

Minute of the 31st Honest Broker Governance Board Meeting (HBGB)

Date of meeting: Tuesday 8th February 2022 (1.30pm to 3.30pm)

By Zoom videoconference.

Present:

Voting members:

Dr Aaron Peace (AP) (Western HSC Trust and Deputy Chair of HBGB); Irene Knox (IK) (SHSCT); Dr Nicola Armstrong (NA) (PHA); Siobhán Morgan (SM) (DoH); Neil Martin (NM) (NHSCT); Laura Moore (LM) (SEHSCT); Ruth Barry (RB) (PPC); Dr Hilary Russell (HR) (Lay Member).

Non- Voting members:

From BSO: Alan Harbinson (AH), Martin Mayock (MM), Cormac O'Brien (CO'B),; Mark Bradley (MB) (BSO); Naomi Mill (NaM) (BSO);

From DoH: Charlene McQuillan (CM) (DoH)

In attendance:

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

Apologies were noted from the following:

Voting Members:

Dr Michael Quinn (MQ) (Health and Social Care Board (HSCB) and Chair of the Honest Broker Governance Board (HBGB)); Dr Peter Sharpe (PS) (SHSCT); Dr Seamus O'Reilly (SO'R) (NHSCT); Lisa Whyte (LW) (HSCB); Alison Murphy (AM) (BHSCT).

Non-Voting Members:

Fiona McNally (FM) (BSO).

1. Welcome

AP chaired the meeting on behalf of MQ, although was delayed slightly in attending. It was decided to run through some of the standard items on the agenda until AP joined the meeting.

2. Minutes of the last meeting

Minutes of the last meeting were subject to a few minor amendments.

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

3. Matters arising

MB queried if the meeting was quorate. KB and AH observed that 2 lay members were present, along with 3 HSCT representatives; however, the vice chair had not yet joined the meeting. AH noted that this could have issues for Quorum of the meeting (which requires either the Chair or Deputy Chair to be in attendance at each meeting). AH noted the previous action about writing to Trust reps to encourage attendance had not yet been completed.

Action: HBGB to send an email reminder to Trusts CEO's and reps encouraging attendance, and encouraging those unable to attend meetings to select a deputy to attend in their stead.

4. Review of the HBGB Action Log - All

Actions were reviewed and updated.

Following the update on the Attendance Registry, LM queried how the process of selecting members for the HBGB had been decided, and suggested this should be updated to ensure the most appropriate people were represented at the meeting. LM also suggested that the Terms of Reference (ToR) for the Honest Broker Governance Board (HBGB) should be re-visited, and these forwarded to members of the group.

Action: MB, AH and KB to re-visit the ToR for the HBGB, and bring back to the group for comment. This will include (a) the purpose of the HBGB; (b) membership of the group; and (c) processes to ensure a more rounded membership going forward.

5. Honest Broker Governance Board Discussion – HBGB Chair

AP joined the meeting.

AH gave an overview of a paper to inform the discussion regarding the HBGB Chair post. AH explained that at the previous meeting of the HBGB (25th November 2021), the current Chair (MQ) had raised the issue around his new role at Queen's University Belfast (QUB). At this meeting MQ had queried if this new appointment could compromise his position as Chair, as he will be making regular use of the Honest Broker Service (HBS).

MB gave an update of discussions with MQ and the Honest Broker Working Group (HBWG), explaining that MQ was happy to continue as Chair of the HBGB. At the meeting with MB and MQ, MQ had suggested a potential solution to the issue, where he could step out of any meetings or abstain from any decisions where a potential conflict of interest could arise.

IK and CM voiced no objection to MQ remaining as Chair. However other members of the group, while emphasising MQ's integrity and enthusiasm, were concerned about the potential reputational damage to the HBGB that could ensue from this conflict of interest. NA mentioned this issue had been discussed with colleagues in HSC Research and Development within the Public Health Agency (PHA), who highlighted the importance of HBGB autonomy and suggested the conflict of interest could raise issues to do with equity and subsequent risk of challenge. NA suggested other individuals who would not have the same conflict of interest and who may be interested in chairing the HBGB should be approached regarding the position.

SM agreed with NA, and re-iterated that the Chair of the HBGB had to be seen as independent, and should not be affiliated with any particular research institution.

IK queried whether the post of Chair was a remunerative post. MB replied that the post holder did not get paid.

AP re-emphasised the integrity and keenness MQ had displayed to date in his position as Chair, but stressed the importance of equity moving forward. AP pointed out that the HBS needed to be seen to serve both academic institutions in Northern Ireland, and regarded as impartial in any decision making processes.

HR pointed out that there was a relatively small pool of people who could act as Chair of the HBGB, given that most people with an interest in the role would have affiliations with one or other of the Universities in Northern Ireland. HR said that while she did not disagree with the views expressed by NA or SM, it would be a

matter of regret if the group were to lose the expertise and enthusiasm displayed by MQ.

HR pointed out that other organisations experienced similar issues, citing the Research Ethics Committees (RECs), who have processes to avoid conflicts of interest within the chairing team.

The issue of being able to have sufficient cover for panels between the Chair and Deputy Chair was also discussed. HR explained that each REC has an Alternate Deputy Chair, and can facilitate putting panels together to consider proposals, and meetings where any potential conflict of interest is declared.

AP agreed with HR, and suggested that some kind of restructuring of the HBGB may be needed. AP also suggested that both academic institutions should be represented in the constitution of the HBGB, in order to avoid a silo-type situation developing.

NA agreed with the suggestions put forward by HR and AP, adding that a similar approach had been used by the Northern Ireland Longitudinal Study (NILS). NA explained that NILS employed a steering group, similar to the HBGB, but with a much wider ranging membership, adding that the time was ripe for a broader approach to HSC data sharing.

MB mentioned that a review of the HBS had taken place a number of years ago, and asked if this had considered any of the issues highlighted above.

MM indicated that the review had focused more on the delivery service plan of the HBS, rather than any governance board membership.

MB highlighted that any future review would need to consider funding issues as well as operational issues. MB felt that any review of the service should be conducted by an independent body.

NA suggested that the group could look to funding and operational models used by other well-established centres, such as NILS, Administrative Data Research Centre (ANRC-NI) or the NICOLA Study.

MB felt that more engagement was needed before any further progress could be made on this issue, with a review of the service undertaken by a credible independent body to consider potential operational and governance structures for the service.

SM highlighted the need for user involvement in any review of the service in order to give an idea what service users needed and what they felt was the best way of running the service.

MM queried if MQ should stay on as Chair of the HBGB in the interim period.

MB suggested that further discussion was needed as to Chairing arrangements in the interim.

Action: MB to discuss proposals for a review of the service with MM and AH, and bring forward to the next HBGB meeting.

6. Update on HBS Projects and outreach activities

(a) Research Activity Report: NaM gave an overview of the Research Activity Report, explaining that in the current financial year (2021-22) a total of 9 projects were approved, with another 5 project applications currently in draft. It is hoped another panel can be convened in March to review a further three applications.

A total of 27 projects are currently live on SeRP, with another project in progress. The Safe Haven is now open 3 days a week and runs at full capacity most days. The ongoing work of HBS staff in supervising researchers and checking outputs was acknowledged.

(b) Non-research Activity Report: NaM reported that no additional non-research requests had been received since the last meeting.

AH referenced the recent non research requests for cardiology data from the Belfast and Western HSCTs and informed the group that the SHSCT were due to make a similar request. It was expected these would become routine annual requests.

7. HDR UK and National Core Studies Updates

(a) AH provided a verbal update on the Dac VaP - Vaccine Study + Co Connect, explaining that the Data Access Agreement required updating as the PHA had now become joint Data Controller alongside the HSCB. This data access agreement still needs to be signed off, so the project is running slightly behind

schedule. It is hoped that Northern Ireland can contribute to the Four Nations Workstream in the near future.

- (b) AH gave an update on Consented studies, mentioning that an outline paper had been passed to the local HSCT R&D Offices for comment. AH noted he had asked for feedback on the proposals by the 25th February 2022. LM asked if there was any flexibility regarding the deadline for R&D feedback, as they planned to engage with the Trust IG leads before providing response. AH replied that this was perfectly fine and that the intention wasn't to have a fully worked through solution by the 25th but to get general feedback which would then lead to further engagement. AH indicated that the Platform Adaptive trial of NOvel antiVIRals for eARly treatMent of COVID-19 In the community (PANORAMIC) Study was progressing, with the research including approximately 100 NI participants. Recruitment of further participants via GPs is starting. AH explained that given the high profile of the PANORMIC work, and request for assistance via the Chief Scientific Advisor it would be good if the HSC could provide a way to allow the requested follow up linkage, although he acknowledged that this process was beyond the current scope of the HBS as involves sharing identifiable data.

NA queried if there were eligibility/ exclusion criteria in order to participate in the study, and if GPs were aware of these, in order to cut down on the numbers of inappropriate referrals passed through.

CO'B indicated that a script had been developed in order to ensure that only records eligible for the study were passed by GPs.

(c) CVD COVID

AH introduced a programme of work run by Health Data Research UK (HDRUK), and the British Heart Foundation 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 demonstrated how the use of linked data from different health care settings was important in establishing cardiovascular events. Northern Ireland (NI) data supplied through the Data Warehouse and Honest Broker Service will be included in this work, subject to approval, and receipt of a data access agreement.

AH noted the team were requesting Programme level approval for access wherein one dataset would be approved and created however this could be used for multiple research projects. These individual research proposals would be

approved through their Approval and Oversight Board with a representative from HBS sitting on this Board.. AH stated that much of the additional work associated with this project would be done by researchers working in the Trusted Research Environments, emphasising that NI data would not be sent elsewhere.

AP queried why additional NI data was to be included in the project, and hoped that there would be tangible benefits from participating in the project.

NA emphasised the importance of NI being included in the 4 Nations work going forward, and highlighted the risk of being overlooked if not included in such high level programmes. She stated that NI needs to be represented in this work, in order that we can feed into outcomes from the work.

HR agreed with NA, but added that it was important that any programme approval and HBS input needed to be well defined at the outset.

AP highlighted the importance of HBS seeking additional resources in return for participation in this programme of work.

Action: AH to share information that had been sent to Scotland and Wales to provide more insight into the scope of the Programme Level Approval.

8. Any Other Business

No other items were brought forward.

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



Signature:

Date: 08-09-2023