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National Health Service Central Register Governance Board

Report to Chief Medical Officer, Scottish Government

July 2011

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**NHS Central Register Governance Board
Report to Chief Medical Officer, Scottish Government, July 2011**

Background

1. You kindly agreed that the NHS Central Register (NHSCR) Governance Board should report to you. The purpose of the reporting line is to emphasise that the NHSCR is part of the NHS in Scotland, not simply a branch of the National Records of Scotland (NRS) - formerly General Register Office for Scotland (GROS). This report covers the period 1 April 2006 to 31 March 2011. I have not reported more frequently partly from pressure of other tasks but mostly because the Board is working well and is happy with the performance of the NHSCR and the improvements which have been made in its services.
2. The Board was set up to implement one of the recommendations of a review of the NHSCR, chaired by Dr Andrew Fraser when he was Deputy Chief Medical Officer:-

'The NHSCR, with its host organisation, should establish governance arrangements that link with representation from the key service users and offers strategic advice on its external relations, governance and effective policy developments.'
3. The Governance Board has the following remit:-

'To provide strategic advice on the operation, future development and external relations of the NHSCR in support of the NHS in Scotland, medical researchers and other users. Issues which relate to the protection of patient information held by the NHSCR will be referred to the Privacy Advisory Committee (PAC) (a pre-existing body with an independent chair and membership, which advises the Medical Advisor to the Registrar General on applications to use NHSCR data for research purposes).'
4. I chair the Board, which has the following membership:-

Paul Rhodes, SG Health
Dr Fiona Bisset, SG Health
Jim Kinney, Improvement Service
Dr Eric Baijal, Director of Public Health, NHS Borders
Martin Morrison, NHS National Services Scotland, Practitioner Services Division
Professor Graeme Laurie, Professor of Medical Jurisprudence
Janet Murray, NHS National Services Scotland, Medical Advisor to NRS
Kirsty MacLachlan, Head of Demography Division, NRS
Muriel Douglas, Head of NHSCR, NRS
Irene Henry, NHSCR, NRS (Secretary)
5. The Board has met 7 times between the date of my last report to you (12 May 2006) and the end of the period to which this report relates (31 March 2011). Initially, the Board met twice yearly – but since December 2008 has considered it unnecessary to meet more frequently than annually. A draft of this report was considered at the Board's meeting on 19 July 2011.

Accommodation, Staffing and IT

6. The NHSCR was relocated from Edinburgh to Dumfries in 2005, as part of the Scottish Government's relocation policy. Having been temporarily accommodated in a building on the Crichton Campus, it moved to its permanent home there (Cairnsmore House) in June 2007.

7. Since the move to Dumfries, there has been remarkable stability in staffing: only one person has left (although four have taken maternity leave at various times). There are 20 staff in total (seven of whom are part time).
8. In December 2007, a new IT system was installed, which considerably improved the efficiency with which staff could match records. In the same year, the records of the 1939 National Register (on which the NHSCR is based and which contain a unique record of changes in the Register until computerisation in the late 1970s) were backed up by a digitised version – the index to which has helped improve efficiency as well as allowing family historians to request extracts from the registers relating to people who have subsequently died.

Client Development

9. The Local Electoral Administration and Registration Services (Scotland) Act 2006 paved the way for the NHSCR to act as the index to the Citizen Account, run by the Improvement Service on behalf of all local authorities, for whom it serves as the customer database to help local authorities introduce new online customer service accounts and to maintain the integrity of their existing customer records. This work is ongoing with the local authorities but 1.7 million people now have active Citizen Accounts – mostly triggered by eligibility for a travel pass or for a Young Scot card. Many had to be allocated a dummy reference number, because the enrolment information was insufficient to allow them to be identified on the NHSCR and allocated a Unique Citizen Reference Number for the Citizen Account. Otherwise, the NHSCR is functioning as planned in relation to Scottish local authorities. The Citizen Account has recently been used to give online access to test results for diabetic patients and this is seen as first of a number of NHS uses of the Account.
10. In 2006, the use of the NHSCR as a tracing service for people who have lost contact with their relatives was resumed, having been suspended because Directors of Public Health had been unsure of the propriety of the service. The restored service, which operates under strict guidelines including the use of charities as gatekeepers to help ensure the bona fides of applicants, has not been problematic. A similar proposal for the NHSCR to be used for tracing sex offenders lost contact with the police was proposed and agreed, but has not been proceeded with by SG Justice Directorate.
11. Work continues on medical research studies approved by the Privacy Advisory Committee including the Scottish Longitudinal Study (SLS) which covers over 5% of the population. Since 2009, the NHSCR has been used in collaboration with the Ministry of Defence (MOD) for tracing veterans for a cohort study. In the past year, the NHSCR has for the first time been used as a sampling frame for a research study, to establish a control group for comparison with people suffering from a particular medical condition.
12. The NHSCR has always been used as a source of statistical information about migration within the UK. Since 2007, regular downloads have been taken, to provide better information for migration statistics and a special download has been taken for linkage with the 2011 census as part of the quality assessment of the census. The NHSCR has great potential, probably unmatched by any other public dataset, to play a fundamental part in the development of a more efficient system for the production of population statistics in Scotland.

Information Governance

13. The privacy of the personal information held on the NHSCR is of great importance. Information Governance standards, modelled on the NHS Quality Improvement Scotland format, were agreed by the Board in May 2008 and are annually inspected by NRS's Information Manager. They take a proportionate and precautionary approach, balancing

the public interest in privacy with the public interest in authorised use of the information. Only 18 approved members of staff can access and update records on the NHSCR. They are fully trained in Caldicott procedures, sign confidentiality statements annually and are reminded about the importance of handling personal data securely. The tightly controlled number of staff who can access the system ensures that access is easily audited. Particular care is taken when transferring data from the NHSCR to users. The transfer of data needed for the Citizen Account, for example, is now made by the NHS's secure N3 connection. There have been no data security breaches in the 5 year period covered by this report.

Streamlining Processes

14. Much work has been done, particularly in collaboration with the Community Health Index (CHI), to improve the accuracy and quality of data on the NHSCR, thanks to a change in 2007 which gave the NHSCR read-only access to CHI records and vice-versa. Recently, after requests from Directors of Public Health, the CHI/Unique Patient Identifier (UPI) number was added to death records and the following data fields were added to all relevant records: Mother's birth surname, Middle Names, Town and Country of Birth, Postcode from the CHI, Postcode and Property Reference Numbers from the Improvement Service.
15. As result of these changes, and the improvement in the NHSCR's IT system, 75% of matches are now achieved electronically, and 99% manually. This has allowed over 99% of electronic records to be processed within 5 days (which triggers the movement of a patient's medical record envelope) and for patients' records to be transferred more quickly from English to Scottish GPs (in 2009/10 52.8% of patients had their paper medical records transferred within 6 weeks; this had increased to 71% in 2010/11).
16. Improvements have also been made in the exchange of information with the analogous organisation in England and Wales, and (as regards serving armed forces personnel) with the Ministry of Defence.

Publicising and paying for the NHSCR

17. In line with one of the recommendations of Dr Andrew Fraser's review report, much more accessible information about the NHSCR was provided in 2007 on the (then) GROS website. The expenditure of the NHSCR, which was met formerly by the NHS, is now shared (in an 80:20 ratio, reflecting relative case loads) by the NHS and the Improvement Service, under Service Level Agreements – except for costs attributable to the research use of the NHSCR, which are recovered from researchers.

Performance Targets and Future Objectives

18. The Governance Board reviews the performance indicators relating to the NHSCR's work. Indicators for the last 2 financial years are tabulated in the Annex. In short, over 3 million updates were made to the Register last year, with very high accuracy and a faster turnaround time than ever before.

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Performance Targets

The NHSCR has a range of performance targets and indicators to support the targets. The main throughput and indicators are set out in the tables below for years 2010-11 and (for comparison) 2009-10.

2010-11	Total Number of Requests/cases	Achieved within performance target	%
NHS updates	3,025,759	3,024,146	100
Medical Research updates	146,714	146,714	100
Notification of Events to Researchers	120,712	120,693	100
Local government updates - received	536	536	100
Local government extracts (12 extracts)	284,053	284,053	100
GROS extract download (6)	52,490,567	52,490,567	100
SLS Events - 2009	20,451	20,451	100
Notification of death from MOD	6,145	6,145	100
Notification of veteran data from NHSCR for MOD/Information Services Division	66,000	66,000	100
Notification of English/Welsh deaths from ONS	601	601	100

2009-10	Total Number of Requests/cases	Achieved within performance target	%
NHS updates	1,069,645	1,072,667	100
Medical Research updates	702,649	702,649	100
Notification of Events to Researchers	45,461	45,461	100
Local government updates	32,335	32,335	100
Local government extracts (11 extracts)	342,537	342,537	100
GROS extract monthly updates (1)	860,207	860,207	100
GROS extract download (2)	17,161,220	17,161,220	100
SLS Census Rehearsal	1,987	1,929	97
SLS Education Pilot	37,725	31,372 SLS members	83.1
SLS Feasibility Study	2,500	2,500	100
SLS Events - 2008	21,718	19,683 SLS members	90.6