

**Honest Broker Governance Board Meeting**  
**Tuesday 05 February 2015 at 2pm**  
**In The Boardroom, ORECNI, Lisburn Square House, Haslem's Lane,**  
**Lisburn, BT28 1TW**

**Minutes**

**Present:** John Growcott BHSCT (Chair)  
Paul Schofield PCC  
Irene Knox, SHSCT (by telephone conference)  
Ian Young, BHSCT

**In Attendance:** Charlene McQuillan DHSSPSNI  
Nicola Armstrong R&D, PHA  
Sandy Fitzpatrick BSO  
Susan Campbell BSO  
Siobhan Morgan BSO  
Jan Daley ORECNI (Secretariat)

**Apologies:** Karen Bailey, BSO; Paul Carlin, SEHSCT; Peter Sharpe, SHSCT;  
Maurice O'Kane, WHSCT; Brendan O'Brien, HSCB (not BSO as  
stated in previous minutes); Eugene Mooney, DHSSPS; Ken Lowry,  
NHSCT; Chris Matthew, DHSSPSNI; Briege Donaghy, NHSCT.

It was noted that the meeting was not quorate as only 4 of the required 5 voting members were present. This had only been established 10 minutes before the meeting commenced, with the receipt of last minute apologies. It was agreed that the business on the agenda would be discussed due to the effort made by those present to attend, but that no formal decisions could be made. It was noted that the issue of commitment to attendance at the Honest Broker Governance Board meeting seems to be proving difficult for some voting members, and that this will have to be addressed, and membership perhaps reviewed. It was suggested that voting members should be asked to nominate deputies, and that they be reminded that telephone conference facilities are available.

Discussion took place regarding engagement with the Public Health Authority, and the fact that representation from that body is only represented by Nicola Armstrong through the PHA HSC R&D Division. Sandy Fitzpatrick presented Honest Broker issues at the recent Data Guardian event, and PHA representatives were engaged through that forum regarding the issues of accessing data without consent.

**1. Minutes of the last meeting:**

- Siobhan Morgan noted that in paragraph 5, only the applications dealt with by the HBG Service is recorded, not the queries received. The minutes will be amended to reflect this.
- Brendan O'Brien requested that his organisation be corrected from BSO to HSCB. The minutes will be amended to reflect this.

**2. Terms of Reference:**

- One comment has been received from sandy Fitzpatrick, to date. Any other comments should be sent to John Growcott. Nicola Armstrong contracted to send her comments to Jan Daley for forwarding.
- Discussion took place regarding public awareness, and whether this needs to be included in the ToR. It was suggested that the Trusts and local

universities should be approached to promote the HBGB role in the provision of data for research purposes. It was agreed that PHA and DHSSPSNI engagement would be very helpful.

3. Memorandum of Understanding Review:

- Comments sent to Charlene McQuillan have been circulated by email to all members for completeness, and tabled at this meeting for those present. It was noted that further feedback should be sent to Charlene McQuillan, and brought forward to the next meeting, **scheduled for Tuesday 02 June 2015, 2-4pm. CMCQ to take this forward.**

4. Board accountability / reporting:

- Discussion took place regarding the need for accountability to the public regarding the security of data and public perception of this, as well as the importance of availability of information or public benefit. Discussion took place regarding the need to be transparent, to raise public awareness, and to avoid potential negative publicity. In order to facilitate this transparency, it was suggested that applicants gaining approval for using data should perhaps be asked to provide a vignette of the benefits gained, to be published at the end of the research project. **SF is to pursue this suggestion.**
- It was suggested that a report to the BSO Board, for the purposes of governance, transparency and accountability, should be prepared, authored, endorsed, and published. **SF is to pursue this suggestion.**
- Discussion took place regarding the means of reporting used by other countries, and it was suggested that any such reports be gathered for guidance on content, from, for example, Scotland. **SF is to pursue this suggestion.**

5. Training:

- It was felt that training in the legal and technical issues in the release of, and management of, personal information should be undertaken by all members of the HBGB. It was suggested that it is necessary of evidence a duty of care as a group, and that the Board's integrity with regards to release of data should be above reproach. It was suggested that time-bound sessions could be bolted onto the scheduled meetings in order to make best use of time. A training provider will need to be identified. **JG is to take this forward with CM.**

6. Engagement with Ethics Committee:

- Further discussion needs to take place.

7. HBS update:

- Project 2, in respect of Hospital Acquired Infection: The researcher reported satisfaction with the safe haven facilities and service. A positive outcome was recorded.
- Project 3 is awaiting approval.
- 6 further enquiries have been made, half of which will result in HSC project. Universities are being encouraged to use the service, and a hybrid application is expected soon.
- Telemonitoring study: It was thought that 2 more students will engage with projects linked to this one.
- Inflammatory Bowel Disease projects are also to be expanded.
- Snapshots of data are now being brought in, including data collected for audit, which can now be used for research.

- Anna Gavin is being encouraged to bring the Cancer Registry under the auspices of the HSC environment, as this would enable other cross-referencing data to be accessed, for example, primary care prescribing.

8. Phase 2 update:

- This was not reported.


9. Dealing with requests for data outside the data warehouse:

- This was not reported.

10. AOB

- New EU Regulations: Impact on use of data in research: Invitation was extended from ORECNI to all HBGB members, to the REC members training day, the last section of which was dedicated to a report from the meeting in Brussels on this issue. 17 February 2015, 3pm, Clady Villa, Knockbracken Healthcare Park.
- Enhanced research approvals sub-group of HBGB to include members who are appropriately skilled to technically review the research applications: This proposal was thought to have merit. Standing Operating Procedures will be required. Further discussion is to take place. **SF is to pursue this.**
- Document circulated by email: New report: ***The collection, linking and use of data in biomedical research and health care: ethical issues***, Nuffield Council on Bioethics.
- Eugene Mooney's concerns regarding charging for the HBS were raised. It was noted that Karen Bailey is to set a working group. Charlene McQuillan suggested that Eugene Mooney should be invited to attend. **CMcQ is to pursue this.**

11. Date of next meeting: 02 June 2015, 2-4pm

Signatures:   
 Dr John Growcott (Chair) \_\_\_\_\_ Date: 11/6/15

Ms Jan Daley  
 (Honest Broker Service Secretariat)  \_\_\_\_\_ Date: 04/06/2015

