

Minute of the 25th Honest Broker Governance Board Meeting (HBGB)

Date of meeting: 25th September 2020 Rescheduled from 21-08-2020

By videoconference

Present:

Voting members:

Dr Michael Quinn (MQ) (Health and Social Care Board (HSCB) and Chair of the Honest Broker Governance Board (HBGB)); Dr Aaron Peace (AP) (Western HSC Trust) and Deputy Chair HBGB); Dr Hilary Russell (HR) (Lay Member); Dr Nicola Armstrong (NA) (Public Health Agency (PHA)); Laura Moore (South East HSC Trust); Lisa Whyte (LW)(HSCB); Siobhán Morgan (Department of Health (DoH)); Colm Burns (Patient Client Council (PCC)); Neil Martin (NM) Northern HSC Trust);

Non- Voting members:

From the Business Services Organisation (BSO): Alan Harbinson (AH), Martin Mayock (MM), Rita McAuley (RM). Charlene McQuillan (CM) (DoH)

In attendance:

Dr Siobhan McGrath (BSO) for purposes of the minute; Fiona McNally for technical videoconference support (BSO, HBGB Secretariat.);

1. Apologies were noted from the following:

Voting Members:

Dr Seamus O'Reilly (SOR) (Northern HSC Trust), Irene Knox (IK) (Southern HSC Trust); Dr Peter Sharpe (PS) (Southern HSC Trust); Alison Murphy (AM) (Belfast HSC Trust); Mary McGonigle (MM) (Western Health and Social Care (HSC) Trust), Karen Bailey (KB) (BSO).

Non-Voting Members:

Susan Campbell

2. Chair's Update

The Chair gave an overview of upcoming Health Data Research UK (HDR UK) projects. There are five core studies looking at the effect of COVID-19 on long term population. (These are endorsed by the Chief Scientific Officer for England, Sir Patrick Valance). The Chief Scientific Officer for Northern Ireland (Professor Ian Young) wants Northern Ireland to be involved. The Honest Broker Service (HBS) Research and Technical Teams, with the Chair of the HBGB, are looking into the feasibility of the HBS being involved including plugging significant gaps in technology and funding. A funding offer (for £750,000) has been made by the HDR UK for the HBS to participate in the National Study as part of a UK network of Trusted Research Environments (TRE). This will provide support for governance, technology, and other BSO HBS and BSO Regional Data Warehouse resources. This will require changes to existing governance structures. The objective of these bids is to begin the process of turning the HBS into a leading edge TRE on a par with those elsewhere in the UK.

There also has been a bid via the Chair and the BSO warehouse to the DoH which aims to support infrastructure and people support (Solution Teams) for £300, 000 and £200,000 respectively.

It is also anticipated that a funding request will be made to the Public Health Agency R & D Division.

The Chair took questions from the HBGB.

NM expressed a need to consider Trust Information Governance Structures in any bids. The Chair agreed to speak to NM about this concern. Action

SM asked should the HBGB have a role in the oversight of bids before submission. The Chair agreed that this would be useful but as these bids were based on COVID-19 projects there was a need to expedite the funding bids.

NA expressed an interest to see the draft paperwork.

AH asked if SAIL input is built into these bids.

3. Minutes of the last meeting:

These were ratified and may be published on the HBS website.

4. Matters arising:

The HBGB welcomed Dr Aaron Peace (R & D Director of the Western HSC Trust) as Deputy Chair and Lisa Whyte (HSCB) as a HBGB Voting member.

5. Synthetic Data and the HBS –A Way Forward (MM):

The paper 'Synthetic Data –Potential for Use within the Honest Broker Service' was presented by MM. This report addressed the advantages, risks and feasibility of synthetic data use within the HBS.

Use of synthetic data does not totally remove the risk of patient identifiability and disclosure and it is also resource intensive to fully protect from external back engineering risks for each project.

The report's recommendations were that:

- the development of synthetic datasets is not pursued within the HBS whilst secure remote access provision is being developed and embedded within the service; and
- this is revisited at a later point if there is still shown to be a demand from researchers, resource is available, and taking account of synthetic data developments in other UK jurisdictions.

These recommendations were supported by the HBGB.

6. Update on Administrative Data Research Network (ADRC) (now Northern Ireland Longitudinal Study led (NILS) and Health Data Research UK (HDR UK) projects (AH):

The historical background to sharing data between the NILS (Northern Ireland Longitudinal Study/ NISRA (Northern Ireland Statistics and Research Agency) and the HBS/BSO was explained.

The NISRA are progressing the pilot project on sharing secondary uses data with the HBS.

An update on the HDR UK pilot project was given. Part of this pilot project involves testing of the SAIL University Secure electronic Research Platform (SeRP) environment with the HBS and this pilot work (Phase 2) is almost finished. The process of managing research projects and testing of the SAIL remote access platform has been completed with non-personal identifiable Open Data.

The HBS Technical staff members have as part of this pilot project also received training in data linkage software called 'LinXmart'. This software has great potential in that it allows end to end encryption for data linkage without sight of the HSC number by HSC staff. It also allows probabilistic data matching. Furthermore it also can perform linkage based on deterministic matching. As part of the pilot, a data protection impact assessment (DPIA) has been presented to the BSO Information Governance Lead looking at potential adaptation of the SeRP platform by the HBS.

The next stage will be to decide whether to use the SeRP platform for the management of HBS research projects with an offering of secure remote access for researchers. This would have the added benefit of use of the associated LinXmart software within the HBS as an alternative for linkage of datasets from outside the HBS with HBS data. The HBS Memorandum of Understanding would also have to be amended if this new approach is adopted. A report will be prepared for this pilot project and presented to the HBGB.

The HBGB was pleased with the findings thus far but recognised that there needs to be planning due to uplift in workload if the HBS becomes involved in the 5 COVID-19 studies alluded to by the Chair in his update. It also recognised that there are still risks in that the HBS does not have all HSC data as yet (some data is still held in the HSC Trust, for example), and that good quality metadata within the HBS is also a limiting factor which needs to be funded and resourced.

The HBGB advised that the HBS consults with HSC Trust Information Governance leads and the HSC Privacy Advisory Group. Action

NM also suggested approaching the HSC Director of Customer Care and Planning Group (DOPS) Action

7. Update on the HBS projects and outreach activities, Research Activity Report

RM gave an update on all research projects and their status including COVID-19 related studies. There have also been some potential project enquiries. The research update was noted by the HBGB. SC had sent in a non-research activity report which was noted.

The HBS Safe Haven has been reopened, on an initial 3 day per week basis, and is currently being fully utilised by researchers within a COVID-19 secure environment.

It was noted by the HBGB that there could be an increased demand for non-research activity which is not resourced. This part of the service should be promoted. Action

The HBGB requested that completed end of study project reports must be provided to the HBS before any publication by researchers. As well as this important requirement, there should be a paragraph in lay language on the project made available by the research team to the HBS for immediate publication on the HBS website as soon as the study starts. This is for research transparency with the public.

Action: The Honest Broker Working Group (HBWG) to take forward.

8. Review of the HBGB Action Log:

This was reviewed and updated.

9. Other e.g.COVID-19 projects and HBS

There is a potential COVID-19 Serology Antibody Test Research Project which may need input from the HBS (University of Nottingham). The Chair will discuss with AH. Action

10. Any Other Business

- Clarification for HDR UK/SeRP comms (AH)

Noted as above

- Update on the Northern Ireland General Practitioner Information Platform (GPIP) Pilot Project (RM /SC)

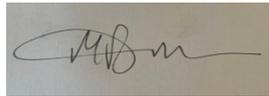
RM gave an update. This project has started. Project outputs will have an impact on current HBS processes.

- Doodle Poll dates for 2021 HBGB meetings.

The HBGB were reminded that responses from members are required to schedule 2021 meetings. Action. The next HBGB Meeting is 12th November 2020, 2 to 4pm via Zoom.

Signed by Dr Michael Quinn (Chair of the Honest Broker Governance Board)

Signature:



Date: 12-11-2020