

## Exploiting Existing Data For Health Research

International Conference, 9-11 September 2011  
University of St Andrews



### International Conference

In 2007 we hosted the first 'Exploiting Existing Data for Health Research' Conference at the University of St Andrews. Designed for researchers and practitioners interested in record linkage and the use of routine health data in their research, this 3-day Conference attracted over 70 papers and 120 participants from across the world including New Zealand, Australia, the United States, Canada, and many countries in Europe. Following funding from the Wellcome Trust, through the Scottish Health Informatics Programme (SHIP), we were pleased that this would become a biennial event. In 2009 the Conference was again held at the University of St Andrews. The 2011 3-day inter-disciplinary Conference will gather together an international group of researchers who have expertise in the linkage of administrative or routine data for health research or health care improvement.

We invite abstracts to be submitted by **Friday 27<sup>th</sup> May 2011** on one of four broad themes:

#### **The value of record linkage in health research**

This theme will include papers based on one-off, general-purpose or longitudinal studies which demonstrate the range of research benefits that result from record linkage. We would be particularly interested in studies that have linked health data to other routine/ survey data (eg housing, education, welfare, census datasets) to data in order to answer health questions.

#### **The use of routinely collected data in clinical trials**

The use of administrative data, registry data and/ or electronic patient records in support of clinical trials. We are interested in the use of such data to support any aspect of trial conduct, including trial design, trial feasibility, recruitment, within- and post-trial follow-up, pharmacovigilance and study monitoring.

#### **Patients' Rights and the Public Interest: What does good governance look like?**

The organisers welcome papers on questions relating to principles and best practices in good governance of research involving health-related records. Topics might include the role of consent and opt-in/opt-out mechanisms, the importance and limits of anonymisation in protection patients' interests, and/or the role and legitimacy of advisory bodies in approving research when consent is not sought.

#### **The methodological challenges of record linkage**

This theme will include 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.

Please submit an abstract of no more than one page via email to [ship@st-andrews.ac.uk](mailto:ship@st-andrews.ac.uk)



University of  
St Andrews



600  
YEARS



**Plenary speakers:**

**Dr Harry Burns** MPH FRCS (Glas) FRCP(Ed) FFPH, *Chief Medical Officer for Scotland*

Harry Burns graduated in medicine from the University of Glasgow in 1974. Over the next 15 years he worked as a general surgeon and for the last six years of his surgical career was a consultant surgeon at the Royal Infirmary in Glasgow. He entered health care management and was, for a time, Medical Director of the Royal Infirmary in Glasgow. Since 1993 he has been Director of Public Health for Greater Glasgow Health Board which is responsible for organising health care and maintaining the health of one million people in the West of Scotland. In 1999 he was awarded a Visiting Professorship in Public Health Medicine, University of Glasgow and is a Senior Research Fellow in the School of Business and Management in the University. He took up post as Chief Medical Officer for Scotland on 5 September 2005.

**Professor Paul Burton** MD, C. Stat, FFPH *Professor of Genetic Epidemiology, Departments of Health Sciences and Genetics, University of Leicester.*

Paul Burton is a genetic epidemiologist with a research program that currently focuses on the design, harmonization, analysis and meta-analysis of large-scale biobanks and on access to, and use of, the data they generate. He chairs the International Steering Committee of the Public Population Project in Genomics (P3G) and the Access Committee for three CLS National Birth Cohorts, including the 1958BC which is one of the UKs leading providers of data and biosamples for large scale genetic epidemiology. He is Science Co-coordinator of BIOSHARE-EU (FP7, Large Scale Integrating Project) which is led by Professor Ronald Stolk, Groningen. He is a member of the International Scientific Advisory Board of UK Biobank, the International Oversight Committee of the Canadian Longitudinal Study of Ageing, the Scientific Advisory Board of the European GEN2PHEN project, and of the data access committees of the Wellcome Trust Case Control Consortium and the ESRC funded Understanding Society.

**Professor Sir Rory Collins** FMed Sci FRCP, *Chief Executive and Principal Investigator of the UK Biobank and co-director of the University of Oxford's Clinical Trial Service Unit & Epidemiological Studies Unit*

Rory Collins studied Medicine at St Thomas's Hospital Medical School, London University, from 1974-1980, and Statistics at George Washington University (1976-7) and Oxford University (1982-3). In 1985 he became co-director, with Professor Sir Richard Peto, of the University of Oxford's Clinical Trial Service Unit & Epidemiological Studies Unit (CTSU). In 1996, he was appointed Professor of Medicine and Epidemiology at Oxford, supported by the British Heart Foundation. He became Principal Investigator and Chief Executive of the UK Biobank prospective study of 500,000 people in September 2005. His work has been in the establishment of large-scale epidemiological studies of the causes, prevention and treatment of heart attacks, other vascular disease, and cancer. He was knighted in 2011 for his services to science.

**William W. Lowrance** PhD, *Consultant in Health Research Ethics and Policy, La Grande Motte, France*

William W. Lowrance, Ph.D., is a consultant in health research ethics and policy, based in La Grande Motte in the south of France. His focus in recent years has been on the use of health information and biospecimens in research. In 2002 he prepared a report, Learning from Experience: Privacy and the Secondary Use of Data in Health Research, for The Nuffield Trust, and in 2006 a report, Access to Collections of Data and Materials for Health Research, for the Medical Research Council U.K. and the Wellcome Trust. During the startup of the U.K. Biobank he chaired the Interim Advisory Group on Ethics and Governance. Recently he conducted a project for the U.S. National Human Genome Research Institute, and, with Dr. Francis Collins, published an article on the issues, "Identifiability in genomic research," in Science. Currently he is writing a book with the working title, Privacy, Confidentiality, and Health Research.

**ESSENTIAL INFORMATION**

**Submitting a paper:**

Those interested in presenting a paper at the conference should submit an abstract of no more than one page via email to [ship@st-andrews.ac.uk](mailto:ship@st-andrews.ac.uk). You should include author details and specify which of the four conference themes your paper is being submitted to. The deadline for abstracts is **Friday 27<sup>th</sup> May**. You will be informed by Friday 3rd June if your abstract has been accepted.

**Registration:**

To register for the **conference** please complete the on-line registration form [here](#). The fee for the conference is **£280**, which includes registration, two lunches, coffees/teas, one conference dinner and a ceilidh (the fee for postgraduates and the unwaged will be **£140**). Registration will close on Monday 15 August. Accepted abstracts will only be included in the programme if the presenter is registered by this date. The conference handbook will be circulated by Monday 29 August.

**Location:**

The conference will be held at the University of St Andrews. Details of the exact venues will be circulated to registered participants.

**Accommodation:**

You are responsible for booking your own accommodation. St Andrews has a wide range of accommodation to suit every budget. For further information log on to [www.stayinstandrews.co.uk](http://www.stayinstandrews.co.uk). Central hotel accommodation can be found at the Greyfriars Hotel, North Street, St. Andrews, Russacks Hotel, The Scores, St Andrews and there are also excellent Bed & Breakfast establishments on Murray Place in St Andrews. **Enquiries:**Please direct any further enquiries to [ship@st-andrews.ac.uk](mailto:ship@st-andrews.ac.uk)