
The Northern Ireland Longitudinal Study (NILS)

Providing a Framework for Policy and an Analysis of Outcomes

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Outline

- Background
- the resource
- Case Studies
- Research Potential
 - ‘straightforward’ projects
 - distinct linkage projects
 - 2001-2011 census link
- the consideration of policy



Background

Northern Ireland Longitudinal Study (NILS)

28% representative sample of NI population (c.500,000);
selected from the health card registration system; and
routinely linked to:

- 2001 Census returns (complete linkage);
- 1991 Census returns (electronic linkage);
- registered vital events (births, deaths, marriages);
- change of address and migration data (health card); and
- characteristics of residential properties.

AND also with the potential to link to

- distinct Health & Social Care datasets
- 2011 Census returns



Background

Northern Ireland Mortality Study (NIMS)

total enumerated population on 2001 Census Day; linked to:

- 2001 Census returns
- subsequently registered mortality data



Background

History:

- ONS-LS (E&W) links census data from 1971-2001;
- Scottish LS since 2006;
- Focus on socio-demographic & socio-economic influences on health

Research-Driven

- Move from Cross-sectional analyses; to
- the Study of change in the circumstances of individuals over time;
- Implementation of the ONS-LS allowed accurate assessment of occupational social class and cause of death.



Background

Legislation

- managed under **census legislation**:
- main concern: **maintenance of confidentiality**

- NISRA have consulted with:
 - Information Commissioner for Northern Ireland
 - Office of Research Ethics NI
 - Health and Social Care Privacy Advisory Committee

Funding

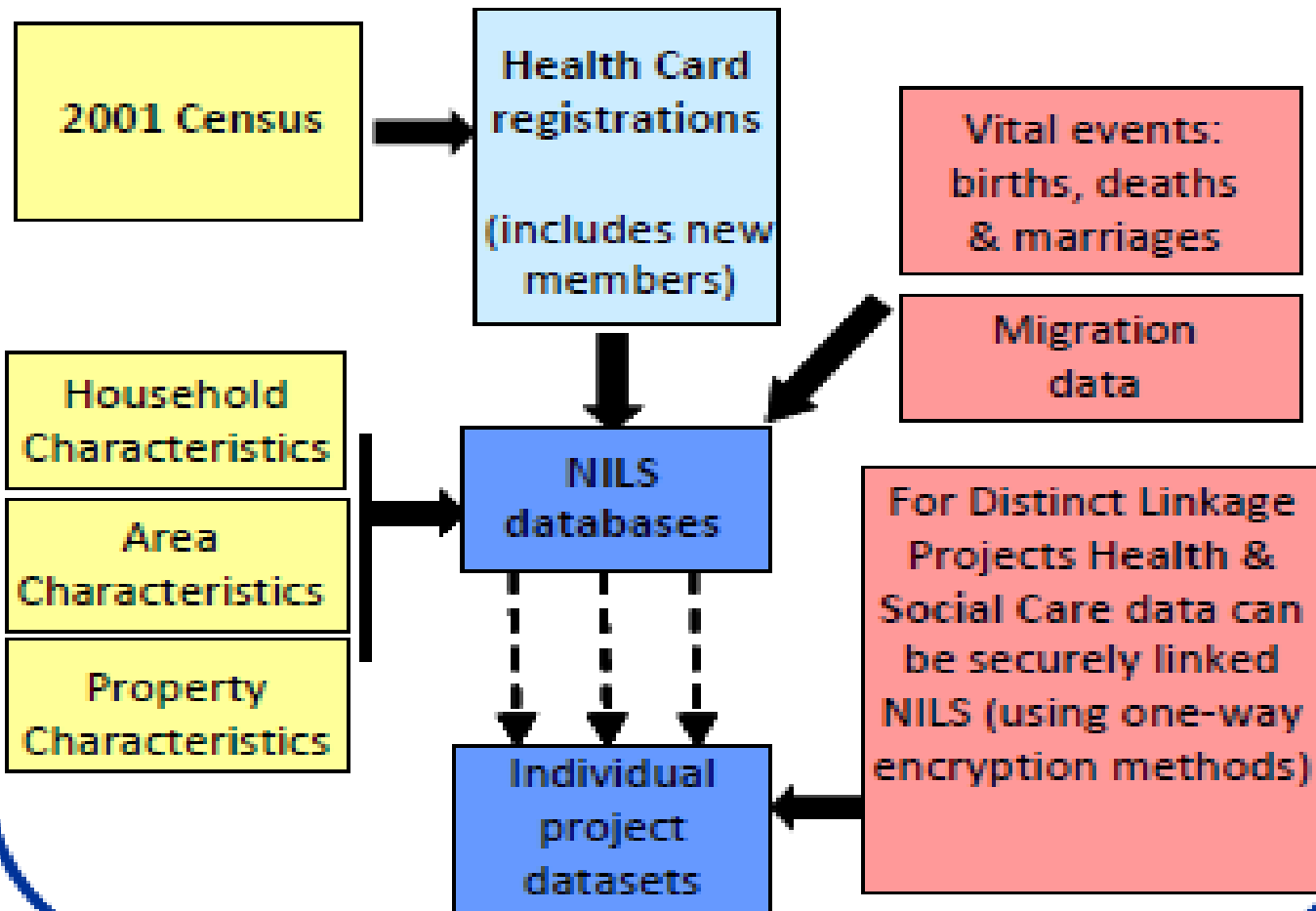
- Infrastructure funded by the HSC R&D Division & NISRA;
- Research funded by ESRC Census Programme & NI Government.

Structure of the NILS

Contextual data

NILS Core data

Events



Databases that are currently routinely available

Census Data 2001

- Age, sex, marital status
- Religion & community background
- Family, household & communal establishment
- Housing, tenure, rooms & amenities
- Country of birth & ethnicity
- Educational qualifications
- Economic activity, occupation & social class
- Migration (between 2000 & 2001)
- LLTI, general health, care-giving
- Travel-to-work

GRO Vital Events Data

- New births into the sample
- Births to sample members
- Stillbirths to sample mothers
- Infant mortality: of children of LS members
- Deaths of sample members
- Marriages
- Widow(er)hoods

LPS Property Data

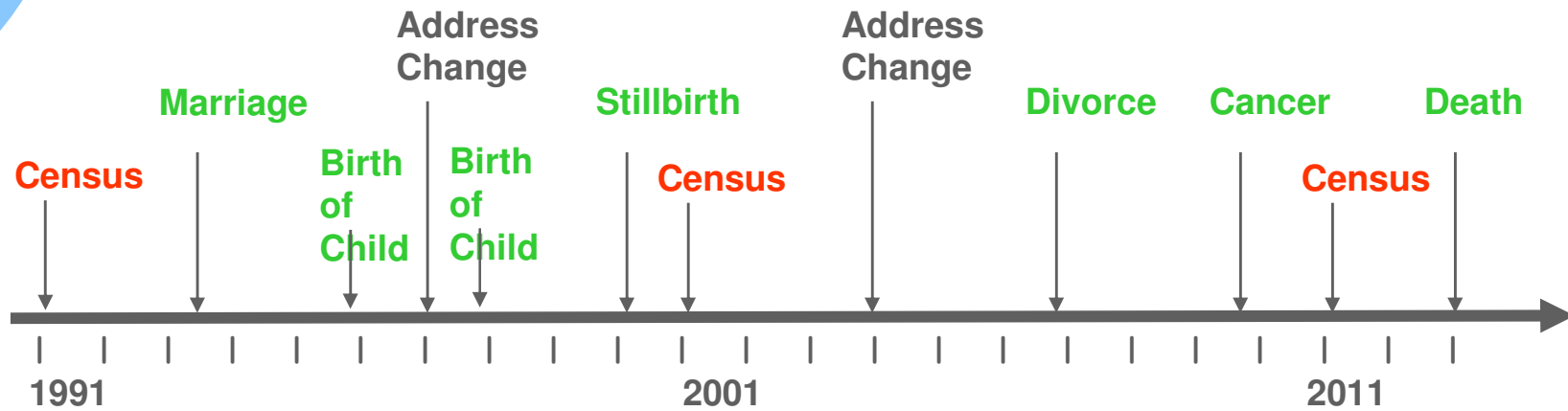
- Capital and rating value
- Household characteristics
(rooms, property type, floor space, central heating)

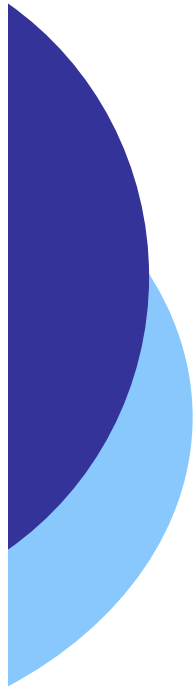
Health Card Registration Databases

- Demographics: age, status & location
- Migration:
 - Immigration into the sample
 - Emigration out of the sample
 - Re-entry of sample members to NI
 - Internal migration

Example

27-year old Female in 1991





Resources: NILS Research Support Unit (NILS-RSU)

Remit:

- raise awareness of NILS research potential;
- assist with development of research ideas and projects;
- facilitate access to NILS resource;
- training & advice in use and analysis of NILS datasets;
- promote policy relevance; and
- promote research capacity: including specifically to develop a programme of research involving government researchers using NILS to undertake public policy research.



Resources: NILS Research Support Unit (NILS-RSU)

Remit:

- See <http://www.qub.ac.uk/research-centres/NILSResearchSupportUnit/> for documents/application forms;
- Necessary conditions for projects:
 - (a) Health dimension - very broadly defined
 - (b) longitudinal aspect
- projects using the main NILS or NIMS data only are classed as straightforward and can expect to be undertaken quickly
- projects which involve linking the NILS to other administrative databases require specific ethical approval and additional data undertakings can take more time to organise and complete.



Research Potential: Policy Outreach

- Government researchers involved in NILS projects
- Researchers engage policy-makers with their findings
- NILS Research Briefs: summary of key findings & policy implications of NILS-based research

<http://www.qub.ac.uk/research-centres/NILSResearchSupportUnit/NILSResearchBriefs/>



Research Potential: Collaborative Government Projects

- Temperature-related mortality & housing: movement between and within Neighbourhood Renewal Areas (**DSD**)
- Distribution of cancer deaths by population & household type (**NI Cancer Registry**)
- Projected fertility levels by area & community background (**DENI**)
- Vital events reporting: Annual standard tabular outputs (**DMB**)
- Educational attainment, occupational group & mobility (**DEL**)
- Pervasive area poverty: modelled household income / Section 75 groups & social disadvantage / Spatial measures of need (**OFMDFM**)
- Equality assessment of health outcomes:
cause-specific mortality for Section 75 groups (**DHSSPS**)
- Socio-economic, cultural & demographic determinants of antibiotic prescribing patterns (**BSO-HSC**)



Case Studies

- Socio-demographic & area correlates of **suicides** (005)
- **Religious denomination** & health outcomes (self reported health/mortality) (011)
- Influence of demographic, socio-economic & area level factors on **uptake of breast screening** (021)
- Equality assessment of health outcomes: cause-specific **mortality for Section 75 groups**
- Socio-economic, cultural & demographic determinants of **antibiotic prescribing patterns** in NI



(1) Area Factors & Suicide

Background:

Suicide rates vary between areas: individual characteristics (composition) or area characteristics (context)?

Aim:

To determine if area factors are independently related to suicide risk after adjustment for individual and family characteristics.

Method:

5-year record linkage study using NIMS based on c.1.1 million individuals aged 16-74 years (and not living in communal establishments)

Results:

- i. suicide risks lowest for women & for those married/cohabiting;
- ii. higher relative risks recorded in more deprived & socially fragmented areas disappeared after adjustment for individual & household disadvantage



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Suicide rates 'not down to area'

Individual circumstances are the key to understanding why someone takes their own life, a study has indicated.

Queen's University researchers said differences in rates of suicide were due to people's characteristics, not differences between location.



Researchers believe it could mean a shift of emphasis in policy

Once individual characteristics were taken into account, "higher rates of suicide found in more deprived and socially fragmented areas disappeared".

The findings are published in the British Journal of Psychiatry.

The researchers believe it could mean a shift of emphasis in policy for those working in the field.

Dr Dermot O'Reilly, who led the research, said it confirmed suicide risk was very strongly related to both individual and household characteristics such as age, gender, marital status and socio-economic circumstances.

"What has been less clear is whether the characteristics of the area in which you live represent an additional independent risk," he said.

"The study shows that variation in suicide rates between areas in Northern Ireland is entirely explained by the differences in the characteristics of the people living in these areas.

"Where you live doesn't add to that risk."

NO LINK BETWEEN SUICIDE AND AREA

By MAURICE FITZMAURICE

WHERE you live has no bearing on whether or not you will take your life, an academic study claimed yesterday.

The study, lead by Dr Dermot O'Reilly, found that people who kill themselves do so for a variety of reasons.

However, he found that once individual and household characteristics had been taken into account, higher rates of suicide found in the more deprived and socially fragmented areas disappeared.

Dr O'Reilly said: "Suicide risk is strongly related to individual and household characteristics such as age, gender, marital status and socio-economic circumstances. What

Study says age, sex & work are 'key factors'

has been less clear is whether the characteristics of the area in which you live represent an additional independent risk.

"The study shows variation in suicide rates between areas in Northern Ireland is entirely explained by the differences in the characteristics of the people living in these areas.

"Where you live doesn't add to that risk."

The findings, published in

this month's issue of the British Journal of Psychiatry, could mean a shift of emphasis in policy.

The research, which involved more than a million people in Ulster is one of the largest long-term studies of suicide risk undertaken in the UK.

In 2006 the Northern Ireland Statistics and Research Agency

linked the records of 1,116,741 people aged 16 to 74, counted in the 2001 census, to deaths in the subsequent five years.

During this period, 566 deaths were suicide or of "undetermined intent".

The report also found suicide is three times higher in men than women and is three times higher in people under 55. Living alone increases the risk by a third.

Unemployment also greatly increases the chances of suicide while married or co-habiting couples face a smaller risk.

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Research Potential: Policy Relevant Themes

Currently:

- Inequalities in health & mortality
- Demographic trends
- Education, employment & income
- Area-based analyses
- Equality research
- **Distinct Linkage Projects**

2011 Census Linkage (planned for end 2013)

- linkage of information from the 2001 & 2011 censuses,
- significant information from the 1991 Census
- 14 years of births data; and
- 9 years of deaths data.
- analysis of health, social, economic & demographic **transitions**
- focus on research & policy interests across health, demography, equality, migration, deprivation, labour market & social change



2011 Census: New Topics = New Research Potential

Equality Research

- Same-sex partnerships
- Language
 - ability in Ulster-Scots
 - main language (if not English, asked how well they can speak English)
- Migration (how long intend to stay)
- Citizenship (what passports they hold)
- National identity

Socio-Economic Trends

- Information on qualifications gained outside the UK
- Voluntary Work

Area-based Analyses

- Travel to school / address of study



2011 Census: New Topics = New Research Potential

Health & Mortality:

Changes:

General health - 5 options : Very good; Good; Fair; Bad & Very bad

Limiting long-term illness - 3 options: Yes, limited a lot; Yes, limited a little, No

New:

-Adapted accommodation

- Nature of disability

- Deafness or partial hearing loss
- Blindness or partial sight loss
- Communication difficulty
- A mobility or dexterity difficulty
- A learning difficulty, an intellectual difficulty, or a social or behavioural difficulty
- An emotional, psychological or mental health condition
- Long-term pain or discomfort
- Shortness of breath or difficulty breathing
- Frequent periods of confusion or memory loss
- A chronic illness (such as cancer, HIV, diabetes, heart disease or epilepsy)
- Other condition



Distinct linkage projects

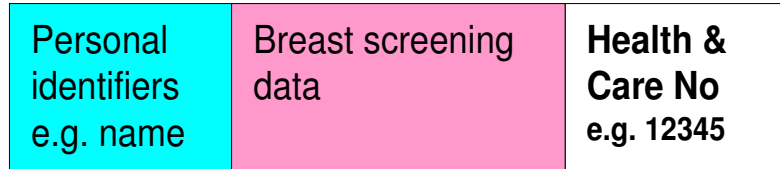
Innovative part of the overall research strategy - allows linkages not possible using the other longitudinal studies

Individual 'health & care identifier' allocated to everyone in NI – provides the key for the linkages noted below.

Currently a number of these ongoing (some noted already in passing):

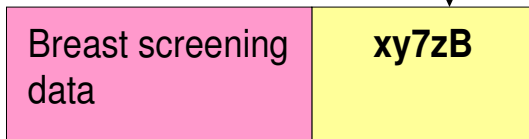
- (1) Breast screening
- (2) Lone mothers & child health data
- (3) The prescribing of anti-depressants around the time of birth
- (4) Socio-demographic influence & anti-depressants
- (5) Socio-demographic & cultural influence on antibiotic prescribing patterns
- (6) Socio-economic determinants of dental activity in adolescents (& children)
- (7) Linkage with NI Cancer Registry data

Breast Cancer Screening Data at (QARC)



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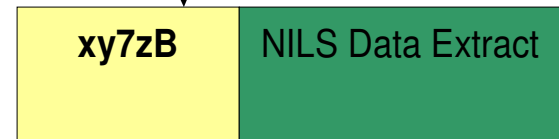
One-way encryption



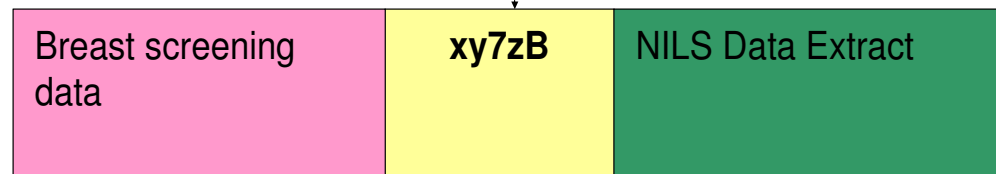
Northern Ireland Longitudinal Study (NILS) Data at NISRA



One-way encryption

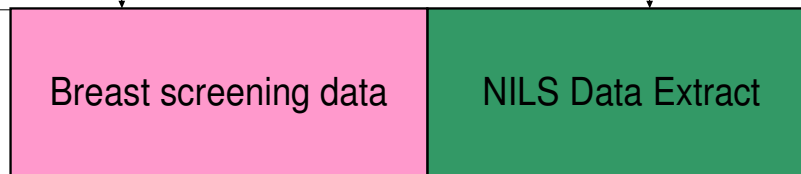


Matching



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Researcher access

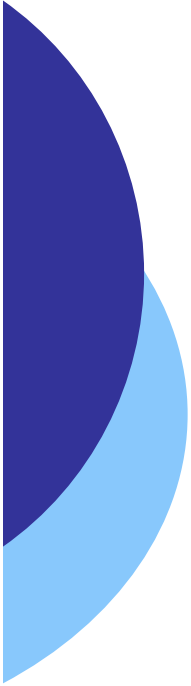




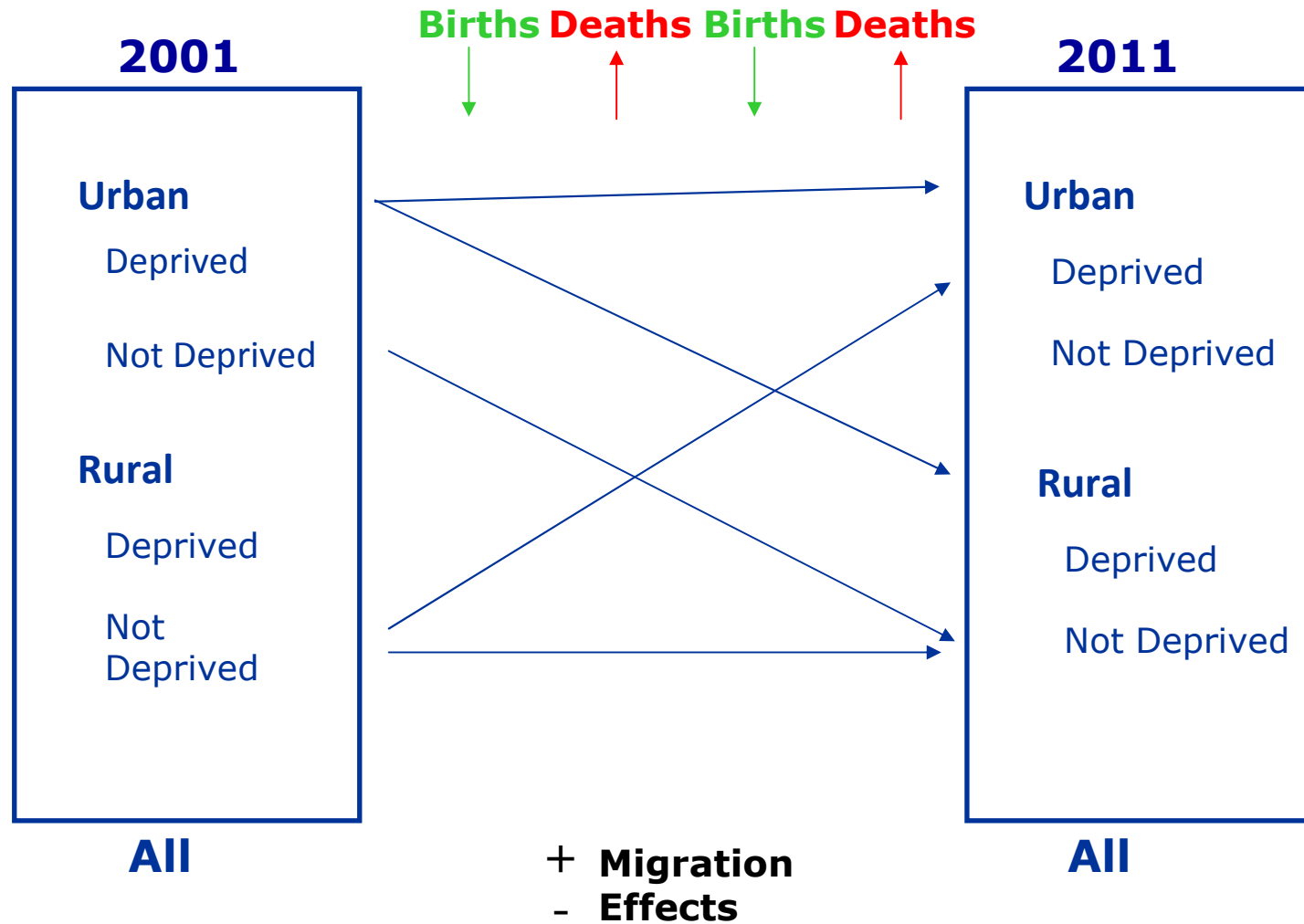
Research Potential

2011 Census Linkage (2013)

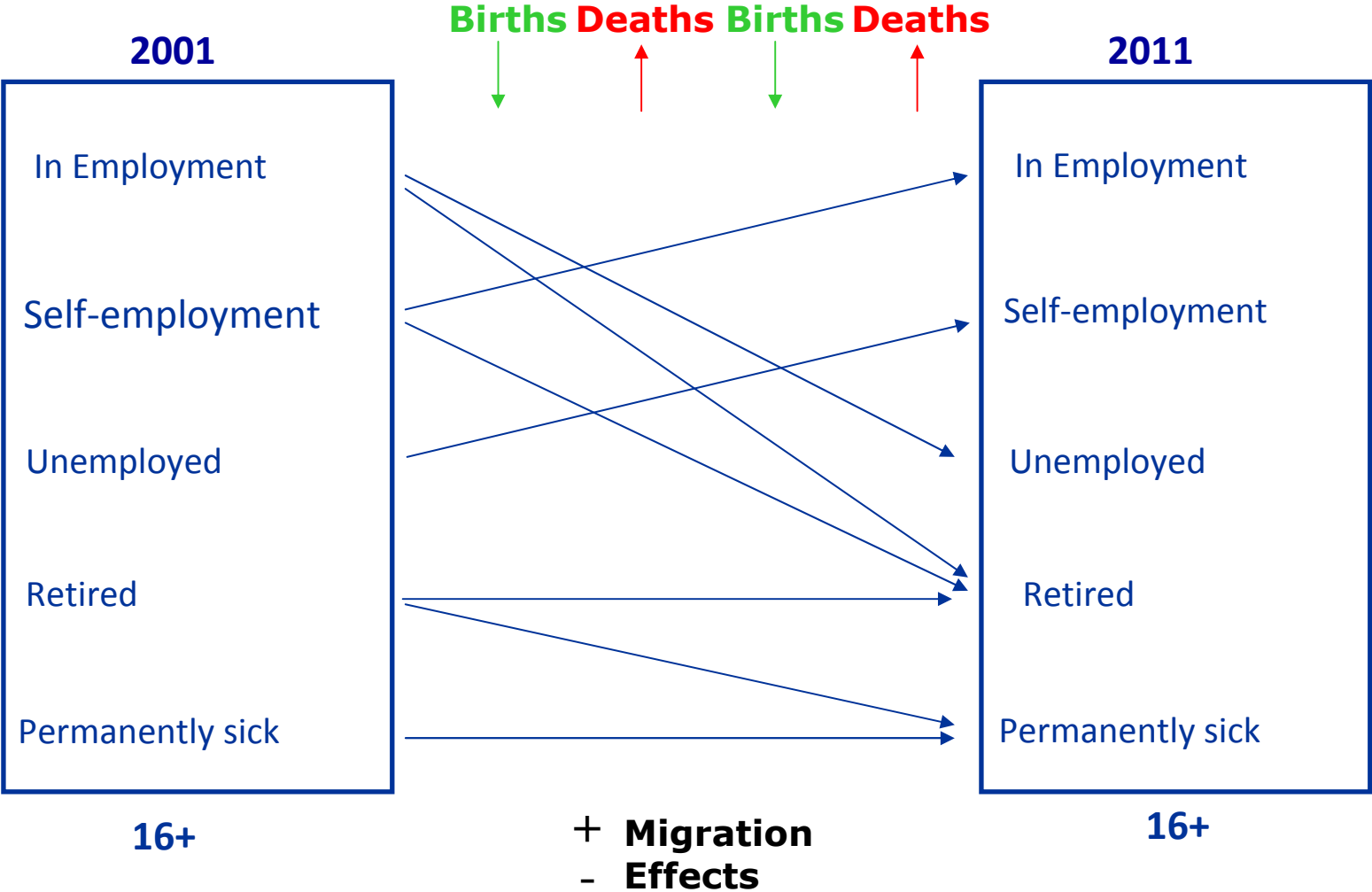
- Will permit analyses of **'NI in Transition 2001-2011'**
- Number of questions/topics that can be explored is wide
 - Who, living where, has been upwardly socially mobile?
 - How stable are housing tenures?
 - How important is religion/community background in the labour market?
 - What is the impact of ill-health in 2001 on labour market status in 2011?
 - What types of people have emigrated?
 - What internal migration patterns are seen amongst immigrant communities?



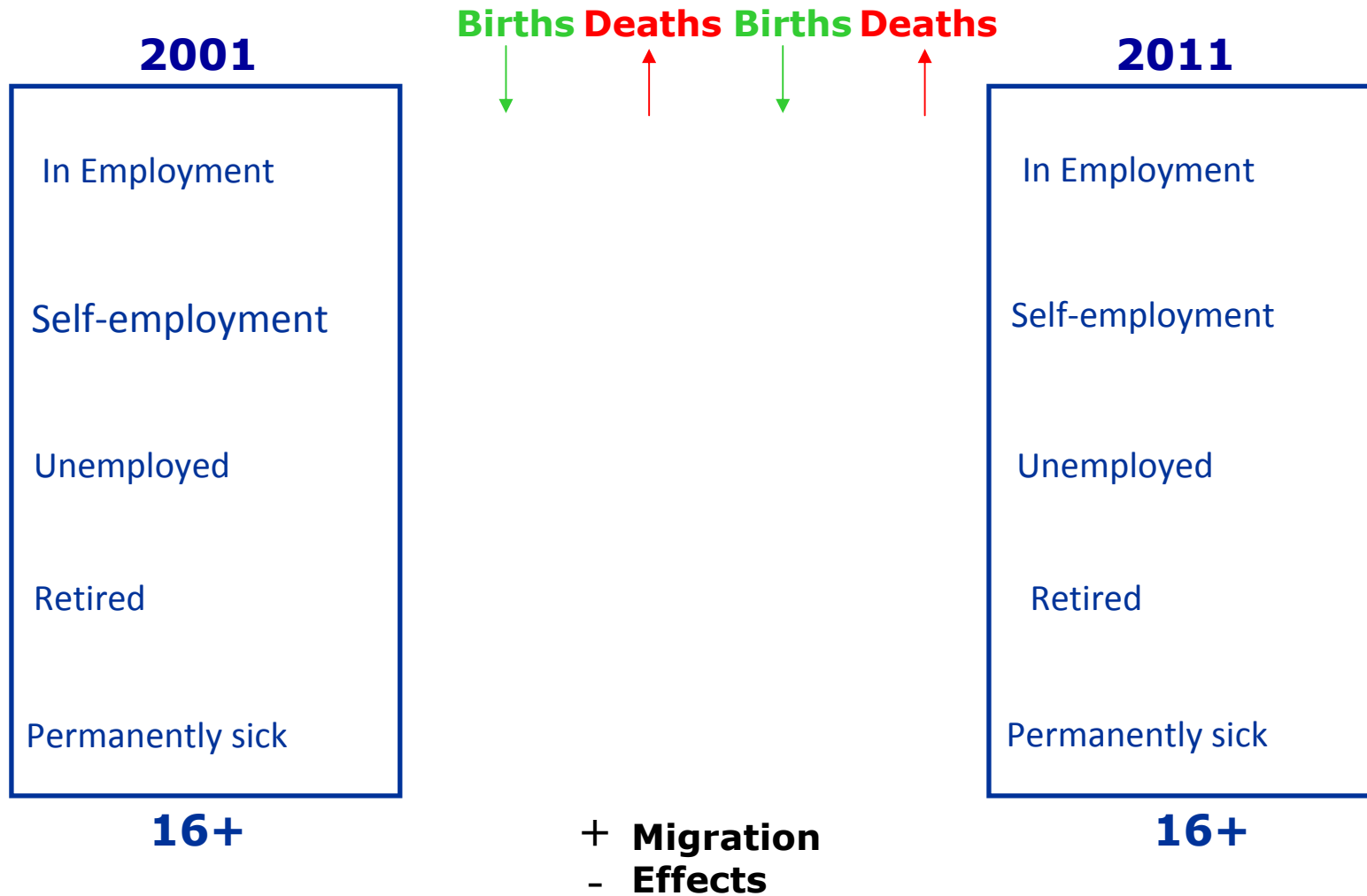
transitions: social mobility

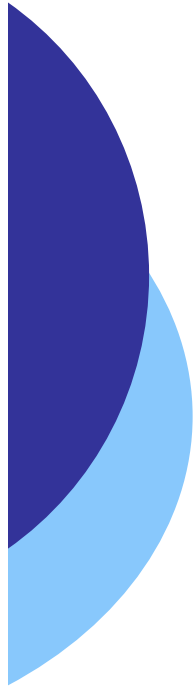


transitions: economic activity



transitions: comparison of cohorts





Policy considerations

- Important to NILS-RSU..
- engagement with government – researchers, policymakers

- Recent meeting at QUB policy forum initiative (QPOL) brought together policy makers, senior civil servants, QUB academics and non-governmental agencies, to
- discuss the research potential of NILS & NIMS databases in relation to policy needs: increasing the **evidence-base**.

- Future of the census – and what could replace it..

- Examples:
 - Education
 - Persistence of sectarian residential patterns
 - Housing
 - Health
 - Employment
 - Migration

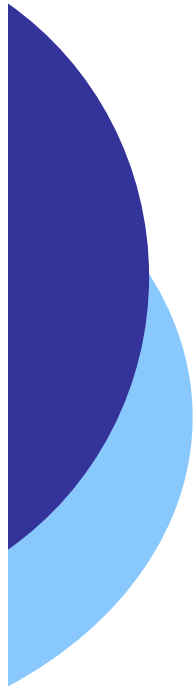


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The authors alone are responsible for the interpretation of the data.



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