

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

## Minutes of the Committee meeting held on 26<sup>th</sup> January 2022 by MS Teams

Present: Dr Lorna Ramsay (Chair) (LR)  
Dr Tara Shivaji (TS)  
Dr George Fernie (GF)  
Kenneth McLean (KM)  
Professor Abbe Brown (AB, from 2pm)  
John Woods (JW)  
Martin Walsh (MW)  
Professor Alison McCallum (AMcC)  
Professor Colin McCowan (CMcC)  
Dr David Felix (DF)  
Carole Morris (CM)  
Alan Ferrier (Al F)  
Penni Rocks (PR)

Apologies: Martin Bell  
Dr Angus Ferguson  
Dr Mark McGregor

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

### 1. Chair's Welcome

The chair welcomed all to the meeting. Mark McGregor Caldicott Guardian for NHS Golden Jubilee National Hospital, who is joining the committee as a new Caldicott Guardian was intending to observe at today's meeting but was not able to attend.

This meeting is quorate.

Conflicts of interest: there were no serious conflicts of interest disclosed, but it was noted that:

- For Item 5 (2021-0313 McVie) TS has been supporting the research team with this application so would like to be recused for decision-making.
- AMcC was previously involved in Scottish Medical Imaging Oversight Board and is happy to be recused from any decisions making.
- LR was also involved in earlier discussion about Scottish Medical Imaging.

It was thought that both AMcC and LR could still take part in any discussion as they have no current involvement and any previous involvement would give a helpful perspective.

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

#### 2.1. Minutes of meeting held on 16 November 2021

These were approved as a true record with only two minor corrections.

- Typo in Item 4.4 New Data Strategy, paragraph 2 line 3 remove 'to'.
- Typo in Item 4.6 paragraph 2 line 2: "RDS Aims to facilitate 'in' public good" replace 'in' with 'for'

**ACTION: 26-01-22 /01: MA**

## 2.2. HSC-PBPP Committee Action Log

The majority of actions are now complete. Action 16-11-21 / 01, previously carried over from June 2021 was further discussed as a number of helpful suggestions had been made.

LR asked what, if anything, needs to be taken forward by the Ops Group?

It was noted by several members that the role of RDS is not yet clear in relation to the suggestions made. This would be for future discussion.

PR noted that discussions have been started about National Clinical Trials, challenge about approval process. In addition, the SG IG review will review where things will sit (e.g. HSC-PBPP). Everyone to be involved in discussion to ensure no duplication and provide effective efficient service and what would be a practical way to take this forward.

CM said that RDS was setting up a Research User Forum to take things forward and was still establishing long-term plans. The RDS User Forum would be a good platform to get suggestions into RDS.

KMcL asked about the vision to have data holdings, streamlining some information governance for less complex research projects. For example, how would it work with commercial applications?

CM explained that all applications would come through an eDRIS co-ordinator for all projects before going to either a PBPP or RDS. The data holdings are the research-ready data that will be a subset of the bigger datasets. With agreements in place up-front, these would be for more straight-forward applications and the more complicated projects approved through the PBPPs. eDRIS will continue to provide the customer interface.

## 3. **Matters Arising**

### 3.1. Committee personnel update.

Dr Mark McGregor, Caldicott Guardian (CG) of NHS Golden Jubilee National Hospital will be joining as a new CG and had hoped to observe at today's meeting. This still leaves one vacancy for a CG role on the committee. The committee is still looking for one more lay person.

### 3.2. Application 2122-0054 McEwan resubmission

From previous committee a letter was sent to the applicant with information as to what needs to be addressed in any resubmission. A resubmission was received in December 2021 but not everything was addressed. A sub-group of the committee met with the applicant and more understanding gained from this meeting. A different model for the business as usual aspect of the application was proposed. A follow on meeting has been scheduled to explore further.

The applicant has requested that they would like start creating of the dataset before full approval of the resubmitted application, as it is not at the stage for approval or approval with conditions.

LR asked for views as this has not been approved with conditions as yet. Can we let them do this work, without addressing the other points previously made?

A discussion took place and LR summarised comments and discussion:

- HSC-PBPP can understand that it takes time to design, build an asset and have it in place and can see why they would want to get on and do this work.
- However, the committee is still concerned around some areas, particularly Public Engagement and recognising the need for a parallel business as usual asset to be developed.

LR suggested that a way forward would be to state that we support starting this work but they need to reply in writing, confirming that they will not use the data at all for anything, and it will be a 'black box'. They will also need to confirm in parallel the development of the research asset in the Safe Haven, progress the public engagement and asset design, with a specified timeframe. They will need to keep the committee updated and acknowledge that if we then decide they have not met the conditions, there is a risk they may need to remove the health data. There needs to be recognition that they are moving forward at risk and for them to write back to us and accept our conditions.

All agreed with this proposal.

**ACTION 26-01-22 / 02: LR, MA and TS to compose a letter outlining all the requirements.**

#### **4. Updates for committee**

##### **4.1. Panel Manager Report**

Report for information only.

##### **4.2. Policy Decisions & Case Law Principles**

Updated report for information only.

##### **4.3. Scottish Government update**

PR updated the committee on the Scottish Government (SG) Data Strategy.

Imme Jones (IJ) from SG joined the meeting.

Development of a new Data Strategy led by IJ who presented to the committee. The slides will be emailed after the committee meeting.

**ACTION 26-01-22 / 03: IJ and MA to send and distribute slides.**

Questions raised:

GF asked about the consultation process, so important for members of public, are they involved just now or further down the line?

IJ: Yes, further down the line the public will be involved and consulted. They are very mindful of this.

GF stressed the importance of absolute transparency on what is happening with the data.

AMcC raised 2 points: 1) related to points raised on SG mechanisms to help with early design and engagement and 2) engagement from local authorities.

IJ stated they are engaging with all stakeholders and involving as many of the people affected by this as much as they can.

KMcL commented on the presentation, the term data users, he feels should be beneficiaries, who we should be thinking more about.

LR asked who was involved with the Data board? Is there anyone from NHS Scotland involved in this?

IJ will flag this up and report back to the Committee.

LR thinks this group will be able to help with future stage.

**ACTION 26-01-22 / 04 MA will pick up with PR and IJ with date of the next meeting.**

#### 4.4. Update from HDRUK

CM will provide a fuller update at next meeting. She is currently working with HDRUK on a data use register.

#### 4.5. Update from Research Data Scotland (RDS)

Roger Halliday (SG Chief Statistician and CEO for RDS) joined the meeting for a short time but due to overrunning from other items there was little time for discussion before he had to leave.

A paper had been circulated regarding the proposed SECURE Process: Definition and Description. Roger gave a brief explanation of the paper: One of the key purposes of RDS is to provide faster, easier access to public sector data in Scotland for research purposes. The focus for 2022 is to simplify data access for researchers and how, at each stage, RDS can make things easier. He is keen to broaden the data range available around individual topics and produce linked research resources, which have high value. IG is a key element and need to ensure Scotland is in line with other parts of the UK and the processing systems are managed.

LR encouraged committee members to put their responses to the paper in writing. This paper will come for a wider discussion at the next committee meeting, as the main topic for discussion for the Development Section. The aim would be to look at this from the HSC-PBPP perspective, especially looking at the current HSC-PBPP processes. With this RDS proposal it needs to be clear what elements will and will not change.

The NHS Scotland CG Forum has a new Chair and will be keen to be informed of the plans and to link in with HSC-PBPP on their thoughts.

LR asked RH to articulate how the proposal will affect HSC-PBPP at next meeting.

**ACTION 26-01-22 / 05: ALL to review paper and comments to MA by 4<sup>th</sup> Feb. MA to add to agenda for next meeting as main development session.**

**ACTION 26-01-22 / 06: LR to introduce RH to CG Chair**

## 5. Application for Review 2021-0313 McVie

GF as lead reviewer outlined the issues raised for discussion and questions for the applicant.

The application requests use of NHS data for non-health research. The proposal is to understand the relationship between health-related and other vulnerabilities in compliance with the corona virus regulations, specifically using police fixed penalty notice (FPN) data as the proxy for the measure of non-compliance, focusing on two questions:

- i. Did the underlying health related and other vulnerabilities increase the likelihood of some individuals being subject to police enforcement?
- ii. Did those who were subject to such enforcement for failing to comply pose an increase public health risk in terms of spreading the virus?

The Public benefit is that it will increase the knowledge of potential impact about the pandemic and the regulations on members of the public and the project will provide individual insights about the impact of introducing criminal justice sanctions during a pandemic.

The applicant, Professor Susan McVie was welcome to the meeting and GF led the discussion. Prof McVie gave a short presentation and with the ensuing discussion, covered most of the points raised.

GF and LR thanked the applicant for a very helpful presentation and discussion.

Further discussion took place. It was agreed that the Committee are supportive to approve this application with a few conditions:

- Evidence of support from senior member of PHS
- Add in some of the content from the presentation for further clarity
- Allow the Directors of Public Health to have view of the outcomes
- More information on how the outcomes will be disseminated to the wider public
- Recommendation that the responsible organisations should review their privacy notices.

**ACTION 26-01-22 / 07: MA /LR to compose and send response from the Committee**

## **6. HSC-PBPP Development Slot**

The committee were updated on some of the recent work on the use of anonymised Scottish Medical Imaging (SMI) data for research. Simon Fleming (SF, Research Manager) and Jackie Caldwell (JC, Information Consultant) joined the meeting to do this. Due to overrunning from other items there was little time than anticipated for comprehensive discussion.

Jackie gave a short presentation to set the scene about what medical imaging is and some of the permissions that have been obtained from HSC-PBPP. This is a long-standing project, which started some years ago and with a recognition of the imaging data that exists and the opportunity this could give to new ways of delivering research and developments. The initial stage was that the data was stored in 'black box' for initial processes to anonymise the data. Use of the anonymised data has been approved for specific projects, some of them as exemplars or for development work.

Related to the use of SMI data some protective measures have been carried out:

- Additional clauses have been added to the eDRIS User agreements to outline procedural, legal or technical constraints within NSH.
- Researchers can use own software in specific areas of NSH.
- There are guidelines for Artificial Intelligence (AI) development in NSH and size of algorithm model and size of image data used, to prevent smuggling out of extra information. This has led to a necessary update of the disclosure checking processes for eDRIS.
- Ongoing work with cyber security within NSH.
- Prevention of facial recognition includes removal skull from brain scans that only need soft tissue images. If skull info required, then can be part of HSC-PBPP approval.

LR thanked SF and JC for a helpful presentation. HSC-PBPP will expect to see some of these applications coming through. The governance would be useful for us to understand.

**ACTION 26-01-22 / 08: JC to send slide set and paper. An invitation to the June committee meeting to help for when applications will start to be coming through HSC-PBPP.**

## 7. Any other business

AMcC notified the HSC-PBPP committee that access to confidential data for COVID-19 research was approved for processing quickly via a Control of Patient Information (COPI) notice during the pandemic (e.g. permission was given to bypass the need for the usual legal avenues like consent and Confidentiality Advisory Group (CAG) approval). The current COPI notice to do this will expire on 31<sup>st</sup> March 2022. For Scottish health data, this was not relied on as HSC-PBPP implemented the COVID-19 rapid review process. It may affect some data from England and Wales that might be held in Scotland (e.g. in the National Safe Haven).

AMcC asked if we should be putting out a statement about this that it does not apply to the things we have approved.

Agreed the Ops Group could develop a short statement for the website.

Note added to minutes: the COPI notices have been extended to end of June 2022.

**ACTION 26-01-22 / 09: Ops Group**

## 8. Date of next meeting

The next meeting will take place on Tuesday 19<sup>th</sup> April 2022.

This date has since been changed to **Tuesday 12<sup>th</sup> April 2022**

## ACTIONS

Action Reference	Action	Responsible person
26-01-22 / 01	Correct minor typographical errors in minutes from 16/11/22.	MA
26-01-22 / 02	A response from the HSC-PBPP committee to be sent to the applicant for 2122-0054 McEwan.	MA / TS / LR
26-01-22 / 03	Imme Jones to send slides for the SG Data Strategy update for distribution to the committee members.	MA
26-01-22 / 04	Pick up with PR and IJ with date of the next meeting.	MA
26-01-22 / 05	Review RDS SECURE Paper and send comments to MA. Add RDS SECURE Pathway to agenda for April meeting for Development session.	ALL MA
26-01-22 / 06	Introduce RH to CG Chair.	LR
26-01-22 / 07	A response from the HSC-PBPP committee to be sent to the applicant for 2021-0313 McVie.	ALL
26-01-22 / 08	Slide set and paper to be circulated to committee members. Invite to the June committee meeting to help for when applications start to come through.	JC MA
26-01-22 / 09	Statement to be drafted for end of COPI notices for use of confidential data for COVID19 research.	Ops Group