

Report to SHIP Scientific Management Group January 2011

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

The Blueprint describing the proposed infrastructure for SHIP has been sent to the International Advisory Board and their comments are being incorporated.

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

C2 governance has continued to work on publications arising from this arm of the project. Public and stakeholders events have taken place and the findings are being written up. Sethi is working closely with colleagues in NHS Scotland to develop case studies to run through the SHIP model to determine its added value and where further work is required. A meeting is to be scheduled in the course of March to undertake this exercise and further refine the SHIP model.

C3: ENGAGING RESEARCHERS (Dr Colin McCowan)

The Engaging Researchers workstream has concentrated on organising events for throughout 2011. Along with three other organisations, SHIP is hosting a seminar on 14 March looking at the benefits of cross-sectoral data linkage with a number of high profile speakers.

Bookings are currently being taken for the bi-annual Exploiting Existing Data for Health Research conference and Prof D'Arcy Holman training course on Introductory Analysis of Linked Health Data. These will be held at St Andrews in September.

Efforts in Dundee have concentrated on the Mackenzie Lecture by Dr John Halmaka (Harvard University, Advisor to President Obama) in May and a missing data training course to be delivered by the London School of Hygiene & Tropical Medicine later this year.

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

The first empirical phase of the public engagement workstream (focus groups) is now completed. This followed the scoping interviews with the steering group and a public engagement literature review. A total of eight focus groups were conducted between October 2010 and February 2011, these included people from diverse backgrounds and with a range of interests (for example the groups included a diabetes support group, a mental health support group, young people, black and ethnic minorities and professionals). Preliminary analysis of these discussions has begun and we expect the first internal report summarising this to be ready for circulation in May 2011.

Over the coming months we will be working closely with the information governance stream to tie in the findings of the focus groups with their scoping work. We will also develop a survey/ discrete choice experiment which will be conducted in May/June 2011. We shall also conduct dialogic engagement events around the proposed SHIP/SHISr model, setting these up as soon as the paper is ready for public consideration.

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

- Completion of work on WOSCOPS endpoint review and validation was delayed due to problems accessing information at Iron Mountain. This work is now complete and we are working on a publication.
- Work on the validation of PROSPER endpoints is now being started.
- We are finalising work on the long-term follow-up of PROSPER that will lead to a publication.
- We are finishing work on the economic analysis of WOSCOPS based on costing data from ISD. This will result in a publication.
- We have initiated a stream of work on standardising our clinical trial and other datasets into C-DISC format to facilitate development of generic software to support confidential data access.

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

The group continues to be active. A paper led by Sarah Wild has been accepted for publication by Diabetes Care: "The effect of socio-economic status on type 2 diabetes incidence, prevalence and mortality". Two further papers are in review with the same journal.

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 back in time to 1855 using DIGROS (Digital Imaging of the Genealogical Records of Scotland's people) to a sub-sample of Generation Scotland (GS) data, since we are waiting on a response from the GS Advisory Board on GS data access, we have discussed with GS our alternative strategy of testing the reliability and linkages for a 3 sample names (rather than GS data). We will report back to GS on the progress once complete. In order to undertake this alternative strategy we have trained students who are familiar with family reconstitution methods using more complex Scottish parish records (pre-1855). This part is complete and we about to assess reliability and linkages 3 sample names/trees.

For the project on fertility and health in later life, which will link Scottish Morbidity Record (SMR) SMR02 (maternity), SMR04 (psychiatric admissions) and SMR06 (cancer registrations), to follow-up SLS women throughout the life-course, we are awaiting a decision from the SLS Research Board and if successful will apply to PAC.

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For the scoping study to observe children's physical and cognitive development from birth through to leaving school, which will link SMR02, child health surveillance data and SQA education data, we are also awaiting a decision from the SLS Research Board and if successful will apply to PAC.

For both new projects we have consulted the relevant ISD contacts for the non-routine SMR data to assess the feasibility of linking the data, as not measures are universally collected throughout Scotland or computerised.

Presentation:

"Fertility Statistics - data issues: birth parity" at the *Fertility in Scotland: Policy and Research* joint meeting of the Centre for Population Change and Scottish Government policy makers and researchers. December 2010.