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

Minutes of the Committee meeting held on 13 April 2021 by MS Teams

Present: Dr Lorna Ramsay (Chair) (LR)
Professor Helen Colhoun (HC)
Dr George Fernie (GF)
Carole Morris (CM)
Kenneth McLean (KMcL)
Dr Tara Shivaji (TS)
Alan Ferrier (Al F)
Professor Abbe Brown (AB)
Penni Rocks (PR)
Martin Bell (MB)
Colin McCowan (CMcC)
John Woods (JW)
Alison McCallum (AMcC)

Apologies: Dr Angus Ferguson (AF)

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

1. Chair's Welcome

LR welcomed three new members to the Committee:

- Professor Colin McCowan as Research representative
- Professor Alison McCallum as Research representative
- John Woods as a lay representative.

LR stated that Dr Steve Pavis has now resigned from this committee however an alternative NDS representative is in discussion.

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

2. Minutes and Actions from the previous meeting held on 20 January 2021

2.1. Minutes of meeting held on 20th January 2021

These were approved.

2.2. HSC-PBPP committee Action Log

Outstanding actions:

10-11-20 / 03 Cara Archibald from Scottish Government (SG) to give update on accreditation of Safe Havens

20-01-21 / 06 Update the application form and review it annually. The new updated application is complete and will be available by the end of the month. This will be reviewed every business year. LR stated that the aspiration to change this application form from a flat word document to an online form has been paused but hopefully in time can look at this again.

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.

20-01-21 / 09 Roger Halliday and Albert King have been invited to the next meeting to discuss their thoughts on commercial applications and access to data but are unable to attend.

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 has updated the case law to identify what we suggested for commercial applications such as academic partnership, DPIA etc. This is good guidance for a commercial application.
For commercial applications, all agreed that consistency is needed. External work is happening and needs to be understood, but it is part of wider discussions and decisions. HSC-PBPP should have an opportunity to give input and feedback from our experiences in these areas.

ACTION 13-04-21 / 01: MA/LR to follow-up with PR and RH

3. Matters Arising

3.1 Committee personnel update

The committee is still in search for new lay people.
MA has been in contact with people from University of Edinburgh and PHS who have contacts in the area if lay involvement with the NHS and may be able to disseminate information and raise interest.

The Operations Group have tried out an induction pack and processes for easier introduction to the committee.

3.2 COVID Review

The prioritisation criteria of the HSC-PBPP for COVID19 and non-COVID19 applications needs to be reviewed. Due to the COVID19 pandemic, and since end of March 2020, HSC-PBPP set in place a rapid review process, using a reduced COVID19 application form according to specific priority levels.

There were three levels of priority:

i. Priority level 2: COVID19 form, reviewed by the Rapid Review Panel, for time-critical applications, which would directly feed into and inform the public health response to the pandemic or vaccination programme, and would have an immediate effect.

ii. Priority level 1: COVID19 form, reviewed by normal Tier 1 panels with applications having priority over non-COVID19 applications.
iii. Priority level 0: Follows same process and timescales as non COVID-19 applications, for the 'good to know' applications, that are important and useful but not time-critical or directly contributing to the immediate response.

Discussion took place as it is not clear what should take priority regarding COVID-19 applications or services opening up again.
It was thought that the rapid review process should continue to be available. The swift responses for these applications has been recognised and should continue in the future. However, such speed does rely on people being available to review applications, and may not be possible for more complex applications. This was apparent for some level 2 applications, which do not get eDRIS review, and some could have done with more preparation work.
Level 1 COVID applications take priority and could be abused as there is also a backlog of 'normal' applications at eDRIS, all of which will be reviewed at Tier 1 panels. Some triage is legitimate for high priority applications, but others should be on first come, first served basis. Need to ensure equity of access to eDRIS and HSC-PBPP.

How can the eDRIS backlog be addressed?
LR stated that she would like to perhaps look at what would it take to do a focus on the backlog to a good place to move forward on a real time basis.

It was agreed to continue with the current 3 levels of prioritisation and bring forward for discussion at the next meeting.

ACTION: 13-04-21 / 02: MA/LR to discuss backlog of applications at eDRIS and HSC-PBPP

4. Updates for the Committee

4.1. Panel Manager Report

Details of a data breach within the National Safe Haven (NSH) were reported. The data breach was discovered by eDRIS and individuals and organisations have acted and responded appropriately. As the breach was in the NSH, there was no identifiable data released and no privacy risks to any data subjects. The matter is now closed.

The metrics for the year 2020/21 were summarised.
LR highlighted that some applications have taken over a total of 50 days for approval, but a vast amount was also done quickly, even with the challenges from COVID-19. Ask the Ops Group to look at those that have taken more than 50 days to understand if there are any common elements.

ACTION 13-04-21 / 03: MA/TS and Ops Group.

4.2. Policy Decisions & Case Law Principles

MA circulated for information.

4.3. Scottish Government update (including COVID DIN, Safe Haven accreditation, NESTA)

4.3.1. *Cara Archibald, SG Head of Information Compliance:* ***Accreditation of Safe Havens***

There is a need to ensure compliance for Safe Havens (SH). The compliance framework is the Scottish Cyber Resilience framework, used for Scottish Public Sector and also is used for Health board audits.

The Scottish Cyber Resilience framework is ISO27001 and 32 additional controls. This will be accredited through the UK Accreditation Service (UKAS), which is accreditation body for Information Security management. So SHs will comply with ISO27001 and have UKAS accreditation so that can have full confidence in the SH.

Currently SHs get 6 monthly visits and an annual review. Hopefully the UKAS visits would be done at the same time. The aim to look at the whole framework to avoid duplication. Currently the review starts with the SHs but the same Scottish Cyber Resilience Framework standards will apply across the public sector, to which everyone should be working.

At the moment the Scottish Cyber Resilience framework is Scotland-specific. Safe Havens outwith Scotland don't have the 32 additional controls. England uses ISO27001 which is the international standard; Scotland has just added more controls.

Need to ensure that the data held elsewhere is held at the same standards. However some technical aspects may not work with older software and platforms.

Even within Scotland there is some data analysis that cannot use the SHs because of complicated file structures and sophisticated analysis.

This work came out of the Data and Intelligence Network (DIN) around the challenges of trust and comfort for sharing data. Initially concentrating on SHs to give consistency across SHs, but this would be spread out to wider public sector.
What does equivalence look like across the UK?

ACTION 13-04-21 / 04: CM / TS / MA (or others) to find out which SHs accredited. How does this affect completion of application?

4.3.2. Update from Data and Intelligence Network (DIN)

The DIN was set up to answer questions around COVID relating to policy. Its aim is to understand the challenges and best use of data and expertise for COVID. The question now is how can it work for business as usual (BAU)?

Now can build data infrastructure across Scotland to educate public about data and how it is used for quick-fix research and to increase efficient and rapid working.

New portfolio board chaired by Richard Fogo, with people from SG and elsewhere.
Three pillars:

(i) Trusted and efficient ecosystem across Scotland
(ii) Data Challenge Delivery

(iii) Building communities of practice for operational processes.

Anne Jamieson from DIN is now looking at COVID vaccinations and more widely: care homes, mental health and reestablishment of NHS BAU. The outputs will be used beyond COVID and to shape wider projects, including Research Data Scotland (RDS).

The DIN Ethics workbook was for assessing ethics of applications to DIN, but has many sections that would overlap with good DPIAs. Not clear whether ethics framework will be used at a wider level, rather than just for SG projects.

What about data that originates in local authorities? There is no single body to look at that or third sector data? There is work going on at Administrative Data Research (ADR) UK about data provided by other data controllers and different governance options, e.g. classifications of variables, data access panels for different levels of variables. Need to explore different levels of comfort with risks.
Data controller authorisation is also needed for use of data for different purposes.

One of the things that holds back researchers, is that there is no single educational identifier from birth to age 25. There are some attempts to address but on agenda for future.

Data initiatives are great but there is no point have data available if don't have sophisticated analytical skills and programming for complex linkages and modelling. Therefore need to think about how to ensure constant Continuous Professional Development (CPD) for analysts for transfer skills across public health and academia. Need training and skills component for this. There is lots of expertise in academia, so could bring in other analysts.

ACTION 13-04-21 / 05: PR to invite Anne Jamieson to June committee meeting with RH and AK.

4.4. Update from HDRUK

Due to time, this will be sent as a report by email.

ACTION 13-04-21 / 06: CM/MA to circulate

4.5. Update from RDS

As Roger Halliday is not available, this will come to meeting in June.

5. Application matters

5.1. Access to GP data

There have been some requests for GP data for COVID applications. It is variable on how quickly the GP opinion has been obtained. There is wider work ongoing to try to make this better. There may be a need to have a GP on HSC-PBPP; this is part of wider discussions on wider access to GP data. At the moment it is not stopping the HSC-PBPP approval.

5.2. Access to COVID19 vaccination data

Access to PHS vaccination data now needs to go through an extra review by PHS for the use of these data. The reason is to ensure that the data are sufficient and fit for purpose.

5.3. 2021-0180 Pell application

Richmond Davies (PHS DPO) attended to talk about this application, which had been approved with conditions by HSC-PBPP rapid review panel. The conditions were that a full DPIA and PECR assessment were completed before the active recruitment began. These are now in place.

This is a study led by Professor Jill Pell from the University of Glasgow for research into Long COVID. They wished to recruit people to this study by SMS/text messages, using data obtained from the COVID Test and Protect contact tracing app. The app was not clear about the fact that they might be contacted for research, so many people would not expect to be contacted.

Use of text/SMS is a new way of recruitment for research and required additional work from PHS to help it comply with Privacy and Electronic Communications Regulations (PECR). These sit alongside the UK Data Protection Act and GDPR. SMS messaging for recruitment for research can be thought of as marketing, as the researchers are contacting people to ask them to do something to benefit the researchers (i.e. take part in their study) and could also be thought of as spam or phishing.

Around a million people could potentially be contacted for this research study. Under PECR they would need a 'soft' option to text people to ask if they wish to opt-in or -out of the research, with a link to a webpage. If there was no response then researchers must assume that the subject did not want to take part; if they opt-in then further questionnaire and further contact with researchers in Glasgow. For subjects there is the risk that they could feel they are being pestered. PHS wants to set up panel to assess such requests to access these data.

SG is putting adverts on TV encouraging people to opt-in to this study, but there is some risk that fraudsters will disguise themselves as part of this study, which has wider implications. This also blurs the lines between clinical care and research and whether people feel they have free choice. The text messages would only include one reminder, and researchers need to ensure they respect those that say no.

There is some evidence from SMS recruitment in other countries that uptake is low. Effectively an SMS is a modern letter and should take into account all the learning from hard-copy clinical research letters. The wording of the SMS could also be critical to avoid 'illness by suggestion' and to maintain research integrity. There is also the possibility that it increases inequality of access, if those worse off cannot access web-based questionnaires.

There is potentially a lot of learning from this application. More widely the research community could look at the pros and cons at looking at this sort of approach.

LR thanked RD and stated found very useful questions and concerns raised regarding this new way of looking at things.

Professor Pell should be invited to come to the meeting in September for learning and sharing, as this will then have been going for a few months.

ACTION: 13-04-21 / 07: MA to invite Professor Pell to committee meeting in September.

6. HSC-PBPP Development Slot

Industrial Centre for Artificial Intelligence Research in Digital Diagnostics (iCAIRD)

Professor David Harrison and Dr James Blackwood joined for this item. A presentation had been circulated previously.

iCAIRD is administered in NHS GG&C and works across Scotland as a formal NHSS, academic and industry partnership. It is a large programme funded by Innovate UK and is one of 5 centres to accelerate the adoption of artificial intelligence (AI) across Health and Social Care. iCAIRD specifically looks at use of radiology and pathology images. It is part of the only national centre for AI research as applied to digital diagnostics and imaging. Part of their aim is to build the iCAIRD programme for future beyond the end of the current funding.

There are a number of workstreams:

- Different platforms for extracting de-identified data and for testing algorithms Radiology had built platform (SHAIP) which sits within a regional SH for researchers to access for analysis. Phillips doing test environment in pathology algorithms. Distinct platforms within NHS.
- Uses DataLoch at Lothian SH for use of data.
- Research projects which are looking at whether these have an immediate and practical application across a number of disease outcomes as core projects of iCAIRD.
- Sustainability to set up operational centre for national work.

Governance lies at the heart of what they do: each partner programme has a governance panel and ethics, with a central governance manager. All programmes have to meet compliance with NHS governance systems. Overall central governance processes for each project, to keep eye on privacy, proportionality of data and public benefit and benefit to NHS, to ensure that Scottish Health and Care are at forefront of iCAIRD.

Engagement with Industry

What is the policy for working with industry? Industry are not getting free access to data. NHS is already buying AI technology but need to buy AI developed for NHS-focused requirements. Industry will work through necessary hoops to do this. iCAIRD works as facilitator of these projects to support the NHS and provide a means by which work can be progressed in a controlled manner without directly releasing data to industry. End-to-end support for development and adoption of AI technology. As such iCAIRD is a major contribution to Scotland's AI Strategy and partnership.
iCAIRD wants the return on their investment but wants the best across the NHS.

NSS has an interest in this to ensure that NHS gets the benefit from what AI can do. CLO and National Procurement were involved in relevant aspects of the setting up of iCAIRD.

These are exemplars to show that these algorithms work. Just because iCAIRD work with a company, does not mean that NHSS has to buy their product.
In the final year of the iCAIRD programme they will be looking at evaluation to help inform procurement.

If people want to use the data in Scotland, need to be sure that the benefit to Scotland is thought through and discussed. Agreements don't allow exclusive access to data by anyone. Access to data in Scotland is not as good as it used to be. Companies now go elsewhere as they can get better data and faster than Scotland. Scotland is no longer the best place to go for access to data. Need to move with the times so that others can access data more easily.

Data is held in trusted research environments (TREs) within the Safe Haven IT network, and use desktop virtualisation and containerisation. This means people can upload their AI model and code and so are allocated access to certain amount of space and can operate within that environment and go through standard disclosure control mechanisms. There is a standard researcher access to environment and data using cost-recovery model but anyone can apply for access. It does have an industry focus, but with academic and NHS partners, to provide products that NHS can use. Focus should also be on small/medium enterprise (SME) clusters and across Scotland.

There has been some international criticism of AI models because of lack of diversity. Ethnicity is an issue, but better with bigger datasets. AI learns from different things within the black box and would then need to take into account ethnicity, sex, age. Need to be able to explain models and the influence of different biases within them. Also examine models in light of different diversities and ask for more data for mitigation of bias within these models. Can do federated learning by training the same model against data from different populations with different demographics.

Intellectual property (IP) for AI is a tricky question, as the AI should continue to learn and the product will continue to change. There is some preferential access for NHS but conversations with regulators are required and this needs to be resolved. Scotland has to have system with interoperable platform so can use products at different stages.

Monetarising of data has been explored a bit in Canada and NZ. They don't monetarise the data but build environments so that gives more than just the data: e.g. clinicians who understand the data and gives the benefit of being a cluster of AI within the environment.

This has been a good discussion. It ties in with the evolution of industrial / commercial applications but policy not totally in place. Where does our comfort lie? How can we be consistent? Clear where work is done within SH and equivalents that is easier to approve. Need to understand how iCAIRD fits with the presentation from CA earlier. It is helpful to have explicit information on controls in place with NHS and industry partnerships and with letters of support. NHS Grampian has done some Public Engagement with public and patient involvement for making datasets available and explore the use of such shared data for cancer projects.

What does iCAIRD want from HSC-BPP? There needs to be a number of conversations regarding the required governance steps for access to data, so that Scotland does things better and faster but without short-cuts.

7. Any other Business

There was no other business.

8. Date of next meeting

Tuesday 15th June 2021.

Actions

Action number	Action	Who
13-04-21 / 01	Follow up with PR and RH regarding the external work regarding commercial applications and how feedback from HSC-PBPP can be provided.	**LR / MA**
13-04-21 / 02	Discuss backlog of applications at eDRIS and HSC-PBPP.	**LR / MA**
13-04-21 / 03	Look at 2020/21 applications that took more than 50 days to be approved.	**TS / MA / Ops Group**
13-04-21 / 04	Determine which Safe Havens have been accredited by SG and how this may affect the completion of HSC-PBPP application form.	**CM / TS/ MA**
13-04-21 / 05	PR to invite Anne Jamieson to the next committee meeting in June 2021. Roger Halliday and Albert King are also expected to attend.	**PR / MA**
13-04-21 / 06	HDRUK report to be circulated to the committee members.	**CM / MA**
13-04-21 / 07	Professor Pell to be invited to September committee meeting to share learning from the use of SMS messages for recruitment for research.	**MA**