Public Health and Intelligence

minutes

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

03 September 2019 at Nine, Edinburgh Bioquarter.

Present: Professor Alison McCallum (AM) – Acting Chair
Professor Danny McQueen (DM)
Dr Steve Pavis (SP)
Carole Morris (CM)
Dr Angus Ferguson (AF)
Dr Maria Rossi (MR)
Professor Corri Black (CB)
Professor Helen Colhoun (HC)
Martin Bell (MB)
Alan Ferrier (Al F)
Professor Abbe Brown (AB) T/C
Kenneth McLean (KM) T/C
Dr Eleanor Anderson (EA) T/C

Dr Marian Aldhous
Phil Dalgleish
Susan Kerr

Apologies: Brian Houston (BH)
Dr George Fernie (GF)
Penni Rocks (PR)

1. Chair welcome and apologies

The Chair welcomed all to the meeting and introductions took place.
AM advised that she was standing in as Acting Chair in the absence of BH.
Martin Bell, Director of Practitioner Services, NHS National Services Scotland, was welcomed to the committee as the representative of the CHI Advisory Group (CHIAG), at the request of the chair of CHIAG.

2. Minutes of the previous meeting

The minutes of the meeting held on 12 June 2019 were approved as an accurate record.

2.1 Matters arising not on the agenda

Discussion took place on the role of panel members at this meeting and the role of panel members at future meetings.

MR stated that both herself and EA are Caldicott Guardians from PHI NSS and asked if all were happy that they both count as two separate Caldicott Guardian opinions at this meeting.
All agreed they were happy that both MR and EA will count in their own right at this meeting but it is recognised that there is a need to increase the Caldicott Guardian representation on this committee.
AM recommended that this issue should be taken to the Caldicott Guardian forum to request an increase Caldicott Guardian representation on this panel. Previous efforts to increase representation were considered. It was noted that there was no formal meeting of Caldicott Guardians, the Caldicott Guardian forum is a meeting for continuous professional development. The Caldicott Guardian role is undertaken in addition to those individual's main post and one intended benefit of the PBPP to reduce the pressure on Caldicott Guardians.

It was agreed to explore the potential for remote participation in more detail. EA suggested video-conferencing (VC) for smaller boards could be an option.

AM and MA agreed to organise a meeting with current Caldicott Guardians on committee to review options to increase membership and participation in review.

Action: AM / MA and Caldicott Guardians on committee

3. Matters arising

3.1 Report from ACONF Issue

MR as chair of the PBPP Ops group reported that they are working through with PHI NSS on analyses completed and an action plan. This is being dealt with by the NSS PHI Information Governance Group and the Clinical Governance group and things are progressing.

CM reported the benefits of implementing the lessons learned to eDRIS' work.

AM asked about resourcing, stating that she felt that a number of things that appear in the action plan are things that NSS ISD should have already had in place.
AM is very appreciative of the amount of work gone into addressing lessons learned to date, but thinks that underlying investment in infrastructure is required.
AM asked if it would it be helpful, if agreed, whether she should speak to the relevant National Services Scotland directors regarding this? [eDRIS is accountable ultimately to Phil Couser (Director of PHI in NSS)].
AM felt she would like to be reassured that the organisation was providing support to complete the action plan and implement the lessons learned.

KM asked CM about the ACONF Action Plan, regarding project level priorities and why some things have not yet been implemented and asked what outstanding risk is remaining by not having these actions completed?

AM stated that PHI Clinical Governance have still to review and does not feel this committee can take a view on this until we get this information back to us.

MR asked CM to attend the next PHI Clinical Governance group meeting. CM agreed and then will feed back to AM who will then inform committee members of the outcome.

Action: MR and CM to feed back to AM and then to committee. AM to write to National Services Scotland directors after PHI Clinical Governance group.

It was noted that the ACONF dataset also involved the NRS data linkage service.

CB asked about indexing and NRS. It was confirmed that NRS is not covered under PHI Clinical Governance, but some actions relate to NRS – how will these be actioned? What governance trail exists to NRS?

CM confirmed that there are regular meetings with NRS and good working relationship, which will identify how these actions are managed.

Action: CM / AlF

3.2 Accountability lines for Public Benefits and Privacy Panel

MR reported that she had not identified detailed documentation that set out the reporting arrangements and accountability of PBPP. She has seen a government letter but no documentation to say that the NHS Chief Executives have delegated authority to PBPP at a national level. She will contact the Chair of the Chief Executives group.

AM stated that as it stands this group is accountable to NHS Chief Executives. She did not think that PBPP is directly accountable to Scottish Government. MB confirmed that this was stated in the PBPP Terms of Reference.

AB agreed that it is very unclear. PBPP make decisions on health data for Caldicott Guardians, but PBPP could be restructured to function under a different legal frame work, and therefore where we sit is important.

AM stated that the NHS (Scotland) Act 1978 states that boards can work together so we have a legal basis to work with all NHS Boards.

CM suggested that PBPP could ask the Chief Executive Group if they would like a report from PBPP for their meetings.

All agreed. MR agreed to take this forward and report back.

Action: MR

There was a detailed discussion of the issues of strategic resourcing and governance in this area at a time of ongoing change and functional review at national level, realignment of arrangements for collaborative working between SG Directorates and expert functions, governance and leadership of multisector data and studies.

Some specific issues associated with these changes were highlighted as they impacted on the work of the Panel. DM asked about progress regarding the Digital Health Platform as the panel was receiving applications that intended their data to sit within NHS Education for Scotland.

SP explained that eDRIS was set up as a Scotland-wide initiative to facilitate the use of NHS data for research and data linkage with Scottish Informatics Linkage Collaboration (SILC) Board being the governance structure.

AM and SP explained that eDRIS is within NSS ISD and health and care data comes under ISD under the NHS (Scotland) Acts. The responsibility for data and statistical functions sit with ISD and it is expected that this will move to the new public health body, PHS (as in other countries). Roger Halliday (SG Chief Statistician) later assumed responsibility for data linkage across SG functions. Non-health data comes under Roger Halliday with the Registrar General responsible for vital statistics.

CM explained that Roger Halliday is setting up the successor to SILC, called Research Data Scotland. This will create a legal entity that draws from different government functions and essentially sits of top of the operational services (eDRIS, ADRC, NRS data linkage, Edinburgh University Parallel Computing Centre). Scottish Government are looking to create an infrastructure to make data available for research. Scottish Government are currently considering options for the establishment of this body.

All parties involved are required to do a service review and this will consider resourcing of this new set up. Al F and CM are on the governance group and will go to the last meeting of the SILC strategic board, and will help mould next incarnation.

CM explained that it is difficult for eDRIS to define roles. Roger Halliday is going to the Scottish Government Ministers to establish whether there was funding for eDRIS.
Claire Wainwright in Scottish Government is leading an Information governance review and there is Domain B, part of the Digital Health and Care Strategy, which is the Health Governance Review. CM stated that these discussions are very operational at the moment regarding what Research Data Scotland could look like in future.

MR asked about Caldicott Guardian representation in the development of Research Data Scotland?
There is no group as such for Research Data Scotland. This would be the Data Delivery Group which has no Caldicott Guardian representation. There was agreement that there should be Caldicott Guardian representation on the Data Delivery Group.

The PBPP committee recommended that Caldicott Guardians should be represented at all levels of these discussions.

AM agreed find out more information regarding who is on which groups and where CGs are represented on these group and feed back to the committee.

Action: AM

3.3 Feedback from the Extraordinary Tier 1 panel to pilot the Scottish Government IG pack.

MA gave feedback from the extraordinary T1 panel which was to review two “national” projects piloting the SG IG pack. Elena Beratarbide was the coordinator for these projects eDRIS had not been involved.

The extraordinary Tier 1 panel took place on 31st May 2019 and involved five IG Leads from across Scotland who are part of the Tier 1 panel rota.

MA explained that it had been considered that the projects were for direct care which meant the Tier 1 struggled with this and had felt that it was not appropriate for this to come to PBPP (at either Tier 1 or Tier 2). PBPP form was not adequate and the panel felt that they could not answer all questions and felt that should go through the NHS boards and not PBPP.

AM described her long involvement with the Family Nurse Partnership since its introduction to Scotland. As a consequence, she knew that the aim of Family Nurse Partnership (FNP) application was to create a new database on the NES platform, to be established as a new data resource. The database sat within NES currently; this had been agreed as an exception because the main role of the database was model fidelity and quality assurance of staff training (the service is licensed and compliance with the evidence based model is essential). This was a database in which most of the patients, including the mothers, were children as the main service was for those <19 years of age or vulnerable adults under 25 (e.g. care experienced) who become pregnant. The purpose of this applications was not just for direct care, but also to provide data for the model reporting requirements, data for audit, research and evaluation as well as having the capacity to enhance national statistics with information about a population where there are often missing data. There is more clinical data on the new database than previously as previously the boards held the clinical data. Taken together this application is entirely within the purview of the PBPP.

MA stated that this had not been apparent in the application form.

MR thought that the applications should have come to Tier 2, but have now gone to the NHS boards.

MR asked as a committee how do we learn from this and will this become a resource issue?

HC stated that it is very difficult for PBPP to be resourced to review every national data project within the NHS, e.g. every new app will have data security and IG issues. NHS Scotland needs to have its own system to deal with this as it seems enormous.

AM said that when PBPP was established for national applications previously a group of Caldicott Guardians met and agreed on them. Then PBPP was established and took over this function. Frequently, new national multi-board projects started small but then become a major undertaking or national projects come out to Boards without any obvious review, e.g. large scale national data collections. AM would like PBPP to deal with approval for these as a class with consistent paperwork and agreed standards met.

HC said within NHS there are some processes that projects have to go through in each Board to be adopted, even for national projects and Caldicott Guardians have an advisory role. What is the relationship between DPO and Caldicott Guardians? Are the processes adequately covered within the boards?

SP explained that territorial boards Chief Executives and DPOs are responsible under the Data Protection Act 2018, whereas the Caldicott Guardian is an advisory role. Even if projects come to PBPP, they still have to go to the boards as the legal framework. So why come to PBPP? Does this not just add another layer?

MR asked if the reason this has come to PBPP is the push for 'Once for Scotland' so applications can be considered in the national context. If there is not a national Caldicott Guardian perspective, then there would be different decisions at each NHS board. Boards still have the right as data controllers to say no and are still accountable. PBPP does not approve local application of DPIAs.

AB stated that PBPP does more than data protection by adding value, such as public benefit, risks of disclosure etc.

CM asked for feedback on the IG pack as the purpose was to look at the IG pack piloting and how it was useful or not for the two applications it was used for.

AM noted that it had been useful to pilot the IG pack but the pack did not do what PBPP needs.

These projects were from SG but were not necessarily the 'owners' of the projects. Should SG have a national project board?

AM stated that there already was a National Innovation Board. BH is a member.
AM highlighted that, as a Panel, we need to do a bit more thinking of how PBPP takes Governance that was fine for one single organisation, to become functional as a 'Once for all Scotland' arrangement. At the moment a significant number of projects go through individual Boards. We need to work out how PBPP should be responding to these classes of applications rather than an individual application. We should work with others to agree standards and obtain specialist advice from academic and lay colleagues in a more systematic way.

HC said that the question is, does it still have to come to PBPP?

AB said that from the Terms of Reference, we clearly can do it, do we have the resources?

AM thought that it is clear that something is necessary but not clear how this would fit it and resource of PBPP. Should the PBPP form have different questions added?

MB asked what do Chief Executives want to be decided? Can it be answered by a lead board or do they want PBPP to take a view on this on behalf of all Caldicott Guardians? Can PBPP make that decision?

HC said information security, legality and data protection and wider data governance are requirements that exist for all projects. Do we need a national review? Or is it more efficient to add on the Caldicott Guardian part of this?

There is a national IG leads / Data protection group but currently collaborates in an informal way. It also populates Tier 1 and often do data security reviews, although not all the Information Security leads sit on Tier 1.

MR asked how do we take this forward? IG review going on by SG eHealth and this includes PBPP. Can we combine these two things? Need to acknowledge there is a resource issue.

KM asked how do boards manage things like clinical audits?

MR explained that clinical audit happens at boards but similarly there are national audits. For individual boards, processes are in place but for national audits, the intention was that they came to PBPP.

AM summed up this by suggesting that we have a conversation with PR as these applications have crystallised some issues.

Agreed MA, MR and AM will discuss further with PR and report back.

Action AM, MR, MA

3.4 Tier 1 Audit

MA stated that some Audit responses are still outstanding. Expressed concern as the Audit cannot be completed without all responses.

This raised concern as in previous two years, the Tier 1 Audit was included in previous PBPP workshops which were valuable.

MA agreed to send out applications to the Tier 2 members who have not responded with a revised deadline of 2 weeks to respond. This will allow the Audit to be part of the PBPP Workshop in October.

Action: MA

3.5 HDRUK gateway and access to health data

CM had invited David Crossman from the Chief Scientist's office to come to this meeting but he was unavailable. He is the NHS Scotland representative on the HDRUK Alliance.

AM, CM and BH have now also been invited to an information session on HDRUK Alliance on the 11th October 2019. CM will report back to the committee after this date allowing further discussion.

Questions from the committee to the HDRUK:

- If HDRUK going to be "trusted brokers" what do people want to see in that? What would that look that?
- By what authority do HDRUK become trusted brokers?
- What is the legality of this whole process? Who gives HDRUK the right to give away data?
- Come back from session and address the questions that arise.
- How is this related to Roger Halliday's work and the Research Data Service?

CM stated that Lorna Ramsay has been invited as the NSS representative and NHS Boards to be invited also.

Action: AM / CM

3.6 1819-0001 Cunningham Application: Quorum of responses not yet received.

At the last committee meeting it had been agreed that documents would be requested from the applicants and circulated around the committee. The committee would respond and decide in the light of the new information.

MA stressed that she needs an answer to go back to the application as it's been 3 months since the last meeting and the applicant is chasing a response.

HC stressed that she was completely recused from this application and will continue to be so. She did agree to answer any questions on the matters of fact, but could not be part of the discussion of this application.

SP stated that this application would set a precedent if it was approved, as it would be the first application to receive data as a separate commercial company, which did not have a public sector partner. There is no SG guidance on the Commercial access to data. We have not seen the legal collaboration agreement.

AB advised that no positive decision could be made today as missing some of the essential documentation which we requested and is without a legal collaboration agreement letter? She suggested we set up a T/C to discuss - all feedback from members and have a separate conversation to make a final decision.

This was agreed. All documentation and responses would be collated and sent out to the committee for a T/C where a decision will be made.

Need to email the applicant and explain that one of the reasons this is taking so long as this would be precedent setting. The default would be a rejections and we are taking time so allow us to look at it in much more detail and potentially identify a suitable way forward.

Action: MA

4. Standing Items

4.1 Panel Manager report

Panel manager report was circulated for information. Committee agreed Tier 1 monthly reports should go to the Caldicott Guardians.

4.2 Policy Decisions and Case Law Principles

For information only.

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

No report had been sent in from the Scottish Government. AM planning to discuss with PR outside the meeting.

4.4 Conflict of Interest

AM requested that a review conflict of interest forms is completed for everyone.
MA agreed to ask members to update these forms, requesting these are done annually for future years. MA agree to make up a pro forma, or use the one from NSS, which will be circulated for all individuals to update.

It was noted that every NHS board has a conflict of interest policy.

If after completing there is any conflict of interest, agreed this can be discussed at later point.

5. Tier 2 Audit results and resourcing of PBPP Committee

Tier 2 Audit results had been circulated around the committee members and the PBPP Operations group. There is still a vacancy for a Caldicott Guardian which affects committee quorum and the timeliness of Tier 2 out of Committee reviews.

MR noted that this was a very good report. She raised concerns that the PBPP Committee had not had quorate meetings and felt strongly that this was embarrassing.

The reasons for not being quorate were discussed: e.g. not enough NHS Scotland representatives, especially if AM chairing, and thus could not be included in quorum as a

Caldicott Guardian. It was noted that both research representatives have honorary NHS contracts. Sometimes it has not been possible for Lay Members to attend, and this reduced the range of perspectives available and thus the value of discussions.

MR asked whether the Panel could be quorate with one lay member?
It was felt that lay input is valuable and it is not normal practice to have only one lay person in attendance. We should encourage attendance not lower the bar.

Clearly this committee has an issue when we have a Caldicott Guardian vacancy. It was noted that previously it has been suggestion to have deputy Caldicott Guardian in attendance; another option is that Caldicott Guardian input to applications on a rolling basis.

AM suggested that we ask Hugo van Woerden (Chair of the Caldicott Guardians Forum) and their secretariat, for a list of all current Caldicott Guardians in Scotland and then we could then try out this approach and then review. Not sure what additional training would be required for Caldicott Guardians to review PBPP Applications.

KM noted that a year ago there was a number of proposals for feedback on looking at make-up of panel and rotas and wondering if this needs to be re-visited? He suggested looking back to answers to questions when this was raised a year ago.
Agreed to revisit issue raised a year ago and the responses to this then pick up the protocol of how to invite rolling input from all Caldicott Guardians or a deputy.

Action: MA to find and recirculate document

It was noted that decisions from inquorate meetings were ratified by the members of the committee who were not in attendance. MR highlighted the difficulties with this approach on other than a very occasional basis.

It was suggested that a written review in advance could be asked for if a person could not attend a committee meeting.

This was agreed, especially for anyone who knows they are unable to attend in advance.

DM asked why no paper from the SG was submitted today, he expressed as a Lay person he was very disappointed there was no update from SG.

CB reiterated issues of accessibility and the use of V/C and T/C at meetings.
It was agreed this will be looked into for better attendance especially for members from more remote boards.

Agreed the PBPP Operations group will investigate the use of V/C and T/C at future meetings.

Action: MA /MR

There has never been a Social care representative on the committee. Do we take social care out or do we involve someone?

At the start of PBPP the Chief Social Work officer was written to, to ask for someone with professional expertise to join committee. This letter needs to be sent again.

Deputies: it was agreed that a deputy Caldicott could attend but discussion took place on whether a deputy could attend in place of other committee members. When the Committee was established, it was decided that this role could not be delegated. In some Boards, the Caldicott role was delegated to the equivalent of a Tier 1 member. It was suggested that instead of a deputy an alternative person could be agreed. These would be people with

similar expertise, but not someone less senior nor without the specialist expertise required by the Panel. It was agreed that members should identify alternative people of equivalent standing and expertise to attend if the regular committee member was to be absent.

AB suggested more lay people? Possibly young more lay people?

There are currently 8 members form the original memberships, with rolling memberships. There was a requirement under the Terms of Reference to have a plan for succession. MA agreed to send out the rolling remit

AF noted that lay members can be asked to give presentations, not just attend meeting and review applications. Public engagement is very important and we should be doing more of this as it is beneficial for people to find out what is involved with PBPP. It was important to recognise the importance of PBPP and the public's perception of how data are used securely and proportionately for public benefit.

AM noted that she had attended the Wellcome Trust Clinical Research Facility Workshop about PBPP, run by MA for researchers and which had been excellent.

Actions to be taken forward by Ops Group:

- Agreed to write to Chief Social Work officer
- Agreed to look for people to identify deputies
- Agreed try out rolling Caldicott Guardian invitation input
- Agreed more increase strength and depth of lay voice particular younger lay members
- Agreed make clear that we have under documented extend to which external presentations are important and should be included in the terms of reference as expectations of members
- Agreed Improve specification of rooms we use for V/C as this is an acceptable method for participation in quorum (needs to be stated).
- Agreed look at issues raised last year and ensure that action plan address these
- Agreed If can't attend provide a brief summary or produce paper for information
- Agreed that deputies of equivalent standing and expertise can deputise

Action: MA and Ops Group

MR asked for it to be noted that AB has reviewed 65 out of 66 applications.

<u>Acting PBPP Chair</u>
AM informed group that members should think about having an Acting chair for the possibility that the current Chair will stand down.

We need to address this until such time as we become a new entity or until we can appoint a new chair. The chair is appointed NHS Scotland boards.
Agree MR will speak to Chief Executives regarding this.
AM is happy to chair but doing so excludes her from her Caldicott Guardian role and can cause quorum issues. Any members wishing to stand in as acting Chair please inform MA.

6. AOB

6.1 PBPP Training day – October 2019

MR asked about the training day and if there is an open invitation to Caldicott Guardians to attend. After discussion agreed that 2 Caldicott Guardians could be invited and for other there is a waiting list. Agreed discuss further at the next Ops group meeting.

No other business was discussed.

7. Date of next meeting

The next PBPP committee meeting will take place on 19th November 2019, in the Craigmillar Room, Nine Bioquarter.

We will endeavour to have VC available.