HSC Business Services Organisation
Honest Broker Service

Minute of the 37th Honest Broker Governance Board Meeting (HBGB)

Date of Meeting: Friday 10th May 2024, 9:30 – 11:30

Venue: Remote meeting via MS Teams

Voting Members		Non-Voting Members	
Present:			
Dr Aaron Peace - *AP*	Chair of HBGB, WHSCT	Martin Mayock - *MM*	BSO
		Alan Harbinson – *AH*	BSO
Dr Hilary Russell - *HR*	Lay Member	Stephen Gibbons – *SG*	BSO
Dr Nicola Armstrong - *NA*	Deputy Vice Chair of HBGB, PHA	Alison Afrifa – *AA*	BSO
		Rachel Coey – *RCo*	BSO
Dr Patrick Donnelley - *PD*	SEHSCT	Scott Mathieson – *SM*	BSO
Rachelle Moore – *RM*	SHSCT	Rory Cunningham - *RC*	BSO
		Laura Moore - *LM*	PHA
		Karen Beattie - *KB*	ORECNI
Apologies were noted from the following:			
Neil Martin - *NM*	NHSCT	Charlene McQuillan - *CMcQ*	DoH
Dr Dave Watkins - *DW*	NHSCT		
Dr Peter Sharpe - *PS*	SHSCT		

1. Welcome

AP chaired the meeting and welcomed attendees

2. Minutes of Last Meeting

Minutes accepted as a true account of last meeting an all actions closed off.

3. Matters Arising

AP informed members of the passing of Austin Tanney from the DoH DI, and passed on sincere condolences from all in the group to his family.

AP made members aware of a current UKRI grant for £625k. Short window to apply, requires joint approach between HSC, QUB & UU. This is currently under consideration, but requires a project lead to take it forward.

AH provided an update on the HDR UK Transparency Award – HBS received a short-term funding grant of £13k in 23/24 financial year to improve transparency of public facing materials about our data use, to bring us inline with the HDR UK Transparency standards. Have been working on a website refresh (going live soon, date TBC) with explanatory videos and promotional brochure to accompany it. Will be circulated to the committee when launched.

AH provided an update on HBS Annual Report –have been working on new HTML version which makes it more accessible & user friendly. Work still underway, but will share for feedback via correspondence within next fortnight.

AH confirmed business case was submitted to PHA R&D dept. for bridge funding for 2024-25 & 2025-26, providing much more stability. More business cases aligning at end of 2025-26, so need to keep on top of developments with

the DI and the UKRI grant previously mentioned as the next steps for making HBS funding more stable. Cost Recovery Model is next priority now the new committee is established, and once TORs review complete. **AP** agreed this needs to be prioritised so HBS can be included in the R&D strategy for the region, and requested a 1st draft be completed and discussed.

ACTION: AH to resume work on HBS Cost Recovery Model & bring to committee for review.

4. HSC Data Access Committee Terms of Reference

AP Thanked all members for comments on the ToR Review. Noted that it may be difficult to get a single IG representative on the new DAC, may be better to invite one Trust (+ Deputy) to take up tenure and represent all Trusts for a given time period. Just need to incorporate feedback from others into the final document.
AH noted that whilst a decision is still to be made on potentially renaming HBS, the group could ratify the final name of this oversight committee as the "*HSC Data Access Committee (HSC DAC)".* **NA** proposed the rename, **HR** seconded. Committee now referred to as HSC DAC.
AH Discussed issue around lay membership; currently no representative from the PCC so HR is only Lay Member. Would like to approach PIER / other groups to recruit 2 other Lay members.

- **AP** suggested speaking to NI PDP to ensure a unified approach, and aren't approaching same people as they have only completed their pilot phase and have not yet recruited their public panel.
- **NA** raised issue of ensuring we have adequate support processes in place for new recruits - HR has a wealth of experience from working in research, but this will not always be the case. Suggested a portfolio of paperwork, support meetings (even before actual meetings for extra reassurance) & training. HSC R&D do run these courses periodically.
- **HR** seconded this, and stressed the importance to the public in knowing that multiple lay people are involved in the process of allowing access to their data, and that extra support may keep lay members in post longer.
- **AP** & **NA** also noted that NIHR had been critical of some NI bids due to weak public contribution.
- Possible contacts to assist in providing support materials: Melanie Morris / Ruth Boyd in the NI Cancer Trials Network, and Debbie Keatney, (NI representative on numerous NIHR England patient groups – **AH** noted she was on steering group for HBS R2C Diagnosis study).
- **AP** also raised the point that all on the committee should have completed Safe Researcher Training, so could be included along with other NHS NIHR materials in a package of support materials which will help us meet HDR Transparency standards.

ACTION – Develop portfolio of training & support materials for lay members of the HBS DAC for September Meeting. Consider groups to approach & plan for how to support and train new lay members (min. 2 people). May require T&F Group to advise.

ACTION – Produce Glossary of terms with every agenda to support all members

AH had proposed a new meeting Framework in the scrutiny paper to balance approvals & oversight functions in each quarterly meeting, all happy to take this forward.

AH noted that the ToR would also include details of the scrutiny process, associated flow charts etc (if approved today) to aid transparency in approvals process for researchers.

AH raised meeting Quoracy: Current model requires Chair / other officer from chairing team, 1 HSC Trust rep and 1 lay member (same as current Project Review panels). Propose same for a new fast-track approval meeting. FB from NITRE had hoped we could include a GP Editorial Board representative to streamline the process for GPIP applications. Would remove the need for dual applications at present, FB has been in discussions with GP Ed. Board so hope we could involve them in future, but not essential at present. **AP** agreed their involvement in the group as a whole would be helpful, but not always essential for subgroup. **HR** agreed and noted it would remove possibility of HBS approving a project and GP Ed Board denying it. **AP** noted that a shared learning group between HBS & GPIP may allow us to assimilate our processes to help researchers when applying for data, and aid in transparency. Similar to how HBS and NISRA / NILS work together.

AH – Appeals process for rejected applications has always been in ToRs, but never utilised. **AP** recommended we remove this and operate a "*De Novo Submission"* system instead – The research team take feedback from the panel, work with HBAS and apply again. **NA** agreed.

ACTION: Remove Appeals Process & explain *"De Novo Submission"*

AH – **NA** had previously raised issue around project modifications. Every NILS modification goes to their RAG. Currently HBAS approve operational modifications (extensions, new team members, additional variables from already approved datasets if within scope of research questions) HBAS refer back to committee for major modifications (e.g. new research aims). **LM** had queried if there was a tiered approach, **AH & AA** discussed and group consensus was that we are content to continue with current approach, with HBAS approving / escalating modifications to HBGB at their discretion.

ACTION: HBAS to continue approving minor modifications, and escalate major requests to Review Panel; who originally approved project. Record as Minor or Major to keep a record, and summarise in Annual Report.

ACTION: AH to accept the tracked changes in the ToR document, and include a note to try and recruit a GP Member. Will send final version for sign off.

5. Scrutiny Process for new Committee

NA offered HBS opportunity to advertise upcoming HBS DAC Meetings in the PHA newsletter, and notify readers of any changes to our processes – Michael Cunningham manages this.

ACTION: AA & AH to discuss with Michael.

AH & AA discussed the proposed project scrutiny process for the new DAC as described in the paper circulated on 28th March 2024. As part of the process, applications would be split into Tiers:

- *Tier 1 Applications – Low risk, lighter touch scrutiny via official approval / correspondence.* HBAS complete initial assessment and send to all HBS DAC members, with request to review application within 2 weeks. If no dissenting response / other feedback received within timeframe, the project will be approved. If committee members request, it can be elevated to Tier 2.
- *Tier 2 Applications – Sub-panel of Full Committee (Fast Track)* – For applications where HBAS Assessment raised issues requiring discussion, but not serious enough to require full committee discussion at the next quarterly meeting. Sub panel to follow same quoracy rules as at present.

- *Tier 3 Applications – Full DAC consideration at quarterly meeting.* These would be the more complex applications, e.g. data linkage projects, particularly sensitive topics, high disclosure risks or novel research methods.

AA demonstrated the HBAS Assessment tool with a current draft application. Utilising a RAG approach (Red, Amber, Green) to score projects based on current HBGB Project Review Template, and basic checks HBAS carry out prior to submitting an application for review.

- A project which is Green in all assessment areas is suitable for Tier 1 Approval, and will be reviewed by correspondence.
- Any criteria flagged as Amber will have further detail explaining the rationale behind the HBAS decision to present for approval, and HBAS will ask for Review by Correspondence (T1) or request it is moved to a higher Tier.
- Any criteria flagged as Red will either prevent the application from progressing any further, or will indicate that it is a Tier 3 application for discussion at quarterly HBS DAC.

NA Raised query regarding recording of timelines within HBAS & effectively "stopping the clock". **AA** confirmed HBAS record some metrics around this but not to this extent. **LM** confirmed the Trusts also stopped doing this as so labour intensive. **KB** discussed OREC's use of the HARP system which automates this, but still requires a fair amount of manual input. **AP** suggested splitting the process into 3 time points: Stage 1 is initial queries, draft application in progress. Once checklist is complete, can commence Stage 2, which is when application process properly begins, then Stage 3 is data provision. These metrics would be helpful for committee to see.

ACTION: HBAS to implement time recording in the 3 stages & report to DAC.

AH requested more discussion around PPI as the extent to which it is required has changed over the years. **NA** explained that PPIE expectations within research community & public views have changed, so much more consideration must be made to PPIE when accessing public data than in the past. **HR** advised that we need to allow exceptions to the rule when not logistically or practicably possible (e.g. rarer health conditions will not likely have the same patient support groups as more common illnesses, so harder for researchers to seek their involvement). But every project needs to have made attempts at this, regardless of their funding or subject nature. (Support documents sent during discussions by **NA**, **KB** & **LM** for HBS to consider)

6. Discussion on next steps

AH informed the DAC that Dr Mark Cross (BHSCT R&D) had proposed / requested a letter from BSO to Trust Exec. Leadership teams r.e. new TORs & DAC membership. Felt that DAC membership should be extended to include IG representation for project scrutiny. **PD** agreed that there may be some merit in this.

HBS MOU update underway (needed DAC & new processes established first.) Old MOU referenced Data warehouse, now have EPIC with own warehousing & NIHAP, so new MOU to widen scope of HBS as security environment of HSC. Also, potential to incorporate cohort discovery and handling identifiable consented data (requires further discussion). DI developing own MOU with Trusts, FB co-ordinating, but will require T&F group.

7. HBS Research & Non-Research Summary Reports

AH summarised the reports on Research & Non-Research activity in HBS in 2023/24, which is included in the annual report (still in draft). Very successful year, 12 new research projects approved. As in previous years, very few non-research projects. **NA** raised this lack of activity as a concern, **AP** commented that as HBS receive funding from research groups then the HSC service evaluation element may require its own funding source. HSC should be utilising the expertise to improve services. **PD** explained that it may be a preconception that HBS is an academic initiative, and a University collaboration is required to deliver research. May be useful for HBS to address this so technical staff members know that the data is available to them when they need it. The barriers to accessing it (concerns about potential bureaucracy, speed of data provision etc.) may also be a deterrent, so key will be to try and bring a rapid turnaround for multi-professional clinical research teams to access data through HBS. Also noted that there is currently a disconnect between Service Improvement, Quality Improvement, Audit & Governance within the Trusts. Need joined up thinking to help promote HBS. **AP** felt that funding is required at DoH level to support HBS to do more work for the HSC. Something the DI needs to consider and ensure it's a key focus.

8. Review Action Log & Risk Register

AH - Some actions still on hold until we've formalised other processes. One of the risks going forward is the availability of data from EPIC system – has own warehousing, no plan at present for HBS to access this. HBS only offering regional data up to Nov '23 for SE Trust, other trusts will drop out as they go live. Obviously patient care is priority so HBS monitoring this, but will begin to have more impact on service as time goes on. Potential for DI to archive on NIHAP, or HBS staff to get trained to do extracts.

AH - Current funding is still a longstanding risk - bridge funding up to 25/26, but still significant risk that HBS can't deliver non-research related activity. The DI business case will focus on their own priorities e.g. developing NIHAP system. Still need the legacy data to be accessible, including when Trusts start moving over to EPIC, so even as NIHAP start onboarding the data, **AP** noted that we would require funding to carry out data linkage across systems, so it's a Quality Improvement initiative, not research. Discussion point for NITRE, if there is funding for HBS to do service improvement for HSC. (**NA** raised point that HSC R&D fund the EPD Statistician for a similar role already, impacting on their own project funding, so when does the HSC take responsibility for collection and maintenance of own data?) **AP** suggested establishing full picture of non-research activity over last 10 years, to present to HSC and highlight risk it cannot continue without funding.

9. AOB

AH introduced RC as newest member of HBS team.

Agreed by HSC DAC on 13/09/2024.

Glossary

BSO – Business Services Organisation

DI – Data Institute

DoH - Dept. of Health

DWH – HSC Data Warehouse

GPIP – General Practice Integration Platform

HBS – Honest Broker Service

HDR UK – Health Data Research UK

HSC DAC – Health & Social Care Data Access Committee

IG – Information Governance

MOU – Memorandum of Understanding

NIHAP – NI Health Analytics Platform

NIHR – National Institute for Health & Care Research

NI PDP – NI Public Data Panel

PCC – Patient Client Council

PHA R&D - Public Health Agency Research & Development

PIER NI – Public Involvement Enhancing Research

PPIE - Patient and Public Involvement and Engagement

T&F group – Task & Finish Group

TORs – Terms of Reference

UKRI – UK Research & Innovation