



*Improving Your Health and Wellbeing*

# **The NILS: Present Opportunities and Future Prospects after 2011**

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# Structure

- The NLS environment
  - Structure
  - Access
  - Context
- Selected current projects
  - Data linkage projects
- Future opportunities
  - 2011 link
  - New data linkages

# The NILS environment

***Northern Ireland Longitudinal Study (NILS)*** – 28% sample (c. 500,000), based on health card registrations, routinely linked to:

- 2001 Census & 1991 Census (part)
- vital events (births, deaths)
- change of address (health card registration)

**AND** potential to link to

- distinct health & social care datasets

***Northern Ireland Mortality Study (NIMS)*** – total enumerated population in 2001 Census Day linked to:

- 2001 Census returns
- subsequently registered mortality data

# The NILS environment

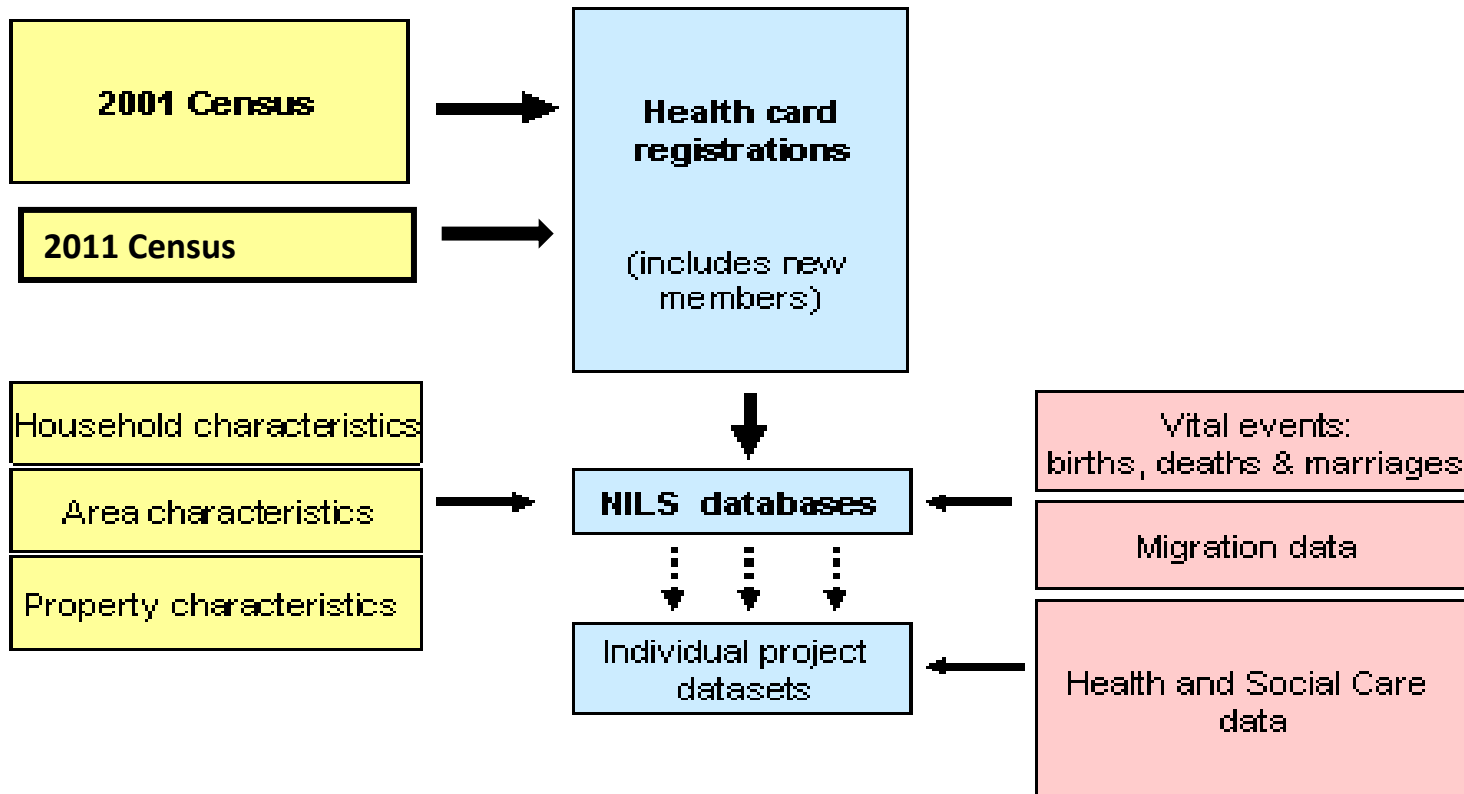
- **Legislation**
  - NILS confidentiality protected, managed under census legislation
  - NISRA have consulted:
    - Information Commissioner for Northern Ireland
    - Office of Research Ethics NI
    - Health and Social Care Privacy Advisory Committee
- **Funding**
  - Infrastructure funded by the HSC R&D Division & NISRA
  - Research support funded by ESRC Census Programme and NI Executive

# Data Structure

Contextual data

NILS Core Data

Events





# Datasets Routinely Linked

## Census Dataset 2001

## GRO Vital Events Datasets 1997 -

Variables include:

Age, sex and marital status  
Religion and community background  
Family, household or communal type  
Housing, including tenure, rooms and amenities  
Country of birth, ethnicity  
Educational qualifications  
Economic activity, occupation and social class  
Migration (between 2000 and 2001)  
Limiting, long-term illness, self-reported general health, caregiving  
Travel to work

- New births into the sample
- Births to sample mothers and fathers
- Stillbirths to sample mothers
- Infant mortality of children of sample mothers and fathers
- Deaths of sample members 2001-
- Marriages 2004-2006
- Widow(er)hoods 2004-2006

## LPS Property Data 2010

## Health Card Registration Datasets 2001-2010

Capital and rating value (based on 2005 valuation exercise)

Variables include:

- Household characteristics (no. of rooms, property type, floor space, central heating) and valuation
- Estimated capital value

- Demographic data: age, status and location
- Migration events:  
immigrants added to the sample  
emigration of sample members  
re-entry of sample members to NI  
migration within NI

# Access

- Access via the NILS-RSU
- Remit
  - raise awareness of the NILS research potential;
  - assist with development of research ideas and projects;
  - facilitate access to NILS data
  - training & advice in use and analysis of NILS datasets;
  - promote policy relevance
  - enhance NILS research capacity including: specific duty to assist government researchers and to undertake exemplar public policy research
- Researchers can access data only within a ‘secure setting’ (NILS-RSU office at McAuley House)
  - However, arrangements can be made to run analyses remotely
  - Researchers must sign and abide by user licenses & security policies;
  - Disclosure control thresholds in place to protect confidentiality of the data: no tabulated cell counts less than 10; and
  - All outputs must be cleared by NISRA staff.

# Access

- Academic or government researchers formulate projects in discussion with NILS-RSU staff
- Projects must be longitudinal; have a health dimension; and are strongly encouraged to have policy relevance
- RSU staff help researchers to complete the research application forms (<http://www.qub.ac.uk/research-centres/NILSResearchSupportUnit/UsefulDocuments/>)
  - They advise on
    - Variable selection
    - Data extraction
    - Policy and health relevance
- Application forms are then sent to the Research Approvals Group (RAG) with membership from NILS stakeholders and funders



# Context

- Each of the UK LSs has special features and advantages
- The large NLS sample (28%) permits more finely-grained geographical analysis than is possible elsewhere
- The NLS is *not* census based (instead based on health registrations) – an important consideration given debates about the future of the UK census
- The NLS also has a strong policy/impact agenda embedded within it – eg. one member of the RSU is funded by the NI government with a specific government policy remit

# Context

- Policy outreach
  - Government researchers involved in NILS projects
  - Researchers engage policy-makers with their findings:
  - Personal contact (**formalised through application**)
  - Dissemination of findings through:
    - NILS-RSU Ezine 'NILS News' / email alerts
    - **NILS Research Briefs**
    - NILS-RSU website
    - NILS User Group / Research Forum
    - Promotional activities i.e. seminars, workshops & conferences
- Future plans aim to increase the policy relevance and impact of NILS-based research

# Context

- The policy emphasis of NILS fits into the ESRC (and REF) emphasis on ‘impact’
- The ESRC also promotes the development of the UK’s data infrastructure and has emphasised longitudinal and administrative data
- The NILS is therefore a major element in the ESRC’s engagement with NI
- The data provided by the NILS and NIMS also is a crosscutting resource for social science research that addresses the three ESRC strategic priorities
  - Economic Performance and Sustainable Growth
  - Influencing Behaviour and Informing Interventions
  - A Vibrant and Fair Society

# **Current Projects: Policy Relevant Themes**

- **Over 50 projects (past and current)**
- **Inequalities in Health & Mortality**
- **Demographic Trends**
- **Education, Employment & Income**
- **Area-Based Analysis**
- **Equality Legislation Groups (NI = Section 75)**
- **Distinct Linkage Projects**

# Collaborative Projects with Government Researchers

- Temperature-related mortality & housing (**DSD**)
- Distribution of cancer deaths by population & household type (**DHSSPS / NI Cancer Registry**)
- Projected fertility levels by area & community background (**DENI**)
- Vital events: Standard Table Outputs (**DMB**): *more detail next slide*
- Educational attainment, occupational group & mobility (**DEL**)
- Pervasive area poverty: modelled household income (**OFMDFM**)
- Equality assessment of health outcomes: cause-specific mortality for Section 75 groups (**DHSSPS**) / Section 75 groups & social disadvantage (**OFMDFM**)

# Vital events: Standard Table Outputs (DMB)

- Vital Events Standard Outputs 2001-2010 – Using the NILS to produce
  - Annual Standard Outputs of Births & Deaths by Demographic, Socio-Economic and Area Characteristics.
  - Correlates of deaths and births by:
    - community background
    - educational attainment/qualifications (at parental level for births data),
    - socio-economic & employment status
    - economic activity
    - household size, composition and tenure
    - household capital value
    - settlement classification
    - area deprivation
- Meet immediate policy needs for accessible information on demographic characteristics and change for all aspects of service planning in Northern Ireland

# Distinct Linkage Projects (DLPs)

- Potential to link to health and social services data for specially defined one-off studies; so far successfully linked to **Breast Screening, Dental Activity** and **Prescribing** data
- Legal and ethical scrutiny and privacy protection protocols:
  - Study period and specific data transfers agreed
  - Legal basis for data transfer
  - Health and Social Care Privacy Advisory Committee informed
  - Ethics – database modification application (ORECNI)
- One-way encryption methodology:
  - Developed in Scotland to safeguard sensitive census and health and care data
  - Datasets are matched and merged on an encrypted unique identifier
  - Researchers not involved in the linkage processes; only have access to an anonymised dataset

# Current & Pending NILS DLPs

- **BSO dental activity data:**
  - adolescent dental health and use of dental care services (PhD thesis)
  - Child dental health and use of dental care services (ongoing)
- **BSO prescribing data:**
  - pharmaco-epidemiological studies of characteristics related to; anxiolytic and anti-depressants (pending) diabetes (pending) & anti-obesity medication (pending), antidepressant use among women of reproductive age (submitted for approval)
- **QARC breast screening data:** variations in breast screening uptake (PhD thesis & 2 peer-reviewed papers published)
- **SOSCARE: social services admin data:** children and families with long term and complex needs (pending)
- **Child Health System data** (gestational age, smoking status and birth weight): lone mothers and socio-economic characteristics (pending)
- Assessing differences between Census and healthcard addresses – GP linkages to explore the influence of practice (pending)



# Future prospects

- The 2011 Census link has been approved
- This opens the way to new research opportunities
- Transitions:
  - Between social strata i.e. the magnitude, direction and correlates of social mobility.
  - Between health states identifying possible causes.
  - Between types of residential accommodation e.g. admission to institutional care etc
  - Between areas:
    - such as deprived and affluent areas, to explore the effect of selection on the increasing health disparities between areas over time.
    - or population mobility, denomination and segregation.
    - or post-retirement residential mobility.
    - or educational attainment and emigration.
    - or changes in travel to work distances over time.
  - Between denominational states e.g. as a measure of secularisation.
  - Between strata of economic activity (e.g. from employment to unemployment, employment to retirement etc).

# Future prospects

- Inequalities:
  - Relationships between socio-economic status and a greater array of health indicators, especially mental and emotional health (which hitherto has been very poorly examined).
  - Change in relationship between socio-economic status and health and mortality risk over time.
  - The role of health selection and social mobility.
  - Variations between educational status at one census and employment status at the next.
  - Geographical distribution, and needs, of ethnic minorities/A8 residents
- Possibility of full link back to the 1991 Census (partial electronic link already in use)
- But future of the NLS may lie in other directions such as the linkage of administrative data

# Future prospects

- Aspirational links
  - Education data?
    - School census, HESA?
  - Benefits data?
    - ESA?
    - Incapacity benefits?
- Large legal, institutional and ethical barriers so further data linkages a long time coming?
- And yet.....

# Future prospects

- Amongst possible replacements for the traditional Census is large-scale administrative data linkage
- Barriers to data sharing could quickly fall down if this is the chosen route forward, data linkage studies like the UK LSs might become 'test beds' for post-2011 UK Census replacements, LSs as data linkage studies might become important elements in UK Census replacements/ supplements

# Future prospects

- The NLS, with its relatively large sampling fraction, is well placed to act as laboratory for
  - Data linkage
  - The assessment of the accuracy of geographical information from administrative data
- Time to increase the sampling fractions of other UK LSs? Time to increase the NLS sampling fraction?
- There is a debate to be had about the place of the UK LSs in a (potentially) post-census era...

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