

# Scottish Health Informatics Programme



March 2010

## SHIP Workshop at Royal Society Feb 2010

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The primary aim of SHIP is to make health-related datasets more available for research purposes and to facilitate secure linkage between NHS datasets and other public/private datasets. The one day workshop on Secure Data Linkage and Access was held in order to learn from best practice in other countries. It was an opportunity for representatives from government, academic, NHS and industry to discuss the problems and possible solutions with colleagues in England, Wales and Canada. The workshop addressed all aspects of data linkage and access including governance, IT solutions and

data security.

A truly international flavour was brought by Don Willison who is Senior Scientist at Ontario Agency for Health Protection & Promotion and Associate Professor of Clinical Epidemiology & Biostatistics at McMaster University.

Don spoke on "Use of data from the Electronic Health Record for health research – governance challenges in Canada and potential Solutions". We were also lucky to have the attendance of Ronan Lyons from the SAIL databank in Wales; Richard Welpton from the Office for National Statistics; Melanie Wright from the UK Data

Archive and Peter Knight who spoke on the Research Capability Programme.

From NHS Information Services Division Caldicott Guardian Janet Murray spoke on "Protecting Confidentiality and Research: the Scottish Landscape" and Steve Pavis presented a draft model for linking Scottish data for research purposes.

Following this the forty delegates broke into small groups for discussion of the draft model. There followed a useful whole group discussion of the issues and this will inform development of the model for taking forward with NHS National Services Scotland.



The Royal Society of Edinburgh

## SHIP website and wiki

The SHIP website <http://www.scot-ship.ac.uk> has a number of informative but static pages. In order to provide a more interactive facility a wiki has been set up for SHIP at <https://scotship.pbworks.com>

A wiki is a website that allows users to add to, comment on and change one another's text using a simple text editor. This allows

documents to be written collaboratively and ideas to be swapped on a message board. Only people working directly on SHIP have access to the wiki. "Wiki" is a Hawaiian word for "fast". The wiki concept is well explained in a four minute video at <http://pbworks.com/content/supportcenter>

The SHIP website is being professionally upgraded. As

well as being public facing there will be private space for SHIP people to work collaboratively. This will render the wiki obsolete. The private space will be capable of being split so that small groups can, for example, work on documents amongst themselves before sharing them more widely. The new website will launch by 20<sup>th</sup> May.

## SHIP in CSO Research Strategy

SHIP features prominently in the Scottish Government's Research Strategy for Health and Healthcare 2009. The five year strategy (available at [www.cso.scot.nhs.uk](http://www.cso.scot.nhs.uk)) describes four broad cross-cutting ambitions for patient benefit. SHIP comes under aim 2: improving population health.

The report says, "Record linkage capability is being developed rapidly throughout the UK, opening up new opportunities for research using federated datasets from more than one country. We will build on... the Scottish Health Informatics Programme... which aims to establish a Scotland-wide platform to enhance the use of patient records for research purposes."

It goes on to describe the vision as being, "to work in partnership with NHS Information Services to create a world-leading research information linkage and data exchange programme within NHS Scotland, supported by an infrastructure that is adaptable and developed in response to the research needs of the NHS, academia and industry."

In the report, CSO undertakes to:

- Ensure that the underlying principles, processes and approaches related to research access to data and associated approvals and governance have broad public support and an appropriate legal basis.
- Ensure information is treated and handled in a safe and secure way to protect the rights and confidentiality of patients and individuals under the law, and also meet researchers' needs effectively.
- Provide access to a comprehensive range of technical resources for accessing health and other relevant data sets, under strict protocols of information governance that will aid the research community to access the data needed to prosecute research of the highest methodological standard.
- Provide high quality training for researchers and NHS staff on technical and applied aspects of data linkage research and the associated legal and ethical principles on which it is founded.
- Maintain Scotland's position as a leader in record linkage based research and in the provision of research support services to academia and industry.



CSO Strategy: Investing in Research | Improving Health

*"We shall invest further in strengthening the infrastructure for record linkage and increasing capacity to carry out and exploit novel linkages" CSO.*

## Introducing Anthea Springbett

Anthea Springbett is the programme principal for SHIS-R in the Information Services Division of NHS National Services Scotland (ISD). She is responsible for coordinating ISD's activities as part of the SHIP project to develop a Scottish system for secure data access and linkage. She

has been at ISD since 2007, initially working on drugs and alcohol data within the Epidemiology and Statistics Group before moving to SHIS-R in 2009. Before joining ISD she first worked briefly as a lecturer at St Andrews University, and subsequently spent the majority of her career in

scientific research as a consultant statistician, firstly at an MRC institute and latterly at Roslin Institute just outside Edinburgh. She continues to take an active interest in research and is currently statistical editor for the journal Reproduction.  
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## Forthcoming events

### Modern Demographic Methods in Epidemiology

Training course 1-3 June 2010.

University of St Andrews

**Course convenor: Bendix Carstensen**

Senior Statistician, Steno Diabetes Center & Dept. of  
Biostatistics, University of Copenhagen, Denmark

The Course will give an overview of modern demographic methods in epidemiology. The course will use the freely available computer package **R**, and will contain a short introduction for those unfamiliar with the package.

**Topics to be covered include:**

- Rates, survival function: Connection between all basic concepts from a probability point of view
- Multistate models, competing risks
- Lexis diagrams and multiple timescales
- Cox-modelling of rates
  - Splitting the follow-up
  - Poisson modelling of rates
  - Modelling multiple time scales
  - Multiple time scales and multistate models
  - Reporting rates and probabilities from models

**Course overview** details, including a workbook that will be useful for those with no experience of **R**, can be accessed via: <http://staff.pubhealth.ku.dk/~bxc/AdvCoh/StAn-2010/>

Details of the exact venues will be circulated to registered participants.

**To register** for the Training Course please complete the on-line registration form at:

[https://onlineshop.st-andrews.ac.uk/browse/extra\\_info.asp?](https://onlineshop.st-andrews.ac.uk/browse/extra_info.asp?compid=1&catid=14&modid=2&prodid=113&deptid=28)

[compid=1&catid=14&modid=2&prodid=113&deptid=28](https://onlineshop.st-andrews.ac.uk/browse/extra_info.asp?compid=1&catid=14&modid=2&prodid=113&deptid=28)

The fee is £90, which includes registration, lunches and coffees/teas.

Registration will close on Friday 7th May 2010.

**Total places for the Training Course are limited to 32, so please book early.**

**Cancellations** after Friday 7th May 2010 may incur a 50% penalty. All cancellations must be submitted via email to [ship@st-andrews.ac.uk](mailto:ship@st-andrews.ac.uk).

You are responsible for booking your own **accommodation**. St Andrews has a wide range to suit every budget, see [www.stayinstandrews.co.uk](http://www.stayinstandrews.co.uk).

While lunches, teas and coffees are provided, breakfast and dinner are not.

**Getting to St Andrews** <http://www.st-andrews.ac.uk/visiting/GettingtoStAndrews/>

<http://www.st-andrews.ac.uk/maps/Universitymap/>



St Andrews Cathedral

If you work  
on SHIP  
come to the  
SHIP Retreat  
at Stirling  
Highland  
Hotel 20-21  
May 2010.  
Contact the  
SHIP  
manager to  
sign up now!

SHIP now has a publications policy available for download at <http://www.scot-ship.ac.uk/publications.html>  
Please refer to it in advance of submitting papers for publication or abstracts for presentation at conferences or meetings

## Comments...

If you have any comments on this newsletter, or ideas for the forthcoming SHIP website, please send to:

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