HSC Business Services Organisation

Minute of the 35th Honest Broker Governance Board Meeting (HBGB)

Date of meeting: Tuesday 13th June 2023 (2.30pm to 4pm) by videoconference.

Present:

Voting members: Dr Aaron Peace (AP) (Western HSC Trust and Chair of HBGB); Siobhán Morgan (SM) (DoH); Dr Hilary Russell (HR) (Lay Member); Dave Watkins (DW) (NHSCT); Rachelle Moore (RM) (SHSCT)

Non- Voting members: From BSO: Alan Harbinson (AH); Martin Mayock (MM); Stephen Gibbons (SG); Cormac O'Brien (CO); Rachel Coey (RC). From DoH: Charlene McQuillan (CM)

In attendance: Karen Beattie (KB) (ORECNI)

1. Apologies were noted from the following:

Voting Members: Alison Murphy (AM) (BHSCT); Ruth Barry (RB) (PCC); Neil Martin (NM) (NHSCT); Dr Nicola Armstrong (NA) (PHA);

Non-Voting Members: Karen Hunter (BSO).

Welcome

AP chaired the meeting and welcomed attendees.

2. Minutes of the last meeting

CM highlighted had sent in a comment in tracked changes.

Actions:

AH to ensure CM comment in tracked change is included in the published minutes.

3. Matters arising

NA

4. HBGB Membership

- **Update on Recruitment of Chair, Vice Chair and suggested Alternate Vice Chair**

KB gave an update that the EOI for positions of VC and AVC for HBGB was sent out in April. There was only one application for AVC, Vicky Armstrong who will be taking the post. There have been no applications for VC. KB added that under terms of reference, if no voting members of HBGB express interest in these roles, HBS can appoint a chair or vice chair from outside the HBGB. This will be taken forward.

- **Deputies for voting members**

KB reemphasised that it would be helpful if people could suggest a deputy to attend in their stead if they are unavailable. AP agreed, particularly for Trust representation. DW noted that either himself or NM would attend future meetings.

5. HBS Memorandum of Understanding

AH noted a refresh of the MOU has been drafted, including key updates to wording in particularly around references to the RDW and better process flow of data sources across HSC and how the HBS gets data. The MOU draft was sent to IGN for feedback and comments. AH currently addressing the comments from IGN and will address any comments that come from this meeting. AH noted that the MOU may need amended to include updated references depending on discussions regarding the wider strategic alignment with NITRE. All documents will be updated at the same time. After addressing comments, AH will send to the board for review and then onwards for signing.
DW commended that has recently read the current MOU and that it reads very well.

6. Future direction of HBGB and alignment with NITRE (NI Trusted Research Environment)

AP noted that one of the biggest frustrations in the data environment is that it is often the same people sitting on various different committees, often discussing the same topics and this can take up a lot of time. Another issue from the HBS perspective is financial sustainability. AP noted moves afoot in terms of the business case development for the Data Institute across NI, there will be data cross-over between HBS, NITRE, GPIP, and ADRC. One of our objectives should be to accomplished a shared safe data environment for both research and service delivery across the region. Going forward income generation model will become a major priority by April 2024.
AP noted there a few things we may be able do under the current governance structure, for example, cohort discovery for studies and follow up where lists of patients are sent to HBS for longitudinal follow up having already provided consent. AP noted Astrazeneca had engaged to do a portfolio of heart failure patients, identified by PIs within the Trust and contacted to provide consent.

AH talked everyone through the background paper that had been circulated prior to the meeting and opened discussion on the proposal.

AP noted (In relation to the proposal of reviewing applications at full meetings rather than sub panels) that the Research Governance Committees within the Trust meet periodically at set times depending on how busy it is and depending on the Trust but as a result of COVID, priority projects can go through a fast track process. An Operations and Approvals committee would probably adopt a similar type of practice. CM agreed with the comment about a lot of repeating discussions as a member of NITRE, GB, WG and part of conversations on DI and welcomed the contents of the paper as they would streamline everything. CM noted the administrative overhead to get all paperwork together for the changes.

AP noted that in his view no huge changes need to be made to the MOU, references need to be made to the fact that the governance processes already exist rather than creating something new. CM said an education piece should be done to ensure all the relevant organisations understand how their data will be used and the roles and responsibilities.

AP noted that at the Research Governance Committees within the Trust, the people on the committee represent different disciplines and when working with the IRAS system, the form is split so different people provide expertise on different sections and nobody is expected to know everything. He felt this was more efficient.

AH noted that the working group currently follows up on actions from the HBGB so would not be required in the new structure. Quarterly meeting agenda could be split into two parts, 1. Operations and actions and 2. Approvals, with only the relevant people attending each part. May need to create task and finish groups to follow up on some actions.

MM said that BSO SMT had been briefed on the proposal and were broadly in support but would want proper SLA in place to define processes and roles and responsibilities. AP agreed and reemphasised the ultimate goal of creating shared safe research environment not only for research but for service improvement. MM noted that takes pressure of funding decisions away from HBGB and to NITRE.

HR said she can see the advantage of aligning with NITRE and is in support of proposal. Noted that her understanding based on this proposal was that everyone would look at every application to use the service in second half of quarterly meeting. AP agreed it would be along those lines but details yet to be finalised. AP reiterated that if structure of Trust Research Governance Committees followed, meeting might be relatively short as not everyone needs to read full application, only specific sections for their expertise. AP said that he did not think current HBS Application

Form needed to be changed, but noted that panel could review IRAS application with specific mention to the HBS that already exists and that could be sufficient. HR said she felt this could make the approval process more laborious than it currently is as one of frustrations with current process is that applicants copy and paste from grant or IRAS application whereas information required for HBS is much simpler. HR noted that almost always these applications have been funded and therefore the review of the research itself has been rigorous and she does not feel that HBS panel needs to look the science as such. HR said when looking at applications the main question is does the research fit within what the HBS is about. AP agreed and noted that one thing HBS may need to consider more in future is whether or not a research project is academic or industry related and if there is sufficient financial income coming to HBS to justify doing it.

HR noted that she firmly supports both universities being represented at the committee but noted that if review of applications is now going to go to a much bigger committee then both universities will be able to chip into the discussion and do individuals need to absent themselves from some reviews. AP said that academic involvement may not be part of application review. Detail yet to be decided.

AH noted that NILS approval group is wider with a statistician from UU so discussion does go into more detail on statistical disclosure control etc than what HBS would normally discuss, while there could be a lot of value to this there would be a danger with a larger group discussion that it might be more difficult to reach consensus.

AH noted that logistically we would need to be very clear with researchers about deadlines and submissions to the panel as if the meetings are being held quarterly rather than ad hoc then all applications would need to be completed by a certain date for consideration at the next meeting. There are advantages and disadvantages to this. AH said that from experience an application can be 90% finished, but it can sometimes be 6 months before being finalised. This could make the process better but it could also mean that we lose some of the flexibility that we do have at the minute where when we do have a number of applications ready then we can get a sub panel set up to approve them.

AP noted that most people applying to use HBS are more familiar with deadlines than ad hoc style. AP noted that a fast track pathway could be used for priority projects. HR agreed that we could try quarterly meetings for one year and agreed that people tend to work to deadlines.

KB asked if people thought that it might increase buy in to the group if everyone could see how the data is being used and have a say in how the projects progress. AP said that he would like to see a research or innovation day where people who have successfully completed HBS projects present the findings to the HBGB. MM

noted that researchers used to present to HBGB when they finished their project but due to the pandemic this stopped. HR agreed. HR said she felt HBS should be promoted to the general public to showcase how their data is being used for the greater good.

AP noted that a lot of the internal communications within the Trusts are exclusive to the Trusts, but we should be promoting the work done by HBS to the Trusts. The Northern Ireland Public Data Panel is maybe a way to do this.

AH noted that other UK TREs have review panels solely made up of members of the public and some have a mixed model. This could be something we could review. AH asked everyone to review Terms of Reference by correspondence and then AH will send round final version with updated name etc for sign off. AP noted that HBGB generally in agreement with new proposal, contingent with definite terms of reference, small amendment to MOU and other small details such as incorporating academic involvement.

CM agreed that there are still details that need to be ironed out, so if everybody could feed back any comments by correspondence. AP said this should be in place by last quarter of 23/24. Everyone agreed.

Actions:

- **All to provide comments on document proposal by correspondence**

7. Submission's from QUB re NICOLA Data Linkage Prospective Project and HARP Study

- **HARP Study**

AH talked through HARP paper circulated prior to the meeting. AH noted that issues from previous proposal still stand as the study will still be following up patients without their consent and data would still have to be received and linked in BSO before it could be provided, however it was good that the research would be done on anonymised data. AH said issues will be surrounding legal frameworks and setting up agreements with NHS England to host their data. CM queried what participants were told at the start of the study about what will happen to their data and who it will be shared with as if it was unexpected then this could be unfair from a data protection point of view. AH noted that he had not seen a copy of the consent form directly. Research team plan to publish what they are doing through privacy notices. HR noted that from a research ethics point of view she would be very comfortable with the proposal, as the proposal is to send out information but within that there is an opt out process so she believes their autonomy has been respected provided we can assure them there will be no

uncovering of their name etc associated with their data and no security risks. MM asked why the research team have approached HBS instead of an English TRE. AH said SAIL database had been suggested to the team but they have links in QUB who are familiar with HBS.

AP noted that the NI cohort will be small within the 540 people across the UK so there could be approximately 15 patients from NI. AP said this could set a precedent for every longitudinal study going forward, however, when secondary use legislation comes in this could become normal business for HBS. AH noted GRO approval would be necessary for this study and legal agreements would be required between QUB and BSO and NHS England, so BSO PDG would need to be in agreement.

MM queried what the legal basis for this study would be. CM said that the legal basis cannot be consent as the team will not be re-consenting the participants, would likely be public interest / task and article 9 would be archiving and research. AH to contact research team to start application process and to start governance process.

Actions:

- **AH to contact research team**

- **NICOLA Data Linkage Prospective Project**

AH talked through the background paper circulated prior to the meeting. AH noted that the research team have said they have re-consented participants and sent their updated privacy notice. Issues with legal agreements etc similar to HARP trial. CM said there is some confusion surrounding HCN number in the paper as it implies the study team will access the HCN and hold it, but it doesn't make it clear whether receive HCN directly from the participants or receive HCN from BSO as part of this process. AH said this is a subsidiary ask and confirmed this is out of scope for the HBS. AH noted that for linking NICOLA data to other datasets we would need to match the participants and assign HCNs. AH noted that study team currently have names and addresses for participants but not HCNs. SM noted that NICOLA HCN issue had been raised several years ago and at the time there wasn't a legal gateway for BSO to provide HCNs.

HR & CM queried if the privacy notice was in place of actually reconsenting participants, with opt out option. HR noted some wording in the privacy notice she felt was coercive, the 'Withdrawing Your Consent' and 'Who we are' sections in particular. CM & KB agreed.

KB noted that NICOLA Wave 1 and Wave 2 have been approved by the QUB School of Medicine, Dentistry and Biomedical Sciences committee and has not been through an NHS REC which is a requirement if using identifiable patient data with a few exceptions. HR agreed.

AH to ask research team for more information on the consent process and ethical approval. All to provide comments on paper by correspondence.

Actions:

- **AH to contact research team**
- **All to provide comments by correspondence**

8. HBS Research and non-research Summary Reports

Noted as attached in interest of time.

9. Review of Action points log (All)

AH to update and circulate after meeting.

Actions:

- **AH to update and circulate**

10. Any Other Business

NA

Agreed by HBGB on 12/09/2023