

NHS Central Register (NHSCR) Governance Board
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Minutes of the NHS Central Register Governance Board:**Eleventh Meeting: 31 July 2012**

Present	Organisation
George McKenzie	Keeper, National Records of Scotland (NRS) (Chairman)
Paul Rhodes	Scottish Government (SG) Health Dept
Graeme Laurie	Edinburgh University
Kirsty MacLachlan	NRS
Muriel Douglas	NHS Central Register
Gail Turner	NHSCR
Ian Young	National Services Scotland (NHS)
Rosalind Dolan	National Services Scotland (NHS)
Janet Murray	Information Services Division
Jim Kinney	Improvement Service
Alex Stannard	NRS
Scott McKenzie	NRS (Minutes)

1. Welcome and introductions

- 1.1 The Chairman welcomed members and everyone introduced themselves. There were apologies from Dr Eric Baijal and Dr Fiona Bisset.

2. Minutes of meeting on 19 July 2011 and matters arising

- 2.1 The minutes were approved. Matters arising were discussed under appropriate agenda items. It was acknowledged there was a mistake in the agenda for this meeting, which was described as the tenth meeting but should have been the eleventh.

3. NHS Central Register (NHSCR) Performance Targets 2012-13 and Objectives 2013-14

- 3.1 Muriel Douglas spoke to Paper 1 NHSCR GB (12) 01. NHSCR has been very busy as usual. Briefly mentioned was the work schedule for 280,000 Scottish Longitudinal Study (SLS) cases, and a number of very important smaller studies which have been undertaken. NHS Central Register (NHSCR) played a vital role in supporting the 2011/12 'In Patient Experience Survey', identifying deaths in files received from health boards and reporting them, preventing surveys being sent out to deceased persons.
- 3.2 The board examined Paper 1 NHSCR GB (12) 01 Appendix A Annual Control Worksheet. The Chairman inquired about some exceptional figures. It was explained that the July figure includes 785,132 surnames which were held on Community Health Index (CHI) but missing from the NHSCR database. This has resulted in more complete surname details on NHSCR.
- 3.3 Problems with uploading the Unique Property Reference Numbers (UPRNs) from the Citizens' account system were due to File Transfer Protocol (FTP) problems with the system. The UPRN data should be provided by a monthly feed but

system problems have led to intermittent results. This is detailed in point 21 of Paper 1 NHSCR GB (12) 01. The Improvement Service have been working hard to find a fix for this issue. Muriel Douglas raised several possible causes of the system problems and discussed with Jim Kinney, who agreed to investigate to try and help.

Action: Jim Kinney to investigate problems in uploading UPRNs to NHSCR

4. NHS Central Register Memorandum Trading Account

- 4.1 Muriel Douglas spoke to Paper 2 NHSCR GB (12) 02, stating that they were on target with performance measures and improved data quality this year. They have been working to generate more business, particularly from medical research and local government. The Memorandum Trading Account (MTA) is kept under review by National Records of Scotland (NRS) Finance.

5. NHS Central Register Scottish Longitudinal Study (SLS) Privacy Compliance Check

- 5.1 The Chairman opened the discussion on Paper 3 NHSCR GB (12) 03 by highlighting that sections 5 and 6, covering confidentiality and Security policy, are things that National Records of Scotland have been doing for some time. It was stressed that information assurance is vital.
- 5.2 Janet Murray raised the issue that the dataset referred to in section 4.4.1 was only a list of variables. It was agreed that owner (e.g. NHSCR, National Records of Scotland) of the data of each variable wasn't clear and needs emphasis.
- 5.3 Graeme Laurie requested re-wording of the 2nd last line in the last paragraph of 4.5. It should not state that permission was granted by the Privacy Advisory Committee on the basis that it is solely an advisory body and provides advice, not permission.
- 5.4 It was suggested that section 5.2.1 required more detail, as the content provides the same information and terminology as on the website. The board agreed that it required a more detailed and deeper analysis. Attention should be given to the use of the term 'safe haven' and care taken to ensure it is always used within the same context.
- 5.5 As the document makes reference to remote access of data, the Chairman asked for more detail of the nature of access. Kirsty MacLachlan explained to the board the specifics of the remote access; that third parties would be given the variable names and labels of the database in order to write their own analysis code, which would be run on the data by the Scottish Longitudinal Study (SLS) team who pass back the results once they have been checked for confidentiality issues.
- 5.6 Kirsty MacLachlan raised concerns about whether some of the details in the Privacy Impact Assessment (PIA) were too confidential to be released. The Chairman responded that it was important this document is released to provide assurance, and that it should be checked over again then published.

Action: Kirsty MacLachlan to make amendments to the NHS Central Register SLS privacy compliance check and arrange for it to be published.

6. NHS Central Register Population & Migration Privacy Compliance Check

- 6.1 Kirsty MacLachlan spoke to Paper 4 NHSCR GB (12) 04, briefly describing how NHS Central Register (NHSCR) is extensively used to estimate migration. She noted that the Population & Migration Branch does not access records containing data identifying individuals.
- 6.2 It was suggested that the last paragraph of this document should be first. Attention was drawn to paragraph 4.7 and it was suggested that the emphasis should be placed more on the legal aspects rather than the practical aspects.

Action: Kirsty MacLachlan to make amendments to the NHSCR Population & Migration privacy compliance check and arrange for it to be published.

7. Beyond 2011 Privacy Impact Assessment Draft

- 7.1 The board examined Paper 5 NHSCR GB (12) 05. In section 2.4, it should be noted that the eight options mentioned for census alternatives are those being looked at by Office for National Statistics (ONS). National Records of Scotland is following the ONS research with interest but concentrating on a hybrid option involving linkage of individual administrative data and a modernised form of enumeration. The board agreed that this document should be a live document which will change as we move forward and should be regularly reviewed after publication.
- 7.2 There was discussion about the synergies between the Beyond 2011 project and other initiatives within the Scottish Government: e-health was looking to share data with partner providers to provide services; the NHS had launched an Information Assurance Strategy last year; the potential use of the Unique Citizen's Reference Number was relevant for public policy as well as administrative purposes.
- 7.3 There had been a recent consultation on the principles of the wider Data Linkage Framework. The board agreed that a 40 page document on data linkage could be hard to understand, and that a smaller half-page list of principles should be derived from it. The concepts defined in the document could also be refined down into a simplified list of policies and principles. There should also be an awareness of the intended audience, and different levels of detail may be needed depending on the audience.

8. NHS Central Register Data Sharing Powers

- 8.1 Muriel Douglas spoke to Paper 6 NHSCR GB (12) 06, which had been prepared at the Chairman's request to provide background on sharing of data from the NHSCR. The board paid special attention to the Sharing powers section of the paper, detailing data items, origins and sharing permissions.
- 8.2 For NHS Numbers 84% are owned by NRS and 16% by NHSCR. It was suggested that the origin of the NHS number field in the paper be amended to show that the 84% were derived as birth entries in Scotland and the 16% assigned from records originating outside Scotland.
- 8.3 It was confirmed that there was a cancer registry at Scottish level which receives regular feeds, and which can provide data for approved medical research. It was

suggested that a distinction be made between sensitive data and readily available data in the paper, and that the paper should be kept under review.

9. Unique Citizen Identification

- 9.1 Paper 7 NHSCR GB (12) 07 was written by Muriel Douglas in response to questions George McKenzie had asked about the Unique Citizens' Reference Number (UCRN). The NHS Central Register was identified as an existing database suitable for creating the Citizens Account system. It could provide the UCRN using an algorithm based on the NHS number. There were legal issues involved in using the NHS number for this purpose and in-depth legal work has already taken place.
- 9.2 Jim Kinney explained to the board the reasoning behind the design of the UCRN and how it is derived, the key point being that no personal identifying information can be extracted from the UCRN but it can be used to link to back office systems.
- 9.3 The board discussed the ownership of data, what is classified as 'ownership' and if ownership meant metaphorical or legal ownership. It was agreed that in the future all data would have a degree of public ownership.

10. Adults with Incapacity – changes to wording on NHS Central Register webpage

- 10.1 Muriel Douglas spoke to Paper 8 NHSCR GB (12) 08, mentioning that the letters attached were for general surveys and not specifically for studies relating to adults with incapacity. Alex Stannard suggested that the letter to patients may be difficult to follow. This was already been considered and the letter had been simplified earlier that morning. The revised letters are to be sent round for review.
- 10.2 For Paper 8 NHSCR GB (12) 08 the Chairman suggested splitting up the 3rd paragraph and removing the last sentence.

Action: Muriel Douglas to take on comments and redraft web page and letters

11. Any other business

- 11.1 Kirsty MacLachlan provided an oral report to the board on a case study with NHS Greater Glasgow & Clyde, where the population count from Community Health Index/NHS Central Register was disproportionately greater than that from the midyear population estimates. The planned work streams were described and it was stated that more resources would be required to take this forward. The next logical step is to scale up the linkage project to encompass the whole country, which is essentially what the National Records of Scotland is trying to do with the Beyond 2011 work.
- 11.2 Muriel Douglas added that they were in a position to take the North Lanarkshire data they have been working on to show other councils how they could create golden records.

12. Date of next meeting

- 12.1 It was agreed that the board would meet again in July 2013, unless business arises that justifies a meeting being held sooner.