

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 is at final draft stage and will be sent to the International Advisory Board shortly for their comments.

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

The personnel of the C2 stream are in the process of writing up two articles for publication: the first is on the nature and benefits of principles-based regulation and reflected the approach now adopted by SHIP; the second article concerns Governance Impact Assessments and how these can be deployed to assess the robustness of SHIP and other developments in the information governance sphere. Additionally, a workshop was held on 13 December with researchers and at which the C2 Principles and Best Practices Template was discussed. Feedback will be incorporated into revised versions of the template. Finally revisions are being made to the Information Governance Scoping Report for this to be loaded onto the SHIP public website.

C3: ENGAGING RESEARCHERS (Dr Colin McCowan)

The Engaging Researchers workstream suffered with the weather like many others in the last quarter of 2010. A half-day seminar planned in Edinburgh was cancelled (to be rearranged for 2011) and some delegates to the December workshop on Information Governance and Public Engagement withdrew due to travel difficulties. However **23** hardy souls from across Scotland attended a thought provoking workshop led by Anthea Springbett (ISD), Graeme Laurie, Sarah Cunningham-Bailey & Mhairi Aitken (all Edinburgh). Their sessions provoked a lot of discussion amongst the delegates. Graeme & Nayha Sethi's paper on a framework for information governance presented at the workshop is available from the SHIP website and they would welcome comments on it.

We have several events scheduled for the next year, the first is a seminar in Edinburgh on 14 March looking at the benefits of cross-sectoral data linkage with a number of high profile speakers. The big event of the year will be our bi-annual Exploiting Existing Data for Health Research conference being held at St Andrews on 10-12 September, which will be pre-ceded by training workshop from D'Arcy Holman on Introductory Analysis of Linked Health Data. We are also in the process of organising a half day workshop to coincide with the Mackenzie Lecture (Dundee) delivered this year by Dr John Halmaka (Harvard University, Advisor to President Obama) in May and other seminars / training throughout the year.

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

The Public Engagement stream (C4) of SHIP began conducting focus groups with members of the public in November. So far four focus groups have been held and between four and six more focus groups will be held over the next month. The focus groups are being conducted across Scotland and include a wide range of members of the public (for example patient support groups, young people

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and people from black and ethnic minority backgrounds). The discussions are exploring a range of issues about how personal medical data is collected, stored and used and particularly how it may be used for research purposes. So far central themes in the discussions have related to how security is ensured; to what extent patients can control how their data is used; who has access to data and; what this data is used for.

In December the Public Engagement stream, together with the Information Governance and Researcher Engagement streams ran a workshop in Dundee to discuss the work of the information governance and public engagement streams. Sarah Cunningham-Burley and Mhairi Aitken delivered presentations on public engagement and how this relates to SHIP.

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

The SDRN epi group currently has 3 papers in review and a further 5 manuscripts in preparation all at least partly supported by the SHIP Wellcome funding. Most recently a further 5 abstracts have been submitted to the American Diabetes Association all of which will acknowledge the role of the SHIP programme.

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

Work on RP4 has been somewhat constrained while we wait on a number of data requests we have pending and the recruitment of a new member of staff. This person should be in place in March. We have been focusing on setting up a number of strands of work, which include a collaboration with The Cambridge Group for the History of Population and Social Structure to use an historical Isle of Skye surnames dataset to test various probabilistic linkage methodologies. We are also running a test to estimate the time it takes to link families back through generations, so that we can effectively assess the potential for linking the scanned registries held by GROS and producing family trees.