Minute of the 24th Honest Broker Governance Board Meeting (HBGB)

Date of meeting: 21st May 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)); Mary McGonigle (MM) (Western Heath and Social Care (HSC) Trust), Dr Peter Sharpe (PS) (Southern HSC Trust); Alison Murphy (AM) (Belfast HSC Trust); Dr Hilary Russell (HR) (Lay Member), Dr Nicola Armstrong (NA) (Public Health Agency (PHA)); Karen Bailey (KB) (BSO).

Non- Voting members: Alan Harbinson (AB), 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 (HBGB Secretariat.)

1. Apologies were noted from the following:

Voting Members: Dr Seamus O'Reilly (SOR) (Northern HSC Trust), Dr Aaron Peace (AP) (Western HSC Trust); Irene Knox (IK) (Southern HSC Trust); Laura Moore (South East HSC Trust); Siobhán Morgan (DoH); Colm Burns (Patient Client Council).

Non-Voting Members; Susan Campbell (BSO)

2. Chair's Welcome

The Chair welcomed the meeting attendees and noted apologies. He is pleased to be part of the important Honest Broker Service (HBS). The meeting was considered to be quorate. KB welcomed Dr Michael Quinn in his role as Chair on behalf of the HBGB. She asked the members to consider if Lisa Whyte should be invited to be on the Board and should be thanked for stepping in as Interim Chair after the former Chair, Dr O' Brien's departure. This was supported by the members of the Board. The Board asked for a letter of thanks to go to the interim Chair Lisa Whyte and to invite her to join the Board as a voting member.

3. Minutes of the last meeting:

The minutes of the last Board meeting (23rd meeting of the Board) were ratified and should be published on the Honest Broker Service website.

4. <u>Matters arising:</u>

The Chair informed the Board that the HBS' funding bid to the Health Foundation had been unsuccessful. He agreed to get feedback to assist in future bids. He agreed to forward the latest Terms of Reference to the Board members for the Strategic Information Group (SIG) and the Information Strategy Board (ISB).

The SIG now meets 3 times per year and it discusses thematic issues such as how to share data uses with citizens, or Secondary Uses Legislation. The Chair will link in from these groups to the HBS and the HBGB.

With respect to the NI Digital Strategy, the Chair updated on current GPIP work which includes primary care data coding using SNOMED which is compatible with ENCOMPASS.

Historic registries will have to recode to link to this. The HBS may be able to link out to these registries. He will share the Draft Northern Ireland Data Strategy with the Board members.

5. <u>Information Commissioner's Office presentation:</u>

Caroline Mooney (Regional Manager) and Conan O' Brien (Senior Policy Officer) from the Northern Ireland Information Commissioner's Office (ICO) were welcomed to the meeting. Caroline delivered a presentation on the Data Sharing Code of Practice, a draft code (See https://ico.org.uk/about-the-ico/ico-and-stakeholder-consultations/ico-consultation-on-the-draft-data-sharing-code-of-practice/). It is hoped that this new code will give organisations more confidence in future.

She also highlighted for information that there is a coronavirus hub on the ICO Hub which is available at https://ico.org.uk/global/data-protection-and-coronavirus-information-hub/.

She recommended that the HBS Memorandum of Understanding should reflect the principles of new code. She also recommended that data quality checks are done within the HBS/Data Warehouse and that there are regular reviews of data sharing agreements.

The Board asked if the impact of the Digital Economy Act had been considered. Caroline confirmed that in the new code there is a section on the Digital Economy Act which will be of help.

The Board also asked if the Secondary Uses of Data falls within the code of Practice.

Caroline confirmed that when the use of data is a secondary use, different legislative requirements apply. However use of properly anonymised data falls out of the scope of the General Data Protection Act.

NA invited Caroline to write an article for the PHA R&D Division's R& D newsletter.

Caroline said that there would be a formal ICO communication plan setting out engagement with others.

The Board thanked her for the important presentation and thanked Conan for his attendance.

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

AH gave a verbal updated on the ADRC (now NILS led) and HDR UK projects.

With respect to the NILS project, historically there would have been data linkage between the NILS and the ADRC. When the Digital Economy Act came into effect, the Northern Ireland Statistics and Research Agency (NISRA) was unsure of the statutory basis for data-sharing. This resulted in engagement with the HSC Trusts to undertake a pilot projects. The Northern Ireland Longitudinal Study (NILS) involving health related data has been limited in the past to sharing of primary care data from BSO (based on individual data access agreements for approved projects).

The pilot project is to look into a mechanism by which secondary care data could be shared and the NISRA which hosts the service has been engaging with the Trusts around this to see if the Trusts would be willing to share data and how best to get these projects approved. NILS' projects involve matching to a 28% sample of the CENSUS and bring together other sources (e.g. education) to provide social research.

https://www.nisra.gov.uk/support/research-support/northern-ireland-longitudinal-study-nils

While the HBS is not directly involved in the pilot, certain staff members are involved in the discussions and it is important that this group is kept in the loop.

Since the lockdown for the COVID-19 disease pandemic this project has been stalled but it is hoped to restart it in the new few weeks.

With respect to the HDR-UK project, AH recapped that this was a collaboration between BSO (HBS), SAIL (Wales) and HDR-UK. SAIL is a secure anonymised data linkage databank. The value of this project to the HBS is the additional offering of a remote data access portal as well as use of 'LinkSmart' software for merging datasets. The Department of Health in Northern Ireland (DoH) had asked for engagement in a pilot between the HBS and the HDR UK. This software has now been installed at the HBS to test with anonymised non-personal data.

There is a package of documents to be signed including a letter of offer from the HDR UK for funding until March 2021 and a soft contract agreement. The project is approaching the start of Phase 2. The BSO Department of Legal services (DLS) has provided advice. Phase 1 PEN testing is still outstanding as it involved cybersecurity and the HBS is still awaiting a contact to enable this cybersecurity testing. This is delaying sign off. Once the collaborative agreement is signed, there will be a Phase 1 report output and a confirmation of readiness for Phase 2's roll out with all appropriate stakeholders.

The Chair commended this project's progress and the importance of liaising with the HDR UK.

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

RM gave an update on the HBS projects and outreach activities and the research and non research activity since the last Board meeting. The Board noted the report presented. It was explained that access to the HBS Safe Haven had been temporarily stood down due to the COVID-19 lockdown but that communication and advice was still being given by the HBS to researchers.

8. Review of the HBGB Action Log:

The Action Log was reviewed by the Board.

The Chair agreed to take forward the Patient Public Involvement action. NA offered the HSC R & D Office's PIER R & D support for this which was welcomed by the Chair.

It was agreed to remove the HDR UK action from the log and make it a standing agenda item for the HBGB.

It was agreed that the HBS Privacy Impact Assessment was now complete and this action should be closed.

It was noted that the term NICC on this log should be changed to NILS.

With respect to the action on synthetic data, MM reported to the board on use of a computer programme to produce synthetic data. However, the HBS recommended that use of synthetic data within the HBS is not feasible. This action is to be closed

9. Appointment of Deputy HBGB Chair

It was agreed that the process for appointment of the Deputy Chair should be now be run by the HBGB Secretariat given that the previous Deputy Chair has left the HSC.

10. Any Other Business

KB informed the Board of metadata in the BSO Data Warehouse and that testing of its quality had been a challenge. However Dan West (Chief Digital Information Officer (CDIO) for the HSC in Northern Ireland, DoH) has agreed to provide funding to help with metadata provision and the HBS. There will also be a requirement as part of this to change the HBS Memorandum of Understanding to allow remote access for researchers.

A business case for this is being produced by the Honest Broker Working Group (HBWG). The Board welcomed this news, as it is important to produce metadata for researchers. The Chair offered to comment on the business case.

KB left the meeting.

The HBS annual report is to be produced and circulated to the board for approval out of session.

The Board was informed that the HBS Safe haven had been stood down during the COVID-19 lockdown. The HBWG and KB to take forward a plan for its reopening.

IK raised the historic issue of poor Trust Representation on the board and that this has been raised with the HSC R & D Managers Group. There were two duties; attendance at the Board and participation at the HBS application review meetings. The Board discussed the important of HSC Trust participation given that the HSC Trusts were signatories to the HBS Memorandum of Understanding. The HBGB Secretariat will keep this under review and raise with the Board as appropriate.

The next meeting will be on 21st August 2020 from 2 to 4pm (likely to be by videoconference TBC).

Actions

The following Actions from this meeting are to be added to the Action log and taken forward by those to whom responsibilities have been assigned.

1. Publish ratified minutes of last Board meeting (HBGB Secretariat)
2. Invite Lisa Whyte to be on the HBGB and thank her on behalf of the Board for her help as Interim Chair of the Board until Dr Quinn joined (HBGB Secretariat)
3. Dr Quinn (Chair) to follow up with Health Foundation as to reason why the funding bid had failed.(Chair HBGB)
4. Circulate the ICO presentation on the data sharing code of practice with the web-link to the code or practice on the ICO website and the coronavirus hub (ICO) web-link to the Board (HBGB Secretariat).
5. Action the ICO recommendation that the MOU is reviewed to see if it covers data linkage and data sharing (HBWG)
6. Action the ICO recommendation that the HBS performs quality checks within the HBS and data warehouse and regular review of data sharing agreements (HBWG).

7. A business case for the HBS' funding from DoH is to be prepared. The Chair of HBGB will be happy to comment on this. (HBWG)
8. The Chair to forward the draft NI Data strategy to the HBGB for comment (Chair HBGB)
9. Share the latest Terms of References of the SIG and the ISB (Chair HBGB)
10. Deputy HBGB Chair expressions of interest to be sought and the process of appointment followed (HBGB Secretariat)
11. The Business case for production of metadata in preparation within the HBS to be shared with Chair for comment (HBWG)
12. The Annual report for the HBS to be circulated to the HBGB out of session (HBWG and HBGB Secretariat)
13. Scope restart of safe haven (HBWG)
14. Current actions on action log to be revised or closed:

15. The Patient Public Involvement action. The Chair to lead this action.

16. Remove the HDR-UK action from the log and make it a standing agenda item for the HBGB.
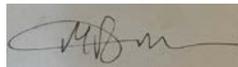
17. Close the HBS Privacy Impact Assessment action.

18. It was noted that the term NICC on this log should be changed to NILS.

19. Close the action on synthetic data with following note: The HBS recommended that use of synthetic data within the HBS is not feasible.

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

Signature: Date: 25-09-2020