

**Seventh Honest Broker Governance Board (HBGB) Meeting
Friday 09th October 2015 at 10am
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)**
Dr Brendan O'Brien (HSCB) **(BOB)**
Dr Maurice O'Kane WHSCT (by telephone) **(MOK)**
Professor Ian Young, BHSCT **(IY)**
Dr Peter Sharpe SHSCT (by telephone) **(PS)**;
Mr Paul Carlin (SEHSCT)

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 (In the Chair) **(SMG)**
Ms Charlene McQuillan DHSSPS **(CMQ)**,

Apologies:

Dr David Hill SEHSCT **(DH)**, Dr Eugene Mooney, DHSSPS **(EM)**; Ms Briege Donaghy, NHSCT **(BD)**. Ms Ruth Fulton DHSSPS **(RF)** Mr John Growcott BHSCT **(JG)** Mr Paul Schofield PCC **(PS)**

It was noted that Dr Siobhan McGrath was chairing this meeting by exception until nominations for new Chair and Deputy Chair are finalised at this meeting. It was noted that the meeting was not quorate in terms of voting members. The Board decided that key decisions would be recorded and checked with PS after the meeting concluded. It was also agreed that the HBGB would benefit from recruiting further lay members.

Actions: The HBGB to recruit two more Lay members unto the Board.

1. The Committee agreed that the actions from the last Board meeting on 2nd June 2015 would be discussed at the end of the meeting to allow Ms Shauna Dunlop from the Information Commissioner's Office to provide a presentation on Data Protection and Anonymisation at 10:30am.
2. Minutes of the Sixth Honest Broker Governance Board June 2015 were confirmed as accurate.
3. Board Endorsement of a New Chair and Deputy Chair

The HBGB agreed to appoint a new Chair and Deputy Chair of the HBGB via each of the nine voting members forwarding a nomination paper and the majority of votes being counted. It was noted that Dr Brendan O'Brien had been nominated as the new Chair of the HBGB and Mr Paul Carlin had been nominated as the Deputy Chair. The HBGB was advised by SMG that seven of nine responses had been received by

voting members in relation to the nomination of the Chair and five of nine responses had been received in relation to the nomination Deputy Chair. As both nominations had received a majority of the total of nine votes it was agreed that Dr Brendan O'Brien had been officially appointed as Chair and Mr Paul Carlin as the Deputy Chair.

There was some discussion surrounding the fixed period of service for both the Chair and Deputy Chair before the HBGB agreed on a period of 2 years.

Actions: The HBGB to write to BOB and PC officially recognising their appointments to the positions of Chair and Deputy Chair respectively.

4. Honest Broker Advice Service (HBAS) update: projects approved, Enquiries update, annual report (SM/SF)

SM and SF provided the HBGB with an update on the HBAS and it was noted that the service is currently very busy. It was noted that three projects were currently with the Board awaiting approval and another seven known projects would be coming to the Board within the next number of months. The issue was raised in relation to whether the HBS would be signing off on publications which had been through the HBS process and planned to reference the HBS contribution within the publication. The HBGB agreed that the way in which the HBS process is described in such publications is significant to the public knowledge and perception of the service. It was acknowledged that there would be a resource issue in relation to the HBS being able to check every publication to ensure the portrayal of the HBS process was accurate. A suggestion was put forward that the HBS should make it a condition as part of the agreement with the research organisations that when referencing the HBS process in their publications, research organisations should only use an approved form of words as authorised by the HBS. The HBS should endeavour to check all (or a sample) of outputs for a period of one year in order to ascertain whether the research organisations were adhering to this agreement.

Actions: The HBS should make it a condition as part of the agreement with the research organisations that when referencing the HBS process in their publications, research organisations should only use an approved form of words as authorised by the HBS. The HBS should endeavour to check all (or a sample) of outputs for a period of one year in order to ascertain whether the research organisations were adhering to this agreement

5. Presentation from Information Commissioner's Office: Shauna Dunlop

HBGB was joined by Ms Shauna Dunlop of the Information Commissioner's office to provide a presentation on Data Protection and Anonymisation. Members were provided with a copy of the presentation slides in advance of the meeting. During the presentation the HBGB was advised of the Data Protection Act 1998 and Anonymisation Code of Practice. The HBGB was advised that the Information Commissioner's Office was totally in support of the HBS which members found encouraging. Ms Dunlop elaborated on the 8 data protection principles which should be adhered to when handling personal data and emphasized that the key test which should be applied when anonymising data was "Is it reasonably likely to be able to identify the participant?" and "Could it lead to the possible identification of the individual?". The HBGB noted that although these tests could be applied as far as possible when anonymising data, a judgement call would always be required in terms of practical considerations.

The HBGB was advised that section 33 of the Data Protection Act 1998 allowed for a number of exemptions in terms of research. This allowed personal information obtained for research purposes to be held indefinitely. It was also noted that if the personal data is anonymised, the right of access for the individual is removed.

Ms Dunlop advised the HBGB that the Information Commissioner's Office provides training on the basics of risk based approach when processing personal identifiable data. The HBGB thanked Ms Dunlop for providing the presentation and C.M for liaising with the ICO and arranging the presentation.

Actions: The HBGB to agree a process for on-going engagement with the ICO.

6. Sponsor peer review recommendations and HBS review- Impact on researchers (Dr Maurice O'Kane)
Deferred for review at next board meeting.
7. Master versions of MOU, Honest Broker Service Working Group Terms of Reference and Board membership for noting.
Deferred for review at next board meeting.
8. Annual Report Update (SM/SF)

SM outlined to the HBGB that members had all received a copy of the HBS Annual Report as part of their meeting papers. It was noted that the Board had requested that the Annual Report summarize everything that had been done within the last year and to give a sense of activity which had been processed to date. SM asked for any suggestions on how the report could be improved. The HBGB thanked SM for her work and acknowledged it was very helpful, clear and intelligible. Some members questioned what the target audience of the report was and how it would be circulated. It was advised that the annual report had been drafted for review by David Bingham but not for a public audience. Members agreed that an extract of the annual report should be added to the HBS website for the stakeholder audience. Some members noted that the report should further augment the contribution to the service from the PHA.

Actions: The HBWG to draft an extract of the Annual Report for addition to the HBS website for the attention of stakeholders.

9. Actions Log

Actions from the last Board meeting on 2nd June 2015 as well as actions which remained open from previous Board meetings were discussed:

- a) *Further comments regarding the latest draft Terms of Reference.* It was agreed that this action could be closed as further comments had not been received and forwarded to John Growcott for collation and forward to DHSSPSNI.
- b) *Discussion took place regarding public awareness and whether this needs to be included in the ToR for HBGB.* The HBGB agreed that no full consultation should be held but there was a need for some public awareness process that should be agreed at the next Board meeting. The HBGB had also agreed on a process earlier in the meeting to provide an extract of the annual report for addition to the HBS website. Some members brought the work of Hillshub to the attention of

other members. It was noted that Hillshub was an initiative to improve and collaborate on the main goals of both HSCNI and the Health Industry.

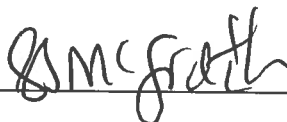
Action: Charlene McQuillan paper to be circulated to HBGB.

- c) *It was suggested that a report to the BSO Board, for the purposes of governance, transparency and accountability should be prepared.* The HBGB acknowledged that this report had now been produced and that his action could now be considered closed.
- d) *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.* The HBGB acknowledged that this action was now closed.
- e) *Enhanced research approvals sub-group of HBGB to include members who are appropriately skilled to technically review the research applications.* SF advised that the subgroup does have members who are appropriately skilled to technically review the research.
- f) *To provide HBGB with history of advice from Information Commissioner on HBS and use of non-identifiable service user data for research without consent.* The HBGB acknowledged that this action was now closed.
- g) *To provide HBGB with argument as to lack of need to engage with general public on HBS by running a Public Awareness Campaign.* SF agreed to prepare a statement for addition to the HBS website.
- h) *Using examples of training to be provided to similar groups as HBGB, the HBWG to define training requirements for Board members which would engender public confidence in discharge of its role.* The HBGB acknowledged that this action was now closed.

10. Date of next meeting: 2nd February 2015, 10 am -12noon.

Signatures:

Dr Siobhan McGrath (Chair)

 Date: 2/2/16

Mr Matthew Mills

(Honest Broker Service Secretariat)

 Date: 24/2/16