

Minutes

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

Thursday 19 November 2015 – Farr Institute Scotland, Nine Bioquarter, Edinburgh

Present: Brian Houston (Chair)
Prof Alison McCallum (AMcC)
Dr Angus Ferguson (AF)
Prof Helen Colhoun
Dr Corri Black (CB)
Dr Daniel Beaumont (DB)
Dr Danny McQueen (DMcQ)
Dr Janet Murray (JM)
Dr Steve Pavis (SP)
Mr Gerry Donnelly (GD) (part)
Dr Harpreet Kohli (HP)
Dr Abbe Brown (By telephone)
Nicola Starkey, PBPP Panel Manager (Interim) (NS)
Carole Morris, eDRIS representative (CM)
Susan Kerr, Secretariat (SK)

Apologies: Mr David Knowles
Dr Hugo Van Woerden

In attendance: Pamela Linkstead

1. Chair's Welcome

BH welcomed all to the PBPP Committee meeting.

2. Minutes of PBPP Committee meeting dated Thursday 17 September 2015.

The minutes from the previous meeting were approved.

Matters arising:

Risk Log – It was agreed that in the absence of the PBPP Panel Manager this should be carried forward to the next meeting and should be a standing item for future meetings.



Interim Chair Professor Elizabeth Ireland
Chief Executive Ian Crichton

*NHS National Services Scotland is the common name of the
Common Services Agency for the Scottish Health Service.*

3. Applications referred to Full Committee

Two applications were referred to the full committee.

1. Application 1516-0240-Factors Affecting Campylobacter Disease Rates in Scotland

Dr Angus Ferguson had agreed to lead on this application.

It was noted that the tone of questions raised from the Tier 1 panel were concerning and slightly aggressive and a formal apology should be provided to the applicant. It was agreed that it is very important that questions are framed in the correct way and consideration is taken with the tone of questions raised.

BH confirmed that we recognise these concerns and apologised to the applicant and his colleagues on behalf of the panel whilst the applicant was in attendance at the meeting to discuss the application.

CB also raised concern that the Tier 1 Panel's role was not to review the scientific merit of the proposal.

It was agreed that further development and training of the Tier 1 panel members was to be looked at and that the panel manager will ensure that all future responses are worded appropriately and carefully before sending on to the applicant

Action – Panel Manager

AF opened the discussion on the application and summarised the key objectives of this application.

Results from Tier 2 Out of Committee were:

7 responses were received

- 1 Full rejection
- 2 Referred to full committee
- 3 Approve with conditions
- 1 Approve without conditions.

It was agreed by all committee members that the following areas would be addressed with the applicant:

- Clarification as to whether linkage was to be carried out an individual level
- Data Flow principles – Assurance at appropriate level of security at each point in the process.

BH invited Dr Strachan and 3 colleagues into the meeting to discuss their application. BH formally apologised to the applicant and his colleagues regarding the tone of the responses from the panel reviews.

The applicant provided additional documentation to the committee members as to the data and parties involved in the project and verbally provided details regarding the flow of information and the linkage to take place.

The applicants were thanked for their attendance and left the room.
It was agreed that the committee see fit to approve this application.

The panel manager will liaise with AF to formulate an approval response to the applicant.

Action AF/Panel Manager

2. Application 1516-0226 Turner – Linkage of the SEATON birth cohort to primary care prescribing for asthma and eczema medications

Dr Janet Murray had agreed to take the lead on this application.

JM opened the discussion on the application summarising the background and key objectives of the proposal. JM explained that in the late 1990s this study was started. Questionnaires were sent out at 5, 10 and 15 year follow-up.

It was agreed by all committee members that they would like to engage in a discussion with the applicant regarding the decision not to seek each participant's explicit consent for linkage.

Dr Steve Turner – in attendance by telephone and was welcomed to the meeting by BH. JM explained to Dr Turner the committee's concern and Dr Turner provided some additional information to explain the timelines of the cohort and the information provided at each interaction.

After discussion BH thanked Dr Steve Turner for his contributions.

The group then agreed that this study has a clear public benefit and agreed to approve this application with strong conditions around the provision of information to the cohort in the future so they are fully informed on the use of their health data

The Panel Manager will liaise with JM to formulate an approval response to Dr Turner.

Action JM / Panel Manager

4. Scottish Longitudinal Survey

JM introduced Chris Dibben (CD) and CD presented background information on the Scottish Longitudinal Study to the committee members

JM explained that under an existing arrangement with the Registrar General for Scotland she is their medical advisor which is why the Privacy Advisory Committee, as was, reviewed and assessed projects which involved NHS Central Registry (NHSCR) JM would therefore like to ask the committee if they would not mind this arrangement continuing and in the absence of PAC that PBPP now take on the role to support NHSCR and NRS in the review/assessment of projects such as the development of SLS to include Justice data in their existing linked dataset or the creation of synthetic data.

GD explained, from NRS perspective that they would like to use this committee to represent NHSCR and potentially other NRS projects.

BH asked if the role of this committee should/could widen its scope. BH also asked if the committee has the appropriate representation on it at each level to support these types of applications on an individual basis to justice or if this would be a higher level.. possibly a wider strategic linkage at a wider basis ?

. DB suggested that the Registrar General submit an official request to the PBPP committee explaining what role they would like PBPP to take on and how NRS will help support that.

SP raised a concern that at the moment Tier 1 is solely made up of health representatives and may require some non-health representation depending on the scope of the request from the RG.

BH said that in principle he had no objection and that it seemed a worthwhile development on adding the justice data but that the committee would need guidance on process by which any future requests should be handled.

5 Safe Haven accreditation

PL presented to the committee members on the background of the safe haven accreditation process which was developed as a result of the Safe Haven Charter's principle around provision of a secure environment for accessing unconsented data. The accreditation of safe havens was a recommendation from Dame Caldicott. The safe haven accreditation process will assess the University environments holding NHS Data first. DB noted there was a meeting week beginning the 23rd November to discuss with all the safe haven leads. SG eHealth will carry out the assessment and review the documentation and then advise the PBPP committee who will ultimately make the decision as to accreditation or not.

DM asked how will adherence to all the criteria continue to be monitored in the future and DB responded to say there will be ongoing audit from eHealth and also through applications to the PBPP. DM asked what those checks would involve.

SP explained that all secure environments including the national safe haven will have a system security policy (SSP). The national safe haven one has in it that there will be annual penetration testing amongst other central controls including regular reviewing of audit logs on key strokes, logins etc..

6. Panel Manager Recruitment Update

CM informed the committee that Ashley Gray, the New Panel Manager starts on Monday 23 November 2015.

7. Panel Managers update – review of Tier 1 approved / rejected applications

NS reported that a total of 48 applications have been received.

24 Complete
1 Rejection
23 Ongoing

It has been agreed that the Tier 1 Panel is capped at a total of 5 applications to ensure the panel members can prepare for the panel meeting prior to the day and give adequate time at the panel meeting to review applications thoroughly. This has so far worked well.

It was noted that there was some difficulty for the panel manager to interpret some of the questions/comments being received from the Tier 2 Out of Committee reviewers to be sent on to the applicant so the Panel Manager has adapted the referral review record, completed by all the reviewers, to include not approved, please state questions for applicant here. This will assist in minimising misinterpretation going forward.

NS explained that an Operational Group has been set up and is chaired by JM. The idea of the Operations Group is to assist in the smooth running of the administrative support function, panels and committee. The committee are supportive of an operations group but see it very much as a delivery mechanism and are therefore keen to make sure that the group has the right people to deliver and that the group is accountable to the main committee. The panel manager agreed to go back to the committee with a clear ToR that includes proposed membership, frequency of meetings, lines of escalation and accountability. After the meeting a couple of panel members commented that they were keen to see the panels working as efficiently as possible and so supported the idea of an ops group but only if it was clearly accountable and delivering added value.

8. Any other business

No other business was raised.

BH thanked the committee for their attendance and apologised for this meeting over running.

9. Date of next meeting

The next meeting will take place on 28 January 2016 at New Register House, Edinburgh.