

**4<sup>th</sup> Honest Broker Governance Board Meeting**  
**Thursday 16 October 2014 at 2pm**  
**In The Boardroom, ORECNI, Lisburn Square House, Haslem's Lane,**  
**Lisburn, BT28 1TW**

**Minutes –**

Actions arising from last meeting and approval of minutes (Paper 1 Attached)

- 1. Present:** John Growcott BHSCT (Chair)  
Karen Bailie BSO  
Nicola Armstrong R&D, PHA  
Paul Schofield PCC  
Brendan O'Brien HSCB  
Peter Sharpe SHSCT (by telephone conference)
- In Attendance:** Charlene McQuillan DHSSPSNI  
Sandy Fitzpatrick BSO  
Susan Campbell BSO  
Siobhan Morgan BSO  
Jan Daley ORECNI (Secretariat)

**2. Apologies:**

Apologies were received from Maurice O'Kane (WHSCT), Paul Carlin (SEHSCT), Chris Matthews (DHSSPSNI), Siobhan McGrath (BSO), Irene Knox (SHSCT), David Hill (SEHSCT), Ian Young (BHSCT), Joan Farley (PHA).

Maurice O'Kane reported that he had sent apologies for the previous meeting, but this had not been recorded in the previous minutes.

**3. Terms of Reference (Paper 2 Attached)**

- **Membership including profile / expertise / public representation**

An extended discussion took place on a number of issues related to governance arrangements informing the remit and related accountability of the Board. John Growcott identified his view of the need to clarify the Board's line of accountability for the discharge of its remit. He suggested that it was essential that the Board had transparent reporting processes which captured the scope of its activity and provided public re-assurance as to its competence and independence. Within this context he felt that issues such as the requisite knowledge and skills set of Board members; induction and related training to support Board members in the discharge of their remit; processes underpinning the nomination of Board members, including the area of service user representation; and the development of robust operational processes to provide assurance with regard to the management of Board business including the Board's interface with the Ethics Committee and standards underpinning request management and decision making required to be reviewed.

There was unanimity that the Board's interface with the public and the likely scrutiny of its functioning were of pivotal importance in securing confidence in the integrity, effectiveness and value of the Honest Broker Service.

**Action:** It was agreed that Board Members would be asked to provide any further comments regarding the Terms of Reference and forward same to John Growcott for his collation and forwarding to the DHSSPSNI for its consideration.

To be retained on the agenda.

It was felt that the inclusion of a lay perspective (the public and patients) is important, as the public needs assurance with regards to the security of personal identifiable information. It was agreed that some research governance representation is also important, as well as expert clinical input, to include primary and secondary care.

There was recognition that, because the population of NI was small and relatively (genetically) isolated, its health data was attractive, and could be an important source of income from multinational companies. There was a consensus that the final membership of the Board should, therefore, inspire public confidence.

#### **4. Memorandum of Understanding Review (MoU) (Paper 3 Attached)**

Discussion took place regarding the provision of data from the Data Warehouse (DW) to individual researchers based in Trusts. It was unclear to members how communication between Trust research governance offices, HBGB and ORECNI is facilitated, and whether, or not, applications were made to each appropriate organisation in parallel.

It was understood that the HBGB would have no influence in Trust governance arrangements, and it was agreed that Trusts should be informed that researchers are approaching the DW, requesting research material. It was not part of the HBGB remit to check that researchers have already fulfilled their Trust governance and/or ORECNI requirements before making their application for access to the DW.

It was noted that researchers should be educated on Trusts' individual processes for applying to undertake research, including accessing the DW before seeking approval for the latter.

It was confirmed that the HBGB represented the interests of all the Trusts when applications were made for accessing DW information via the MoU in an effort to streamline such access.

It was agreed that the Trust Research Governance Managers names and contact details should be circulated.

#### **5. Board accountability / reporting**

It was agreed that processes to ensure clarity of communication between the interested parties should be put in place. It was noted that applications regarding the DW are listed on the website, and available for review.

It was agreed that reports regarding the outcome of the application process should be circulated to the Board.

#### **6. Training**

It was noted that when the Board membership is finalised, training requirements would need to be assessed and facilitated.

#### **7. Engagement with Ethics Committee**

It was agreed that comments regarding engagement with ethics committees should be forwarded by email directly to the Chair.

## 8. HBS update

To date a significant number of enquiries (26) have been made to the Honest Broker Advice Service, which might result in 3 or 4 new applications being made. These had not been published on the website.

The availability of anonymised data via the DW was currently being advertised. The first (pilot) application was indicative of about 25% of the enquiries made so far. It was made clear that no "fishing expeditions" would be facilitated, and that all applications must have measureable outcomes, and be in a condition to make meaningful use of the information requested and provided.

Lessons had been learned in balancing what can be released, and the constraints which must be imposed on researchers. Furthermore, it was acknowledged that the researcher involved with the pilot project was a very experienced researcher, and that this would not always be the case.

A cautious approach had been adopted, whereby only anonymous as opposed to pseudonymised information was made available, and researchers used a secure, dedicated room to access the information made available. It was agreed that the researchers would be asked to provide feedback on the processes, procedures, and their experience. A report will be provided for the HBGB.

## 9. Phase 2 update

**Cost Recovery:** It was noted that the DoH supports the BSO proposal to implement a cost recovery model. BSO's legal and finance teams were involved in progressing this matter, and Karen Bailey will report back to HBGB. The issue of cross-departmental charging was discussed.

## 10. Dealing with requests for data outside the data warehouse

A paper was tabled with a request for data collected from the Telemonitoring NI project to be included in the DW. Discussion took place with regarding to the significant resource implications that inclusion of such unsolicited data might give rise to. It was noted that such requests were outside of the remit of the HBGB, and should be directed to the Regional Information Group for prioritisation. The resource implications were described (need to understand and define the information, removal of identifiers, make available within the safe haven), and those present recognised the resource requirements for undertaking such a significant piece of work.

It was agreed that because this particular piece of work had a high profile, was time sensitive, and was subject to particular pressures, a deferral for other work, and the provision of additional resources would be requested.

It was suggested that additional data from outside of the DW should be accepted for inclusion only if resources and capacity were available.

**11. AOB**

It was agreed that a one page summary of actions should be circulated to the HBGB membership prior to the dissemination of the meeting's minutes to keep those who were unable to attend informed.

**12. Dates of next meetings**

It was agreed by those present that quarterly meetings should take place in order to establish the purpose and requirements of the HBGB. Meetings will, therefore, be scheduled during the following months, and members are requested to respond to the following Doodle poll:

February 2015, June 2015, October 2015, February 2016.

Signatures: John Growcott  
Dr John Growcott (Chair) \_\_\_\_\_ Date: 1/6/15

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