Exploiting Existing Data For Health Research

18th to 20th September 2007
Lower College Hall, University of St Andrews

There is a growing recognition of the value of linking routine administrative data for health research, evidenced by the increasing number of bespoke projects and larger general purpose studies. This 3-day inter-disciplinary conference brought together an international group of researchers who have expertise in the linkage of administrative or routine data for health research or health care improvement.

Themes discussed were:

1. The value of record linkage in health research

The use of linked data is commonplace in health research. This theme included papers based on one-off and general-purpose studies which demonstrated the range of research benefits that result from record linkage.

2. Record linkage for health care improvement

Linked datasets are also vital to the improvement of health care services. This theme included papers covering a range of themes including linkage to support health surveillance, health needs assessment, patient safety and quality improvement activities, performance assessment and accountability.

3. Longitudinal record linkage

Of particular research value are longitudinal studies which track information about individuals or organisations through time, providing the opportunity to examine how different characteristics influence one another sequentially. This session included papers that addressed the particular strengths of longitudinal data collection.

4. The methodological challenges of record linkage

This theme included papers on state-of-the-art techniques for record linkage. Techniques might include methods for record linkage, disclosure control, data management and analysis of linked data.

5. *Confidentiality, disclosure and ethical issues*

The linkage of potentially sensitive data for health research and health care improvement raises various ethical issues. This theme included papers that evaluate, for example, the public perception of record linkage, or advance the debate about balancing people's right to privacy and the public benefits of linked data for health research.

EXPLOITING EXISTING DATA FOR HEALTH RESEARCH – CONFERENCE PROGRAMME

Times	Tuesday 18th September		
11.00-12.50 pm	REGISTRATION and BUFFET LUNCH *(Lower College Hall)*		
12.50-1.00 pm	WELCOME: **Paul Boyle** University of St Andrews and Director of the Longitudinal Studies Centre – Scotland *(Upper College Hall)*		
1.00-2.00 pm	**KEYNOTE: William Lowrance** Author of the Nuffield Trust Report "Learning from Experience: Privacy and the Secondary Use of Data in Health Research" and the MRC/Wellcome Trust Report "Access to Collections of Data and Materials for Health Research" ***Exploitation of existing data: opportunities and challenges*** *(Upper College Hall)*		
2.00-3.30 pm	***SESSION 1a – General Introduction*** *(School 1)* 1. Finlayson Linking health information in Scotland 2. Notkola Registers as rich data source for health research in Finland 3. Verweij Linking hospital admission data with population register data, an overview	***SESSION 2a – Health Research*** *(School 2)* 1. Anandan A critique of existing Scottish healthcare datasets with particular reference to data linkage capabilities using allergy as an exemplar long-term condition 2. Brooks Identifying potential participants for clinical trials from a linked patient data warehouse using standard inclusion and exclusion criteria from a trial of Diabetes Mellitus medication 3. Diggens Childhood cancer research: using hospital episode statistics to augment the national registry of childhood tumours	***SESSION 3a –Longitudinal*** *(School 3)* 1. Lloyd From Kindergarten's EDI to Grade 4's FSA: Longitudinal analysis with linked population data 2. O'Reilly Unlinked vital events in census based longitudinal studies can bias subsequent analysis 3. Costa The Turin longitudinal study: the design and some results	
3.30-4.00 pm	TEA/COFFEE *(Lower College Hall)*		
4.00-5.30 pm	***SESSION 1b – US Panel Session*** *(School 1)* 1. Prevost The opportunities and challenges of integrated health research data sets: A US example 2. Baugh An overview of data linkage issues and activities at the Centers for Medicare & Medicaid Services 3. Davern Opportunities and challenges facing the construction of integrated datasets to serve policy research purposes 4. Cox Data policy and legal issues in creating and managing integrated data sets	***SESSION 2b – Health Improvement*** *(School 2)* 1. Cannings-John The protective effect of antibiotics against complications arising from acute respiratory tract infections 2. Bunch Cardiac transplantation in childhood cancer survivors: a record linkage study using data from the National Registry of Childhood Tumours 3. Davey Using record linkage in Scotland to add value to BURDEN	***SESSION 3b –Longitudinal*** *(School 3)* 1. Boyle The Scottish Longitudinal Study: A new resource for health research 2. Cameron Improving mental health care through a longitudinal study in schizophrenia: the Scottish Schizophrenia Outcomes Study (SSOS) 3. Fisher Career pathways of UK junior doctors: a 10 year longitudinal perspective	

Times	Wednesday 19th September
9.00-10.00 am	**KEYNOTE: Mark Elliot** Director of "Centre for Census and Survey Research (CCSR)" University of Manchester ***Confidentiality, privacy and disclosure in health data: a 20th century problem needing a 21st century solution?*** *(Upper College Hall)*

Times	SESSION 1c – Confidentiality (School 1)	SESSION 2c – Health Research (School 2)	SESSION 3c – Methodology (School 3)
10.00-11.30 am	1. Bagnall Use of routine data in research: does it discourage participation? 2. Dezateux Predictors of consent to linkage to health service records in the UK Millennium Cohort Study 3. Ford Overcoming confidentiality and disclosure issues in health-related data warehousing: The Split File approach to anonymisation	1. Cardy Does second trimester amniocentesis increase the risk of clubfoot in the offspring? A record linkage study 2. Fleming M Using record linkage to investigate congenital anomalies in Scotland 3. Gnavi Revascularisation and survival after acute myocardial infarction by educational attainment and marital status. A population study in Torino, Italy	1. Cortina-Borja Using data linkage from unlinked anonymous surveillance of neonatal dried blood spots 2. Calderwood Methodological challenges in enhancing the Millennium Cohort Study through linkage with data from birth registration and routinely collected hospital episode statistics 3. Lancaster Linkage of survey data with district level lung cancer registrations: a method of bias reduction in ecological studies

Times	TEA/COFFEE (Lower College Hall)
11.30-12.00 pm	

Times	SESSION 1d – Confidentiality (School 1)	SESSION 2d – Health Research (School 2)	SESSION 3d – Methodology (School 3)
12.00-1.30 pm	1. Brown The use of medical records for research: an analysis of media reporting and reflection on ethical issues 2. Fleming T Privacy preserving record linkage 3. Henney Reuse of health administrative records: the ethical and practical challenges	1. Hattie Research opportunities through a maternal linked database 2. Ivory Neighbourhood fragmentation and mental health: exploring the relationships 3. Kujala The effect of early school performance of Finnish Students on mortality later in life	1. Lix Web-based tools to facilitate the use of administrative data in population-based research 2. Molitor Low birthweight and water disinfection byproducts: a multiple-bias modelling approach 3. Simonato Developing standard algorithms for diseases definitions based on routine data from electronic health archives: results from a national working group in Italy

Times	LUNCH (Lower College Hall)
1.30-2.30 pm	

Times	Wednesday 19th September		
2.30-4.00 pm	**SESSION 1e – Confidentiality** *(School 1)* 1. McGilchrist A new model of multi-institutional linkage and anonymisation supports patient confidentiality, research governance and quality assurance 2. Meagher Enabling research: improving access to data in a privacy-sensitive world 3. Dowell The benefits and technical, ethical and acceptability problems of establishing a longitudinal qualitative dataset of routinely recorded primary care consultations: The Scottish Clinical Interactions Project (SCIP)	**SESSION 2e – Health Research** *(School 2)* 1. McCowan Poor adherence to prescribed Tamoxifen and increased risk of death from breast cancer 2. Bird Mortality in hepatitis C diagnosed persons with and without HIV coinfection in Scotland: a record-linkage study 3. Pearce Linking routinely collected data in neighbourhoods and health research: the example of food retail provision, diet and obesity in New Zealand	**SESSION 3e – Methodology** *(School 3)* 1. South Service utilisation, self care and the challenges of using routine data in evaluation studies 2. Storey Record linkage using probability matching and the challenges of limited identifying information 3. Tromp Ignoring dependency between linking variables and its impact on the outcome of probabilistic record linkage studies
4.00-4.30 pm	TEA/COFFEE *(Lower College Hall)*		
4.30-6.00 pm	**SESSION 1f – Unallocated** *(School 1)*	**SESSION 2f – Health Research** *(School 2)* 1. Rasulo Mortality risk of immigrants and Turin-born 2. Ravelli Risk factors for Dutch perinatal mortality in the period 2000-2004 3. Wild Lower socio-economic status is associated with higher prevalence of cardiovascular disease and diabetes-related hospital admissions among people with diabetes independently of current risk factor levels	**SESSION 3f – Methodology** *(School 3)* 1. Tromp An efficient validation method of probabilistic record linkage including readmissions and twins 2. Bird Record linkage illuminates public health and other jurisdictions: best laid plans….. 3. Merrall Investigating the risk of variant Creutzfeldt-Jakob disease (vCJD) transmission via surgical instruments
7.30–midnight	CONFERENCE DINNER AND CEILIDH *(Upper and Lower College Hall)*		

Times	Thursday 20th September		
9.30-11.00 am	**SESSION 1g – Methodology** (School 1) 1. John Enhanced measurement of disease risk through use of address history 2. Geneletti Adjusting for selection bias in retrospective case control studies 3. Clark Can people involved in road traffic accidents be linked to hospitalisations in the absence of names, dates of birth and unique person-identifiers?	**SESSION 2g – Health Improvement** (School 2) 1. Gnavi Administrative data to monitor the prevalence of diabetes and the quality of diabetes care 2. Elders Linking the Scottish Health Survey to hospital admissions data to determine the factors influencing health service demand 3. Feijten Marital status, health and mortality: the role of living arrangement	**SESSION 3g – Health Improvement** (School 3) 1. Hilder Improving birth information in England and Wales 2. Katzenellenbogen Use of population-based linked data system to enhance burden of disease estimates for stroke in Western Australia 3. McLernon What happens to patients with no clinically obvious liver disease after their initial liver function tests in primary care?
11.00-11.30 am	TEA/COFFEE *(Lower College Hall)*		
11.30-1.00 pm	**SESSION 1h – Methodology** (School 1) 1. Atherton Substance misuse and homelessness: researching difficult to access populations using linked hospital and death records 2. Fischbacher Can we retrospectively analyse Scotland's health databases by ethnic group? A demonstration project focusing on linkage of census and health records 3. Lyons Allocating a consistently applied, anonymous identifier to individuals found in electronic datasets from NHS and non-NHS data sources	**SESSION 2h – Health Improvement** (School 2) 1. Flynn The generation of a regional record linkage database for the investigation of the pharmacoepidemiology of secondary stroke treatment 2. Donnan Development and validation of a model for Predicting Emergency admissions Over the Next Year (PEONY): a UK retrospective study 3. Hardie Encouraging practice-level engagement with primary care data: "linking" aggregate datasets	**SESSION 3h – Health Improvement** (School 3) 1. Slobbe Improved assessment of mortality indicators for hospital quality using a linked recordset 2. Thorne The availability of routinely collected, service-related NHS endoscopy unit data in NHS Trusts in England 3. van den Einde-Bus The possibilites of linkage of GP electronic medical records to population registers
1.00 pm	DEPART		