

# minutes

**NHS Scotland Public Benefit and Privacy Panel for Health and Social Care  
26 April 2018**

**Farr - Edinburgh**

**Present:** Mr Brian Houston (Chair)  
Prof Alison McCallum (AMcC)  
Prof Helen Colhoun (HC)  
Dr Janet Murray (JM)  
Dr Angus Ferguson (AF)  
Prof Abbe Brown (AB)  
Kenneth McLean (KM)  
Prof Danny McQueen (DM)  
Penni Rocks (PR)  
Ashley Gray (AG)  
Dr Marian Aldhous (MA)  
Carole Morris (CM)  
Susan Kerr, Secretariat

**Apologies:** Dr Stephen Pavis (SP)  
Dr Emilia Crighton (EC)  
David Knowles (DK)  
Dr Corri Black (CB)  
Dr George Fernie (GF)  
Stuart Law (SL)

**In attendance:** Patricia (Trish) Ruddy (TR)

## **1. Chair's Welcome and Introductions**

BH welcomed all to the PBPP Committee meeting.

BH welcomed Penni Rocks from Scottish Government as a new member of the PBPP panel.

BH informed the panel Ashley Gray is moving into a new position and is resigning from the Panel Manager role and that this will be her last meeting.

BH introduced Marian Aldhous as the new Panel Manager.

BH informed the panel that Dr Janet Murray is retiring in June 2018 and this is Janet's final attendance at the PBPP Committee meeting.

BH thanked both AG and JM for all their hard work and contributions to the PBPP Panel.

BH asked HC if she would attend as a representative of NHS Fife, which she agreed to do. EC was to attend via teleconference but sent her apologies just before the meeting. Therefore, as there were only 2 representatives from NHS Boards, the meeting was not quorate. Any decisions taken during this meeting will have to be ratified by email.

**Action MA/AG**

## **2. Minutes of the PBPP Committee dated 24 January 2018**

The minutes were approved as a correct record.

### **3. Matters arising from previous minutes**

#### 3.1 New data collections

KL was absent from the meeting regarding feedback from DPHs. To come to next meeting.

#### 3.2 Synthetic Data

SP sent apologies but no further update.

### **4. Standing items**

#### 4.1. Year End Performance Update

The year-end performance update was circulated for information only.

JM asked for it to be highlighted how much improvement there has been in time processing of applications.

#### 4.2 Policy Decisions & Case Law Principles

The Policy Decisions & Case Lay Principles document was circulated for information only.

It was requested that these go onto the website (About the Panel).

AG noted that the website needs to be completely redesigned, possibly with some professional input.

### **5. PBPP Annual Report 2016/17**

The PBPP Annual Report was circulated for information only.

AMcC stated that this report was very helpful and ask if this document can now be circulated to UK Council. AG explained that this document is public facing and can be circulated.

KM asked if this will be available on the website. AG stated that this will be available on the website.

It was agreed that a circulation list of who will receive this update is to be set up for future distribution. MA agreed to do this. **Action MA**

DM stated he had seen an error and AG explained she had been in touch with publications to have this amended. DM also stated that when this document becomes public facing that we must ensure the language within the report is appropriate for a public audience. MA noted to do this.

**Action MA**

## **6. PBPP Resource Scottish Government Update**

PR reported that she had met with BH in October to discuss PBPP resource. It has now been agreed that funding is available for a Band 7 Panel Manager plus additional support of 2 days per week. Both these positions have now been filled by Dr Marian Aldhous, Panel Manager and Phil Dalgleish, 2 days per week.

PR also stated that she is now a permanent member of the PBPP as the Scottish Government representative.

HC asked about additional resource for a new system being put in place for web placed applications and streamlining the PBPP process.

It was agreed there is a need for resource for this. AG explained that the system which is used by IRAS is being re-developed and the possibility that this could potentially be a solution for PBPP to join IRAS.

It was noted that resource and input needs to be available to undertake any development work as it is beyond that of business as usual. Time is required to ensure these are developed appropriate to support PBPP in the future.

HC asked what the PBPP OPs group was and AG explained that it is a sub group of this committee working on prioritising and planning of the work needed to underpin the operations of PBPP.

It was agreed that the latest version of the workplan for the Ops group should come to this committee.

**Action MA**

It was agreed that the PBPP Resource update should be a standing item on the agenda

**Action MA**

TR stated that the Digital Health and Care Strategy has now published and is available on the Scottish Government website.

BH raised the question of who is PBPP accountable to within the Scottish Government. It was agreed that the committee needs confirmation of where this panel sits within the Scottish Government.

## **7. Commercial Access to Safe Havens**

In the absence of Steve Pavis, AG asked for comments on the changes made to this paper and asked for comments on the appropriate direction of this paper.

Requests for commercial access to unconsented de-identified data have come into the PBPP so we need to agree how we handle those requests. PBPP has to scrutinise but raises fundamental questions on NHS policy on commercial access to NHS data, both nationally and at local level and under which bounds could this be allowed.

AM said that we cannot allow commercial access to data that would not be allowed to NHS staff and we need to keep the public trust.

HC asked if this level of strategic direction was in the remit of the PBPP? Does this assign value to NHS data? How does the NHS nationally manage the discussions on IP and pricing contracts that may arise as a result of the use of NHS data. We need to be clear about the user groups and the principles and rules for access to the data.

BH pointed out that some NHS boards are already working with Scottish Enterprise and other companies, sharing processes rather than data but the principles overlap.

AB suggested that IP agreements are a bit late on in the process.

HC asked if IP is in the remit of the PBPP, as we are tasked to encourage public benefit to be returned to NHS.

KM raised the need for ensuring good communication to the public and the need to maintain public assurance of security and privacy of their data.

DM suggested that applicants should report back to the public via a lay summary of their projects and an impact statement via the PBPP website.

HC said that researchers spend a lot of time reporting on impact statements for grant funding bodies and public engagement process and these could be included for PBPP. Should we also include annual reporting?

AG said that end of project reporting (EPR) is in place but annual reporting on projects cannot be resourced. Currently EPR more of a governance check and record of any dissemination, but could add in impact statement as part of the report. Impact statements could be added to the website, but as already highlighted the website needs some expert input for its redesign.

PR said some of this was being addressed in the new Digital Health and Care Strategy from the Scottish Government and suggested that a separate session/workshop on the digital strategy might be useful for the committee? She will send the documentation and possible dates to the panel manager for sending round.

**Action PR/MA**

PR also pointed out that a new NHS/SG Board was being set up to oversee the implementation of the Digital Health and Care Strategy components.

Panel agreed that:

- That the paper needs to be updated to reflect the discussion and take into account the new digital health strategy

**Action PR/HC/SP**

- The panel needs to work through the recommendations of this paper for implementation, even if it is only a transition position until the new board gives specific direction on governance regarding commercial entities.

- That the panel is represented by someone from the PBPP on to the IG for the new Digital Health and Care Oversight board.

## **8. HFEA & PBPP Relationship for Scottish Applications**

CM presented a proposal outlining a similar relationship to that CAG has with HFEA in relation to advising on the IG of Scottish specific studies requesting access to HFEA data..

Based on the low volume of applications and the likelihood that the majority of applications to HFEA will also involve a linkage to NHS Scotland data the recommendation would be that PBPP consider acting in an advisory capacity to HFEA and that all Scottish originated studies are advised to apply to PBPP in the first instance in the same way that they do in England and Wales under the 2010 regulations. This will also provide an opportunity to monitor the use of HFEA data within research in Scotland.

All in support and agreed.

## **9. PBPP Workshop Scenario 5**

This was brought to the panel for clarity regarding use of CHI for processing. This arose out of a study of pregnancy that applied to PBPP for access to CHI from other health boards, in those instances when the patient gave birth or required treatment outwith their own health board. This was a study of consented patients who gave identifiable to the researchers as part of the study. However, as it was CHI that was being used for obtaining the patient data, people had thought an application to PBPP was required. Other applications had raised the question: if CHI was then used in the University (e.g. for clinical trials) did it have to have a PBPP application? CHI is not just an index number as it contains information on date of birth and sex of patient, such patient identifiable data are also collected for consented patients.

The panel agreed that in the scenario of consented patients, clinical data may be obtained from other health boards using CHI and can be stored at the University (on suitably secure servers). Therefore consented clinical trials or research studies do not need to come to PBPP (this is written in the Terms of Reference for PBPP) and each study comes under the IG scrutiny through local R&D.

## **10. GDPR Update**

The PBPP paperwork for compliance with GDPR is all in place and will be ratified at the Ops Group on 3<sup>rd</sup> May 2018. The Tier 1 panel meetings before 25<sup>th</sup> May are now full so an early release of the new form is in circulation. The new ratified form will be on the website from the week of 7<sup>th</sup> May 2018.

There should be no major changes for the committee, apart from seeing any studies that are referred from Tier 1 on a new form.

The responsibilities for receiving the data remain under the onus of the receiving organisation.

The question was raised as to how long panel members can store the applications and their own reviews. This will be clarified at the Ops Group on 3<sup>rd</sup> May.

**Action MA**

## **11. 1516-0472 British Society of Urogynaecology (BSUG) Database – Complaint to MSP**

A complaint has been directed to an MSP regarding an application to BSUG. The application was to allow the transfer of consented data from national health boards to a central registry run by the BSUG for an audit/study

The application was approved at Tier 1 subject to conditions in 2016. These conditions have not been satisfied and Scotland should not be contributing to this study/audit. Applicant applied on behalf of Scotland and applicant finding it difficult to gain access to assistance to meet the condition imposed by PBPP. Tier 2 agreed that the condition was appropriate. BSUG chairman has written to the Cabinet Secretary.

The panel needs to be aware as this may lead to some scrutiny processes.

JM raised a query as to whether the panel should review conditions applied to approvals. It was noted that the practicalities of this is not sustainable. .

The conditions added to approval were:

- Security questionnaire regarding BSUG.
- Information sharing agreement. This is the sticking point. Has the data-sharing agreement been finalised – by local boards. BSUG not willing to comply with local agreements. National agreement had been 'promised' but did not come forth.
- Consent form and letter should be better for Scotland.

It was suggested that a lesson learned from this is to look again at the requirements for data sharing agreements. This is ongoing within the Ops Group and we will try to get something ready for a future committee meeting.

**Action MA**

## **12. AOB**

No other business was raised.

**13. Date of next meeting:** 26 June 2018