

**MINUTES OF THE INAUGRAL MEETING OF
HONEST BROKER GOVERNANCE BOARD (HBGB)**

02 DECEMBER 2013

15.00 – 17.00

OFFICE SUITE 3, LISBURN SQUARE HOUSE, HASLEM'S LANE, LISBURN

Present: Dr John Growcott (Chair), Ms Carol Beattie, Mrs Karen Bailey, Ms Susan Campbell, Mr Paul Carlin, Mr Sandy Fitzpatrick, Ms Irene Knox, Mr Chris Matthews, Dr Eugene Mooney, Mr Brendan O'Brien, Mr Paul Schofield, Dr Martin Sloan, Professor Ian Young.

Apologies: Dr David Hill, Ms Joan Farley, Dr Maurice O'Kane, Dr Peter Sharpe, Dr Calum McLeod (received 03 December 2013).

In Attendance: Miss Jan Daley

1. Introductions and Welcome

Dr John Growcott (Chair) welcomed members to the meeting and introductions were made.

2. Presentation by Chris Matthews (DHSSPS)

Mssrs Chris Matthews and Sandy Fitzpatrick provided a PowerPoint presentation outlining the motive for the inception of an Honest Broker Service (HBS). Brief examples were given regarding potential use of data stored with Northern Ireland's Health and Social Care (HSC) systems, and how these may be used for planning future services.

It was emphasised that data would be provided to users (researchers, auditors, etc.) in anonymised and pseudo-anonymised forms only, and that a safe haven would be set aside for interrogation of datasets. No identifiable information would be released.

It was noted that currently data is not routinely shared between HSC organisations, and that to date Data Access Agreements have been established before this can take place. Currently those wishing to gain access to data do not have an explicit pathway to appropriate data guardians. It was agreed that account would have to be taken of those non-employees of HSC organisations, such as GPs or pharmaceutical companies, who may also have legitimate reasons for seeking access to patient data, as these users will not have signed up to the Memorandum of Understanding.

It is envisioned that, as all HSC organisations have signed up to the Memorandum of Understanding for the HBS, non-identifiable information may now be shared between those organisations, streamlining the process for accessing such data and precluding the need for individual Data Access Agreements. It was unclear to those present whether data governance is part of the role of this Board, and if so, is there potentially a conflict of interest.

It was suggested that the data currently stored is of varying quality, and work is being undertaken to improve this situation. It was noted that researchers' expectations

would have to be managed accordingly, and the release of data regulated appropriately. Intrinsicly, metadata have to be improved. It was unclear to those present whether or not datasets currently stored in the data warehouse are validated. It was noted that the HBS will manage the information already contained within the data warehouse, but will not change current priorities. More than 40 separate systems are currently feeding into the warehouse, and separate agreements prioritise these feeds.

Management of the data warehouse is currently resourced by Business Services Organisation and the DHSSPSNI, but should requests for the service increase, further resources will be required. It is unclear how this will be financed, although brief discussions regarding a tiered approach for commercial companies, universities and HSC organisation employees took place. It was suggested that if researchers are asked to fund their access to data, early engagement so this can be built into grant applications will be necessary. It was agreed that Chris Matthews would take these issues back to the Working Group for further consideration.

Consultation will take place in March 2014 regarding legislation in England for using identifiable data for purposes without consent.

Further consideration will also need to be given to the following:

- Metadata of current datasets
- New core datasets
- Cost recovery for work on the above
- How to stimulate appetite for using the data available. It was acknowledged that resourcing service provision would be challenging.
- Prioritisation of requests from potential users
- Whether the HBGB has a data governance role
- Whether the service represents value for money (it is hoped that the pilot studies being submitted by Dr O'Reilly and Professor Bunting will advise)
- Management of user expectations
- Whether commercial companies should be involved as partners (it was agreed caution should be employed and processes established before this could happen)
- The risk of public perceptions vis a vis potential damage to reputation

3. Agreement of Terms of Reference

1. Membership

No changes were proposed to the membership of the HBGB. Membership was content that until appetite for the service has been ascertained, the Secretariat should remain care of ORECNI.

2. Roles and Responsibilities

Discussion took place regarding the limitations of the level of responsibility expected from the Board. It was unclear whether the HBGB is expected to have a pro-active approach to reviewing and monitoring the outcomes of research projects, or whether another group would take this responsibility. The members present reflected on the time commitment required for this, should researchers realise the potential of the service. The membership of such a "sub-committee" was unclear.

It was felt that the HBGB did not have the authority and/or expertise to review final outcomes of projects, but that it may be possible to comment on journal articles, for example. It was unclear what value could be added by such comments.

Concerns were discussed regarding the potential for misinterpreted data to be released into the public domain, along with issues surrounding Quality Assurance, and the resourcing of this. Risks to the integrity of the service were discussed. It was felt that as long as metadata were described correctly, the responsibility for ensuring the integrity of the outcomes, appropriate use, and therefore risk of reputational damage could be placed on researchers. A point of control must, however, be established.

It was decided that the HBGB does not want or need to approve final output, but should have sight of final reports, abstracts, and journal articles.

Prioritisation of use of, and access to, resources was discussed in relation to funding. It was agreed that a cost recovery method should be developed, and a tiered system was initially suggested. The Regional Information Group is responsible for the prioritisation of access, and has accountability for oversight of the same.

Discussion took place on the issue of the most efficient operational means of reviewing requests for access to anonymised data for research purposes. It was stated that the HBGB had always been intended as the review board for this, enabling easy access to anonymous information.

Provision of resources for supporting HBGB was discussed. It was thought that the PHA R and D Division should be approached to fund 2 WTE staff.

It was suggested that a meeting should be arranged with Dr Dermot O'Reilly and Professor Brendan Bunting, Chief Investigators for the 2 pilot studies, should be arranged to gain feedback on the service provided thus far.

It was unclear to members present how to move forward to establish parameters for this board, and it was suggested that an Advisory Board could be established.

4 Agreement of Membership and Meeting Chair

Membership of the Board was discussed. It was unclear to those present whether the membership should remain as that currently in place, or whether a conflict of interest could be perceived through members' other professional activities. No decision was reached.

5 Dr D. O' Reilly Honest Broker Service Pilot application

Professor Young declared a conflict of interest and left the meeting prior to discussions commencing.

Discussion took place regarding whether the HBGB was legitimately established to review Dr O'Reilly's application. The HBGB members were unsure what status an endorsement from the board would have, due to lack of clarity regarding the Board's remit. It was felt that review should not take place at this time. Dr Mooney agreed to supply an advisory paper. The HBGB was assured that this is not a high risk study, and that all data will be anonymised.

It was agreed that the Minute Taker should approach the Research Governance Officer at QUB to obtain peer reviews to provide assurance that the methodology is fit for purpose. It was noted that ethical approval has been obtained already from ORECNI.

6 Honest Broker Board Training Needs

Training needs for the Honest Broker Board members were not identified, and it was suggested that this should be discussed after the remit and level of responsibility of the Board has been established.

7 Schedule of HBGB Meetings

Discussion took place regarding the frequency of meetings for the HBGB. It was suggested that although Board meetings have been mooted as being quarterly, if applications for access to data are being submitted regularly, interim meetings may have to take place.

It was noted that timelines for proportionate Review by the Office of Research Ethics Committees NI (ORECNI) are 14 days from receipt of application to final opinion, suggesting that in order to not disadvantage researchers; this issue would have to be addressed.

No schedule of meetings was agreed.

8 ACTIONS

- Dr Eugene Mooney: Provide advisory paper prior to review of Dr Dermot O'Reilly's application.
- Mr Chris Matthews: Research level of accountability, responsibility and remit expected of HBGB, and provide advice. Assess whether processes regarding use of data are fit for purpose.
- Miss Jan Daley: Request peer reviews from QUB research Governance in relation to Dr O'Reilly's application. Ascertain who will provide a contact point for HBGB.
- Chris Matthews to confirm arrangement details for the next meeting of the group.

8 AOB

There was no other business.

9 Date of Next Meeting

TBC

Signatures:

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

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