

Minute of the HSC Data Access Committee

Date of Meeting: Friday 13th September 2024, 14:15 – 16:15

Venue: Remote meeting via MS Teams

1. Apologies

Voting Members		Non-Voting Members	
Present:			
Dr Aaron Peace - <i>AP</i>	Chair of HSCDAC, WHST	Martin Mayock - <i>MM</i>	BSO
		Alan Harbinson – <i>AH</i>	BSO
Dr Nicola Armstrong - <i>NA</i>	Deputy Vice Chair of HBGB, PHA	Stephen Gibbons – <i>SG</i>	BSO
Dr Patrick Donnelly - <i>PD</i>	South Eastern Trust	Charlene McQuillan - <i>CM</i>	DoH
		Rachel Coey – <i>RCo</i>	BSO
Dr Peter Sharpe - <i>PS</i>	Southern Trust	Rory Cunningham - <i>RCu</i>	BSO
Mark Cross - <i>MC</i>	Belfast Trust	Laura Moore - <i>LM</i>	PHA
Neil Martin – <i>NM</i>	Northern Trust	Karen Beattie - <i>KB</i>	ORECNI
Cormac O’Brien	BSO		
Apologies were noted from the following:			
Dr Dave Watkins - <i>DW</i>	Northern Trust		
Dr Hilary Russell - <i>HR</i>	Lay Member		

AP chaired the meeting and welcomed attendees.

2. Minutes of Last Meeting for Approval

Minutes accepted as a true account of last meeting.

3. Matters Arising

AP informed members of the ongoing work, under the NITRE programme, to improve the data ecosystem within NI, involving linkage to go between new prospective data from Encompass, the historical DWH, GPIP and FPS data to accomplish projects presented in the R&D strategy workshop.

AH informed members that the new HBS website is in place and live, with tailored sections for researchers, internal users and information for the general public. There will be a news and development section as well, where new policy documents will be posted. The HBS brochure is live and to be used as a promotional tool, but waiting for new charging policy to be in place before sending the brochure to different universities in England. Feedback on brochure and website has been very positive so far from various researchers and some HDR UK groups. **KB** noted good feedback from a REC member in terms of the layout and easy navigation. **NA** noted the website looked professional and fresh.

NA explained that when ready, the PHA newsletter would be pleased to accept an article from HBS. **AH** explained how the PHA has been reached out to, and are happy to re-engage at any point to assist, **AP** and **NA** encouraged HBS to reach out as soon as possible.

ACTION: AH to reach out to PHA R&D public engagement team for feedback on website

4. **ACTION: AH to write an article for the newsletter that goes out to all researchers** [HBS Charging Policy](#)

AP explained the rationale for this new policy is for HBS to increase revenue from charging, as HBS is not a recurrently funded service. The review and cost increase would put HBS more in line with charges for similar environments across the UK. **AH** explained the current cost recovery model has been in place since 2014 and only covers data extraction, not additional work, such as liaising with researchers during project applications, administrative support, answering queries from researchers during the life of the project and output checking. Hence the need to increase the portion of funding coming from cost recovery, while bearing in mind we want to support research and don't want cost to be a barrier. PHA R&D currently providing bridge funding until 2026 and HBS will be relying on a level of funding from the Data Institute business case from 2026 onwards however it is expected that a proportion of funding towards running the service will always need to be met by cost recovery.

AH talked through the attached paper, outlining the new costs and how it is proposed that projects will be classified into different costing baskets based on the complexity, how many approvals are needed and number of datasets etc. There are additional new charges for project set up and administration as well as ongoing support and output checking. The new proposals are based around elements of the Scottish and Welsh charging policies and HBS are keeping a lookout for development of the NHS England policies.

NA asked how this transition will be managed in terms dissemination so researchers are aware of the new policy before they submit their applications. **AH** asked if this should be published now for 2025/2026 as many researchers may have already applied for grants for projects. **NA** said from the perspective of funders, they would hopefully not be ill-disposed to a researcher saying in light of the new charging policy they require an increase in funding

ACTION: AH and NA to discuss about how to approach announcing new cost policy and how this would work with existing applications, and to provide a timeframe for this.

AH explained that with this new charging policy, HBS would still be a long way off full cost recovery based on the number of projects that came through last year. Substantial discussion around how much additional money should be charged for commercial projects. The group asked to consider increasing the rate against what was proposed in the paper and looking at the HSC Trust R&D policies on this to be in line with what Trusts charge for similar work. **PS** did not think this increase in cost would be a deterrent to commercial sector. **MM** pointed out that part of the criteria for approving a project is that there must be some public benefit, so even commercial projects still have to be of public benefit. **LM** advised care around defining commercial and non-commercial research, to ensure commercial projects are not being passed off as non-commercial and advised on ongoing work across the UK in this area. **NA** suggested seeking support from the industry engagement unit. **AP** mentioned the importance of marketing this well so that there are clear signposting as to what the resource is and what is available..

ACTION: Consider increase commercial rates, follow up meeting to be held with LM – possible liaise with PHA industry engagement team around marketing

There was a group discussion around full cost recovery and advice given at outset about the service not being able to make a profit, AP asked for clarification on this and if had the original advice that was given.

ACTION: Send on original advice on not making profit, and look into changing the policy that no profit can be made.

AH raised if cost could be waived or reduced in exceptional circumstances with agreement from the HSC DAC and the host organisation, and if this should be left in the new document. AP and NA thought this should be left in as it does not commit to costs being waived but gives the option, however costs unlikely to be waived very often. KB noted the importance of communicating effectively around the benefits of research for healthcare provision and that HSC is not selling data but recovering costs. NA suggested engaging with staff from the ESRC funded behaviour science initiative, to look at the wording and the influence it may have on the public. CM suggested being upfront and transparent explained it may be useful to check updated guidance from the ICO to ensure the public facing information is as good as can be.

5. Research Update

AH presented a paper around the process for project applications and the different stages in the application along with metrics that had been collected on how long each stage can take on average. The report highlighted that there is significant room for improvement and some projects have had extreme delays in the past. In particular when involving additional legal agreements. There are potential improvements that can be made in the data provisioning stage also and we would like to significantly decrease turnaround times for providing access to data once all approvals are in place.

AH talked through the MuM Predict 2 study, which is a very large extract of NIMATS data, as an example of a complicated project with significant delays due to the complexity of the project,

There was a discussion around value of the metrics and necessity to be able to “stop the clock” if possible to show when work is paused due to issues outside of HBS control.

AH updated that steps being taken to improve timelines include:

- improving the guidance on applications to make the process clearer,
- the new scrutiny process to help turn around simple projects quicker,
- project management solutions through Microsoft teams to coordinate work better with DWH,
- new MOU to reduce need for additional DAA’s in some cases, and
- working with the DI to see potential of new cloud technology and how this could be useful in HBS pipelines for automating and reducing time to produce datasets once they have been approved.

CM asked what sort of things are causing delays, and **AH** responded that often legal review can be a slow process so often it is the initial review of the data sharing documents if they are required. **AH** and **CM** discussed the importance of the new MOU to speed up the process of project applications, so that it covers all HSC data rather than only data held in the DWH. **CM** suggested a presentation to the IG advisory group to ensure buy in before it goes to SIRO, to help it get signed off by chief executives.

ACTION: Prepare a presentation for the IG Advisory Group around new MOU.

NA suggested quarterly reports of metrics instead of annually, to enable impact of changes to be seen more clearly, as well as periodic meetings with data providers outside of the MOU agreement, to keep organisational memory and relationships of working with us and let them have a flavour of what that working relationship has brought them, and overall improve experience of working with us. Could maybe be done by bringing the research teams to them to present where the research is up to.

MM highlighted that HBS is a very small team compared to other TRE's, which has had a reduction in staff, and so it was inevitable there would be a knock-on effect of slightly longer delays in terms of processing and data extraction times, due to this.

AH explained how generally the metrics used are in line with other TRE's across the UK. As an example HBS is slower than SAIL data bank, who seem to have an automated process enabling them to turn around huge data much quicker than we could. There is a lot of room for efficiencies if can create research ready datasets rather than recreating data from raw sources each time and also in looking at benefits of additional technology such as the new cloud analytics platform being developed by the Data Institute. It may be possible to get the Data Institute to present at the Committee on the development of the platform and they will be electing a representative to sit on the Committee also.

6. Progress Update- Data Access Committee Terms of Reference & HBS Memorandum of Understanding

AH explained most comments on the TORs have been completed, it is recognised more lay membership is needed on the HSC DAC committee, and progress has been made while this is not yet completed. The Committee had asked for training and induction materials to be prepared so that lay members can feel empowered to take full part in the committee and not feel intimidated by the complexity of the HSC terminology as well as the HBS processes. **AA** has done a lot of work on this, and looked at various different online resources, but still needs tidied up into a final package. Volunteers asked for from this committee to do a task and finish group on it to complete this. **AP** and **KB** happy to help with this, and **AP** suggested speaking to PHA R&D public engagement team, **AH** explained how the PIER group may be a potential resource to recruit members of the public, who have no previous engagement as employees of HSC.

ACTION: Task and Finish group to tidy up and package training/induction material for new lay members

The Terms of Reference, has been tidied up with version control and official title now, and nearly all comments have been actioned. One new addition to report is that the HSC Data Institute are hoping the HSC DAC can play a role in oversight of requests for data for internal analytics use, this will likely be more like a data use register to give a holistic overview rather than coming to the committee for approval as they have their own IG process. This is to be documented in a process flow in the annex.

ACTION: Once ready, final comments from the committee on the TORs , before sharing with stakeholders for sign off.

AH explained that there have been a lot of changes to the Memorandum of Understanding since it was last presented to the group and that the document had expanded in size with a lot of annexes explaining key information about the service. to the next steps are to send to BSO Personal Data Guardian for review before bringing it to IGAG group with a presentation about why the changes are important for continued delivery of the service.

ACTION: Presentation to IGAG group about changes we are making to MOU

7. HBS Research & Non-Research Summary Reports

Just for noting.

AH gave an update on how the pilot of the new scrutiny process had went with applications processed over the summer.

8. Review Action Log & Risk Register

AH reviewed the action log with the group, including discussions around possible GP Editorial Board representation on the HSC Data Access Committee.

AH – minor updates to risk register. Current position on funding is we have it for this year and next year, DI progress in the business case and will pick up some level of recurrent funding for the HBS from 2026 onwards. NITRE board meeting due to happen.]. Progress being made on application management system using MS Teams to better track projects and actions. **NA** asked about this and if possible to demonstrate to PHA R&D as they also have requirements for better collaborative tools.

ACTION: **SG** to have meeting with **NA** to discuss useful collaboration tools

9. AOB

Annual report just for noting.

NA – requested assistance with input for a round table looking at activity that's being undertaken within NI on public trust in the use of health and social care data. **CM** suggested the NI public data panel.

Agreed by HSC DAC on 15/11/2024.

Glossary

[BSO](#) – Business Services Organisation

DAA – Data Access Agreement

DI – Data Institute

[DoH](#) - Dept. of Health

DWH – HSC Data Warehouse

FPS – Family Practitioner Service

GPIP – General Practice Integration Platform

[HBS](#) – Honest Broker Service

[HDR UK](#) – Health Data Research UK

HSC DAC – Health & Social Care Data Access Committee

ICO - Information Commissioner's Office

IG – Information Governance

IGAG – Information Governance Advisory Group

MOU – Memorandum of Understanding

NIHAP – NI Health Analytics Platform

[NIHR](#) – National Institute for Health & Care Research

NIMATS – NI Maternity Systems Data

[NI PDP](#) – NI Public Data Panel

NITRE – NI Trusted Research Environment

[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

SIRO – Senior Information Risk Officer

T&F group – Task & Finish Group



Business Services
Organisation

Honest Broker Service

TORs – Terms of Reference

UKRI – UK Research & Innovation