

Minutes

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

Monday 12 June 2015 – New Register House, Edinburgh

Present: Brian Houston (Chair)
Prof Alison McCallum (AMcC)
Dr Angus Ferguson (AF)
Dr Corri Black (CB)
Dr Daniel Beaumont (DB)
Dr Danny McQueen (DMcQ)
Mr David Knowles (DK)
Dr Eddie Coyle (EC)
Mr Gerry Donnelly (GD)
Dr Janet Murray (JM)
Dr Steve Pavis (SP)
Margaret Dakers Thomson (MDT)
Aidan Robertson, Panel Manager (AR)
Aimee Brown, Secretariat (AB)
Susan Kerr, Secretariat (SK)

In attendance: Patricia Ruddy
Gail Turner

Presentation: Jill Pell (11.25-11.45)

Apologies: Dr Abbe Brown
Dr Harpreet Kholi
Prof Helen Colhoun

1. Chair's Welcome

Brian Houston introduced himself as the Chair of this committee. BH is currently a non executive chair in NHS Lothian.

BH explained that he is looking for support and guidance in his role as chair of this Panel. This panel is a new way of working and there will be a review of this in time.



Interim Chair Professor Elizabeth Ireland
Chief Executive Ian Crichton

NHS National Services Scotland is the common name of the Common Services Agency for the Scottish Health Service.

2. Panel overview

Daniel Beaumont gave an overview and thanked the people involved in setting up the new panel.

He explained that Aidan Robertson, who at present is the Panel Manger, has done a great deal of work in setting this up. There is nothing comparable to this committee across the UK.

DB advised that AR will be in place as the Panel Manager for the next 4 weeks and that NSS are currently in the process of recruiting a new Panel Manager.

DB expressed that in time he hopes that this panel has an influence on the e-Health Strategy Board and that we have a duty to make best use of public data but with all the safe guards in place and with minimal risks.

3. Panel Managers update

AR gave an update and presentation to the group on the PBPP.

It was advised that the PBPP website went live on 1 May 2015.

The panel team include Aidan Robertson, Susan Kerr and Aimee Brown who are based at the Farr Institute along with the eDRIS team. The panel team are currently double running with PBPP and PAC. The new PBPP process has only had a few applications so far. NSS are in process of recruiting a Panel Manager who will replace AR and will also be based at Farr.

AR advised that PBPP has had some initial positive press.

AR explained that the panel has been set up to provide the following:

- A **single, consistent, open and transparent scrutiny process** allowing health and social care data to be used for a range of purposes including research
- To ensure the **right balance** is struck between safeguarding the privacy of all people in Scotland and the fiduciary duty of Scottish public bodies to make the best possible use of the health and social care data collected
- To provide **leadership** across a range of complex privacy and information governance issues, so that the people of Scotland are able to gain the benefits – ultimately better health and social care – from research and wider use of data, while managing emerging information risks, addressing public concern around privacy, and promoting the protection of privacy as in the public interest

This panel succeeds three previously existing processes in their scrutiny of applications for access to NHS-controlled data: NHS National Services Scotland's Privacy Advisory Committee (PAC); National Caldicott Scrutiny Panel (NC) and CHI Advisory Committee (CHIAG)

It provides a single, simplified and truly national process, and prevents the creation of any further authority to deal with specific requests for access to data relating to more than one NHSScotland board.

It is a Decision making (not advisory) body.

It does not replace any other existing local approval or scrutiny processes in operation within individual NHSScotland boards (where local scrutiny is conducted for access to data owned by the individual board).

It does not replace existing Research Ethics approval processes and it has an open door to Primary Care, Social Care, etc Data Controllers.

Key points for the panel to consider are:

- Clarity of scope/jurisdiction
- Awareness raising
- Resources
- Training
- Publication
- Public engagement/public benefit
- Feedback
- Equivalency
- Approvals and amendments
- Priorities, strategies, resources, etc

AR advised that going forward there needs to be discussions around a work plan.

Action: AR agreed to develop a work plan to bring to the next meeting.

AR is currently managing a draft risk log and suggested that this could be a standing agenda item at future meetings to review any risks.

BH thanked AR for his presentation.

4. Future Relationships with CHIAG and national Caldicott Guardians Forum (AMcC)

AMcC explained that she is a member of the CHI Advisory Group and that there have been a number of applications on the use of the CHI number. These applications could be reviewed by this panel but until this panel is well established, CHIAG will have a continuing role to review applications at present. CHIAG has therefore not changed their Terms of Reference as yet.

EC stated that Caldicott Guardians will remain Caldicott Guardians to their Boards. The CG forum will continue but through time moving towards this group. CG's will be making contributions to the work plan going forward for this panel.

EC expressed that a message needs to be sent out to the Boards advising them of the role of this new panel going forward.

DK advised members that NHS Scotland are procuring a new CHI system but this will not be in place for some time and will need to be reviewed.

5. Presentation from Jill Pell

JP welcomed this panel being set up and wanted to make the panel aware of the researcher's perspective and new types of applications needing to be accommodated by the new approvals process.

JP explained that the following were identified by Farr Scotland researchers as new types of applications which the old PAC system was not well equipped to deal with and where early discussion with the PBPP would be welcomed with a view to ensuring that the approvals process evolves alongside research to ensure it remains fit for purpose.

1. Applications in which the aim is to "test the system" rather than "answer a research question"
2. Applications in which the aim is to "provide training and skills" rather than "answer a research question"
3. Use of novel approaches such as "data dives" to develop new, generic methodologies.
4. Applications for programmes of research rather than a single research project.
5. Fast-tracking of applications for specific needs – eg pharmaco-vigilance
6. Record linkage of cohort or trial participants who have provided consent

JM expressed that PAC have never had a problem with dealing with programmes of work and suggested that perhaps a dialogue about a programme of work would be useful.

EC advised that the panel may need to modify scrutiny if there is a change in research as scrutiny has to fit purpose.

DB explained that most applications do not use a Safe Haven and he feels that applicants should not be discouraged by being advised that a Safe Haven should be used.

AF thanked JP for her interesting presentation. He feels there are cultural issues on both sides and that we need to ensure everyone is understanding all aspects.

JM explained that with the new ways of using data, part of the research could be focusing on the privacy implications.

Discussions took place and it was agreed that workshops and education for researchers would be very helpful.

Action: Workshop to be arranged.

BH thanked JP for her presentation.

6. Any other business

AMcC explained we are currently focussed on health data but will expand to Social Care Data. DB agreed and informed members that the door is open to both Health and Social Care Data. Private sectors will need to create governance structures. Most applications are for Health data at present.

GD expressed that from an NRS perspective they are keen to work with this panel to expand and take things further.

Communications

Discussions took place on wider communications.

DB explained that the website is up and running.

DMcQ spoke about press publication to allow the public to be made aware as most of the public will not look at the website. We need to consider how we communicate with the public.

AMcC suggested that we develop a communication strategy.

PBPP Applications

It was discussed and agreed that this group will be considering new applications and any issues at future meetings.

AR advised that the first two applications received were very well completed by an experienced researcher.

The first application is for linkage of data within the Safe Haven environment with very low levels of risks.

The second application has commercial involvement and the Tier 1 panel used proportionate governance to assess this.

AMcC advised that we may need expert advice around commercial involvement.

7. Date of next meeting

The next meeting will take place on Thursday 17 September 2015 at Farr Institute, Edinburgh