

### **Scottish Health Informatics Programme (SHIP) Procedures for accessing from January 2013**

This paper lays out the initial criteria for accessing data within SHIP. It reflects the fundamental principles of the good governance framework that promote safe data being accessed by safe people in safe environments. This launch procedure reflects the outcomes of the SHIP public engagement work that suggests that while there is strong support for data linkage in the public interest there are some concerns about commercial access. Accordingly, in order to give public and researchers the opportunity to develop trust around access using SHIP, these procedures reflect a public-private partnership model with respect to commercial access in the first instance. This position is adopted for the first year and will be reviewed thereafter to ensure that it continues to deliver a trusted framework for facilitating scientifically sound, ethically robust health-related research.

- 1) All studies will have received data controller permissions prior to data being made available. Studies which require ethical approval will also have this in place before the research commences.
- 2) Anyone accessing data will have completed an approved course which covers the law relating to confidentiality, individual privacy, data protection and freedom of information. Courses will also ensure that researchers are familiar with issues around small numbers and disclosure control procedures.
- 3) Researchers will sign a user agreement/confidentiality statement prior to accessing data
- 4) Only researchers employed by an 'approved institution' will have direct access to data. At launch this will be restricted to public sector organisations (e.g. Universities, NHS, Local Authorities and Scottish Government).
- 5) Direct access to data will not be granted to any commercial organisation, the media, lobby groups or 3<sup>rd</sup> sector organisations. The needs of these organisations will be met through partnership with either an academic or NHS institution. Under these arrangements either an academic or NHS employee will undertake analyses of data on behalf of the partnership with 'non-disclosive' results released to all parties.
- 6) At launch remote access to data will be made available to academics and NHS staff who have a strong track record in research. These will be people who have a history of using large complex datasets and who are familiar with issues related to confidentiality, protecting individual privacy and the measures required to minimise risk. Researchers with a less strong track record will be asked to use the physical safe havens while they gain further experience and expertise, (located at either: NSS; Dundee University/Tayside HB; Glasgow University/GG&C HB; Aberdeen University/Grampian HB; Edinburgh University/Lothian HB).
- 7) Researchers from the Scottish Government and Local Authorities will be allowed direct access to data but initially only within a physical safe haven.