HSC Business Services Organisation
Honest Broker Service

Minute of the HSC Data Access Committee (HSC-DAC)

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

Venue: Remote meeting via MS Teams

Voting Members		Non-Voting Members	
Present:			
Dr Aaron Peace - *AP*	Chair of HSC-DAC, 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 HSC-DAC, PHA	Rachel Coey – *RCo*	BSO
		Rory Cunningham - *RC*	BSO
Dr Peter Sharpe - *PS*	SHSCT		
Dr Mark Cross - MS	BHSCT	Laura Moore - *LM*	PHA
		Charlene Maher - *CM*	DoH
		Karen Beattie - *KB*	ORECNI
Apologies were noted from the following:			
Neil Martin - *NM*	NHSCT	Alison Afrifa – *AA*	BSO
Dr Dave Watkins - *DW*	NHSCT	Rachelle Moore – *RM*	SHSCT
Dr Patrick Donnelley - *PD*	SEHSCT		

1. Welcome

AP chaired the meeting and welcomed attendees. Aideen Maguire (*AM* - Director ADRC-NI) was welcomed as a guest speaker, and opened the meeting with a presentation on the uses of HSC data in ADR projects.

2. Presentation from Dr Aideen Maguire (Director ADRC-NI) - *Self-Harm and Suicide: new evidence from linked administrative data on NI*

AM gave a brief overview of ADR & ADRC-NI, and the breadth of topics their researchers have been working on in recent years. The main focus of today is their work on self-harm & suicide, which has utilised the Self Harm Registry, EPD, Mortality data and other secondary care datasets. They have published 5 papers in the past 2 years, from 3 HBS projects, and hope to have an impact on policy recommendations as a result of their findings. The presentation summarising their main findings is attached here:

ADRCNI_DACpresentation_Value of Self

Recommendations based on their findings were presented to the All-party group on Self Harm & suicide when reviewing the Protect Life 2 strategy. A policy brief is currently being drafted and will be shared with the DAC when completed. AM thanked all involved and invited questions. It prompted a discussion around the difficulties in implementing these recommendations into practice, which the team are just starting to do now, and how clinicians working with patients have witnessed the mental health of the population declining over the years, and there are many factors which are causing this. NA highlighted the NIHR evaluation scheme for public health interventions, and a recently launched manifesto with Prof. Mahendra Patel looking at research equity which will be moving forward in the next year or so which may be of interest, and will discuss with AM outside the meeting. HR queried if any cluster analysis has been completed on multi-sibling families – AM discussed an upcoming project which will be looking at

this in more detail, with ability to identify households. AH offered the HBS website as a space for the research teams to highlight their work, as they do on the ADR website currently. AM left the meeting, with all in agreement that this was an extremely useful and engaging presentation which shows the impact of HBS projects in the real world.

3. Minutes of Last Meeting

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

4. Matters Arising

- Chair Updates
- Noted that all matters arising would be discussed within the action log update.

  Updates

5. Synthetic Data Briefing Paper

AH had circulated a synthetic data paper in advance of the meeting. HBS had explored the idea in 202, but then with availability of SeRP, it became less of a priority. UU have re-opened discussions around its utility in training new researchers, and HBS also feel it would be useful in helping researchers determine which variables should be requested for a project (in conjunction with current metadata). The paper discusses the various options available when creating synthetic data and granting access to it. HBS are attending workshops and discussions with other TRE's. It will be a considerable piece of work with need for governance approval at trust level for HBS to process the data in this way, and various other decisions around which model to follow.

AP & AH discussed the (very low) risk around changing real data into synthetic data, primarily being the accidental creation of a real patient record, but there are ways in which this risk can be reduced with good management. NA highlighted the use of this in training and succession planning for researchers to ensure there is capability to work with real HSC data going forward. MM pointed out that the risk of accidental disclosure does increase with the more lifelike you make the synthetic data (i.e. preserving patterns and links between variables) but by reducing this, it makes the data less useful to the end user. So, it's a delicate balance which the team creating the data will have to manage, but this does all come with a resource overheads. Creating these datasets "to order" would potentially be problematic and needs careful management, but using SeRP / the Safe Haven for the access route does minimise risk.

6. HBS Research & Internals Progress Update

RC provided the research project update and demonstrated the new HTML format of the report. 5 new research projects have been approved YTD (4 of which are using maternity data) with 2 more currently submitted for approval, and 12 in draft stages. RC highlighted an improvement in time between project approval and data provision to approx. 55 days, and the large increase in outputs over the summer months (largely due to a number of conferences the research teams were presenting at). Overall, outputs are decreasing over time as more teams work collaboratively and efficiently on SeRP, rather than requesting outputs for clearance to discuss in person. Still seeing a high amount of modifications requesting additional team members and extra variables, and the time taken to complete these has increased on these, largely due to the need for data being sent to us from external data controllers (e.g. ELC study).

In total, 58 projects have been live on SeRP; 40 are currently active with 64 active users working across them (average 1.6 projects per user)

Internal projects – 1 project approved – DoH inequalities Monitoring report, completed Sept '24. Work has started on the Patient Level Costing Project for this year, which is being completed on NIHAP (and HBS have received training on this). Have also been reviewing the National emergency laparotomy project, but this will take place in 25/26. NA commended RC's work on improving the format of the report. Questioned if possible to look historically at time taken for data to be provided after approval, particularly for projects requiring DAAs, and see how this has changed over time. RC explained a lot of this info was never recorded and only exists in old emails, some of which may be with old staff members and not in shared mailbox / folders. But we will try. Led into the discussion around time stamping software and its usefulness. ORECNI use HARP, but don't think any of the Trusts use anything.

7. Review of Action log & Risk Register

In Progress:

- Website updates: AH spoke with Janet Diffin in PHA, she has identified 2/3 people in patient rep group who may be able to provide feedback on site. May require small payment, so will provide details and commission when able to.
- PHA newsletter article still to be written
- Charging Policy: AH & KM have discussed this in more detail following the last meeting, especially the commercial aspect. Lots of work ongoing in her team at present. AH now reconsidering the proposed HBS model and potentially incorporating the staff-based rate into the model as Trusts do. The UK wide framework currently in development will have impact on this; expected to be released December / Jan, so will review HBS charging policy and take this into consideration. Hope to still have new policy in place for new financial year. Will work with NA & PHA to communicate changes to researchers, and can get this built into their research grants.
- Had discussed the "not for profit" element, it can be problematic in public sector if creating additional income above what is budgeted for staff, then surpluses can have impact on next year's budget for the directorate, and no guarantee on the income the following year to meet that. But if can have recurrent funding from the DoH then any money brought in from cost recovery model can be re-invested into R&D or the HBS itself. But Update will be provided at next meeting.
- HBS MOU – CM advised to present new MOU to IG Advisory Group. AH will prep an internal package for the BSO Personal Data Guardian and the new Director (Ben Doran) for review next week, so get legal feedback before sending to IGAG. CM offered AH support on this.
- HBS ToR – Will include the DHCNI application as an appendix, then will be circulated for sign off. Need to reach out to numerous groups to ensure representation on the DAC (e.g. SPPG not represented currently, NIAS also keen to join and share their data as part of HBS, and PCC). PS strongly endorsed the NIAS joining the DAC, they've been very active in last 5 yrs and lots of research approvals coming through the SHSCT for them.
- Lay member information pack – NA recommended AH speak with Janet D & Alan McMichael in PHA regarding training materials. AH welcomed input from other members on this. NA also offered to get the details of the new PCC member who attended the recent Strategic Advisory Group meeting (may also have attended the National steering group too) so they may be interested in joining the DAC. HR offers support with this aspect.
- Risk Register – 2 new risks added.
- Propose to close the risk around application management system as new MS Teams is working well.
- Encompass fundamentally changing data warehousing for all HSC data. The MOU update will future proof the HBS to try and link the data in the future, but we do not currently have any flows of data. At present, researchers are ok as typically getting 5-10yrs of data, but soon will become untenable. Particularly if a focus

is on interventions for new programs, or internal projects. Working with DHCNI, and know that long term plan is for data feeds from Encompass to go into NIHAP, which HBS could then access. Pilot project is to bring in Cancer data from EPIC. But potentially more than a year before full data downloads will be available on NIHAP. HBS staff will need training on NIHAP, EPIC & ENCOMPASS to fully understand the system & the data feeds, and how they link to legacy data. CM has been working with Joy Beaumont (NIHAP) on a Controller Processor MOU with the Trusts so appropriate governance is in place for Cancer data. Once this is in place, future datasets will be added to the MOU as a new Annex. Also working with Declan Bradley in PHA to establish processes around their data access and purposes for this as both a processor and controller. This is subject to approval by NITRE, and will set process for how we do this with other organisations. Briefing paper will go to NITRE for approval, then to Trust IG leads in same way Cancer data was. CM will keep DAC updated on progress as will have a big impact on HBS and need to ensure alignment between HSB & Data Institute. PS expressed concerns as some Trusts being concerned as only just moving to EPIC, some Trusts can't input to Waiting time metrics due to the move, so concerned this will be a low priority compared to the need for real time data feeds for those metrics. CM advised that the RISOH Cancer data should be moving to NIHAP quite quickly, with other cancer related datasets following shortly after. Hope that with the pipeline between EPIC and NIHAP already in place, and using these early pilot projects to set a precedent for the governance elements, then we can have a more streamlined process for future access.

- SG provided further info about the DWH in future. Some systems are not moving to EPIC – CHS & Social Care data will continue in the DWH until 2026, 25% of BadgerNet data is moving to EPIC, but will be input into BadgerNet and remain in the DWH. Current workloads within the reporting team for EPIC and cogito are extremely high, so data requests will not be high priority. They are currently training other data teams so hope this will improve as time goes on. NA expressed concerns about this for the research community as they are writing grants etc. and we need to inform them of the full picture to ensure they can deliver. AH advised that HBS have communicated to researchers that the last regional snapshot available is November 2023. AP & NA agree his needs to be wider communicated through all channels, not just to researchers (including NIPDP as patients need to know this too). Obviously direct patient care is priority but still a lot of work required to ensure future access is also prioritised. AP suggested this information is sent to Ian Young & Janice Bailie, so it can then be communicated to all trusts as well. PS & SG discussed role of DWH in future. It will be an archive for legacy datasets, but still supporting those datasets with no plans to move to EPIC as reporting still required for those. NIHAP will essential become the next version of the DWH, but lots of unknowns still at present with regards to where research will be in their priorities.
- Data Controllership – Datasets previously under FPS in BSO now under controllership of SPPG in DoH (EPD, NHAIS, Dental). Reemphasizes importance of having SPPG member on DAC. But also having impact on data sharing with NILS as require individual DAAs per project, so currently updating SPPG on data flows for these and other large sharing exercises such as support for NICR. But this is having long delays and impacting on work, and have a number of new projects which will need to go through this process. Have provided briefing papers on the issues faced for SPPG, not progressed, but think will need someone in the Research Approvals Group in future (part of briefing paper suggested SPPG could utilise the DAC to approve linkages to NILS data to streamline the process) But will keep group updated on any progress.

8. AOB

NA – Update on UK round table organised by ABPI & AMS looking at public trust in data. Decision to co-ordinate this UK-Wide. Understanding Patient Data are taking the lead, and proposing it becomes a Health Data Public Engagement Forum. NA will update on any new developments within this. AP questioned where NIPDP sits within this, NA had presented on this with an update on NI PDP provided by Elizabeth Nelson.

They had a successful induction day in Oct, next meeting is 25th Jan 2025. NA will also circulate information following the All-Party Group on Policy and Data on 28th Nov.

PS – Requested that the inclusion of research outcomes be included in future agendas (they have also introduced this in Trust RG meetings recently). Would encourage more sharing of published papers, outcomes, changes in policy practice etc. as are all of interest. AP agreed, could open each meeting with similar presentation to AM's, and also provide annual summary of the outputs. Presentations could be shared within the Trusts also to see the relevance of the work carried out. Meeting closed with all in agreement that this would be a welcome addition to the agendas.

Agreed by HSC DAC on 07/03/2025.

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

NICR - NI Cancer Registry

NIHAP – NI Health Analytics Platform

NILS – NI Longitudinal Study

NIRSH – NI Registry of Self Harm

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

SeRP – Secure E-Research Platform (used by hbs researchers to access data)

T&F group – Task & Finish Group

TORs – Terms of Reference

TRE – Trusted Research Environment

UKRI – UK Research & Innovation