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

Minutes of the Committee meeting held on 13th September 2023 by MS Teams

Present:	Dr Lorna Ramsay (Chair) (LR)
	Dr Tara Shivaji (TS)
	Dr Arun Chopra (AC)
	Dr Pamela Johnston (PJ)
	Chioma Dibia (CD)
	Martin Walsh (MW)
	Dr Stacey Noble (SN)
	Kenneth McLean (KMcL)
	Carole Morris (CM)
	Professor Colin McCowan (CMcC)
	Professor David Felix (DF, until 11am)
	Julie Ramsay (JR)
	Lisa Hill (LH, until 10am)
Apologies:	Dr George Fernie (GF)
	Dr Mark McGregor (MMcG)
	Professor Alison McCallum (AMcC)
	Martin Bell (MB)
	Susan Kerr (Secretariat)
In Attendance:	Dr Marian Aldhous (MA)
	Phil Dalgleish (PD)

1. Chair's welcome and apologies

LR welcomed all to the meeting.

Personnel changes:
- LR stated that George Fernie had given his apologies but this would have been his last meeting, as his 6-year term has come to an end. LR will contact George to express the thanks of HSC-PBPP for all his valuable work over the time.
- LR officially welcomed Julie Ramsay as the new National Records of Scotland (NRS) rep (replacing Alan Ferrier) and Lisa Hill as the new Scottish Government (SG) rep (replacing Penni Rocks).

Quorum
The meeting was quorate.

Conflicts of Interest
JR expressed a potential conflict of interest for item 3 as she has had some involvement of data provision. LR noted this but thought JR would be able to give informed contributions and useful insights and there would be no decisions to be taken.

2. Minutes and actions from previous HSC-PBPP Committee Meeting

2.1. Minutes of meeting held on 13th June 2023

There was a correction to be made for the previous minutes: on p2 Julie Ramsay's role is Head of <u>Demographic</u> Statistics. With this correction, the minutes of the previous meeting were approved as a true and accurate record.

ACTION 13-09-23 / 01: MA to ensure correction is made to final minutes

2.2. HSC-PBPP Committee Action Log and Matters Arising

      2.2.1.<u>Action 13-06-23/03: Updated paper on definitions, scope and routes of approval.</u>

Further work has been done on this paper in response to the comments received. A few comments were made:

- A really small point in the definition of audit: some audits are not one-off and are part of a continuous process for improving health care. Perhaps this should be added?
- If we do that then audit leaves a gap for benchmarking, which gives a current comparison to the external standards, which may indeed be a one-off audit.
- For HSC-PBPP applications, the bigger audits tend to be the ongoing ones, whereas the smaller audits tend to be single ones.
- It was agreed that the term audit should be used as a looser term to include ongoing audits, benchmarking ones and those improving quality. The key differences between audit and service improvement need to be clear and examples of practices / applications that have followed this pathway.

It was agreed that the paper now in a good place and should be published on the HSC-PBPP website as v1, without the appendices, and circulated to other stakeholders (e.g. RDS, eDRIS). This could be reviewed every 12-18 months to added in feedback and refine with use.

Appendix 2 was the summary of parallel conversations with PHS about the routes to approval for their use of NHSS data, which is separate but it is helpful that HSC-PBPP is aware of the thinking by PHS. This Action can now be closed.

ACTION 13-09-23 / 02: MA/TS to do final updates and make available to stakeholders.

      2.2.2.<u>Action 13-06-23/04: Update on joint Development session with Tier 1.</u>

TS updated the committee: It is clear that people want an in person event with a hybrid option. We have sought to identify venues, with prices and dates for Jan/Feb/March 2024. Date will need to be finalised with new /interim Chair.

ACTION 13-09-23 / 03: TS / MA and Ops Group to keep working on this.

      2.2.3.<u>Action 13-06-23 / 05: Update on 2223-0074 Smith</u>

This application was discussed at the April meeting and a resubmission requested. This has been received and circulated to the whole committee, who have provided their responses and the application was approved with conditions.

- There was a query of how the applicant had received the number of conditions?

From the meetings with the applicant / SG there had been positive discussions and clear guidance given and so many of the Conditions were already expected by the applicant. They are currently working on fulfilling these conditions.

Since this application was submitted, another Care Experience Survey has been received and approved at Tier 1. It was noted that some of the points for this application had been taken on board in that one.
This Action can now be closed.

2.2.4. Action 13-06-23 / 07: Update on 2223-0165 Barnett

This application was reviewed and not approved at the June Committee meeting, to create a national Diabetes Research Data Asset. The Committee had agreed that such a dataset was needed but did not agree that the proposed mechanism was the best approach.

There have been further discussions internally with relevant NHS boards and externally with the applicant. It was suggested that they do not progress with this application, but that they approach it in a way similar to that used for the creation of the Scottish Medical Imaging (SMI) research data asset: this would start with initial discussions and making a case at the Caldicott Guardian Forum (for all the NHS Scotland boards), followed by an Options Appraisal around different possible solutions against specific criteria. It had been a constructive discussion. There will need to be further discussions with PHS, as a possible Data Controller of the new national asset. It is hoped that the applicant will take this forward and keep HSC-PBPP informed.

Questions:
- If this new data asset will be used to support research, is this the same as what Research Data Scotland (RDS) is trying to do? Can RDS not be joint data controllers?

Once the data asset has been created, then this may be made available and used by RDS. But this is for the creation of the dataset, which requires input from the source data controllers (i.e. the NHSS Boards) from which the data will be obtained.
- The applicant had stated in the discussion that they didn't know how to go about this process and so had started with an HSC-PBPP application. Should we try to capture this process to give guidance on how to establish a new data asset, drawing on the experience with Scottish Medical Imaging (SMI) and then possible refinement for this dataset?

This could be a good thing to do and would potentially require input from Caldicott Guardians, SG and maybe others. This could be something for the Ops Group to take forward. This action can now be closed.
ACTION 13-09-23 / 04: TS /MA & Ops Group to progress in discussion with key people.

3. Adverse Event: 2122-0023 Dennison

An SBAR for an Adverse event for the above application was circulated.
Event: This study was contacting mothers and fathers of babies born within the last year to invite them to take part in this longitudinal family cohort study. While complete adoptions

are excluded, incomplete adoptions would not be, which was the cause of this adverse event causing distress to the family.

This was a pilot study for a new longitudinal cohort study, which was discussed at the HSC-PBPP Committee last year. How this study goes forward will need to take into account the learnings for this piece as the pilot has flushed out some of the problems. NRS and PHS are involved in providing the parental and child data and various checks are in place but this event was unforeseen. A Lessons Learned process is still to take place.

After discussion the following recommendations were made:
- For future studies, inappropriate contact of incomplete adoptions may be prevented if families where the mother and baby not living at the same address are not approached, unless there have been further checks or contact by the local health board or GP.
- Where possible, dates of updates of addresses should be taken into account where these differ on different systems.
- Ensure options considered and tested against pilot data so evidence of how to approach higher risk scenarios in future for improved mitigation.

ACTION 13-09-23 / 05: MA to summarise the discussion, actions and update the Case Law Document.
ACTION 13-09-23 / 06: MA to apply the recommendations to other relevant applications and contact SG as this impacts the next Maternity CE survey.

4. For Information
4.1. *Panel Manager Report*
MA gave an update. There were no particular comments.

4.2. *Health Data Research UK (HDRUK) update*
CM gave an update: there was no particular news relating to HDRUK.
The National Safe Haven (NSH) has been going through an accreditation review process under the Digital Economy Act (DEA) for processing non-health data. In future this accreditation may be extended to include heath data.

4.3. *Scottish Government update*
There was nothing immediate from SG.

5. Development Session: Research Data Scotland (RDS)
Roger Halliday attended the meeting for discussion of details of data approvals process.
A paper was circulated to the members.
- RDS now has an information sharing agreement for joint data controllership for minimal research datasets, which will be used for the low-risk route to limited datasets for use in research in the NSH. This will test out a new researcher access

service. These applications would not be reviewed by the PBPP panels. A similar process will be put in place with SG and NRS to do something similar for their data.

Data Approvals review
- RDS now focusing on data approvals review: how to maintain public confidence and trust with their data, but remove friction in the request and access process? At the requested of SG, RDS and CapGemini carried out a review of existing processes for pandemic preparedness, including HSC-PBPP, Stats-PBPP and CHI Management Board) and also to provide some learning for non-emergency times.
- <u>Findings</u>: there were variations in complexity, messaging to and from applicants and quality of the applications received. The current system works for the data controllers. There is scope for learning from each other and elsewhere, and there is potential to increase the level of public involvement.
- <u>Recommendations</u>:
    o Need to balance speed, quality and cost.
    o Simplify and digitise, and build on what already exists
    o Align processes between national and local panels.
- Need governance in place and resources to implement this.
- There is an opportunity to work collaboratively to address concerns of researchers accessing the data.

Discussion with the Committee:
- Need to clarify whether this work is only for pandemic or wider and whether for research or wider.
The Pandemic preparedness group wants to look more broadly and have consistency for all applications and not just for research. Needs further engagement with data controllers, such as through the Caldicott Guardian or Data Protection Officer Forums.
- For automation of the application process, HSC-PBPP did do some work on this but has stalled. There are not a lot of resources available, but HSC-PBPP does want to be a part of this. It does need to work for all applications, not just for those that go through RDS pathways as things change and people need to be able to switch application types / routes.
- How would the need for agility in responding to requests during emergencies be balanced with comments from public and ethical reviews which all take time?
This is a key question: some will have had ethical review by a committee, others not. There will be an ethics self assessment and refer to ethical review for high risk applications. For public review the proposal is that half of the committees will be public representatives – this already happens in some places and works well but would need to be supported for reasonable timetables.
- This is aspirational to achieve: the times to approval of applications during the pandemic were short and these were big applications. This puts a lot of burden on support staff, who currently will highlight and define what are the outstanding issues for the reviewers who then only have to review the outstanding issues.
Pressure on panel members will be eased through digitising the process so that information is correct the first time. The proposal is to move to digital-based panels so comments will be placed online rather than through a meeting. There will be increased resource for panel management to do some of the work up front to secure some of the assurances so that

panel members don't need to review the entire form, so individual members will review individual applications. The range of the Tiers will be extended so that lower risk applications are approved by lower risk panels.

- This would this require a more robust risk analysis and risk assessment structure so that it ensures that risks are tested outside a pandemic high risk situation.

The form will be structured in a way so that there will be some semi-automated triage for panel manager, which occurs for panels elsewhere in Scotland and UK.

- We have been looking at an adverse event. The balance between benefits and risks, shows that we need to understand unusual scenarios that will arise. Some things can be lighter touch, but there are complicated nuances that will need to be explained and understood.

Agreed. The changes will need some careful design.

- In a recent T2 audit of T1, quality of public involvement that fed back to participants could be improved. HSC-PBPP's role is too far down the line and the opportunity has often passed by then. It is useful to have lay view, but should be done much earlier with the public and intended beneficiaries, rather than panels. Can public involvement in research can be improved in general? There needs to be support for applicants to understand different ways to support public involvement.

There needs to be proportionality but for larger projects or setting precedents in data sharing then should expect public to be involved. Data controllers want assurance that this has taken place and the cost of doing this is disproportionate. Something for people to thing on this further. Networks and building capability in public engagement so some way to go before making this a standard part of researcher's thinking.

- With all of this happening, how does this fit with the review of IG that is going on?

RDS is engaged with SG IG team, as this is one component of what they are trying to achieve: robust approach to data sharing. Will continue to engage with them in trying to move this forward and make these changes. LH will be an active partner in doing this.

- How will IG capacity be increased? Many move around but without increasing knowledge or expertise.

There is a new Information Governance Code of Conduct for organisations, that will build skills in IG and standardise processes across the public sector organisations.

- HSC-PBPP needs to continue to be involved with close engagement so we can make this work for all of our activities.

RDS will continue to engage with HSC-PBPP management.

6. Any other business

Two items were raised.

6.1. *HSC-PBPP Chair*

LR is standing down from HSC-PBPP as of this meeting and will be retiring from her role as Medical Director for NHS NSS.

LH outlined the interim and longer-term plans for finding a replacement:

- A job specification for the Chair will be circulated to the wider community to invite application as soon as possible as timescales are a bit tight. There will be formality around the process.

- In the meantime an interim Chair will be appointed.

ACTION 13-09-23 / 07: LH to carry forward process of finding a new Chair for HSC-PBPP.

6.2. Unlocking Value of Data (UVOD) Report

The UVOD report has now been published by Scottish Government. The report highlights numbers of principles which align with what HSC-PBPP does.

https://www.gov.scot/publications/final-report-independent-expert-group-scottish-government-unlocking-value-data/pages/1/

ACTION 13-09-23 / 08: MA to circulate the report to the committee and ensure a link is included in meeting minutes.

7.   Date of next meeting

The next meeting will be held on 15th November 2023

Action List

Action Reference	Item No.	Action	Responsible person
13-09-23/01	2.1	Ensure correction is made to published minutes	MA
13-09-23/02	2.2.2	Final updates to be made to Definitions and Scope paper and make available to stakeholders.	MA/TS
13-09-23/03	2.2.3	Continue work on joint Development session. Timing likely to depend on availability of new Chair.	TS / MA / Ops Group
13-09-23/04	2.2.4	To outline and take forward the process of creating a new data asset from health data, in discussion with other key people.	TS /MA / Ops Group
13-09-23/05	3	Summarise the discussion, actions and recommendations and update the Case Law Document	MA
13-09-23/06	3	Apply the recommendations to other relevant applications and contact SG as this impact the next Maternity CE survey.	MA
13-09-23/07	6.1	Take forward the process for finding a new Chair of HSC-PBPP.	LH
13-09-23/08	6.2	Circulate the UVOC report and ensure a link is included in the minutes.	MA