

minutes

NHS Scotland Public Benefit and Privacy Panel for Health and Social Care

27th June 2017

Lord Clerk Room – General Register House, Edinburgh

Present: Mr Brian Houston (Chair)
Mr Gerry Donnelly (GD)
Mr David Knowles (DK)
Prof Helen Colhoun (HC)
Dr Kirsty Licence
Dr George Fernie
Dr Abbe Brown (AB) by tele conference
Ashley Gray, Panel Manager (AG)
Jenny Scott (JS)

Apologies: Dr Hugo van Woerden
Dr Angus Ferguson
Prof Alison McCallum (AMcC)
Prof Danny McQueen (DMcQ)
Dr Stephen Pavis (SP)
Dr Corri Black (CB)
Dr Janet Murray (JM)
Carole Morris, eDRIS representative (CM)

1. Chair's Welcome

BH welcomed all to the PBPP Committee meeting and noted apologies received.

BH informed the group that Hugo Van Woerden is no longer a member of the PBPP Committee and Dr George Fernie has joined the Committee in his role as Deputy Caldicott Guardian from NHS Healthcare Improvement Scotland.

2. Minutes of PBPP Committee meeting dated 18 April 2017

The minute was approved as a correct record.

3. Matters arising

3.1 *Interview for Lay Member*

AG reported that an interview had taken place to recruit a Lay Member to the PBPP Committee. The interview panel found the applicant to be a strong candidate for the role and intend to offer the position to him. AG advised that she had not been successful in contacting the candidate as of yet.

3.2 *1516-0560 McDermaid*

AG reported that there has been no further correspondence with the applicant(s) to date, but believes that they are exploring the options available to complete the data analysis within the UK. The Committee agreed to await further communication from the applicant.

3.3 *PBPP Panel Development SLWG: Update*

GD reported that there had been no further progress with the merging of NHS Scotland PBPP and SG Stats PBPP

3.4 *PBPP Workshop*

GF asked about the upcoming PBPP Workshop. AG advised the committee of the content and agenda for the day and that a diary invitation will be extended to GF. Email invitation to be sent to GF.

Action AG

3.5 *Synthetic Data*

KL provided an update on the status of the Synthetic data request previously discussed in January. KL advised that she is following up in Janet's absence and that an NSS Information Security reviewer will undertake an assessment of the platform. The applicant has been asked to complete a separate document to enable the IS reviewer to carry out the assessment.

3.6 *New National Data Collections*

KL advised that paper is still under review and discussions are continuing with AMcC and it is hoped that this will be finalised very soon. BH requested that the final version of the document is ready for the next meeting in September

Action KL

4. Performance Update

The performance update was circulated for information only.

4. Review of Tier 1 Applications

AG reported that the workshop for the review of Tier 1 applications had taken place, bringing the audit of Tier 1 applications to a close. AG presented the Outcome Report for comments and advised that she has circulated by email round the full committee prior to this meeting..

DK and KL suggested that a lay summary should be made available on the PBPP website, with the full report available on request. HC also suggested that a similar summary be prepared for the Chief Executives with a link to the full report included. AG and JS agreed to write a summary for both internal and external purposes.

GD asked how often this exercise should take place. AG explained that due to the commitment required for preparation and participation in the workshop alternatives should be explored.

AB noted the value in a group exercise, whilst DK suggested that randomly selected Tier 1 approvals should be reviewed at every second Full Committee meeting. HC queried if the annual training day may also present an opportunity to discuss or review applications as part of an audit. BH also advised that a process should be proposed for the audit of Tier 2 Out of Committee approved applications.

AG and JS agreed to prepare a paper outlining future approaches to the Tier 1 application reviews and draft a process for the review of Tier 2 decisions. AG requested that those in attendance assist by reviewing and commenting on potential audit mechanisms prior to presenting to the full group at the next available meeting. .

Action AG / JS

5. PBPP Operational Group

5.1 Recruitment update

AG stated that as Hugo van Woerden has now resigned from his position within the PBPP work is underway to recruit a new Caldicott Guardian. AMc has recommended a candidate and the PBPP management team are following up on this contact.

BH suggested the Hugo van Woerden, in his capacity as Chair of the Caldicott Guardians, should assist in nominations for a replacement should the representative nominated by AMc not be feasible.

GF suggested that an outline of the induction process should be made clear to all potential candidates in order to encourage reticent applicants. GD added that the fixed term of the positions should also be clearly advertised.

DK suggested that Chief Executives should be contacted to encourage participation from all Caldicott Guardians, to which BH added that CMOs should also be involved in the process.

The Panel discussed whether the best approach is via Chief Executives and Board Medical Directors, or if persuasion and encouragement of willing applicants would be preferable.

KL agreed to request an item on the National Caldicott Forum agenda and it was suggested that this could be used as an opportunity to give Caldicott Guardians some further background on what the role entails.

Action / KL

5.2 PBPP Workshop October 2017

AG reported that the next PBPP Workshop is scheduled to take place on 03 October 2017. A draft agenda will be circulated by email for review prior to the next meeting in September as the content of the day has not yet been finalised.

Action AG / JS

5.4 End of project reporting

The documentation for the proposed End of project reporting was circulated for discussion.

HC noted some grammatical points for correction and recommended that PubMed IDs are requested in place of full articles as this will be easier for researchers complying with copyright laws. HC also recommended that PBPP seek agreement for this request upfront, at the point of approval.

AB added that a lay summary should also be requested, for publication on the PBPP website.

AG advised that the approval letter could be amended to incorporate these requests.

DK asked if interim reports should be requested throughout a project's duration, rather than follow up at the end of the project when changes may have already taken place without amendment requests necessarily having been submitted to the PBPP. AG advised that due to capacity, the End of Project Report was currently the only feasible process in terms of administration requirements and implementation. Annual reporting had been considered as a potential route and would be desirable but cannot be taken forward at the present.

GD noted that as a capacity is currently stretched that it was important to agree what, if any, action would be taken relating to any breaches reported.

AB suggested that it should be stressed to applicants that they have an obligation to report any breaches which have occurred as part of their declaration.

The Committee agreed that the proposed process was currently the most fit for purpose and should be sent to the others member not in attendance for ratification.

Action AG / JS

6. PBPP Resource

AG reported that there are still concerns relating to the capacity of Tier 1 Panels. The number of applications being reviewed is continuing at 6 applications per panel to attempt to manage the demand. A quality improvement exercise took place in May and this produced a number of potential options to deal with the increasing number of applications. AG noted that current volume would suggest the Panel will receive near 200 applications with available capacity to consider 144. The paper presents the mechanisms discussed as part of the QI exercise but that no preferred option has been identified.

AG explained that currently there is no financial remuneration for the support offered by CM and JS and that without this additional staffing resource the operation of the Panel would be significantly impacted. For example CM provides senior leadership for the Panel Manager and acts as an immediate escalation point for urgent issues. The time provided by JS enables AG to develop Panel processes as well as providing cover for annual leave/sickness.

The Committee discussed funding for personnel and a database system as the ability to process applications more efficiently would potentially help in resolving capacity issues. In terms of making efficiency gains, HC suggested that an online system could be designed to automate a percentage of the application process. The human element will need to remain but should be focused on the key areas which require subjective assessment and this could lead to more productive reviews

The Group agreed that the request for financial support should be direct at SG eHealth, who established the PBPP. In the absence of Daniel Beaumont it was unclear who initial contact should be made with. HC suggested that the academic community should also be invited support the implementation of a data management system. BH agreed to contact Graham Galt and Andrew Morris to discuss the situation.

AG commented that the IG leads within the NHS Boards are a finite resource and it is difficult to involve them further to assist with capacity issues as they already contribute a substantial amount of time to the Panel which is not protected within their normal working hours. AG also explained that efforts are made to ensure that all NHS boards are participating and that no one board is overburdened with representation.

AG agreed to draft a brief note on BH's behalf to chief executives, Chairs and Caldicott Guardians to increase / maintain awareness of the work undertaken by the PBPP on behalf of NHS boards and the expectation that IG resources are made available to the Panel.

Action BH / AG

7. Any other business

No items raised.

8. Date of next meeting

The next meeting is scheduled to take place on Thursday 5 October 2017 at Lord Clerk Room – General Register House