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

Inaugural Annual Report 2016/17



Chair's introduction

NHS Scotland is a world leader in capturing, storing and maximising data on the health and care of millions of people, providing an exceptional opportunity for large scale research projects, quality improvement and patient care exercises to be undertaken. Through the development of world- leading proportionate governance criteria the Public Benefit and Privacy Panel (PBPP) supports a transformational information governance structure. This enables NHS Scotland to conduct and contribute to the investigation and understanding of the health of populations through the safe and trusted use of patient data.

Since its inception in May 2015, the Public Benefit and Privacy Panel has provided a centralised, simplified and truly national Information Governance scrutiny process. It has been successful in harnessing the expertise from across NHS Scotland health boards to implement a collaborative approach to information governance which contributes to consistency and continues to develop capacity across the sector.

In this the first annual report of the PBPP, I would like to acknowledge the achievements that have been made in a short period of time. These include, but are not limited to, the development of new processes which help to provide a fair, clear and transparent service to applicants, as well as the public. In this constantly evolving landscape PBPP must continue to work together with information governance colleague across NHS Scotland and beyond to adapt and grow existing processes. This will ensure that PBPP remains robust and consistent in its scrutiny for requests to access NHS Scotland data.

This annual report demonstrates some of the activities Panel members have been engaged in over the past year. The Panel has been involved in the scrutiny of a number of complex linkage projects which seek to exploit the power of administrative data to its full potential. Much work has been undertaken by clinicians and academia to enrich the use of data and translate outcomes to benefit NHS Scotland. In addition to the review of individual applications the PBPP is actively pursuing improving relations between NHS R&D, NHS ethics and Information Governance to further streamline the landscape for the research community.

This work showcases the PBPP as a centre of excellence for privacy, confidentiality, and information governance expertise in relation to Health and Social Care in Scotland. It highlights the PBPP's objective to work towards connectivity between the many strands of relevant governance activity, and the need to react quickly to the changing landscape and research evidence regarding public interest and benefit. The PBPP support the development of innovative information governance streams and look forward to being able to contribute in the development of the new Digital Health & Care Strategy.

The PBPP will continue to work to effectively to maximise the value of Scotland's health data so that the people 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.

Brian Houston
Chairman



Overview

The Public Benefit and Privacy Panel for Health and Social Care is a governance structure of NHS Scotland that exercises delegated decision-making on behalf of NHSScotland Chief Executive Officers and the Registrar General. The panel operates as a centre of excellence for privacy, confidentiality, and information governance [IG] expertise in relation to Health and Social Care in Scotland, providing strategic leadership and direction in this area to NHSScotland Boards, the research community, and wider stakeholder groups.

The panel:

- Streamlines existing governance processes for the scrutiny of requests for access to NHSScotland originated data for a variety of purposes other than direct care – for example for research, audit or health and social care planning
- Provides robust, transparent, consistent, appropriate and proportionate information governance scrutiny of such requests
- Provides leadership and acts as a centre of excellence for privacy, confidentiality, and information governance expertise in relation to Health and Social Care in Scotland
- Further strengthens the direct involvement of members of the public in the scrutiny process and decision making regarding access to NHSScotland originated data.

The PBPP operates on a two-tier structure utilising the proportionate governance method, thus ensuring that scrutiny is proportionate, and that available resources are effectively used. Each of the two tiers focuses on the assessment of risk and the balancing of privacy risk with likely public benefit – the more operational Tier 1, comprising IG practitioners from across NHSS Boards, facilitated by the Panel Manager and guided largely by agreed proportionate governance criteria, and the more strategic Tier 2 Committee guided by both these criteria and the Panel's guiding principles. The tiered structure provides for the approval, conditional approval and indication of non approval of applications to use data.

Tier 2 Committee provides the intellectual space for senior leaders, Caldicott Guardians, researchers and public representatives to consider the wider privacy issues in regard to particularly contentious cases or proposed policies in The Scottish Government / NHS Scotland relating to the use of health and social care data. The work of Tier 2 Committee comprises both a larger sitting committee, regularly convened, and a smaller group working out of committee, convened as required to consider applications escalated ('referred') from Tier 1.

“Fully supportive of what the process achieves and it is very interesting. Panel Members do feel confident about the decisions made by Tier 1 “

Tier 1 Panel Member

PBPP Committee Membership 2016-17

Mr Brian Houston (Chair)

Dr Abbe Brown (Public Representative)

Professor Alison McCallum (NHS Caldicott Guardian)

Dr Angus Ferguson (Public Representative)

Dr Corri Black (Research Community Representative)

Professor Daniel McQueen (Public Representative)

Mr David Knowles (CHI Advisory Group representative)

Mr Gerry Donnelly (NRS Representative)

Professor Helen Colhoun (Research Community Representative)

Dr Hugo van Woerden (NHS Caldicott Guardian)

Dr Janet Murray (NHS Caldicott Guardian)

Dr Steve Pavis (NSS IG/Informatics Data Linkage Lead Specialist)

The following members of the committee resigned during 2016-17:

Dr Daniel Beaumont (Scottish Government IG Policy Lead)

Dr Harpreet Kohli (NHS Caldicott Guardian)

Mrs Margaret Dakers-Thomson (Public Representative)

Meetings

Tier 1

The Tier 1 Panel met fortnightly at a central Edinburgh/Glasgow location during 2016-17.

A total number of 20 IG practitioners from across NHS Scotland participated in the scrutiny process in 2016/17.



Tier 2 Out of Committee

A total number of 16 applications was scrutinised by the Tier 2 Out of Committee with only NHS Caldicott Guardians and Public Representatives undertaking these reviews.

Tier 2 Full Committee

Full Committee Meeting	Tuesday 19th April 2016
Full Committee Meeting	Tuesday 28th June 2016
Full Committee Meeting	Tuesday 4th October 2016
Full Committee Meeting	Thursday 26th January 2017

The clear concise briefing presented by T1 for applications referred to T2 out of committee is impressive.

The independent scrutiny by individual T2 panel members is thorough and detailed, and the importance of privacy and public benefit is paramount. When applications are referred to the full PBPP committee meeting they are given detailed and fully transparent consideration.

(Tier 2 Public representative)

Funding and Resourcing

The Panel is managed centrally from NHS NSS by the Panel Manager (fully funded by Scottish Government) and a Panel Administrator (part-funded by NHS NSS).

The Tier 1 Panels are resourced by IG Practitioner staff whose time is provided by the Boards at the request of Scottish Government.

The Tier 2 Panel members contribute their time voluntarily, which is not formally committed by any organisation.

All members are entitled to reimbursement of expenses for travel to and from meetings or PBPP events, reimbursed by Scottish Government.

Key Achievements of the Year

PBPP Workshop

On 1st September 2016, the PBPP's first annual training and review day took place at Strathclyde University's Technology and Innovation Centre, bringing together delegates from the Tier 1 and Tier 2, as well as the eData Research and Innovation Service eDRIS team and applicants involved in the process. It provided a unique opportunity for everyone involved in the process to participate in discussions and training. The agenda for the day covered a review of first year with viewpoints from each stakeholder group and a review of PBPP documentation, including the application form, proportionate governance and the overall application process. Scotland's research environment was the focus for the afternoon, with presentations from experts in Ethics, NHS Research & Development, funding applications and NHS Central Registry. The feedback from the day was positive, with many recommendations which have since been implemented such as revisions to the application form.

Operational Group

A group focused on the development of PBPP processes, public engagement and support for the PBPP management team was established at the start of 2016. Membership includes the PBPP Management Team, an eDRIS representative, an expert Privacy Advisor, two Information Governance leads, a Caldicott Guardian and a representative from NHSCR. Some key areas that the group worked on throughout the year were:

- Formalisation of an amendment process
- Establishment of a recruitment procedure and engagement in a recruitment drive
- Assist in the publication of a clearly defined scope
- Review of the application form and guidance documentation

Tier 1 Review Process

The Panel has a duty to the public to correctly identify and support public benefit in the use of NHS Scotland data.



Given that the vast majority of applications are approved at Tier 1, it was considered appropriate to undertake a review of these decisions in the first instance. This would help to establish whether the governance process is robust, and that the proportionate governance criteria is the correct measurement tool under which to assess the principles of safe information handling.

It also presented an opportunity to identify whether any errors have been made in the application of the proportionate governance criteria and to consider whether it is fit for purpose. The Panel also considered if any releases of data should not have taken place and decide if action should be taken to assess the risk of any breach of confidentiality.

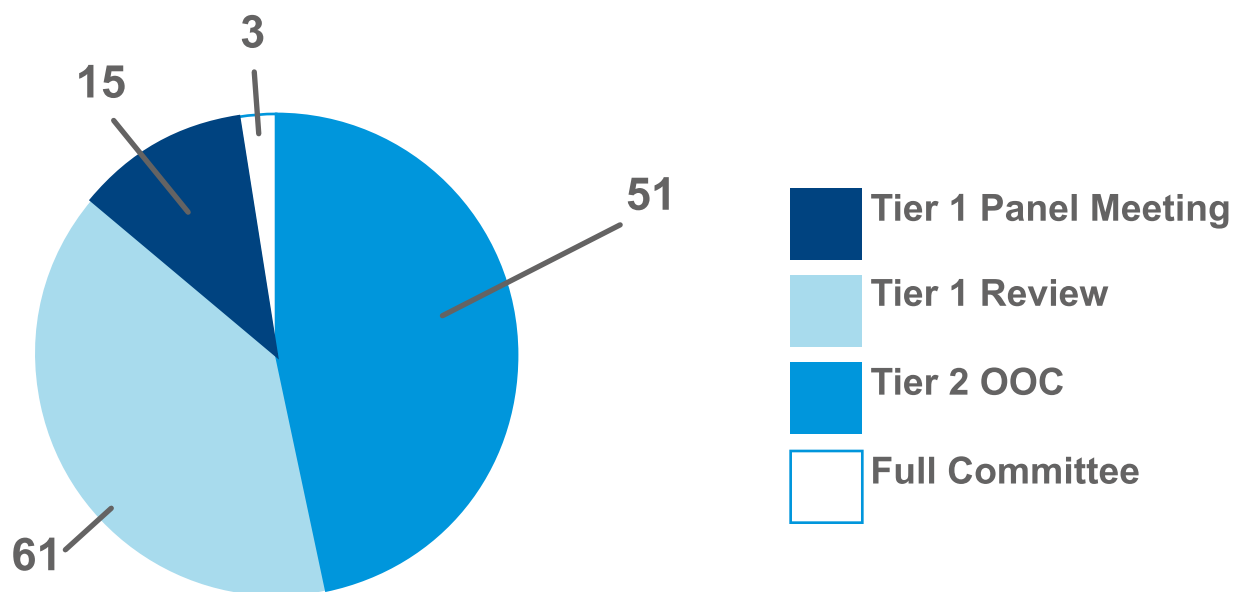
Eighty percent of applications selected for the purpose of the review were considered to have been appropriately approved by Tier 1. It was considered that two of the applications should have been referred to Tier 2 Out of Committee for further scrutiny.

A number of recommendations have been put forward which aim to strengthen the application review process.

Statistics for Core Business Activities 2016 – 2017

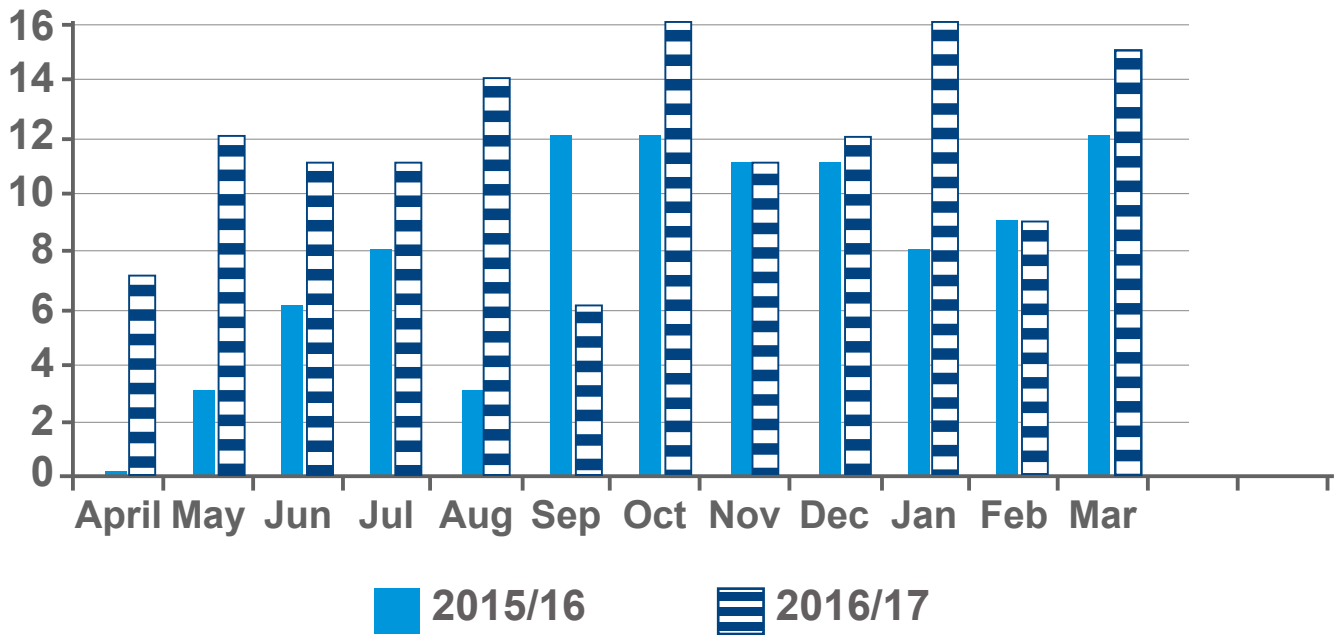
From April 2016 – March 2017, 130 applications were approved by the PBPP.

PBPP Approvals 2016/17

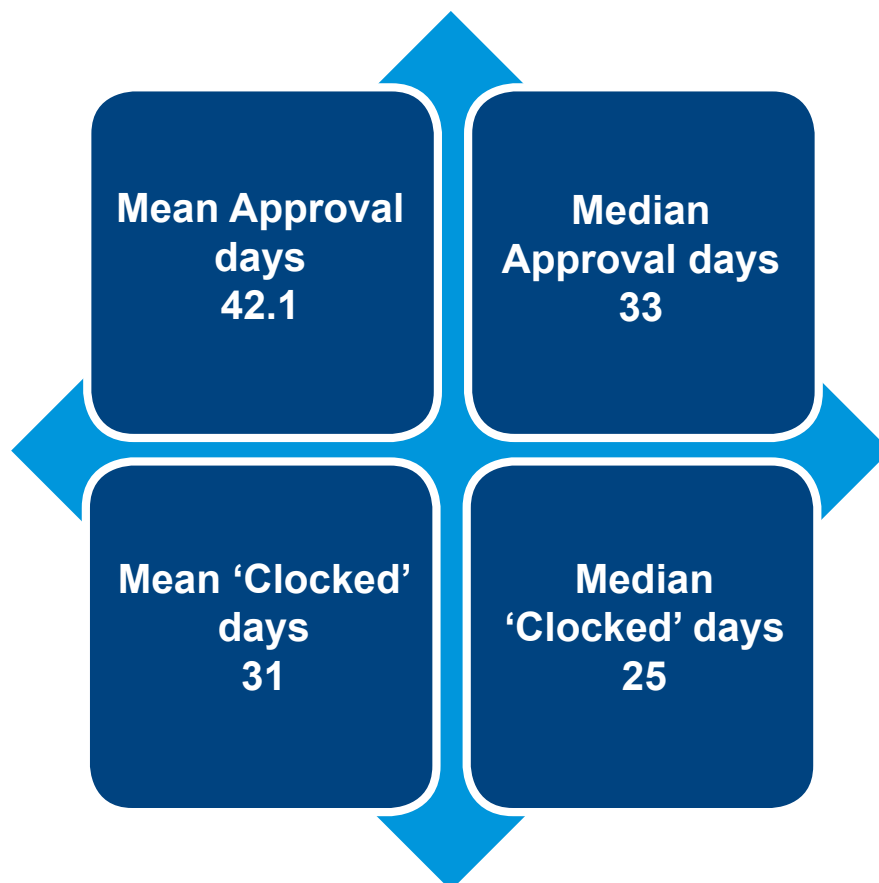


- The majority of applications are approved either at the Tier 1 Panel Meeting or shortly afterwards, following clarification sought from the applicant (Tier 1 Review)
- Around 10% of applications assessed by Tier 1 are referred to the Tier 2 Out of Committee for further scrutiny as they have been deemed higher risk from the proportionate governance criteria.
- Only a very small number of applications are escalated to Full Committee and these are usually highly complex or novel proposals

Application Submissions



- The number of applications received by the PBPP has gradually increased following its launch in May 2015.
- Knowledge of the PBPPs existence and remit has widened through the experience of applicants engaging in the process as well as the recognition and understanding amongst other governance bodies such as R&D and ethics
- Submissions fluctuate across the year and the PBPP is monitoring peak times in order to avoid long delays for applicants.



- Currently there are no official performance targets: however PBPP are keen to ensure that the process is as streamlined and efficient as possible.
- PBPP monitor 'clocked' days, which is the time the application is being processed by the PBPP. The number of days spent while the applicant responds to queries is not counted – see above Mean and Median 'clocked days'
- PBPP also record the total calendar days from submission until the final decision is made (this includes any time spent back with the applicant) – see above Mean and Median approval days

The PBPP as a single point of contact for health and social care data is welcomed. The frequency of T1 meetings is helpful and eDRIS coordinators are a useful intermediary. It would be beneficial to invite applications to join discussion regarding applications as with NHS ethics”

PBPP Applicant

Key Priorities for 2017 – 2018

Promoting Transparency

The PBPP acknowledge that transparency in decisions made to access NHS Scotland data is vital in order to protect the rights of participants and patients and that patients must benefit from improved outcomes and care informed by high quality research, ensuring the right balance is struck between safeguarding the privacy of all people in Scotland.

To assist in achieving this aim, the development of a communications strategy been planned for 2017-18, with an objective to ensure information about the PBPP is more accessible to the public.



Protecting the Interests of the Public

The PBPP strive to provide leadership across a range of complex privacy and information governance issues so that the people of Scotland gain the benefits, namely better health and social care, from research and wider use of data. This has to be achieved while managing emerging information risks, addressing public concern around privacy, and promoting the protection of privacy as being in the public interest. During 2017-18 one of our key objectives is to ensure that the PBPP is staffed appropriately with a fair balance of public representatives, information governance experts and senior academics.

We are committed protecting the interests of the public. With the success of the Tier 1 Review Process during 2016-17, a key priority for 2017-18 is to broaden the audit process across all Tiers of the PBPP and adopt this as a business objective, holding the Panel accountable to the public.

This work will provide important reassurances to the public and is part of the duty to support good quality proposals.

Working in Collaboration

The PBPP are committed to working with governance partners across the UK in order to streamline the approvals process for those seeking access to health and social care data.

The Information Governance principles which underpin access to NHS Scotland data are evolving. As the arena becomes more complex, we are keen to work in partnership with our counterparts across the country and beyond to assist those who wish to use our valuable resources in navigating the permissions landscape.

To assist in achieving this aim, a key objective for 2017-18 will be to continue building and strengthening collaborative relationships across the UK in order to maintain and develop knowledge- sharing and to promote the UK as a centre of excellence for research.



For further information please contact

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www.informationgovernance.scot.nhs.uk/pbpphsc/

The PBPP will continue to work to promote the value of Scotland's health data to the benefit of the population through research and wider use of data , while managing information risks and balancing privacy in line with public interest and regulatory frameworks.