

“STEPPING TOWARDS BETTER DECISION-MAKING IN HEALTH”

Launch of

**ALL-IRELAND HEALTH DATA INVENTORY.
PART 1: METADATA FOR KEY DATA SOURCES
(VERSION 1.0)**

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OVERVIEW

- The rationale
- How we went about it
- What we've produced
- How we're disseminating it
- Our aspirations
- Online demonstration
- Questions and answers

THE RATIONALE (1)

If we want people to make better decisions they have to make better use of existing knowledge.

‘Knowledge is of two kinds. We know a subject ourselves, or We know where we can find information upon it.’

Samuel Johnson 1709-84: in James Boswell *Life of Johnson* (1791)
18 April, 1775

Knowledge generated from many different sources such as numerical data but also ...



THE RATIONALE (2)

As the first step towards consistently better decision-making in health, we need to increase people's awareness of and access to health-related data and other sources of knowledge.

WHAT IS A “DATA INVENTORY”?

A data inventory is a comprehensive list of relevant data sources, described in an agreed systematic way, that is used to improve data quality and is appropriately managed and disseminated to support better decision-making.

STRONG POLICY SUPPORT

- Action 7 of *The National Health Information Strategy* states that ‘a national health information database inventory will be developed and maintained’
- The *Review of the Public Health Function in Northern Ireland (Interim Report)* by the Health Improvement and Knowledge Management Subgroup included a brief knowledge inventory that highlighted how it could ‘increase awareness of and accessibility to resources’



WHAT WE DID

- Selection of initial data sources
 - Not meant to be comprehensive
 - Based on four recent major reviews
- Metadata tagging
 - Agreed metadata standards utilizing controlled thesauri
- Production
- Dissemination
 - And not just to a few dusty bookshelves!

THE RECENT REVIEWS

Developing Irish Social and Equality Statistics to meet Policy Needs. Report of the Steering Group on Social and Equality Statistics. National Statistics Board, 2003

Statistical Potential of Administrative Records (SPAR): An Examination of Data Holdings in Six Government Departments. Central Statistics Office, 2003

Statistical Potential of Business and Environment Enterprise Data Holdings in Selected Government Departments: Working Report. Central Statistics Office, 2007

Economic & Social Data Service: Guide to Data Sources for Northern Ireland (Version 1.1). Economic and Social Data Service, 2007



CORE METADATA ELEMENTS

Title

Creator

Subject (NPHL/SNOMED)

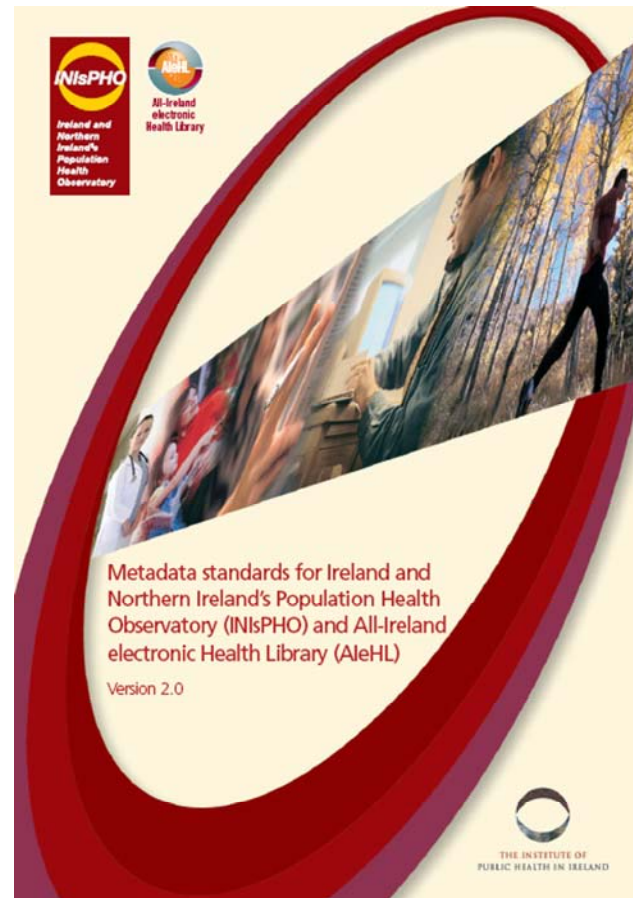
Description

Date

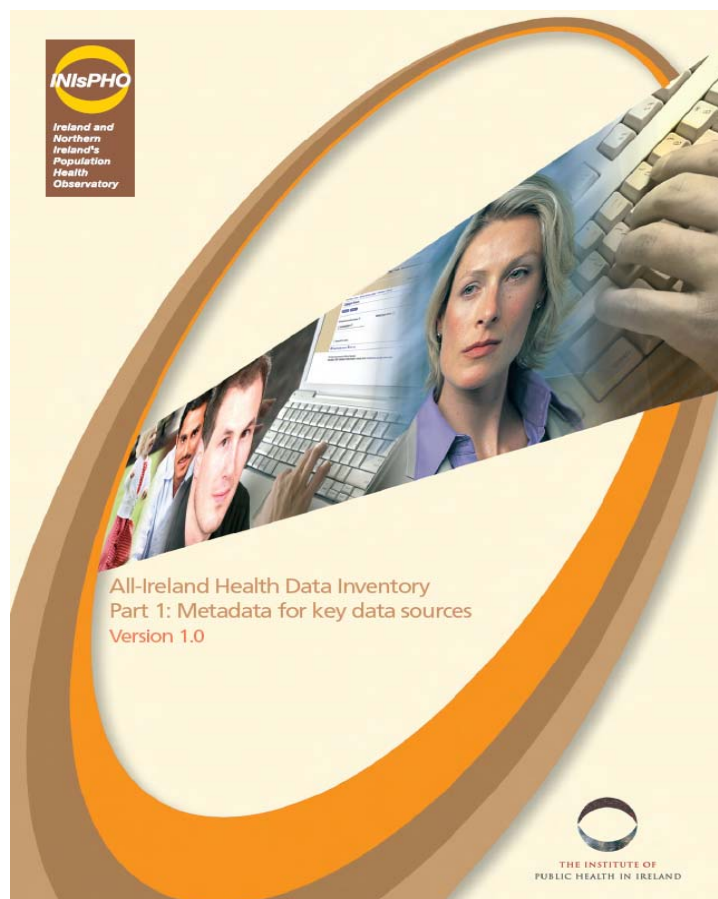
Type (using PHRTES)

Identifier

Rights



AUGUST 2007



VERSION 1.0

Includes:

- Initial Abbreviations List
- Alphabetical Listing of 151 initial data sources
- A metadata page for each of these data sources



All-Ireland Health Data Inventory (Part 1)

Child of the New Century Survey

TITLE	Child of the New Century Survey
CREATOR	Moira McKee, Central Survey Unit, Northern Ireland Statistics and Research Agency
SUBJECT	Refer to NPHL Terms
NPHL TERMS	QUALITY OF LIFE, CHILDREN, COHORT STUDIES, BIRTH RATE, INCOME, ENVIRONMENTAL DETERMINANTS
DESCRIPTION	<p>This birth cohort study tracks people from birth to improve understanding of experiences and conditions in early childhood which might affect chances in later life. This study is part of the Millennium Cohort Study and is the first new UK wide birth cohort study since 1970. The survey aims to provide answers to questions such as: what influence will a traditional upbringing have as opposed to the arrival of a step-parent and step-brothers and stepsisters? Who will succeed in school and who will encounter difficulties? Who will overcome difficult beginnings or challenging circumstances in early life? The Survey is comprised of three questionnaires and covers a range of topics: Languages spoken, non-resident parents, involvement with baby, pregnancy, labour and delivery, Baby's health and development, child care, grandparents and friends, parent's health, employment, income and education, housing and local area and interests. When possible, interviews were carried out when babies were 9 months and 15 days.</p>
DATE	6/25/2003
TYPE	dataset
IDENTIFIER	www.csu.nisra.gov.uk/surveys/survey.asp?id=41
RIGHTS	© Northern Ireland Statistics and Research Agency (NISRA)





All-Ireland Health Data Inventory (Part 1)

Database of Irish Historical Statistics: Vital Statistics (1864 - 1911)

TITLE	Database of Irish Historical Statistics: Vital Statistics (1864 - 1911)
CREATOR	Clarkson, L.A., Kennedy, L., Crawford, E.M., Dowling, M.W., Queen's University Belfast
SUBJECT	Refer to NPHL Terms
NPHL TERMS	DEATH, MARRIAGE, CHILDBIRTH, CENSUS DISTRICT, HISTORY
DESCRIPTION	<p>The main tables are:</p> <ul style="list-style-type: none">• Total number of births for the whole of Ireland grouped by gender• Total number of marriages for the whole of Ireland• Total number of deaths grouped by gender and age groups• Total number of deaths grouped by counties (1875-1911). <p>The Database of Irish Historical Statistics holds recurrent statistics for Ireland for the nineteenth and twentieth centuries collected from a variety of printed census sources. It contains quantitative information, including decennial census data, emigration statistics, annual total of births, deaths and marriages collected by the Registrar General, yearly statistics of agricultural production, poverty data from Poor Law records, and crime statistics. All population censuses from the first comprehensive Irish census in 1821 to the last not already in digital form in 1971 are included.</p>
DATE	11/12/1997
TYPE	dataset
IDENTIFIER	www.data-archive.ac.uk/findingData/snDescription.asp?sn=3576
RIGHTS	© L.A. Clarkson, L. Kennedy, E.M. Crawford & M.W. Dowling



Environment Statistics

TITLE	Environment Statistics
CREATOR	Environmental Protection Agency (EPA)
SUBJECT	Refer to NPHL Terms
NPHL TERMS	ENVIRONMENT, CLIMATE CHANGE, POLLUTION, TRANSPORT
DESCRIPTION	Statistics are provided for: <ul style="list-style-type: none">• area by province• total rainfall• environmental pressures - transport• total primary energy requirement by fuel type• final energy consumption by sector• greenhouse gas emissions• acid rain and ozone precursors• acid rain precursors• total household and commercial waste collected.
DATE	1/1/1980
TYPE	dataset
IDENTIFIER	www.cso.ie/statistics/EnvironmentalAccounts.htm
RIGHTS	© Central Statistics Office

DISSEMINATION

Print:

- Ring binder
- Expanding numbering system
- Data nomination form
- Limited distribution

Web:

- PDF version on www.inispho.org
- A collection on the Observatory's library
- Inclusion in the All-Ireland electronic Health Library (AleHL) of grey literature

Training



Other sources of knowledge – “the grey literature” (PHRTES)

Current members:

- INIsPHO (Online) Library)
- HSE’s Irish Health Publications Archive
- HSE’s Health-data.-info
- HRB’s National Documentation Centre on Drug Use
- IfH’s Wellnet (Eastern Health and Social Services Board)

Uses agreed metadata standards and uniform search mechanism for specific searches (keywords on NPHL/SNOMED)

AleHL can be accessed through the websites of any of its members.



	DATA INVENTORY	INIsPHO (Online) LIBRARY	AleHL
Distribution	<i>Limited</i>	<i>Wider</i>	<i>Much wider and growing</i>
Searchable?	<i>No</i>	<i>Yes – keywords or NPHL/SNOMED terms</i>	<i>Yes – keywords or NPHL/SNOMED terms</i>
Information included	<i>Specified data sources only</i>	<i>Specified data sources and other types</i>	<i>Specified data sources and other types</i>
Access to data	<i>Left to user</i>	<i>Some assistance</i>	<i>Some assistance</i>
Help to use data?	<i>No</i>	<i>Access to associated reports only</i>	<i>Access to associated reports only</i>

OUR ASPIRATION

- We wanted to produce a resource that would be immediately helpful to practitioners, planners and managers, and policy makers
- We want to stimulate and support the formal development of a more comprehensive all-Ireland health data inventory
- *And then there is the question of analysing, interpreting and using the results to directly support decision-making!!!*

“The publication of this Inventory will help increase the application of existing data in driving improvements in the quality and safety of our health and social care services. It also represents a significant contribution to the future development of the national health data inventories in the two jurisdictions on the island”

Dr. Tracey Cooper
CEO, Health Information and
Quality Authority.
Republic of Ireland.

Dr. David Stewart
Chair, Knowledge Management
Working Group, Review of
Public Health (2006).
Northern Ireland.



QUESTIONS AND ANSWERS