

Minute of the 30th Honest Broker Governance Board Meeting (HBGB)

Date of meeting: Thursday 25th November 2021 (3pm to 5pm)

By Zoom videoconference.

Present:

Voting members:

Dr Michael Quinn (MQ) (Health and Social Care Board (HSCB) and Chair of the Honest Broker Governance Board (HBGB)); Irene Knox (IK) (SHSCT); Dr Nicola Armstrong (NA) (PHA); Siobhán Morgan (SM) (DoH - BSO); Ruth Barry (RB) (PPC); Dr Hilary Russell (HR) (Lay Member).

Non- Voting members:

From BSO: Alan Harbinson (AB), Martin Mayock (MM), Cormac O'Brien (CO'B), David Bryce (DB) (Director ITS BSO)

Kelsey McQuaid (KM) (Observer)

In attendance:

Karen Beattie (KB) (ORECNI) and Dr Bethany McDowell (BM) (BSO) for the purposes of the minute.

Dr Siobhan Murphy (SMu) (Guest) and Prof Dermot O'Reilly (DO'R) (Guest) were in attendance to give a summary presentation of their work on one of the HDR UK funded National Core Studies.

Apologies were noted from the following:

Voting Members:

Dr Peter Sharpe (PS) (SHSCT); Mark Bradley (MB) (BSO); no apologies noted from Dr Aaron Peace (AP) (Western HSC Trust and Deputy Chair of HBGB); Alison Murphy (BHSCT); Dr Seamus O'Reilly (SO'R) (NHSCT); Neil Martin (NM) (NHSCT); Lisa Whyte (LW) (HSCB); Laura Moore (LM) (SEHSCT).

Non-Voting Members:

Naomi Mill (NaM) (BSO); Fiona McNally (FM) (BSO); no apologies noted from Charlene McQuillan (CM) (DoH); Frances Burns (FB) (Guest)

1. Chair's Welcome

The Chair (MQ) acknowledged that both the Honest Broker Service and Regional Data Warehouse are open and are able to facilitate research despite the ongoing pandemic.

2. Minutes of the last meeting

Minutes from the last meeting were approved.

3. Matters arising

MQ mentioned that he has changed jobs and now works at QUB. This may compromise his position as Chair as he will be making regular use of the HBS.

Action: MQ to discuss with KB and MB regarding this potential issue.

RB introduced herself as being from PPC and mentioned that she will be taking over from Kate Lavery.

AH observed that only one HSC Trust representative was present. HR noted that this could have issues for Quorum of the meeting (which requires at least 1 Trust representative be present at each meeting). MQ and IK agreed and MQ took action to write to Trusts highlighting the importance of regular attendance. AH suggested updating the attendance log which had been previously circulated.

Action: OREC/HBS - to update attendance log and send to Chair

Action: MQ to send an email reminder to Trusts CEO's and reps around attendance, it was suggested under AOB that could combine this with writing out with the timetable for meetings in 2022 calendar year.

4. National Core Study – Data and Connectivity: COVID-19 Vaccines Pharmacovigilance (DaC-VaP) - SMu

SMu gave a Powerpoint Presentation summarising work on DaC-VaP, including a summary of both published and forthcoming papers to date.

SMu mentioned that an additional year of funding had been obtained for DaC-VaP 2 which will build on the group's work and will focus on pregnancy and COVID-19 related outcomes using data from the Northern Ireland Maternity System (NIMATS) database.

SMu noted that the work on DaC-VaP highlights the need for investment in data infrastructure in Northern Ireland as there is a lack of access to primary care data which would be beneficial for research.

SMu praised the HBS team for their help in navigating the HDR UK gateway and for offering advice and support. She also mentioned that she found remote access via SeRP invaluable to her research.

MQ thanked SMu for her presentation and acknowledged HBS and BSO for helping to facilitate this research. AH thanked SMu and her team for their patience as they were the first group to access the remote platform.

DO'R agreed with SMu that he sees benefits of enhancing NHAIS data and suggested that adding social housing indicators to indicate social standing could help to improve things. He concluded that more work is needed to figure out how to get closer to full population representation, including capturing important markers such as ethnicity, and to resolve issues with care home data.

DB stated that NHAIS is in the process of being replaced with the NI Digital Identity Service, a master data management product. He mentioned that this service will have a lot more capability than NHAIS and would give researchers more options as it would be more than just a demographic index. MQ agreed, highlighting the opportunity to improve data available for researchers.

Action: KB to share presentation with Honest Broker Service Governance Board members.

5. Potential HBS partnership with SafePod Network – AH

AH presented a paper on the potential HBS collaboration with the SafePod Network. AH noted that whilst we now have full remote access in place via the UK SeRP platform, there would still be potential benefits to engaging with the Network and that this could be done with very little effort and no cost. Prior to the launch of the HBS SeRP the SafePod Network would potentially have been another way of researchers to access data outside of the HBS Safe Setting, SeRP allows researchers to access data from home if required but it can also easily be accessed from a SafePod so if researchers are on Campus and wish to make use of a quiet working environment this could be something they could avail of. Also the engagement with the network may publicise the HBS across a range of UK based Universities.

AH informed the HBGB that there is currently only one SafePod in NI which is located at University of Ulster in Coleraine. This would be very useful for UU

researchers. AH commented that believed this partnership would be worthwhile as the set-up of SafePods requires little in terms of work and cost.

MQ confirmed that he is happy to go ahead with this partnership. NA agreed. There were no objections from the voting members of the HBGB.

Action: AH to begin the process of collaborating with the SafePod Network.

6. Update on MOU/SAIL/HDR UK National Core Studies –verbal update AH

AH noted that HDR UK that HBS received one additional application from the latest funding call for COVID-19 research and that this was the modification to the Dac-Vap project which had been discussed in the earlier presentation.

AH noted that several research teams had indicated would like to carry out include Northern Ireland in their analyses if time permits however most teams were focusing on one country initially. In particular the new British Heart Foundation Data Science Centre is acting as a TRE for NHS Digital has been very popular and includes primary care data for England obtained using COVID-19 emergency regulations.

Additional requests from DaC-VaP were approved internally through project modification forms and the HBS team are now working on data updates. The main priority is adding on NIMATS data to allow the pregnancy related analysis, this data is already available via the Regional Data Warehouse and is being prioritised first. AH noted that additional paperwork is required for access to influenza vaccine data via the VMS and that the establishment of Critical Care data in the Regional Data Warehouse is an ongoing project.

Critical Care Data is the last outstanding asset requested by HDR UK. Work is ongoing to gain access to this data for research purposes. AH mentioned that a Data Protection Impact Assessment for NHSC is underway and will be followed by a regional agreement and MOU. A pilot of the process is underway with NHSC to work on process for connecting WardWatcher Critical Care Data to the Regional Data Warehouse. MQ agreed that Critical Care Data would be beneficial and comments that it is good to see this progressing.

7. Update on HBS Projects and outreach activities – verbal update AH

Research Activity Report: AH informed the HBGB that there are four projects nearly ready to go to panel potentially in scope for the upcoming application

panel in December. He anticipates that the first three applications to be completed will be submitted for approval by the board.

The Safe Haven is now open 3 days a week and runs at full capacity most days. AH acknowledged the ongoing work of HBS staff in supervising researchers and checking outputs.

There are now 25 projects live on SeRP and as such HBS has seen a recent increase in SeRP output requests by researchers. AH noted that there are a number of researchers still accessing the Safe Haven for sensitive data that could not be migrated to SeRP, such as mortality data.

AH observed that the number of output requests is much higher than previous years which he attributed to the complexity of projects. He also noted that researchers are making use of their limited time in the Safe Haven and are requesting more outputs to allow them to continue their work from home.

Non-Research Activity Report: AH noted that there have been numerous queries for new projects but few have transpired into actual applications.

AH highlighted projects 61 and 62 as success stories of the HBS. MQ spoke favourably of the significance of this work and mentioned that he is keen to promote this methodology. NA agreed and suggested that an article from a Clinician in the PHA R&D bulletins may help to publicise and increase use of the methodology amongst colleagues.

8. NILS and GPIP Updates – AH Verbal update

AH updated the HBGB on good progress on the NILS Secondary Care Pilot and that Data Access Agreements have been put in place with the HSC Trusts for access to NIMATS data for linkage to the Northern Ireland Longitudinal Study (NILS). This is a significant achievement however the process is very time consuming as requires individual agreements from multiple organisations. We will provide feedback to the HBGB on any reporting that NISRA carry out on the success of the pilot.

AH informed the HBGB that work on GPIP is ongoing, having recently underwent a test linkage process to attempt to extract data in a safe way and allow for linkage to HBS datasets. AH noted that this is a complex process in which no one staff member has access to all of the data at any one time to avoid disclosure issues. This initial process was trialled with dementia data and we suspect there were some issues with the linkage due to the match rates found. AH advised that this process is currently being repeated to try and address these issues.

MQ commented that GPIIP would be very beneficial for researchers but acknowledged the complexity of the data. NA agreed.

MQ excused himself from the meeting and appointed AH as Chair for the remainder of the meeting.

9. Review of the HBGB Action Log - All

Actions were reviewed and updated.

10. Any Other Business

SMo suggested that DaC-VaP could form the basis of a business case to justify further HBS funding.

AH confirmed that HDR UK funding is secured until September 2022. AH noted that a paper about cost recovery and justification for the HBS was shared with MB who is keen to progress with the Department.

NA agreed and commented that the HBS should capitalise on its contributions to COVID-19 research and informing healthcare. NA cited a paper by Dr Ruth Hussy which reviewed PHA functions and gave recommendations which would support the need for PHA to be using data. NA suggested a similar approach would be beneficial for HBS.

Action: NA to find out if aforementioned paper is shareable with the HBGB.

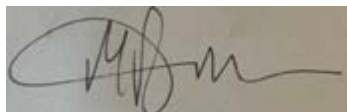
KB shared the proposed dates for HBGB meetings in 2022.

IK suggested that MQ should include these proposed dates in his letter to the absent Trust representatives. She added that a representative from the SHSCT had usually attended the HBGB meetings, and hoped this would be reflected in any letters to the Trust CEO.

Action: MQ to send proposed dates for 2022 in letter to Trust representatives.

Signed by Dr Michael Quinn (Chair of the HBGB)

Signature:



Date: 08/09/2023