

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

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

Present: Dr Lorna Ramsay (Chair) (LR)
Dr Tara Shivaji (TS)
Dr George Fernie (GF)
Kenneth McLean (KMCL)
Carole Morris (CM)
Martin Bell (MB)
Professor Alison McCallum (AMcC)
Professor Colin McCowan (CMcC)
Alan Ferrier (Al F)
Dr Arun Chopra (AC)
Chioma Dibia (CD)
Martin Walsh (MW)

Apologies: Penni Rocks (PR)
Dr Mark McGregor (MMcG)
Dr Pamela Johnston (PJ)
Professor David Felix (DF)

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

1. Chair's Welcome

The chair welcomed all to the Committee meeting. Two new people were welcomed and introduced: Dr Arun Chopra as a new Caldicott Guardian representative and Chioma Dibia as a new Lay representative. Dr Pamela Johnston has also joined as a new Caldicott Guardian representative but is unable to attend this meeting.

LR confirmed that there are now three Lay representatives on the Committee, but still looking for a fourth.

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 29th November 2022 were approved.

2.2. HSC-PBPP committee Action Log and Matters Arising

- **Action 29-11-22/01:** the updated Terms of Reference v2.6 were circulated to the committee members and are on the HSC-PBPP website.
- **Action 28-09-22/04:** this has now been completed.

Any other outstanding actions should be completed by the next committee meeting in April.

3. For Scrutiny

3.1. Application Matters

There are no applications to be reviewed at this committee meeting.

3.2. Update on researcher access to GP data

LR and MA provided updates on various discussions on the preferred approach, some of which has been incorporated into the circulated paper. People from Scottish Government Primary Care Directorate, Public Health Scotland (PHS) and NHS National Services Scotland (NSS) are setting up a Primary Care Data Intelligence Platform (PCDIP). As part of this process, NSS will procure Albasoft (the current function/software used to access GP systems) and is coordinated by Dr Brendan O'Brien in NSS. A GP data access panel called the GP Editorial Board (GPEB) is proposed to give access to Primary Care data, as required for operational purposes. This will also review requests to access to GP data for research.

MA and CM had previously met with Brendan to discuss the process of access to GP data for research use only, via eDRIS and how it should align with HSC-PBPP processes. The paper has been written on the basis of this ongoing discussion. One problem is that future demand is difficult to assess.

Questions and Comments were received from Committee members:

- When HSC-PBPP was established, it was intended that it would take on the research approval functions of the Scottish Caldicott Guardian group and the CHI Advisory Group, both of whom approved primary care research projects. If this is an oversight then needs to be dealt with in an appropriate manner.
- The specific proposal does not include anyone from the CHI Management Board (CHIMB) or NSS Practitioner Services who are responsible for GP records out with practices and for patients' GP records after death.
- The local GP sub-committees are the statutory group for primary care rather than local negotiating committees. A GP eHealth lead should also be included.
- It is important to get some mechanism set up for Scotland to access GP data. Many in the Research Community do not use NHS Scotland (NHSS) data because they cannot access GP data.
- Work is required for those research projects that require and depend on access to GP data, as opposed to those where GP data would strengthen an application. For these projects, it will need to be clear what happens to that research if the GPs say no. Some potential or existing projects would need to be run via the GPEB to see how they would be managed.

- The exact remit of GPEB in reviewing requests for data and aspects of information governance and the relationship with HSC-PBPP will need to be made very clear.
- The creation of this process adds in another data access panel. There will be lots of researchers who want access to GP data and the expected timeframes for approval will need to be managed carefully.
- Communications to researchers are key to manage expectations, as this is another access panel for researchers to navigate.
- Who sets the terms of reference?
It was thought that the Terms of Reference will developed by the PCDIP and GP community but that HSC-PBPP should have some input.
- Will there be any Lay members on the GPEB?
There is no lay input at this stage. Some applications would also come to HSC-PBPP.
- Where there is an application with commercial interest what support will the GP panel be given?
If there is commercial involvement and it includes other NHS Scotland data it would also come to HSC-PBPP.
- If the commercial request relates only to GP data would it still need to come to HSC-PBPP?
Some of the issues will be addressed as the GPEB 'stands up' and develops operationally.
- What happens when national NHSS data and GP data is required from only one Health Board area? Would that go through the GPEB process when it would not require HSC-PBPP and the request would go directly to the NHSS board?

These questions and comments should be fed back for further discussion.

Action 26-01-23/01: MA to send feedback to Brendan O'Brien.

These are the types of things that HSC-PBPP needs to make sure are being considered. Brendan should be asked to attend the HSC-PBPP Committee meeting in April to talk through the plans.

Action 26-01-23/02: MA to invite Brendan O'Brien to the Committee meeting in April.

4. For Information

4.1. Panel Manager Report

The development of an online application form has been temporarily delayed to a lack of resources in key specific roles. Further discussions are ongoing within PHS as there is wider work and challenges in IT requiring some reprioritisation.

4.2. HDRUK update

There was no update from HDRUK.

4.3. Scottish Government update

There was no formal update from Scottish Government for this meeting.

AMcC asked about use of ethnicity data for business as usual? There is cross-government work going on but the quality of the underlying data is not the best.

Action 26-01-23/03: MA to ask PR to cover at a subsequent meeting

4.4. RDS update

There was no update from RDS at this meeting.

5. Development Session: *Unlocking Value of Data update: Principles discussion*

Sophie Ilson (SI) and Angela Daly (AD) from the Independent Expert Group (IEG) for Unlocking the Value of Data (UVOD) joined the meeting to give an update. Feedback had been sent from the discussion at the last Committee meeting.

LR explained that HSC-PBPP is the data access panel for NHS Scotland (NHSS) data. For Commercial use of NHS data HSC-PBPP tried to establish guidelines to give consistency in review due to lack of official steer and policy guidance. HSC-PBPP is very keen to have official approaches and to hear about the processes and key thoughts and elements. The draft report had been circulated among Committee members and feedback requested.

AD stated that the IEG for UVOD was asked to consider private sector access to public sector personal data. The IEG consisted of people from different backgrounds and had consulted with various stakeholders. The final report is not completed but the most controversial bits had been circulated and feedback was welcome. There had been limited contact with the private sector which was unfortunate given the nature of the work.

Comments and questions that arose from discussion with Committee members:

- Opting out: while the principle is good, and in particular in the context of private sector access to personal data, there are concerns raised by the practicalities of implementing this and the implications for introducing bias.
- Transparency of use of data and public awareness of its use. How can the public be made aware and how can they realistically opt out?
- What is appropriate public engagement about this issue?
- National opt-out was not implemented in NHS Scotland as the decisions for use of health data was often a clinical one after discussion between patient and clinician.
- Public sector partnership can hold a company to account about the use of data.
- Scotland has a programme of public understanding of science to look at what the public think of use of health data.
- The previous approach about being proactive with public to seek views to inform has been sound and stood in good stead, so Scotland was not forced down route of opt-out as to how health service uses data.

- It was good to note that the previous feedback from HSC-PBPP has been reflected in the report. This is a difficult area and requires a wide range of different views and perspectives.

Action 26-01-23/04: Any further comments from committee members should be sent to MA by 27/01/23.

Action 26-01-23/05: MA to collate comments and send to AD by 30/01/23.

LR thanked SI and AD for coming to the meeting today.

6. AOB

No other business was raised.

Date of next meeting: Wednesday 26th April 2023

Action List

Action Reference	Item No.	Action	Responsible person
26-01-23/01	3.2	Feedback on approval process for GP data to Brendan O'Brien.	MA
26-01-23/02	3.2	Invite Brendan O'Brien to the Committee meeting in April.	MA
26-01-23/03	4.3	Ask PR to cover use and quality of ethnicity data for business as usual.	MA / PR
26-01-23/04:	5	Comments on UVOD paper to be sent to MA by 27/01/23.	ALL
26-01-23/05	5	Collate all comments and send to AD by 30/01/23.	MA