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

Minutes of the Committee meeting held on 29th November 2022 by MS Teams

Present: Dr Lorna Ramsay (Chair) (LR)
                Dr Tara Shivaji (TS)
                Dr George Fernie (GF)
                Kenneth McLean (KMcL)
                Martin Walsh (MW)
                Carole Morris (CM)
                Professor David Felix (DF)
                Martin Bell (MB)
                Professor Alison McCallum (AMcC)
                Professor Colin McCowan (CMcC)
                Alan Ferrier (Al F)

Observer   Dr Arun Chopra

Apologies: Penni Rocks (PR)
                Dr Mark McGregor (MMcG)

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

1.   Chair's Welcome
The chair welcomed all to the meeting. Arun Chopra attended as an observer at this meeting as a potential new Caldicott Guardian representative.

The meeting was 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 28th September 2022 were approved.

2.2. *HSC-PBPP committee Action Log and Matters Arising*
The new structure to the agenda was noted and the aim for shorter meetings when there is no application to consider.

- Committee personnel update

A new Lay representative has accepted to join the Committee.
At the last Caldicott Guardians Forum both Arun Chopra and Pamela Johnstone expressed an interest in joining the Committee.

- Delegation of alternative attendee

There is scope within the current Terms of Reference (ToR) in foreseen absence to allow Committee members to delegate to another individual. The circulated paper highlights guidance around the choice of appropriate individuala. A deputy cannot be sent due to the process of appointment to the panel, but delegation is acceptable. The paper highlights suitable delegates, although it cannot be someone who also sits on Tier 1. There is offer of advice or guidance for any delegate. If a committee member is absent for a prolonged period, there would be some concern about not being up to date with the current issues. Any individual must inform Chair if not attending the committee for a prolonged period.

It was agreed that a delegate must have experience and might be someone in a senior position whom one would consult for wisdom and advice. Good judgement when delegating is required. It was confirmed that lay reps cannot delegate to others.

The process was agreed and the ToR to be updated.

ACTION 29-11-22 / 01: MA/TS/ Ops group to update ToR

- Online application form.

This is progressing and to be kept on the agenda.

- Access to GP Data

The previous paper has been updated.
There have been a number of discussions to get something in place for access to GP data.
There is a meeting in December to explore how primary care data can be approved for research uses and which can feed into HSC-PBPP without duplicating processes.
This will be discussed at the next meeting.

ACTION 29-11-22 / 02: MA to update Access to GP data paper on progress for next meeting

3. For Scrutiny
3.1. *Application Matters*
There are no applications to discuss.

3.2. *Tier 1 Audit Report*
A key thing to highlight is that most of the approved applications aligned with the proportionate governance criteria. Some of the applications that were audited were HSC-PBPP Only applications, which were not supported at the time although support is now in place. There did not appear to be anything of particular concern. The majority of the recommended updates for the proportionate governance questions will be useful to Tier 1

panels. Some recommendations will also be helpful to applicants and will need to be incorporated into the guidance provided to applicants.

The additional suggestions for examples of public benefit were: environmental impact (e.g. health planning for pollution); equality, diversity or inclusivity (EDI) issues. It was noted that while HSC-PBPP does not want to duplicate work or decisions taken elsewhere about EDI issues (e.g. funders or ethics committees), it is important that these are drawn out where it is a key element. How can this be fed back to key research funding bodies?

It was suggested that the articulation of what we mean by public benefit would be a good topic for a future development session, possibly as a joint session with Tier 1.

The committee agreed that for the audit outcomes, all are content that Tier 1 has been operating in a good manner.

ACTION 29-11-22 / 03: Suggested changes to Tier 1 panel guidance and ToR
ACTION 29-11-22 / 04: HSC-PBPP website to be updated with Tier 1 Audit Report Executive Summary and additional information for applicants
ACTION 29-11-22 / 05: MA to bring together a joint session for Tier 1 and Tier 2

3.3. *HSC-PBPP Communications Plan*
A Communications (Comms) plan was provided for the committee's comments.

It was noted that NHS boards produce annual reports. Could HSC-PBPP provide a summary of the HSC-PBPP Outcomes for inclusion in NHS Board Governance Reports? This could be sent with the March Outcomes Report.

How do we give stakeholders, particularly the public, more regular updates, e.g. about EDI or safeguards for data?

It was agreed that the Ops group should prepare a couple of set paragraphs that could be made available for these purposes.
ACTION 29-11-22 / 06: TS / MA & Ops group to discuss

3.4. *Unlocking Value of Data (UVOD): Discussion of Principles*
The draft principles are available here: [Digital Draft principles for unlocking the value of Scotland's public sector personal data for public benefit - Digital (blogs.gov.scot)](#)

This was to look at the draft principles produced by the SG group looking at Unlocking the Value of Data (UVOD).

The general response was the principles are broadly in line with what has been previously discussed by HSC-PBPP regarding commercial access to data, but don't go far enough to address the practicalities nor the safeguards and controls that would be required for providing personal data to commercial organisations. The definition of public benefit would

need to be clear. The principle of 'Do no harm' is within the principle of collecting data, however, public sector data is usually collected to provide a specific service and so is administrative data and not 'research ready'. Requiring public sector organisations to collect data specifically for research or external organisations would require resources and a clear legitimate purpose. Some of the gaps previously identified have not been addressed.

The committee agreed that the Chair and manager of the Independent Expert Group should be invited for the development session at the next committee meeting.

ACTION 29-11-22/07: MA to pull together feedback; and invite to next meeting.

4. Development Session
Scottish Medical Imaging update https://www.youtube.com/watch?v=fdM8y2RkFM8

Jackie Caldwell (JC) gave a presentation of the Scottish Medical Imaging to allow the committee to be updated on this work.

Questions from committee members:
- What about Intellectual Property (IP)? What mechanisms are in place to allow algorithms to be shared?

There are ongoing discussions about IP: e.g. if a company offers a discount of any product to the NHS, how genuine is any discount and how that could be verified?

- What about commercial access?

Other discussions regarding commercial algorithms in National Safe Haven running on real world data and the safety mechanisms that are required, especially if the company does not want the algorithm scrutinised. Work with iCAIRD is to define the governance arrangements of SMI as well as the potential development of an artificial intelligence (AI) hub for Scotland.

- There was some early research work looking at governance when SMI was first established, particularly around image data. Are there any advances from this early work, particularly relating to privacy and security?

There is a UK-wide workshop for looking at this. Lots of work looking at Natural Language Processing (NLP) but it is context-specific.

- There is a need to continue to reduce the impact of adverse events. Technical research in this area should be in step with privacy research and protection of confidentiality.

The University of Edinburgh is using NLP to analyse soft language in structured reports so that they can be routinely reported.

LR thanked JC for an interesting and helpful presentation and asked for the slides to be circulated to committee members.

ACTION 29-11-22 / 08 Slides will be circulated with committee members.
ACTION 29-11-22 / 09 Committee members are invited to give feedback to JC

5. For Information

5.1. Scottish Government update on Digital Data Strategy.

Ryan Anderson (RA, Policy Officer from Scottish Government [SG]) gave an update on the Digital Data Strategy. The slides for this presentation were circulated before the meeting.

The aim is to improve access health and care data, particularly with recording and collection and appropriate ways for access for research. A formal consultation has taken place with engagement with many different groups.

From the consultation key themes have emerged:
- Ethical approaches to data is of primary importance and should affect all subsequent decisions. It includes a commitment to address inequalities and human rights.
- Data access would require the right access at the right time. A digital front door might be through the Health and Care website or app.
- Technology and infrastructure is required to support the health and social care, with the best use of available data. SG would set out how and when to employ what technology.
- Skills, talent and culture will include SG and NHS Education for Scotland's (NES) support to expand the use of digital and data across the NHS.
- Creating insight from data will include the internal use of data for service improvement and statistical analysis. There is a joint commitment with PHS to give context to statistics that are released.
- Industry, innovation and research: there is recognition that health and social care data are a national asset and should be used to benefit the population. Quicker access to data is required. Public trust in the use of data needs to be increased, especially for/by industry. People tend to worry about nefarious uses of data by industry.

IG & IT security interventions are being discussed:
- Data standards and interoperability is required. SG will create guidelines for governance and decision-making for data both for data owners and IT suppliers.
- The National IG programme of work aims to streamline and balance governance, creating code of conduct for privacy by design for partner organisations. A Cyber Centre of Excellence has been set up to address cybersecurity strategy and standards.
- Decluttering the IG landscape by developing a federated model of IG, while still respecting local needs
- Co-producing solutions with public and partners to provide truly transformational outcomes
- A digital and IG maturity assessment process is being developed, which will scale up what has worked well for other areas.

The methods to put all this Digital Strategy in place will be done in an iterative manner. At the moment the plans are high level and will be reviewed annually. The detail will develop

with time, but will be in this general direction of travel. There is a National Data Board for Health and Social Care being set up under SG leadership.

Next steps will include:
- There is an aim to publish the Strategy in February 2023
- Impact assessments of topic areas
- Governance review and sign off: Strategy Board, National Data Board, COSLA and health and social care boards

The committee members thought this was a helpful update. A few comments were made:
- Caution against any attempt to overstate any industrial development beyond partnership.
- What safeguards are in place to ensure health data to remain excluded under trade agreements with other countries? UVOD has some principles in development and HSC-PBPP will feed back to them.
- Patient identifiable information will be used by environmental health colleagues. These will be included in the Health and Care outcomes in later iterations of the strategy.

LR thanked RA for an interesting and helpful presentation and requested that the Ethical Principles mentioned could be provided to the Committee.
ACTION 29-11-22/10: RA asked to share the ethical principles mentioned.
ACTION 29-11-22 / 11: Committee members are invited to give specific feedback to RA.

5.2. Panel Manager Report
This report was circulated for information. There were no comments.

5.3. RDS update
This report was circulated for information. There were no comments.

5.4. HDRUK update
This report was circulated for information. There were no comments

6. Any other Business
No other competent business was brought to the committee.

Date of next meeting: Thursday 26th January 2023, 09.00-12.00

Action List

Action Reference	Item No.	Action	Responsible person
29-11-22/01	2.2	To update ToR regarding alternative delegate.	TS / MA / Ops group
29-11-22/02	2.2	To update Access to GP data paper with any progress for next meeting.	MA
29-11-22/03	3.2	Update to Tier 1 panel guidance and ToR with suggested changes from Tier 1 Audit Report.	MA
29-11-22/04	3.2	HSC-PBPP website to be updated with the Tier 1 Audit Report Executive Summary and additional information for applicants.	PD / MA
29-11-22/05	3.2	Coordinate a joint session for Tier 1 and Tier 2 on public benefit.	MA
29-11-22/06	3.3	Implementation of the Comms Plan	TS / MA / Ops group
29-11-22/07	3.4	Provide feedback to UVOD on draft principles and invite to next meeting.	MA
29-11-22/08	4	SMI Slides will be circulated to committee members.	MA
29-11-22/09	4	Committee members are invited to give feedback on SMI to JC.	ALL
29-11-22/10	5.1	SG Ethical Principles to be shared with committee members.	RA
29-11-22/11	5.1	Committee members are invited to give specific feedback on the Digital Strategy to RA.	ALL