

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



Committee Meeting: 20th January 2021

Item No.: 2.1

Paper No.: 2020/21-027

Unapproved Minutes of the meeting held on 10th November 2020

<u>Purpose</u>
A record of the discussions and decisions of the committee.
<u>Recommendation</u>
For committee members to check and approve minutes at the meeting.
Name of the Author: Susan Kerr, Dr Marian Aldhous, Dr Lorna Ramsay Designation: Email: phs.pbpp@phs.scot

Public Health Scotland

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

Minutes of the Committee meeting held on 10th November 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)
Penni Rocks (PR): part of meeting
Alan Ferrier (Al F)
Dr Steve Pavis (SP)
Kenneth McLean (KMCL)
Dr Tara Shivaji (TS)
Dr Angus Ferguson (AF)

In attendance: Professor Roger Halliday (RH)
Doreen Grove (DG)

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

Apologies: Professor Corri Black (CB)

1. Chair's Welcome

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

The chair welcomed all to the meeting and introduced new member, Dr Tara Shivaji who is a Consultant in Public Health Medicine and representative of the Caldicott Guardian in PHS.

Professor Alison McCallum has now moved to a new post and therefore given her resignation from the HSC-PBPP committee. LR thanked Alison for all her work with the Committee. There is now no territorial NHS board representation on the HSC-PBPP committee. A number of risks have been identified in relation to this and these were highlighted in the paper for item 7.

2. Minutes and Actions from the previous meeting held on 8th September 2020

The minutes from the previous meeting on 8th September were approved.

The Action Log was updated. It was agreed that a number of paused actions could be combined with other ongoing actions. Only one paused action (04-02-20/ 02 FNP) was carried forward.

ACTION: 10-11-2020 / 01 MA

3. Matters Arising

3.1. Update on special (commercial) applications

LR informed the committee that the Health and Social Care Innovation Steering Group had completed discovery work with outputs to NHS Board Chairs and Scottish Government (SG). The recommendations include

- Leadership and governance structure for health and social care innovation, including the establishment of the Scottish Health Innovation Partnership (SHIP) which would make cross-SG policy decisions and the Health and Social Care Innovation Steering Group to provide strategic leadership and oversight.
- A national HSC innovation system programme, including a project to design and develop a delivery mechanism for innovation in health and care. A 'playbook' would be developed for applicants so they are made aware of what is required, including in relation to privacy.

3.2. PBPP online Development Day

MA stated that the HSC-PBPP Operational group have discussed how and when an online development day could be held 2021. It was felt that January would not be possible due to availability and Tier 1 panel members being extremely busy. The Ops Group thought that Tier 1 members would not be able to attend, as they are struggling to meet the requirements of Tier 1 panels. At present some are not available for any HSC-PBPP work but this could possibly be held later in the year. 3 options are:

- No development day
- Go ahead with a development day albeit using different formats
- Have topics covered in a development section of the PBPP Committee meeting

PR agreed that people are very busy but thinks it is important we come together collectively, also stated that she like the idea of someone coming to the committee meeting for updates/discussions. AB agreed, with so much work ongoing thinks it would be good to set aside time in the spring. GF and KM supports this. KM stated that he feels it would be very useful to show a journey of an application, possibly a rapid review application and look at how it progressed and the outcome, with possibly the applicant presenting their outcome.

It was agreed we do need to do development as a group and a development slot will be part of the January meeting. LR agreed and will discuss further with MA.

ACTION: 10-11-2020 / 02 MA / LR

4. Standing items

4.1. Panel Manager Report (metrics to October 2020)

MA stated that she has added in metrics for non-COVID applications: these are taking slightly longer overall by about 5 extra working days but all in all generally doing okay.

LR asked about a non-COVID application which took over 4 months to approve, MA explained that this was due to the applicant taking a long time to send in response then adding a lot more data request so there was more to review. Tier 1 panel members were unable to review quickly due to other COVID priorities.

4.2. Policy Decisions and Case Law Principles

These have been updated for NHS Data Sharing Accord. The terms of reference have also been updated.

4.3. Scottish Government Update

PR gave an update on the proximity app, Test and Protect is part of the proximity app which is now launched successfully with 1.5 million people using it. This app now works and will collect any notifications across UK. Work is going on to open up the app to children age 11-15 years. This is part of Children's Rights and Wellbeing. Consultation is still ongoing and being fed back to ministers but overall assessment is looking towards lowering the age.

Safe Haven Accreditation: The Data and Intelligence Network (DIN) is looking at a proportionate approach through a Short Life Working Group (SLWG). This will look at the landscape and how to develop a framework to develop this and the burden of security into a consistent approach for continuing assurance around compliance. Led by Cara Archibald, who also runs the Competent Authority for Assessment of network. SLWG contains people across the landscape and wider platforms.

Digital Health and Care Strategy refresh is now looking at how to link digital delivery to NHS boards, to reflect the Digital Strategy for Scotland. Includes AI, commercialisation, procurement and ethics. Aims to ensure consistency across different areas.

SP asked about the governance of Safe Havens –what is the organisational governance and where do they sit? Who do they report to? Any governance depends on how they can be held accountable? Where is their accountability?

PR said this was not covered in accreditation. Not something thought about yet, but maybe should do so. Wider monitoring might be needed.

HC asked what is the legal position if children can sign on to the app without parental consent? AB asked about ethics and human rights. Are the Scottish Human Rights Commission involved? PR indicated that they will be and were brought in for the Children's work.

HC commented that for Safe Haven accreditation, we need to be careful about the idea that persons logging in had certain status in terms of access and how they interacted with the environment, whereas those inside had wider access. But with different complex environments, we now need more involvement between staff within and outwith the Safe Havens. Functionality needed for development of datasets. As rules change how do we let researchers know?

PR-said that CM is working on inventory of datasets shared with other Safe Havens.

DM asked about access, as not everyone can access everything electronically. How will this be made available to everyone if don't have digital accessibility? Need to have a strategy for those who can't go digital. He suggested NHS "hubs" similar to Citizen's Advice Bureau so that people can go and get advice on NHS.

PR agreed that digital exclusion is under consideration and we need to get the balance right and encourage digital enabling.

LR thought it helpful to hear Cara Archibald is leading the development of training. All agreed. Cara to be invited to next meeting to provide more information on this work.

ACTION: 10-11-2020 / 03

PR/MA

4.4. Update from HDRUK

CM gave an update explaining that PHS is now a member of the HDRUK Alliance. The main focus has been around COVID and a 3-year programme of work.

COVID Research - National Core Studies

This is a 3-year programme of work established by Sir Patrick Vallance and coordinated by HDRUK.

There are 5 work streams

- i. Surveillance & Epidemiology,
- ii. Transmission and Environment,
- iii. Clinical Trials - Vaccines
- iv. Clinical Trials – Therapeutics
- v. Longitudinal Cohorts. The 4 national safe havens (known as Trusted Research Environments TREs) are all involved and will be asked to support research projects under these by providing rapid access to key health and non-health datasets and analytical environments.

LR asked about the integrated application process, if HDRUK are looking to use an automated application form.

CM stated that PBPP are looking at using Service Now to support this but cannot automatically do this from a word version but work is going on to try and align with systems already in place, so that alignment may take place in the future.

KM asked if HDRUK are acting as a gateway for these different data sets?

CM confirmed yes this is correct, working toward data not having to travel, infrastructure of working together.

HC asked if the HDRUK Gateway is for access, is there a single TRE where the datasets will be held?

CM said no, but they would use the federated infrastructure so data doesn't have to travel.

LR thanked CM for this update.

4.5. Update from RDS

RH indicated that several working groups were established over the last year. Below is an update on each one:

- *Legal Working Group*: A number of options were examined by SG Legal representatives as to how RDS could be established and it was agreed that the best option was a Company Limited with Guarantee who would seek to obtain charitable status once formed.
- *Information Governance Working Group*: RDS aims to work with data controllers to host research ready key public sector datasets with a view to improving speed of access, data availability, metadata and encouraging collaborative research.
- *User Journey / Service Design*: The SG commissioned an evaluation of existing services provided by NRS, UoE and eDRIS to understand the user journey. This looked at how the process currently operates, how users interact with the services and how service providers interact with each other. A report was written and the recommendations will be turned into a development plan for the next 2 years.

A position paper was circulated outlining

- the proposed IG approach for RDS and progress to date
- summarises how ADR Scotland as a separate and distinct programme will support and complement RDS over the period of the current ADR investment to March 2021 and beyond; and
- what potential changes to the IG approach may mean in terms of delivering the RDS vision.

KM asked about the scope and its limitations. What about next steps of e.g. commercial applications and their time-frame?

RH establishing commercial framework is priority and next thing to think about. Need unified and clear statement of use of private sector organisations.

KM asked about synthetic datasets?

RH thought there could be a range of analytic developments that would include synthetic datasets to help researchers develop code and understand the complexities of the data. Connecting with others to look at this and make a reality.

LR asked what does this mean for HSC-PBPP and how does it need to change?

RH thinks it would lower the volume of work, if various data agreements would mean that not all applications need to come to HSC-PBPP. The aim is to simplify process as much as possible. HSC-PBPP and Stats-PBPP need to have some common mechanisms to reduce the need to justify to different places.

Timeframe: Formally launched in the new year. RH will update again at the January 2021 meeting.

5. HSC-PBPP Review of COVID-19 update

5.1. Review of approved application from rapid review

LR thanked everyone for this review and confirmed that the quality of decisions in the rapid process were all ones we would stand by and all agreed the process is working to a high standard.

5.2. eDRIS minimal standard datasets

CM stated eDRIS presented an SBAR to the PBPP Committee in May recommending progressing discussions on establishing a set of research ready key health datasets that could help streamline the PBPP review process and improve data provisioning times for a proportion of projects. Thus improving throughput in general.

This proposal received support in principle from the PBPP committee and has been trialled in part via the COVID Research Database which hosts a subset of variables from key health datasets within the National Safe Haven.

Some work has progressed building on the COVID database and what to do to create the minimum standard datasets. These should contain enough info for researchers, but only for data analysed within NSH, with eDRIS doing disclosure control. Need to look at what should be removed from these datasets, in terms of identifiers, geographical variables and completeness of variables.

Initially concentrate on six most popular; then can go onto more complex datasets.

Having a pre-defined list of variables that researchers can receive quickly for analyses and only within the secure national safe haven environment will be also be controlled via disclosure of outputs. It will also negate the need for PBPP to scrutinise the data section extensively. Therefore, focussing more on the public benefit, the people involved, the purpose of the project and the dissemination of the outputs.

All agreed helpful to see this progressing.

5.3. COVID Data and Intelligence Network

PR left the meeting.

Doreen Grove from Scottish Government gave a presentation on an Ethics framework for the Data Intelligence Network (DIN).

The Ethical framework has now been produced and sent round. All came from work of managing the pandemic but goes into new territory. Challenge of use of people's data and what does ethics

mean in this context? Trying to get culture of ethics throughout all data work being done. What we do with data should always be in the public interest. Now working with Datalab to make language more accessible to the public. Does the public recognise same benefits and risks as we do? Now also working with Human Rights groups too.

GF thought we need to articulate the public benefit. Concerns of whether public consultation is adequate for transparency – not sure the public is suitably informed.

DG replied that working with civil society organisations for how to involve people effectively in use of sensitive data. DIN includes public engagement organisations. Public should sit on randomly selected panel as sort of citizen audit.

GF thought also needed to consider digital exclusion and address their views.

DG said they were pulling together a participation framework for SG. E.g. recognise how COVID affects those who are already disadvantaged. Initiatives to address this but should not assume that everyone wants to be online.

SP: What are the practical implications of this?

DG Projects that come to the DIN have to fill in templates that articulate some of the problem and the solutions. Level of proportionality but more interested in framing conversation that ethics and public benefit are addressed early on in design. Any project of any scale needs to do an ethics assessment and whether it met its aims also will be assessed. Needs external scrutiny but not sure from whom. Need a Data Ethics Commissioner.

LR: Good to see some of the things on the framework e.g. reinforcing the public engagement, data flow documentation, plain English. This endorses the approach that has already been taken. Is there something that PBPP needs to change in light of framework?

DG said it had been really difficult to understand the IG landscape due to its complexity. For PBPP there is a real need to understand how we use data and set out clearly and transparently how data is used. Public engagement is very important but is also expensive. But need to get better at articulating that this isn't an option. No major changes to PBPP needed.

HC said that the presentations were about future framework but starting from COVID work.

RH said that the initial set up of COVID DIN in March/April was about public sector responses to manage harm from COVID. Moved on to non-COVID harms to data, economy and support better responses to health issues. Now has been expanded to look at how data supports decision making across network. National performance network and DIN allows people to connect and be transparent outside of COVID.

CM DIN is not a data platform but mechanisms and infrastructure by which people can be brought together. E.g. COVID research database was a way of bringing COVID data together for use for COVID research.

KM asked if the COVID database is a data common? Basically a repository for data that can be applied to for use?

CM COVID data base does not have its own governance board, and all approvals go through HSC-PBPP (or Stats-PBPP).

6. Application matters

Presentation from Duncan Heather from Health Informatics Centre (HIC), University of Dundee

HIC is a regional SH for Tayside and Fife and provides local support to local researchers: mailings, governance approval and advice, software development and host environment; data linkage, data

entry. All data usage is covered by ISO27001 and audited twice annually as part of that, IT security etc.. It also covers secure web connections and databases held at HIC. HIC maintains they are a data processor acting on behalf of data controllers. Different areas of work are:

- Software development, e.g., through Generation Scotland, with secure data collections. E.g. EmBark which collects data from around the world; Childsmile was also developed and held at HIC kept on NHS network.
- BPSU – potential for in-house support for them, monitoring the research and engage with HIC system. Consultants will enter data directly into HIC BPSU database and stay in HIC, who would do disclosure control.
- Mailing: research support from start to finish and handle mailing lists, which go through GPs or clinician of care via NHS. Tracker allows monitoring but will only allow clinical approach once patient consents. Mailing is done through DocMail.

KM for consenting of participants are there challenges and mitigation actions?

DH thought this was more through SHARE to pre-consent people for research. Otherwise can be logistical nightmare if using GPs. SHARE makes things more streamlined but still use primary and secondary care. Validation of lists required; not sending directly from researchers.

LR asked whether the regional safe havens will link in with RDS? How will additional services be involved? Will they be used more widely?

DH thought they could be used for local and more specialised datasets. Could be used more UK-wide.

CM –RDS is having discussions with regional SH as part of the infrastructure and data availability.

LR thanked Duncan for coming and he agreed to send his slides for circulation to the committee.

ACTION: 10-11-2020 / 04 MA

7. Committee personnel

MA informed the committee that now that Professor Alison McCallum has moved on to a new post there is a gap around a territorial CG on HSC-PBPP committee.

MA circulated a paper which outline recruiting people for the committee.

DMcQ asked if it would be possible for *ad hoc* people or a rota base could stand in, in the meantime? GF did see benefits from this approach but feels like due to nature of the work being so specialised that he is not convinced how well this would work.

MA asked for feedback on how to recruit new Lay members.

HC suggested of contacting Young Scot to recruit a younger member or suggestion of contacting charities, for example in diabetes they have a lay committee they work with.

It was suggested that it may be useful to have someone with security technical background.

LR thought that a research rep with clinical/NHS connection would give a bit of resilience

HC suggested names for the research representatives, which were noted.

LR asked if anyone has any suggestions please can they share with MA to take this forward for discussion at the January meeting, when we will hopefully have some potential replacements, possibly even inviting them to observe at the January meeting.

ACTION: 10-11-2020 / 05 ALL

8. Any other Business

No other business was raised

9. Date of next meeting

The next meeting will take place on Wednesday 20 January 2021.

LR stated that due to bigger discussions and Cara Archibald attending from SG the agenda may need to be reordered.

ACTION: 10-11-2020 / 06 MA

ACTIONS LIST:

10-11-2020 / 01	To combine and close previously paused actions with other ongoing actions.	MA
10-11-2020 / 02	Discuss how to achieve a development slot for the committee.	LR/MA
10/11/2020 / 03	Invite Cara Archibald to the next HSC-PBPP to give an update on the Safe Haven accreditation.	PR/MA
10/11/2020 / 04	Circulate slides from Duncan Heather from HIC to committee members.	MA
10/11/2020 / 05	Suggestions for potential committee members to be given to MA.	ALL
10/11/2020/ 06	Reorder future committee agenda to reflect changes in updates and items.	MA