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

Committee Meeting: 8th September 2020

Item No.: 2.1

Paper No.: 2020/21-009

Unapproved Minutes of the Committee meeting held on 16 June 2020 by MS Teams

Purpose
Unapproved minutes of previous committee meeting, previously circulated. For review and approval by committee members
Recommendation
Unapproved minutes of previous committee meeting, previously circulated to committee members. For review and approval by committee members
Timing **Background** **Engagement**
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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 16 June 2020 by MS Teams

Present: Dr Lorna Ramsay (Chair) (LR)
Professor Helen Colhoun (HC)
Professor Danny McQueen (DM)
Dr George Fernie (GF)
Carole Morris (CM)
Professor Abbe Brown (AB)
Martin Bell (MB)
Angus Ferguson (AF)
Dr Maria Rossi (MR)
Penni Rocks (PR)
Alan Ferrier (Al F)

In attendance: Professor Roger Halliday (RH)

Dr Marian Aldhous (MA)
Phil Dalgleish (PD)
Susan Kerr (Secretariat)

Apologies: Dr Steve Pavis
Professor Alison McCallum
Kenneth McLean
Professor Corri Black

1. Chair's Welcome

The meeting is quorate and there are no conflicts of interest.

2. Minutes and Actions of the previous meeting held on 4th February 2020.

The minutes from the previous meeting were approved.
Due to COVID19 lockdown, the committee meeting scheduled for 5th May 2020 was cancelled.

3. Matters arising from previous minutes

Due to current COVID19 priorities the following actions from the 2019/20 Action Log will be carried forward:

04-02-20/02: Lesson learnt in relation to Family Nurse partnership (FNP)
04-02-20/04: SHARE
04-02-20/06: Amendments to HSC-PBPP applications
04-02-20/09: Advice for HDRUK applicants
04-02-20/11-13 relating to Commercial applications.

4. Standing Items

4.1 Panel Managers report (March 2020 and May 2020)

Circulated for information. Nothing was raised.

4.2 Policy Decisions and Case Law Principles

Circulated for information. The Policy has been updated for COVID19, which includes a shortened application form and processes which have been in use for the last two months (see Item 5.2).

4.3 Scottish Government Update

PR shared a presentation and gave an oral update. A number of things had been put in place in response to COVID19, with four task forces. The ones of interest to HSC-PBPP would be task forces 3 and 4: Task force 3 is Communications and public engagement, which includes the test and protect, and covers both care and research. Task force 4 is Data and intelligence and is about technology and its use for delivery of requirements. The information governance (IG) group is led by PR and is looking at what is already in place and what gaps are needed to be filled.

LR thanked PR for a very helpful update and asked what HSC-PBPP could do to help?
PR explained the need to consider HSC-PBPP involvement in public engagement, rapid scrutiny and work with Stats-PBPP. Also support for any rapid things that are happening, generally engaging and supporting rather than specific tasks.

GF asked about encountering the false / negative result or presumed COVID19? Patients can show classic signs of COVID19 but can still show up as negative. PR stated that this has not come up as specific pieces of work but looking at all round testing, and how the virus varies around people's genetics.

HC asked whether there was integration of complexity e.g. health and other non-health data in next while for SG? Will we be evaluating those? PR replied that it was early days and involvement with HSC-PBPP may be affected with the remit for data. SG are considering whether there will be other IG approval routes beyond HSC-PBPP and exploring how that might happen. Stats-PBPP is involved.

LR thanked PR for a very helpful presentation and discussion.

4.4 Update from HDRUK

Initial pause in HDRUK activity but discussions have continued on a more limited basis. There has been some redirection of HDRUK to support COVID19 research at a UK level.
CM has some more involvement in a couple of areas, including providing COVID19 figures on a weekly basis. She has been in discussion with the HDRUK Cardiovascular work stream and also around their data catalogue, providing them with a list of datasets which are hosted for COVID19 in the National Safe Haven (NSH).

5. PBPP Review and Update

5.1 Review for Chief Execs

This is currently on pause. However, it is felt that all of the work that has been done and changes in processes will tie in to how HSC-PBPP works and identify additional support that might be required.

5.2 COVID19 response from PBPP and eDRIS

LR thanked all that were involved in the COVID19 processes which has been put in place by the panel managers in discussion with PHS DPO and eDRIS.

Approval of process
LR asked for any questions or concerns on the rapid process?

There was general agreement that it was working well and the reviewers were challenging the applicants appropriately. There was not feeling that we are losing anything, although timescales are tight, we still deliver what we previously delivered.

MR asked how are we looking at this from an evaluating point of view? How has the more rapid process affected the IG process? MA explained that in terms of IG, applications are either reviewed by the rapid review panel, which includes either of both of the PHS or NSS DPO, or by normal Tier 1 panels.

MR asked about the relation to the GP dataset, should the Scottish Trauma Audit Group (STAG) IG model be considered? PR explained that they looked at this model, but the GPs are happy with the HSC-PBPP scrutiny process.

CM confirmed that we are starting to see less urgency in the applications coming through, this meaning that eDRIS can spend bit more time on initial reviews.

MB stated that CHIAG have also set up a fast track application. Many appreciate the faster pace and do not want to go back to taking a long time. A lesson to be learned is that they need a new normal not back to the old way. LR agreed that it would be good to retain the pace as we return to business as usual. CHIAG and PBPP will share thoughts on this. LR stated that PBPP and CHIAG can share learning and there will be a Lessons Learned review process.

ACTION: 16-06-2020 / 01 CM / MA /MB

CM said that some applications had been quite rushed and they were now going back to some of the early applications to see whether we need further updates and to ensure that protocols and data management plans were in place. People are now taking more time over their applications.

All agreed to continue with rapid process which is in place.

Query from SICSAG
LR noted that a question had been raised from Scottish Intensive Care Society Audit Group (SICSAG) about the details of the data requested.

MR asked what oversight of applications do the asset owners have? CM replied that eDRIS and HSC-PBPP have fed back the advice from SICSAG and suggest that the applicants contact SICSAG themselves. Normally this type of work would be via an information request to SICSAG.

MR what about GPs if GP data is now included? Should GPs review applications first? PR replied that GPs are happy that HSC-PBPP reviews first and then GPs would see the GP data element and provide an opinion. GPs didn't want to ask questions that HSC-PBPP would pick up anyway. This is an opportunity for primary care clinicians to have input.

National Records of Scotland (NRS) deaths
CM explained that NRS are getting a number of requests around deaths due to COVID19 and asked how can PBPP support NRS with this and if they would be happy to include this in the HSC-PBPP Tier 1 process? NRS would provide someone to sit on the relevant Tier 1 panel.

LR asked if the committee has an opinion on this?

Al F stated that it would help NRS add data to the safe haven for linkage or individual data sets. The volume of requests they have received for COVID19-related deaths has increased. This would use the HSC-PBPP COVID19 rapid process and application form. There are currently 12 requests outstanding.

LR confirmed that most of these would be Level 1 priority (for review at Tier 1 panels) although there may be a small number that would be Level 2 priority and go to the rapid review panel.

There was general agreement for this.

CM and Al F to review NRS data requests; CM and MA to provide a process and identify any potential issues.

ACTION: 16-06-2020 / 02 Al F / CM / MA

5.3 Establishment of PHS and update of Terms of Reference
The Terms of Reference has been updated in to include the establishment of Public Health Scotland (PHS). This document will go on the HSC-PBPP website.

ACTION: 16-06-2020 / 03 PD / MA

HC asked if this would now mean that some of the work that we previously had issues with like the budget for HSC-PBPP might be able to progress. What about automated processes for HSC-PBPP? MA stated that the HSC-PBPP team (MA, PD, and SK) are now all funded by the Scottish Government. Regarding automated processes, HSC-PBPP moving to Service Now is in discussion. The HSC-PBPP system will talk to the eDRIS system. This is in progress but has been diverted due to COVID19 at present. MA stated that an online application form is more difficult but we are looking at updating the current application form. This will be picked up again as priorities allow.

6. Application
No applications to come to this committee meeting.

7. Minimum Standard Datasets (Michael Sibley from eDRIS)
In the absence of Michael Sibley from eDRIS, CM gave a summary of the paper.
HC said she was in support and this was long overdue. LR said it was worth exploring the scope of the datasets. CM said that the scope would come back to committee, with the mitigations of any privacy risks in place (e.g. use of NSH, disclosure control). MR asked whether this would improve accessibility to the data and funding? CM replied that if there is a faster throughput of projects, with less time spent with researchers, this will reduce costs.

All agreed to go ahead.

CM to scope out the scope of the datasets and bring to next committee meeting in September.

ACTION: 16-06-2020 / 04 CM

8. Research Data Scotland (Roger Halliday)
RH is the Chief Statistician at the Scottish Government. He gave a presentation on Research Data Scotland (RDS). He is presently leading a COVID19 analysis team looking at the model of the progress of COVID19 through Scotland.

A National Performance Framework has been developed for Scotland which gives an outcome focus but needs data for evidence. Currently a lot of public sector data does not 'speak to each other'. Linkage of data is important for access across different domains. E.g., analysis of health and homelessness data highlighted the barriers to healthcare for the homeless. It also gave clear indicators and predictors of homelessness, leading to trials to prevent homelessness.

Currently we are in position to do more as Scotland has great data, with academic expertise to do the analyses. The size of Scotland is good with enough data to test different approaches. However, the data are not well organised and not held in the same place, where it can be brought together and linked for specific projects. This is where RDS comes in.

- RDS is for systematic use of data, to save time, money and effort.
- RDS team will make analytical platforms available but also will address ethical and governance concerns.
- RDS has been set up as a company and associated charity. Key word is trust so needs to be separate from government but draws from the expertise across Scotland.
- RDS is about data for research in the public good, in a safe, secure way.

Financial aspects: RDS will need to obtain money from different sources to operate, e.g. research councils, Scottish funding council, national investment bank, Scottish Government. RDS will charge for the service it provides and this will be reinvested back into the service.

RDS will commission a secure IT infrastructure that will bring data together from different places. It will be an end-to-end process and will also give advice. This will need to be collaborative and build on what already exists, with integration with the regional Safe Havens.

Commercial models for this need to be established with rules for the road for commercial applications.

During 2020 the organisation will be set up. There is work still to be done on setting up a company, with correct service model and business case and necessary staff. RH will be interim CEO.

Information Governance (IG) is one of the things that takes too long. COVID19 has shown that it isn't straightforward but that it can happen faster. What is the system of IG so more cross-sectoral data linkage can happen? Use of Standard datasets is one way to go which comes with a level of scrutiny.

RDS will start with high profile test projects to show what this can do for people, businesses and places. COVID19 has shown the power of data linkage and data access to provide information to ministers and leaders for them to make decisions about COVID19. RDS would be launched on the back of this.

There is now route map for data to be brought together, from the response to COVID19: CM and eDRIS team as well as Al F and NRS team brought together information for COVID19, which is now being used for high profile projects of relative risks from COVID19 through housing, occupation, demographics, ethnicity, health factors, age and sex.

This is good data to offer public bodies, research organisation, industry and others.

HC was confused as to how this would relate to eDRIS and EPCC (Edinburgh Parallel Computing Centre which hosts the NSH)? Would the datasets sit within RDS? Is there a separate technical

infrastructure? RH replied that RSD will build on the eDRIS, EPCC and NRS infrastructures that are already in place. CM confirmed that RDS will use the NSH.

HC commented that the NSH is OK for small research projects, but it does not have the appropriate architecture for 'heavy duty' data analysis. RDS is exciting but needs to be set up differently so that this can take place so that epidemiologists can work alongside data and computer analysts for deep data analysis. RH thought it would be good for the designers to talk to HC regarding this point.

ACTION: 16-06-2020 / 05 RH / HC

AB said this echoed much a lot of what has been done on the health side. E.g. references to trust, safe data, safe places. It is good that commercial benefit will be shared back to resource but need to be sure that this is not reinventing the wheel. RH said RDS was not creating something new but addressing the ongoing issues that hold us back.

DM questioned the security from a public perspective, e.g. datasets on the cloud being hackable. Will the data be held in places where there is suitable security in place? CM replied that data will be held in NSH environment, and will be under same security processes, which are being updated. Additional non-health data sets will be in same environment. Data not held by any other organisation but by University of Edinburgh EPCC on our behalf. No one will see the identifiers so that it cannot be traced back to an individual.

LR asked that what does this mean for HSC-PBPP? RH replied that HSC-PBPP acts directly on behalf of data controllers. There will need to be a federated set of panels that would act across all public sector, not just health. There would be some generic or difficult privacy issues for which health might be the most significant and important one. Ideally he would like to do more of the assessment of individual projects without needing to come to a full panel, with arrangements with data controllers for access to specific programme datasets. There might be more connection across the privacy panels to make thing work faster. LR keen to work with RDS as this evolves, including lessons learned for COVID19.

MR: RDS is a network for bringing in resources and partnerships but is a company which has income requirement for access to the data. If adding in non-health to health data, building on well-established process, what does this add, apart from accommodating non-health data? RH said that it adds leadership to bring together different parts of the system to function as a whole. Non-health elements and linkage have not necessarily been straightforward and maybe have been more informal. A system review needs leadership and flexibility that a centralised system can bring.

MR: what will happen to the data controller or asset owner function? RH still working through this at the moment. Need to bring forward proposals about IG arrangements for non-health data. He is keen to bring back proposal to September HSC-PBPP meeting.

ACTION: 16-06-2020 / 06 RH

AF: If RDS is a commercial company and charity, how would this relationship work? Also talked about public benefit and trust: how would this be defined? RH replied that the Company would be not-for-profit and would register itself as a charity, so would have to have a public service mission: to enable access to data in the public benefit. Setting RDS up makes the finances a bit more straightforward. Definition of public benefit is in line with the National Performance framework: wellbeing of public, allowing people to flourish and reduction in inequality, so everything should have an equality element to it.

AB: this seems to be quite a narrow scope for RDS: reducing inequality and drawing together the different governance frameworks. RH Wellbeing is quite a wide remit and brings together information from members of the public. What would people expect or be unhappy with the use of their data? Certainly for service improvement and improving wellbeing of lives of people, but the public are nervous about use of data for profit for specific organisations.

HC-asked how does this related to HDRUK and brokering commercial access to data? RH said RDS was engaging with range of funders, including NRS and research councils, but all needs to be part of same system so conversations ongoing with HDRUK, with the hope that HDRUK would be one of funders for RDS. Regarding commercial access, further discussions as to how and by whom such decisions will be made and who should be drawn together who have an interest in this and what would be the basis of the commercial access. HC hoped that the control of that would remain in Scotland. LR said that that is part of the discussion.

LR asked if there will be lay representation on the board for RDS? RH replied, that is the intention.

It was agreed that for immediate future this should be a standing agenda item.

ACTION: 16-06-2020 / 07 MA

9.Accreditation of Safe Havens

Concern previously expressed about responsibility for accreditation of Safe Havens to go to NHS Boards. LR has discussed this in the context of HDRUK and RDS. Need an agreed approach with consistency across all and done on regular review process. Organisation that holds the Safe Haven has responsibility but need external assurance too. One option is to explore using external organisation for accreditation, e.g. UK Statistics Authority.

CM said that eDRIS, NRS and EPCC were audited by the UK Statistics Authority for the NSH, as a trusted research environment providing data under the Digital Economy Act. It was a very robust process, with a lot of forms and a full site visit. eDRIS was accredited with a few things to follow-up for full accreditation; EPCC has full accreditation; NRS not yet had the full site visit.

HC stated that the original NSH was set up under Safe Haven charter but dealt with simplistic analyses. Are the local/regional Safe Havens using the same settings? For heavy duty data analysis with a lot of complexity, it needs a different technical environment, which EPCC cannot host. Specific datasets need good interactions between computer and data analysts. If have to go through an expensive and bureaucratic accreditation process, this could limit the processes available.
LR noted that the caveats around this could have a negative impact.
RH said that this is about provision and maintenance and need to look at this from a system perspective as part of public sector in Scotland. The points made are really important. There is enthusiasm to get national and regional Safe Havens to work together.

LR agreed that where the Safe Havens work, they need to be accredited to particular standards, but also need to recognise and provide alternative areas where sophisticated analysis can take place.

10. **Any other business**

A document and email from Dr Lesley Jackson was circulated regarding a request from the National Neonatal Research Database. As there was no time for discussion, please respond electronically.

ACTION: 16-06-2020 / 08 MA / ALL

11. Date of next meeting

The next meeting will take place on Tuesday 8 September 2020, probably by MS Teams.

LR would welcome feedback on the meeting today using MS Teams

ACTION TABLE

Action ref	Action	Responsible
16-06-2020/ 01	Lessons Learned for HSC-PBPP and eDRIS (and CHIAG) responses to COVID19	**MA / CM / MB**
16-06-2020/ 02	Review data requests for NRS deaths data, provide a process and identify any potential issues.	**Al F / CM / MA**
16-06-2020/ 03	Approved updated Terms of Reference (v2.3) to be put on the HSC-PBPP website	**PD / MA**
16-06-2020/ 04	Scope out the Minimum Standard Datasets (health data) and mitigations for privacy risks for September meeting.	**CM**
16-06-2020/ 05	Conversations to be had with RDS designers to talk about requirements for 'heavy duty' data analysis in Safe Haven.	**HC / RH**
16-06-2020/ 06	Proposal for Information Governance Arrangements for RDS to come to September meeting	**RH**
16-06-2020/ 07	RDS to be added as a standing item on HSC-PBPP committee agenda	**MA**
16-06-2020/ 08	AoB item to be circulated and committee members to respond by email.	**MA / ALL**