

Scottish Health Informatics Programme



November 2012

SHIP paves the way for “Digitizing Scotland” project

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SHIP work led by Chris Dibben at St Andrews University on ‘Demographic, Socio-Economic and Environmental Data Linkage’ has resulted in a major award from the ESRC. £1.8 million will fund the transcription of Scotland’s 24 million vital events records into machine encoded text. The records hold births, marriages and deaths for all people in Scotland since 1855. This will allow research access to individual level information on some 18 million individuals, a large proportion of those who have ever lived in Scotland between 1855 to the present day. At the moment these records are kept as indexed images. This means that to extract any data, a researcher must search for an individual record by name and then manually transcribe the information they

need themselves (eg cause of death, occupation etc.) this of course makes any large scale research impossible.

The transcribing phase will then be followed by a programme of linkage where these records will be matched to individuals in existing studies and more generally to the already highly developed Scottish health informatics systems. This will allow the characteristics (place of birth, age at marriage, occupation, longevity, cause of death, etc) of parents, grandparents and other relatives of those found in these datasets to be analysed, significantly enhancing contemporary Scottish and UK health datasets, health informatics systems, longitudinal datasets and genetic studies.



SHIP enlists Brian Cox

SHIP has been very lucky to have Hollywood actor Brian Cox record the voice over for a forthcoming animated film. Brian originally hails from Dundee and as Rector of the university he takes a keen interest in its work. As well as being known for his work with the Royal Shakespeare Company Brian has appeared in many films including Braveheart, X-men and the Bourne films. Brian who now lives in New York was in Scotland in connection with “Addicted to Pleasure” a new four part documentary series he’s presenting for BBCI Scotland. SHIP is grateful for Brian’s time and talents on the animated film which will explain how SHIP data linkage will work. The film will appear on the website in January to coincide with the launch of the SHIP data linkage infrastructure at NHS Information Services Division, South Gyle.

Scotland to be an e-health centre of excellence

Scotland has been chosen to be one of four e-health research Centres of Excellence that will open in late 2012. The Scottish centre will be in Dundee, the other centres being in London, Manchester and Swansea. The historic £19 million investment comes from a consortium of 10 UK government and charity funders, led by the Medical Research Council (MRC).

Maximising the unique value of the NHS, the Centres will undertake cutting edge research that links e-health records with other forms of research and routinely collected data, which will lead to patient and public benefit and ensuring the UK remains at the forefront of global medical research.

By combining clinical, social and research data, researchers

aim to identify more effective treatments, improve drug safety, assess risks to public health and study the causes of diseases and disability.

The four Centres will make use of patient data sets available through the Clinical Practice Research Datalink, a £60 million service recently launched by the Medicines and Healthcare Products Regulatory Agency and the National Institute for Health Research.

A network will be formed to capitalise on the expertise in the Centres, and to encourage wider collaborations among UK and international researchers to make sure there are effective links between different types of health and social data sets. The Centres will also offer career development and training opportunities to increase the UK's capacity and capability in re-

search using health records.

Professor Andrew Morris, Principle Investigator of SHIP said "Colleagues in Scotland are thrilled to be awarded Centre of Excellence status. This builds upon over 40 years experience of using electronic patient records not only to drive improvements in the quality of health care in Scotland, but also to innovate in the way we deliver clinical trials and discover the best treatment options for patients and communities. The spirit of collaboration between NHS Scotland and the Universities of Aberdeen, Dundee, Edinburgh, Glasgow, St Andrews and Strathclyde has been tremendous. There is a great opportunity to make the United Kingdom the destination of choice of eHealth research, and in doing so help deliver the best quality health care to the people of Scotland."



Engineering and Physical Science
Research Council



All ten funders in the e-health consortium

Health Data Research at British Science Festival

The crucial role of healthcare data in research was showcased at the British Science Festival at the University of Aberdeen on 5th September. A session entitled 'Your life story in our hands: a walk through life with your healthcare data' was hosted by Health and Data Linkage in North East Scotland (HEADLINES). The two-hour mix of presentations, panel debate and discussion was delivered to a packed audience of almost 200 members of the public, academics and clinicians.



A scripted focus group using snippets of participant responses

SHIP Training Course: An Introduction to Bayesian Statistics Using WinBUGS

Presented by: Prof Nicky Best

Dates: Monday 3rd to
Wednesday 5th December
2012

Location: University of
Glasgow

Further details at www.scot-ship.ac.uk

Dr Corri Black began the session on using healthcare data by describing how data is collected throughout the life course and Professor Peter Helms highlighted important clinical benefits of pharmacovigilance studies in his overview of the Child Medical Records for Safer Medicines (CHIMES) research programme. Dr Lindsey Masson rounded up stage one describing the use of nutrition data in finding ways to improve health.

The second session was opened by Dr David Shaw with a talk on 'Confidence and Confidentiality', looking at balancing privacy with

public good. A scripted focus group was acted out by the Scottish Children's Research Network Young Person's Group, using snippets of participant responses from interviews and focus groups from the CHIMES study on the views of young people and parents/guardians on data linkage. The responses highlighted some concerns about the extent of information sharing and who can access data, but that in general there was public support for data linkage. Yvonne Hopf also highlighted her key research

findings from the CHIMES study on the views of healthcare professionals, in a scripted interview with Dr Peter Murchie, a GP and Senior Lecturer at the University of Aberdeen.

Finishing up with a session on safe data handling Professor Andrew Morris emphasised the need for better integration and more effective use of data to tackle the global rise in chronic disease. He advocated the 'safe haven' approach to support data sharing recommended by SHIP, which lead nicely to the two final speakers Professor Phil Hannaford and Katie Wilde who talked about the Grampian Data Safe Haven and described the robust procedures to link, manage and store data; ensuring this important research can be done in a secure environment protecting patient privacy and confidentiality.

The concluding panel discussion highlighted that more work still needs to be done to effectively engage with the public to demonstrate the benefits of using healthcare data for research, particularly when working with the pharmaceutical industry, to build confidence and address concerns.



A lively discussion between the audience and the full panel of speakers brought the session to a close.

Introducing Fiona Campbell

Fiona Campbell is an Information Consultant at the Information Services Division (ISD) which is part of NHS Scotland. Fiona joined SHIP in summer 2012 and is responsible for implementing the ISD Research Co-ordinator service for SHIP researchers.

Fiona has a degree in Mathematics and Statistics from Edinburgh University and after graduating worked as a medical statistician in the pharmaceutical industry before joining ISD in 2000. Since joining ISD, Fiona has worked in a variety of roles including supporting quality improvement and cancer statistics.

More recently, Fiona was on a 5 year secondment to the Scottish Government where she produced statistical analyses and briefings to support ministerial decision making.

Fiona's role in SHIP involves working with ISD's record linkage team to develop procedures for running the safe haven within the ISD building in West Edinburgh, updating the information on the datasets that ISD have available and ensuring that appropriate procedures are in the place to support the current record linkage team as they move into the research co-ordinator role. Once the new service research co-ordinator

service has been implemented, Fiona will be keen to hear from you with any feedback.

Fiona.Campbell2@nhs.net



Fiona Campbell

Colin McCowan moves to Glasgow

Colin McCowan has moved to a new position of Reader in Health Informatics at the Robertson Centre at the University of Glasgow, working with Prof Ian Ford.

He will be involved with the development of the Glasgow Safe Haven providing access

for researchers to routine data held by Greater Glasgow & Clyde Health Board and will also be hoping to utilise this data in answering his own research questions.

Colin will continue in his role with the Engaging Researchers work stream of SHIP and hopes

to arrange more training courses in the coming year as well as helping plan the Exploiting Existing Data for Health Research Conference, with Chris Dibben & Tom Clemens, which is running from 28th-30th August 2013. His new e-mail is Colin.McCowan@glasgow.ac.uk.

SHIP Manager Dr Violet Warwick is leaving SHIP at the end of the year to pursue a full time MSc in Business Intelligence.

Check the SHIP website: www.scot-ship.ac.uk/contact

where contact details of her replacement will appear in due course.

First study on legal status of consent forms for research

A new study finds that consent forms for research have a valuable role, but on their own cannot fully protect all of the rights of research participants.

Part of a Wellcome Trust project to examine views of participants in long-term research, the study shows that research participants now enjoy stronger rights than ever before when they take part in research. While it identifies the key role of the

consent process in securing those rights, it also points out the dangers of excessive focus on upfront, one-off signatures on consent forms.

"There can be little doubt that consent, and the signed forms that document it, now occupy talismanic status in a research culture," said Graeme Laurie, Professor of Jurisprudence at University of Edinburgh, who led the research. "But there is a real danger that we are beginning to drift towards valuing form over func-

tion. Signing the consent form is just one moment in a long term relationship of equals. The consent form should be seen as a starting point to capture participant expectations, not the end."

"Researchers need to make sure partnership is a reality for research participants" said Professor Mary Dixon-Woods of University of Leicester. "That means providing better and clearer communication throughout the life of a project, including changes to research design."