Public Health and Intelligence

minutes

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

16th April 2019 at NINE, Edinburgh Bioquarter.

Present:	Brian Houston, Chair (BH) Prof Alison McCallum (AM) Acting Chair for part of the meeting Dr Stephen Pavis (SP) Penni Rocks (PR) Alan Ferrier (Al F) Dr Maria Rossi (MR) Dr Helen Colhoun (HC) Dr Eleanor Anderson (EA) Dr George Fernie (GF) Kenneth McLean (KM) T/C part of the meeting Prof Corri Black (CB) T/C part of the meeting Dr Marian Aldhous (MA) Phil Dalgleish (PD) Susan Kerr, Secretariat
In attendance	Elena Beratarbide (EB)
Apologies:	Prof Danny McQueen (DM) Dr Angus Ferguson (AF) Prof Abbe Brown (AB) Carole Morris (CM)

1. Chair's Welcome and Introductions

BH welcomed all to the meeting.

It was noted that due to no Lay members in attendance, today's meeting is not quorate. It was therefore agreed that this committee can make recommendations but not final decisions. Any decisions to be made will be circulated electronically to all members with an active response required.

There is one application for discussion at this meeting, this will be for discussion only and will be brought forward to the next meeting in June when the applicant is available to attend and a decision can be made.

GF raised concerns about not being quorate, due to being vulnerable to Freedom of Information (FOI) Requests and, if challenged, a decision could cause implications.

GF also raised concerns about discussions taking place on an application over 2 meetings.

BH stated that no decisions will be made although views could be made available to the applicant.

BH expressed concern on the lack of ownership of committee which causes issues around governance of committee (Historically)

PR – decisions could go to public reps separately after committee outputs (homologated offline).

2. Minutes from previous meetings

2.1 Minute of meeting held on 27th November 2019

Amendment now complete, and the minute was approved.

2.2 Minute of meeting held on 15th January 2019

SP asked for one change on page 6, MA agreed to complete. The minute was then approved.

3. Matters Arising

3.1 Report from the ACONF Data Issue

MR informed the group that the report has now gone to the NHS NSS PHI Clinical Governance Group.

Discussions took place on the Action Plan.
CM and team progressing action plan and it will be made available to the committee members. MR agreed that she will have the report and the action plan available for the committee to see at the next meeting taking place in June 2019.

AM feels NHS NSS internal processes (including the NHS NSS Clinical Governance Group Meeting in May) should be concluded before PBPP committee for final sign off.

MR noted that this is slightly dependent on the dates of the respective meetings.

Action MR/CM

3.2 Proportionate Governance paper

MR reminded that committee that the purpose of this paper is looking at ways of streamlining the process of applications going through eDRIS. Majority are research applications.

MR went on to explain that this paper had been agreed in principle at the previous Committee meeting and following that had also been reviewed at the PBPP Ops group.

The paper has been agreed in principle by PBPP Ops Group although the following questions had been raised:

- Clarity required around definition of low risk applications
- No metrics for process elements to compare old and new process (CM is working on developing indicators)
- PBPP delegation from Chief Executives, trying to clarify firmly where this group sits and where this is written down.

EB spoke about how the PBPP was created and explained how she may have found evidence of this, from the National information Sharing Committee. EB stated that NHS, Public sector and others which should be available in previous minutes.

There is a letter from Scottish Government to NHSS Board (stating that PBPP is part of the Information security network).

PR stated that there was approval including from CMO, however since then groups have disbanded.

GF asked if CLO could support and suggested writing to them for advice.

HC stated that the Legal indemnity is required for accountability.

GF stated that CLO could provide support and felt it would be worth speaking to the CLO for confirmation.

AM found minute from 2014 (Daniel Beaumont, Eddie Coyle) on the creation of PBPP. PBPP succeeds three previously existing processes in their scrutiny of applications for access to NHS-controlled data: NHS NSS PAC; National Caldicott Scrutiny Panel and CHI Advisory Committee.

EB – safe information framework DL2015/17 implement framework

SP stated that NHS Boards are the legal entities and that the boards are responsible for data, SG do not have the authority. NHS is not legal entity.

PR stated that CLO advised not everything has to be made an act, a “letter” seems acceptable for some things.

HC asked who wrote the SOP for this committee – this was Daniel Beaumont from SG.

More conversations took place and BH expressed the need for clarity being required for planning going forward as cannot modify and engineer these forth coming changes until we get this clarified.

MR, AM, MA all agreed to investigate the accountabilityand report back at the next meeting.

Action MR, AM, MA

3.3 SG papers sent out after committee meeting of 15/01/2019

EB reported that she currently has 2 studies ongoing (FLORENCE and Family Nurse Partnership (FNP)) which are using the new IG pack.

EB explained that she now has 4 volunteers from the Tier 1 panels who are happy to look at a trial of these applications going through PBPP without eDRIS support. This is a trial only for these two applications.

AM raised concern as IG and methodology should not be of a different standard, there are international standards to ensure safe effective care. If this was allowed to process with tick boxes for technical aspects then this is less scrutiny than a normal PBPP application.

EB explained that it is the same form as current application form, but that project leads say eDRIS RCs don't understand the project's contents.

SP sated that he has used the IG pack and the flow chart is wrong way around, as the DPIA is most important as this highlights IG over the purpose. EB thanks SP for his input and agreed to change to layout of the flow chart.

MR asked for clarity about research/non research/ linkage/non linkage.

EB explained again that she would like any feedback and would like to trial two projects only using the IG pack to take an application through current process.

MR asked for this to be clarified: is this 2 projects to go through bypassing eDRIS RC and using IG pack? Yes. The applications would come direct to PBPP.

EB said that the IG pack is all about helping the project leads knowing what forms to use for information and why, to improve non-research applications for National Studies.

Helen – Universities support their researchers? This is an internal process for Scottish Government to support their applicants.

BH summarised that this will bypass eDRIS coordinator for these 2 projects – Yes agreed.

EB explained that this pilot will be extraordinary scrutiny with 4 T1 volunteers.

This was agreed and the outcome of both these projects to be reported at the next PBPP Committee meeting in June.

Action MA

4. Standing Items

4.1 Panel Managers Report
For information only

4.2 Policy Decisions and Case Law Principles
For information only

4.3 PBPP Resource Scottish Government update, including new Digital Health and Care Strategy Board

PR – will work up specification for participants (expertise)

PR refresh on the new digital health and care strategy domains:

A National direction and leadership
B IG, Assurance cyber security
C Service transformation
D Workforce capability
E Digital Platform
F Transition process

EB described in detail domain B (see attached presentation and circulated after meeting). The Domain B strategy aims to:

- Partner with other groups across health and social care, with access and privacy by design
- Use data for research and innovation, but this needs to work with the wider NHS and public sector
- Prepare research-ready data for research and statistics.
- Streamline Information Governance (IG) and assurance landscape reducing unnecessary complexity and develop a national approach assurance and cybersecurity – "Once for Scotland."

Different stages will occur along the process.
Different groups will be needed to set up to review IG structures and processes with established ways.

EB stated that she is looking for volunteers for steering group and working groups.

AM suggested circulating the TOR for steering group and working group to match expertise.

BH felt that the SG should not be asking for volunteers but selecting right people for what they need.

5. Application 1819-0051 Cooper

Please see the paper from the Lead Panel reviewer (sent with agenda for the meeting).

The aim is to use Scotland's Census, 2011 to link data on people with autism and learning disabilities (and comparison groups) identified from 2011 Census to their health datasets. There was clear public benefit to the proposal but the questions related to:

1. The validity of use of the self- or family-reporting of learning difficulties / autism from the census data for identifying individuals;
2. The use of 95% of the population as controls.

There was discussion regarding the justification of using census data, e.g. individual level social variables rather than SIMD.
HC asked what is the logic of using 95% of the census data? Al F explained that the PBPP Stats group have refused 95% sample of census data as appears unnecessary for the proposal. HC then asked if the census has been used at this level before; Al F said that it had not.

EA pointed out that for cancer the numbers are likely to be low but relative to age- and sex-matched peers there may be a higher cancer incidence in people with learning difficulties. This might raise issues or biases that might affect the incidence, diagnosis of treatment of cancer. The at-risk population would give wide confidence intervals.

There was discussion regarding the study design – whether this is or should be a cohort study or a case-control study. International studies of this nature might use 4-5 controls per patient. Further clarity was needed regarding methodology and purpose. There was also some feeling that the predicted outcomes were unrealistic.

It was felt that the statistics were not well described and were lacking in sophistication for statistical modelling, as relatively simple models were described which would identify large differences, but not necessarily small differences. A formal Statistical Analysis plan should be put in place.

It was recommended some scientific input so the scientific outcomes are clear and the recommendations are based on sound evidence. Even if they don't find differences in diagnosis or treatment of cancer, there would be public benefit in describing or measuring the use of services or uptake of screening by people with learning disabilities and/or autism.

Have the applicants had any contact with the data controllers for Scottish Bowel Screening or SCI Diabetes? Is there justification for all the variables requested?
Some concerns were raised that some people might be identifiable through combinations of the health and social data.

Data will be in the Safe Haven, so no security issues envisaged.

There was general agreement that this study could have public benefit as it would inform Scottish Government policy and possibly help plan and deliver services.

Lay input – KM had sent in some comments and all lay members have been sent this application as part of the Tier 2 Out of Committee process.

Agreed that recommendations from the above discussion to be sent to the applicant.

Action MA

BH left the meeting and AM now chairing

6. Resourcing the T2 Committee and Annual Review of Committee membership

6.1 CG Vacancy / CHIAG rep

David Knowles has now retired from his post as Director of Practitioner & Counter Fraud Services within NHS National Services Scotland (NSS). This post-holder automatically becomes a member of CHI Advisory Group (CHIAG), because CHI sits within Practitioner Services.

Martin Bell, as David's replacement, will automatically sit on the CHIAG will be offered to replace him in the interim.

AM will meet with Martin Bell and invite him to be part of the PBPP Committee (as her post is Chair of CHIAG)

Action AM

There are a couple of people whom Alison has approached regarding the Caldicott Guardian vacancy on committee, who should be approached formally from the committee.

Action MA

6.2 Annual Review of PBPP Committee membership

As part of the annual review it was suggested that a possible panel of people could be involved with particular expertise.

Also suggested that a pool opt of experts could possibly be available as required regarding particular types of studies or topics. There could be a potential conflict of interest as there may be only a few people around with the expertise in some areas – which might include those doing the study (including the applicant), those who might have reviewed the study already and those in competition to the applicant. If this is the case, the expert could still give more generalised advice on the topic / technique / methodology without reviewing the application itself.

PR suggested a possible pool of Lay reps.

EA suggested that more V/C and T/C facilities are available. These facilities are available now that meeting are being held in the Edinburgh Bio quarter. With appropriate layout of the room, these could be used more effectively.

Al F asked how public health representatives are recruited? Previously PBPP has tried to use patient panels and has contact with Carol Porteous (Patient Public Involvement Advisor for University of Edinburgh / NHS Lothian), who may be able to help with possible pool of lay expertise; Scottish Health Council, Health Improvement Scotland. For all of these routes, training would be needed as sometimes the PBPP application and process is not easy to grasp.

Discussions took place on the Constitution being reviewed to allow a deputy to attend meetings when required as at present no deputies are allowed to attend. This is because the danger was that the deputies would be sent, rather than those who were asked to sit on the committee.

It was suggested that agreed delegates, with the stress on the importance of "appropriate delegates" with similar seniority could be used, but a different person if someone was unable to attend.

MR suggested inviting NHS Board CG to the June meeting to observe.

Other possible suggestions for contacting were:

Clinical Fellows in training
Clinical Leadership Group for SG
Academics in data protection
Explore SIRO reps

EB suggested a Data Protection rep. Some of these already sit on Tier 1.

AM agreed to write to the CMO.

Summary:

- Larger Lay panel
- Panel of experts
- Agreed appropriate delegates if principal could not attend
- Data protection officer
- SIROS from boards?

Agreed all good to explore and bring back to a future meeting.

AM stated that a business case to look at resourcing to be sustainable. A piece of promo work is needed for committee show work done, work expected, expertise of committee, future model of good practice and ahead of other countries.

AM stated that this should be fed into the Digital Health Strategy, looking at good ways to take this group forward.

EA stated that more resources for the work of the PBPP are necessary going forward, concern raised that the current resource will not be sufficient to sustain developments.

AM summarised by acknowledging the importance of increasing the range and depth of the PBPP Committee.

Action MA

Annual Report

MA confirmed the annual report is now complete.
BH to send or present this at the NHS Board Chief Executive meeting with MA.

Action MA /BH

7. Tier 2 and Tier 1 Audits

AM thanked all those who participated last year's audit.
MA is in the process of planning for next Audit which will include for the first time an audit of Tier 2.

AM thought that there is some work to be done to define what standards we hold to in terms of quality rather than timescales.

Agreed that the Ops group would look at this.

8. Any other Business

No other business was raised.

9. Date of next meeting

The next meeting will take place on 12 June 2019, in Edinburgh Bioquarter.