

Public Health and Intelligence

# minutes



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

**04 October 2016**

**Waverley Gate, Edinburgh**

**Present:** Brian Houston (Chair)  
Prof Alison McCallum (AMcC)  
Dr Angus Ferguson (AF)  
Prof Helen Colhoun (HC)  
Prof Danny McQueen (DMcQ)  
Mr Gerry Donnelly (GD)  
Dr Stephen Pavis (SP)  
Dr Daniel Beaumont (DB)  
Dr Corri Black (CB)  
Dr Abbe Brown (AB)  
Dr Janet Murray (JM)  
Dr Harpreet Kholi (HK) by tele-conference  
Carole Morris, eDRIS representative (CM)  
Ashley Gray, Panel Manager (AG)  
Jenny Mann (JM)  
Susan Kerr, Secretariat

**Apologies:** Mr David Knowles

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

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

## **2. Minutes of PBPP Committee meeting dated 28 June 2016**

The minute was approved as a correct record.

Actions recorded in the previous minutes were noted as either complete or to be discussed as an item on the agenda.

No comments received.

## **3. NHS Generic Ethics Approval: National Safe Haven**

A paper was circulated for information only.

The National Services Scotland, via eDRIS, has made a generic application to the East of Scotland Research Services regarding research studies that use NSS governed administrative data. The outcome means that research studies will be able to proceed without project level ethical review as long as they satisfy the criteria outlined.

eDRIS will keep a record of all studies that meet the criteria and submit an annual report to the Research Ethics Service.

In addition, it has been clarified that research studies using de-identified data held by NSS do not require local health board R&D approval. If however, a research project involves the use of any resource from a territorial health board or additional data provided by a territorial board then R&D approvals will still be needed.

DB asked if the application form will be modified for Tier 1 reviews. AG confirmed that this change will be made alongside all other application form amendments in due course

JM queried the requirements of scientific peer review. AG confirmed that studies covered under this approval are required to submit evidence of peer review. The PBPP application also request details of any peer review undertaken.

At this point BH confirmed this paper was to be read as information only and further discussion points arising should be heard by inclusion of a formal agenda item

#### **4. Panel Manager – Performance Update**

The Performance Update was circulated for information only.

No comments received.

#### **5. Applications referred to Full Committee**

5(a) 1516-0351 - Dr Andrea Williamson

*Serially missed appointments in the NHS: a linkage pathfinder project to inform future interventions.*

DM introduced this application and summarised the main concerns on behalf of the Panel

DM explained that this “pathfinder” linkage study aims to establish whether regularly missed GP appointments are a risk marker for vulnerability and poorer health outcomes and highlighted the following issues for discussion by the Panel:

- Complexity of data request/linkages
- Projects applicability to DPA definition of medical research
- Further clarification of ‘pathfinder’ terminology to describe proposal
- No evidence of scientific peer review
- Difficulties in establishing evidence of public benefit from the description of the research aims/objectives detail in the application form
- .Consideration of the privacy risks associated with release of large amounts of confidential personal information
- No evidence of public/patient consultation
- GP’s role as data controllers and requirements to inform patients regarding uses of personal information
- Review of the security procedures of third party contractor Albasoft who will act as data processor in this application

The applicant, Dr Williamson, joined the meeting in person and responded to the issues (as pre-notified by email)

- The applicant confirmed that Public consultation has not been the preferred option up front due to the conceptual shift and advised that generally the public will not be aware of serially missed appointments.
- The applicant advised that they had approached the RCGP Scotland panel and are due to receive feedback on 25/10/2016
- The applicant commented that support for the project could be seen from the fact that 155 GP practices had signed up to provide data for this project and GP's are difficult to recruit to research projects unless considered 'worthwhile'
- The applicant explained that there was a clear intention to undertake public engagement as part of any intervention trial proposals.
- The applicant confirmed Albasoft have:
  - Trusted third party status
    - Proven track record with Health Boards and Scottish Government
    - Has been approved from NHS Scotland – principal information security
    - Completely independent company that must operate within the terms of contract for each piece of work
- They have been involved in other well established projects e.g. Scottish extracts from UK Biobank
- Dr Williamson noted that GPs do have the right to pass on personal information concerning their patients to a 3<sup>rd</sup> party as GPs are data controllers.

The applicant explained to the panel that low engagement with healthcare is recognised as a good predictor of health harming behaviours in life and this project will provide evidence which does not currently exist.

A final brief dialogue took place on the points noted above and the applicant was thanked for their attendance.

The Panel considered that there were several significant concerns which remained outstanding at the end of the collaborative discussion:

- The public benefit within the application had not been expressed well in relation to the research objectives.
- This research will look at the whole population which will include vulnerable/sensitive population
- The research questions were not sufficiently articulated to provide a fuller understanding of what the proposal was trying to address and how this would be achieved
- Some concerns regarding the potential for hidden hypotheses not properly defined within the application to identify vulnerable populations
- The number of data sets being requested and the totality of information received about individuals was not proportionate to the research objectives and perceived public benefit
- whether the application has had sufficient external peer review (notably no ethics review required) and that view that statistical analysis advice should be sought

It was further noted that:

- The request for Child Protection information had been refused

- The request to release information to the Scottish Government to inform the funding allocation has been removed from the application.

The panel were satisfied that Albasoft are a bone-fide, approved organisation currently used by the NHS. The Panel were also content in respect of data security as the proposed analysis would be undertaken in the National Safe Haven and NSS disclosure control policy applied.

The Committee agreed that a decision could not be made on the outcome of application at this time and that a sub group should consider the issues further to allow a final a decision to be made. AG agreed to send a request for a teleconference to facilitate this discussion as soon as possible.

AG suggested that a holding response should be communicated to Dr Williamson. The Committee agreed this was appropriate.

Action AG/CM

5 (b) 1516-0526 - Dr David McCollum

*Economic change and internal population dynamics: an innovative study of new residential mobilities in Scotland*

AM introduced this application and summarised the main concerns on behalf of the Panel.

The project is designed to improve understanding of migration and residential mobilities in Scotland. Requiring an extension to the current NRS use of CHI in estimating migration and its impact link to the Scottish Longitudinal Study.

AM highlighted several key issues for discussion:

- Consideration as to whether the research is sufficiently health related
- Consideration as to whether this application is a valid use of CHI number
- Lack of public engagement
- The approval of this proposal will set a precedence regarding the use of CHI number for this type of research

The applicant Dr McCollum and Dr Zhiqiang Feng joined the meeting.

The applicant explained briefly to the Panel the purpose of the application and intended use of the CHI to investigate mobility patterns between the censuses.

The Panel asked that the applicant explain the reasoning behind the decision to use CHI as this is not designed to be used as a population identifier.

The applicant explained it is 100% full sample of the population across Scotland (NHSCR 5.3%) and CHI data is much more reliable than using the electrical register. The applicant also advised that the lowest level of geography requested would be data zone.

The Panel asked that the applicant explain why there had been no public engagement.

The applicant advised that they had expected that as the information was not considered disclosive this would not result in any concerns from the public regarding the data.

The Panel queried whether the applicant could carry out the research by receiving information from the CHI database in aggregate form.

The applicant confirmed that this would be feasible.

A final discussion took place on the application generally and logistics of receiving this information in aggregate form. The applicants were thanked for their attendance.

The Panel agreed it was appropriate to approve the application subject to the provision of aggregate data from the CHI database. The Panel were content if NSS disclosure control policy is applied and eDRIS work with closely with applicant to create the data scripts to be run by the indexing team.

## **6. PBPP Operational Group**

### 6a: PBPP Training and Review Day – Feedback

AG thanked everyone for their participation at the PBPP Training and Review day.

AG explained that feedback has been very positive and that there is a lot of work pending which is being reviewed and taken forward via the PBPP Operational Group

### 6b: PBPP Amendment Process

AG explained that currently requests for amendments to approved PBPP, PAC or National Caldicott applications are submitted via the PBPP mailbox and at present the Panel Manager has authority to approve changes to the research team or other personnel involved but that all other requested changes are submitted to the next available Tier 1 Panel for review.

AG asked the committee for agreement to delegate responsibility to the PBPP Manager for approving some further amendments to previously approved applications which meet a set review criteria. The proposed request form and criteria was circulated to the group.

JM asked if a set of high risk variables could be made available in an appendix which would automatically trigger a referral to Tier 1. It was agreed that this could be incorporated and would welcome further discussion with JM.

AM queried the process if an amendment was received and viewed to be substantial shift from the original purpose and/or significant methodological changes. AG confirmed that there is currently an option available for the Tier 1 to advise that the proposed request will not be considered as an amendment but should be considered as a new application due to the nature of the changes.

SP suggested a support mechanism for the Panel Manager to discuss requests before processing an approval or referring to Tier 1 if the privacy implications/risk are unclear. The Panel agreed that this should be CM, SP or JM.

The committee agreed to the Panel Manager being given authority to approve other requested changes where an amendment meets the agreed proportionate governance criteria with the support of CM, SP or JM.

### 6c: Recruitment Process for Panel Members

Due to time restraint it was agreed that this item will be carried forward to the next meeting in January.

### 6d : PBPP ToR/Scope

JM proposed changes to the terms or reference highlighted for discussion and decision.

JM advised that a proposed change had been made regarding the quorate NSS representation on every Tier 1 Panel. JM suggested inclusion of a clause to allow the Tier 1 Panel meeting to take place in the unexpected absence of NSS IG lead but that their opinion should be sought on any approvals relating to national data.

The Panel raised some concerns regarding the logistics of the above component of the proposal in terms of Panel functionality and customer expectations regarding timescales. JM agreed to remove this amendment pending further discussion at the PBPP Operational Group

HC asked for it to be noted that on Page 12, should be “study” and not trial. JM agreed to change this.

AG asked the committee if they would be agreeable to meet 5 times per year due to the volume of business and applications being heard at each meeting. BH agreed and stated that the possible re-design of committee meetings may be required in light of time pressures experienced

It was agreed that these amendments to the ToR will be taken forward including the removal of the proposed change to NSS Panel representation.

Action JM

#### *6e Audit and Reporting*

JM proposed a method of audit of decisions taken with a plan for routine future audit of applications approved at Tier 1.

JM suggested random and purposeful sampling of 1/10 applications a . Applications could then be circulated to all members of Tier 1 and tier 2 for review along with the application record.

It was agreed that there should be an audit and a set of specific questions should be completed for each application.

It was felt that to review 14 applications was a lot in the time-line proposed indicated with in the paper and capacity may not allow for this.

BH suggested that further discussion on this paper is required and it was agreed that the Panel should send comments and suggestions to the Panel Manager for collation.

AG will forward the information to JM who will amend and update the proposal for discussion at the next meeting.

Action AG & JM

### **7. Enhancement of Safe haven IT Architecture – Dave Robertson**

SP introduced this item to the Committee and explained this was an update on the progress of creating a national research ready imaging database and advised that Dave Robertson was in attendance to give the Committee some insight into the potential conceptual IT architecture illustrating the storage and access levels to the final database.

### **8. SILC Efficiency Gains**

SP explained that the Scottish Informatics and Linkage Collaboration (SILC) Strategic Management Board requested that he consider ways in which the eDRIS service could operate more efficiently.

The following proposals were presented for discussion and support:

- a) Proposed that the PBPP Panel Manager be allowed to grant amendments with clearly specified limits – discussed in item 6d and agreed by the Panel
- b) Consider and support the idea of delegating responsibilities within clear constraints to the eDRIS team – SP advised that this proposal should not be discussed at this stage as further developments required
- c) Consider and support the idea of creating programme level datasets

The Panel agreed that proposal a) had already been discussed under another item and support from the Committee agreed. The Panel considered that the proposal of programme level datasets was one which should be supported and would like to request that a full paper on the details of this work is provided for further discussion and comment by the Committee

## **9. Statistics Public Benefit and Privacy Panel**

SP asked the committee to consider and give an opinion on the following proposals:

- to extend the PBPP to include data governed by the Scottish Government's Analytic Services Division.
- to agree to the creation of an NHS and SG combined task group to take this forward

The Committee were supportive of the principle of expansion but raised some concerns that the PBPP is also in infancy and the Panel must be confident in the processes and decisions which are emerging from the current set up. Therefore it was agreed that the risks associated with an expansion plan should be taken forward in the task/working group.

The Panel agreed to the creation of the working group (as above) and noted that this should be chaired jointly between NHS and SG, a suitable NHS representative to be recommended.