



NHS Central Register Governance Board

Terms of Reference

January 2015

Purpose

1. To set out the terms of reference and current membership for the NHS Central Register Governance Board.

Background

2. The NHS Central Register (NHSCR), part of the National Records of Scotland (NRS) operates and maintains a register of NHS patients in Scotland. A fundamental review of its work was carried out in the latter half of 2003 under the leadership of the Scottish Executive Health and Social Care Directorates (SEHD) Deputy Chief Medical Officer, on behalf of the NHS.
3. The [Review Group's report](#) in February 2004 established that the NHSCR is vital to the smooth running of the NHS in Scotland and proposed no change to its management arrangements. It made a number of detailed recommendations, including:-
“The NHSCR, with its host organisation, should establish governance arrangements that link with representation from key service users and offer strategic advice on its external relations, governance and effective policy developments.”
4. In 2015 a consultation was carried out relating to NHSCR. Responses to this consultation re-enforced the importance of strong governance arrangements for NHSCR.

Current Information Management Structures for NHSCR

5. As part of NRS, NHSCR falls within the management and governance structure of NRS. NHSCR sits within the Data Resources business area and the Head of Data Resources (who is a member of the NRS Business Leadership Group) is the Information Asset Owner for NHSCR. Ultimate responsibility for NHSCR lies with the Registrar General as Data Controller. Day to day operations are carried out by the dedicated NHSCR team.
6. The NHSCR provides services to a range of partners who provide funding to support the service. Its key service users are the NHS Boards, NHS National Services Scotland (NHS NSS), Improvement Service and Local Authorities. These partners are represented on the NHSCR Governance Board.
7. The Public Benefits and Privacy Panel with an independent chair and membership, provide advice on sharing data from the NHSCR. The committee advises the Medical Advisor (who works for NHS NSS) to the Registrar General on all applications to use NHSCR data for research purposes.
8. Ultimately the NHSCR is controlled by Section 57 of the Local Electoral Administration and Registration Services Scotland Act 2006 (LEARS). LEARS sets out the reason for the NHSCR, the data it may contain, the data it may share and who data from NHSCR may be shared with.

The Composition of the NHSCR Governance Board

9. The governance board draws its membership from main stakeholders in NHSCR; namely NRS, NHS Scotland, the Improvement Service and Scottish Government. In addition it includes a member providing independent advice from the academic sector as well as an NRS Non-Executive Director acting as an informed lay person specifically around matters of Information Governance and Privacy.
10. The group is chaired by the Registrar General

Timetable for Meetings

11. The board should meet twice per year.

Function of the Board

12. The remit of the NHSCR Governance Board is:-

“To provide oversight and strategic advice to the Registrar General on the operation, future developments and external relations of the NHSCR in support of its partners”

More specifically it should:

- Oversee the operation of NHSCR ensuring it appropriately safeguards the citizen data in its care.
- Oversee the operation of NHSCR ensuring it meets its requirements to deliver service to its customers and does this within the constraints placed on it.
- Provide advice on ethical, privacy and data standards issues.
- Provide advice on proposals to share data from NHSCR.
- Provide strategic direction to future developments for NHSCR.
- Review the operations of partners in relation to NHSCR.
- Consider emerging and importance issues relevant to NHSCR.

Administration of the board

13. The secretariat for the working group will be provided by NHSCR and Board meetings will be held at Ladywell House.

Appendix A

Board Membership

Role	Name	Function
Chair	Tim Ellis	Registrar General for Scotland (CEO), NRS
Group Member	Gerry Donnelly	Head of Data Resources
Group Member	Muriel Douglas	Head of NHSCR
Secretary	Irene Henry	Deputy Head of NHSCR
Group Member	Dr Janet Murray	NRS Caldicott Guardian, NSS ISD
Group Member	Dr Abbe Brown	Lay member and member of Public Benefit & Privacy Panel (PBPP)
Group Member	David Knowles	Director of Practitioner and Counter Fraud Services, NSS
Group Member	Eddie Turnbull	Deputy Director/Head of e-Health, Scottish Government
Group Member	Paul Dowie	Director of Shared Service and Customer First, Improvement Service
Group Member	Stuart Law	Digital Directorate, Scottish Government
Group Member	TBC	NRS Non-Executive Director