Maternity and Neonatal Linked Data Files

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Background

- The linkage of the Maternity and Neonatal datasets was traditionally carried out using long established probabilistic linkage algorithm programmes on an intermittent/ad hoc basis, usually every 6 months.
- Reliant on people with the appropriate computer programming knowledge and skills to understand these in detail in the event there is a problem with an update.
- Need to re-assess the way the files were linked to ensure the best possible linkage success rate is achieved between records
- Recent projects highlighted there may be potential under linkage of babies in particular groups such as premature and low birth weight

What data does this cover?

Dataset	Source	Description				
Birth Registrations	National Records Scotland (NRS)	Birth Registration Records from 1975 to present day				
Stillbirth Registrations	National Records Scotland (NRS)	Stillbirth Registration Records from 1975				
Infant Deaths	National Records Scotland (NRS)	Death Registration Records from 1975, aged under 2 years – This is a subset of the main NRS deaths file				
SMR02	Maternity hospitals in Scotland	Obstetric records from 1981				
SMR11	Neonatal Units in Scotland	Neonatal records for "sick" babies from 1981 to 2002				
Scottish Birth Record (SBR)	Maternity hospitals in Scotland Neonatal Units in Scotland	Web based system recording all births in Scottish hospitals and home births, from 2002/03				
Scottish Stillbirth and Infant Death Survey (SSBID)	Maternity hospitals in Scotland Neonatal Units in Scotland NRS death records	Extended survey data collected by Health Improvement Scotland on all stillbirth and infant death events in Scottish Hospitals from 1985 to 2010				

Project Objectives

- Develop and maintain a central file (NRS birth registrations) that contains an ISD-wide UPI (CHI) for both the mother and the child
- Add maternal and/or child CHI to all other datasets to give flexible linkage capacity across generations and life courses
- Use modern, sustainable, CHI seeding programmes wherever possible aiming for maximum linkage completeness and accuracy and transparency around linkage quality
- Ensure automated processes and regular updates to maximise access to timely data

Limitations to proposed solution

- NRS cannot provide external organisations with the mother's date of birth on the birth or stillbirth registration files as it is collected under the provisions of the Population (Statistics) Acts 1938 and 1960. Informants are advised that the information collected will be treated as confidential and used only in the preparation of statistics by the Registrar General.
- Secondly CHI was only introduced in parts of Scotland from the late 1970s and was not national until 1993. Records where the person has died before the introduction of CHI will not match to a CHI record.

Information Governance

- Permission sought from Privacy Advisory Committee to CHI seed the files and link as needed for:
 - internal analyses,
 - to respond to Information Requests, FOIs and Parliamentary Questions
- Other work will need to be reviewed by either the Information Governance Team or the Public Benefit and Privacy Panel

CHI Seeding

Dataset	Mother's CHI Number	Baby CHI Number				
Birth Registrations	Records from 1981 to 1999	Records from 1981-2013				
Stillbirth Registrations	Records from 1981 to 2013					
Infant Deaths	NRS have matched the Birth Registration and Infant Death Records. Death Records now contain the corresponding Birth Registration ID fields – Registration Year, Registration District and Entry Number					
SMR02	Records from 1981-2013					
SMR11	Records from 1981-1996	Records from 1981-2002				
Scottish Birth Record (SBR)		Records from 2002-2013				
Scottish Stillbirth and Infant Death Survey (SSBID)	Stillbirth Records from 1985-2012	Infant Death Records from 1985- 2012				

Rerunning prior analyses – Congenital Anomalies

The congenital anomalies register links together the SMR02, SMR11, SBR, SSBID and SMR01 and death datasets to identify all babies admitted to neonatal care or as an inpatient in their first year of life with a congenital anomaly diagnosis

Singletons born in Scotland & detected with congenital anomalies at birth or during infancy ²									
	2004	2005	2006	2007	2008	2009			
Neural Tube Defects (Linked Database)	17	28	18	37	34	28			
Neural Tube Defects (CHI)	18	28	18	35	35	29			
Anomalies of the heart & circulatory system (Linked Database)	559	492	489	518	521	514			
Anomalies of the heart & circulatory system (CHI)	559	485	486	506	510	548			
Down's Syndrome (Linked Database)	68	64	52	68	61	67			
Down's Syndrome (CHI)	68	65	53	69	60	72			

Checking the overall utility of linked data by estimating neonatal mortality

- EuroHOPE project
- Cohort of extremely preterm/low birth weight babies
- Used linked data to assess a range of outcomes including neonatal mortality rate
- Estimated mortality rate found to be much lower than the 'gold standard' rate – based on unlinked data – previously published in SPIMMR

▶ 7% cf 13%

Learning Points from Project

- Babies born at very low gestation and/or those who die shortly after birth less likely to be assigned a CHI number
- Babies and mothers who died prior to full roll out of CHI system inevitably don't have a CHI number for any of their records
- Lack of maternal date of birth on vital event records compromises identification of the maternal CHI Number
- As it is legally not possible at this time to receive the maternal date of birth further work is required with NRS to review the quality of our maternal CHI seeding.
- There is a general lack of scrutiny of quality of CHI seeding and linkage in ISD for all record types