

**Public Health Scotland
NHS Scotland Public Benefit and Privacy Panel for
Health and Social Care**



Minutes of the Committee meeting held on 15 June 2021 by MS Teams

Present: Dr Lorna Ramsay (Chair) (LR)
Professor Helen Colhoun (HC)
Dr George Fernie (GF)
Carole Morris (CM)
Kenneth McLean (KMCL)
Dr Tara Shivaji (TS)
Alan Ferrier (Al F)
Professor Abbe Brown (AB)
Penni Rocks (PR)
Martin Bell (MB)
Colin McCowan (CMcC)
John Woods (JW)
Alison McCallum (AMcC)
Martin Walsh (MW)

Apologies: Dr Angus Ferguson (AF)

In Attendance: Dr Marian Aldhous (MA)
Phil Dalglish (PD)
Susan Kerr (Secretariat)

1. Chair's Welcome

The chair welcomed all to the meeting, introductions took place.

- Martin Walsh was welcomed as new Lay member to the committee.

The meeting is quorate and there are no conflicts of interest.

2. Minutes and Actions from previous HSC-PBPP Committee Meetings

2.1. Minutes of meeting held on 13th April 2021

These were approved as a true record.

2.2. HSC-PBPP Committee Action Log

All actions are complete.

Two of the actions were further discussed:

2.2.1. Action 13-04-21/02: Backlog of applications

Currently there is no backlog of applications at HSC-PBPP, but there is at eDRIS but they are in a process of recruitment to help with this work. Concern was raised for the "PBPP only"

applications, those which do require any input from eDRIS apart from help with the application process, as these have no support. This has been raised and needs to be addressed at PHS level. Most of these applications will not have been reviewed by anyone from eDRIS before submission.

There is good guidance available to researchers with hints and tips provided. Previously, dedicated Information Governance (IG) support was also helpful for the operational element in applying to HSC-PBPP.

Researchers do not distinguish between HSC-PBPP and eDRIS. They just see that their application is being held up. Need to prioritise on an electronic form.

Part of the problem is capacity and with multiple institutions putting in applications.

Perhaps we should encourage institutions to build capacity outwith organisations to help other applicants?

ACTION 15-06-21 / 01: CM to discuss with AM and CMcC

ACTION 15-06-21 / 02: MA to provide update on online form at next meeting

2.2.2. Action 13-04-21 / 04: Safe haven accreditation

NSH was accredited in 2016 and also under the Digital Economy Act (DEA) Nov 2020. There will be a light-touch review in Nov 2021 based on the ISO 27001 approach.

3. Matters Arising

3.1. Committee personnel update.

- Martin Walsh is a new lay representative. Still need one further lay representative and have tried different routes including Young Scot. We will continue the process.
- NHS Education for Scotland (NES) Digital representative is required as the previous one has resigned. The NES CG is a possibility.

3.2. COVID Review

- COVID Priority level 2 applications should only be required for time critical applications with an impact on policy decisions and treatment plans.
- COVID Vaccination variables are now in the COVID Database, to be approved by HSC-PBPP and analysed in NSH. Anything more will require further conversations with PHS / NES.

3.3. Timelines for HSC-PBPP approval 2020/21

A paper to review the time-lines to approval for those applications that took a total of more than 50 days for approval was circulated.

Delays to application approvals, particularly for non-COVID19 applications, were a direct effect of:

- the prioritisation of COVID19 applications and
- the increased workload due to the response to the pandemic across the NHS boards without additional resources, and the IG leads who sit on Tier 1 panels,.

4. Updates for committee

4.1. Panel Manager Report

This was circulated for information. No comments were raised.

4.2. Policy Decisions & Case Law Principles

This had been updated from the previous meeting and was circulated for information. No comments were raised.

4.3. Scottish Government update (including COVID DIN, Safe Haven accreditation, NESTA)

PR gave an update on the Digital Health and Care Strategy (DH&CS)

- Digital Health and Care Policy; Cara Archibald gave update at the last meeting for regional and national safe havens and a view to widening that out.
- Digital health looks after health and care across the organisations and sets out policy. A refresh strategy will be agreed by the end of the summer.

Currently the DH&C Strategy is mostly COVID-related focused and involves data, information governance (IG) and assurance of data. DH&C strategy highlighted concerns about consistency and how decisions are made across to ensure data flows more smoothly and more rapidly. Now DH&C Directorate (interim Director Jonathan Cameron) is moving on from COVID and looking at refresh strategy which will take into account what we have already learned. New data strategy with other public sector people.

The IG review will make things quicker and more consistent, with recommendations from SG on redesign to address problems that have arisen.

Recommendations from IG review

- Establishment of balanced federated national IG body
- Monitoring IG maturity across different organisations
- Enabling IG by providing right tools for the job
- Improving transparency and openness to develop public trust in SG's use of data.

Next step to present at strategic portfolio board in July.

- Work on health & care IG programme
- IG and access to data at the heart of it all.
- Stakeholder engagement and plans for this.

There is a plan for a 'citizen journey' for transparency and people will be grouped according to digital need and will include education.

The strategy will set out programme for governance and then divide into manageable chunks and commission others to do the work for them, e.g. other organisations and/ or commissioning groups.

Inconsistencies are well-recognised and need to be unpacked and addressed together. The National IG body would set out clarity for interpretation of the law, or risk appetite and will set guidance and principles but will include flexibility to be used at local level.

LR good to know this is going to the portfolio board next month. Aware of challenges and gap in policies in commercial use of data. Helpful to have clarity on what is the SG position.

Anne Jamieson from Scottish Government, Lead Manager for the Data Intelligence Network (DIN) was welcomed and gave an update.

The purpose of DIN is to find data to support Government Policies.

DIN is a community of data experts across Scotland (e.g. Government, health boards, PHS, NHS24, academia, Police Scotland) who have interest in data and use of data to inform and help people to develop services in Scotland.

DIN is an advocate to support data sharing, good analytics, ethics, and connect people together so that the experts can do their jobs to join up the public sector. Within organisations people can deliver data projects easily. Provide forum for people to share their experience via a network delivery group, and provide support for people to show what they are doing across lots of data projects. DIN aims to champion the use of available data and connect different resources. Help people when they get stuck.

There are a number of challenges.

- Everything has some commercial value but finding insights to develop policy to help the Scottish people, e.g. use of mobile data. There are ongoing discussions with providers to access this.
- CHI / UPRN data: health info to be connected to home addresses so these can be used, e.g. for Care homes, other projects.
- Equality: set of data to look at protected characteristics (especially ethnicity) to assess processes and solutions.
- Communications and practice across different subgroups across orgs. Provide support and infrastructure across these groups.
- Support PHS so that can maximise data flows from PHS to and from health boards.
- CivTech – defederated data management tool so interested parties can access data.
- Monitoring of international travel – to ensure that Scots comply with RAG policies to ensure that enough hotel accommodation available to implement and monitor this policy.
- Test & Protect clinical trial enrolment as close as possible to receiving positive test result to ensure success of clinical trials.
- QCOVID algorithm to support shielding team.

LR thanked Anne for her presentation and asked about extending remit further than COVID. AJ The clear object is to retain essence of success learned with COVID and to build and maintain the work across the public sector. Portfolio Board oversees work (Chaired by Richard Foggo).

AMcC asked if NHS Central Legal Office (CLO) is involved.

AJ No they do not have a direct link to the NHS Central Legal Office but would be helpful for information to be disseminated.

ACTION 15-06-21 / 03: LR will link Anne with CLO colleagues.

LR asked if there are there any insights that are important for HSC-PBPP to know?

AJ thought that people who need to engage with HSC-PBPP do not have a wide knowledge of HSC-PBPP. Perhaps DIN could have a role in demystifying the process, as part of their role to communicate and share.

TS offered to engage with DIN with the Ops Group.

ACTION 15-06-21 / 04: TS and Ops Group

4.4. Update from HDRUK

CM gave an update on HDRUK.

ISARIC Data Platform

Aims to bring on board UK Wide Data to within the National Safe Haven and within the ULTRA Data Platform which is part of University of Edinburgh. We are continuing to expand the data holding on behalf of the ISARIC Consortium. This data includes

- Clinical Data collected by the ISARIC consortium
- Sample Data collected by the ISARIC consortium (held in ULTRA)
- Post Hospitalisation COVID study data
- COG-UK data for Scotland
- NHS Digital Data
- PHOSP data

Shortly bringing in GeNOMICCs study data (to be held in ULTRA) and Cancer Data.

Sample and genetic data is hosted within the University of Edinburgh where the appropriate software is available to analyse this type of data.

ISARIC data is held within secure management zone of the National Safe Haven. Data Sharing Agreements and Data Processing Agreements are in place and subject to normal security and National Safe Haven controls. Eventually ISARIC will be used by wider researchers, not just consortium members.

Co-Connect Study

The Co-Connect Study was set up with an aim of making serology data across the UK more accessible to researchers. Part of this work was implementing a front end to allow prospective researcher to run feasibility queries returning aggregated numbers allowing them to see if the data was available and contained sufficient numbers to take the study forward and apply for access to individual patient level data in a secure trusted research environment.

This project has now been absorbed into the HDRUK National Core Studies data and connectivity work-stream with a view to expanding the feasibility querying functionality across all datasets available within a Trusted Research Environment (TRE). Software required to access front-end feasibility querying to look for groups of particular demography to see whether study is feasible. Security and user work for the software. Application coming to HSC-PBPP for that. The raw data will remain where it is with different 'layers' to translate codes into descriptions. Researchers would only see numbers. HDRUK Gateway would be allowed to use this for asking for high-level questions.

At present PHS implementing this to accommodate serology data and other PHS datasets, with a view to replicating the setup and extending it to other datasets held within the National Safe Haven for COVID research.

5. Application matters

1920-0211 Turner: Application at Tier 1

Application is not for approval but for discussion of the questions it raises and potential precedent, it might set.

This application is from the University of Aberdeen with funding from HDRUK. The request is for foetal scanning data from 1985–2016, to be put into a research database for linkage for research use.

Discussion took place, as this is an unusual application and one that we have not had before, but might set a precedent for external organisations to request long-term retention of NHS data for research, regardless of whether there is a clinical or public health importance in retaining the data.

It was not felt that this was an appropriate application for HSC-PBPP since there is no specific research proposed. It was agreed that more appropriate routes to explore whether the data should be retained should be pursued, potentially the NHSS Records Management Group or through Scottish Birth Record discussion. There should be a clear clinical and/ or public health need/ benefit to justify this.

ACTION 15-06-21 / 05: LR to discuss with CM and MA to identify an appropriate route for such applications.

6. HSC-PBPP Development Slot

6.1. Commercial applications

Albert King, Chief Data Officer from Scottish Government, was welcomed and gave a presentation

Case for Action:

- Need to maintain public trust – can be undermined.
- Public trust is nuanced and dynamic and can change – needs to be sustained.
- Public service improvement
- Economic use case.

Stakeholders need to action

- Landscape of stakeholders – wide range of issues but policy decisions required
- SG policy decision
- Framework
- Issues exposed for consideration

Issues:

- Value of data – social economic impact
- Public benefit – what is this?
- Contractual and transactional issues - benefit sharing, Intellectual Property (IP)

IP and value exchange needs to be unpacked as part of this work. Once we know what that might look like, then how we get assurance on those questions will be addressed. Not sure we know what it's going to look like, but it is a big challenge.

Chief data officer in SG will take high level work back to ministers to show how this would look. Data protection is reserved matters, IP, contractual law – all converging together. This will give policy position for Scottish Public bodies.

Proposal

- High level policy statement
- Framework and guidance

Outputs

- Public consultation
- Programme of ongoing meaningful public engagement
- Establishing an expert group
- Robust understanding.

Public engagement will use an open government approach to this work by publishing minutes and papers to give meaningful public engagement. Membership of expert group is still open.

The aim is to start within next month and continue for rest of the year.

LR thanked Albert King. It is helpful for HSC-PBPP to get more clarity on Commercial applications.

AK agreed to keep this group sighted as this work continues to move forward.

6.2 Update from Research Data Scotland (RDS)

Roger Halliday from Scottish Government gave an update on RDS.

RDS aims to improve people's wellbeing through data driven innovation and research through organising the data better for research use.

RDS has been set up and established with its partners: eDRIS (PHS), National Records of Scotland (NRS) and University of Edinburgh.

There will be a relatively light-touch launch in September 2021, which will focus on a few noticeable changes for researchers:

- End to end researcher journey from idea to results.
- How do we improve the process for researchers?
- More information available:
 - Data catalogue of datasets;
 - Standardised information for researchers (IG process and documents)
 - Digitisation of process through online application forms.

Short-term differences will lead to longer-term pathway for service improvement.

IG process: Dec 2020 proposal for IG process – two pathways:

- i. Follow current data access processes but streamline where possible. Guidance and SOPs and developing Data Sharing Agreements for RDS and data owners.
- ii. Data in functional anonymised environments, for a faster process. Data controllers deposit their data via RDS and data used under particular circumstances and user agreement between RDS and Researcher. Not yet explored as lots to work through, especially with functional anonymisation. HSC-PBPP is a key stakeholder in this.

RH is a member of UK Research Accreditation Panel and has seen a range of changes so that work is more manageable. RH will explore with the HSC-PBPP Operations Group to see how anything can be translated to here.

RDS is constituted as a private company / charity which partners with Scottish Government. It is sponsored from within the Digital Directorate in SG. RH is Chief Executive of RDS and co-director of ADRC-S. ADRC-S is sponsored by ESRC, which is all about bringing data together around children, schools, looked-after children, with themes around vulnerable people and families, homelessness and health, and looking at quality of data available. Families, equalities are current themes, protected characteristics. New user forum starting in August for bringing together priority datasets.

Synthetic data is on the list of things to do, as it can be used to develop codes, understand the datasets better, while the application for data is underway. Not sure will be able to be made available this year through lack of resources.

RDS and DIN work closely together to connect data controllers and people who might benefit. User forum being set up in August, as a community of practice within DIN to span whole network and can feed into that.

LR asked re HSC-PBPP intending to move the application process online. What about the time-frame? Should we be doing that by ourselves or link in with RDS?

RH: This needs to be done alongside Stats PBPP and RDS, so can work together and simplify processes. He agreed to discuss with the Ops Group on how they could align/ link with his wider work on this

ACTION 15-06-21 / 06: RH and Ops Group

LR thanked RH for a very useful update.

7. Any other business

No other business was raised.

8. Date of next meeting

The next HSC-PBPP Committee meeting will take place on 15 September 2021.

Actions

Action Reference	Action	Responsible
15-06-21 / 01	Discussion as to how academic institutions can support with the application form.	CM / CMcC / AMcC
15-06-21 / 02	Provide update on an online application form	MA
15-06-21 / 03	Link Anne Jamieson of Data Intelligence Network (DIN) with NHS Central Legal Office (CLO)	LR
15-06-21 / 04	Engage with DIN and HSC-PBPP	TS and Ops Group
15-06-21 / 05	Discussion of appropriate routes for applications requesting long-term retention of health data for research.	LR / CM / MA
15-06-21 / 06	Discuss how Ops Group can link with wider RDS work on online application process	RH and Ops Group