

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 NHS Scotland (NHSS) Chief Executive Officers and the Registrar General of the National Records of Scotland. Its remit is to carry out information governance (IG) scrutiny of requests for access to health data for purposes other than direct patient care, such as research and other well-defined and *bona fide* purposes, on behalf of the data controllers.

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, consisting of NHSS 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 own 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 NHSS 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 NHSS data. Due to the tiered approach, the majority of applications are approved at the Tier 1 level, with ~10% of applications being referred to the Tier 2 level. Those applications with an increased scope, complexity, with a number of different risk factors, or set a precedence with implications for the wider policy and use of health and social care data, usually require Tier 2 scrutiny. With the onset of the COVID19 pandemic, a rapid review panel was set up, which included the lay members and a larger number of applications to enable the response to COVID19 have been reviewed by this group.

Lay Representative Role

HSC-PBPP is seeking competent individuals to provide lay representation in support of the 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 Tier 2 committee regarding discussions of application and policy and is considered to be an important role. The lay representatives also bring key issues, which may be of interest to the public, to the attention of committee members.

The lay representative will help with the review of those applications for use of personal and sensitive data that have been referred to Tier 2. These applications 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. Lay representatives also bring their own 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 advice as to the suitability of the request from the perspective of a member of the public, and assurance that the principles and standards set out by the HSC-PBPP are upheld.

Lay representation ensures appropriate external 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.

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.
- Contribute to out of committee activities as requested, and in particular requests to participate in a Tier 2 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:

- Have an understanding of public / patient engagement.
- Have an understanding of public benefit.
- Have an understanding of risk.
- Have an understanding of the monetarization of health data.
- Have an understanding of the principles of proportionality in terms of data usage.
- Have an understanding of consent in the use patient data.
- Have an understanding of the implications of artificial intelligence in health research.
- Maintain an interest in a field relevant to the Panel's work, such as patient rights, privacy law or data protection, health, care, research ethics, health and care, statistical research, policy and/or strategy.

Many of the above desirable attributes can be learned as part of the work. HSC-PBPP will provide some relevant information as part of the induction process. Training will be provided.

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. Meetings can take place across Scotland, but usually take place in Edinburgh with the option to tele-or video conference, or by MS Teams.

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 development day.

The lay representative would be appointed for a period of three years in the first instance, with the option to renew once.

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

Context of 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); preferably two from territorial NHS Boards
- One representatives from each of the four Data Asset holders:
 - 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 (NDS)
 - Representative of the National Records of Scotland (NRS)
- 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

It is hoped that the successful candidates would be appointed to attend the committee meeting later in the year.

Recruitment Process

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

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