

Lay Representative Person Specification

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

Background

The Public Benefit and Privacy Panel for Health and Social Care (HSC-PBPP) is a governance structure of NHSScotland, established with delegated authority from NHSScotland Chief Executive Officers and the Registrar General. Its remit is to carry out information governance (IG) scrutiny of requests for access to health data for purposes of health and social care administration, research and other well-defined and bona fide purposes, on behalf of individual data controllers. The HSC-PBPP acts as the final arbiter of requests which fall within its remit, but does not replace any existing or future requirements for ethical review or approval. The HSC-PBPP has dotted line reporting to both The Scottish Government's cross-sector data management board and its eHealth Strategy Board.

The HSC-PBPP operates on a two-tier structure utilising a 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 panels, consist of NHS Scotland Information Governance leads, are guided by agreed proportionate governance criteria; the more strategic Tier 2 committee, is guided by these criteria and the panel's guiding principles. The tiered structure provides for proportionality in the approval or refusal of applications to use data. The Tier 2 committee provides the intellectual space for senior leaders and public representatives to consider the wider privacy issues in regard to particularly contentious cases or proposed policies in NHS Scotland or the Scottish Government relating to the use of health and social care data.

Currently, the HSC-PBPP is responsible for scrutinising and considering over 100 applications per year for the use of NHSScotland data. Due to the tiered approach, the majority of applications are approved at the operational Tier 1 level, with ~10% of applications requiring scrutiny at the more strategic Tier 2 level. Those applications with an increased scope, complexity and/or a number of different risk factors or ones that set precedence of an application usually require Tier 2 scrutiny.

Lay Representative Role

HSC-PBPP is seeking competent individuals to provide Lay Representation in support of the IG scrutiny of requests for access to Scottish health data.

The role of the lay representative is to provide a public or lay perspective on the HSC-PBPP service, with input into the HSC-PBPP scrutiny of applications. The lay representatives also bring key issues, which may be of interest to the public, to the attention of the committee and is considered to be an important role in the Tier 2 HSC-PBPP committee.

The Lay Representative will help with the review of applications for use of NHSScotland data (and possibly other personal or sensitive data) that have been referred to Tier 2, as outlined in the panel Terms of Reference. These reviews are done in concordance with the panel's own proportionate governance criteria and guiding principles and previous decisions concerning privacy protection and information risk management. Panel members also bring their relevant knowledge and experience to form their opinions or decisions in respect of such applications, and in respect of other relevant HSC-PBPP business.

As a lay Representative you would be involved in this interesting work, giving impartial, external advice as to the suitability of the request and assurance that the principles and standards set out by the HSC-PBPP Terms of Reference and information governance are being upheld; public benefit and safe people, safe places, safe data and safe projects.

Lay representation ensures appropriate externality and accountability during these processes and is a valuable mechanism by which the voice and opinions of the public can be heard and acknowledged during this important governance process. The lay representative will be expected to contribute independent and objective views representing the interests of the wider public, but to not act as a representative of any organisation or specific group of people.

The lay representative would be appointed for a period of three years in the first instance, with the option to renew once. Meetings can take place across Scotland (if no legitimate restrictions apply), but usually take place in Edinburgh, with the option to tele-or video conference or by secure virtual methods. Some training will be provided.

This post is unpaid, but legitimate expenses are available for travel and subsistence costs incurred whilst acting as a Lay Representative.

Essential and desirable attributes

It is essential that members:

- Exercise dispassionate and unbiased judgement regarding ethically and practically complex and finely-balanced issues.
- Express the reasons for their decision making clearly and concisely.
- Can rapidly assimilate and understand large amounts of information about high-level medical and social project proposals and strategic developments.
- Are familiar with the current legislative and advisory environment regarding personal data, especially health and social care data.
- Contribute to out of committee activities as requested, and in particular requests to participate in a Tier 2 Out Of Committee application review, responding in a timely manner.
- Are suitably equipped to participate fully in the work of the panel by having access to adequate computer facilities. Details of the minimum requirements can be requested from the HSC-PBPP Panel Manager.
- Undertake any training as might be deemed appropriate by the HSC-PBPP Chair
- Attend five half-day committee meetings per year, and one annual development day.

It is desirable that members:

- Maintain a strong interest in a field relevant to the Panel's work, such as patient rights, privacy law or data protection, health, care and/or research ethics, health and care, statistical research. policy and/or strategy.
- A clinical, healthcare or technical background is useful but not necessary.

Commitment

HSC-PBPP Tier 2 committee meetings occur 5 times per year. All the relevant documents be provided for reading prior to committee meetings. The lay representative is expected to read and comment, as necessary, on the documents at the meetings.

The lay representative will be requested to review and comment on applications that are referred to the Tier 2, by Tier 1 colleagues. These will already have been reviewed by the Tier 1 panel, who will highlight their thoughts and concerns about the application. It is the role of the lay representative to consider these concerns and use their wider experience and knowledge of how they think the public would respond to such an application.

The lay representatives will be invited to attend and contribute to an annual service training or development day.

The HSC-PBPP Tier 2 committee

The Tier 2 meetings membership comprises: -

- Chair (Senior representative from NHSS Board)
- Four Public/Lay representatives
- Two Research Community representatives
- Three Caldicott Guardians from NHSS Boards, other than NHS National Service Scotland (NSS) or Public Health Scotland (PHS); it is hoped that two of these would be from territorial NHS Boards
- 4 Representatives from the Data Asset Holders (one from each):
 - Representative of the PHS Caldicott Guardian
 - Representative of the NHS NSS and CHI (Community Health Index) Advisory Group (CHIAG)
 - Representative of the NHS Education Scotland (NES) Digital Services
 - Representative of the National Records of Scotland
- Data Linkage Lead Specialist / Head of eDRIS
- Scottish Government IG Policy Lead
- Senior social care representative

Quorum for meeting: Chair + 7 panel members, including 1 PHS representative, 3 other NHSScotland members and 2 public representatives

Recruitment Process

Please contact **Dr Marian Aldhous**, HSC-PBPP Manager, for more information or to express an interest on the email address: pbs.pbpp@pbs.scot.

For those who express an interest, there may be an opportunity to observe a HSC-PBPP committee meeting. After that, if people are still interested, they would be asked to fill in an application form. It is hoped that the successful candidates would be appointed to attend the committee meeting in April 2021.

Further information about the HSC-PBPP can be found on the website, <https://www.informationgovernance.scot.nhs.uk/pbphsc/>