEVEL DATA**

A project that involves the linking of individual level data to the NILS is called a **Distinct Linkage Project (DLP)**. DLPs require further steps to be undertaken to comply with legislation and safeguard the confidentiality of the data. Please ensure a letter of support from the external data supplier is submitted to NILS-RSU along with the application form.

**Description of Individual Level Data**

Data Supplier

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Please describe the individual level data and provide information on the Data Custodian and how the data was collected.

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**Individual Level Data Variable List**

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| Variable Name | Description | Justification for Inclusion |
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If you have requested an anonymised GP Practice identifier variable please provide justification for your request below.

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If you have requested an anonymised GP Practice identifier variable will it appear on any outputs? If so, please describe below.

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**Requirement for Individual Level Data**

Please provide evidence of the research need for individual level data to be attached to the NILS and the additional research benefits that could be obtained.

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**Feasibility of Linkage**

Please describe how you have investigated the feasibility of the linkage (e.g. the coverage of the Health & Care Number), the quality of the data and any experience in using the new data.

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**One-Way Encryption Methodology**

The method of linking data using one-way encryption is described in Annex 1. Please confirm that it is appropriate for the data to be linked in this way. If the linkage requires any deviation from this methodology please describe it in detail below.

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**Legal Basis**

Please provide details of any discussions regarding the legal framework for the data and the support of the Data Custodian.

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| **I have provided a letter of support from the Data Custodian.**  **I understand I will require ethical approval from the Office for Research**  **Ethics Committees Northern Ireland (ORECNI).**  **I will adhere to the** [**DoH Code of Practice on Protecting the Confidentiality of Service User Information**](http://www.qub.ac.uk/research-centres/NILSResearchSupportUnit/GuidesResources/Access/Steps1-2Application/)**.**  **I agree to keep NISRA informed of progress and will assist the NILS team**  **in drawing up a Data Transfer Agreement between NISRA and the data**  **supplier.**  **Signature: Date:**  (electronic signatures accepted here) |

**Please ensure that all named researchers provide their signature above.**

**Annex 1 -** **One-Way Encryption Process – for Distinct Linkage Projects**

As part of the Data Transfer Agreement each Distinct Linkage Project requires encryption of the unique identification field (e.g. Health and Care Number).

The NILS encryption software uses the Advanced Encryption Standard (AES) 256 algorithm for a one way encryption of the unique identifier and this will be carried out on both datafiles in situ. The software is designed to read in a dollar ($) delimited text file with column headings where the first column is the unique identifier. It requires 2 distinct text strings, one is the password which forms the basis for the encryption key and the other is additional text to enhance the security of the encryption. Each of these text strings will only be known by the external data provider so that the process cannot be replicated by NILS staff.

The resulting file contains the encrypted unique identifier plus the remaining variables (without the unique identifier) and is sorted in a random order to ensure that the encryption cannot be reversed on record order.

This file is further encrypted using an additional password for transport to the Linkage Centre where the NILS lookup table undergoes the same process with the same password & key (again input by external data provider).

Linkage staff will check both files to ensure fields are as specified in the Data Transfer Agreement. The data file is then matched to the lookup table using the encrypted unique identifier present on both files. This encrypted identifier is removed from the final datafile. This finalised file is then passed over to NILS-RSU where it is made available to the approved Researcher(s) in the safe setting for analysis.

**Diagram 1: Formation of a dataset for a NILS Distinct Linkage Project**

**Researcher Access**

Health & Care No (HCN)

Personal Identifiers removed

**One-way Encryption**

**Full file Encryption**

**Full file Decryption**

**One-way Encryption**

#HCN

Breast Screening Data

NILS Data Extract

NILSID

Breast Screening Data

#Breast Screening Data

NILSID

#NILSID

#HCN

#NILSID

NILS Data Extract

#Breast Screening Data

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NILS Data Extract

**Matching**

**Data Integration & Linkage (DIAL)**

**Northern Ireland Longitudinal Study (NILS) Data at NISRA**

**Breast Cancer Screening Data**

A checklist, with signatures, is used by the relevant parties at each stage of data encryption.

# Document Management

|  |  |
| --- | --- |
| Access Limitations: | None |
| Maintainer: | RSU |
| Document Identifier: |  |
| Replaces: | Version 8 - DF1/15/50478 |
| Review period (months): |  |
| Is related to: | NISRARSU001, NILS013, NILS016, NILS006 |

# Version History

|  |  |  |
| --- | --- | --- |
| Version | Notes | Last Amended |
|  |  |  |
| V10.4 | CMcL: Added Latest Available | 29/10/18 |
| V10.3 | CMcL: Institutional Address | 07/06/18 |
| V 10.2 | CMcL: DHSSPS updated to DoH | 25/11/16 |
| V 10.1 | Updated to add marriages CMcL | 23/09/16 |
| V 10.0 | Reviewed and updated by CMcL | 26/10/15 |
| V 9.2 | DLP section updated | 08/07/15 |
| V 9.1 | Version Control Added – DB RSU | 06/03/15 |
| V 9.0 | Created by RSU | January 2015 |