Public Health and Intelligence

minutes

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

Jury's Inn, Edinburgh

28 November 2018

Present:
Brian Houston, Chair
Prof Danny McQueen (DM)
Dr Kirsty Licence (KL)
Kenneth McLean (KM)
David Knowles (DK)
Dr Stephen Pavis (SP)
Penni Rocks (PR)
Dr Angus Ferguson (AF)
Dr Maria Rossi (MR)
Stuart Law (SL)
Dr Marian Aldhous (MA)
Phil Dalgleish (PD)
Susan Kerr, Secretariat

Apologies:
Prof Alison McCallum (AM)
Dr George Fernie (GF)
Dr Helen Colhoun (HC)
Prof Corri Black (CB)
Alan Ferrier (Al F)
Prof Abbe Brown (AB)
Carole Morris (CM)

1. Chair's Welcome and Introductions

BH welcomed Dr Maria Rossi, Consultant in Public Health Medicine and Caldicott Guardian for NSS to the meeting.

It was noted that due to number of apologies the committee was not quorate and need to be aware for policy decisions.

2. Minutes from the previous meeting, 25 September 2018

Minutes were approved as an accurate record.

3. Matters Arising

3.1 Tier 2 PBPP Resource

BH informed the group that he has written to all NHS Chief Executives but so far has had no response.
BH agreed to follow this up and report back at the next meeting.

Action BH

3.2 Report from ACONF Data Issue

Aberdeen Children of 1950s (ACONF) Data Linkage Error – Final report circulated for information.

SP informed the group that this has now been resolved, the data is correct and Lessons Learned report is complete. The final report was sent to the PHI Clinical Governance group.

DM asked if acronyms can be defined (e.g. DASH), as he is aware that as both these reports may be read by members of the public.

BH suggested a standard glossary of acronyms should be made available with this report. This was agreed.

DM also asked whether routine checks as a matter of course are being done?

SP explained that although this is a very good point but that no single organisation sees individual data and the other organisation does not see the patient identifiers. The separation of function, to improve privacy means that it is much harder to check the quality of the linkage. It would require someone to check the linkage and payload data.

The separation of function for data linkage, with the indexing being done by NRS and linkage done by NSS is part of the guidance principles of NRS. These can be reviewed to enhance the Quality Assurance process and have better transparency but these cannot be changed.

Concerns were raised that there was no reassurance on correct linkage and PBPP Committee could be exposed to risk if errors happen.

No linkage is 100% accurate and any research project should contain variables to verify the linkage. The need to be clear about reproducibility and validation of the linkage needs to be incorporated into the system.

SP suggested Al F from NRS should also be involved to review and make any recommendations. This was agreed.

Action SP / Al F

A question arose as to whether and how this was to be fed back to the ACONF Cohort after the lessons learned? SP said that Carole had been part of these discussions and would report back to the committee.

Action CM

3.3 PBPP and CAG Approval: Reciprocal arrangement

MA reported that guidance was currently being updated.

Action MA

3.4 MOU with HFEA

After discussion it was agreed that BH will sign-off these as PBPP works on behalf of Chief Executives. It was noted that this is not a legally binding document.

Action MA/BH

4. Standing Items

4.1 Panel Managers Report

The Panel Managers report was circulated for information only.

4.2 Policy Decisions & Case Law

The Policy Decisions & Case Law was circulated for information only, all agreed and happy with this.

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

PR had nothing new to report on resources.

PR explained that Digital Health and Care Strategy is sitting in a much wider context. Lots of initiatives going on and all facing similar IG challenges. A working group (including SP and KL) has been set up to look at these challenges, which include:

- Research and statistics
- Policy including industry
- Service Delivery – direct care, planning and local government
- Policy changes to be made
- Personal centred – rather than system/service led including public engagement
- More innovative models of engaging with the public from a digital perspective
- Level of public trust – looking at models of engagement with public and best way to work with public

Collective working, looking collectively at all challenges.

PBPP Approval process (PBPP) is part of an efficient way, speed and efficiency.

KM asked if there is a process of audit at certain points/outcomes measurements?

PR – Digital Health Care and Strategy is all about measuring outcomes

SP – Consistent approach across all public sector datasets as we move to Public Health Scotland

PR – Set of principles base lined (acceptable with the public)

BH asked if there is at timescale for all these new processes?

PR The different aspects need to be broken down a bit more – not just health/ non-health and need to assign areas of responsibility; thus far none have been defined.

PR agreed to keep this group up to date with developments

Action PR

5. PBPP Panel Resources

5.1 Actions from the Recommendation from Lessons Learned from Application 1516-0560 (Radio DX-PFS Genomics

KL stated that the previous discussions and actions from this report will be picked by the Ops Group. But what hadn't been discussed was the area of Public Engagement for PBPP applications. MA agreed to discuss further at the PBPP Operational group and report back.

Action MA

Public engagement was discussed and whether this questions needs to be a key question on the application form, stating that if public involvement is not happening, why is this? Do we wish to make this a key question? No but need to say important. Is the proportionate governance criterion asking enough? Not appropriate for all projects.

SP asked members to reflect if we generally want each researcher to do public engagement as he felt that some individual projects should not do public engagement as although he recognises the importance if everyone does it may not achieve what PBPP are expecting.

BH pointed out there was a danger of being tokenistic because applicants are not very good at it.

KM pointed out that for a previous application where it was not possible to re-consent a cohort, reassurance was given to the application by the level of public engagement activity However, its usefulness and validity does depend on the type of application.

KL remarked that big ongoing studies can do excellent public engagement, but that there should be some indication that appropriate public engagement had been considered.

SP maybe it should be considered according to different types of project (big vs. little, types of research).

It was agreed the people should however be encouraged to have public engagement when there is an opportunity. This will be added to guidance notes and website.

Action MA

It was agreed that a signpost to good practice on public engagement is required and that guidance should be provided on what might be expected for different types of projects. It is important but not a 'one size fits all' and we should not expect people to jump through unnecessary hoops.

KM and DM suggested that there could be some possible input from the Scottish Health Council or at least links to their website from the PBPP website.
KM suggested signposts on websites for tools for community engagement.

DM stated that he felt the PBPP Website is very poor considering PBPP has been running for over 3 years.
PD said it was still an ongoing and we hope to get it finished in early 2019.

Action PD

5.2 Proportionate Governance Paper

SP circulated a paper on proportionate governance requires proportionate administration.

This paper was provided as a "think piece" that aims to allow the PBPP to reflect upon whether it is possible to improve efficiency through a streamlined administration process. Project could be assessed against a certain set of criteria and approved more quickly, e.g. Safe people and safe projects, without taking all applications to a panel.
Currently applications are considered individually against proportionate governance criteria. HIC and SAIL (Wales) do this as an administrative process.

BH pointed out that a standard template to control processes can be good but can also mean that definitions can become too specific or too general and can easily fall down.

DK felt that the current model was not sustainable.

BH agreed that this was an important issue regarding the working and resourcing of panels.

PR pointed out that NHS boards already have devolved some Data controller function to PBPP.

SP suggested one such example would be clinical trials where there are already a number of approvals in place.

KL said that the HRA website had a model of modified application forms for some specific categories, e.g. follow-up of clinical trials and would lead to decreased bureaucracy.

PR suggested that he look at other international models too.

BH felt that this should happen at national rather than board level.

PR supports in this and felt that there was nowhere else where this could go to be taken forward.

KL suggested that we should come up with definitions of risk appetite options and the percentage of applications to which this might apply to give us an indication of its potential effectiveness. Otherwise it could be a lot of work if it only applies to a few applications.

SP agreed to develop an application form with lower level risks, setting out a process and indicating what this might actually look like in principle. Maria to have some input. SP will report back at the next meeting.

Action SP/MR

6. T1 Audit 2017 Report

The PBPP committee reviewed ten applications approved at Tier 1 between January 2017 and December 2017 selected at random by the PBPP Manager.

Results were presented at the PBPP Annual training day on 04 September 2018. From the ten applications, eight were considered to be appropriately approved by Tier 1.

Recommendations have been put forward which aim to strengthen the application review process including minor modifications of the proportionate review guidance. Ops Group are happy with the report and its outcomes.

MA expressed concerns of the late response to this Audit from Committee members which caused the delay in reporting.
DM expressed concern that the delay in Tier 2 review of Tier 1 led to an increased risk of reputational damage.

Discussions were held on widening pool of T2 members.

KL suggested that an improvement plan be included.

As there have been new panel members joining Tier 1 panels, it was agreed to continue with an audit for this year in April 19, for post GDPR applications only. Committee members will be allocated 4 applications and have 6 weeks to respond.

In addition it was suggested that there should be an audit for T2 decisions for consistency and fairness.

Possible criteria would be:

- Time to respond
- Whether previous policy decisions and case law principles, were taken into account.

Agreed this will be discussed further at the PBPP Operational group.

Action KL/MA

7. PBPP Annual Report

MA asked for comments on the draft annual report for 2017/18.

PR suggested priorities for 2018/19 should include details of the Digital Health Care Strategy and the wider landscape and development plans could be summarised

KM suggested that something about aspirations and partnership working across the UK (e.g. HFEA, CAG).

KL suggested significant lesson learned (from PFS Genomics) and how PBPP managed the situation. However it was agreed this would be more relevant for 18/19 annual report and use as success story, especially in regard to the subsequent similar application that was approved within 60 days at T2 OOC.

DK suggested the T1 participants should be acknowledged.

KM suggested that, as this was public facing, should it show examples of the different types of applications and the perceived public benefits of these (e.g. Health surveys).

MR asked that it should be checked for accuracy as the numbers don't add up. This is to do with applications being submitted in 2016/17 and approved in 2017/18 and can be clarified.

MR asked if NHS and SG projects could be separated.

SP said that an executive summary was required with key messages.

MA to update and bring back to the committee.

Action MA

8 AOB

8.1 Location of Committee meetings

Agreed meeting rooms 5 or 8 at NHS Lothian, Waverley Gate is not suitable and should only be used if no alternative.

PR suggested St Mary's hub conference centre as reasonable cost and central.

Majority of committee members agreed they are happy to have future meetings in the Craigmillar meeting room at 9 Bioquarter.

SK agreed to book meetings to be held at Bioquarter for next year, whenever possible.

Action SK

8.2 Brexit

KM asked if there is anything we need to consider with regard to European institutions?

SP explained that the current position to access data from outside UK is that if you are in the European Union you can access data.

It was noted that the risk lies in flow of data from EU to UK rather than from UK to EU. This may affect researchers from the EU accessing the National Safe Haven.

BH asked about brexit co-ordinating.

There is a range of preparatory work ongoing across Scottish Government, under Shirley Rogers.

Date of next meeting

Tuesday 15 January 2019