

**NHS Central Register (NHSCR) Governance Board
31st July 2012**

Adults with Incapacity – Amendment to wording on NHSCR Web Page

In December 2009, the Privacy Advisory Committee in Scotland gave approval for the National Health Service Central Register (NHSCR) to be used as a sampling frame. During consultation it was highlighted that consideration should be given to adults (people over 16) who have impaired capacity and are unable to make decisions either temporarily or on an enduring basis. The Adults with Incapacity Act 2000 sets out the framework to help safeguard the welfare and finances of these individuals.

NHS Central Register takes into account this group of people and the risks of excluding their views from research projects as well as the risk of engaging them in projects where ethical issues have not been considered by the appropriate committee. NHS Central Register are fully aware that their data coverage will include adults with incapacity. However the NHSCR database, correctly does not allow us to identify these individuals who may be subject to protection under the Act.

We therefore recommend that if there is the potential for a person to fall into this category, researchers should take responsible action by including as part of the patient information leaflet and or consent form, appropriate wording which demonstrates clear paths for carers and adults to follow. Also where researchers aim to include adults with impaired capacity they must seek prior ethical approval from the appropriate committee. Where these circumstances apply, a letter (annex A) is included on behalf of the Registrar General of Scotland which outlines NHSCR's role.

Action required

The Governance Board's views are sought on the recommendation