



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

**Annual Reports
2019-20 and 2020-21**

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1. Abbreviations and Glossary

Caldicott Guardian	A senior person within an NHS board responsible for protecting the confidentiality of patients' health and care information
eDRIS	electronic Data and Research Innovation Service. Applications to HSC-PBPP are assigned an eDRIS coordinator to support applicants.
IG Lead	Person in an NHS board responsible for Information Governance in that board, under the Caldicott Guardian
IG	Information Governance
GDPR	General Data Protection Regulations, introduced into UK law with the Data Protection Act 2018
HSC-PBPP	Public Benefits and Privacy Panel for Health and Social Care
NES	NHS Education for Scotland, a data asset holder
NHSCR	NHS Central Register
NHSS	NHS Scotland
NRS	National Records of Scotland, a data asset holder
NSS	NHS National Services Scotland, a special (national) NHS board and data asset holder
PHI	Public Health and Intelligence, a business subunit if NHS NSS, which became part of PHS
PHS	Public Health Scotland, a new special (national) NHS Board and data asset holder, established in April 2020
RDS	Research Data Scotland, a SG initiative set up to bring together public sector data for use for research. To be formally established in 2021
SG	Scottish Government
Tier 1	Operational level at which all applications to HSC-PBPP undergo their first review
Tier 2	Higher /strategic level of HSC-PBPP, which has oversight of HSC-PBPP, and at which higher risk applications are reviewed
Tier 2 OOC	The Caldicott Guardians and Public Representatives who sit on the full committee who review applications "out of Committee"

2. Executive Summary

Background

This Annual Report covers the operation of the NHS Scotland (NHSS) Public Benefit and Privacy Panel for Health and Social Care (HSC-PBPP) for the years April 2019-March 2020 and April 2020-March 2021. Due to the response required to the COVID-19 pandemic in March 2020, the annual report for 2019-20 was delayed and is included here.

Created in May 2015, HSC-PBPP is an information governance (IG) structure of NHS Scotland that provides a central national IG scrutiny process focussed on requests for access to NHS Scotland-originated data for purposes other than direct care. Such purposes include research or service planning.

Support is provided to all applicants seeking access to data, via the electronic Data Research and Innovation Service (eDRIS). The HSC-PBPP works on a two-tier basis: the operational Tier 1 panel or the more strategic Tier 2 committee. Applications are scrutinised at fortnightly panels of NHS IG leads (Tier 1 panel). The majority of applications are decided at this level. Where the applications are of greater privacy risk and require a higher level of consideration, applications will be referred to a convened-as-required subgroup of the Tier 2 Committee for scrutiny (Tier 2 Out of Committee, T2 OOC), and if necessary, by the full Tier 2 committee.

Response to COVID-19

The response to the COVID-19 pandemic required changes to the HSC-PBPP processes: this included prioritisation mechanism for applications, a shorter “COVID-19” application form and the requirement for a Rapid Review Panel. This consisted of a pool of reviewers from Tier 2 and Tier 1 HSC-PBPP members, specifically convened for high priority applications for data to be used in the response to COVID-19. These changes were implemented quickly in March 2020 and the first COVID-19 application was approved in early April 2020. While these changes were necessary and appropriate for a response to an emergency, they are not sustainable long-term with current resources. However, many of the helpful changes have been taken forward as business as usual.

Performance

Through these two years of operation, HSC-PBPP has continued to show good performance across a range of metrics, despite the increased activity. Approvals for non-COVID-19 applications continued, though there were some delays due to COVID-19 applications taking priority. HSC-PBPP has built on and developed the processes previously established. IG leads from the territorial and national NHS Boards within NHS Scotland, have been engaged in the process, thus embedding IG in the general operational approach of the NHS across Scotland.

Following a slight dip in numbers of applications submitted in 2019/20, the number of submitted applications in 2020/21 were similar to those in previous years. As in previous years, these applications came mainly from academia (~60%) and the NHS (30-35%) with the remainder from Scottish Government and commercial companies. As seen in previous years, the majority of applications were from organisations within Scotland, with although in

2020/21 there was a slight increase in those from other parts of the UK, possibly due to UK-wide applications for COVID-19.

An internal review of a small number of randomly selected COVID-19 applications approved by the Rapid Review Panel was undertaken, which showed the approvals were appropriate and robust. A questionnaire evaluation of the whole process (from triage to provision of data) was also undertaken. The feedback was generally good and showed the benefits of the close working relationship between HSC-PBPP and eDRIS.

During 2019/20 the annual audit of Tier 1-approved applications from 2018/19 was carried out. This was particularly important as the introduction of Data Protection Act 2018 with General Data Protection Regulations (GDPR) had taken place in May 2018 and this audit highlighted the challenges that such changes in legislation can bring.

During 2019/20 a review of the Tier 2 Committee was also undertaken, based on attendance and the numbers and timings of the reviews of referred applications. The review concluded that the HSC-PBPP Tier 2 Committee is under-resourced. This concurs with the opinion from 2020/21 that the rapid review process was appropriate for an emergency but is not sustainable long-term.

During 2020/21 a review of amendment requests was undertaken, at the request of the Tier 2 committee as there was concern that some applications were growing beyond the scope of their original approval. The review showed that there were processes in place, which had been updated during the year and that these were robust and thorough.

Future developments in 2021/22

Looking forward to 2021/22 HSC-PBPP must continue to ensure that the right balance is struck between safeguarding the privacy of people in Scotland and the benefit to all from improved treatment and care informed by high quality research. Ongoing development to improve processes will continue.

The establishment of Research Data Scotland aims to expedite the process of data provision for research. The role of HSC-PBPP as part of the scrutiny process will adapt to its creation, ensuring consistency and streamline of process will continue to develop alongside.

3. Chair's introduction

This report covers the work undertaken by HSC-PBPP during 2019/20 and 2020/21. The COVID-19 pandemic has dominated many of our lives in the past 18 months. The HSC-PBPP management team and panels prioritised and focused their efforts on the COVID-19 response and so the HSC-PBPP annual report for 2019/20 was postponed and is included here.

NHS Scotland has a wealth of health data for its population, providing an exceptional opportunity for large scale research projects, quality improvement and patient-care audits to be undertaken. This became even more apparent during the COVID-19 pandemic. The rapid scrutiny of applications by HSC-PBPP for use of NHS Scotland data in the public benefit has contributed to the response to the pandemic in Scotland and the wider UK.

During the years 2019/20 and 2020/21 a number of changes have taken place. The establishment of Public Health Scotland (PHS) was planned but was not expected to take place during a pandemic, with the majority of people working remotely. The changes put in place in response to the COVID-19 pandemic shows how quickly and well HSC-PBPP and others in NHSS have responded to an emergency situation. It is a testament to the robustness of the processes and close working relationships that were already in place. Some further developments as a result of those changes are ongoing.

The HSC-PBPP has continued to involve the IG Leads across the different NHS Scotland Health Boards, thus ensuring that the HSC-PBPP scrutiny is a truly national process and not limited to select individuals within specific Health Boards. From its inception in 2015 up to the end of March 2021, in total, the HSC-PBPP has approved over 600 applications, showing that the demand remains high for using NHSS health data.

HSC-PBPP recognises the need to react quickly to the rapidly changing landscape of governance in an increasingly technological age. The establishment of Research Data Scotland (RDS) is part of this, so that the use of data in the public interest and benefit is expedited but the scrutiny processes are not compromised. As RDS develops, the scrutiny processes will continue to develop its procedures to improve efficiency, while maintaining integrity. Ultimately the aim is that this will all work together so that the people of Scotland will gain the benefits of better health and social care.

Dr Lorna Ramsay

Interim Chair of Public Benefit and Privacy Panel for Health and Social Care

4. Purpose and Structure of the Public Benefit and Privacy Panel for Health and Social Care

HSC-PBPP is an IG structure of NHS Scotland that exercises delegated decision-making on behalf of NHS Scotland Chief Executive Officers and the Registrar General of the National Records of Scotland (NRS) for NHS Central Register (NHSCR) data.

The HSC-PBPP endeavours to operate as a centre of excellence for privacy, confidentiality and IG in relation to Health and Social Care in Scotland, providing strategic leadership and direction in this area to NHS Scotland Boards, the research community, and wider stakeholder groups.

The panel aims to:

- Streamline the governance processes for the scrutiny of requests for access to NHS Scotland-originated data for purposes other than direct care, e.g. audit, service-improvement, research, or health and social care planning;
- Provide robust, transparent, consistent, appropriate and proportionate IG scrutiny of such requests;
- Strengthen the direct involvement of members of the NHS and public in the scrutiny process and decision making regarding access to NHS Scotland-originated data.

Since its inception in May 2015, the HSC-PBPP has provided a national IG scrutiny process for the secondary use of patient data. It has successfully harnessed expertise across NHS Scotland health boards implementing a collaborative approach which contributes to consistency and continued capacity development across the sector.

Structure of the HSC-PBPP

The HSC-PBPP structure and process is summarised in the flow diagram shown in Figure 1. eDRIS provides a single entry point for all applications to HSC-PBPP. This helps to maintain consistency of advice for all applicants, including those from NHS services or Scottish Government for core business, as well as those wishing to use NHS data for research.

The eDRIS team provides support to all applicants applying to HSC-PBPP. They do this by providing an eDRIS Coordinator to facilitate applicants to refine their data-linkage projects, as well as review and assist applicants to finalise their applications for submission. The eDRIS team works closely alongside the HSC-PBPP. Through shared learning between the two teams, this aims to ensure that applications are fit for submission, thus making the HSC-PBPP review process as efficient as possible for both applicant and reviewer.

The HSC-PBPP operates on a two-tier structure (see figure 1). Tier 2 is the level of strategic oversight and consideration of policy, whereas Tier 1 is the more operational level at which most applications are approved.

Tier 1

Tier 1 is the first level of scrutiny of applications, acting at an operational level, meeting every 2 weeks. Facilitated by the Panel Manager, each panel comprises of specialist IG

practitioners from across the NHS Boards. Applications are reviewed according to agreed proportionate governance criteria. The Tier 1 scrutiny examines the technical and IG aspects of an application and takes place at a Tier 1 panel meeting. If the Tier 1 panel is satisfied that the public benefit of the proposal is clear and that all privacy risks will be managed appropriately and securely, the application is approved. There may be an exchange of questions seeking clarification before the approval or another outcome is agreed. For more complex, novel or potentially contentious applications, the Tier 1 panel may refer the application on to Tier 2. This would be assessed by a subgroup of the full committee, the Tier 2 OOC. The panel members considered each application against a set of proportionate governance questions and criteria. Up to five applications and two amendments were considered at any one meeting.

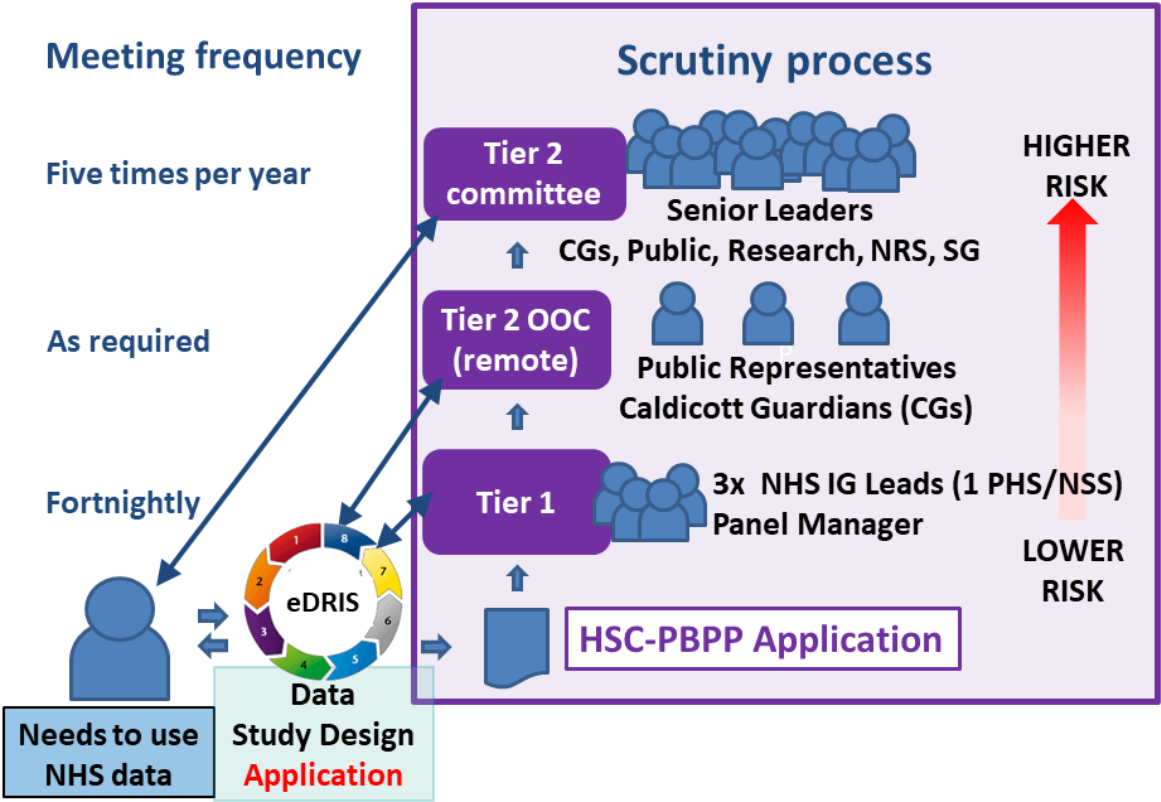


Figure 1 Flow-diagram of the HSC-PBPP scrutiny process

- CG: Caldicott Guardian
- SG: Scottish Government
- IG: Information Governance
- NRS: National Records of Scotland
- OOC: Out of Committee

Tier 2

Tier 2 comprises a regularly convened strategic Full Committee, and a smaller subgroup of committee members working as ‘Out of Committee’. The latter comprises of the Caldicott Guardians and public representatives from the Full Committee. Applications referred from Tier 1 are reviewed by the Tier 2 OOC. Most applications referred to Tier 2 are approved at this level, with only a minority referred on to the full committee. When applications are

referred to the full committee, the applicant is invited to attend to answer questions and inform the discussion.

The full 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, sensitive or novel applications;
- Applications that would set precedence;
- Proposed policies in the Scottish Government and/or NHS Scotland relating to the use of health and social care data.

The use of the two tiers also ensures that scrutiny is proportionate, and that available resources are effectively used. Each of the two tiers focuses on the assessment of privacy risks as well as the balancing of privacy risk with likely public benefit.

5. HSC-PBPP Committee Members 2019/20 and 2020/21

Brian Houston (*Chair, resigned August 2019*)

Dr Lorna Ramsay (*Interim Chair, appointed October 2019*)

Dr George Fernie (*NHSS Caldicott Guardian*)

Professor Alison McCallum (*NHSS Caldicott Guardian, resigned October 2020*)

Dr Eleanor Anderson (*NHS NSS PHI Caldicott Guardian*, resigned December 2019*)

Dr Maria Rossi (*NHS NSS PHI Caldicott Guardian*, resigned August 2020*)

Dr Tara Shivaji (*PHS Caldicott Guardian representative, appointed October 2020*)

Professor Abbe Brown (*Public Representative*)

Dr Angus Ferguson (*Public Representative*)

Kenneth McLean (*Public Representative*)

Professor Daniel McQueen (*Public Representative*)

Professor Corri Black (*Research Community Representative*)

Professor Helen Colhoun (*Research Community Representative*)

Dr Stephen Pavis (*NHS NSS Data Linkage Lead Specialist and Head of eDRIS, to March 2019*)

Carole Morris (*PHS Data Linkage Lead Specialist and Head of eDRIS, from April 2019*)

Dr Stephen Pavis (*NES Representative, from April 2019*)

Alan Ferrier (*NRS Representative*)

Penni Rocks (*Scottish Government representative*)

* NHS National Services Scotland (NSS) Public Health and Intelligence (PHI Caldicott Guardian was a shared role and either member can attend the committee.

Vacancies

During the year 2018/19, one Caldicott Guardian role became and remained vacant and in 2020/21 another Caldicott Guardian role became and remained vacant.

The Social Care representative role on the committee remained unfilled during 2019/20 and 2020/21.

5.1. Recruitment for Tier 2 Committee members

As of March 2021, the tenure for some of the original members of the HSC-PBPP committee was completed. This was originally designed to allow changes of personnel and new members to be appointed, particularly for the roles of Caldicott Guardians, Public Representatives and Research Community Representatives. These roles are vital for stakeholder input into the work of HSC-PBPP. Recruitment of Research Representatives has not taken place before and a process was drawn up for this.

The HSC-PBPP is grateful and thanks all those who have left the Tier 2 committee for their contribution over the years and in particular in the early years as HSC-PBPP has grown and developed.

Recruitment of Research Community Representatives

The role of the Research Representative is to help the dialogue between HSC-PBPP and the academic research community. A list of researchers heavily involved in the use of NHS Scotland data was drawn up and these were invited to apply for the role. Once applications were received these were reviewed using pseudonymised applications, to compile a short-list for interview, the only caveat being that no two people from the same institution could be appointed. Interviews with existing Tier 2 committee members and the HSC-PBPP interim Chair took place via MS Teams. Two research community representatives were appointed to start in April 2021. The current research community representatives were asked to stay on committee to overlap for six months, if possible, to provide continuity and time for the new members to settle in.

Recruitment of Public Representatives

A similar process was used for the recruitment for people who would be interested in being Public Representatives as three Public representatives were due to retire. However, finding people with the time and inclination to do so has been difficult. Various routes have been used to approach people, but thus far only two representatives have been appointed. As with the research representatives, two of the public representatives have remained on the committee, to ensure quorum for meetings and review of applications referred from Tier 1 and to provide continuity and overlap with new members. The search for a third new public representative continues.

6. Meetings of the HSC-PBPP

Tier 1

The Tier 1 Panels met fortnightly at central locations in Edinburgh and Glasgow during 2019/20. From March 2020 these meetings continued on a fortnightly basis but were convened using MS Teams. Each panel comprised of three IG Leads/Practitioners from NHSS Boards, on rotation, and the HSC-PBPP Panel Manager. The IG leads were drawn from the territorial (regional) and national NHS Health boards around Scotland. Each brings their experience and viewpoint from their NHS Board.

Tier 2 OOC

The Tier 2 OOC was convened as required to consider applications referred from Tier 1. This group consists of the NHS Caldicott Guardians and Public Representatives, who sit on the full committee, but who also undertake these reviews. During 2019/20, five applications were scrutinised and approved by the Tier 2 OOC and a further four applications were referred to and approved by the Full Committee.

In 2020/21 the creation of the rapid review panel for high priority COVID-19 applications took up much of the time of the Tier 2 OOC. For non-COVID-19 applications, three were scrutinised and approved by the Tier 2 OOC and a further application was referred to and approved by the Full Committee.

The HSC-PBPP would like to acknowledge and thank the Tier 1 and Tier 2 members for all their hard work in the scrutiny process and during 2020/21 often under busy and trying circumstances.

Tier 2 Full Committee

In 2019/20 and 2020/21 the Full Committee met on the following occasions. From June 2020 the meeting was held virtually using MS Teams.

Full Committee Meeting Thursday 16th April 2019
Full Committee Meeting Tuesday 12th June 2019
Full Committee Meeting Tuesday 3rd September 2019
Full Committee Meeting Tuesday 19th November 2019
Full Committee Meeting Tuesday 4th February 2020

Full Committee Meeting Tuesday 5th May 2020 (cancelled due to COVID-19 restrictions)
Full Committee Meeting Tuesday 16th June 2020
Full Committee Meeting Tuesday 8th September 2020
Full committee meeting Tuesday 10th November 2020
Full Committee Meeting Wednesday 20th January 2021

Minutes of these meetings are available on the HSC-PBPP website:

<http://www.informationgovernance.scot.nhs.uk/pbphsc/application-outcomes/>

7. Changes to HSC-PBPP in 2020 not due to COVID-19

7.1. Establishment of Public Health Scotland

Public Health Scotland (PHS) was established on 1st April 2020, at the beginning of the NHS Scotland response to COVID-19, with most people working remotely. The role of PHS is to provide public health leadership and to enable and support the delivery of national public health priorities, using the expertise, data, intelligence and innovation needed to improve

the health of Scotland's population. NHS Health Scotland (HS) and the Public Health and Intelligence (PHI) strategic business unit from within NHS National Services Scotland (NSS) were brought together to form this new body, and are ideally equipped to fulfil this role.

For HSC-PBPP, the panel manager, depute panel manager and the administrator moved from NHS NSS to PHS, with new email addresses, including the HSC-PBPP inbox. The information assets held by HSC-PBPP were also moved to PHS. HSC-PBPP members (at both Tier 1 and Tier 2) from NHS NSS remained involved in HSC-PBPP, whether they have remained in NSS or moved to PHS. These changes are listed below:

For Tier 2:

- Interim Chair of HSC-PBPP remained in NHS NSS
- The PHS Caldicott Guardian or their representative sits on the HSC-PBPP committee, as PHS is a major data asset holder.
- Existing representatives of the other major data asset holders remained unchanged. These are NHS NSS, NHS Education for Scotland (NES), which also hosts the national clinical data store and NRS.
- CHI Advisory Group (CHIAG) representative remained in NSS as the Director of Practitioner and Counter-Fraud services (P&CFS) and on the HSC-PBPP Committee as the representative of NHS NSS.
- Head of eDRIS transferred to PHS.
- All other HSC-PBPP committee positions remained unchanged.

For Tier 1:

- The NSS PHI IG leads have become part of PHS and remained on the Tier 1 NSS rota (to be renamed the PHS/NSS rota).
- The CHIAG representative on the Tier 1 NSS rota, has stayed on the Tier 1 NSS rota (renamed PHS/NSS rota) and remained in NSS. Two other NHS NSS IG leads have joined the PHS/NSS rota.

The HSC-PBPP paperwork, including the HSC-PBPP Terms of Reference were updated according to the changes.

7.2. Name change of PBPP to HSC-PBPP

Two Public Benefit and Privacy Panels are in existence: this one for NHS Scotland data and Stats-PBPP that scrutinises and approves requests for data from SG and NRS, including data from the National Census. As more people have become more aware of the existence of both Public Benefit and Privacy Panels, Stats-PBPP requested that that an identifier be added (e.g. health PBPP) to differentiate more easily between the two panels. The Tier 2 committee agreed that the full name will remain as the Public Benefit and Privacy Panel for Health and Social Care, but the shortened name be given a prefix for the Health & Social Care: as **HSC-PBPP**. All paperwork has been updated accordingly.

8. Changes in HSC-PBPP processes in response to COVID-19

8.1. Rapid approval processes for applications for data for COVID-19 research and surveillance

A rapid approval process was developed for supporting priority applications to HSC-PBPP in response to the COVID-19 pandemic, when fewer staff may be available and time to approval must be kept as short as possible. The process was commissioned by the HSC-PBPP interim Chair and developed by the HSC-PBPP Managers, Heads of Service for eDRIS and PHS IG, and two eDRIS coordinators.

The changes consisted of:

1. A shortened 'COVID-19' application form, approved by the HSC-PBPP interim Chair.
2. Triage process by eDRIS, with discussion with the applicant, to determine the priority level of the applications. The priority level would depend on: who commissioned the application, what it was to do and how it would contribute to the response to COVID-19. Applications at priority level 2 would be reviewed by the rapid review panel; those at priority level 1 would be reviewed by Tier 1.
3. Review processes:
 - A rapid review panel was set up using a pool of reviewers, consisting of available Tier 2 committee members and Tier 1 IG reviewers, who would review priority level 2 applications. These reviews would be sent to two each of: senior clinicians / Caldicott Guardian, IG reviewers, public representatives and senior eDRIS staff for a data perspective. A review from at least one of each perspective was required for all applications. The outcome of these reviews would be approval for the project to start but with conditions or recommendations to ensure that the necessary and appropriate paperwork would be put in place. Some applications did require further clarifications before they could be approved.
 - Tier 1 would review level 1 COVID-19 applications, which would take priority over non-COVID-19 applications. HSC-PBPP would remain open for review of non-COVID-19 applications, the reviews of which would be fitted around the COVID-19 applications.
 - A further review process was set up for review by GPs for the use of a specific GP dataset for COVID-19 applications.
 - With discussion with NRS, a process was put in place for review of data requests for only NRS data at Tier 1, but no such applications were received.
4. Amendments to existing applications requesting COVID-19 data would follow normal processes but would be prioritised and processed as quickly as possible.
5. Both HSC-PBPP and eDRIS websites would be used for communications to applicants and the public. A list of approved applications with their lay summaries was posted on the HSC-PBPP website and updated weekly.
6. All meetings (Tier 1 panels, HSC-PBPP Tier 2 committee and Operations Group) would be carried out remotely, using MS Teams.
7. Evaluation process for the governance and provision of NHSS data for COVID-19 proposals would take place, within 6-12 months after these changes were introduced.

8.2. Evaluation of the HSC-PBPP and eDRIS response to COVID-19

Review of applications approved by Rapid Review panel

To determine whether the decisions made by the rapid review panel were robust, four applications (~10% of those reviewed) were chosen at random that had already been approved by the rapid review panel. These were sent to three committee members and one NHS NSS IG lead, who had agreed to review these applications who had not previously reviewed these applications. The reviewers agreed that all the applications reviewed had merit and would deliver outcomes of benefit to the public, but that applicants need to ensure that the public benefit is articulated clearly. For the applications reviewed, there was general agreement that the decisions made by the rapid review panels were appropriate and suitable responses and clarifications had been requested.

‘Provider experience’ questionnaire of HSC-PBPP and eDRIS processes

For the evaluation process, the HSC-PBPP Manager devised a questionnaire to try to assess these changes to HSC-PBPP processes and their effects on the review of the applications. This was carried out in September 2020, 6 months after the COVID-19 changes were introduced. Questionnaires were sent to the HSC-PBPP Tier 2 committee and Operational Group, all Tier 1 members and eDRIS staff. Responses were received from all levels of HSC-PBPP and eDRIS.

Responses to the questionnaire were received from all levels of HSC-PBPP and eDRIS. Comments were received regarding changes to the application form, triage and application completion, the application review process, provision of COVID-19 data and the necessary changes to HSC-PBPP meetings due to COVID-19 restrictions.

Responses from the areas for evaluation were:

- Shortened COVID-19 HSC-PBPP application form
The COVID-19 application form was shorter and aimed to be easier to complete, with guidance throughout. It had been thought that most COVID-19 applications would be from established NHS or University Clinical Research groups and, therefore, some assumptions could be made.

Responses: Some said that the form was more ‘trusting’ of the applicant, their organisation and their local IG training, which could help foster better working relationships with applicants. The guidance and prompts were good, if used. However, even with the guidance, applicants still did not answer the questions and some applications were obviously rushed and very unclear. Some applications lacked forethought in study design, detail and justifications and the public benefit was not always clearly articulated.

- Triage and application process
eDRIS triaged COVID-19 applications as to their priority level.

Responses: On the whole, the triage worked well. There were some applications that said they were COVID-19 to get themselves up the priority list. This arose on several occasions for eDRIS and rather than risk a COVID-19 project not being processed, several researchers were given the benefit of the doubt, which was noted during review. Not all high priority applications would feed directly into the response; others were highly complex and sensitive and would have benefitted from a full review and more time to consider them.

- Application rapid reviews

The reviewers at all levels have been excellent and without some individuals, these processes would not have worked.

Responses: some reviewers thought that, at times, the speed of turnaround of reviews was at the expense of thoroughness and without time to reflect further. This applied particularly to the large and complicated applications. Another concern raised was the onward sharing of unconsented data and whether this was done in the public interest.

- eDRIS data provision and amendment requests

The use of a standard dataset (COVID-19 database) has made data provision quicker and easier as the applicants could look through a data dictionary with stated variables.

Responses: the use of the database has streamlined data provision, which has led to provisioning times that would not have been possible previously. The more frequent data updates (weekly or fortnightly/weekly, when normally done at 3-or 6 monthly intervals), has been time- and labour-consuming for eDRIS, although some automation of processes are now in place. The ambiguity of some applications has led to confusion in data provision and the need for amendment requests. As COVID-19 applications were prioritised, a backlog of non-COVID-19 application developed, with strains on other parts of the service and some customer dissatisfaction.

- Meetings using MS Teams

All HSC-PBPP meetings have taken place remotely using MS Teams.

Responses: For **Tier 1**, MS Teams has worked well, with more flexibility in the timing as there were no bookings or travel. This could take into account the circumstances of the individual panel members (e.g. child care, other meetings). The use of *ad hoc* meetings by Teams for further discussion of applicants' responses, has improved Tier 1 review times, especially for the more complicated applications. The disadvantages were less time for informal chat which can be very informative and people missed the genuine interpersonal contact; distractions from children / pets / outside environment; the fatigue of long online meetings and sometimes difficulty in concentration; the requirement for a good and sustained internet connection. Despite the drawbacks, these meetings are likely to continue on MS Teams.

Operational Group meetings have more members and are slightly bigger than Tier 1 meetings but have functioned well and are likely to continue by MS Teams. Some of the same disadvantages were expressed.

For **Tier 2 committee meetings**, the use of MS Teams has been harder, partly due to the higher numbers of members in the same meeting. Again, these rely on a good internet connection, and technical difficulties can arise. Such meetings require good chairing and the use of the "hand-up" feature has been invaluable. As with Tier 1, there is the loss of opportunity for informal dialogue, which may be more important as the committee meets less frequently.

- Non-COVID-19 applications and processes

HSC-PBPP remained open to non-COVID-19 applications, but these were subject to delays due to prioritisation of COVID-19 applications.

- Capacity
Capacity has been, and still is, an issue, at all levels. Because the NHSS COVID-19 response has been addressed by key NHS clinical and IG personnel within different NHS Boards, there has been reduced availability of some Tier 2 and Tier 1 personnel for HSC-PBPP work. This led to some unforeseen delays in reviews of clarifications, especially for non-COVID-19 applications, but also for some COVID-19 ones. Without some specific Tier 2 members, the rapid review process would not have worked. Similarly, without other Tier 1 panellists making themselves available at short notice, more Tier 1 panels would have been cancelled due to unavailability. Non-COVID-19 applications for have been subject to delays (sometimes by several weeks) before going to a Tier 1 panel meeting and the applicants become frustrated.

Responses: It was thought that the rapid turnaround for reviews, was acceptable for a short-term emergency situation, **it would not be feasible in the long-term**. This is due to availability of people at all levels, other non-HSC-PBPP work, backlogs of tasks and fatigue from working remotely at such a fast pace and intensity.

- General Feedback on the experience of all involved

Responses: There was a general feeling that both eDRIS and HSC-PBPP have done extremely well, which was made possible by the strong working relationship between the two teams. Feedback from some applicants had indicated that they were impressed by how quickly NHS Scotland changed the governance landscape for approving studies and data availability for COVID-19 research compared with other parts of the UK. Applicants have indicated that devolution has made UK-wide processes challenging due to governance differences across the UK. The fact that HSC-PBPP expedited their processes, rather than waived them, was thought to be a good strategy for addressing privacy concerns and especially for the processing of unconsented data. It was hoped that this would also reassure the public that their health data has been used appropriately. A number of recommendations were made for updating the HSC-PBPP application form.

In conclusion the response to COVID-19 by HSC-PBPP and eDRIS has been quick and efficient. Some of these changes will be carried forward for use as business as usual as these are thought to have improved the processes that were already in place.

9. Performance Metrics for HSC-PBPP applications for 2019/20 and 2020/21

9.1. Summary Tables of HSC-PBPP metrics for 2019/20 and 2020/21

The applications and amendments submitted to HSC-PBPP for the year 2019/20 to 31st March 2020, are summarised in table 1 below. The applications and amendments submitted to HSC-PBPP for the year 2020/21 to 31st March 2021, are summarised in table 2 below.

	Number submitted	Number with decisions *	Level of decision	(n)	%
Applications for 2019/20 at 31/03/20	95	Approved: 89	T1 panel meeting	33	36%
		Not approved: 4	T1 review	51	55%
		Total 93	T2 OOC	5	5%
			T2 full committee	4	4%
		Withdrawn: 12	Total (for 19/20)	93	
Amendments for 2019/20 at 31/03/21	261	Approved: 240	eDRIS	116	47%
		Not approved: 5	Panel Manager	111	45%
		Total 245	Tier 1	14	6%
			Tier 2	4	2%
		Withdrawn: 2	Total (for 19/20)	245	

Table 1: Summary of the applications and amendments submitted to HSC-PBPP in 2019/20.

* Some of these decisions are for applications that were submitted in 2018/19 so the numbers do not correspond to the total number of submitted applications for 2019/20.

	Number submitted	Number with decisions*	Level of decision*	(n)	%
ALL applications for 2020/21 as of 31/03/2021	126	Approved: 105	T1 panel	37	33%
		Not approved: 5	T1 review	44	40%
		Total 110	T2 OOC	3	3%
			T2 full committee	1	1%
		Withdrawn: 13	COVID-19 rapid review	25	23%
	Total	110			
ALL amendments for 2020/21 as of 31/03/2021	236	Approved: 213	eDRIS	96	44%
		Not approved: 6	Panel Manager	103	47%
		Total 219	Tier 1	17	8%
			COVID-19 rapid review	3	1%
		Withdrawn: 1	Total	219	
COVID-19 applications as of 31/03/2021	55	Approved: 50	T1 panel	17	34%
		Not approved: 0	T1 review	8	16%
		Withdrawn: 3	COVID-19 rapid review	25	50%
		Ongoing 2	Total	50	
		Total 55			
COVID-19 Amendments for 2020/21 as of 31/03/2021	53	Approved: 51	eDRIS	12	23%
		Not approved: 2	Panel Manager	33	65%
		Withdrawn: 0	Tier 1	3	6%
		Total 53	COVID-19 rapid review	3	6%
			Total	51	

Table 2: Summary of the applications and amendments submitted to HSC-PBPP in 2020/21 for all applications and COVID-19 applications.

*For 'all applications' some of these decisions for 2020/21 are for applications that were submitted in 2019/20 so the numbers do not add up to the number of submitted applications for 2020/21.

Types of Applications

Applications for different types of studies were submitted and reviewed, reflecting the variety of research and service assessment that used NHS Scotland data for the benefit of the public. The different types of study are:

- Local and national audits assessed the outcomes and needs of different conditions or procedures.
- NHS Scotland data were used to investigate the long-term outcomes of a number of Clinical Trials.
- Epidemiological studies investigated the risk of different factors on the patterns of disease incidence or health outcomes.
- Longitudinal studies of specific cohorts used NHS Scotland data to look for patterns in disease onset, processes and responses to interventions.
- Use of NHS Scotland data for NHS service planning and improvement, for assessing the cost-effectiveness of specific interventions, or the interactions of social and environmental factors on health outcomes.
- Use of NHS Scotland data for technological advances such as machine learning and the development of mobile phone apps to monitor patient care.
- Applications relating to the COVID-19 pandemic and the effects of the response to it.

Lists of the approved applications for each year with their lay summaries, where available, is available on the HSC-PBPP website:

<https://www.informationgovernance.scot.nhs.uk/pbpphsc/application-outcomes/>

9.2. Comparisons with previous years

Comparisons with previous years indicates the demand for NHSS data and HSC-PBPP scrutiny.

Submissions

During 2019/20, a total of 95 applications were submitted to the HSC-PBPP; in 2020/21 this increased to 126 applications, which included COVID-19 and non-COVID-19 applications. As can be seen from figure 2, the number of applications has fluctuated with a mean of 124 per year over the past 5 full years of HSC-PBPP.

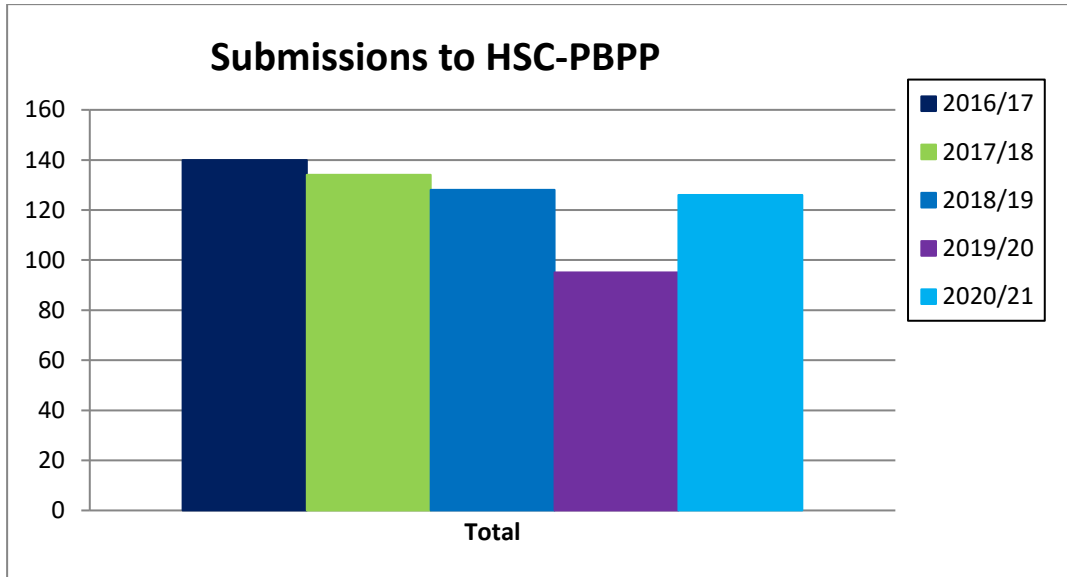


Figure 2: Numbers of applications submitted to the HSC-PBPP in the five years from 2016/17 to 2020/21.

Sources of applications

The organisation category and countries from which applications were received are shown in figures 3a and 3b for the years 2016/17 to 2020/21.

Figure 3a shows that the majority of applications were received from academia and NHS with only a small percentage from commercial companies or Scottish Government.

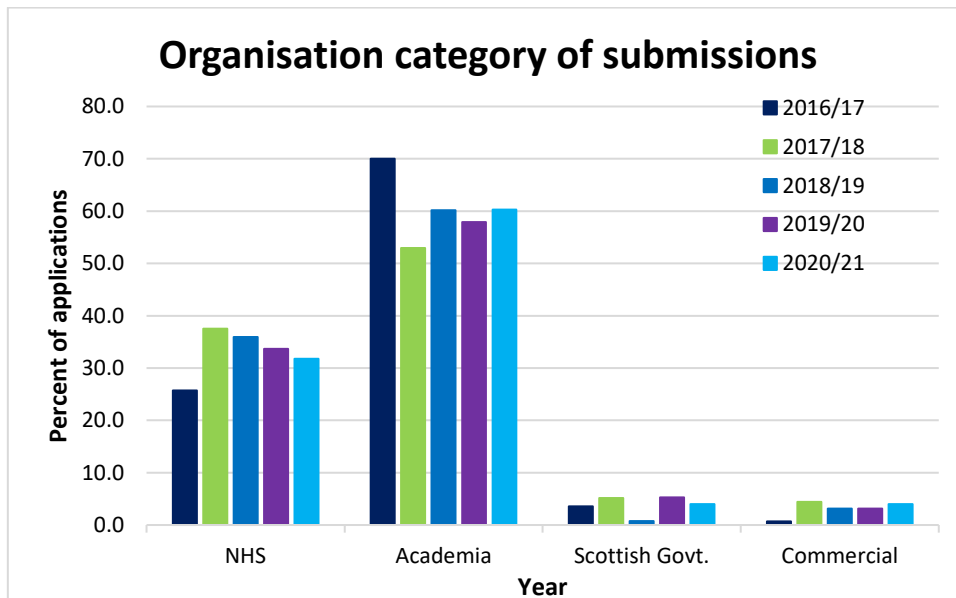


Figure 3a: Sources of applications to the HSC-PBPP in 2016/17 to 2020/21

Figure 3b shows that the majority of the applications were initiated from within Scotland with the others applications from the rest of the UK.

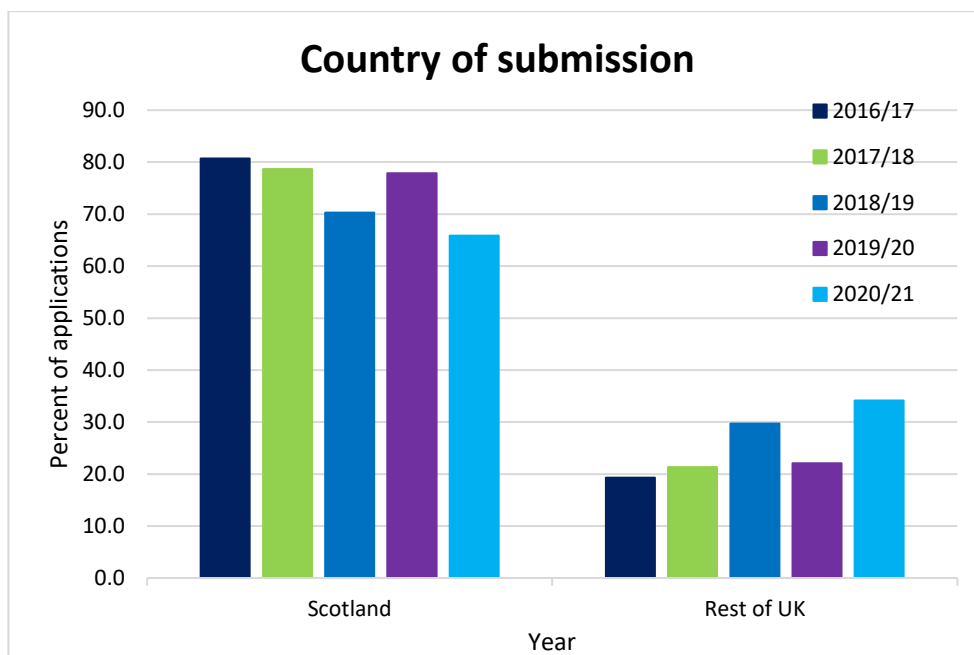


Figure 3b: Sources of applications to the HSC-PBPP from 2016/17 to 2020/21

Application Decisions

The number of application decisions per year are shown in figure 4, with 93 decisions made in 2019/20 and 110 in 2020/21. This is similar to previous years, with a mean of 114 decisions per year from 2016/17 to 2020/21. The level of HSC-PBPP at which these decisions were made are shown in figure 5. As can be seen the majority of applications were approved by Tier 1, either at a panel meeting or after the questions clarifications have been reviewed by Tier 1 panel members.

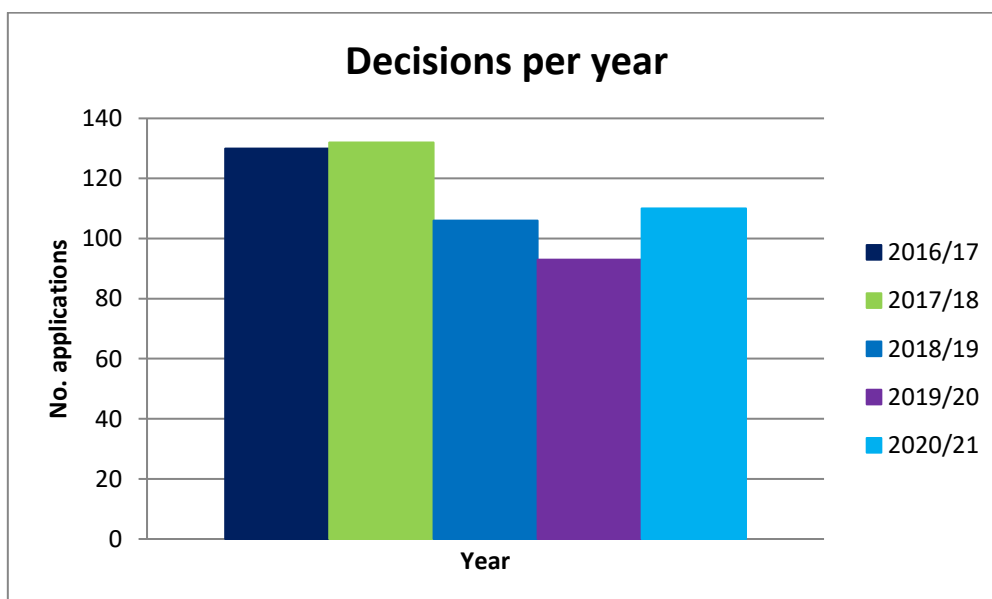


Figure 4: Number of applications with decisions from 2016/17 to 2020/21

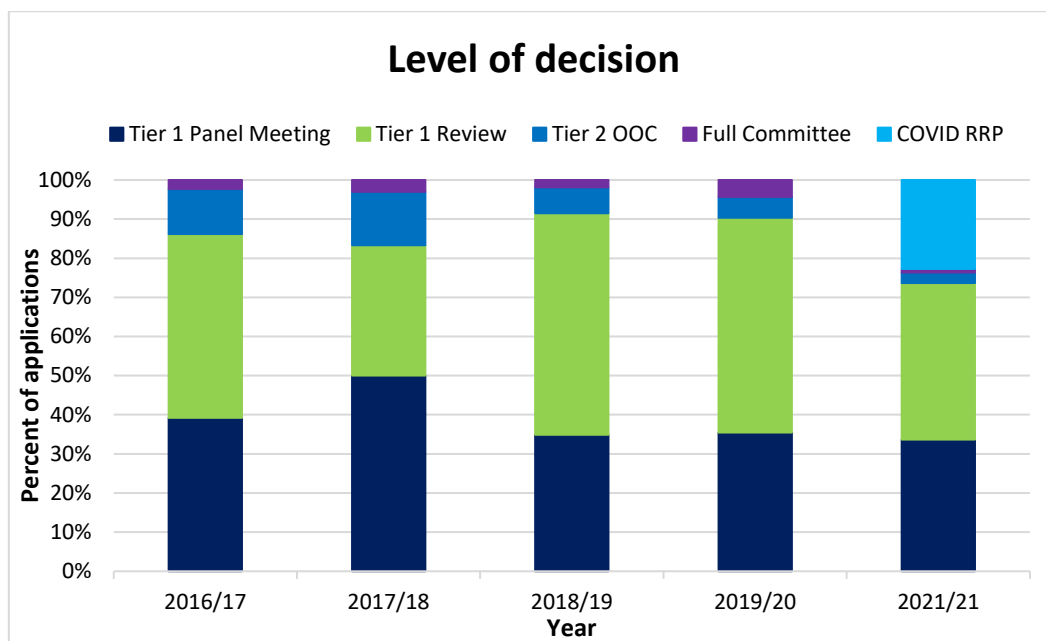


Figure 5: *Level of decisions for applications from 2016/17 to 2020/21*

Requests for data and/or flagging from the NHS Central Register (NHSCR)

The NHS Central Register contains demographic details of everyone who was born or died in Scotland, and everyone registered with a General Medical Practitioner in Scotland. The register exists to allow the smooth transfer of patients who move between health board areas, across borders within the UK or in and out of the Armed Forces. The NHSCR can ‘flag’ patients (for cancer or death) as part of a medical research project, so that researchers can keep track of their progress and be notified if their patients develop cancer or die. In 2019/20, 8 applications (8.4%) and in 2020/21 11 applications (8.7%) requested flagging by NHSCR, either as part of a study requiring other NHS data or as the only data requested. This is similar to that requested in previous years. The mean over the past 5 years is ~11% of applications requesting NHSCR data.

Time to decisions

The HSC-PBPP measures two time-periods for decisions to review its efficiency and processing times, between an application being submitted to the HSC-PBPP and the decision by the panel:

- ‘Clocked’ time: this is the number of working days for which the application is being processed by the HSC-PBPP, from submission to decision. The time taken by the applicant to respond to any queries from the HSC-PBPP regarding the application is not included.
- Total time: this is the total number of working days from submission until the final decision is made, which includes any time the application spent back with the applicant.

Neither of these measures includes the time that any application spends with an eDRIS coordinator before submission to HSC-PBPP, nor the time taken between HSC-PBPP approval and provision of the data requested.

Time to decisions (days) for applications 2019/20

The time taken for decisions to be made by HSC-PBPP for 2019/20 are summarised in table 3. These data are presented for all applications (ALL), those applications decided at Tier 1 and those applications decided at Tier 2.

	ALL		Tier 1		Tier 2	
	Total	Clocked	Total	Clocked	Total	Clocked
N	93	93	84	84	9	9
Mean	50.8	30.6	42.3	23.8	130.9	95.6
Median	39	23	36.5	22	129	78

Table 3: Time to approval for applications (to end March 2020)

Total time is the number of working days that the application took for a decision from the date of submission to HSC-PBPP to the date of the decision. This includes weekends and holidays, and any time that the applicant took to update the application in response to queries and clarifications from the panel.

Time to decisions (days) for applications 2020-21

The time taken for decisions to be made by HSC-PBPP are summarised in table 2. These data are presented for all applications and divided into COVID-19 and non-COVID-19 applications. The times are given for all decisions (ALL) and separately for those decided at Tier 1 and those applications decided at Tier 2/COVID-19 rapid review panel to 31st March 2021.

		ALL		Tier 1		Tier 2	
		Total	Clocked	Total	Clocked	Total**	Clocked**
ALL applications for 2020/21 to 31/03/21	N	110	110	81	81	29	29
	Mean	30.7	19.4	33.9	21.6	21.8	13.1
	Median	23	14	31	18	6	6
		ALL		Tier 1		Tier 2	
		Total	Clocked	Total	Clocked	Total	Clocked
COVID-19 applications to 31/03/20	N	50	50	25	25	25	25
	Mean	18.2	10.6	20.1	12.7	16.2	8.6
	Median	7.5	7	12	9	5	5
		ALL		Tier 1		Tier 2	
		Total	Clocked	Total	Clocked	Total	Clocked
Non-COVID-19 applications to 31/03/20	N	60	60	56	56	4	4
	Mean	41.2	26.7	40.1	25.6	56.8	41.0
	Median	36.5	22	35	21.5	57	36

Table 4: Time to approval for applications for applications with decisions in 2020/21 to 31/03/2021.

** For 2020/21 applications, this is the time to responses from the rapid review panel for COVID-19 applications and three applications that were approved by Tier 2 OOC.

Total time is the number of working days that the application took for a decision from the date of submission to HSC-PBPP to the date of the decision. This includes weekends and holidays, and any time that the applicant took to update the application in response to queries and clarifications from the panel.

Clocked time is the number of working days during which the application was being processed by HSC-PBPP, from submission date to approval date. It does not include the time that the applicant took to respond to queries and clarifications from the panel.

Comparison of Times to decisions across years

The median times to decisions at the different levels of HSC-PBPP from 2016/17 to 2020/21 are shown in figure 6. The figures for 2020/21 are just for non-COVID-19 applications. The times for all applications shows that these have remained fairly constant over the years. By the nature of their referral to Tier 2, the few applications that are referred to Tier 2 will take longer. The Tier 2 times increased in 2019/20 compared with previous years, but decreased in 2020/21 to their lowest level.

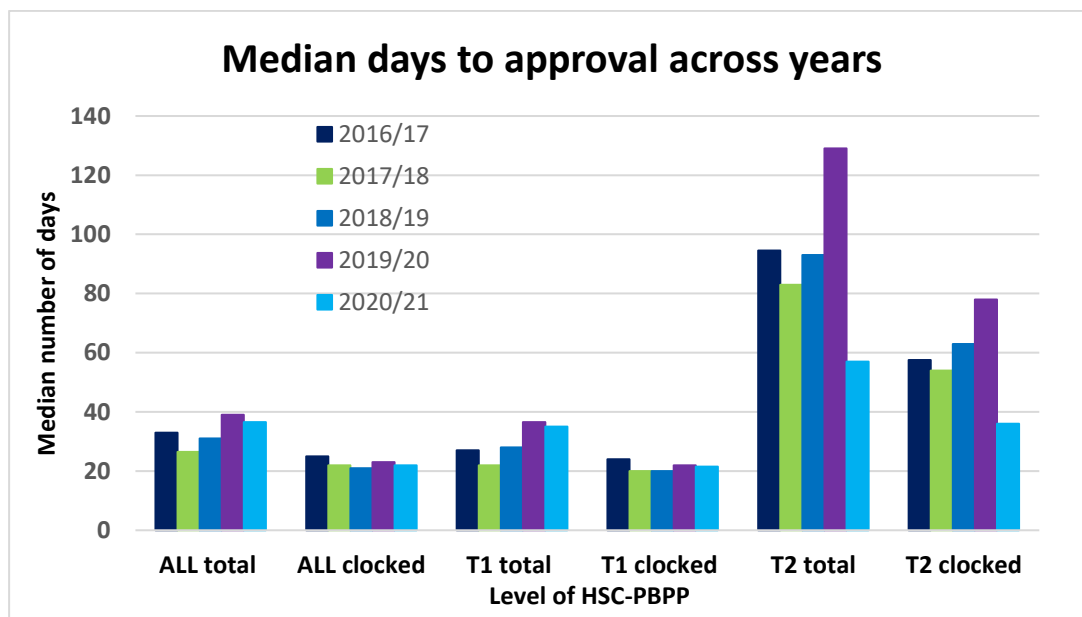


Figure 6: Median times (days) to decisions at different levels of HSC-PBPP

10. Performance Metrics and continuous Quality Improvement

The HSC-PBPP has a duty to be accountable to the public and stakeholders and strives to improve its processes continuously, so that applications are processed as efficiently and quickly as possible, whilst maintaining standards of governance. In addition to regular monitoring of processing times of applications the HSC-PBPP also takes on board lessons

learned from novel, complex or commonly sighted applications often recording Policy Decisions and Case Law Principles to enable consistent decision making at both Tiers.

10.1. 2019 Audit of Tier 1 reviews 2018/19

In 2016/17 an auditing process was introduced with the purpose of reviewing the approvals at Tier 1 for applications to the HSC-PBPP. For this process, a set of applications that had been approved at Tier 1, were chosen at random to be reviewed by the Tier 2 committee. The Tier 2 review was to consider whether these applications had been approved appropriately, using the same proportionate governance criteria by Tier 1, or whether they should have been referred to Tier 2 for further scrutiny.

The audit in 2019 of applications approved in 2018/19 was carried out, and was especially important in the light of the introduction of the new Data Protection Act with GDPR in May 2018. The results and feedback was considered as part of the Annual HSC-PBPP training day in October 2019. From the applications that were randomly selected, the majority were considered to be appropriately approved by Tier 1. Three applications each raised 'red' referral points, but each from only one of its Tier 2 committee reviewers. The points raised were discussed and a number of recommendations were proposed to strengthen the application and review processes. Minor modifications to the application guidance documents and the proportionate governance review documents were done.

This review was important to highlight some of the challenges encountered from interpretation of the new legislation. Many of the Tier 1 panels and Tier 2 reviews raised similar points, which demonstrates the shared learning across the different tiers of HSC-PBPP and across the NHS Boards. The audit report summary is published on the HSC-PBPP website at the link below.

<http://www.informationgovernance.scot.nhs.uk/pbpphsc/application-outcomes/>

10.2. 2019 Review of Tier 2 Committee attendance and application reviews

In 2019, the HSC-PBPP Manager carried out a review of the Tier 2 Committee. The aim of this review was to determine the resilience and capacity of the HSC-PBPP Tier 2 Committee meetings and Tier 2 OOC reviews of referred applications, between June 2015 and March 2019. It was decided that it would not be possible to review the actual decisions made for applications at Tier 2, as the applications referred to Tier 2 can be highly complex, unusual and often precedent setting. Therefore, would be difficult to audit these decisions according to any specific external criteria. Conformation of such applications to the HSC-PBPP Guiding Principles is a matter of judgement made by each Tier 2 reviewer as part of the review.

Questions to be assessed were:

1. Committee meeting attendance from June 2015 to April 2019.
2. Tier 2 OOC application review participation from June 2015 to end of March 2019.
3. The time taken for the above Tier 2 OOC reviews of referred applications.

Committee attendance

Between June 2015 and April 2019 there were 20 committee meetings. Individual committee member attendance ranged from 20-100% of their eligible meetings. The longest-serving (original) committee members have attended 60-85% of all meetings. While individual attendance at committee meetings has varied, there has been attendance from each of the different representative groups at between 60% and 95% of the meetings. There were 7/20 (35%) committee meetings that were not quorate, due to insufficient public or NHS representation at specific meetings. This has been particularly the case when there were vacancies for these representatives on the committee. The highest turnover in committee membership has been in the Caldicott Guardians and those that have resigned, have cited pressure of work as their reason for leaving. There has not been any Social Care representation at any HSC-PBPP committee meeting.

Tier 2 OOC application reviews

Between June 2015 and March 2019, a total of 66 applications were referred to Tier 2 and had an initial review by the Tier 2 OOC. A further application was referred straight to the Tier 2 committee. Of the 67 applications seen at Tier 2, 61 had decisions by March 2019; of these, 58 were approved and three were not approved. In total 15 people have reviewed applications at Tier 2 OOC. The participation in the review process ranged from none to all their eligible applications; the median at individual level was that each reviewed 70% of their eligible applications. The majority of the Tier 2 OOC members reviewed over 80% of the applications which they are eligible to review.

Time-lines for Tier 2 OOC reviews

First reviews by Tier 2 OOC should be returned within a (calendar) fortnight of sending the review request. This is an arbitrary time-frame but is the same as that requested for reviews at Tier 1, and is designed to help maintain momentum. Analysis of the time-scales for returning the review used two categories: i) returned within the deadline or within four days after the deadline (“on time”); ii) returned five days or more after the deadline (“late”). There was a wide range of responses returned within or near the deadlines but these differed across the individuals. For some Tier 2 OOC members, overall, up to 66% of applications have had late responses. For all applications, the proportion of applications that had received a quorum of reviews by the first deadline was 32% and this has decreased over the years, especially when there were vacancies for public representatives or Caldicott Guardians on the committee. The time taken to review applications by Tier 2 OOC has increased over the years.

Conclusion

This review has shown that vacancies on the HSC-PBPP committee increase the likelihood for HSC-PBPP committee meetings not being quorate and delays in Tier 2 OOC reviews. Such delays in the reviews of applications leads to frustration, with the consequent reputational damage to HSC-PBPP. A number of suggestions were made to address the HSC-PBPP committee vacancies and the delays in the Tier 2 OOC reviews.

10.3. 2020 Review of Amendments Requests 2015–2020

In 2020, the HSC-PBPP Manager carried out a review of amendment requests received and approved by HSC-PBPP, at the request of the HSC-PBPP Committee. Concern had been expressed that, through amendment requests, some applications were growing beyond the scope of their original approval. The review looked at the numbers of applications that had requested amendments, the reasons for such a request and the review processes in place.

From the establishment of HSC-PBPP in 2015 to end of June 2020, 964 amendment requests have been received for 406 applications, previously approved by HSC-PBPP or its antecedent bodies, i.e. applications that were approved by the CHI Advisory Group (CHIAG), the Privacy Advisory Committee (PAC) and the National Caldicott Guardian Scrutiny Panel. In 2015, HSC-PBPP took over the responsibilities of the ongoing applications and the scrutiny and approval and requests for amendments to these previously approved applications.

Over the past three years, HSC-PBPP has received over 200 amendment requests per year, with ~60% of all applications requesting at least one change. The reasons for the requests are many and varied but tend to arise through turnover of research staff, extension of duration of approvals due to unforeseen delays, addition of data variables and new ideas.

All amendment requests undergo initial review by the Depute HSC-PBPP Panel Manager, who directs requests towards the appropriate level of approval according to the proportionate governance criteria for amendments. In June 2018, the HSC-PBPP committee approved the approval by eDRIS coordinators for minor amendment requests. As part of this process there are often conversations between eDRIS coordinators and the panel managers as to the suitability of the amendment request and its required level of approval.

The amendment request review process now includes a general application review. This ensures that the amendment request is reviewed in the context of the whole application and its history, and not as an isolated change. This can be time-consuming, if it is a long-standing project, but it is more thorough and ensures that the whole application is kept up to date. Within the amendment review process, there is the provision for the request for a new application when data or scope increase beyond the original application request. For individual applications, this is a matter of judgement and will depend on the nature, extent and proposed duration of the original application.

From the recent update of the amendment request form (approved by the HSC-PBPP Operational Group), the amendment request must be fully justified, including an explanation of how it remains within scope of the original application. A check-list was added for the applicant to review their application, including an update of the legal bases under GDPR for processing data (where necessary). Since its introduction, the quality of and justification for the amendment requests has improved.

The review concluded that it is inevitable that amendments to applications will be requested, especially for the longer-term projects, but a thorough scrutiny process is in place.

11. Annual HSC-PBPP Workshops

2019 workshop

In 2019 the HSC-PBPP Annual Workshop was held at the Technology Innovation Centre, Strathclyde University, in Glasgow. The programme consisted of a mixture of presentations and workshop-style discussions.

The morning session concentrated on the challenges of commercial applications. Professor David Crossman, Scottish Government Chief Scientist opened the presentations by outlining Scottish Government (SG) policy on commercialisations and industry involvement. This was followed by two video presentations from Professors David Cameron and John Bartlett from University of Edinburgh discussing the IG challenges of commercial collaboration in research, based on their experiences with two related applications with commercial involvement and how the challenges were addressed. Professor Abbe Brown, from the University of Aberdeen, and HSC-PBPP Tier 2 member, then presented on Intellectual Property and the issues of commercialisation. After coffee, the Breakout group session discussed different scenarios of commercial applications and what needs to be in place for these.

The afternoon session concentrated more on the opportunities and challenges associated with the use of medical images in research. The results of the Tier 1 Audit for 2018/19 were presented. This was followed by Professor David Porteous, from Generation Scotland and the University of Edinburgh, showing how data linkage has been so essential to Generation Scotland. He then outlined the benefits of the use of medical images in their ongoing research. Jackie Caldwell from eDRIS and the Scottish Medical Imaging group gave a presentation on the processes being used to remove personal identifiers from medical images and their potential use in research. The afternoon breakout discussion was led by Erin Gray from the Scottish Centre for Administrative Data (SCADR) as a Stakeholder engagement session for use of images in research.

At the end of the afternoon, Kenneth McLean from the Tier 2 committee summarised and closed the day, with comments on the day and what we had learned.

2020 Workshop

In 2020, the HSC-PBPP Annual Workshop was cancelled due to ongoing COVID-19 restrictions. As an interim measure, a development slot was added to the agenda for the HSC-PBPP Committee meetings, to discuss new processes or innovations from applications or introduction of new policies. The best way to communicate such new developments to Tier 1 panel members is still under discussion. It is unlikely that the HSC-PBPP annual workshop will be able to be resumed in 2021/22.

12. Achievements and Priorities

12.1. Achievements for 2019/20 and 2020/21

Many of the developments started in 2019/20 were put on hold due to the restrictions imposed due to COVID-19, with increases in workload for many HSC-PBPP members. The new developments and achievements through the response to COVID-19 have been described above.

The training course for applying to HSC-PBPP was held at the Wellcome Trust Clinical Research Facility, in Edinburgh, in March 2020 but has since been put on hold due to COVID-19 restrictions. This course aims to inform applicants about when and why HSC-PBPP applications are required for access to data, and the data protection principles and processes to consider when filling in the application form.

The HSC-PBPP website was used for posting weekly outcomes of COVID-19 applications and is updated regularly with outcomes and meeting reports. A plan of ongoing website updates is in place and these will continue.

12.2. Priorities and Challenges for 2021/22

A number of tasks will be done in 2021/22, arising from the response to COVID-19:

- i. The application form will be updated. The previous 'Toothfairy' application will be updated accordingly for the new form. This is an application that was written by the HSC-PBPP team and approved by Tier 1, as an example of an approved application to help applicants.
- ii. The previous training offered through the Wellcome Trust Clinical Research Facility will be trialled online. One of the strengths of this course was the interaction with participants and the question is how this can be replicated online. If this can be done, a further advantage is that it could then be offered more widely throughout the UK.
- iii. A User Experience Survey has been proposed for HSC-PBPP. This will give feedback on the applicant experience and ways in which the process can be improved.

Research Data Scotland

Research Data Scotland (RDS) is a Scottish Government initiative which aims to bring public sector data together specifically for use in research for the public benefit. The aim is to improve and expedite the processes from initial discussion and application to provision of data for research. If NHS Scotland health data is included in these applications then HSC-PBPP will continue to be part of the scrutiny process and discussions with RDS as to the mechanisms of how this will take place are ongoing. In the meantime HSC-PBPP will continue to function as normal. HSC-PBPP scrutinises applications for NHS Scotland data that will not go through RDS and these will benefit from any improvements that are made.

13. Conclusion

From this report it can be seen that the years 2019/20 and especially 2020/21 have been years of change and development, building on what was already established. These processes will continue to be refined as the HSC-PBPP continues to operate to ensure the safe use of NHS Scotland data for the benefit of the public in Scotland.