

Scottish Health Informatics Programme



March 2011

Academy of Medical Sciences advocates safe havens

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In January this year the Academy of Medical Sciences published a report on “A new path for the regulation and governance of health research”. The report contends that “a complex and bureaucratic regulatory environment is stifling health research in the UK” and cites “inappropriate constraints on access to patient data” as one of the problems.

In order to streamline the regulation and governance pathway several recommendations are made including some designed to provide access to patient data that protects individual interests and allows approved research to proceed effectively.

In particular the report urges the Government to evaluate progress in implementing the recommendations of the 2008 Data Sharing Review, and specifically recommends that:

- Accredited investigators and research team members should be considered part of a clinical care team to enable identifying patients eligible for approved studies.
- The UK Data Protection Act should be reviewed to identify and amend aspects requiring clarification and to inform proposed revisions to the EU Data Directive.
- ‘Safe havens’ are established as a matter of urgency to allow access to data for approved research.

Safe havens are secure environments for coding and handling data and have three key characteristics (as outlined in the Data Sharing Review):

- They provide a secure environment for processing identifiable personal data
- Only ‘approved researchers’ can gain access to the data.
- There should be penalties for anyone who abuses personal data.

It is described as vital that the work to develop safe havens is accelerated. The introduction of legislation is advised if necessary.

The authors propose the creation of a new Health Research Agency (HRA) to oversee the regulation and governance of health research. It will incorporate a new National Research Governance Service to oversee a streamlined, common process for NHS R&D permission in the NHS in England. However the authors envisage the HRA working with devolved nations to develop a seamless regulatory system for the UK, starting with an evaluation of the differences in law and practice across the UK. The Health Research Agency should support researchers and raise research standards by providing consistent advice and interpretation of legislation and a single point of contact to ensure better communication in navigating the regulation and governance pathway. A priority for the HRA will be the coordination and development of guidance for healthcare professionals and researchers relating to the use of data in research.

The report foresees the approval for use of data in research studies switching away from Caldicott Guardians to other bodies and the role of Caldicotts shifting to facilitating the delivery of research studies.



The safe haven network model

Plans for the SHIP infrastructure centre around a collaborative network of safe havens.

At the heart of the SHIP infrastructure will be a national safe haven within National Services Scotland (NSS). Local safe havens will be situated within NHS Grampian, NHS Greater Glasgow and Clyde, NHS Lothian, and NHS Tayside, and possibly elsewhere. Each safe haven or 'node' in the infrastructure must comply with SHIP governance principles to maintain consistently high standards of confidentiality and data security. These governance principles include standards for careful handling of personal data, training of personnel, controlling data access and disclosure, maintaining security, and independent ethics. SHIP will bring together best practice from around the world to provide a safe and effective research

environment for health-related research in Scotland.

The three key elements of the infrastructure will be:

Safe Havens They will provide facilities for approved researchers to obtain secure access to data in accordance with the SHIP governance principles.

Indexing Service This body will maintain a population index based on a unique patient identifier (UPI) eg the Community Health Index number (CHI). The key function of the indexing service will be the addition of anonymised identifiers (referenced to the UPI) to individual records for the purposes of linking these records across two or more datasets.

Linkage Agent This body will use anonymised identifiers to perform the matching of records belonging to individuals from two or more datasets to form a single linked dataset.

This service will be provided by the safe haven but will be separate from the research data centre, where datasets will be stored and made available for analysis.

Anticipated benefits of the SHIP Infrastructure include:

- High standards of governance and practices
- Clarity around governance and processes for researchers
- Better data security and less data travel
- Dedicated research coordinators to assist researchers with projects
- Register of approved researchers
- Statistical disclosure control to protect patient confidentiality
- Excellent research that has a beneficial impact on society and the economy

Introducing Lindsay Govan



Dr Lindsay Govan

Lindsay has a degree in statistics and a PhD funded by Chest Heart and Stroke Scotland and the Robertson Centre for Biostatistics. Since completing her PhD in 2009, Lindsay has been working as part of the Health Economics and Health Technology Appraisal Unit based in the Centre for Population & Health Sciences, University of Glasgow. In collaboration with the Scottish Diabetes Research Network (SDRN) Epidemiology group as well as SHIP, she has been responsible for analysing a large, unique dataset of all people with diabetes in Scotland. The Scottish Care Information – Diabetes Col-

laboration (SCI-DC) is a dynamic national register of people with diagnosed diabetes in Scotland. SCI-DC contains records for almost all people with a diagnosis of diabetes in Scotland, containing detailed clinical information such as body mass index, creatinine, age, sex, and HbA1c. Record linkage using the Community Health Index allow these data to be linked to routinely collected datasets on hospital admissions (Scottish Morbidity Records) and deaths (General Registrars Office).

Lindsay's role in these collaborations focuses on identifying the total inpatient, outpatient and prescription costs of people with

diabetes and the extent to which specific diabetes complications and other diabetes factors further predict costs. She has developed a prevalence-based model to predict the expected annual cost of people with diabetes in Scotland, while also investigating the effects of clinical characteristics on admission and cost of admission. Previous research in this area has focussed on small samples of people with diabetes. However, the national register of all people with diabetes provides an excellent opportunity to look at the entire diabetes population of Scotland.

Lindsay.Govan@glasgow.ac.uk

International record linkage workshop

A workshop on Scottish Cross Sectoral Record Linkage entitled "Envisioning the Future" was held on 14th March at the British Medical Association in Edinburgh. This incorporated great insight into record linkage internationally with presentations from Manitoba and South Australia.

Professor John Lynch from the University of Adelaide spoke on the SA NT Datalink which provides data linkage to South Australia and Northern Territory, Australia. He stressed the great value of an accurate and accessible way to communicate data linkage to people from all walks of life: the SA NT promotional animation was widely admired by delegates.

Professor Patricia Martens, Director of the Manitoba Centre for Health Policy gave an inspiring presentation describing how MCHP works alongside government while maintaining academic freedom. She highlighted the importance of building relationships with healthcare providers and health authorities.

The workshop was very successful, and Rob Wishart, the Chief Statistician for Scotland highlighted the opportunity to build upon the SHIP safe haven model to look at record linkage beyond health in Scotland.

"Scotland has more achievements and potential than anywhere except Scandinavia"

Professor John Frank.

SHIP Conference St Andrews Sept '11



Looking North to St Andrews from the Castle Course, image by David J Whyte

The next SHIP biennial conference "Exploiting Existing Data for Health Research" will be held on 9th - 11th September 2011 at the University of St Andrews. The conference is designed for researchers and practitioners interested in record linkage and the use of routine health data in their research.

We invite abstracts to be submitted by Friday 20th May 2011 on one of four broad themes:

- The value of record linkage in health research
- The use of routinely collected data in clinical trials
- Patients Rights and the Public Interest: What does good governance look like?
- The methodological challenges of record linkage

Prior to the conference there will be a 5-day course from 4th-8th September 2011 on the theory and practice of analysis of large sets of linked health and social data at an introductory to intermediate level.

Registration for conference and workshop is now open on the University of St Andrews online shop: <https://onlineshop.st-andrews.ac.uk/>

Please direct any enquiries to ship@st-andrews.ac.uk

Forthcoming SHIP Retreat at Dunblane Hydro

This year the SHIP Retreat 2011 is being held from 4pm on Thursday 19th until 4pm Friday 20th May 2011 at:

The Doubletree by Hilton Dunblane Hydro Hotel
Perth Road
Dunblane
FK15 0HG

The aims of the day are:

- to present plans for the SHIP infrastructure
- draw together the various branches of SHIP to foster collaborative working
- to take stock of the past year and plan for the next
- to give junior researchers the opportunity to present

Please contact Caroline Glen to register: c.glen@cpse.dundee.ac.uk tel 01382 496483.



Dunblane Hydro Hotel

Comments. . .

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

[Violet Warwick](#), SHIP Manager

University of Dundee

Mackenzie Building

Kirsty Semple Way

DUNDEE

DD2 4BF

Tel 01382 420105 Mobile 07751128455