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

Minutes of the Committee meeting held on 28th September 2022 by MS Teams

Present: Dr Lorna Ramsay (Chair) (LR)
Dr Tara Shivaji (TS)
Dr George Fernie (GF)
Kenneth McLean (KMcL)
Martin Walsh (MW)
Professor Alison McCallum (AMcC)
Carole Morris (CM)
Alan Ferrier (Al F)
Penni Rocks (PR)

Apologies: Martin Bell (MB)
Professor Colin McCowan (CMcC)
Dr Mark McGregor (MMcG)
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 meeting. Due to the unexpected absence of some members, the meeting is not quorate. Therefore any decisions made will be followed up with the other Committee members.

1.1. Conflict of interest

Both AlF and CM have expressed conflicts of interest in the application to request NHS data for NRS being discussed.

The Chair thought both did not need to leave this meeting as they may have useful information to contribute, but they will not make any decisions on this application.

AMcC expressed that she sits on the NHS Central Register stakeholder group.
GF stated he works closely with NRS
The Chair did not think that either of these this would impact on decisions. It was agreed that AMcC and GF could remain present and take part in the decision making.

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

2.1.   Minutes of meeting held on 29 June 2022

These were approved as a true record.

2.2. HSC-PBPP Committee Action Log

Item 16-11-21/08 Paper on National audit can be closed as part of the agenda for development slot at this meeting.

Item 29-06-22/02 The T1 audit is now nearing completion. MA only awaiting a couple of more responses. The findings of the audit will be provided at the next meeting in November. MA thanked all who have replied so promptly.

3. Matters Arising

3.1. Committee personnel update on Caldicott Guardians and Lay membership.

LR has not raised anything with the NHSS Caldicott Guardian (CG) Forum for the outstanding CG at this stage. The CG Forum has started meeting again and LR will ask for this to be on the agenda at the next meeting.

The possibility of deputising or delegation was raised. This was previously agreed and the Terms of reference were updated. This could be possible to cover annual leave. It had been stated that the delegate should not be someone who is part of the T1 panel.

It is not really possible for a delegate to be sent for lay representatives, but for a research role, a delegate may be possible, especially if it is someone who has shown interest in the committee and could be used for succession planning.

Action 28-09-22 / 01: Ops group to explore the mechanisms by which committee members could send a replacement delegate to the committee meetings.

Lay Representatives

MA informed the group that David Webster, an SG contact from PR, has lots of contact with other Lay groups. HSC-PBPP has recently received one new enquiry. We do hope to have two additional Lay representatives in the future, as the total required is four Lay members.

PR stated another route is through unlocking the value of data work that Sophie Ilson is taking forward. There are a number of Public Engagement workshops so may have links to help.

3.2. Update on online HSC-PBPP application form

MA stated that a paper has been circulated stating the current progress on the online HSC-PBPP application form. The project team has discussed initial requirements. Workshops will be set up with eDRIS and HSC-PBPP. The discussion noted that:

- This would be an online form with different fields and hopefully be a much easier process for applicants.
- The process would be done in stages as this includes management of applicants and their access to the form.
- The process will potentially evolve as we understand more about how it will work. At one point we thought we might not need this because of RDS, but not all applications will go through RDS.

- The ability of the application form to 'talk' to other mechanisms will provide some integration with other data access request forms to reduce the need for the applicant to duplicate the same information to multiple parties.

4. Current and Future Access to GP Data

The brief paper identified a number of options about access to GP data. It is not for HSC-PBPP to make a decision in isolation but HSC-PBPP can have a view and make recommendations, and the paper supports our thinking. Access to primary care data has been valuable during COVID and it will be hard to go back, but there is no current mechanism to do this on an ongoing basis. It may be that the remit of HSC-PBPP remit is extended, or a new governance route that interacts with HSC-PBPP and so HSC-PBPP is keen to be part of the discussions. It is aimed to bring back to November meeting for discussion.

The discussion raised the following points:
- Lothian Health Board has used GP data very successfully with local approval arrangements in place.
- The HSC-PBPP NHS NSS Rep from Practitioner Services should be involved given their understanding of use of national primary care data for operational purposes.
- Integration of primary and secondary would be helpful and interpretation of the legislation needs to be clear.
- There would need to be appropriate structure in place so that there is better integrated access to different data, rather than separate structures for access to different datasets.

PR thought that as NHS boards and GPs have joint data controllership under national agreement, and that NHS boards have contracts with GPs, the use of these data could come under HSC-PBPP already. PR is willing to help with clarification of the legislation around GP data.

LR thanked PR and welcomed the help. When HSC-PBPP was established, which was before the current agreements between NHS territorial boards and GPs, there was not the expectation that GP data would be included. Clarification may be required in our terms of reference.

Action 28-09-22/02: MA / PR/ LR to update paper and invite others who might usefully contribute to the discussion

5. Application Matters: 2223-0075 Fenney for Review

Due to timings of submission and committee meetings, this application had come directly to the HSC-PBPP Committee for review, without a review by the Tier 2 Out of Committee first. Therefore there was no lead reviewer, so the HSC-PBPP Chair led the discussion with the applicant team.

AlF gave a brief introduction to the application: This application comes from the National Records of Scotland (NRS) Census Team, to request access to NHS Scotland data to fill in the gaps from the 2022 Scotland Census as there was a lower turnout than expected. Census statistics are used for resource allocation throughout Scotland so they need good population-wide estimates of the population and demographics in Scotland, using other Scottish population-wide data available. The NRS International Committee thinks there is no other route available to gain this information. The legal basis for the request is under the Census Act.

The questions that should be discussed with the applicants relate to:
  i.   Expectations of the public as this is not something for which people would expect their health data to be used.
  ii.   Awareness of the limitations of using health data for this purpose.
  iii. Justification and timescales of the processing of the data in NRS as opposed to using the National Safe Haven.
  iv.   Quality and assurance as the NHS data have been obtained for another purpose and whether there has been any consideration of the impact of this approach on the quality of data that will be used for the next 10 years?
  v.   Any Equality implications for changes in census process over the last few years to ensure appropriate coverage. What would need to be in place going forward?

These questions were discussed with the team from NRS: Caroline Ellis, Peter Whitehouse, Professor James Brown, David Rowley and Ralph Devitt, who explained the work and focused on driving public benefit of the census to deliver critical information for the population of Scotland.

LR thanked the NRS team for attending.

After further discussion, the Committee members agreed that this application could be approved subject to certain conditions being fulfilled:
  • Further justification of the standardisation processing to take place within NRS to be added to the application
  • Addition of further information about how the NHS data will help in the statistical processes and imputation of missing data and the limitations of this approach.
  • Public Engagement:
      o Assurance that a stakeholder engagement plan is in place through to the period of the census outputs being released.
      o Further engagement with public representative groups to inform them of the additional quality work being undertaken, the use of health data and the controls in place, in order to ensure transparency and to mitigate the risk of misunderstanding.
      o Strong recommendation that public engagement on the use of administrative data, including health data, as part of the process to ensure high-quality census outputs is embedded from the outset in the planning for the next census.

As this meeting is not quorate, the decision will require ratification by absent members and any further comments to be included.

Action 28-09-22 / 03: MA to ensure ratification of this decision and draft approval letter
Action 28-09-22 / 04: TS to check/ensure that the review and update of PHS Privacy notice is undertaken.

6. Updates for Committee

6.1. HSC-PBPP Annual Report

The HSC-PBPP Annual Report had been circulated for comment and approval. The report was approved with one change requested:

- That the reference to the HSC-PBPP Development day be reworded to indicate that development sessions were now embedded into Committee meetings and that we should consider how this would be done in the future and the different options that could be used instead.

Action 28-09-22 / 05: MA to update the appropriate part of the Annual Report and publish/circulate the report to the appropriate people.

6.2. Panel Manager Report

The Panel Manager Report was provided for information.

6.3. Policy Decisions and Case Law Principles

This document had been updated in the light of complaints received about an application. It was commented that if an application uses phone apps or text messaging HSC-PBPP may need the applicant to indicate whether what is proposed is or is not a medical device.

6.4. Scottish Government update

PR had circulated slides giving a high-level update on the first draft of the Data Strategy for Health and Social Care. She suggested she bring a fuller update at the meeting in November once full analysis has been done.

The National Information Governance Programme for Health and Social Care has been approved by its board and the related work-streams are being set up. The relationship of this programme to HSC-PBPP would need some further thought. SG are working with stakeholder groups, especially the public, regarding managing the changing use of data.

It may be appropriate at a future HSC-PBPP committee meeting to get an update from the Royal Colleges and any work with GPs, possibly as a future Development Slot for early 2023.

It was also noted that given this is for health and social care, this might be a good time to reopen the discussion of a Social Care Representative on HSC-PBPP Committee as it is within the scope of HSC-PBPP. This may have an impact on the evolving role of HSC-PBPP and its membership.

Action 28-09-22 / 06: MA to invite SG rep to the next committee and discuss with PR what a development session might involve

6.5. RDS and HDRUK Updates

A written update was sent from RDS, but no update from HDRUK. These will remain on future agendas as a written update for awareness with any matters of particular interest brought to the Committee as a more substantive item for discussion.

7. Development Slot: Use of NHS Scotland data for National Audits and Research Databases

A summary paper had been circulated to articulate the range of different issues in use of NHS Scotland data for UK-wide audits. Many audits have arisen as organic projects and grown. Decision-making in Scotland and UK and what is done for public benefit, regarding audit and service improvement will also relate to variations in structure and processes. While it has been difficult to articulate the issues, this paper is to try to clarify the roles and responsibilities of the people involved to give a balanced approach and apply the same criteria across the NHS. Points to bring out:

- Need a systematic process to ensure that approval is in place for historic audits so it is not done in urgency
- Need a consistent set of principles for all national audits with guidance and a checklist for the website. This would help people to navigate an ever-changing landscape and allow high quality work to continue.

Comments on the proposed checklist:
- Checklist needs to be clear that it is a closed loop: once the data have been used for the purpose, the outcome should be made clear to HSC-PBPP and the public.
- When do audits stop and become business as usual (BAU)? Should this be added? Should the year on year request for data be challenged?
- Need to ask about who will be data controller or take responsibility for the data? Sometimes this is unclear. It had been proposed previously that in Scottish Audits would be done by the most appropriate National NHS board to be data controller but this does not solve the complications in England. There needs to be some agreement in principle but also need conversations regarding UK-wide audits led from England or other devolved countries.
- If a project establishes a research database it also requires an access and governance group to ensure quality of the data and access.
- What about the location of the data? Should it be in a Trusted Research Environment (TRE)? There would have to be clear requirements regarding use of Safe Havens/ TREs and locations with equivalent data security. Who decides what is equivalent? Need to be sure that recognised IT standards are met.
- What about processes for engaging with the public?

Further discussion raised the following points and questions:
- Some of the points are not just for HSC-PBPP but should be considered by national audit teams. How do we provide input to them? Do we need a wider discussion of standards and processes, or whether this is good use of resources? How can we engage the wider stakeholders?

- What is the IG pathway for audits and what is the touchpoint of HSC-PBPP with that pathway? Can we visualise the process that we can take to a wider network of people for further discussion?
- What about the cyclical nature of audits, with new questions and then reviews of change of practice? This may take place over several years.
- Some things that are called audit are not actually audits. May need some clear definitions and general principles and the same standards to apply so that those doing the work have professional and contractual responsibilities to ensure the 'Five Safes' are met.
- Need to be aware that there may be audits that were previously approved by the Caldicott Guardians (pre-PBPP) that have not come back to HSC-PBPP since. These may need to be addressed in the future.

It was agreed that a Plan of Action needs to be formulated, with shared discussion about the approach, what needs to be done and by whom, what are the levels of risk and what are the resources required? Start with the quick and easy things.

Action 28-09-22 / 07: ALL to give feedback and comments
Action 28-09-22 / 08: TS to work on definitions and scope of what is 'in' and what is 'out', how this overlaps with research / surveillance etc., with input from the PHS SNAP team
Action 28-09-22 / 09: Ops group to develop visualisation of pathway, timelines and where check list might apply.

8. AOB
No other business was raised.

9. Date of next meeting
The next meeting will take place on Tuesday 29th November 2022.

Action List

Action Reference	Action	Responsible person
28-09-22 / 01 (Item 3.1)	To explore mechanisms by which committee members could send a delegate to attend a committee meeting.	**Ops group**
28-09-22 / 02 (Item 4)	To update paper on GP data and invite others who might usefully contribute to the discussion	**MA / PR/ LR**
28-09-22 / 03 (Item 5)	To ensure ratification of the decision regarding the reviewed application and draft the approval letter	**MA / CM / LR**
28-09-22 / 04 (Item 5)	From the application decision, to check/ensure that the PHS Privacy Notice is reviewed and updated.	**TS**
28-09-22 / 05 (Item 6.1)	To update the appropriate part of the Annual Report and publish/circulate it to the appropriate people.	**MA**
28-09-22 / 06 (Item 6.4)	To invite SG rep to the next committee regarding the SG Data Strategy and discuss what a development session might involve.	**MA/ PR**
28-09-22 / 07 (Item 7)	To give feedback and comments regarding Audit paper	**ALL**
28-09-22 / 08 (Item 7)	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	**TS**
28-09-22 / 09 (Item 7)	To develop visualisation of pathway, timelines and where check list might apply.	**Ops group**