

NHS Scotland (NHSS) Public Benefit and Privacy Panel for Health and Social Care

Minutes of the Committee meeting held on 16th November 2021 by MS Teams

Present: Dr Lorna Ramsay (Chair) (LR)
Dr Tara Shivaji (TS)
Dr George Fernie (GF)
Kenneth McLean (KMCL away 10.30-11.30)
Professor Abbe Brown (AB, until 10.45)
John Woods (JW)
Martin Walsh (MW)
Dr Angus Ferguson (AF)
Professor Alison McCallum (AMcC)
Professor Colin McCowan (CMcC)
Martin Bell (MB)
Dr David Felix (DF)
Carole Morris (CM)
Alan Ferrier (Al F)
Penni Rocks (PR)

Apologies: None

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

1. Chair's Welcome

The chair welcomed all to the meeting. Dr David Felix was welcomed to the committee as the new representative for NHS Education for Scotland (NES).

Due to timings of inviting external people to the meeting, the items on the agenda were deliberately taken out of order.

There were no serious conflicts of interest disclosed:

- PR stated she would stand back for the application from Scottish Government;
- AMcC stated that she had some background into both applications for discussion under items 5 and 6, due to her previous professional roles. It was agreed that this could give useful insight rather than a need to be recused.

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

2.1. Minutes of meeting held on 15th September 2021

These were approved as a true record.

2.2. HSC-PBPP Committee Action Log

The HSC-PBPP Terms of Reference (ToR) had been updated as previously agreed but also with the changes for the proportionate governance criteria for the updated application form. These were circulated to the committee for information.

One item was outstanding (from 15th June 2021) and further discussed:

2.2.1.Action 15-06-21/01: CM to discuss strategies for PBPP Only applications with CMcC and AMcC

This action is still outstanding as the conversation has not yet taken place but the intention is that it will take place in December 2021.

ACTION 16-11-21 /01: CMcC to take forward, MA to send reminder

A brief discussion took place about the regional safe havens and how does the HSC-PBPP ToR relate to these? Is HSC-PBPP responsible for them? With the establishment of RDS has there been any thought to standardise any approach to governance for regional safe havens?

The regional Safe Havens (SH) were previously aligned but have diverged over the years. They are important for carrying out local work.

The Data and Intelligence Network noted some inconsistency in how regional SH are certified and have different approaches, so how SH are accredited is under consideration. Cara Archibald from Scottish Government (SG) previously spoke to the committee about accreditation and how consistent security standards could be applied.

3. **Matters Arising**

3.1. Committee personnel update.

The committee still needs one further lay representative and have tried different routes including Young Scot and will continue the search.

Dr Mark McGregor, from the NHS Golden Jubilee National Hospital, has agreed to come onto the committee as a Caldicott Guardian. This would still leave one vacancy for a Caldicott Guardian representative.

There was a brief discussion on the previous agreement for requirement for Caldicott Guardian from patient-facing NHS boards. Is this an artificial distinction, if the totality of knowledge on the committee is more important, particularly regarding 'big data'?

The original HSC-PBPP ToR said that territorial NHS Boards should be represented but some national boards also see patients. It was agreed that the mix of people is good for overall perspective, but representatives from patient-facing NHS boards face specific challenges and gain important insight.

4. **Updates for committee**

4.1. Panel Manager Report

This was circulated for information and included three parts:

- HSC-PBPP User Experience survey summary and draft implementation plan
- Capacity at T1. Quick analysis of attendees showed 5 NHS Boards not contributing to T1 in 2021/22.
- Performance metrics to October 2021

A few comments were made:

- Regarding metrics, there are still difficulties accessing data and some confusion regarding the roles of eDRIS and HSC-PBPP and this reflects badly on HSC-PBPP.
- Regarding resourcing for Tier 1, there have been people advocating for additional resources for eDRIS, the use of data for evaluation of services and the need for more staff. Some of the complex datasets have their own IG leads: would it be feasible for them to join the IG leads, even as a temporary solution?
- The system is under strain which has an impact on HSC-PBPP. This also ties in with longer-term decisions through Data Strategy, still under discussion.

ACTION 16-11-21 / 02: Capacity at Tier 1 to be explored by the HSC-PBPP Ops Group.

4.2. HSC-PBPP Annual Report

LR had given her comments as HSC-PBPP Chair. There were no further comments and was approved pending the update.

ACTION 16-11-21 / 03: MA to finalise and circulate

4.3. Policy Decisions & Case Law Principles

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

4.4. Scottish Government update

PR gave an update from Scottish Government (SG).

The Digital Health and Care (DH&C) Strategy has been refreshed. The report can be found here:

[DIGITAL HEALTH & CARE STRATEGY – Digi Health Care](#)

The new Data Strategy has not progressed as fast as expected. A number of challenges come via the DH&C strategy which build on the response to COVID. SG want to use digital as much as possible but realise that it is not accessible by everyone, and need to determine how this can be done for all. This also maps into performance framework and best use of technologies to give the greatest benefits to all. The three main aims are:

1. Citizens to have greater control over own data;
2. Health care services are people-centred, safe, secure and ethical;
3. Health care planners, researchers and innovators have secure access to health data to help develop improved ways of working.

Information governance (IG) flows through all the different streams through IG maturity assessments; streamline IG landscape and setting out roles of key organisations and build on learning; invest in IG and cyber skills across entire workforce by developing appropriate resources. This will be part of a National IG programme.

The new Data Strategy will encompass data standards, data platform, ethics and trust. There is an engagement plan as part of this, which will work through winter and spring for launch in late summer 2022.

Any questions on this should be sent to PR directly.

ACTION 16-11-21 /04: PR to send slide set to MA for circulation to committee members

4.5. Update from HDRUK

Due to lack of time this was deferred to the next committee meeting.

4.6. Update from Research Data Scotland (RDS)

Roger Halliday from SG attended to give a brief update.

RDS aims to facilitate research for public good by bringing public sector data together. This is to be achieved by two current approaches: 1) make access simpler and faster; 2) develop new services. For the new services, they now have a data catalogue; access to anonymised medical imaging data; better information for researchers to get through the processes and standardise documentation to make it all straight-forward.

Two pathways for IG processes:

Pathway 1) Similar to what already exists for IG but with simplification of processes.

Pathway 2) recognises the '5 safes' model (safe people/organisations, safe projects, safe data safe settings/places and safe outputs) including the use of the National Safe Haven (NSH). They are looking at the precedent of getting permission from data controllers to obtain minimum datasets for use by researchers, under governance of RDS committee having oversight rather than full applications to the HSC-PBPP or Stats PBPP. This would be precedent setting as examples but would not be appropriate for every application. A further update would be brought once documentation is developed. RDS still needs to talk to the data controllers about this.

RDS is making range of other changes to the user journey and engaging with secretariats to help researchers to get right information to panels in the first place, so easier to make decisions.

LR: with reference to Medical imaging data available? What is HSC-PBPP role in this?

This has been approved through HSC- PBPP and making anonymised image data available in the NSH. RDS has given resources to make medical imaging data into a research-ready dataset and data controllership remains with PHS.

LR: Think the committee needs to look back at medical imaging data and its use as part of the development slot for next meeting and invite the medical imaging research manager. This could be combined with more discussion on the ongoing and future development of RDS. Can something more tangible for next meeting be brought? What would be possible process for engaging data controllers? Need to have more discussion for this in the development slot of the next meeting.

ACTION 16-11-21 / 05: MA to add to agenda for the next committee meeting

5. Application matters

Application for discussion and decision: 2122-0054 Macintyre

This application has been referred to the full committee for discussion with the applicant and decision.

This application was to use health, education and National Records of Scotland (NRS) Census data, to create a dataset of protected characteristics of the whole of the Scottish population, to be made available for use in research in the NSH.

The preliminary discussion highlighted the outstanding issues and questions for discussion with the applicant.

LR welcomed Cecilia Macintyre (CMcI, the applicant) and Roger Halliday (RH, the sponsor) both from Scottish Government to the committee.

LR led a helpful discussion with the applicant about the agreed questions.

LR thanked the CMcI and RH for coming to the committee and thought it had been a very useful discussion and had helped to clarify the outstanding issues about this application. The committee would have further discussion and send the response in due course.

Post-discussion reflection

After discussion with the applicant and further discussion the committee thought the application could not be approved in its current form. However the following points were made:

- i. The creation of such a dataset could have public benefit but would need to be done with suitable safeguards as this is potentially a highly sensitive dataset.
- ii. Scottish Government cannot be sole data controller of this dataset. NRS would not cede controllership of NRS census data and would be at least joint controller. The role of PHS is unclear.
- iii. Substantial public engagement would be required and should include minority groups that might be affected.
- iv. As this dataset will be derived from other datasets which are not complete, the completeness and therefore usefulness of the data currently available should be assessed before any long-term implementation.

The committee agreed that a resubmission should be requested as a pilot study with linkage to a specific group of people for a specific purpose. The pilot should include an evaluation of the quality of the data available and would inform a review of the process and outcomes. This review would then inform further decisions and any future application for the long-term implementation. A number of areas that would need to be addressed in any future application were agreed.

ACTION 16-11-21 /06: LR and MA to agree a response to be sent on behalf of the committee

6. HSC-PBPP Development Slot

Application for discussion and decision: 1819-0107 Feltbower

This application has been referred to the full committee for discussion with the applicant and decision. This application is for the transfer of NHS Scotland data to the University of Leeds for Paediatric Intensive Care Network (PICANet) for use for audit and research. This is a long-term dataset, to which NHS Scotland has contributed for a number of years. The complication is that this is one of the audits commissioned by the Healthcare Quality Improvement Partnership (HQIP) from which Scottish Government has withdrawn. While this application is for decision, a 'frameworks' needs to be decided for such applications as there are themes that have emerged for similar audit and research datasets in other applications and they need to be treated consistently.

Lead reviewer: AMcC

The preliminary discussion highlighted the outstanding issues and questions for discussion with the applicant.

LR welcomed Professors Elizabeth Draper (ED, University of Leicester) and Richard Feltbower (RF, University of Leeds). The Universities of Leicester and Leeds are the main leads for PICANet.

AMcC led a helpful discussion with the applicant about the agreed questions. Some of the concerns raised have actually been addressed but had not been included in the application form. The applicants thought that links between PICANet and NHSS could be improved.

LR thanked the ED and RF for coming to the committee and thought it had been a very useful discussion and had helped to clarify the outstanding issues about this application.

Post-discussion reflection

After discussion with the applicant the committee thought there was much reassurance on certain aspects, particularly parent/public involvement and infrastructure.

The committee were supportive of the work of PICANet and its use of data, but there are things that require to be detailed more clearly and in particular the long-term place and more visibility on the use of the data provided from NHS Scotland.

The committee agreed that the application could be approved with specific conditions, which would be outline from the discussions, including the requirement for HSC-PBPP approval for external researchers requesting individual-level data from NHS Scotland.

ACTION 16-11-21 / 07: AMcC, TS and MA to compose a letter for LR to send on behalf of the committee

Due to lack of time the discussion on the wider framework was not completed. This could be done within a subgroup led by AMcC to include, TS and the Operational Group and anyone else who wishes to be involved.

ACTION 16-11-21 /08: AMcC / TS and MA to coordinate further discussions and come back to the committee, possibly for the meeting in April 2022.

7. Any other business

No other business was raised.

Date of next meeting

The next HSC-PBPP Committee meeting will take place on 26th January 2022.

Actions

Action Reference	Action	Responsible
16-11-21 / 01	Outstanding action from June 2021 to be discussed. CMcC to take forward; MA to send reminders.	MA, CMcC, CM & AMcC
16-11-21 / 02	Discussion of resources for Tier 1 panels.	TS & Ops Grp
16-11-21 / 03	Finalise approved Annual Report and circulate among stakeholders.	MA
16-11-21 / 04	PR to send slides from her update to MA to circulate to the committee.	MA
16-11-21 / 05	Development slot at next committee meeting to include discussion on: i) use of medical imaging data and ii) ongoing and future development of RDS, and their engagement of data controllers.	MA
16-11-21 / 06	A response from the HSC-PBPP committee to be sent to the applicants for application 2122-0054 Macintyre.	MA / LR
16-11-21 / 07	A response from the HSC-PBPP committee to be sent to the applicants for application 1819-0107 Feltbower.	MA / AMcC / LR
16-11-21 / 08	Discussion of the wider framework of provision of data for ongoing and long-term audits and databases. To come to committee in April 2022.	AMcC / TS/ MA & Ops Grp