



**From the Chief Executive
Professor Colin Blakemore FRS**

Statistical Reform Team
Room 3/07
HM Treasury
1 Horse Guards Road
London SW1A 2HQ

14 June 2006

Dear Sir or Madam,

Thank you for seeking the views of the Medical Research Council on Independence for Statistics, the Government's consultation proposals on the future provision of national statistics.

The MRC is a national organisation funded by the UK tax-payer. It supports medical research aimed at improving human health, meeting the needs of the health services, industry and the academic world. The MRC spends approximately £500 million each year supporting research across the whole range from basic laboratory science to clinical studies. Many MRC researchers, particularly in the area of epidemiological research, depend on accurate, comprehensive and timely national statistics, and on the ability to link their own results with mortality and other data offered by the NHS Central Register (NHSCR). Assurance on the continuing reliability of national statistics is therefore a key criterion for the MRC in judging any changes in the way that national statistics are delivered. The significance of the NHSCR is considered further later in this response.

As a general principle, we would endorse the idea that national statistics should be as objective as possible. The proposal for the production of these statistics, with quality and integrity guaranteed by an independent Board, and with direct reporting of statistics to Parliament rather than Ministers, would be consistent with this principle.

The concept of a decentralised service with statisticians remaining within Government Departments close to data suppliers and customers, and to policymakers has obvious advantages. It is vital to ensure that any new structure will have sufficient safeguards in place to enable Departmentally-based statisticians to maintain the highest professional standards in their work.

We would caution against taking a too restrictive approach to making national statistics available for use by others. Provided suitable steps are taken to ensure confidentiality, there would seem to be no reason why the data should not be made freely available for research that has been approved by a Research Ethics Committee.

Whatever funding model is adopted for the new service, it will be important that it provides sufficient resources to enable the national statistical service to continue to provide high quality data.

The NHS Central Register

Turning to the specific issue of the NHSCR, researcher access to data on the NHSCR has been crucial in a number of landmark epidemiological and other studies, for instance:

- Follow-up of large groups of people, e.g. workers in the nuclear and asbestos industries, looking for occupational disease;
- Follow-up of residents in Seascale after the scare about childhood leukaemia associated with exposure to radioactivity at the Sellafield nuclear facility;
- The Hertfordshire study which showed that diseases in adulthood such as high blood pressure could be related to the nutrition of the individual's mother during pregnancy;
- The ability to undertake long term follow-up of survival on the completion of clinical trials of health interventions in life threatening diseases.

These studies would have been much more difficult and expensive to conduct without the NHSCR – to the extent that they might not have been funded. Indeed, the existence of the NHSCR and its link with the census work of the Office of National Statistics, has given the UK an international edge in epidemiological research. It is therefore vital that any future arrangements for the NHSCR assure the quality of data in the Register, facilitate the conduct of epidemiological and other medical research, and retain the vital link with the census work of ONS.

yours sincerely

Colin

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