

Minutes of the 19th Honest Broker Governance Board Meeting

Friday 1st March 2019

Venue: Conference Room BSO Lissue Site Moira Rd Lisburn

Present: Voting members of the Board:

Dr Brendan O'Brien (Chair and HSCB member); Christine Kennedy (DoH); Dr Seamus O'Reilly (Northern HSC Trust) (by telephone); Ms Karen Bailey (BSO); Dr Nicola Armstrong (PHA); Dr Hilary Russell (Lay Member); Ms Alison Murphy (Belfast HSC Trust); Ms Irene Knox (Southern HSC Trust); Mrs Karen Bailey (BSO); Dr Hilary Russell (Lay Member).

Non-voting members: (all from BSO) Mrs Susan Campbell, Mr Neil Marsden (Secretariat), Mr Alan Harbinson, Naomi Mill; Dr Siobhan McGrath (As Secretariat)

1. Formal Apologies

Voting members:

Mr Paul Carlin (Vice-Chair and South East HSC Trust); Dr David Hill (South East HSC Trust); Dr Aaron Peace and Mrs Mary McGonigle (Western HSC Trust); Ms Alison Murphy (Belfast HSC Trust); Dr Nicola Armstrong (PHA); Dr Peter Sharpe (Southern HSC Trust) (sent his representative Ms Irene Knox)

Non-voting members:

Ms Charlene McQuillan (DoH)

2. The Chair gave an update on the GPIIP project and the Strategic Information Group.

Building Capacity in Northern Ireland in Clinical Informatics

The Chair made the board aware of formal career structures becoming available in clinical informatics in Northern Ireland which will be launched this year. This had arisen as a result of the Strategic Information Group (SIG) initiative to professionalise clinical informatics and would apply to all clinicians, nurse, midwives and include social workers. The Chair is also establishing a Northern Ireland Branch of the Association of Professional Healthcare Analysts (AphA) and aims to establish an analytics capability in HSC. The AphA launch will occur at the HSC Informatics Professionalisation Conference on 20th March 2019. AphA membership will be £30 p.a. and funding for 50 memberships in the first year will be centrally funded. The information Standards Board (ISB) will nominate individuals to receive the funded memberships.

Information Structures

The Chair will share letters describing the Terms of Reference about the new information structures in Northern Ireland (SIG and ISB). He also recommended that it would be useful for the researchers who had presented their research to this Board today, to present to the SIG.

The GP Information Platform (GPIP)

A GP Editorial Board has been established which represents the views of GPs in any proposed uses of the data that will be held in GPIP. Data from the 6 pilot practices is expected to be loaded into the platform within the next few weeks. There is now support from GPs to enable the GPIP data to be linked to the HBS for research. Linking in GP data will greatly improve data quality and demonstrates that GPs have gained confidence in information governance arrangements

The Board welcomed this news.

National Audit Debate

A potential business opportunity for the HBS would be a Regional pseudo-anonymization service for audit purposes (non-research activity). It could be a technical solution in absence of secondary uses legislation.

This was broadly supported in principle but the BSO would need to be presented with a growth proposal and business case to ensure adequate resourcing before this could be taken forward.

3. Presentations were given from the following researchers who had completed their PhD studies through the Honest Broker Service:

Hafi Saad – Congenital Heart Disease;
Mary Gillespie – Complex Medical Needs During Maternity; and
Evi Zafereidi - Using big data to understand the dynamics of dementia in Northern Ireland.

The Board asked the presenters for feedback on their experience of the Honest Broker Service. Their experiences had been very positive in terms of the support given by the service and that it was important that the HBS should receive investment for future big data analysis. They could see many future research opportunities. The presenters stated that the safe haven needs to be expanded and in the future remote access would be beneficial. One presenter stated that the length of approvals process delayed their proposed start date.

The board was able to highlight that the safe haven had just been expanded and that it was hoping to explore the logistics of implementing remote access with colleagues at the HDR-UK. The Board also indicated that it was going to organise a showcase event for the Honest Broker Service and invited the presenters to speak at that event. The presenters indicated that they would be happy to assist. The Board was very impressed that 3 PhDs had been achieved through the Honest Broker Service. The Chair also made the presenters and the board members aware of the HSC Informatics Professionalisation Conference on 20th March 2019 and invited the presenters to speak at that event. He agreed to circulate details for distribution via the Board's secretariat.

4. The Minutes of the 18th meeting of the Board on 9th November 2018 were approved by the Board.
5. Reports on Research and Non Research Projects which had been approved and processed through the HBS since the last Board meeting were presented to the Board and formally noted. Questions were invited from Board members.

It was also indicated that there had been an expression of interest in using HBS from Analytics Engines. The board also discussed the feedback from an earlier research

presenter that the length of the HBS approvals processes delayed the project start date. It was agreed that this seemed unlikely but that further specifics should be sought and reviewed to enhance customer experience.

6. An update was given to the Board on the proposed pilot between ADRC and HBS. This project has now been impeded due to recognition that health data is specifically excluded from the scope of the Digital Economy Act (2017).

There was also an update on the proposed collaboration of the HBS with the HDR-UK.

It was noted that further to meetings in December 2018 and January 2019, it was agreed that a formal project is to be initiated. The main objective of the project is to explore how HSC might work with HDR UK. The project outcomes are expected to include:

- Data Protection Impact Assessment.
- Report on advantages/disadvantages of collaborating with HDR UK/SAIL (from the various perspectives i.e. HSC Trusts, PHA R&D, DoH, BSO, Honest Broker Service, researchers).
- Recommended preferred technical option.
- Estimated infrastructure costs, if any.
- Estimated on-going resourcing requirements, if any.
- Establishing impact on current Honest Broker arrangements.
- Evaluation of any data use for initial prescribing dataset.
- Recommended governance arrangements.

The benefits of the collaboration are expected to include:

- Access to a proven platform for safe data sharing.
- Remote access to widen the user base and increase its reach.
- Availability of a wider range of analytical software tools
- Availability of deterministic and probabilistic matching software
- Promotion of Northern Ireland as a centre of excellence for health research

It was also noted that Prof Ian Young has agreed to act as Project SRO on behalf of the DoH. Furthermore Queen's University Belfast has agreed to provide a Project Manager to initiate the project with a proposed start date in March 2019. BSO have provided document templates for Project initiation. A positive development has been that the BSO is to be funded to provide technical resource and infrastructure. As the HDR-UK funding may only be available in financial year 18/19, Queen's University Belfast has indicated that it may be able to provide funds in 19/20.

The Board welcomed this exciting development.

7. The board heard a presentation on the mechanisms of use of synthetic data for research from Scott Mathieson, BSO. The Board enquired as to how long it takes to generate data. Scott indicated that for simple data sets no more than 5 minutes and with a good computer even complex datasets synthetic data can be efficiently produced. Most synthetic data is produced with flat demographic data, however, longitudinal patient histories are more challenging to interrogate. In particular projects in polypharmacy can be difficult to link with particular patients.

The Board request that the Honest Broker Working Group scopes a synthetic data approach for HBS.

8. The Board discussed the Board's current Terms of Reference. It was agreed that a process should be added to the Terms of Reference to indicate the selection process for the Chair and Vice-Chair and to reflect a maximum term of office for each should be 5 years. The Terms of Reference should also state that member attendance will be monitored. A report of member attendance should be made available to the Board at its meetings.
9. The Board Action log was reviewed.

AP16: the Chair agreed to give a presentation on the HBS at the next Strategic Information Group Meeting.

The Board requested that an invitation should be extended to the Information Commissioners Office to update the HBGB, particularly with respect to the GDPR in September 2019.

The action from 21-Jul-17 should be subsumed into another action on the log.

The Board would also like the action log to include a RAG status

10. AOB

The Patient Client Council has recruited a new research manager and he has been invited to join the HBGB.

11. Date of next meeting:

24th May 2019 at Conference Room BSO Lissue Site Moira Rd Lisburn

Signed by the Chair of the Honest Broker Governance Board:



Date: 25.5.2019