



Public Benefit and Privacy Panel for Health and Social Care

Guiding Principles and Policy for Decision Making

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The Public Benefit and Privacy Panel for Health and Social Care (HSC-PBPP) is a governance structure of NHSScotland (NHSS). It was established with delegated authority from NHSS Chief Executive Officers (CEO's) and the Registrar General of National Records of Scotland (NRS). It operates as a centre of excellence for privacy, confidentiality, and information governance expertise in relation to Health and Social Care in Scotland, providing strategic leadership and direction in this area to NHSS Boards, the research community, and wider stakeholder groups. In doing so it ensures connectivity between the many strands of relevant governance activity, and reacts to the changing landscape and research evidence regarding the public interest. The panel's focus on public awareness, concern and benefit demonstrates a commitment to the protection and promotion of privacy as a public good and in the public interest.

The HSC-PBPP has a formal mandate to scrutinise requests to use NHSS-controlled data, and the NHSCR, controlled by the Registrar General, for research, direct care, healthcare planning, audit, or other well-defined and *bona fide* purposes. Its principal focus is on what are deemed national data-sets, data from more than one NHS Board, or cases involving data from one NHS Board which are highly complex, contentious or have national implications and/or require anonymisation, linkage or matching of data, or transfers of data outside NHSS. The HSC-PBPP acts as the final arbiter of requests which fall within its remit, making a determination as to whether or not access to data can be approved. In doing so it operates both a series of technical, proportionate governance (risk) criteria (described separately), and a strategic set of guiding principles, described here. These principles and risk criteria provide a strong base for robust and legally compliant scrutiny and decision making, thus ensuring that NHSS CEO's, whose decision making is delegated to the panel, but whose legal accountability for the release of data is retained, have confidence in its operation.

The HSC-PBPP operates to fulfil three main aims:

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

Principles that guide the HSC-PBPP

In addition to the data protection and Caldicott principles, the following principles guide and inform the deliberations of the HSC-PBPP when considering applications to use NHSS-originated data:

Privacy

1. The starting point for considering any application to use NHSS-originated data is to recognise that everyone has a right to respect for their privacy.

Public interest

2. Before approving access to data, the HSC-PBPP must be satisfied that the public interest will be furthered by the proposal at hand, that there is both a demonstrable social need for such processing and a reasonable likelihood that it will result in tangible benefits for society.

Appropriate science

3. If applicants wish to process data in ways that may increase risk to privacy, then they must demonstrate that their research is scientifically-sound and ethically robust. This may be evidenced, for example, by approvals from an ethics committee and/or a scientific peer-review committee.

Consent

4. There is a general expectation that, wherever practicable, individuals should be made aware of the need to process their data, and consent obtained. Consent obtained for taking part in clinical studies is usually obtained according to the UK Research Governance Framework. This is different from specific consent to process personal or special category data, as outlined under the Data Protection Act 2018 and GDPR. But it is recognised that in some circumstances it is not possible or appropriate to obtain consent. In such circumstances, a clear explanation and justification should be given.

Transparency

5. Processing of data should fit with patients' reasonable expectations, the framework for which is set within NHSS policy and guidance. This would include privacy notice information on websites, general leaflets on confidentiality (e.g. 'How the NHS handles your personal information', available from the NHS Inform website), as well as in consent forms relevant to the processing.

Pseudonymisation or Anonymisation

6. Pseudonymising or anonymising data before release can considerably help to reduce risk to privacy. **Pseudonymised data** are data from which an individual can no longer be easily or immediately identified because information such as name or date of birth, have been removed or masked, but the identifiers are still held, and linkage can still be made back to the original person. Such data are still classed as personal data under data protection legislation. **Anonymised data** are data from which an individual can no longer be identified because information such as name or date of birth, have been removed or masked, and that link is permanently broken, so that there is no way by which any individual can be re-identified. The HSC-PBPP operates on the basis that data should be anonymised as fully as possible, consistent with their use. However, sometimes it is not appropriate to fully anonymise the data because this will interfere with legitimate processing. In such circumstances, a clear explanation and justification should be given.

Privacy impact

7. The HSC-PBPP must be satisfied that any impact on individual privacy is clearly outweighed by the public benefit resulting from the processing, and in any case is reduced to the absolute minimum necessary to achieve the outcomes of the proposal. Any likely impact on individual privacy should, therefore, be fully explained to allow a meaningful assessment of the risk.

Safeguards

8. If special safeguards are to be used to protect individual privacy, these must be described and meet acceptable standards.

Security

9. The HSC-PBPP must be satisfied that data will be held securely as long as they remain in the custody of the recipients.

Proportionality

10. Processing of data must be proportionate to the objectives. This can only be assessed on a case-by-case basis but it signals that processing should be no more than necessary to meet the social need. Relevant factors include the type and amount of information to be use or linked, and the nature and number of parties to whom it is to be disclosed. Use of data will be approved only for the purpose/s detailed in an application, and will not extend to any use for additional or secondary purposes.

Precedent

11. The HSC-PBPP will reflect on the precedents which its own past decision making, and the decision making of its antecedents (as far as these can be deemed to be relevant and in keeping with good practice and its own principles), represent, and will take these into account where they are relevant to the application at hand.

Principles to which the HSC-PBPP adheres

The following principles inform good practice in health and social care, and in public life more broadly, for all public bodies and their employees, and as such inform the way the HSC-PBPP operates:

Public Service

You have a duty to act in accordance with the core tasks and in the interests of the public body of which you are a member/employee

Selflessness

You have a duty to take decisions solely in terms of public interest. You must not act in order to gain financial or other material benefits for yourself, family or friends

Integrity

You must not place yourself under any financial, or other, obligation to any individual or organisation that might reasonably be thought to influence you in the performance of your duties

Objectivity

You must make decisions solely on merit when carrying out public business

Accountability and Stewardship

You are accountable for your decisions and actions to the public. You have a duty to consider issues on their merits, taking account of the views of others and must ensure that the public body uses its resources prudently and in accordance with the law

Openness

You have a duty to be as open as possible about your decisions and actions, giving reasons for your decisions and restricting information only when the wider public interest clearly demands

Honesty

You have a duty to act honestly. You must declare any private interests relating to your public duties and take steps to resolve any conflicts arising in a way that protects the public interest

Leadership

You have a duty to promote and support these principles by leadership and example, to maintain and strengthen the public's confidence in the integrity of the panel and its members in conducting public business

Respect

You must respect fellow members, employees and independent healthcare contractors of your public body and the role they play, treating them with courtesy at all times

Policy Decisions and Principles

A chronology of decision making in respect of the guiding principles and policy of the HSC-PBPP is recorded below.

Date	Decision	Rationale
DD/MM/YYYY	Adoption of the initial guiding principles of the HSC-PBPP	To articulate clear principles in relation to recognising and promoting the public interests in both privacy and the use of NHSScotland originated data for research, direct care, healthcare planning, audit, and other well-defined and <i>bona fide</i> purposes

Relevant Related Guidance and Information

Anonymisation
Information Commissioner's Office Anonymisation Code of Practice (2012)
Caldicott
NHSScotland Caldicott Guardians Manual (2012)
Information: To Share or Not to Share? The Information Governance Review (2013)
Community Health Index (CHI)
Scottish Government The Use of CHI to Support Integrated Care in NHSScotland (2013)
Conduct
Scottish Ministers Codes of Conduct for Ethical Standards in Public Life
NHSScotland A Common Understanding 2012: Guidance on Joint Working Between NHS Scotland and the Pharmaceutical Industry (2012)
NHS Scotland Standards of Conduct, Accountability and Openness
Standards of Business Conduct for NHS Staff (1993)
Confidentiality
NHSScotland Code of Practice on Protecting Patient Confidentiality (2012)
NHSScotland Your Health, Your Rights: Confidentiality leaflet
NHS Inform: Confidentiality
NHS Inform Confidentiality: It's Your Rights leaflet (for young people)
Information Commissioner's Office Conducting Privacy Impact Assessments Code of Practice (2014)
British Medical Association Confidentiality and Health Records guidance
General Medical Council Confidentiality guidance
Confidentiality and Security Advisory Group for Scotland, Protecting Patient Confidentiality: Final Report (2002)
Consent
NHS Inform: Consent
NHS Inform Consent – Your Rights leaflet (for young people)
British Medical Association Consent guidance
General Medical Council Consent guidance
Medical Research Council Patient Consent guidance
Data Linkage
Scottish Government Joined Up Data For Better Decisions: Guiding Principles for Data Linkage (2012)
Data Sharing
Information Commissioner's Office Data Sharing Code of Practice (2011)
Patient's Rights
NHSScotland Charter of Patient's Rights and Responsibilities (2012)
Public Engagement
NHSScotland Your Health, Your Rights: Communication and Participation leaflet
Public Interest
Information Commissioner's Office The Public Interest Test guidance (2013)
Research/Ethics
General Medical Council Research guidance
British Medical Association Requests for Disclosure of Data for Secondary Purposes (2014)
Strategy
Scottish Government Data Management Board: A Data Vision For Scotland (2014)
Health and Social Care Information Sharing Strategic Framework 2014-2020 (2014)

Relevant Legislation and Statute

[Patient Rights \(Scotland\) Act 2011](#)

Data Protection Act 2018

Common Law Duty of Confidentiality

[Access to Health Records Act 1990](#)

[Human Rights Act 1998](#)

[Ethical Standards in Public Life \(Scotland\) Act 2000](#)