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

Minutes of the Committee meeting held on 26th April 2023 by MS Teams

Present: Dr Lorna Ramsay (Chair) (LR)
Dr Tara Shivaji (TS)
Dr George Fernie (GF)
Carole Morris (CM)
Professor Alison McCallum (AMcC)
Professor Colin McCowan (CMcC)
Dr Arun Chopra (AC)
Chioma Dibia (CD)
Martin Walsh (MW)
Dr Mark McGregor (MMcG)
Dr Pamela Johnston (PJ)
Professor David Felix (DF)
Dr Stacey Noble (SN)

Apologies: Penni Rocks (PR)
Martin Bell (MB)
Alan Ferrier (AF)
Kenneth McLean (KMcL)
Phil Dalgleish (PD)

In Attendance: Dr Marian Aldhous (MA)
Susan Kerr (Secretariat)
Dr Brendan O'Brien

1. Chair's Welcome

The chair welcomed everyone to the Committee meeting.

- Dr Stacey Noble was welcomed to the Committee as the new Lay member.
- The meeting is quorate and there were no conflicts of interest.

2. For Approval

2.1 Minutes from Previous PBPP Committee Meetings

The minutes from the previous meeting held on 26th January 2023 were approved.

2.2 HSC-PBPP committee Action Log and Matters Arising

All the actions from 2022/23 have been addressed and no actions remain open.
As this is a new year, a new Action Log will be created for 2023/24.

Matters Arising

- **Action 28-09-22/08&09 Ops Group**

  The Ops Group were given the task to work on definitions of audit and scope of what is 'in' and what is 'out' and how this overlaps with research / surveillance etc., with input from the PHS SNAP team and to develop visualisation of pathway, timelines and where check list might apply.

A paper was circulated from the Operations Group.
There have been substantial discussions at previous committee meetings and the approach is to try and provide a series of descriptions because the boundaries between what is an audit, surveillance or research can be very fluid; the aim is to try to create descriptors. The paper then goes on to the different requirements expected for each: e.g. ethical approval, Data Protection Impact Assessment (DPIA) etc. The paper tried to visualise the relationship and connections and use this to understand different contact points for applicants.

A number of comments were made:

- The applicant organisation in the NHS will have a Caldicott Guardian (CG) and an Information Governance (IG) lead and could also have a data custodian. These things are implicit, but perhaps these need to be explicit.
- We need to ensure that the same level of governance and scrutiny takes place, regardless of what label a piece of work had on it at the time.
- Some audits will become research databases and so this indicates the fluidity between categories, so similar principles to cover all types of application are good.
- Who is going to determine the standards/ scope for any audit? Looking at the overview table, audit requirements will likely differ between applications, and we will need to explore what best practice looks like for each. As mentioned in the paper, an audit is a cyclical process and time frames will need to be set and again may be different for each entity.
- Measurement and compliance: would be helpful to hear where oversight would sit.
- Communication of outcomes: would this become part of the HSC-PBPP communication strategy?
- One of the problems encountered in all these types of studies is that definitions are not always the same elsewhere. Where does service improvement or quality improvement fit in? Are the same definitions used in all NHS boards?
- Lay engagement and engagement of all boards is important. Over time, agreements have been put in place but there may require some updating of legacy approvals and ensuring these are fit for purpose.
- The differentiation between audit and research is helpful. Do Research databases need to be for specific purpose and use or whether generic for multiple uses?
- Some case studies would be very helpful with examples from previous years.
- This paper is for large datasets and use is defined in very broad terms. It is about creation of assets and how we handle that in the absence of clear research purposes.
- We need to be clear about the types of activity that are covered by HSC-PBPP governance and what should be approved by another route. Research should come to HSC-PBPP and also audit, but different types of surveillance are less clear.

ACTION: 26-04-23/01:

MA to update the paper; LR, MA, TS to discuss and highlight the different circumstances when applications go via HSC-PBPP or another route.

- **Action 29-11-22/05:** Coordinate a joint session for Tiers 1 & 2 for networking and / or development session.

The Ops group were asked to consider how we could go about having a joint networking event and development sessions for Tier 1 and Tier 2. The proposal put forward from the Ops group is that if there was another event that people could potentially go to and meet up as part of that.

The committee were in agreement that this should be an in-person meeting and it was envisaged that something more along the lines of the previous Development Day could be done, perhaps on a smaller scale? Suggested venues were NHS Golden Jubilee Conference Centre at Clydebank, Gyle Square or COSLA (next to Haymarket Station).

The counter argument was that Tier 1 members are from NHS boards across Scotland, which raises challenges to the Tier 1 members from the more distant boards in terms of access to an event geographically further away. One question was whether people would expect a remote access option, which itself raises challenges for available technology in any conference centre and how it would be managed on the day.

ACTION 26-04-23/02:
LR, TS and MA to discuss out with the meeting and report back.

3. For Scrutiny

3.1 Application 2223-0074 Smith

This application from Scottish Government was referred to the full committee for discussion with the applicant and decision. The purpose of the application is to obtain data to repeat a survey carried out a few years ago and then use the survey results and data from PHS to inform local and national improvements to wider Cancer services.

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

LR welcomed Euan Smith (ES, the applicant), Gregor Boyd (GB, the data custodian) both from Scottish Government to the committee and Hazel Mackay (HMcK from PHS).
TS led a helpful discussion with the applicant about the agreed questions.

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

After further discussion the committee thought the application could not be approved in its current form. The committee agreed that a resubmission should be requested. A number of areas that would need to be addressed in any future application were agreed. The

Committee were willing to work with the applicant to address the concerns of the members. There may need to be further conversations with the applicant and others in Scottish Government, to ensure that this work goes ahead with the appropriate governance in place.

ACTION 26-04-23 /03: LR, TS and MA to discuss how this should be taken forward and agree a response to be sent on behalf of the committee

4. For Information

4.1 Panel Manager Report

1. Lessons learned from COVID applications: paper provided for SG pandemic preparedness group.

There is a 'Lessons learned from COVID' meeting with Roger Halliday to talk about pandemic response and how these have been incorporated into the ongoing processes of HSC-PBPP. There was nothing else specific to add to the report to that meeting.

ACTION 26-04-23/04: MA will summarise responses from that meeting to the Committee

2. Questions to add for application form update.

These were agreed. A digitally enabled approach to guide people thought the form is still a goal.

3. Suggested changes to metrics to report externally (PHS and RDS).

These were agreed. Initially we may have to give more information for context, but this is OK for routine reporting.

4. Performance metrics for 2022/23 to 31st March 2023.

There were no comments.

4.2 Updates from HDRUK and DARE

The written reports were taken as read.

4.3 Scottish Government update

A set of slides from PR was circulated but she was unable to attend.
It was noted that the SG thinking on their proposed National Information Governance Programme could be a suitable subject for a joint development session with Tier 1.

4.4 RDS update

Roger Halliday will come to the HSC-PBPP Committee meeting in June 2023.

5. Development Session

Researcher access to GP data

Brendan O'Brien, Chief Clinical Informatics Officer gave an update on access to GP data, for routine and research work.

Background

- GPs are technically small private businesses that are contracted to provide services to NHS but are outside the NHS. Each GP practice holds data for their own patients and are data controllers for that data; there are 908 GP practices, which means 908 data holdings and controllers.
- Currently primary care is under pressure.

A Primary Care Data & Intelligence Platform (PCDIP) will be set up. Initially this will:

- Extract data from GP clinical systems to a single location (NHS-controlled data centre). This will be migrated to a new NHSS data platform in future.
- Data will be dually coded for Read2 (current clinical coding) and SNOMED CT (new clinical coding)
- A GP Editorial Board (GP EB) will be set up to represent interests of GP data controllers for routine and research requests to access GP data.

GP Editorial Board (GP EB)

- This will have GP input and training for GP members
- Admin support will include a GP EB manager to work closely with HSC-PBPP manager and eDRIS staff and support coordination of operational requests for GP data.
- A similar system was set up in Northern Ireland and is the framework for the same in NHS Scotland.
- Managing demand to GP data for research
    - GPEB processes will be aligned to eDRIS and HSC-PBPP so there is a single front door for researchers.
    - Should not replicate checks and balances already covered
    - The details will be clarified at each step of implementation

The discussion focused on the following questions:

- For the data available, will there be a set of defined indicators or will be access of minimal datasets?

GP data will be accessed in the National Safe Haven (NSH). The plan is to put all raw data onto PCDIP and NSS will aggregate it into useful datasets. Usefulness of data may improve over time as data will be ingested.

- Will all GP practices devolve governance to GPEB?

Support of data for operational needs for primary care should help encourage other GPs to come onboard for use for research. NI started with 70-80% and now up to 100% involvement. GPs will be up skilled to be able to improve governance: as practices benefit from this process they are more likely to wish to be involved in the process.

- Will the data be available for operational / performance management use as well as research? Are the indicators standardised? What timescales for getting to 100% in NI?

There is some nervousness from GPs about performance management and the platform will have ability to be used for population health, performance of different areas.
Regarding indicators, the GPs moved away from the Quality Outcomes Framework, so data quality has gone down. The ambition is to build a standardised dataset with clear standards, checklists and indicators.

Regarding timescales it took 3-4 years to get Northern Ireland fully running with 100% of all GPs on board.

- Previous work with Local Medical Committees to ensure GP involvement for data sharing partnership. GPs are good at focussing on 'how will it help patients and what do I tell patients in clinic?' Are there lessons that can be learned from the pandemic that allow GP data to be used?

GPs that were less keen on being involved did allow data for other uses, but feedback and learning can help the practical issues to be resolved. Wider clinical informatics team are doing cohort generation for different things using codes and can include robustness for clinical safety cases and risk strategies for individual patients.

- What about requiring GP data for public health surveillance, particularly for mental health? Would governance for that be via the GP EB? What would be the boundary between research and surveillance?

The capability involved would be to do all the work, but the permissions need to be correct – IG processes or patient consent: the platform would be able to handle both. Need to be able to get it right so that there is no reputational damage. Data would be available for public health purposes.

LR thanked BO'B for coming to the meeting and asked that the Committee be kept informed of progress.

6. Any other business

No other business was raised.

7. Date of next meeting

The next HSC-PBPP Committee meeting will take place on 13 June 2023

Action List

Action Reference	Item No.	Action	Responsible person
26-04-23/01	2.2	Update paper on approval routes for different application types and report back to June meeting	**MA**
26-04-23/02	2.2	Discuss the practicalities of a joint Tier 1 and Tier 2 development day and report back to June meeting.	**LR / TS / MA**
26-04-23/03	3.1	Discuss response to unapproved application, with report back to June meeting.	**LR / TS / MA**
26-04-23/04:	4.1	Summarise discussion on Lessons Learned from pandemic and report back to June meeting.	**MA**