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

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

Present:	Dr Lorna Ramsay (Chair) (LR)
	Dr George Fernie (GF)
	Kenneth McLean (KMcL)
	Professor Alison McCallum (AMcC)
	Penni Rocks (PR)
	Dr Tara Shivaji (TS)
	Professor Colin McCowan (CMcC)
	Martin Bell (MB)
Apologies:	Martin Walsh (MW)
	Dr David Felix (DF)
	Carole Morris (CM)
	Alan Ferrier (Al F)
	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. The meeting is not quorate therefore any decisions to be made will be followed up and ratified by email.

Gemma Wilson (GW, from Scottish Government) joined the meeting, to give a presentation on the SG Data Strategy. Mark Simpson (MS, also from SG) also joined the meeting, as he is the Communications Manager for the Data Strategy

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

2.1. Minutes of meeting held on 12 April 2022

These were approved as a true record but will need to be ratified by missing members.

ACTION 29-06-22 / 01: MA to ensure minutes are ratified by rest of committee

2.2. HSC-PBPP Committee Action Log

The Action log for 2020/2021 is now complete. The new action log for 2022/2023 has been started.

3. Panel Manager Report

3.1. Tier 1 Audit

The Tier 1 Audit is done yearly, although this was not done during COVID. MA has written out instructions for this year's audit and hopes all is clear. However, any questions please get in touch. These applications will be sent out by the end of July. It is hoped the report will be ready for the meeting in November 2022.

ACTION 29-06-22 / 02: MA to send out applications for audit

3.2. Committee personnel update

MA has received one enquiry, but still struggle to find people.
LR asked if anyone thinks of any potential lay representatives to let MA know.

3.3 Online form update

A brief update: this is progressing slowly but is more complicated than just creating an online electronic form. This requires an applicant management system, so that applications can be accessed and amended before submission to HSC-PBPP, during the review process and after approval so that amendments can be requested. Each application will need to be accessed by one or more of the applicants. Various conversations and meetings are in progress.
MA will update at the next meeting.

4. Updates for committee

4.1. Scottish Government update

PR gave a brief update and Gemma Wilson gave a more comprehensive update about the SG Data Strategy and its development. This follows on from the previous presentation given by Imme Jones. This update is about the consultation process.

Context: Data strategy has been updated in light of refreshed Digital Health and Care Strategy, which aims to improve the use of data to improve health and care in Scotland. This would include: People having greater access to their own health and social care data; better ways of recording data to improve service delivery and using data to improve working and treatment.

Consultation: for this consultation, 70 workshops and public presentations have taken place since Dec 2021, engaging with 700 people.

Feedback has been analysed under the following themes:

- Communication and engagement
- Data access and control over own data
- Technology and infrastructure
- Talent & culture
- Ethical approaches to data

- Industry and innovation
- IG and security
- Data standards and interoperability

The consultation and reporting take an iterative approach, starting with ground work and the driving principles. The first iteration of the report sets direction of travel for use of data. The idea is not to stop work currently ongoing but to align with those things.
The 'deliverables' of the Strategy need to be clarified and defined.

Public consultation now live on citizen space, and aims to publish the first report in in Nov 2022.
https://consult.gov.scot/digital-health/data-strategy-for-health-and-social-care/

Questions and comments from committee members:

- What about the importance of data held by the Third sector who are part of multiple-disciplinary teams who also need to share data? SG promised to deliver in 2007.
- There is a difference between patients and public knowing and consenting to share data and what that actually means. Is this a legal basis or more about general agreement and transparency to the public?
- Local authorities hold a lot of information for health purposes but these are not held within the formal health framework. How will this be addressed in terms of infrastructure and governance?
- There is some resistance to appropriate sharing to data. You will need mechanisms to keep the public and professionals on board. The UK Caldicott Forum when looking at other federated data platforms for data sharing has highlighted concerns about communications being a bit light and complaints raised.
- What about wider agencies, where health can be important such as justice settings of prison and police? Rights-based considerations may be affected by these. Have these been addressed?

Response from GW, PR and MS:
The Strategy aims to provide leadership on the approach and set out what is the way forward for Scotland.

- Regarding the wider agencies, this is more than just approving for health and social as the wider benefit to public is important e.g. housing, homelessness, employability and how these can be addressed on a wider scale. Will focus in on health and social care first and widen out later, especially to look at inequalities and sharing data for justice purposes.
- Aware of that NHS England and GP data has driven the need for engagement. Mark Simpson is the Communications Manager for the team and communication is a key part of the development of the strategy.
- People hesitant with data sharing is a common problem but the Strategy will align with the national IG programme of work and should address some of the issues raised. Health care is less risk averse than social care where sharing is more disparate.

- The National Care Service overarches everything and will also address engagement with the third sector.
- Engagement with the public regarding access to their data and what that will mean for them. People cannot have full access and control over their data but what access they do have must be appropriate and need to give clear expectations. Each service will need to define the dataset for which people can access and have control, and this will differ for each service. The use of the word consent has different meanings in ethics and data protection. There will be some instances where people will identify themselves, but there is a need to be clear about what people will want to be shared and what not to be shared. People need to feel that data is control managed suitably.

LR noted that Albert King previously spoke to HSC-PBPP about the work they are doing regarding what is public benefit for research and innovation and especially commercial access. There are some things with which this committee grapples for consistency. Is there anywhere in the data strategy for a position to be taken on this?
MS responded that the communications and engagement work would provide the assurance and confidence that people need, not just for processes but the general culture too.

LR thanked GW, MS and PR for their time and input and looking forward to more specifics to come to future meetings.

5. Application Matters

5.1. Question on remit of HSC-PBPP for further use of data provided from NHSS and approved by HSC-PBPP

An SBAR had been circulated as a separate document. The general response was that:

- Any application for NHS data must state what they will do with the data to fulfil the aims and objectives of the application. Any amendment request must be within the scope of that application.
- Once the data has been disclosed it is in the public domain and therefore cannot be the responsibility of HSC-PBPP.

LR confirmed that the response from the Tier 1 panel was appropriate.

5.2. SBAR for ongoing use of GP data for COVID19 surveillance and research

Recent discussions with one of the Primary Care GP Leads have highlighted concerns from GPs regarding the ongoing use of individual-level GP data, now that the emergency measures for COVID19 are no longer in place in Scotland. These data were extracted and used to support the EAVE II programme of COVID19 surveillance and research. The concerns raised related to the legality of the ongoing hosting of the GP Read-cluster data by Public Health Scotland (PHS) and the provisioning and use of these data by PHS and the wider research community.

Responses from committee members:

- The pandemic is not yet over, so removing access to GP data at this point would not be helpful as there are still actions required under the directive.
- GPs are joint data controllers with health boards.
- An approach would be to ask what are we trying to do with the data and how will it be of benefit to patients? Can we keep going with sharing data? A process for use of GP data was put in place and managed by HSC-PBPP with GP ratification. Now would be a good time to look at the process again with joint controllership of NHS Boards with GPs.
- It is appropriate that these questions have been asked and good points have been made. Feedback to the GPs is that use of the data should not just stop but need to have longer term discussions. Need further feedback from other GPs and need to get something more formalised than the interim approach.
- We need to be pragmatic and sensible and would expect those who have the data would follow usual IG processes. This is all part of the wider work for access and use of GP data.

Further discussions with the GPs are required.

ACTION 29-06-22 / 03: LR & PR to progress discussions with GPs

5.3. <u>2021-0180 Pell complaints</u>

This paper was to inform the committee of the complaints that had been received at PHS from the use of Test and Protect data for recruitment for the above application. The nub of the complaint was that the people did not know how their data was being used and thought it had been shared inappropriately.

LR agreed, helpful to get this type of feedback. This application was using a new way to approach potential participants. This feedback must Inform approaches for subsequent applications. The Policy Decisions and Case Law Principles document needs to be revised and updated in the light of this feedback. Need to address these things for future applications.

LR asked MA to consider if any of these aspects should be revised and update of precedent for helpful learning.

ACTION 29-06-22 / 04: MA & TS to consider how this feedback could be used for helpful learning

6. Any other business

No other business was raised.

7. Date of next meeting

The next meeting will take place on 28th September 2022.

ACTIONS

Action Reference	Action	Responsible person
29-06-22 / 01	Ensure minutes from the meeting of 12/04/2022 are ratified	**MA**
29-06-22 / 02	Applications for Tier 1 audit to be sent to committee members for review and return within 6-8 weeks	**MA /ALL**
29-06-22 / 03	To progress discussions with GPs about use of GP data provided for EAVE II and COVID research.	**LR & PR**
29-06-22 / 04	Update the Policy Decisions and Case Law Principles in light of complaints for 2021-0180 Pell application. Consider how these can feed into helpful learning.	**TS & MA**