

**NHS Scotland Public Benefit and Privacy
Panel for Health and Social Care (HSC-PBPP)**



Committee Meeting: 13th April 2021

Item No.: 2

Paper No.: 2021/2-001

**Unapproved minutes of Committee meeting held on 20th January
2021**

<u>Purpose</u>
A record of the discussions and decisions taken at the committee meeting held on 20 th January 2021
<u>Recommendation</u>
For committee members to check and approve the minutes at the meeting to be held on 13 th April 2021.
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Public Health Scotland NHS Scotland Public Benefit and Privacy Panel for Health and Social Care

Minutes of the Committee meeting held on 20th January 2021 by MS Teams

Present: Dr Lorna Ramsay (Chair) (LR)
Professor Helen Colhoun (HC)
Professor Danny McQueen (DM)
Dr George Fernie (GF)
Carole Morris (CM)
Kenneth McLean (KM)
Dr Tara Shivaji (TS)
Dr Angus Ferguson (AF)

Apologies: Professor Abbe Brown (AB): written comments provided before meeting
Penni Rocks (PR)
Alan Ferrier (Al F)
Dr Steve Pavis (SP)
Martin Bell (MB)
Professor Corrie Black (CB)

In Attendance:
Dr Marian Aldhous (MA)
Phil Dalglish (PD)
Susan Kerr (Secretariat)

1. Chair's Welcome

The meeting is quorate and there are no conflicts of interest.
Thanks to HC and CB (*in absentia*) as this is probably their last committee meeting as research representatives.

2. Minutes and Actions from the previous meeting held on 10th November 2020

2.1. Minutes of the previous meeting on 10th November 2020.

These were approved.

2.2. Action Log

Only one paused action (04-02-20/ 02 Family Nurse Partnership [FNP]) was carried forward. As time goes on a Lessons Learned for FNP will be harder to carry out. At the time, a report for the HSC-PBPP committee was written and feedback was sent to Elena Beratarbide. LR suggested that we ask SP if he wants to make any comments and for this to be closed.

ACTION: 20-01-21 / 01 MA

3. Matters Arising

3.1. Committee personnel update

Research representatives

MA stated that there have been nine researchers interested and application forms have been sent to them, with a request to reply by end of January. MA asked for help with short listing applications and interview.

HC asked how people were selected. MA explained that this was discussed at the committee meeting in November; the list from the previous meeting was based on researchers who have an ongoing knowledge of the issues involved in health data research. It was proposed that the Chair of PBPP Committee plus two committee members would sit on the interview panel with MA in attendance.

LR asked that now as we are receiving applications for the research vacancy would anyone like to volunteer to be on the interview panel?

ACTION: 20-01-21 / 02 ALL

Lay representatives.

DM said that he was one of the Lay members who are stepping down.

MA stated that various people been contacted to identify potential lay representatives but no one has shown an interest as yet.

KM suggested that Rosemary Hampson from Healthcare Improvement Scotland would be a good person to contact regarding recruitment of lay members. KM will pass details to MA.

ACTION: 20-01-21 / 03 KM / MA

AF stated that reading through the lay representative specification, that it is the one which is least well defined and quite broad. He thought a more defined role should be stated. He feels this may be part of the problem recruiting new Lay members and needs to be a clearer sense of what is needed by a lay person on this group.

LR agreed that it is a challenge in defining the role clearly, but HSC-PBPP has received great value from lay people just now. LR would like us to try Young Scot as keen to understand the balance of different backgrounds to give this committee a broader balance.

AB suggested contacting the Citizen Advice Bureaux and Social Media.

LR ask MA if could define the Lay representative role more clearly. Any other suggestions, please send to MA.

ACTION: 20-01-21 / 04 MA & Lay Reps

Caldicott Guardians

A discussion took place on Caldicott Guardian membership of the committee and how this is an ongoing challenge.

MA informed the group that the PHS Caldicott Guardian has provided a representative for this committee and could the CGs ask a senior clinician to be a member of this committee as their representative? This would not be the IG leads.

LR and committee agreed.

Terms of Reference

MA stated that the Operations Group have proposed that the Terms of Reference to be changed to extend Lay members time on the committee for a short period.

In addition, as we presently only have two CGs for reviews of application, and the Operational Group had asked if it can be agreed that we can ask a clinical research representative for a third review, as there needs to be three CG responses for quorum. This was agreed.

AF agreed he was happy to stay on and suggested that a transitional overlap would be beneficial.

KM agreed and thought overlap for 6 months in the first instance, given time it takes to recruit and the challenge of recruiting in these times and not put the committee in a difficult position.

DM stated that this would not suit him, as he has taken on other roles, as he assumed he was finishing his time with this group.

LR confirmed that committee members are happy to make change to Terms of Reference for all retiring members of HSC-PBPP. This then allows us to also have overlap with new people joining. We will then follow up who is able to make this commitment.

The Terms of Reference to be updated to reflect the above.

ACTION: 20-01-21 / 05 MA

3.2. COVID review: update to HSC-PBPP application form

The full HSC-PBPP application form has been updated, mostly with addition of guidance notes and additional questions, to make things clearer. Any suggestions from committee members would be helpful.

Minor changes have been made after discussing with a senior coordinator from eDRIS and their project specification document. The guidance notes will be updated.

Suggestions from committee will be added to the form and guidance notes. Then MA will go through form in detail with eDRIS so they know what information is required from applicants.

AB had made some minor suggestions.

DMcQ asked about the communication back to the public about application outcomes and these need to be strengthened on the form and in guidance notes.

All agreed to the changes to this form and MA confirmed that this will continue to be reviewed annually.

HC asked about the application form becoming web enabled?

MA explained that we have been working with Service Now for this but this was also put on hold, due to COVID taking priority.

CM stated that eDRIS have been looking at Share-point and experimenting with this, which may benefit HSC-PBPP and link with Service Now.

LR confirmed this is to be addressed but updating the form first was a good starting point.

KM ask if could ask for any SG funding?

LR felt that the capacity is the issue rather than funding.

It was agreed to accept changes to the application form. We will keep the aim for automating and making more of a digital focus as a future aspiration to be reviewed by the Operations Group.

ACTION: 20-01-21 / 06 MA & Ops Group

3.3. HSC-PBPP Development

In the absence of a development day, a development slot is now being added to each committee meeting.

MA stated that the Ops group felt that Tier 1 leads do not have time for an online training session but any developments could be presented using the fortnightly IG leads meeting which is chaired by Eilidh McLaughlin in NHS NSS.

Proposal agreed there is a slot with BPSU today and then see how that goes as a development slot at each meeting.

Agreed to then feedback to group and potentially in the future, meetings could be opened for T1 people to join in if they wish to. We can review what works best.

ACTION: 20-01-21 / 07 MA

4. Updates for committee

4.1. Panel manager report – for information

MA stated that approximately half of the approved applications are for COVID.

LR thought that there is a lot of activity going on and HSC-PBPP are managing to cope well with the work coming to the panel, which is really positive. LR thanked all for the work and the members supporting panel.

CM said that there were some delays around business as usual with eDRIS, as they have been prioritising COVID work. CM is recruiting additional staff.

4.2. Policy Decisions and Case Law - for information

This was circulated for information only as there were no changes.

4.3. Scottish government (SG) update

Cara Archibald unable to attend this meeting but did send a brief update on accreditation of Safe Havens. This will be carried forward to the next meeting.

PR was also unable to attend this meeting but had sent an update, with a request for help from committee members. This would be circulated again after the committee meeting.

LR asked members if they could please read it and pass any comments to MA or directly to Elena Baratarbide. All agreed.

ACTION: 20-01-21 / 08 ALL

4.4. Update from HDRUK

CM gave a short update

There is a three-year programme of COVID research, including access to vaccination data.

Vaccination data is a new resource held jointly between PHS and NES Digital Services (NDS), who do not want to open up this resource until PHS and NDS have done their vaccination monitoring. Any requests for these data will also be reviewed by NDS and PHS. Data needs to be cleaned so is fit for purpose.

KM asked about long COVID.

CM stated that long COVID will need to be defined from all relevant data sources. It will not be a separate dataset.

HDRUK have funded four studies with a view to these project finishing by end of March.

These will go through PBPP process.

HDRUK is also doing lot of work with public engagement, and any studies coming through should have a public engagement element.

4.5. Update from Research Data Scotland (RDS) including commercial access

CM gave an update; there was some overlap with HDRUK for COVID.

RDS hopes for formal launch on 1st April 2021. Roger Halliday is stepping back from SG work and the first year of RDS would be used to establish its processes.

Engagement with commercial sector

KM commercialisation of data, how will HDRUK or RDS help to address this?

CM said that HDRUK works UK-wide. At the Scottish Government level, Albert King is looking at how people currently engage with industry. However, a framework of how this works is needed, especially at national level, as there are potentially multiple legal entities.

LR suggested that we invite Roger Halliday and Albert King to the next meeting to discuss their thoughts on commercial applications and access and how can we contribute to that.

ACTION: 20-01-21 / 09 MA/LR

5. Application matters

5.1. 2021-0004 Jefferson

This application requests access to imaging data to develop an algorithm by a commercial company that will be sold back to NHS. It sets a precedent for imaging data and there are likely to be more applications of a similar nature coming to HSC-PBPP in the future.

A wide-ranging discussion took place covering different aspects of the application. This included the discussions, collaboration and contractual arrangements between the NHS and other industry partners; ongoing governance; location of processing; use of open-source software so that others can redo the same analysis; commercial output. It was noted that this application is one of a programme of work, and for which other applications will be submitted to HSC-PBPP.

The application was approved with no conditions. Any subsequent applications will need to go through PBPP process and be scrutinised and approved on their own merits. This outcome will be communicated to the applicant.

ACTION: 20-01-21 / 10 MA

5.2. Approaches to commercial applications in light of the Jefferson application.

This will come back to the meeting in April 2021.

Following on from the application, we need to use it and any previous applications to develop clear guidance of how applications with a commercial element should be handled,

and what should be in place before it comes to HSC-PBPP: e.g. formal processes for agreements; the five “safes”; wider public benefit and public perception of that.

ACTION: 20-01-21 / 11 MA, Operations Group and others

Could someone external, e.g. from Scottish Government or from a business unit, be co-opted on to the committee to comment on the financial and legal aspects of the arrangements?

It was noted that Albert King and Roger Halliday (as already mentioned above) were already looking at this, as is the Innovation Support Group. Further developments are likely to come in the next 6-12 months.

6. HSC-PBPP Development Slot

Use of Health Informatics Centre (HIC, Dundee Regional Safe Haven) for studies from the British Paediatric Surveillance Unit (BPSU)

Richard Lynn (RL), Jacob Avis, Rachel Knowles from BPSU, and Duncan Heather (from HIC) were invited to attend. Due to a technical issue, Duncan Heather was not able to be admitted to the meeting. The HIC involvement in the BPSU studies was previously outlined to the committee in the meeting of 10th November 2020, after which the slides were circulated to committee members.

RL gave a summary of the supporting paper: BPSU has developed data platform for data in HIC, which is an accredited safe havens that to allows access to external researchers. There are two parts to this data platform: one part to send out the ‘orange eCards’ by HIC to inform clinicians of the current studies for the BPSU. Once a clinician sees the eCard, if they indicate that yes, they have a case of one of the conditions under surveillance, then the clinician will be automatically connected to the data collection part of the data platform and will access a desktop area specific to themselves. The data entered by the clinician will not be seen by BPSU, but only by clinician who entered the data, the research team for that particular condition and HIC. Once data has been entered on the data platform, the personal data will be de-identified by HIC and can then put into a Safe Haven area for analysis by the research team. The applicant will be able to download the fully anonymised data for analysis. When the data platform is launched it has to work and with same level of involvement from paediatricians. As far as they are aware it is the first time this will have been done for multiple projects.

KM thought it is a great idea and hopes it does succeed. What mitigations would be in place, if the response rate changes?

RL thought that the evaluation will be sent out to gauge user experience, as people are familiar with RedCAP eCard system. Prototype studies will be done. Tests will use commercial safe haven, RedCAP and some data worked and looking for more personal experience for clinicians.

LR asked CM to what extent does the set up suggested align with process through National Safe Haven (and with knowledge of HIC) and how can we standardise or speed up the process?

CM all the processes in place will help for pre-filling some of the application form, with covering knowledge of standardised systems in place at HIC.

RL has drafted forms for IRAS and CAG and do something similar for PBPP.

LR now lots of things automatically there, that will make the processes easier. We will watch how this goes and ask for feedback from HIC or BPSU and work to improve any processes.

7. Any other business

No other business was raised.

DM declared this is his last committee meeting. LR formally thanked him for all his work and contribution over the years, wishing him the very best for the future.

HC, AF and AB were also thanked for their work but we are hoping to keep them both a little longer, to cover the transition for new members joining.

LR thanked the whole committee for the tremendous work this year, under trying circumstances, particularly turning round the rapid reviews for COVID19 applications

8. Date of next meeting

The next meeting will take place on 13 April 2021.

ACTIONS LIST

Action number	Action	Who
20-01-21 / 01	Contact SP for any comments regarding paused action 04-02-20/ 02 FNP and then close.	MA
20-01-21 / 02	Request for volunteer to be on the interview panel for the prospective research representatives.	ALL
20-01-21 / 03	Contact HIS to ask if any of their public partners would be interested in HSC-PBPP as a lay representative.	KM / MA
20-01-21 / 04	Try to improve the Lay Representative specification to try to define the role more clearly.	MA & Lay Reps
20-01-21 / 05	Update the HSC-PBPP Terms of Reference in light of agreed changes.	MA
20-01-21 / 06	Update to the application form and review it annually. Aim for online form as a future aspiration.	MA & Ops Group
20-01-21 / 07	Use the IG Leads meeting to update the IG Leads on proposed changes to BPSU and any other developments in the future.	MA
20-01-21 / 08	Request from Penni Rocks for help from committee members.	ALL
20-01-21 / 09	Invite Roger Halliday and Albert King to the next meeting to discuss their thoughts on commercial applications and access to data	MA/LR
20-01-21 / 10	Outcome of 2021-0004 Jefferson application review to be communicated to the applicant.	MA
20-01-21 / 11	Develop clear guidance for applications with a commercial element, and what should be in place before it comes to HSC-PBPP.	MA, Ops Group & others