

Minute of the 32nd Honest Broker Governance Board Meeting (HBGB)

Date of meeting: Tuesday 17th May 2022 (2.30pm to 4pm) by videoconference.

Present:

Voting members: Dr Aaron Peace (AP) (Western HSC Trust and Interim Chair of HBGB); Irene Knox (IK) (SHSCT); Dr Nicola Armstrong (NA) (PHA); Siobhán Morgan (SM) (DoH); Neil Martin (NM) (NHSCT); Laura Moore (LM) (SEHSCT); Dr Hilary Russell (HR) (Lay Member); Lisa Whyte (LW) (HSCB); Dr Peter Sharpe (PS) (SHSCT).

Non- Voting members: From BSO: Alan Harbinson (AH), Martin Mayock (MM), Cormac O'Brien (CO'B); Naomi Mill (NaM). From DoH: Charlene McQuillan (CM)

In attendance: Karen Beattie (KB) (ORECNI) for the purposes of the minute.

1. Apologies were noted from the following:

Voting Members: Dr Seamus O'Reilly (SO'R) (NHSCT); Alison Murphy (AM) (BHSCT); Mark Bradley (MB) (BSO).

Non-Voting Members: no apologies were received from non-voting members.

2. Welcome

AP chaired the meeting and welcomed attendees.

3. Minutes of the last meeting

Minutes of the last meeting were subject to one minor amendment.

Action: KB to amend and send amended minutes to group.

4. Matters arising

- Attendance at HBGB meetings

AH noted the previous action about writing to all Trust CEOs and reps to encourage attendance had not yet been completed. FMcN said she had contacted the BHSCT

rep to ask if a deputy could be selected to attend future meetings, as attendance had been particularly poor.

AH said the email reminder to the other Trusts had not been sent as they were awaiting the review of the Honest Broker Service (HBS).

Action: AP asked LM if she could circulate an email to the other 4 HSCT Research Governance managers to encourage their attendance or, for those unable to attend meetings, encouraging them to select a deputy in their stead until the review determined who was best suited to sit on the HBGB.

- Review of the HBGB

MM said that the Leadership Centre had been contacted in order to progress the review of the service pending agreement of a final ToR. MM shared a document outlining membership of the review group, and the scope of work, including deliverables, tasks, timelines for the review. MM said that this draft ToR for the review had been expanded following a discussion at the NI Trusted Research Environment (NITRE) Strategic Project Board. MM mentioned that there was an element of confusion surrounding the relationship between the HBGB and NITRE, and an exploration of this relationship had been added to the ToR.

MM explained that funding for the service was not to be included in the review, as this was being looked at separately as part of the overall Data Strategy business case.

AP queried if there had been any consideration of the interaction of Trusted Research Environments (TREs) elsewhere and how these worked with the equivalent of the HBS in the UK.

AH explained that there were various different models in the UK, which worked differently to the HBS. He cited the example of the Scottish Privacy Board and Advisory Panel which has a wider remit than the HBS, as it deals with requests for identifiable data, as well as access to their TRE. AP also told the group that NHS Digital in England already have an independent group (IGUARD) to advise on the release of data, but don't have a TRE model, although this is being set up shortly. In contrast, the HBGB tends to deal with management issues, plus the approvals function as well as the overall direction and governance of the service.

NA raised the need to consider the ToR and membership for different organisations in Northern Ireland when considering future relationships with the HBS, including

NITRE, the NI Privacy Advisory Committee, the NI Longitudinal Study, and the Administrative Data Research NI (ADR) in order to give us an idea of the areas of potential overlap.

MM asked if this should be done before or alongside the review of HBS. NA felt that this work should be done now.

AP agreed, saying that there was probably a good deal of duplication in each of these organisations, NA felt that because the same people are involved in each of these different bodies, it was important that the HBS has a good idea of the landscape.

CMcQ outlined the parallels between the aims and objectives of NITRE and the HBGB as both groups deal with HSC data, and the same Data Controllers, and suggested that the two groups could be more closely aligned. CMcQ asked MM to share the document he presented outlining the ToR for the review in order that the duplication might be tackled.

MM asked whether the group felt the HBS should press forward with this preparatory work prior to the review, or whether this should form part of the review itself. MM said that the HBS could gather the ToR for all those groups operating in NI, and produce a summary paper for the HBGB, however, he mentioned that this would push back the timelines for the review.

NA felt that the HBS service themselves were best placed to do this initial work, rather than an outside person.

AP highlighted that the initial work being proposed could be quite cumbersome and time consuming. However, NA felt that getting a list of committees, their ToRs and their members would be relatively easy. AP agreed, but said the difficulty would be in analysing the information that came back in order to determine where the common objectives lie and overlap.

NA was concerned that NI lags behind other UK nations with regards to the sharing and use of our NI health service data.

CMcQ then explained that NI doesn't have the same legislation in place as other areas of the UK. NITRE were considering whether some of the work in NI could be fast-tracked, similar to what the Data Institute has attempted to do in trying to streamline the processes involved. CMcQ said that she and Austin Tanney were to meet with Dan West in order to try and speed up the process, as business cases and additional staff still needed to be put in place. CMcQ highlighted that it would be at least 9 months before the Northern Ireland Secondary Uses legislation could be

implemented, so the issue was what could be done in the interim to expedite the process.

AP highlighted that a very joined up approach within Northern Ireland was needed to move this work along.

AP also felt that it was important that the review should include consideration of a representative from the 2 academic institutions in Northern Ireland, highlighting the importance of the synergy created by people within healthcare settings working alongside those in Universities.

MM agreed, and added that how best to engage with our Universities would be one of the main elements of the review. He offered to put together a summary paper outlining the ToR of other committees and boards in Northern Ireland, and GB, working within a similar context to the HBGB, and circulate this via email to the group. He felt that at the next meeting the group might be better placed to see if the ToR for the review should be expanded, and subsequently the ToR could be finalised and endorsed by the group.

Actions:

- **MM to forward the paper summarising the draft ToR for the HBGB review to the group for comment.**
- **MM to compile a paper summarising the ToR for committees in NI, and GB, working in a similar remit to the HBGB. This will outline common objectives and overlap, and highlight areas where each organisation is unique. MM to circulate this paper to HBGB members.**

- CVD COVID

AH gave an update on the programme of work run by Health Data Research UK (HDRUK), and the British Heart Foundation (BHF) Data Science Centre. Entitled “Developing infrastructure to accelerate UK-wide research for the CVD-COVID-UK/COVID-IMPACT programme”, one of the main aims of the work is to understand the relationship between COVID-19 and cardiovascular diseases through the use of nationally collated, structured and coded data.

AH had previously shared information that had been sent to Scotland and Wales to provide more insight into the scope of the Programme Level Approval. As a result,

the HDRUK and the BHF Data centre teams are to submit an application to the HBS, although no application has been received to date.

5. Honest Broker Governance Board Discussion – HBGB Chair Expression of Interest (EOI)

KB gave an update regarding the EOI for the position of HBGB Chair. The EOI was issued to members of the group on 25th March and again on 5th April 2022, however no responses were received. KB explained that in the ToR for the HBGB, the HBS reserves the right to appoint a Chair and/or Deputy Chair from outside the HBGB if none of the Voting members express interest in these roles.

KB suggested that the vacant HBGB Chair position could be advertised via newsletters, websites or social media of HSC organisations such as the PHA, Northern Ireland Medical and Dental Training Agency (NIMDTA), Northern Ireland Clinical Research Network (NICRN), Northern Ireland Cancer Trials Network (NICTN), Health Innovation Research Alliance Northern Ireland (HIRANI), NISRA (Northern Ireland Statistics and Research Agency), and ADR NI (Administrative Data Research Centre Northern Ireland).

KB suggested making the application slightly more prescriptive than the previous EOI form that had been issued to HBGB members. She suggested that this could include criteria such as experience of providing clear strategic direction within the HSC; evidence of being research active; demonstrate a clear understanding of research priorities within the HSC; building effective and constructive relationships at a strategic level; liaising with both internal and external stakeholders, and; experience of leadership in health or social care. KB then asked the group if there were any other criteria they felt were necessary for the position.

NA queried eligibility for the position, and felt that the individual needed to be someone within one of the HSC organisations. This would ensure buy in and leadership from an internal champion to promote the use of HSC data for evaluation and research purposes.

PS queried what qualifications would be required for the post, and if there was a job description, and estimated time commitment needed for the position. PS also highlighted how difficult it would be to get a clinician to provide time as a goodwill gesture, and queried if there would be a financial commitment for a PA or backfill to cover this, arguing that this would make the post more attractive. PS felt it would be difficult to attract a Chair as clinicians within the HSCTs are increasingly pressurised for time.

AP agreed with PS, and felt that remuneration for 1 PA backfilled in order to dedicate 4 hours per week to the HBS and HBGB was needed.

LM agreed with comments made by NA and PS. She also felt that the HSCTs themselves should promote this opportunity, but felt that it was highly unlikely that anyone would come forward without some sort of remuneration.

CMcQ reminded the group that it was intended that the Chair would be a member of the HSC, with a clinical background and a Personal Data Guardian, in order that he or she would have a good grasp of the issues associated with the HBS. However, CMcQ felt that remuneration for the position would be difficult given the current funding situation of the HBS.

HR suggested that the criteria for the Chair position should also include previous experience in attracting funding, as well as previous experience of Chairing.

LM agreed with HR, and added that the criteria should include previous experience of data knowledge and management.

AP felt that the individual also needed to have an awareness of the unique situation within Northern Ireland and NI legislation relating to research, governance and data sharing.

MM felt that for NISRA and ADR involvement could result in a conflict of interest, as both these organisations could be competing for similar funding. MM felt that these organisations could be used to disseminate the EOI or advertisement, but didn't feel that the Chair should be drawn from these.

AP queried if the individual needed to be solely recruited within the HSC.

NA suggested that the individual could have a "substantive" post in the HSC.

NM asked if there was any money or funding available in order to make the post remunerative.

KB said that traditionally Chairing positions are not remunerative.

NM asked where the HBS is sited and lead from. CMcQ answered that the HBS is situated within BSO, as the Data Warehouse and all the staff were BSO employees. CMcQ added that the BSO are not the data controllers for the data, explaining that this is why the other organisations represented on the HBWG had signed a Memorandum of Understanding (MOU) in order for their data to be used.

NM suggested that funding should be sought for a PA position, and then that might increase the chances of a clinician coming forward for the Chair position. However, he did point out that the list of criteria suggested by the group would decrease the pool of people who would be eligible to apply. He also suggested that the PHA should be approached as a place to house the HBS, and that Ian Young should be approached to provide a Chair from among the senior PHA staff.

NM pointed out the difficulties in trying to get a Personal Data Guardian from one of the Trusts to act as Chair, as they were particularly time challenged.

He acknowledged that lack of funding to remunerate a clinician would be make recruitment more difficult.

AP said he would approach the PHA, specifically Janice Bailie and Ian Young in R&D, to see if they could provide funding for 1 PA's worth of time to support the HBGB. He said that the future chair of the group would be instrumental in feeding into the review of the whole data ecosystem that NA is involved in.

NA interjected at this point, and said that if the PHA were to contribute to the funding of the HBGB, they would expect more control over delivery plans, targets and project management.

CMcQ said that previously, a member of the HBGB had suggested someone for the post. NA then said that the situation was different now, highlighting the urgency and need for a structure, given the competition from other regions.

AP agreed with the need to professionalise the HBWG, and felt that it was no longer viable to rely on volunteers.

CMcQ felt that having the member organisations represented within the HBGB could help to secure funding needed and recruitment.

AP then asked the group if funding for a Chair should be sought in order to make the group more professional.

NA then made the point that the PHA funds different strands within the Northern Ireland Clinical Trials area, with professional leads within each clinical specialty, but this includes the targets and KPIs in order to show how investments have delivered value for money.

PS then highlighted the difficulties with paying a clinician to take on additional paid work as a Chair, given the significant yearly pension tax in Northern Ireland. He felt this would make it less likely that certain clinicians would take up a remunerative post. AP agreed with PS.

LW agreed that funding for the Chair should be sought, but pointed out that this would take some time to organise this, and suggested an interim solution was needed. She also suggested that the benefits of such a position needed to be more clearly highlighted in any advertisement.

AP suggested that Janice Bailey and Ian Young in the PHA should be approached to discuss funding to support the Chair.

MM agreed, and said that the PHA had been approached for bridge funding for the next 18 months for the HBS as a whole, of which the HBGB is part. MM went on to say that this could be built into a future business case.

Action:

- **AP to write a letter on behalf of the group to Ian Young and Janice Bailey in the PHA asking about the possibility of funding to support the HBGB Chair, citing reasons detailed above.**

6. HDR UK and National Core Studies Update

AH gave an update on work with the Heath Data Research UK, describing how work was generally decreasing in relation to Data connectivity surrounding COVID.

There is 1 new COVID study approved at the last HBS sub-committee. This study is sponsored by the Economic and Social Research Institute, and came via the Innovation Gateway, which was positive for the HBS, showing greater awareness of the service.

AH noted another NI application requesting access to the Northern Ireland Maternity System (NIMATS), aiming to explore intimate partner violence during COVID pandemic.

With regards to the HDRUK, currently the main work aims to progress is the CO-CONNECT project investigating federated cohort discovery. The Data Protection Impact Assessment and MOU with the Data Controllers is ready for submission, and engagement sessions have been organised with key stakeholders. The project is currently starting in Scotland and Wales also.

AH also discussed the ongoing work with the PANORAMIC trial, and mentioned that he and LM were working alongside the Northern Ireland Clinical Research Network (NICRN). Recruitment in Northern Ireland for this trial has been very successful, and AH mentioned the important role that BSO ITS had played in this. However, the NICRN wants ongoing linked data for follow up, exploring hospitalisation for the next 10 years. In Northern Ireland, there is no streamlined governance route for this, so the team are exploring if a series of data access agreements, signed by different data controllers could facilitate this, although AH acknowledged this was cumbersome.

In addition, the study team had omitted to include the different health organisations in the devolved nations in consent documentation issued to participants. Although the consent form has been rectified, this raises legal issues as to whether Northern

Ireland data collected to date can be used. The study team have spoken to the Privacy Advisory Committee, but ultimately the decision will rest with the Data Controllers themselves. This example illustrates the difficulties arising from Northern Ireland's lack of a service similar to the NHS Digital Independent Group Advising on the Release of Data (IGUARD).

AH also highlighted the importance of the HBS involvement in the CPD COVID study, discussed in the last HBGB meeting. One of the main aims of the work is to understand the relationship between COVID-19 and cardiovascular diseases through the use of nationally collated, structured and coded data. AH will be encouraging the research team to submit an application to the HBS.

The group had no further questions or comments.

7. NILS and GPIP Updates

NILS: NaM explained that the HBS had been working alongside the Northern Ireland Longitudinal Study (NILS) team to progress the Secondary Care Data pilot, where HBS secondary care data could be used for NILS projects. This pilot has been completed, and an evaluation highlighted the success of the pilot. Subsequently, a decision has been taken to progress the work with established research teams, who have used the datasets before. One of the key issues is the effort required to get the Data Access Agreements (DAAs) signed off by all 5 HSCTs, and NaM highlighted the lack of resources available within the HBS to progress a large number of research requests. This will be kept under review, with the aim of speeding up the DAA process.

GPIP: NaM gave an update at one of the recent GP Editorial Board meetings it was suggested that the HBS may be able to get access to the QOF datasets to allow researchers to utilise this information. However, NaM emphasised that these are not "tidy" datasets, and the HBS will work alongside the GPIP team to get an idea of the type and format of these datasets. This in turn will allow the HBS to include GPIP data within future research projects.

AP queried if GPIP were currently very active. NaM said that GPIP have been progressing the GP Registers and dashboards, although the primary role of these dashboards is to support GPs rather than for research purposes. However, as the dashboards are rolled out, the HBS would get access to the supporting datasets. LW confirmed that the Diabetes dashboard has been established, with plans for the Asthma dashboard next and other disease registers.

AP asked if there was capability within secondary care to look at longitudinal outcomes within primary care.

LW answered that this was possible, but progress was slow. Progress has been made since January of this year, and updates to the Vision data should be completed by the summer.

NM asked if GPIP data could help inform decisions and monitor outcomes within the realm of public health. LW indicated that other organisations were interested in the progression of GPIP, and if the funding were made available, then the GPIP team could explore this.

AP asked NaM exactly what the difficulty was with the NILS. NaM explained that for most HSC projects, an MOU was in place, so researchers wishing to access the data in the data warehouse do not have to get individual DAAs. However, because NILS is external to HSC, researchers then have to get signatures from all 5 HSCTS, which is very time consuming. Similarly, if any of the research teams request data from a dataset that is outside the core data in the regional Data Warehouse, then accessing this via a DAA is cumbersome, and can put off researchers from including this in studies.

NM explained that he is the Senior Information Risk Officer (SIRO) for the Northern Health and Social Care Trust (NHSCT). He suggested closer engagement with local Information Governance leads, as they can speed up the process. The Information Governance Leads have an Advisory group, chaired by the DoH, and NM suggested engaging with the Information Governance Leads via this route, in order that decisions can be made more quickly by the SIROs.

AH agreed with this approach, and described how helpful it had been working with the Information Governance Network when trying to progress the Secondary Use Pilot project. AH highlighted the importance of building relationships with the Information Governance staff.

NA agreed that this was a good approach, but highlighted that it can be difficult to progress a new approach through the system.

NM said that SIROs had a statutory duty to be accountable for the information for which they were controllers, and so due process had to be followed, but he could look at different ways of helping the system be more efficient. NM said that the SIROs from all 5 HSCTs meet monthly, and that slots are made available at these meetings for guest speakers.

NA asked NaM to make Orla Bateson (NISRA) aware of this monthly SIRO meeting, as this would be very beneficial to attend; and to keep NA informed if there was anything she could do to expedite the process.

8. HBS Research and non-research summary reports

(a) Non-research Activity Report:

NaM reported that only 1 additional non-research request had been received since the last meeting. This new request focused on neurology waiting lists.

(b) Research Activity Report:

NaM gave an overview of the Research Activity Report, with a total of 3 projects approved in the last quarter. In the current financial year (2021-22) a total of 12 projects were approved.

As mentioned by AH earlier, two of these recent projects relate to COVID and deprivation, and Intimate Partner Violence during the COVID pandemic lockdown. The 3rd application relates to health in the preconception period, using the NIMATS and deprivation data.

There a number of project applications currently in draft, and it is hoped another panel can be convened over the summer months to review a further three applications.

Output requests have grown in the last financial year, with most of these migrated over to SERP.

The Safe Haven is still open 3 days a week; 135 days were offered and only 127 have been taken, possibly because so many projects have been migrated across to SERP.

NA asked how the HBS were manging due to the upturn with SERP.

NaM replied that all of the team have received training in checking outputs, and that not only have the volume of outputs increased, but these have also become more complex. The team have also implemented a new rota basis for output checking, which has helped manage the burden. NaM indicated they are still working well within the guidelines, which state that up to 5 working days are allowed for intermediate outputs and up to 20 working days for final outputs.

NA congratulated the team on this.

9. Review of Action log

The group reviewed and updated the action log.

10. Any Other Business

AH mentioned the COMORANT project as an example of using routine data in trials, and mentioned the use of a model for data linkage for consented studies. AH is currently looking at the funding and governance issues experienced in other areas, and has presented a paper at the HSCT Research Directors Forum identifying service gaps.

AP mentioned one of the projects focusing on a cohort of Looked After Children, had resulted in low numbers at HSCT level, and impacted on HBS disclosure thresholds. The Project team then requested further information without the HSCT variable, with the guarantee that previous documents would be destroyed.

AH also mentioned the draft HBS Annual Report was available. He will forward this to HBGB members, and invited members to provide comment on this via email.

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



Signature:

Date: 08-09-2023