

## **Minute of the 34th Honest Broker Governance Board Meeting (HBGB)**

**Date of meeting: Wednesday 1 February 2023 (2pm to 4pm) by videoconference.**

### **Present:**

**Voting members:** Dr Aaron Peace (AP) (Western HSC Trust and Interim Chair of HBGB); Dr Nicola Armstrong (NA) (PHA); Siobhán Morgan (SM) (DoH); Neil Martin (NM) (NHSCT); Dr Hilary Russell (HR) (Lay Member); Dr Peter Sharpe (PS) (SHSCT); Neil Martin (NHSCT).

**Non- Voting members:** From BSO: Alan Harbinson (AH); Martin Mayock (MM); Naomi Mill (NaM); Stephen Gibbons (SG); Alison Afrifa (AA). From DoH: Charlene McQuillan (CM)

**In attendance:** Fiona McNally (FMcN) for zoom facilitation and Karen Beattie (KB) (ORECNI) for the purposes of the minute.

### **1. Apologies were noted from the following:**

**Voting Members:** Alison Murphy (AM) (BHSCT); Mark Bradley (MB) (BSO); Dave Watkins (NHSCT); Ruth Barry (RB) (PCC).

**Non-Voting Members:** Karen Hunter (BSO).

### **2. Welcome**

AP chaired the meeting and welcomed attendees. AP welcomed Stephen Gibbons, Head of Operations for the GP Operational Planform and the Regional Data Warehouse.

### **3. Minutes of the last meeting**

Minutes of the last meeting were agreed.

### **4. Matters arising**

- Attendance at HBGB meetings

LM was to circulate an email to encourage the Medical Directors in the HSCTS to attend meetings, and if they are unable to attend, to encourage the other 4 HSCT Research Governance managers to attend instead. KB noted that LM was not in attendance and had no update on this item.

- **HBGB Chair Recruitment**

KB confirmed a suggested personnel description had been circulated to group members, who had provided comments.

- **Review of the HBS**

AH indicated that members had provided useful feedback on the paper presented at the last meeting and had highlighted points of interest for inclusion helping inform the development of the review process.

- **Funding of the HBS and strategic direction of the HBGB**

AP told the group that funding had been secured for the forthcoming financial year following discussions at the NITRE Strategic Programme Board. The Secure Research Platform has secured funding for the next 3-5 years. AH indicated that the service was still awaiting confirmation from Health Data Research UK for the exact time period, and that the contract for this should be progressed fairly quickly once confirmation is received.

AP also pointed out that members of the HBGB sit on a number of very similar forums and groups, with all of these discussing similar issues in relation to data. From a Data Strategy point of view, it is important that, rather than working in silos, there is a shared drive to implement the Secondary Use of Data agenda for NI. These discussions will involve Information Governance leads, and the Department of Health, as well as other key stakeholders. AP emphasised the importance of this agenda, and ensuring NI can act competitively within the UK.

## **5. Honest Broker Governance Board Discussion – Update on Recruitment of Chair, Vice Chair and suggested Alternate Vice Chair**

KB updated the group that AP had been confirmed as the new HBGB Chair, for a period of 5 years.

KB informed the group that an EOI would be circulated in order to recruit a Vice Chair for the HBGB, who could participate in HBS Application Review Panels and in chairing the HBGB where necessary, and encouraged members to apply.

KB asked the group whether they would consider introducing an Alternate Vice-Chair position also, although this is not in the terms of reference for the HBGB, in order to

have a chairing team of 3 people, which would make it easier to facilitate the HBGB meetings and associated work load.

HR mentioned that the Ethics Committees ran with a chairing team of 3 people, including a Chair, Vice Chair and Alternate Vice Chair, and that this approach worked well.

PS voiced concern over the 5 year tenure period for the Chairing team positions, and suggested a 3 year tenure period instead.

AH explained that the 5 year tenure was a maximum period of time the post holder could expect to remain in the Chairing team position, and if an individual changed roles or was no longer able to maintain the role within the Chairing team, the HBGB would have to recruit again for the position.

NH reiterated that the tenure should be up to 5 years, in line with REC and public appointments practice to ensure good practice.

The group agreed that it should be clear the tenure period for members of the chairing team should be for up to a maximum of 5 years.

KB asked voting members to consider whether they would like to assign deputies, as currently there are no deputies for the BHSCT, SHSCT, the PHA or the PCC, and highlighted that this would help to ensure group quoracy, and take the burden of individual members.

CM agreed the deputies should be formally assigned, especially given that the HSCTs are the primary data controllers, and that this should be escalated to the Chief Executives if needs be.

PS indicated that the SHSCT will have a new Research Manager starting after Easter, Rachelle Moore, who will replace Irene Knox, who retired at the end of November.

#### **Actions:**

- **KB to send circulate an EOI to voting members for position of Vice Chair and Alternate Vice Chair of the HBGB for a period of up to 5 years.**
- **KB to ask voting members to assign a deputy member, who can attend HBGB meetings in their stead.**

## **6. HBS Memorandum of Understanding**

AH indicated that there had been some useful comments back via correspondence when the paper was initially circulated. AH reminded the group that the purpose of the MOU is to streamline the process for data linkage with HSCT information that isn't in the Data Warehouse, with proposals involving the HSCT Research Governance offices also. AH indicated that LM from the SEHSCT had provided useful feedback on the future processes. AH indicated that if anyone still wanted to provide feedback, the team are still in the process of finalising the MOU with CM,

and the HBWG. The HBS are keen to have the MOU progressed this year. AH also plans to broaden the Data Impact Assessment for the HBS.

AP indicated that the main changes to the document were to reflect the changes to internal data sharing arrangements with the DoH and the PHA for service evaluation, to strengthen the position of the HBS as the trusted research environment for use of NI HSC Data. There will also be amendments to a number of key processes, including where data is shared with another organisation outside of the HSC, such as the NI Housing Executive. Another major change includes additional references to Article 28 of the GDPR, and the relationships between data controllers and processors, and role of the BSO in the controlled access for researchers.

AP asked why the document was being updated.

AH that the aim of the service is to reduce the IG (Information Governance) burden and the number of data access agreements needed in order to share data. AH explained that the HBS has streamlined this process, as before the HBS was established, in order to get access to regional data, 5 or 6 legal agreements would have to have been drawn up for each project. However, the new MOU will ensure the service is future-proofed in the face of new systems (such as EPIC and new Labs systems) and the changing role of the Data Warehouse.

NA commented on the language within the document, saying that there had been a move away from “Trusted Research Environment” to “Safe Data Environment”, with the HDR UK voicing a preference for the latter term.

AP felt that the “Safe Data Environment” better reflected the additional safeguards and checks that were in place within the HBS.

SM suggested that the MOU should contain a list of systems that are within the scope of the HBS, so that potential users know what is available.

CM disagreed, and felt this would limit the remit of the MOU. AH agreed with CM, and felt that any data that was not in the Data Warehouse that required liaison with the HSCTs should involve a joint process with Ethics and Trust R&D Departments responsible for Capacity and Capability.

AP asked what the process would be if identifiable information was used by the HBS in order to track HSC/ NHS patients’ longitudinal data.

AH indicated that, although this was outside the remit of the HBS (which deals solely with anonymised data), a number of projects have adopted this approach, which required separate legal agreements with the data controllers in order to use consented patient identifiable information. Prof Ian Young has been involved in discussions to establish a service in NI that would facilitate this type of data linkage involving identifiable patient data with consent. AH explained the earlier discussions with CM had determined that a separate application process would be needed if the HBS was to start to provide identifiable data with patient consent.

CM explained that moving to this model would change the scope of the current service, and there would be a great deal of work needed to provide this type of linked identifiable data, particularly given the lack of NI Secondary Uses legislation.

AP argued that under common law, as long as patients have consented to their data being used for longitudinal purposes, then the secondary uses legislation is not required.

CM agreed, but stated that rather than including the use of identifiable data in the current MOU, the low numbers of studies involving use of consented identifiable data could be handled on a case by case basis.

AP asked if the provision of longitudinal information was not possible as part of the current HBS due to issues relating to validation and a lack of resources needed to ensure that an informed consent process had been followed.

CM and AH agreed, and AH added that this would also involve additional resource issues for the Data Warehouse, and for the individual systems, such as EPIC.

## **7. HDR UK and National Core Studies Update**

- a. AH indicated that the Data and Connectivity programme run by Health Data Research UK (HDR UK) is in the process of closing, as the HDR UK move into their new 5 year funding cycle. The only study still running as part of the Data and Connectivity programme is the Covid Vaccination Study, which includes data up until the end of 2022. However, HDR UK have confirmed funding for the HBS Remote Access Platform.
- b. The CBD COVID Project run by the British Heart Foundation Data Science Centre, and funded by HDR UK, are hoping to include NI data in order to make this a 4 Nation study, although the HBS resource required to implement this study is NI is considerable and discussions are ongoing as to the level of support to be provided. If this project does go ahead, a member of the HBGB would be required to sit on the study's UK forum.
- c. The Co-connect project (the federated co-discovery tool mentioned at previous HBGB meetings) has stalled. DAAs have been submitted to the HSCTs and work is ongoing with the HSCT Information Governance Leads.

AP asked why this project had stalled.

AH answered that the DPA was in the process of being considered by the HSCTs, which is a lengthy process, alongside other projects. AH is going to see if he can attend the Regional Information Governance meeting to see if the project can be advanced.

NA asked if additional pressure could be applied by the R&D Directors in order to facilitate the project, given that national funding has been awarded for the study, and it is important the NI is part of this wider UK work.

AP said he would be happy to try to facilitate the work, but AH indicated that he should try to talk to the group again before any further influence is placed.

NM indicated that he was happy to circulate information around the SIROs if there was no further movement on the project.

## **8. NILS (Northern Ireland Longitudinal Study) and GPIIP (General Practitioner Information Platform) Updates**

### **GPIIP**

The first HBS application linked to the GPIIP data has been submitted, with a draft application for a project led by Dr John Busby from Queens University Belfast (QUB). The proposed project aims to explore different types of lung disease, linking hospital data with GPIIP data. The GP Editorial Board is supportive of the project, which is funded by HDR UK.

Datasets and metadata created from the GPIIP data for this project could be also reused for other work.

PS queried the term “GPIIP”. AH explained the background to GPIIP, highlighting that all the data from GP practices in NI has now been warehoused centrally, which was very challenging. Funded through the Dementia Analytics User Group, this work has been ongoing for a number of years, with original aim that the data would support the suite of HBS Dementia projects. Before the implementation of GPIIP data, researchers studying dementia had to rely on proxy information and prescribing data, but as AH pointed out, this had not painted a full picture, as many dementia patients do not use medications for their condition. GPIIP data allows for a fuller study of the condition, as the information comes from GP surgeries and clinics.

Another key benefit for GPs themselves is the dashboard facility available as part of the GPIIP platform, to allow for regional comparison and disease tracking.

AP mentioned that the governance for GPIIP and the HBS are very similar, and thought that in the future both services could be amalgamated.

SG added that the GPIIP had been running for about 4 years, and by the end of February, every practice in NI will be included. Major challenges have included getting buy in from the practices, and ensuring that the information is sent in in a timely fashion.

AP mentioned that projects involving secondary care should also be facilitated by GPIIP, rather than simply focusing on primary care.

For the benefit of new members of the HBGB, NA gave an overview of the HSC R&D, describing the clinical care research networks that are funded by the R&D

Office. NA explained that her office captures information on how the GPIIP data is used in research, and the key champions of this type of data collection. These individuals might well be willing to act as key advocates for the GPIIP service in the future.

### **NILS**

A second application seeking HSCT social care data has been drafted. This follows a pilot in 2021, where secondary care data was linked with 28% of the census data. Legal agreements are to be set up with the HSCTs and the HBS.

## **9. HBS Research and non-research Summary Reports**

### **Research Activity Report:**

AA explained that a review panel would be convened soon to review 3 new applications, one of which requires additional work. It is proposed this will be held via correspondence rather than in person.

The HBS has seen an large increase in draft applications, with another 7 additional applications in draft form (4 of these are in a final draft stage, with the remaining 3 still requiring further work).

All eligible projects are live on SERP.

With regards to research applications, 2 applications have been approved at the end of November, one of which is led by the BHSCCT and the other led from QUB. Both projects are awaiting final paperwork and sign off before work can start.

### **Non-research report:**

There have been no new applications for non-research requests. However, data provision is ongoing for projects looking at Health Inequalities (DoH); Ambulance Delays (NIAS); the Prescribing Dashboard Pilot (DoH/ SPPG); and Neurology Waiting Lists (DoH/ SPPG).

AP commented that the HBS has been very busy and noted that the volume of applications has increased, and emphasised the importance of recruiting a Vice Chair and Alternate Vice Chair to review new applications.

HR congratulated the HBS on the numbers of applications to date. She asked why the next application review is planned to be done via correspondence.

AA said that this had been suggested due to the volume of new applications coming through. She explained the Terms of Reference/ MOU indicated that application review panels could be done via correspondence.

However, HH felt that discussion was needed in order to review the applications effectively, with conversations sparking off issues that the review panel may not previously have considered.



AP agreed with HH.

FMcN highlighted that her role had now changed and that the administrator post within ORECNI, which had previously facilitated the Application Review Panels, was currently vacant. In order to facilitate the review of HBS applications, this was another reason why it had been suggested that applications are reviewed via correspondence.

AP asked if there were plans to replace FMcN, and KB indicated that ORECNI were in the process of running a recruitment exercise to replace the REC Administrator, and this would hopefully be filled in the near future, and confirmed this would be a temporary move only.

PS queried if there was a target for turnaround of approvals, and if not, should this be considered.

AH replied that currently, there were no target turnaround times, and this was something the new MOU could consider. AH highlighted that a major problem for the HBS is the requirement for Data Access Agreements, which frequently take 6 – 12 months to complete, which impacts on the timelines for the service.

AP felt that this was something that needed consideration, as this element falls outside of the remit of the HBS, and information needed to be captured on the time taken to progress these DAAs to completion.

PS also queried one of the projects looking at excess deaths, and asked what type of data would be included in the project.

AH gave some background to the Excess Deaths Project, and explained this was still in formulative stages, and not limited solely A&E data.

PS expressed an interest in reviewing this project.

## **10. Review of Action points log (All)**

The group reviewed and updated the action log:

- AH noted that the action for LM to circulate an email to encourage the Medical Directors in the HSCTs to attend meetings, or the HSCT Research Governance Mangers in their stead was still outstanding.
- One of the actions relating to the draft TOR for the review of the HBGB will stay open. It was originally envisaged that the BSO Leadership Centre would undertake the review of HBS, but with developments around the new Data Strategy, Information Governance structures and the development of the NI Secondary Use legislation, it was felt that BSO review was no longer appropriate for the strategic elements across the structures.

AP clarified that that the review of the HBS will fall out of the wider review of the NI Data ecosystems and structures. AP indicated that those on the HBGB would feed into this wider NI Review, so rather than closing the action, this will be part



of that wider review, and suggested that the action should be left open, and simply updated.

MM added that the review undertaken by NITRE will consider strategic relationships.

AP felt that however, representation on the HBGB could be widened to include the two NI Universities.

NA added that it was important to include the universities in order to understand the user experience, and AP agreed, and asked how this could be implemented.

MM thought that a letter should be drafted by AP to invite representatives from the Universities to sit on the HBGB.

MM indicated the ToR for the HBGB should be amended to reflect this increase in membership.

HH felt that this could also be an opportunity for representatives from the medical community, particularly for the review panels.

AP agreed and asked that members should provide names of interested parties.

NA suggested Prof Dermot O'Reilly, the Director of the Administrative Data Research Centre, who has a research interest in secondary use of data.

FMcN also highlighted that a lay person was needed as part of the review panels to ensure quoracy, in order to reduce the burden on HH.

AP agreed and suggested approaching the Cancer Network.

NA suggested approaching PIER (Public Involvement Enhancing Research) members, one of whom sits on the NILS Steering Group, who could be a valuable addition to the HBGB.

NA highlighted that LM had been successful in securing a post in the Central Governance Facility, and that this would involve a new representative from the SEHSCT coming onto the HBGB. AP suggested that LM should be invited to sit on the HBGB to represent the Central Governance Facility, as she already has a background and knowledge of the HB work.

- The action relating to use of project data should stay open, with the HBWG developing a paper on policy options.
- The review of the functionality of the HDR UK Portal is still open, and work is progressing to allow applications to be displayed on the Gateway. AH asked for members of the HBGB to review functionality of the Gateway as an application management system going forward.
- The action relating to student placements should be kept open, and will progress if representatives of Universities are invited to sit on the HBBG. NA suggested this should be widened to include those outside of medical sciences, for example, to include computer science also.

**Actions:**

- **MM and AH to review ToR to see if these need to be updated in order to invite representatives from the universities and other organisations to sit on the HBGB.**
- **Members should provide names of interested parties, including those who are medically qualified, who may wish to join the HBGB to KN and FMcN.**

## **11. Any Other Business**

NA had asked for the attached NICE document on Real World Data to be shared, in order to give the HBGB an idea of the standards and quality issues associated with systems providing real world data needed by customers of the HBS. NA highlighted the importance of raising the profile of the HBS within the research communities.

AH will issuing a HBS user survey, and asked group members if they had any particular areas they would like included in the survey.

**Actions:**

- **KB to issue dates for forthcoming HBGB meetings**
- **AA to circulate the draft User Survey to HBGB members for comment.**

Signed by Dr Aaron Peace (Deputy Chair of the HBGB)



Signature:

Date: 08-09-2023