

Public Health and Intelligence



Minutes

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

19 April 2016

Waverley Gate, Edinburgh

Present: Brian Houston (Chair)
Prof Alison McCallum (AMcC)
Dr Angus Ferguson (AF)
Prof Helen Colhoun (HC)
Dr Danny McQueen (DMcQ)
Dr Abbe Brown (AB)
Mr David Knowles (DK)
Mr Gerry Donnelly (GD)
Mr Steve Pavis (SP)
Dr Hugo Van Woerden (By telephone)
Dr Harpreet Kohli (By telephone)
Carole Morris, eDRIS representative (CM)
Ashley Gray, Panel Manager (AG)
Susan Kerr, Secretariat (SK)

Apologies: Dr Daniel Beaumont
Dr Janet Murray
Dr Corri Black

1. Chair's Welcome

BH welcomed all to the PBPP Committee meeting.

2. Minutes of PBPP Committee meeting dated 28 January 2016

JM has notified the PBPP admin of a corrective action required to the minute record of 28th January 2016. 'Section 7 Resources for PBPP' has been amended to the following text:



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.*

'JM suggested the Data Management Board can review resources and the panel agreed that the Chairman should take this forward to this group'

Matters arising from previous minutes

Terms of Reference

AG reported that the PBPP website is accessible although currently under review. The amended terms of reference have not yet been published and will be updated in due course along with other aspects of the website.

Action AG

All other actions recorded in the previous minutes were noted as complete.

3. UK Wide Safe Researcher Training

A paper was circulated, for information only, on the current Safe Researcher Training in Scotland and the UK .

HC asked about guidance on approved courses and whether this information was available in the public domain.

SP confirmed that a list of all currently approved courses is available on the eDRIS website.

SP explained that there is discussion of a single approved training course across for the UK and that this is currently under review for future development.

4. Applications referred to Full Committee

Two applications were referred to the full committee for review.

4a . Application1516-0075 - Preterm Birth and associated outcomes in the Scottish population

Dr Alison McCallum had agreed to lead on this application and prepared a summary paper to accompany the application documents.

AMcC introduced the application and summarised the key objective.

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

- Clarification on independency of peer review
- Assurance on Public/Patient Engagement
- Process of research ethics
- Publication strategies and analysis plan

Dr Lambrelli and colleague joined the meeting by telephone conference to discuss her application.

A brief discussion took place on the points noted above and the applicant was thanked for their attendance by telephone.

It was agreed to approve the application subject to compliance with the following conditions.

- An independent/external academic should sit on Steering Committee to inform the scientific element of the peer review process
- No restrictions applied on the right to publish
- Papers from this proposal should be published in a Peer Reviewed Journal
- Public/Patient representative from Tommy's project should be invited to join Steering Committee as part of the public engagement exercise
- An application should be made to the Scotland A Ethics Committee
- The analysis plan should be specified and submitted to eDRIS
- The dataset created will be retained for future use by NSS/eDRIS

AMcC agreed to draft a reply to the applicant and circulate this to Panel members for comments.

Action AMcC

A further discussion then took place on the development of a number of key principles/criteria to be applied to future applications which involve commercial organisations. SP suggested that eDRIS can develop a set of terms and conditions which enshrine this agreed criteria. SP agreed to produce a paper for discussion at the next Committee meeting.

Action SP

4b. Application 1516-0022 - Understanding Society – The UK Household Longitudinal Study (UKHLS) Health Linkage

Dr Janet Murray had agreed to lead on this application but in her absence AG led this application.

The applicant did not join the meeting on this occasion.

AG introduced the application summarising the background with reference to the summary paper prepared by JM. AG noted that the key objectives concerned the security of the UKDA and appropriateness of approving ongoing access to the anonymised linked dataset by other researchers.

The Committee agreed to approve the application with the following conditions:

- Provision of evidence of completed Information Governance for those individuals listed as having access to the data
- The approval does not grant access to the linked data beyond those individuals within the Understanding Society Team.

The Panel considered the request to make the data available through the UKDA and did not consider it appropriate to approve this at this time. Whilst the Panel were content with the security arrangements and understand that access to the data is appropriately governed they were not satisfied that consent for this aspect is robust enough to allow this accessibility to the anonymised data set. The Panel did not feel that those individuals who have completed the survey and agreed to the subsequent linkage to administrative health data are adequately informed that this linked data would be stored in the UKDA and accessed by researchers out with the Understanding Society team for different research objectives to the original collection.

Action AG

The Panel consider that the request for ongoing access will have wider implications for future applications and that decisions will impact on the research landscape. The Panel felt that this principle of arms length governance required further detailed discussion.

HC agreed to work with JM to prepare a discussion paper on this area for the next meeting.

5. PBPP Operational Group

5a) Brief Update – Information Only

The first meeting of the PBPP Ops group was held in March 2016.

Membership:

Dr Janet Murray (Chair) - Consultant in Public Health Medicine, Deputy Caldicott NSS
Ashley Gray – PBPP Panel Manager NSS
Carole Morris – Information Consultant, eDRIS
Deirdre Coyle – Head of Information Governance, NHS Forth Valley
Tracey McKinley – Information Governance Manager, NHS Lothian
Patricia Ruddy – NSS Privacy Advisor
Gail Turner - NHS Central Registry, Dumfries.

A draft work plan and action plan from the PBPP / FARR Research Group meeting were consolidated into a single work plan.

5b) Tier 2 Panel Member Recruitment Strategy

The Committee considered the accompanying paper which informed that recruitment to the Tier 2 Panel was done pragmatically by invitation and without a specifically designed recruitment process.

The Tier 2 Panel, as a priority, needs to progress the development of a robust and transparent approach to Tier 2 recruitment.

The Committee agreed a recruitment strategy is required and that, once developed, the finalised process should be published on the PBPP website.

5c) PBPP Training and Review Day

A paper was presented to the Committee which proposed a PBPP Training and included an outline of a draft programme for the day. The review day is an opportunity for all those involved in the PBPP process to discuss the first year of operations, discuss experiences between the 2 levels within the panel structure and share information and learning.

CM requested that the Committee endorse the proposed PBPP training and review day to be held in September 2016 and contribute to any items listed on the programme for the day.

The committee all agreed that this event would be very beneficial and intimated that a date should be sent out as soon as possible in light of diary commitments for the year. CM advised that a date in September has been suggested and will be finalised then communicated as soon as possible.

Any proposed items for the PBPP Training day should be sent to the CM or the PBPP mailbox.

6. Accreditation of Safe Havens

SP confirmed he would address any questions on the report on behalf of DB.

SP gave a brief summary of the purpose of the paper and provided the Committee with some background information to ASH.

HC advised that the Committee would request to review the ASH criteria to understand if this is appropriate and sufficiently clear. HC also queried who the authorising body for the application is. DMcQ advised that the content of the paper intimated there may be problems (section concerning Residual Risks/concerns for NHSS) that require more attention and requested clarification on this aspect of the document

SP addressed the queries raised by DMcQ and provided a more detailed explanation regarding the process which the NSH has been through in terms of the review by the KLAS consultant.

AB queried why the PBPP were being requested to 'sign off' and what specifically the PBPP are being asked to approve.

The committee agreed a more detailed accreditation paper or presentation is required which includes information on:

- Context and background
- Assessment criteria and assessor information
- Authorising body
- PBPP role and remit in terms of approval

SP agreed to discuss these requirements with DB

Action SP/DB

7. Generic Questions

AG presented the Generic Question received from the Tier 1 Panellist which asked the committee to consider, in general terms, the appropriateness and legal acceptability of a primary care recruitment process in which GP practices permit research teams to access patient information of potential participants eligible for inclusion within their GP practices, without prior patient consent.

The Committee discussed the principle questions outlined in the paper and felt it would be beneficial for a member of the Committee to review the question in more detail in the context of the application which generated the query.

AMcC agreed to take this forward and report back to AG.

Action AMcC

8. Performance Update

Tier 1 Panels and IG Resource

It was noted that a number of IG leads will be leaving post and in many of these cases there are no immediate succession plans or a guarantee that roles will be replaced in the same capacity. DK asked if this presented a risk to the PBPP process. It was agreed that this is a concern and will impact on Tier 1 panels in respect to over burdening other boards in requesting attendance.

AG advised that in the interim the issue will be raised with the PBPP Operational Group.

Action AG

Tier 2 Out of Committee

AG explained that the Tier 2 Out of Committee has 8 members. In order to progress an application a response must be received from the NSS Caldicott Guardian, 2 other Caldicott Guardians and 2 lay members.

Quorum can prove difficult at times which results in delays with PBPP application process.

SP advised that delays in the PBPP approval process is a significant risk if the Caldicott Guardians from Tier OOC are unable to respond. SP suggested the possibility of having reserve members in the form of other NHS Scotland Caldicott Guardians who may be able to cover periods of annual leave etc. SP also suggested the possibility of having a diary of when Caldicott Guardians are not available to review applications in order to assign applications to others to prevent unnecessary delays in the PBPP process.

AG agreed to explore the possibility of including other NHS Scotland Caldicotts in the Tier 2 OOC process.

Action AG

9. Any other business

AMcC advised that she had received a draft data sharing agreement for the Mental Health & Learning Disability Inpatient Bed Census but was unsure if this had received approval from the PBPP.

AG confirmed that an email had been received from Ellen Lynch at SG to advise that this project was originally a one off , approved by the National Caldicott Scrutiny Process but it has now been confirmed that the census will run annually as routine 'Official Statistics'. Ellen requested that the update paper be circulated to the PBPP – this has not yet been actioned.

AMcC advised she will be having a further meeting in the coming week regarding this and to hold the update paper release until after the meeting has taken place.

10. Date of next meeting

The next meeting will take place on Tuesday 28 June 2016 in Waverley Gate, Edinburgh.
Proposed agenda items to be emailed to PBPP mailbox by 31st May 2016