NHSCR Governance Board
First Meeting: 7 November 2005

Minutes

Duncan Macniven, Registrar General (Chairman)
Dr Malcolm McWhirter, Director of Public Health, Forth Valley Health Board
Dr Graeme Laurie, University of Edinburgh
Rod Muir, NHS National Services Scotland, Medical Adviser to GROS
Charlie Knox, SE Health Department
Dr Fiona Bisset, SE Health Department
Graham Jackson, Head of Vital Events and NHSCR Branch, GROS
Muriel Douglas, Head of NHSCR, GROS

Welcome and Introduction

1. The Chairman welcomed members to the first meeting of the Governance Board.

Function of the Committee

2. The Board discussed the Paper NHSCR GB 1/05. The following comments were made:-

- The Privacy Advisory Committee (PAC) did not in practice consider individually all applications to use NHSCR's data for research purposes: it established principles within which all applications were considered, and all problematic cases were referred to it;

- As well as providing advice on the use of NHSCR data for research purposes, the PAC provided advice on the use of other GROS and ISD data;

- It was important to avoid overlap and duplication between the work of PAC and the Governance Board and close liaison would be necessary, with the PAC remitting to the Governance Board questions which related to running the organisation and the Governance Board referring to the PAC questions about the use of NHSCR data;

- Contrary to what the Paper said, Malcolm McWhirter was not a member of the PAC, although he had chaired it in the absence of Graeme Laurie.

3. In the light of the discussion, it was agreed that the remit of the Governance Board should be:-

> "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."

4. It was agreed that, while advice would normally in practice be provided to GROS, the Governance Board would be more closely aligned with the NHS if it reported either to the NHS Chief Executive or to the Chief Medical Officer. Fiona Bisset and Charlie Knox would consider which reporting line was best.

5. It was agreed that the membership of the Board should be expanded to include a representative from Practitioner Services Division; the chairman would issue an appropriate invitation. It was agreed that it was unnecessary to have a representative of patients because issues concerning the protection of patient information would continue to be considered by the Privacy Advisory Committee, on which patients were strongly represented.

6. The proposals in the Paper were otherwise approved.

Review of the future of the NHSCR – progress on recommendations

7. NHSCR GB 2/05 was discussed. On recommendation 1 of the Review (that the NHSCR should establish, maintain and project a clear purpose, role and function with respect to key service users, and governance of its operations), it was agreed that the GROS website was the best vehicle for providing information. GROS would prepare a paper for the next meeting proposing how this was best to be done. The information would be relevant to NHS Education Scotland which was preparing training materials on information governance; Rod Muir would make the necessary contacts.

8. On recommendation 2 (that the NHSCR should maintain robust internal quality assurance procedures consistent with the law and best practice, and develop a strategy for external quality assurance), GROS would prepare a paper for the next meeting of the Governance Board. It would be useful to draw parallels with arrangements in England & Wales.

9. It was agreed that the establishment of the Governance Board implemented recommendation 3 (that the NHSCR, with its host organisation, should establish governance arrangements that will include representation from key service users and offer strategic advice on its external relations, governance and effective policy developments).

10. Recommendation 4 (that the NHSCR should continue to explore opportunities with its key service users to maximise its use for health, population and research purposes while upholding its reputation and avoiding any diversion from its prime purpose) was in part implemented by paper NHSCR GB 5/05 (see below). But it was important also that the website should make it clear that GROS was committed to maximising use of the valuable NHSCR data resource, subject to the necessary

compliance with the Data Protection Act and other protection for patient confidentiality.

11. Recommendation 5 (that the NHSCR should track closely the proposals for change in residency and population registration, and plan to enhance the NHSCR's ability to support population enumeration and NHS entitlement for those residents in Scotland who were not born in the UK) underlay paper NHSCR GB 4/05 (see below). Other relevant developments were the UK-wide Single Patient Record and the possibility of linkage with DWP information about benefit recipients leaving the UK.

12. Little progress had been made on recommendation 6 (that the NHS should examine the cost effectiveness of creating a backup to its paper resources, proportionate to the risk of destruction of vital archive material and irreplaceable information). It appeared that the cost of digitisation would be high. Meantime, however, the task of a rebinding the original register was being completed, in a way which would facilitate future scanning. A paper would be put to the future meeting of the Governance Board.

13. Recommendation 7 concerned the future of the NHSCR as part of GROS and its future location. Ministers had concluded that the NHSCR should remain part of the GROS and should relocate to Dumfries, as reported in paper NHSCR GB 3/05 (see below).

14. The Board noted progress on the recommendations and looked forward to further consideration of recommendations 1, 2 and 6.

Relocation of NHSCR – progress report

15. Paper NHSCR GB 3/05 reported progress with the relocation of the NHSCR from Edinburgh to Dumfries. The Board noted that good progress was being made and that service quality and speed was being maintained. A further report would be presented to the next meeting.

The NHSCR and the Citizen's Account

16. The Board discussed the paper NHSCR GB 4/05. It was recognised that this was an important development for the NHSCR, which would require careful management. But the potential benefits in efficiency for the local authorities and the NHS were significant and the fact that the Citzen's Account was founded on informed consent ensured that the privacy of individual patients would not be eroded. The Board noted the proposal.

Tracing People in Scotland

17. The Board discussed paper NHSCR GB 5/05. Muriel Douglas explained that there were essentially 3 groups of people in respect of whom the NHSCR could potentially provide a tracing service:-

- People whose families had lost touch. Applications were mediated through organisations such as the Salvation Army which followed strict procedures;

- Legatees and insurance policy beneficiaries, who were sought by solicitors and insurance companies;

- People with a medical (and particularly genetic) problem, who were sought by medical practitioners.

18. Muriel Douglas explained that applications were carefully vetted and contacts with the patient sensitively handled in the way described in the paper. As a result, there had been no problems with the pre-1999 system, nor with the post-2000 system in England & Wales, which was handling around 6000 cases per annum.

19. The Board agreed that it would be desirable to re-introduce the tracing service. It would be best to handle centrally the small number of cases, with the NHSCR routing inquiries through Practitioner Services Division rather than through Directors of Public Health. Malcolm McWhirter agreed to clear this approach with Directors of Public Health, on the basis of a paper provided by Muriel Douglas setting out a clear protocol for each type of case. There was scope for referring particularly difficult cases to the Privacy Advisory Committee. Sensitive medical cases might benefit from case-by-case guidance to the patient's GP.

Any Other Business

20. It was agreed that the next meeting would consider a revised draft of the Service Level Agreement between SEHD and GROS, on the operation of the NHSCR – which Charles Knox would prepare.

Date of next meeting

21. It was agreed that the next meeting would be held on Monday 8 May 2006 at 12.30 pm (starting with lunch), at New Register House.

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