

Northern Ireland Longitudinal Study - Data Sharing / Linkage 24 April 2012

Dr David Marshall

- What is the NI Longitudinal Study?
- NLS Security/Ethics/Governance
- NLS Distinct Linkage Projects
- GB Developments

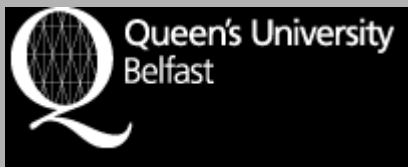
1. What is the NILS?

- A socio-demographic and health **research** tool to understand the population of NI between one census and another
 - partial 1991 Census
 - 2001 Census
 - 2011 Census (in progress)
 - Civil registration births, deaths
 - demographic data from health registration
- Policy relevant research



Background

- Funding:
 - Public Health Agency since 2003
 - ESRC, OFMDFM
 - NISRA (2011 link)
- Government keen for NLS to be used for research only
 - ***NOT used for audit***



Northern Ireland Longitudinal Study Research Funders

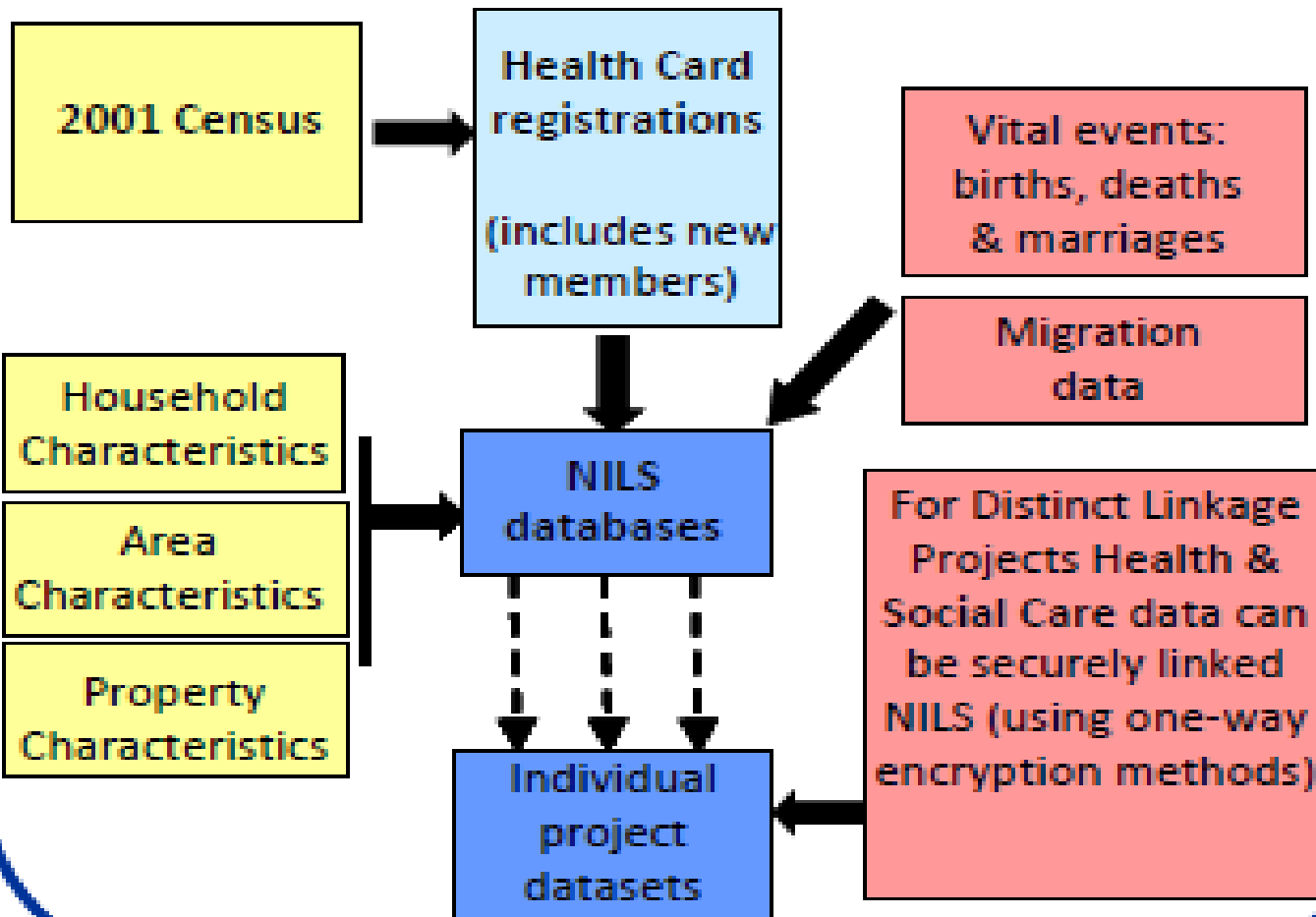


Structure of the NILES

Contextual data

NILES Core data

Events



International Experience

- Longitudinal Study (LS) in England and Wales since 1971 Census
- Study in Scotland (SLS) from 1991 Census
- New Zealand, Ireland, Canada etc...

NILS Research

- 57 accredited research projects
- 100s of research publications
- 8 PhDs/ 12+ MSc
- Presentations
- policy briefs e.g: Suicides, winter mortality
- Details at www.qub.ac.uk/nils



2. NILS Ethics & Privacy

- ORECNI Approval for creation of database & associated research
- Privacy Advisory Committee
 - ‘My Committee was very impressed with the arrangements and commend the NILS team for their high standards and exemplary approaches to the secondary uses of service user information’.
 - ‘...we strongly support the arrangements required of applicants to NILS. Privacy Advisory Committee adds its general support for such arrangements’.



Legal Basis

- Approved by Information Commissioner
- Required change to NI Census Act
 - The Law Reform (Miscellaneous Provisions) (Northern Ireland) Order 2004 (section 22);
- "duty" to comment on status of the population
- Conforms with Data Protection Act



Security, Confidentiality & Disclosure

- Security is paramount
 - CRAMM accredited
 - ISO27001 compliant
- Strict disclosure policy
- Only those who need to see identifiable data do so (Census Act)
- researchers only ever see **anonymised** data

Data Agreements

Data Transfer/Access arrangements with:

BSO

simple basic demographic data only

GRO

vital events registrations

Census Office

1991, 2001 and 2011 data

Approvals & Access

- Research Approvals Group (independent assessment)
- Application Process

Researchers:

- **Must** analyse data in **secure setting** only
- Microdata is **not** released
- Work on project specific data sets
- Supervised **at all times**
- **Cannot remove outputs**

Outputs are cleared by NLS Research Support Unit Staff

- Statistical models or high level outputs only released

Take all security, confidentiality, privacy, ethical, legal issues **very seriously**

Summarise:

Positive to research but with a very **CAUTIOUS** approach

3. NILES Distinct Linkage Projects

- Case by case link to other HSS data
 - Breast Screening
 - Dental
 - Cancer Registration (Approved)

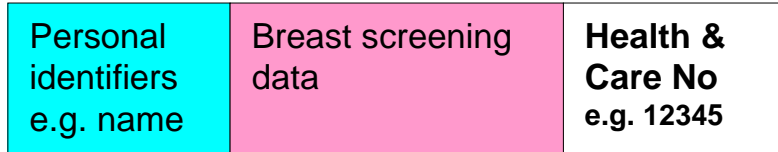
Distinct Linkage Projects

- Additional Constraints:
- RAG Approval subject to
 - Legal gateway to share pseudo-anonymised data
 - Ethical approval for specific project
 - Privacy Advisory Committee aware of process
- One-way data encryption (**cannot go back**)
- Project by project basis
- Data Transfer Agreement



Breast Cancer Screening Data at (QARC)

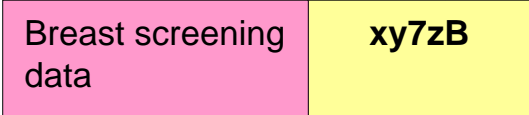
Northern Ireland Longitudinal Study (NILS) Data at NISRA



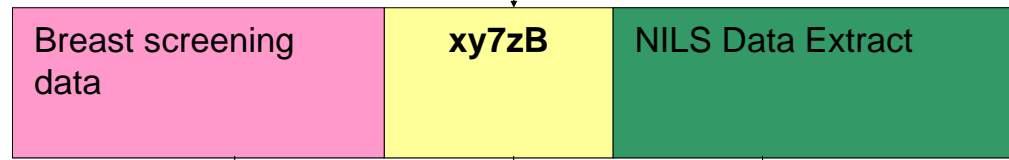
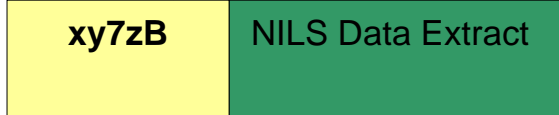
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One-way encryption

One-way encryption

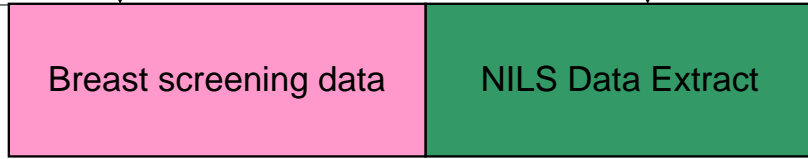


Matching



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Researcher access





4. GB Developments

- Beyond 2011 – The Future of the Census
- ESRC Administrative Data Task Force – Scotland & Wales
- Prime Minister's Announcement

Beyond 2011 – The Future of the Census



The Rt Hon Francis Maude MP

Minister for the Cabinet Office and Paymaster General



The future of the Census

Your letter recognises the increasing costs and difficulties of carrying out a Census. I therefore welcome the urgent work on considering alternatives that the Board has instructed ONS to carry out with the intention that the 2011 Census will be the last of its kind. I ask you to consult widely across Government on this work.

<http://www.ons.gov.uk/ons/about-ons/what-we-do/programmes---projects/beyond-2011/index.html>



ESRC Administrative Data Taskforce – Scotland / Wales

The Administrative Data Taskforce seeks to

- (i) propose new mechanisms and agreements to enable the wider use of administrative data for research & policy

SHIP: Scottish Health Informatics Programme



SAIL Databank: Secure Anonymised Information Linkage (Wales)

5 December 2011 Last updated at 21:22



Everyone 'to be research patient', says David Cameron

COMMENTS (654)

Every NHS patient should be a "research patient" with their medical details "opened up" to private healthcare firms, says David Cameron.

The PM says it will mean all those who use the NHS in England will be helping in the fight against disease.

He hopes the result will be that patients get faster access to new treatments and Britain's life sciences sector will become a world leader.

But critics say commercial interests are being put ahead of patient privacy.

In a speech in London Mr Cameron said he would consult on changing the NHS constitution, which governs how the the health service is run, so that all patients' data is used for medical research unless they want to opt out.

'Anonymous data'

He also announced that three million patients with chronic illnesses like diabetes or heart conditions are to get hi-tech equipment to monitor their health at home.



David Cameron has said he wants to make huge numbers of patient records in England available to the drugs industry

Related Stories

[NHS-life sciences partnership](#)

[Private firms 'to share NHS data'](#)

[Challenges ahead over free data](#)



Acknowledgement

NILS is funded by the Health and Social Care Research and Development Division of the Public Health Agency (HSC R&D Division) and NISRA.

The NILS-RSU is funded by the ESRC and Northern Ireland Government.

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