

Minute of the 29th Honest Broker Governance Board Meeting (HBGB)

Date of meeting: Tuesday 21st September 2021 (2.30pm to 4.30pm)

By Zoom 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); Lisa Whyte (LW)(HSCB); Siobhán Morgan (Department of Health, DoH); BSO); Dr Nicola Armstrong NA (PHA).

Non- Voting members:

From BSO: Alan Harbinson (AB), Martin Mayock (MM), Naomi Mill (NaM), Cormac O'Brien (CO'B), David Bryce (Director ITS BSO)

Charlene McQuillan (CM) (DoH); Frances Burns (FB) (Guest)

In attendance:

Fiona McNally (BSO) for purposes of the minute and technical videoconference support (HBGB Secretariat).

Apologies were noted from the following:

Voting Members:

Dr Seamus O'Reilly (SoR) (Northern HSC Trust); Neil Martin (NM) (Northern HSC Trust), Mark Bradley (MB) (BSO); Laura Moore (South East HSC Trust); Kate Lavery (KL) (Patient Client Council, PCC); Dr Peter Sharpe (PS) (Southern HSC Trust); no apologies noted from Alison Murphy (BHSCT)

Non-Voting Members:

None

1. Chair's Welcome

The Chair noted the absence of a representative from the BHSCT at the last few meetings.

Action: Chair will write out to see if can get a backup representative if the member cannot make meetings.

2. Minutes of the last meeting

Minutes from the last meeting were approved.

3. Matters arising

No matters arising.

4. Update on HBS Projects and outreach activities: Research; Non Research Activity Reports 2021 – NaM

NaM noted that six research projects have been approved as of today with four more applications in draft so there may be a need to convene another panel soon.

Migration of projects to the UK SeRP continues with 14 projects currently live and another 10 (including eight dementia projects) due to be uploaded in the near future. A number of outputs have been cleared via the UK SeRP.

Non-research – NaM noted one new non-research project had been approved since the last meeting and discussions had been held with a number of other individuals about potential projects however applications hadn't yet been submitted.

NA suggested the format of the non-research report be amended to align with the research report.

Action: NaM to make the necessary changes to the non-research report.

AH informed the HBGB a request had been received for the findings of a non-research project to be submitted to a scientific journal for peer-review and publication. This potential outcome had been stated in the original application. MQ noted it was important that findings from any type of HBS project should be published where possible and this should be permitted going forward. FB and NA both noted their support to this suggestion.

5. Update on MOU/SAIL/HDR UK National Core Studies –verbal update AH

AH noted that the two current National Core Studies were ongoing with the DaC VaP team having recently received a crucial update to the vaccine dataset. HDR UK have recently launched a new funding call so there may be potential for an application panel to be convened to review any resultant applications.

AH informed the HBGB a process was now in place to routinely access the vaccine management data with oversight from the HSC Board.

Metadata for COG-UK data was now live on the HDR UK Innovation Gateway. And work is ongoing to gain access to Critical Care Data for research purposes.

Recently metadata for HBS datasets has been uploaded to the HDR UK Innovation Gateway. However as part of the UK SeRP contract there is potential for Mauro to be used to create a Federated Data Catalogue for the HBS. This would require re-training of the HBS metadata developer. MQ suggested this should be pursued. NA questioned whether the metadata would continue to be maintained on the Gateway. AH clarified that updates would be made to the Mauro catalogue and then the HDR UK Gateway would extract any updates from this. AH also noted the metadata would contain only the characteristics of the data and not the data itself.

MQ thanked AH, FB and the rest of the Honest Broker Service staff for their continued hard work in relation to these developments.

6. Project Modifications briefing paper –NaM

NaM informed the HBGB the purpose of this paper was to outline the current HBS modification approval processes to ensure the HBGB were content with the approach. NaM outlined a range of types of modifications that HBS have received and how they are currently dealt with to check understanding is correct or if HBGB had any concerns.

NA queried the nature of the requests for re-use of project datasets. This item was due to be discussed under AOB, however was addressed at this stage of the meeting.

MQ spoke favourably around maximising utility of data and efficiency of use of data.

Some questions were raised by NaM around this, for example if researchers have carried out a series of cleaning actions on data they would have made decisions about inclusions/exclusions that a different research team may have treated differently. DB also raised a query about consistency in terms of the

technology available for analysis of the data if research teams use different packages.

Action: HBWG to consider proposal and any practical issues that might impact feasibility.

7. HBS Annual Report –AH

AH apologised for the lateness of this report and noted the team would aim to have next year's draft report available by the May meeting. He noted the foreword was language that had been suggested by HBS and needed to be signed off, but the remainder of the report was finalised. AH asked if HBGB could return any comments within the next two weeks so the report could be published on the website.

Action: Board members to return comments on Annual Report by 22/10/2021.

8. Review of the HBGB Action Log

Actions were reviewed and updated.

9. Any Other Business

NaM informed the HBGB requests had been received for two individual researchers to access their project data using the UK SeRP from outside of the EEA. Swansea University have confirmed they don't have any restrictions on access since no data leaves the platform. NA suggested the HBAS inform the BSO Legal Team of the request to get their view.

Action: NaM to write to BSO Personal Data Guardian (Alphy Maginness) re: access to project data outside of the EEA.

NaM summarised the remote access request re: Project 30. The HBGB approved the migration of HBS Research Project 30 to the UK SeRP platform provided the necessary paperwork was in place.

AH raised a query around data linkage for follow up for consented studies. There appears to be an increasing trend in this type of request and several UK-wide COVID studies have involved linkage and follow up as well as hosting data collected in consented studies in different TRE's. There are projects in Northern Ireland that have asked about feasibility of BSO providing linked data (Protect CH, NIMRAD and an Early Life Cohort Study).

There were multiple contributors to the conversation including MQ, NA, CMQ, DB and MM. In theory if consent is in place it should be possible to pull records from various systems including those held in BSO, however there would need

to be a signposting mechanism and way of managing this (For example would it become part of the Honest Broker Service MOU?).

There were questions about whether validation is required as to if consent is valid and what the extent of consent is (implicit vs explicit) and where the onus is on this. It was agreed that if the project has been funded by a major funder then all those requirements will be in place and responsibility has to be with the researchers.

It was also noted that key paperwork like consent wording is agreed at the commencement of projects so there would perhaps be chance to influence the consent wording from the outset for future proposals.

Any impact on BSO resources would need to be taken into consideration.

It was agreed that the issue required further discussion perhaps involving the Trust R&D teams.

Action: HBWG to consider issue and to write to Trust R&D teams for views.

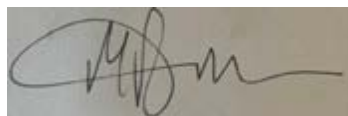
FM noted that the August meeting of the HBGB had to be rescheduled this year and last and suggested this meeting be moved to September instead.

Action: FM to send out September dates when arranging the 2022 meetings.

10. Date of next meeting 25 November 2021 @3 to 5pm via Zoom

Signed by Dr Michael Quinn (Chair of the HBGB)

Signature:



Date: 08/09/2023