HSC Business Services Organisation

Minute of the 33rd Honest Broker Governance Board Meeting (HBGB)

Date of meeting: Tuesday 6th September 2022 (2.30pm 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); Laura Moore (LM) (SEHSCT); Dr Hilary Russell (HR) (Lay Member); Dr Peter Sharpe (PS) (SHSCT); Ruth Barry (RB) (PCC); Dave Watkins (DW) (NHSCT).

Non- Voting members: From BSO: Alan Harbinson (AH), Martin Mayock (MM), 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: 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 agreed.

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. LM had contacted the R&D managers in the

HSCTs, but clarification needed as to who should actually be invited to participate in the HBGB.

Action: AP asked LM if she could 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.

All other matters arising are discussed as part of the main agenda items.

5. HBGB Chair Recruitment

AP contacted Janice Bailey and Ian Young in the PHA to see if there would be any funding available for the Chair post of the HBGB. Both Janice Bailey and Ian Young felt that the post should not be funded as they felt this would be setting a precedent, as current Chairing positions within ORECNI are not funded. AP then explained to Janice Bailey that the Chairs within the Ethics Service do not necessarily work within the HSC infrastructure, whereas Chairs for the HBGB are traditionally drawn from the HSC staff.

AP reiterated to the group that he still feels that the Chair of the HBGB does need to be paid, so that their time is protected in order to support the Honest Broker Service.

HR agreed with AP, and pointed out that REC members and Chairs are public appointments and that the structure is very different to the HBGB structure.

NA explained that this situation was challenging for HSC R&D not only because their budget was lower per capita than other UK regions, but that it was difficult to support a thriving research culture if funding was being spent on infrastructure rather than actual research projects.

AP felt it would be difficult to get the HSCTs to provide funding.

AP felt that the EOI should be advertised, and if there was still no interest in the position, the group should approach the PHA again for funding. MM pointed out that the funding of the Chair position was tied into the wider funding issues associated with the whole HBS, and felt that the group needed to progress with the recruitment, with the issue of funding of the post revisited in the future, once funding for the whole HBS was certain.

AP also felt that a conversation should be held with Dan West regarding funding.

KB went on to give an update on proposals to recruit a new HBGB Chair, incorporating feedback from the HBS staff, and the Honest Broker Working Group, as well as responses from the last HBGB meeting. Given the large number of suggestions for the personnel specification and description of the position at the last HBGB meeting, KB suggested that rather than listing all of these, a number of key areas where the Chair could add value to the HBS should be included, as well as the minimum expectations of the Chairing position.

KB explained that although the existing ToR for the HBGB indicated that the Chair should be working within the HSC; have a clinical back ground, and a Data Guardian,

previous post holders did not demonstrate all these criteria. KB asked the group as to what should be listed as essential or desirable criteria, drawing attention to an earlier discussion held with the HBWG, where some members felt the term “clinical” could put good candidates off applying for the position, while at the same time ensuring there were enough members with a clinical background to ensure business of the group. MM reiterated that having a “clinical background” as an essential criterion could put some people off applying, and queried with this should be mandatory or desirable.

HR felt this could be reworded, feeling that this suggested someone who was medically qualified, and didn’t feel that this was essential and could be expanded to include other types of research. HR also felt that having an understanding of how the Health Service works was important.

However, AP felt that it was important to have a medical person to review the submitted applications otherwise the adjudicating group may not be suitably qualitied in terms of providing a clinical/ medical steer on proposals.

HR queried if this person had to be the Chair. NA agreed with this, citing the discussion in the HBWG, that as long as the Chair was adequately supported and the review panels were constituted appropriately, then a clinical background should not be essential.

AP agreed, as long as people on the group who were medically qualified participated in the subcommittees to review research applications, and these were rotated for subcommittee work. NA pointed out that this could be an opportunity to reinvigorate members with a clinical background in the work of the group.

MM said that the ToR would need to be revisited to ensure there would be clinical representation on the subcommittees.

NA emphasised that there have been a good number of developments in the secondary use of data field since the original ToR were written, and the service had changed, and needed flexibility to flourish.

MM then asked if a clinical background should be removed, or kept as desirable. AP answered that it should be kept as desirable, but with more granularity in what is actually meant by the term.

NA said in the R&D Funding Applications include a list of backgrounds that are desirable, rather than just one, and suggested that these should be included alongside the term clinical.

AP said that members should indicate what elements of the personnel spec should be essential. AP felt that a sound understanding of information governance within the HSC should be essential.

SM said she would circulate the EOI around the Chief Medical Group in the DoH and felt that there might be a medic within the DoH that might be interested.

MM asked others to circulate the EOI as well within their own professional circles to widen the potential pool of applicants. NA added that there could be other professional groups who might be interested, including pharmacy, nursing, social care etc. as all their data was represented within the Data Warehouse.

AP queried if the group wanted to go out with the original EOI or add these new suggestions into the EOI. MM suggested that these suggestions would be built into a new EOI which would then be circulated.

Action: KB to circulate suggested personnel description to group members, who will provide comments.

6. Review of HBS (paper attached on ToR for other NI and UK Trusted Research Environments) (Alan)

MM gave a recap on the review of the HBS, explaining that the original terms of reference was to look at the HBS membership etc and how the HBS might best engage with academia and other stakeholders. However the scope had been widened as part of discussions about future relationships between the HBS and the Northern Ireland Trusted Research Environment/Information Institute etc coming out of the Data Strategy. BSO were initially going to commission the leadership centre to carry out the review however they did not feel it appropriate that BSO should lead on wider review involving relationship with the Department.

MM highlighted that a review including NITRE and Departmental bodies could take some time, and queried whether, in the interests of time, our review should move forward in the interim looking at how the HBS might best engage with academia and other stakeholders. AP felt that the initial focus of the review should be solely on the HBS, and could feed into a wider review at a later stage.

AH presented a summary comparing UK Trusted Research Environments and Supporting groups, comparing their membership and structure. AH highlighted the similarities between groups across the UK, where most TRE's have a single advisory panel to approve projects, made up of representatives of the data owners, and academics, and public representation. AH asked members of the group to read through the document, and think as to whether the HBS should have academic representation from the 2 universities, and members of the public. AH also pointed out that some of these groups have Chairs appointed by the Health Trusts on a rotational basis, rather than operating an EOI.
AH said to the group that if anyone wanted more information on anything in the paper to contact him, and welcomed feedback on the document.
AP said that the document was useful as a reference document, and asked AH if there were any examples of good practice that the HBS could replicate.
AH said that having academics and/ or statisticians as voting members would be particularly helpful for the HBS to help make decisions on disclosure control. At present the team within the HBS fulfil that role.
AH mentioned that when the HBGB was being set up, the team did consider examples of good practice from elsewhere, and based many of the current processes on these. For example, other TREs are made up of members of the public, using this as a public license for use of the data. HBS has a Lay member, plus Ruth Barry from the PCC to help fulfil this role.

NA asked if there was any information on the volume of activity for the respective TREs as this could inform the structure of the service.
AH indicated that the SAIL databank produces reports on the volume of applications processed, and this something that could be added into the report if members so wished.
AP asked if there was information on who funds the TREs in different jurisdictions, and what is their charging policy for applications.
AH mentioned that Ian Young had also asked about the charging policies of each of the TREs, so the HBS team are developing a short paper to explore this. AH described how most other TREs in the UK are centrally funded.
LM asked if the organisations listed for the other parts of the UK had the same functions as those listed in Northern Ireland. AH indicated that although some of these bodies (e.g. SAIL in Wales) did perform similar functions to the HBS in NI, there were differences, particularly in funding, e.g. SAIL received Economic and Social Research Council (ESRC) funding.
NA felt that information presented was useful for inclusion in a business case highlighting support needs for the service, compared with other UK services; and secondly for the forthcoming review.
AP felt the document was a good summary document, but felt there could be more information added, particularly in terms of good practice.
NA mentioned that the HDRUK have restructured again, demonstrating the need for flexibility in order to make the service as competitive as possible.

ACTION: Members to provide feedback to AH on the paper before the next HBGB meeting in November, highlighting any points of interest for inclusion in the forthcoming review of the HBS.

7. Projects updates and discussions (Alan)

a. PANORAMIC

AH gave an update on the PANORAMIC Trial, which aims to examine treatments to reduce the numbers of people hospitalised with COVID. AH pointed out that NI does not have a streamlined process or single point of application, such as NHS Digital, for these studies. As a result, the team are working with the Trusts on a series of Data Access Agreements, which makes the process more difficult and time consuming. The study team are now making decisions based on the data received as to the efficacy of certain drugs included in the Trial. AH indicated that correspondence had been sent out from the PANORAMIC study team, and Prof Ian Young, in an attempt to expediate the process of getting the Trusts' involvement. The HBS team will be involved in supplying part of this follow up data as this is stored in the Data Warehouse. However, AH pointed out that this trial support is not strictly HBS work as identifiable data is involved, but he felt that this was work members of the HBGB should be aware of.
AP asked for clarification around Trusts involvement in this work.
LM explained that the Trusts had been supporting this project, but they work via a single point of contact. LM explained that she was the single point of contact for the Trusts, and had been dealing with the IG Network on behalf of the Trusts, and to date there were 4 Trusts who were willing to sign up.
LM then asked AH to clarify the number of DAA's the Trusts had to sign, as there was some confusion over this. AH confirmed that there was 1 DAA for each Trust

to sign to confirm they were happy for their data to be released. AH acknowledged the process was quite complex, and he understood that the Trust Research Directors are considering different ways of providing clinical data for research purposes in the future. AH, while acknowledging the importance of the Hospitalisation Data held in the Data Warehouse, described how this had also led to an expectation that record linkage, but in Northern Ireland there is no streamlined way for this to take place. AH hoped that in the future there would be a single point of contact for studies to approach in the future for this data.
NA suggested that this single point of contact could be added to the remit of the facilities offered by the HBS in the future.
AP added that this was something that could be added to the HBS Review paper.

b. Co-Connect

AH stated that the governance documents for this project were currently with the Trusts, including a Data Impact Assessment (which has been completed) and a Memorandum Of Understanding (MOU) for the data to feed into the Cohort Discovery tool. AH informed the group that this tool is being developed across the UK, and aims to provide information on the size of cohorts within different datasets and allowing researchers to develop queries, enabling researchers to judge whether their study will be viable before they make an application via their TRE. The HBS is hoping this will be signed off based on feedback from the Information Governance Network. However, the Co-Connect project is due to end at the end of October, so the Trust MOUs may not be signed off in time for this. It is intended is that the Co-connect project will be handed over to Health Research UK, and the resource will continue to be available via their Gateway.
AH highlighted the benefits of the work, including the facility for data standardisation.

c. Harp/Recovery (paper attached)

AH gave an overview of the HARP/ Recovery Trial paper circulated prior to the meeting. AH was keen to hear members' view on the request, which was unusual as the application does not actually include use of HSCNI data. The application focuses on follow up analysis for two UK wide trials who have requested access to a TRE to store pseudo-anonymised data for long-term use. The research team are based in QUB, and want to be able to access the data in a controlled environment with information governance assurances and output protections provided by the HBS. The team would send English and Welsh data and follow up data provided by NHS England to the HBS, with the latter acting as a host for this data by way of a TRE. AH highlighted that due to the lack of secondary use legislation in NI, NI long term follow-up data cannot be included without patient consent, whereas the infrastructure in England supports setting aside the common law duty of confidentiality for research such as this. The research team plan to apply to the Confidentiality Advisory Group (CAG) and NHS Digital for a Section 251 approval to enable the linkage, although this would go beyond the period initially specified in the original consent.
To enable the application to be considered, a Section 251 approval would need to be in place. There would also need to be data sharing arrangements between the two research teams in QUB and Warwick University, and NHS Digital, plus an agreement

for the transfer of data to BSO and for the data to be made available via the SERP platform. AH asked if the group would be willing to consider the proposal for the HBS to act as a TRE for this project, once all the approvals and legal agreements were in place.
AP asked for clarification on two points: with regards to the consent process, although the patients did originally provide consent for their data to be used, consent had not been taken for use of their data in follow up studies. Secondly, AP asked if the proposal had been raised with the Privacy Advisory Committee in NI.
AH didn't believe that the researchers had spoken to the Privacy Advisory Committee in NI, and had confirmed that HSCNI data would be not be included in the research.
AP felt that longitudinal studies of this kind were very valuable in determining what happens to patients over time, and contributing to improvements in health care provision.
CMcQ sought clarification that no HSCNI patient data would be used, given the lack of consent from patients, and the lack of secondary use legislation in NI. AH confirmed this.
CMcQ felt that the proposal was outside the normal scope of the HBS because the applicants were solely using the HBS as a repository for English data. CMcQ added that if the BSO did provide a TRE as a Processor and the other organisations named in the proposal acted as Controllers, then a Controller Processor MOU would need to be in place setting out very clearly the role of the BSO in providing that TRE.
LM queried why the data had to come to the HBS, and couldn't be utilised in a TRE in England or Wales.
AM answered that the applicants could have possibly approached the team in Swansea, as Swansea offers a similar service to the HBS. However, the project team are based in Northern Ireland, and having used the HBS in the past were keen to use the service again, and to promote the HBS.
CMcQ also queried the use of HBS resources in the project, and felt there was no benefit to the HSC, given the lack of NI patient data in the study.
NA asked if the project was hosted elsewhere, would the hosting body (e.g. SAIL) charge for this type of activity, and was there a possibility that the HBS could explore this avenue.
AH indicated that SAIL and the HBS do charge for this type of activity, but pointed out that as the funding for this type of work was non-recurrent, it cannot be used to expand the HBS service. AH also pointed out that there were not only costs associated with the actual delivery of the service, but also costs incurred by others outside of the HBS, for example in setting up the necessary MOUs and Data Processor Agreements.
AP asked if the group felt that the research team should approach SAIL instead of the HBS. AP felt that because there were no NI patients involved in the research, it was difficult to balance the resource implications with the benefits of the HSC.
NA queried if the NI Secondary Use legislation was going to implemented in the near future, could NI patients' data could then be used in the long-term follow up study?
AP felt that the project should be used a test case to highlight that the lack of infrastructure and legislation in NI supporting our participation in such high-profile studies. He felt that the researchers should approach the Privacy Advisory Committee in order to get a view on this.
NA felt that it would be useful to have on record that the lack of legislation and resources in NI to support research of this kind.

AH then asked if it would be useful to participate in the study in order to raise the profile of the HBS?
CMcQ again reiterated the benefits versus the resource implications of taking part in the work.
AP felt that participation in the project could in some aspects enhance the reputation of the HBS, but on the other hand processing of data can always cause reputational damage if there are any breaches or leaks associated.
LM then queried the title of the study. AH indicated that the title of the study was "RECOVERY RS, HARP 2".
AP indicated that both RECOVERY and RECOVERY RS were both priority studies on the Priority portfolio. He wondered if Northern Ireland data could be included on basis of public interest.
AP suggested that the response should be that the HBS would like to be involved in the work, but unfortunately were unable to do so at this point in time. AP suggested that Dr Jonathan Stewart should seek an opinion from the Privacy Advisory Council, on the basis that this is a priority study. AP highlighted that it was important that NI do participate in important high-profile studies, but are unable to do so because of our lack of legislation, such as in this exemplar case.

8. Update on Funding (Martin)

MM outlined that the plan for long-term funding for the HBS is via a business case associated with implementation of the new Data Strategy and, in particular, the Data Institute. However, MM highlighted that existing COVID funding for the HBS is due to run out in March 2023. MM relayed how, at the last meeting of NITRE, the valuable service provided by the HBS was acknowledged, and Prof. Ian Young subsequently asked for a breakdown of HBS costings to enable bridge funding for the service between March 2023 and March 2024. Costings were to be split by "pure research" versus "research support" activities undertaken by the HBS. MM and AH then met with Prof. Young to discuss potential funding, where it became apparent that the maximum amount of funding that could be provided by R&D was about 50% of the total current HBS running costs. Prof Young suggested that other contributors could make up the remaining 50% needed to run the service; proposing that the DoH should be approached, and that NITRE could also help identify potential funders. Prof Young also suggested these funding sources could also be supplemented with a revised charging policy in order to make up the shortfall.
Prof Young has asked for proposals to be brought to the next NITRE meeting, to see if a funding package can be implemented until long-term funding is in place.
MM indicated that, in his view, BSO would not wish to fund the HBS, as the organisation is commissioned to provide services for the HSC, whereas the HBS is an actual HSC service.
MM emphasised the critical nature of the funding shortfall, explaining that the service had already lost admin support posts and, if funding cannot be found, he expected critical posts to be lost in the near future.
MM felt that the additional charging wasn't an option to cover the gap in funding, as this would be need to be worked up and consulted on, so couldn't be implemented quickly, although would feature in the business case for funding after 2023-24.

All members agreed that it would be extremely disappointing if the service disappeared until the longer-term funding was in place, as the profile of HBS has gained momentum both within NI and throughout the UK.
NA shared that the funding from HDRUK was unlikely to be renewed, as it was expected that this service should be funded centrally from health service money, rather than money allocated for research. NA emphasised the need for the Data Strategy to be implemented.

9. HBS Summary Reports (Naomi)

NM gave a verbal update on the two summary reports, noting that there had been another two internal applications – one from the Northern Ireland Ambulance Service (NIAS) and one from DoH.
With regards to research applications, three applications have been approved in the last quarter, although NM highlighted that another panel should be convened in the near future, in order to meet the HBS target of 12 applications per year.

10. Review of Action points log (All)

The group reviewed and updated the action log:

- AH noted that the actions from the previous meeting had all been addressed.
- One of the actions relating to the draft TOR for the review of the HBGB will stay open and be updated following the outcome from the forthcoming NITRE meeting.
- The actions for the Chair and LM regarding attendance at HBGB meetings should be amalgamated.
- 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 on this.
- Exploration of application management systems is ongoing, and involves licensing costs, so will be updated once the HBS wider funding issues are addressed.
- Student placements have been on hold during COVID, but it was agreed this should be kept open, and form part of the review of HBS. This should be brought forward as a standard item on the next HBGB agenda.
- The NI Data Strategy item can be closed.

11. Any Other Business

MM mentioned that he and AH had been successful in working up an arrangement with NISRA to ensure coded mortality data is now part of the usual HBS SERP offering. MM outlined the benefits of this for researchers, who previously had to access this data via the Safe Havens.

AP congratulated MM and AH on this important work.

AP asked if there was a list of what data is in the Data Warehouse. AH indicated that the HBS has a menu available on the Health Data Research Gateway, which contains all the metadata for the standard HBS data within the Warehouse. Some systems aren't listed where there are gaps in Trust provision of data (e.g. Labs data).

AP queried if researchers would be made aware that the mortality data would now be available. AH said that researchers would be made aware.

NA asked if disease registries would ever be part of the HBS portfolio, and it would be beneficial for the service if researchers could access these through the HBS.

AH indicated that there had been a number of projects that had brought data in from the NI Cancer registry, but it is more difficult when the data sits outside the HSC.

NA highlighted the Cerebral Palsy Registry that is sited in QUB, and felt that these registries should be more open for researchers, in order that benefits might be seen for the patients who have contributed to them.

AP agreed, and highlighted the benefits of linking the mortality data to the different disease registries in order to explore mortality for those different population groups.

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

Signature: Date: 08-09-2023