

## Report to SHIP Scientific Management Group November 2010

### [C1: PROVISIONING DATASETS FOR RESEARCH](#) (Prof Andrew Morris, Dr Hester Ward)

The three short life working groups have now presented their findings to the SHIS-r programme board and submitted their reports. These reports are now being amalgamated into a definition document. The aim of this document is to build momentum and highlight a step-change in practice. The primary audience will be our International Advisory Board; NHS National Services Scotland Clinical Governance Committee; Caldicott Guardians; Chief Executives of NHS Scotland; Medical Directors and Directors of Public Health. It will also be the basis of engagement with public and researchers.

### [C2: GOVERNANCE](#) (Prof Graeme Laurie, Dr Claudia Pagliari, Prof Sarah Cunningham-Burley)

The C2 stream has concentrated on completion of a number of outputs in the last few months. These include (i) finalisation of the Information Governance Scoping Report which is now on the SHIP website, (ii) completing of the Short Life Working Group report and the production of the SHIP Guiding Principles and Best Practices Good Governance document which will be published in hard copy in due course and once subject to public stakeholder engagement input, and (iii) writing up two articles for publication on (a) principles-based regulation in information governance and (b) Carrying out governance impact assessments. Aitken and Sethi have worked closely together on interviews with key stakeholders in SHIP and related SHIP-governance issues and are currently organising a researcher engagement workshop for 13 December at which the Good Governance document will be discussed. Distance learning modules for training researchers will also be developed at the University of Edinburgh. Sethi represented SHIP at the Oxford (HeLEX) Data Sharing Conference with a presentation on SHIP and Governance. Wellcome have approved the extension of Sethi's contract until the end of the project.

### [C3: ENGAGING RESEARCHERS](#) (Dr Colin McCowan)

There will be a series of lectures, seminars, workshops and training courses tailored to the needs of the research community working with routine data. A key aim over the next year is to start disseminating the findings of the SHIP workstreams to the research community which will be initiated by a workshop in Dundee from the Information Governance and Public Engagement programmes on December 13<sup>th</sup>. The below table details currently organised and proposed events until the end of 2011. One of the key events for 2011 will be the bi-annual Exploiting Existing Data for Health Research conference being held at St Andrews on 10-12 September.

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SHIP Draft Seminar Programme

Date		Lead / Venue
26 <sup>th</sup> November	Linked health care data for research and health service use in the e-lab programme	Prof Ian Buchan / Edinburgh
13 <sup>th</sup> December	Public Engagement / Information Governance	Nayha Sethi / Mackenzie Building, Dundee
<i>Q1 2011</i>	<i>Showcasing linkage in Scotland</i>	<i>St Andrews</i>
<i>14 March 2011</i>	<i>John Frank &amp; Others</i>	<i>Dundee (Andrew M)</i>
26 <sup>th</sup> May 2011	Dr John Halmaka (Harvard University) Mackenzie Lecture / SHIP workshop	Dundee
4-8 Sep 2011	Introductory Analysis of Linked Health Data	Prof D'Arcy Holman / St Andrews
10-12 Sep 2011	Exploiting Existing Data for Health Research	All
<i>Q4 2011</i>	<i>Working with missing data LSHTM</i>	<i>Dundee</i>
<i>Q1 2012</i>	<i>Probabilistic record linkage, ISD</i>	

*Meetings in italics are proposed at present but may still require agreement & organisation.*

Potential others that could be used by SHIP staff (please contact Colin with any others)

Jan-Mar 2011 (Fridays) Applied Statistics with Observational Datasets (MPH-EH module): Dundee

Q4 2011 Geographical Weighted Regression. Stewart Fotheringham : Applied Quantitative Methods Network

Jan-Mar 2012 (Tuesdays) e-health Records Research (MPH-EH module): Dundee

Jan-Mar 2012 (Fridays) Applied Statistics with Observational Datasets (MPH-EH module): Dundee

**C4: PUBLIC ENGAGEMENT** (Dr Claudia Pagliari, Prof Sarah Cunningham-Burley, Prof Graeme Laurie, Prof Ian Ford)

A review of literature on public engagement in science and technology and summary of different engagement methods has been produced. This review (together with an executive summary) was circulated amongst the Scientific Management Group (SMG).

A series of scoping discussions has been held with members of the SMG to discuss their expectations for the Public Engagement workstream and the ways in which this might be carried out. A summary report of these discussions is now being prepared and will be circulated later this month.

The Public Engagement stream is now beginning its empirical phase. We will be conducting focus groups with various public groups throughout November and December. A pilot focus group was held in October to test the topic guide and structure. Two further focus groups have been set up and recruitment is on-going for more. We are presenting at the upcoming researcher workshop and the discussion will help inform our work.

We will hold a larger public engagement event in the first few months of next year.

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[RP1: EPR SUPPORT OF CLINICAL TRIALS](#) (Prof Ian Ford, Dr Allan Gaw, Prof John Norrie, Prof Frank Sullivan)

1. We are just completing the manual review of all stroke endpoints in the West of Scotland Coronary Prevention Study (WOSCOPS). This will complete the endpoint review in the WOSCOPS trial. A paper has been partially drafted and will be submitted in the New Year.
2. Record linkage data for the PROSPER trial (Prospective Study of Pravastatin in the Elderly) are now available. Work will start on the endpoint review for this study as soon as the WOSCOPS paper has been submitted.
3. Additional funding has been obtained from the Chief Scientist Office to support use of the PROSPER record linkage data to study long-term effects of statins in the elderly, to look at prognostic factors in the elderly.
4. A paper has been submitted on the record linkage study of aortic valve disease in Scotland. This work was used as pilot data for a funding application to CSO for further work in this area looking at other types of valvular heart disease and also heart valve disease identified in GP records (in collaboration with the Primary Care Clinical Informatics Unit in Aberdeen).
5. Work has been started on the development of tools to provide remote access to confidential datasets in a manner that prevented the analyst from viewing the source records.
6. Building work for the Glasgow Centre for Health Research Informatics was completed in the summer. Discussions are ongoing with Greater Glasgow & Clyde health board on the IT infrastructure for the Centre.

[RP2: NATIONAL EPIDEMIOLOGY](#) (Dr Robert Lindsay, Dr Sarah Wild, Prof Helen Colhoun, Prof Andrew Morris)

The SHIP initiative allowed funding for three postdoctoral researchers (Dr Lindsay Govan, Dr Jeremy Walker and Dr Todd deWees) working directly on diabetes epidemiology and working closely with the SDRN epidemiology group. A number of papers have been prepared: the first publication led by Prof Helen Colhoun (Use of Insulin Glargine and Cancer Incidence in Scotland: A Study from the Scottish Diabetes Research Network Epidemiology Group. *Diabetologia* 52(9):1755-65) was published in 2009. Other work by funded researchers relates to:

- i) The effect of socio-economic status on type 2 diabetes incidence, prevalence and mortality
- ii) Inpatient costs for people with type 1 and type 2 diabetes in Scotland
- iii) Likelihood of hospital admission in type 1 diabetes in the Scottish population

The SHIP researchers have also been directly involved (usually as first author) on abstracts at Diabetes UK (3 abstracts in 2009), the American Diabetes Association (3 abstracts in 2009) and European Association for the Study of Diabetes (3 abstracts in 2009) including a large number of oral presentations at these meetings.

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[RP3: PHARMACOVIGILANCE](#) (Prof Helen Colhoun, Prof Paul McKeigue, Dr Ewan Pearson, Prof Frank Sullivan)

Work is ongoing utilising national datasets to address specific safety questions relating to diabetes drugs. We are also evaluating whether there are some diabetes related benefits in use of other non diabetes drugs. Development of tools that combine self controlled case series with survival methods for evaluating drug effects in observational studies is ongoing.

[RP4: DEMOGRAPHIC, SOCIO-ECONOMIC AND ENVIRONMENTAL DATA LINKAGE](#) (Dr Chris Dibben)

Longitudinal Research Support: Linking genetic studies back through time:

For the main pilot data development project on attaching family history data to a sub-sample of Generation Scotland (GS) data, we are awaiting a response from the GS Advisory Board. We are pursuing the alternative strategy testing the reliability and linkages for a small set of names linking back in time using DIGROS (Digital Imaging of the Genealogical Records of Scotland's people). For the project on fertility and health in later life, we identified a need for linkage to additional Scottish Morbidity Record (SMR) data, above that of the maternity data we already have linked, and are therefore in the process of applying and extending the existing project into a new project with a larger sample of women over a longer timeframe.

We are also in the application process for a scoping study which will make use of various health data in order to observe children from birth through to leaving school, where we are primarily interested in low birth weight and smoking during pregnancy and their impact on physical and cognitive development. Through data linkage we will make use of Scottish Qualifications Authority education data and possibly child health surveillance data.

Permission for the linkage of pollution, Scottish Longitudinal Study and health data has been granted and the datasets are being created and should be available in December, January.