

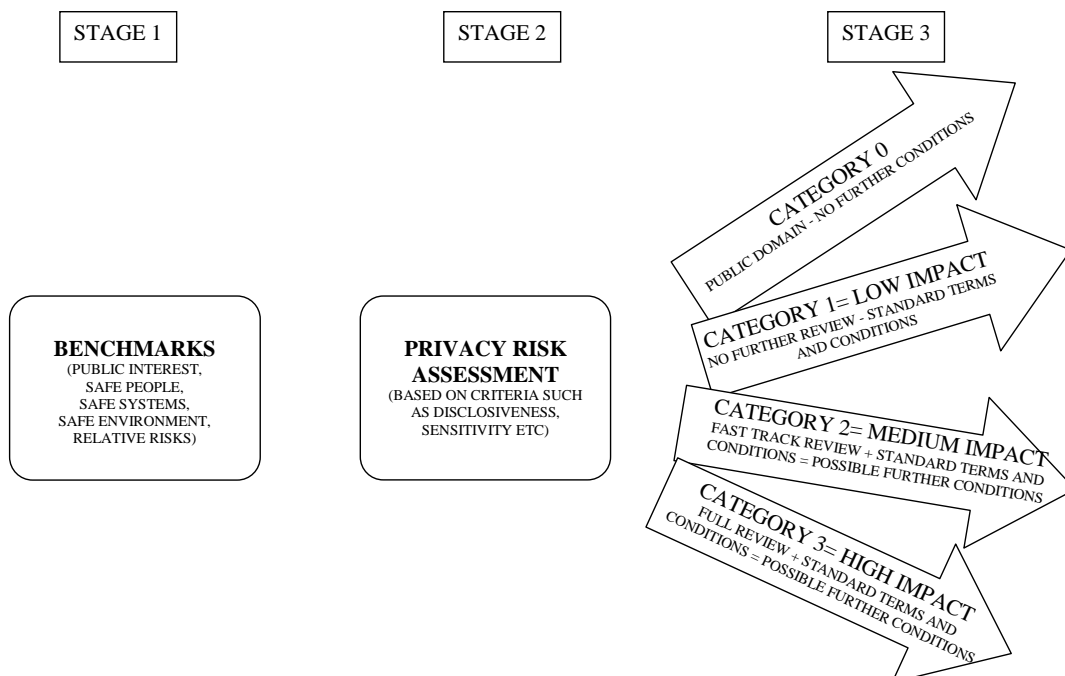
Report to SHIP Scientific Management Group May 2011

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

ISD are now offering an indexing service and is actively engaged in the IT specification for the linkage agent. Comments from the International Advisory Board have been incorporated into the blueprint and the new version will be circulated shortly.

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

- Sub-group meeting to refine proportionate governance and appropriate research pathways for SHIP, 5 April (below diagram)
- Presentation to PAC on SHIP and proportionate governance approach [well received], 28 April
- Presentation and discussion between PAC and SAREC (ethics); proposal to establish sub-group to examine PAC/Ethics interface, 28 April
- Presentation to Caldicott Guardians Forum, 4 May [will report verbally at SHIP teleconference]
- Continued work in writing up article on principles-based information governance



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C3: ENGAGING RESEARCHERS (Dr Colin McCowan)

The Engaging Researchers workstream has organised a technical workshop led by ISD to coincide with the Mackenzie Lecture (Dundee) delivered this year by Dr John Halmaka (Harvard University, Advisor to President Obama) on 26th May. Graeme Laurie, Nayha Sethi, Anthea Springbett and Steve Kendirck will lead sessions on information governance and advances at ISD. There is also a missing data workshop delivered by the London School of Hygiene & Tropical Medicine arranged in St Andrew's for 20th-22nd June. We are also continuing to plan for this year's conference and looking to organise other seminars / training throughout the year.

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

Analysis of focus groups conducted between October 2010 and February 2011 is now complete. The findings are now being written up and will be presented to members of SHIP during the annual retreat in May. This work has identified key considerations shaping public attitudes/responses. These include: the extent of individual control over personal information; security; confidentiality and; the purposes and uses of data-linkage and/or sharing.

We are working closely with the information governance (IG) stream (C2) to relate the focus group findings to scoping work conducted by IG and to the IG model of best practice. We are working on a joint publication which will explore public responses to proposed governance mechanisms.

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

- Preparing draft of paper on WOSCOPS endpoint validation.
- Work on the validation of PROSPER endpoints is ongoing.
- Writing paper on the long-term follow-up of PROSPER.
- Writing paper on the economic analysis of WOSCOPS based on costing data from ISD. This will result in a publication.
- Ongoing work on developing approaches to standardising clinical trial and other datasets into C-DISC format, to facilitate development of generic software to support confidential data access.

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

SHIP RP2 continues to progress well. In the last three months, three papers based on the SCI-DC dataset and supported by SHIP analysts have been accepted for publication, while two further papers are under review. We look forward to the SHIP meeting later this month.

Titles:

The effect of socio-economic status on type 2 diabetes incidence, prevalence and mortality: a study from the SDRN epidemiology group: Diabetes Care lead author Sarah Wild

Inpatient costs for people with type 1 and type 2 diabetes in Scotland: a study from the SDRN epidemiology group: Diabetologia, lead author Lindsay Govan

Assessment of the under reporting of diabetes as a co-morbidity in hospital admission data: Diabetic Medicine lead author Hannah Anwar

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

The fractures paper was submitted and is being revised and resubmitted. The glargine meta-analysis work is ongoing. The Edinburgh team are at late draft stage on a manuscript showing the new method they've developed. PPI and glycaemia analysis is complete and report being finalised.

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

For the main pilot data development project on attaching family history data back in time to 1855 using Digital Imaging of the Genealogical Records of Scotland's people (DIGROS), we are pursuing an alternative research strategy of testing the reliability and linkages for a 3 sample names (rather than Generation Scotland data). We are currently in the process of assessing reliability and linkages of the 3 sample names/trees found by the trained students using DIGROS.

For both new projects on "understanding impact of fertility history on health outcomes in later life" and "a scoping study investigating low birth weight and its impact on child development, linking maternity, child surveillance and education data", these are now approved by the Scottish Longitudinal Study (SLS) Research Board and we are in the process of applying to PAC.

Work on the "time space exposures to pollutants and health" strand of RP4 is on-going and a new post-doctoral research fellow (Tom Clemens) has been appointed. Currently we are looking to complete linkages between the various acquired sources of pollution data and the SLS data extract in order to begin analysis of possible health outcomes (particularly pregnancy outcomes) and to explore the time and space component of pollution exposure in terms of where individuals live and work. Additionally, we will be examining the reliability of smoking indicators in the Scottish Birth Record and the possibility of using synthetic estimates to adjust for maternal smoking patterns.