HSC Business Services Organisation

Minute of the 36th Honest Broker Governance Board Meeting (HBGB)

Date of meeting: Tuesday 12th September 2023 (2.30pm to 4pm) by videoconference.

Present:

Voting members: Dr Aaron Peace (AP) (Western HSC Trust and Chair of HBGB); Siobhán Morgan (SM) (DoH); Dr Hilary Russell (HR) (Lay Member); Alison Murphy (AM) (BHSCT); Rachelle Moore (RM) (SHSCT); Dr Patrick Donelley (PD) (SEHSCT); Dr Nicola Armstrong (NA) (PHA)

Non- Voting members: From BSO: Alan Harbinson (AH); Martin Mayock (MM); Stephen Gibbons (SG). From DoH: Charlene McQuillan (CM), PHA Approvals: Laura Moore (LM)

In attendance: Karen Beattie (KB) (ORECNI)

1. Apologies were noted from the following:

Voting Members: Neil Martin (NM) (NHSCT); Dr Dave Watkins (DW) (NHSCT), Dr Peter Sharp (PS)

Non-Voting Members:

Welcome

AP chaired the meeting and welcomed attendees.

2. Minutes of the last meeting

Minutes accepted as a true account.

3. Matters arising

AH confirmed funding is in place for the SERP platform for the next 3 years. Funding for core staff runs out at the end of this financial year.

AP provided an update on issues on secondary use legislation which are likely to lead to delays in implementation.

4. HBGB Membership

- **Update on Recruitment of Chair, Vice Chair and suggested Alternate Vice Chair**

KB confirmed that there had been no interest within the current group for the possession of Vice chair and advised that appointing a chair from outside was being looked into.

- **Deputies for voting members**

KB highlighted that there is no deputy for Hilary, as there is no other lay member due to the other lay member having left the PCC.

A number of suggestions were raised by members of the board for possible ways to recruit additional lay members:

AP raised the possibility of approaching members of the Northern Ireland Public Data Panel (when established). He also suggested asking current investigators for a point of contact within their support groups/PPI groups listed on research applications.

NA raised the possibility of approaching the HC R&D Divisions.

HR raised the possibility of approaching patient groups like Macmillan, Charities or Hospital chaplains and suggested drawing up a template with what is expected.

5. Future direction of HBGB and alignment with NITRE (NI Trusted Research Environment)

AH opened discussion on the terms of reference for the new oversight committee

AH highlighted that first the issue is around the scope of this new committee. There will be a new HSC data board, which has already been established and NITRE Strategic Board will report to that. In the future there will be a replacement for

the Privacy Advisory Committee which will have a bigger role when the secondary use legislation comes in. There is a possibility the new Approvals and Oversight Committee may have a role to play in approving and implementing requests for data that have been approved by the secondary use legislation, the processes around this will need to be worked out in detail closer to the time.
In England there are two arms to the process for NHS Digital/NHS England. The Confidentiality Advisory Group (CAG) considers the applications where there is a request to set aside the common law duty of confidentiality, and they have the Data Access Request Service (DARS) which considers the detail of the data request and oversees extraction and delivery of the data.

AH highlighted that another issue for discussion is the approval of projects involving data from the General Practice Intelligence platform. Currently there's a dual stream application process where, if a researcher wants access, they have to apply both to the GP editorial board and also to the Honest Broker service. There are preliminary talks on streamlining this, which could entail GP representation on the new Approvals and Oversight Committee.

AH Noted that the terms of reference for the committee would need to list all of the different types of approvals and the different routes and then what gives the cover for those approvals (e.g. the Memorandum of Understanding for the HBS). Essentially the committee would be becoming a regional application service for a range of secondary data uses.

AP noted that There should be many different paths to get into the honest broker service. There are a lot of studies with cohorts who have provided consent to access their medical records. What we need is a modification that allows that access to the honest broker service, which more efficient way to access the data. The cohorts lie underneath the UK research governance framework. There will be other information they will not have access because of the lack of a legislative framework to support it. But hopefully at some stage we will have a secondary data usage legislation that protects us and doing that.

AP noted it is really important to work this out in order to try and make this a sustainable service. The access to the service should widened and the new approvals and committee will adjudicate on that access. The focus of the committee should focus on the right to access and should not be adjudicating on the scientific integrity of the studies.

NA confirmed her support for expanding the scope HBS to include consented studies and amending the MOU in order to support this.

CM advised a notification need to be sent to the IG leads across the organizations to make sure that you have their buy in before an amended MOU is sent to the CEOs.

AP advised that this should only need an additional line in the MOU to say that consented studies fall under the research governance framework.

LM Highlighted the possible increase in volume and asked how this would fit into the current approvals process.

AP advised it should only be one additional item to confirm HBS access.

NP highlighted the importance of speaking to the research community about this change to ensure that they put the costings into any grant application.

AP highlighted the immediate need for a conversation around cost recover for this service and the need for transparency that the access to this data is going to cost money and it's paying for the resource intensity and not for the access to data.

MM asked if there was role for the service in checking the correct type of consent was in place for the study.

LM advised she would share information on how this dealt with by NHS Digital.

AP advised that the consent needs to be checked but is keen to avoid any duplication of work.

AH highlighted additional issues to be addressed within the new terms of reference. The membership of the new group needs to be addressed. As part of the proposal the working group would be scrapped and you would have new approvals and oversight committee so part of it would deal with operational updates and progress, the other part being approvals. The proposal is to combine the representation that we have currently within the working group and splitting it into voting members who give their approvals and then advisory members who, like honest broker service team, who would actually bringing the proposals to the committee but need to be involved for the secretariat and advice.

AH advised this restructuring could be an opportunity to strengthen the lay membership or representation from the universities.

AH advised that the new roles and responsibilities again are a combination of the two current groups. Oversight that the Governance Board currently does and then the operational aspects that the working group are currently responsible for.

AH agreed to circulate discussion document to members to add their comments

Actions:

- **All to provide comments on document proposal by correspondence**

8. **HBS Research and non-research summary reports**

Research Activity Report:

AH advised there has been five applications approved in this financial year and three that are due to be reviewed at the next panel. Assuming they were approved, in year total would be eight would match the total approved last year. which is great and we already have another three applications that are in the final draft and a further 8 in early discussions.

AH highlighted this was a good level of growth considering there has been no outreach work done to promote the service since the onset of COVID. It is envisaged that this should start again in the near future.

AH provided a quick overview of the three projects to be reviewed, these are investigating, the effect of restrictive licencing laws in Northern Ireland; the health benefits of the Connswater Community Greenway and the second Mum-predict study.

AH advised there were currently 39 live projects on SERP with 50 active users

AP requested information on the pathway and process applications go through before they come before the approvals panel.

NA advised she is currently engaged in a piece of work around grading the complexity of projects in order to help plan for future work.

Non-research report:

AH advised the Department of Health Run, an annual exercise using the enhanced prescribing data and that's just been updated this year.

AH advised there is a major piece of work. Involving the strategic plan and performance group and the department, as well as the five trusts. This is related to the patient level costing project. This is looking at basically attributing a cost to all interactions with the HSE and they're performing itemized analysis of this.
All 5 trusts have been working on their costs for the 22/23 financial year for submission to SPPG accountants, they want the honest broker service manage the pseudonymization of the data. A pilot with the Northern Trust has been completed.

An overarching MOU involving like the five trusts, SPPG and BSO has been put in place in order to facilitate it. This will involve significant resources to complete and will involve a few weeks work each year.

AH gave an overview of a potential project looking at metrics and outcomes for patients undergoing laparotomy surgery.

9. Review of Action log & Risk Register

Action Log

AP advised the first item that's open is in relation to the UM option of placement students. After discussion it was decided to remove this item due to cost and ongoing changes in the service.

AP advised the next item is in relation to the terms of reference. This is an ongoing item and was discussed earlier in the meeting.

AP advised the next item is in relation to the HDR online portal and using it the approval process. It was decided this should be looked again after the new approvals process has been set up.

AP advised the next item is relates to NICOLA and HARP studies.

AH provided an update on the and advised of upcoming meetings with project teams.

Risk Register

AH advised the lack of current funding for the service had been designated as a high risk and should remain so. Discussions around funding for 24/25 year have started.

AH advised there is a standard risk on the register relating to a data breach from the service. There are process in place to mitigate this risk and there no updates in relation to this.

AH advised the risk level relating to the ongoing support for SERP can be lowered as funding is now in place for this.

AH advised there will be a new risk added in relation to the new encompass system and the impact on the HBS access to data on this new system.

10. Any Other Business

NA advised the group that there is a funding call from HDR UK for projects supporting greater transparency in the way that we access data. This will have a short turnaround time

NA advised the group about a conference to be held on the 21st of November relating to availability of data and the impact of COVID and other unexpected societal impacts.

Agreed by HBGB on 10/05/2024