

## COHORT PROFILE

# Cohort description: The Northern Ireland Longitudinal Study (NILS)

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## How did the study come about?

Northern Ireland has traditionally been well served with cross-sectional studies, including episodic surveys of poverty and social exclusion,<sup>1</sup> and of health and social well-being.<sup>2</sup> However, such studies are of limited use in either analysis of life-course transitions or in the separation of cause and effect, both important goals of current research strategies where renewed interest in equity and social exclusion is stimulating research into the effects of disadvantage on individuals over time. This is all the more urgent given the increased social and geographical mobility and greater fluidity in people's lives. Such information can only be derived longitudinally, and there was a dearth of such large-scale general purpose studies in Northern Ireland. Information had not been included in the three British Birth Cohort studies of 1946, 1958 and 1970<sup>3-5</sup> and although other longitudinal studies, such as PRIME<sup>6</sup> and Young Hearts,<sup>7</sup> are available they were designed to answer research questions related to specific diseases. Although the British Household Panel Study<sup>8</sup> has recently been extended to include Northern Ireland and there is now a Northern Ireland component to the Millennium Birth Cohort Study, neither is large enough to function as a general purpose longitudinal study to meet the general research or policy needs of Northern Ireland.<sup>9</sup>

In the early 2000s, a group of senior statisticians from the Northern Ireland Statistics and Research Agency (NISRA) and academics was convened to estimate the cost of a Northern Ireland Longitudinal Study (NILS), equivalent to others either already available in England and Wales<sup>10</sup> or, at the time, in development in Scotland.<sup>11</sup> The aim was to have a multi-cohort study that would fulfil a range of academic and policy-related purposes, with a sample size

large enough to enable robust analysis of population sub-groups and of areas of policy relevance. Because the experience of the Scottish Longitudinal Study (SLS) team had shown that linkage to the 1991 census would incur considerable costs, especially if social class for earlier years had to be recoded to the NS-SEC classification<sup>12</sup> used in the 2001 census, it was decided to start with the 2001 census.

Funding for the establishment and maintenance of NILS (and its sister study NIMS, see below) was jointly secured in 2003 from the Department of Health, Social Services and Public Safety and the Research and Development Office of the then Health and Personal Social Services. All funding for the development and maintenance of NILS and NIMS now comes from the Health and Social Care Research and Development Division of the Public Health Agency (HSC R&D Division). NISRA helps to fund the NILS/NIMS project both through the provision of accommodation to house all aspects of the NILS/NIMS operation and staff to maintain and develop the databases and provide strategic management of the project. Both NILS and NIMS were launched in December 2006.

## What does it cover?

The goal for NILS is to provide a mechanism for understanding the population health dynamics of Northern Ireland equivalent to that provided by the ONS-LS which has, for the past 30 years, fulfilled this function for England and Wales.<sup>10</sup> The ONS-LS used 4 days of birth in a year to define an initial cohort of ~1% of the population (500 000 people) from which the 1971 census information was extracted and to which routinely collected vital statistics data such as births, deaths, cancer registrations and migration data

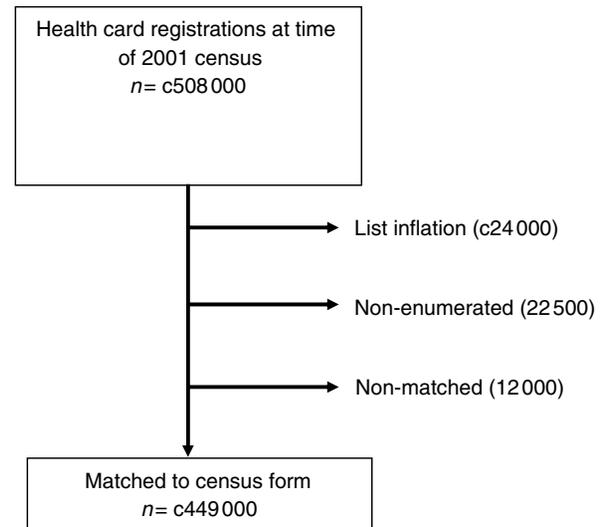
were linked on an annual basis. Using the same days of birth equivalent, cohorts were drawn from censuses of 1981, 1991 and 2001 and linked to the initial cohort as they became available. A similar study has recently been established in Scotland (SLS). This is based on 20 birthdays and currently includes 265 321 people (5.3% of the population), with initial linkages to the 1991 and 2001 censuses.<sup>11</sup>

Although the ONS-LS has been the basis of many academic and government papers,<sup>13</sup> it was thought that, because of the distinct historic, demographic and social conditions of Northern Ireland, a locally implemented longitudinal study would be more directly applicable to these conditions. For example, Northern Ireland has traditionally had the highest fertility and the youngest age structure of any UK region. It is also one of the most deprived regions of the UK and the highest rates of both unemployment and long-term unemployment and lowest proportions of the working age population defined as economically active.<sup>14</sup> Average gross weekly earnings in Northern Ireland are ~15% less than in the rest of the UK and there is a heavier reliance on state benefits, especially means-tested benefits.<sup>15</sup> Northern Ireland also experiences some of the highest levels of poor self-reported health in the UK.<sup>16</sup> Finally, it has a need to monitor its unique social equality legislation,<sup>17</sup> with particular emphasis on the religious divisions and 30 years of civil unrest known locally as 'the Troubles'.<sup>18</sup>

## Who is in the sample?

NILS is a representative sample of the Northern Ireland population (estimated at 1.78 million in June 2008). If someone within the centralized Northern Ireland Health Card registration system has one of 104 pre-designated days of birth they are included in the sample and linked to the census data. In Northern Ireland, people are entitled to 'free at the point of use' health and social care, but they must be registered. Almost 100% of entitled people are contained in this Health Card registration system. This marks an important difference with the ONS-LS and SLS, where inclusion is defined using the census data and then linked to the respective health card registration systems to facilitate linkage to other data sources. Therefore, although the NILS uses date of birth, sex and location (home postcode) from the health card registration system, the majority of cohort attributes are derived from the census record (Figure 1). The health card registrations are arguably a more robust source for the basic demographic data as the census data are captured only once and in 2001 depended on accurate interpretation of electronically scanned census forms.

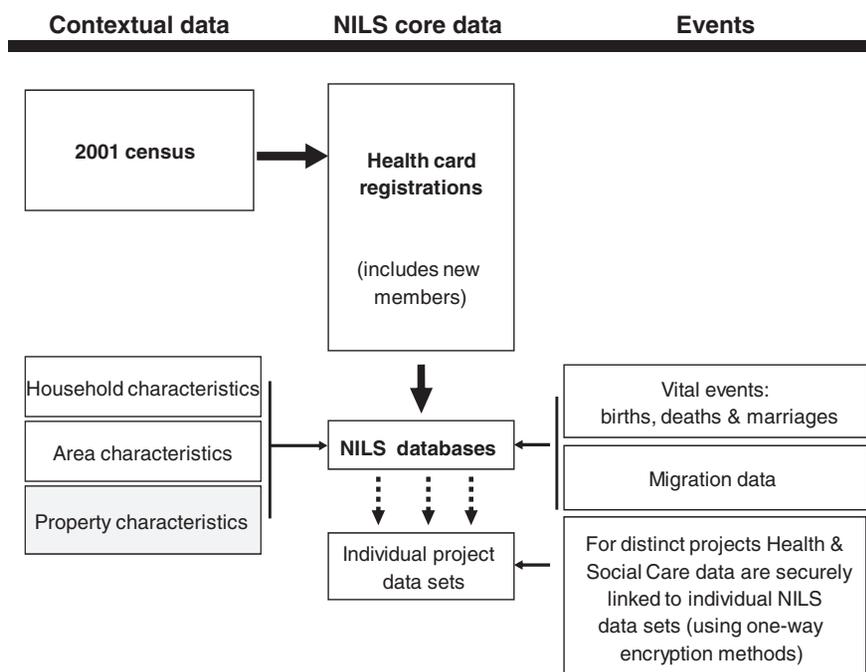
The NILS cohort of c508 000 represents ~28% of health card registrations (Figure 2). An aim of the 2001 census was to produce detailed estimates of



**Figure 1** NILS composition: relationship between health card registration and census records

under-enumeration and to adjust the census counts for this undercount using a process termed the One Number Census<sup>19</sup> approach. Therefore, an additional 4.8% of people were statistically imputed to produce an adjusted total on which the final census results were based. For NILS, this equates to c23 500 people estimated to have been alive and resident in the country but not enumerated in the census. Finally, although the health card registration system contains almost 100% of the population it also includes some records that cannot be matched to the census. These relate primarily to people who have emigrated but not informed the health service, cross-border workers, as well as a small number of duplicate entries. This 'list inflation' is estimated at 4.7%, or approximately 24 000 records of people who ought not to be on the register and therefore cannot have a 2001 census record match. The initial linkage between census and health card registration records was based on an exact electronic match of forename, surname, gender, date of birth and location. For those remaining unlinked records, the matching process was relaxed to include fuzzy matching techniques with clerical assessment and confirmation, and finally, where this proved unsuccessful, wholly manual detailed searching and manual processes were undertaken.

The second study, the Northern Ireland Mortality Study (NIMS), is census based and comprises the whole of the 2001 census-enumerated population (1 603 641 people), to which subsequently registered deaths among residents are linked using a sequence of processes similar to that outlined above for use with the NILS.<sup>20</sup> NIMS is recommended to researchers whose primary interest is mortality, where the larger cohort size enables more robust examination of sub-populations and of specific causes of death.



**Figure 2** Structure of the NILES and linkage of contextual and event data sets

Table 1 compares the NILES and NIMS databases with the 2001 census returns. This shows the capacity of the data sets to represent even relatively small sub-populations and demonstrates that both the NILES and NIMS cohorts are representative of official census outputs. The census returns include imputed persons and therefore have a slightly greater proportion of younger adults, males and people from larger conurbations than in NILES and NIMS.

## How often have they been followed up?

Because with NILES the major linkages are across censuses, the first ‘follow-up’ point will be when the 2011 NILES census cohort is linked. However, a partial linkage with the 1991 census data has been completed; this is classed as partial because it is based on exact electronic matching only. After matching, no personal identifiers that would allow identification of cohort members are included on the research data sets. Vital events such as births and deaths are updated regularly from routine registration data. Linkage to health and social care data is also possible (see below).

## What has been measured?

Table 2 describes the cohort attributes and the outcomes measured. The census is a rich source of

information and includes data on demographic and socio-economic characteristics, employment status and housing tenure. It also includes two indicators of self-reported health status—limiting long-term illness and general health in the year preceding the census. As the census form is based on households NILES can also provide contextual information at this level including: household composition and family structure; the relationship of the cohort member to other household members; access to household amenities; presence of a carer; and number of dependents in the household. Only data for the cohort member are linked over time. One unique household characteristic linked to the NILES database is the rateable value of the residence of the cohort member. This had been derived previously, in 2005, as part of an exercise to determine the level of local tax payable by each household. In addition, NILES receives information on change of address and date of move from the health card registration system, providing data on migration between census dates. Currently, for NILES sample members, these data provide migration information (from 2001 to 2010) on immigration into the sample, emigration out of and re-entries into Northern Ireland and internal migration within Northern Ireland.

The lowest level of geography normally available for analysis of NILES/NIMS data is Super Output Area (average size of approximately 2000 persons), allowing a wide array of area-level characteristics to be added as contextual data, for example an indicator of urban/rural residence;<sup>21</sup> relative deprivation;<sup>22</sup>

**Table 1** Numbers and percentage of NILS and NIMS members and the 2001 census counts

In cohort (number)	NILS, <i>n</i> (%) 448 949	NIMS <i>n</i> (%) 1 603 641	2001 Census <i>n</i> (%) 1 685 267
<b>Age (years)</b>			
0–15	107 337 (23.9)	377 559 (23.5)	398 056 (23.6)
16–34	114 769 (25.6)	421 345 (26.3)	453 703 (26.9)
35–64	165 781 (36.9)	587 391 (36.6)	610 183 (36.2)
65–74	34 160 (7.6)	120 139 (7.5)	123 193 (7.3)
≥75	26 902 (6.0)	97 207 (6.1)	100 132 (5.9)
<b>Sex</b>			
Male	217 430 (48.4)	777 782 (48.5)	821 449 (48.7)
Female	231 519 (51.6)	825 859 (51.5)	863 818 (51.3)
<b>Marital status (≥16 years)</b>			
Married	181 492 (53.1)	640 198 (52.2)	658 083 (51.1)
Never married	107 293 (31.4)	394 885 (32.2)	426 214 (33.1)
Sep/Widowed/Divorced	52 827 (15.5)	190 999 (15.6)	202 914 (15.8)
<b>General health</b>			
Good	313 437 (69.8)	1 121 963 (70.0)	1 179 678 (70.0)
Fair	87 260 (19.4)	310 953 (19.4)	325 929 (19.3)
Not good	48 252 (10.8)	170 725 (10.7)	179 660 (10.7)
<b>Housing tenure</b>			
Owner	337 806 (75.2)	1 193 525 (74.4)	1 233 620 (73.2)
Social renter	77 248 (17.2)	273 645 (17.1)	295 235 (17.5)
Private renter	29 072 (6.5)	113 228 (7.1)	129 958 (7.7)
Other <sup>a</sup>	4823 (1.1)	23 243 (1.5)	26 454 (1.6)
<b>Settlement band</b>			
Urban	176 499 (39.3)	631 086 (39.4)	670 290 (39.8)
Intermediate	150 764 (33.6)	536 153 (33.4)	559 340 (33.2)
Rural	121 686 (27.1)	436 402 (27.2)	455 637 (27.0)

<sup>a</sup>Other category relates to unassigned responses including those residing in communal establishments.

modelled indicator of relative poverty and income inequality;<sup>23</sup> or others supplied by the researcher.

Current routine NILS linkages to vital events data include births to NILS members (mothers and fathers), births of NILS members (babies) and deaths of NILS members. Births data are currently available from 1997 to 2007, whereas mortality data are available from census day 2001 to 2007. Other events, such as deaths among NILS members in infancy, infant deaths to NILS members and stillbirths to NILS members are also available (though this latter is not routinely linked at present). Marriage data sets have been linked for the period 2004–06 and there is potential to link to more updated marriage data based on research demand. Widow(er)hood data sets have also been linked for the period 2001–06; these linkages can also be routinely updated depending on researchers' needs. Ethical approval has been pre-obtained for all research which utilizes these

regular linkages providing the research proposal itself has obtained approval from the NILS Research Approvals Group. These data sets will not include information about the health condition, practitioners or treatments of members.

With NILS the inclusion of the Health and Care number facilitates linkage to health and social care administrative data—including hospital and laboratory systems, screening services, prescribing data (through the electronic capture of dispensed prescriptions) and uptake of dental services. Northern Ireland, unlike the other parts of the UK, has combined health and social services, sharing the same unique Health and Care identifier, so it is possible to link data relating to the care of people in the community or on admission to care facilities. Cancer incidence data from 1993 to the present are held by the Northern Ireland Cancer Registry and can also be linked to NILS. Projects seeking to utilize this type of

**Table 2** Data sets currently held in the NILS

Census data 2001 <sup>a</sup>	GRO vital events data 1997–07
<ul style="list-style-type: none"> <li>• Age, sex and marital status</li> <li>• Religion and community background</li> <li>• Family, household or communal establishment type</li> <li>• Housing, including tenure, rooms and amenities</li> <li>• Country of birth, ethnicity</li> <li>• Educational qualifications</li> <li>• Economic activity, occupation and social class</li> <li>• Migration (between 2000 and 2001)</li> <li>• Limiting, long-term illness, self-reported general health, caregiving</li> <li>• Travel to work</li> </ul>	<ul style="list-style-type: none"> <li>• New births into the sample</li> <li>• Births to sample mothers and fathers</li> <li>• Stillbirths to sample mothers (on demand)</li> <li>• Infant mortality of children of sample mothers and fathers (on demand)</li> <li>• Deaths of sample members</li> <li>• Marriages 2004–06</li> <li>• Widow(er)hoods 2004–06</li> </ul>
LPS property data 2010	Health card registration migration data 2001–10
<ul style="list-style-type: none"> <li>• Capital and rating value (based on 2005 valuation exercise)</li> <li>• Household characteristics (no. of rooms, property type, floor space, central heating)</li> </ul>	<ul style="list-style-type: none"> <li>• Immigrants into the sample</li> <li>• Emigration out of Northern Ireland of sample members</li> <li>• Re-entries into Northern Ireland after previous emigrations of sample members</li> <li>• Migration within Northern Ireland of sample members</li> </ul>

<sup>a</sup>These data are available for NILS members and for all members of households with at least one NILS member.

linkage—i.e. data not routinely linked—are regarded as very sensitive. They are called Distinct Linkage Projects and each must have specific ethical approval from the Office of Research Ethics Committees for Northern Ireland (ORECNI). With these projects a process of one-way encryption is employed on the key linking fields of each data set to maximise confidentiality and security of the data. This is done on a project by project basis.

## What is attrition like?

Northern Ireland has a relatively stable but growing population: in the decade from 2000 to 2009 this has amounted to an average increase of approximately 11 000 persons per year—with a range of 3938 (2000) to 17 529 (2007). Because of the dynamic nature of the NILS databases this increase is fully reflected in the NILS sample (which increases at ~2.3% per year). However, these additional cohort members will not have any census contextual data until the linkage of the 2011 census. As with its sister UK longitudinal studies, linkage to routine administrative databases involves no responder burden so responder bias is not a problem.

## What has it found? Key findings and publications

The majority of published outputs thus far are of studies using NIMS, though this is likely to change as NILS analyses develop. One of the earliest studies

published used a unique opportunity afforded by the NIMS linkage of all deaths to Northern Ireland residents, to study the characteristics of people whose registration events could not be linked to the enumerated population.<sup>20</sup> In other longitudinal studies this is estimated by comparison against mortality rates for the country as a whole.<sup>24</sup> In the NIMS data set, although all deaths can theoretically be linked, the actual overall linkage between mortality data and the census was 94%, comparing favourably with other mortality linkage studies (such as New Zealand<sup>25</sup> and Switzerland<sup>26</sup>). The characteristics of the unlinked deaths records related primarily to non-enumeration at the census and to differences in the information recorded on the census form and death certificate which precluded linkage. These findings are likely to be applicable to all other census-based longitudinal studies.

The completeness of NIMS coverage allows more robust analyses of smaller population subsets than is generally possible using other UK longitudinal studies. For example, the one strand of research has focused on health outcomes associated with the different religious denominations in Northern Ireland: one study examined cause-specific mortality and reported that those who could be classified as being from a more 'fundamentalist' Protestant tradition showed low mortality risks when compared with other religious denominations, especially from diseases related to alcohol and tobacco.<sup>27</sup> NIMS also facilitates study of less frequent causes of death such as suicide<sup>28</sup> and mortality related to alcohol consumption<sup>29</sup> and found little apparent independent area influences on either cause of death.

One of the unique features of NILS is the ability to study migration patterns. In general, although researchers using census-based longitudinal studies have to wait for the following census to determine change of address and living circumstances, but because NILS is built around the health card registration system, changes to registration details (including address) are regularly integrated with NILS providing information on population movement during the inter-censal periods. Although such data are known to provide limited information on international migration they are considered robust for internal migration, albeit with some delay before address changes are registered centrally.<sup>30</sup> NILS has used these data to study the relationship between migration and health<sup>31</sup> and, by reference to lists of registered nursing homes, the predictors of admission to these institutionalized settings.<sup>32</sup>

The inclusion of the unique Health and Care number in NILS enables the potential linkage of the census to health care data for distinct projects. To date, two Distinct Linkage Projects have been undertaken: one looking at the socio-demographic and area-level factors related to uptake of breast screening; and a second examining variations in registrations for free dental care and uptake of dental services among younger people.

A complete list of current, pending and completed projects and outputs in terms of papers and reports is on the NILS website (see below).

## What are the main strengths and weaknesses?

The primary strength of NILS is that it is large and representative. It is also extendable: as noted in detail above, the presence of the Health and Care number provides a conduit for potential linkage of health services databases. Finally, unlike other population-based studies NILS includes residents in institutionalized care and it has been used to quantify higher mortality among residents in care homes and mortality differences between those in nursing and residential homes.<sup>33</sup> NILS, therefore, has the potential to study a wider range of outcomes of possibly more immediate relevance to policy makers than the vital events such as mortality usually associated with such studies.

NILS is similar in structure to the ONS-LS and SLS and, given the close correspondence in census questions across the separate jurisdictions, this means that three equivalent longitudinal studies now cover the whole of the UK, allowing the potential for pan-UK analyses and cross-country comparisons. A feasibility study combined aggregate data sets from NILS with equivalent extracts from its sister studies to show variations in the relationship between self-reported health and mortality across the UK that are strongly

suggestive of cultural difference in the perception and reporting of health.<sup>34</sup>

## Weaknesses

The census, which is the basis for much of the power and utility of NILS, is also the source of some of its limitations. Approximately 5% of the Northern Ireland population was not enumerated in the 2001 census and this is thought to disproportionately affect younger adult males from deprived inner city areas.<sup>35</sup> For those who are not enumerated vital events and other outcomes cannot be linked to a census record and this may be further compounded by data matching which is needed when there is no unique identifier as in countries with a population register.<sup>36–38</sup>

The cohort attributes are largely dependent on the breadth and depth of the census questions. The two self-reported health measures, though potent-independent predictors of future mortality risk and health services usage,<sup>39</sup> are limited, especially with regard to measures of mental health. This, however, may be addressed to some extent by an expanded array of health-related questions to be included in the Northern Ireland 2011 census. Unfortunately, UK censuses do not contain information on lifestyle factors such as smoking, as is the case in New Zealand.<sup>40</sup> No measure of income is included, though with NILS this is compensated for to some extent by the inclusion of the value of the household residence which can be used as a proxy of longer-term socio-economic status.<sup>41</sup>

A further limitation with NILS and similar studies is that they begin with a census, essentially a cross-sectional study from which, in its initial phases, it is difficult to separate cause from effect. Controlling for health selection effects was a problem faced by the earliest researchers using the ONS-LS to understand the relationship between unemployment and subsequent mortality,<sup>42,43</sup> but it has also surfaced with NIMS when studying the (lower) mortality associated with caregiving.<sup>44</sup>

## How can I collaborate? Where can I find out more?

Both NILS and NIMS contain extremely sensitive data and great care is taken to ensure their appropriate and safe use. They are managed by NISRA under census legislation and access is strictly controlled and governed by protocols and procedures that ensure data confidentiality. All NILS research project data sets are held on a stand-alone isolated network, access to which is password protected, on PCs which are not connectable to any peripheral devices and with all ports disabled. Access to this network is possible only from within the controlled 'secure setting'

located in NISRA Headquarters in central Belfast, entry to which must be pre-arranged. Researchers are supervised at all times. Only the small group of individuals responsible for maintaining the databases have access to the days of birth used for selection to NILS. Data sets are anonymized at the point of use and all electronic and hardcopy outputs are scrutinized to ensure they do not breach disclosure limits—for example, tables with individual cell counts of less than 10 are not released to researchers.

All aspects of NILS are overseen by a Steering Group and prospective projects assessed by a Research Approvals Group (RAG), who grant access to the data. All researchers involved with a NILS project must sign a set of licence agreements to ensure compliance with statutory and regulatory rules relating to data protection and privacy before using the data.

Operationally, a NILS Research Support Unit (NILS-RSU) is available to guide users through these processes and to provide advice and assistance to prospective users of the data. Anyone wishing to use NILS or NIMS data should contact the NILS-RSU who will help in defining a project; selecting appropriate variables; and completing an application form for submission to the Research Approvals Group. When a project has been approved, NILS-RSU will set up a project data set and assist with analysis and interpretation of results. Although researchers are expected to carry out their own analyses, it is possible for researchers to carry out these remotely, by sending command files to be run on their data, with the results checked and forwarded to them.

Anyone interested in accessing NILS or NIMS should visit our website [www.nils-rsu.census.ac.uk](http://www.nils-rsu.census.ac.uk) where they can obtain further and more detailed information about the data sets and a step-by-step guide through the processes. Alternatively potential researchers can contact the support officers at [nils-rsu@qub.ac.uk](mailto:nils-rsu@qub.ac.uk).

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**Conflict of interest:** None declared.

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