

**Sixth Honest Broker Governance Board (HBGB) Meeting**  
**Tuesday 02 June 2015 at 2pm**  
**In the Boardroom,**  
**Office for Research Ethics Committees Northern Ireland (ORECNI) at BSO,**  
**Lisburn Square House, Haslem's Lane,**  
**Lisburn, BT28 1TW**

**Minutes**

**Present (voting Members):**

Mrs Karen Bailey (BSO) **(KB)**  
Ms Ruth Fulton DHSSPS **(RF)**  
Mr John Growcott BHSCT (In the Chair) **(JG)**  
Miss Irene Knox, SHSCT **(IK)**  
Dr Brendan O'Brien (HSCB) **(BOB)**  
Dr Maurice O'Kane WHSCT (by telephone) **(MOK)**  
Mr Paul Schofield PCC **(PS)**  
Professor Ian Young, BHSCT **(IY)**

**In Attendance (Non-Voting members):**

Dr Nicola Armstrong R&D Division, PHA **(NA)**  
Mrs Susan Campbell BSO **(SC)**  
Mr Alexander Fitzpatrick BSO **(SF)**  
Mrs Siobhan Morgan BSO **(SM)**  
Dr Siobhan McGrath (Secretariat) **(SMG)**

**Apologies:**

Ms Charlene McQuillan DHSSPS **(CMQ)**, Dr David Hill SEHSCT **(DH)**,  
Dr Peter Sharpe SHSCT **(PS)**; Dr Eugene Mooney, DHSSPS **(EM)**;  
Ms Briege Donaghy, NHSCT **(BD)**.

It was noted that the meeting was quorate for voting members.

1. Actions from last Board meeting 5<sup>th</sup> February 2015 were discussed:

- a) *HBGB members review. The Chair asked for those present to review current membership and to ask for Deputies to be named for all voting members.*

Actions: The DHSSPS to write to the PHA to ask for a nomination for a voting member. (CMQ). SMG to update membership list.

- b) *Discussion took place regarding public awareness, and whether this needs to be included in the ToR for HBGB.*

SF made the HBGB aware of an on-going programme of engagement about the Honest Broker Service (HBS) with relevant research communities in the Local NI universities and the Cardiovascular Group Belfast HSC Trust.

Action: Each member of the HBGB to suggest a forum with whom the HBS should engage to promote the HBS.

There was a sense of discomfort from members of the HBGB as to the limited engagement so far with the general public about the HBS. The HBGB requested that Public Awareness become a standing item on the agenda.

Actions: The DHSSPS to provide the HBGB with a history of previous advice from Information Commissioner on the HBS and the legitimacy of use of non-identifiable service user data for research without consent. It should also advise the HBGB on what type of public awareness or engagement would be feasible (CMQ).  
Public awareness is to become a standing item on future HBGB agendas (SMG).

- c) *Discussion took place regarding engagement with the Public Health Authority (PHA), and the fact that representation from that body is by Dr Nicola Armstrong through the PHA HSC R&D Division. SF 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.*

Action: The HBGB requests that the DHSSPS writes to the PHA asking for representation from an appropriate senior person who can act as a voting member on the HBGB, and to better understand any PHA concerns.

- d) Memorandum of Understanding Review:  
*It was noted that further feedback should be sent to CMQ, and brought forward to the next meeting.*

Actions: CMQ has confirmed that no further feedback was received from the HBGB membership. SMG to circulate latest MOU to the HBGB membership. The Honest Broker Working Group (HBWG) to determine if private sector research is within remit of the HBS MOU, the HBGB supports HSC data access by the private sector as long as the research fulfils the HBS principles as stated in Appendix 1 of Honest Broker Application form.

- e) *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 noted that the HBS was now recommending this to applicants. This was noted by the HBGB.

- f) *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.*

The HBGB delegated the format and content of the annual report on HBS activity for the BSO Board to the HBWG with the recommendation that it cover activities in the past financial year and proposed activities in this financial year.

Action: the HBWG to base design of report on samples of annual reports produced by the PHA R & D Division and the ORECNI at BSO.

- g) *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.*

Action as f) above.

h) Training:

- *It was thought 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.*

Actions: The HBGB wishes the HBWG to define training requirements.

Circulate presentation on 'New EU Directive: Impact on Use of Data in Research: Horizon Scan', given at the Office for Research Committee Northern Ireland (BSO) Health and Social Care Research Ethics Committees (HSC RECs) Training Day 17<sup>th</sup> February 2015 to HBGB membership (SMG).

- i) *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.*

It was noted that the PHA has expressed concern at the concept of a sub-group of the HBGB reviewing the HBS applications. Therefore there was a lack of confidence in the integrity of data release and the robustness of the process.

The HBGB supports this method of review as it is based on the precedent of proportionate ethical review of anonymised data by 3 people and the system is designed with this process as an exemplar. It is not the function of this sub-group to perform a scientific review. The studies will have already been technically reviewed by the Honest Broker Advice Service (HBAS) and by the research sponsor. The group's role is to determine if the research studies meet the principles set out in Appendix 1 of the HBS application form. It proposes that this method continues including rotation of the role around the membership of the HBGB.

Actions: The HBWG to set out a clear standard operating procedure for sharing. The DHSSPS to write to the PHA about appropriate engagement as a voting member on the HBGB.

- j) *EM's concerns regarding charging for the HBS were raised. It was noted that KB is to set a working group. CMQ suggested that EM should be invited to attend.*

KB outlined the paper on the HBS charging model and that it was based on cost recovery principles. This was supported by the HBGB.

k) *CM to identify a committed senior representative for HBGB from PHA and from DHSSPS.*

Noted as per above.

2. Minutes of the Fifth Honest Broker Governance Board February 2015 were confirmed as accurate.

3. Chairman's update and Review of Honest Broker Governance Board membership

JG confirmed that he is stepping down as Chair of the group and the DHSSPS is to appoint a new Chair. The HBGB thanked him for his contribution. JG thanked SMG and her staff for their secretarial support to the HBGB to-date.

Actions: Chair to be nominated within 1 month (CMQ)

The current membership was reviewed and duties were nominated as appropriate. The membership list to be amended (SMG).

4. Terms of Reference (ToR) Honest Broker Working Group (ENC) (CMQ)  
Deferred for review at next board meeting.

Actions: Revise TOR for the HBWG to exclude 'empty' bullet point and to add 'BSO' to title Director of Customer Care and Performance (CMcQ) and place on agenda for next HBGB (SMG)

5. Honest Broker Advice Service (HBAS) update: projects approved, Enquiries update (SM/SF) (ENC).

These were outlined by SM and noted.

6. HBAS Research application guidance Vs.5, HBS Research application form Vs. 13, anonymisation checklist (ENC) (SM/SF).

These were noted.

7. HBAS Charges (SM/SF)

The paper submitted was approved.

8. HBAS Disclosure Control Protocol and Policy Agreement Vs. 2 April 2015 (ENC) (SM/SF)

These were noted.

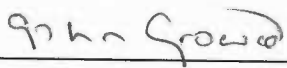
Action: RF to work with SM on some rewording.

9. NICH alliance event 16<sup>th</sup> June 2015 (SF)

SF that this event was primarily concerned with digitalization of services, it was not directly relevant to the HBGB remit.

10. Date of next meeting: 09 October 2015, 10 am -12noon at the ORECNI at BSO Boardroom.

Signatures:

Dr John Growcott (Chair)  Date: 9<sup>th</sup> October 2015

Dr Siobhan McGrath

(Honest Broker Service Secretariat) \_\_\_\_\_ Date: 9<sup>th</sup> October 2015