



Ethical Framework to Inform Phase Two of the Expert Review of Records of Deceased Patients of Dr Watt

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Why is an ethical framework required?

The framework, which sets out principles to guide decision making, aims to ensure that Phase Two of the Expert Review is conducted in an open, transparent, sensitive and fair way.

Who developed this framework?

The framework has been developed by an Ethical Advisory Group (EAG) in partnership with the Project Team. The EAG consists of individuals who have relevant experience in the field of ethics, including via membership of bodies such as the HSC Clinical Ethics Forum and the Department of Health and Social Care's Moral and Ethical Advisory Group. The background to the Expert Review and the Terms of Reference for the EAG can be found on the RQIA website¹.

How was this framework developed?

A series of workshops were held to consider how established ethical principles could be embedded into the Expert Review.

How will this framework inform decision making?

In conducting their work, the Project Team, the EAG and third parties are obliged to apply the principles outlined in this framework. The Project Team will also be able to seek advice from the EAG.

Although legal and ethical issues are often interrelated, this framework does not address legal matters. The Project Team has access to specific legal advisors to support this Review.

Where we commission third parties to undertake work, all parties involved will be asked to follow these principles.

For those who require further guidance as to the application of these principles, the EAG will be available to provide advice where requested.

¹ Ethical Advisory Group Terms of Reference, including pen bios:

<https://www.rqia.org.uk/RQIA/files/87/87b92be5-89fc-409a-b3a1-c3b417126ebd.pdf>

Ethical Framework

Introduction

This framework sets out principles that the Project Team and the EAG are obliged to apply when conducting their work.

The principles are not intended to be a rigid set of rules but will act as a guiding framework. They will be applied throughout Phase Two of the Expert Review, taking due account of context.

The principles are:

- Respect for Persons (which includes Privacy, Confidentiality and Data Protection, and the Right to Know and the Right Not to Know)
- Transparency and Candour
- Fairness
- Responsibility

Respect for Persons

Respect for persons acknowledges that people should be treated as autonomous individuals, free to make their own decisions about how they want to participate in Phase Two of the Expert Review. In engaging with next-of-kin / family members², the Project Team should respect the choices these persons make.

To promote respect for persons, the Project Team:

- Should be thoughtful and consider when and how to engage with next-of-kin / family members and demonstrate sensitivity to the cultural differences of persons involved in the Expert Review.
- Should ensure that the voice of the next-of-kin / family members will be listened to and their contribution recorded and considered with the same significance as any other party contributing information to the Project Team.
- Should ensure psychological & bereavement support is in place for next-of-kin / family members who wish to avail of it.

² Including appointed representatives

- Should support next-of-kin / family members who lack the capacity to make decisions for themselves, to assist them in their decision-making in relation to this Expert Review.

i. Privacy, Confidentiality and Data Protection

Respect for persons also means respect for privacy and confidentiality.

Deceased patients are entitled to the same confidentiality as living patients with respect to their medical records.

To promote privacy, confidentiality and data protection, taking due account of legal requirements to disclose information in the public interest, the Project Team:

- Should be open and transparent about what organisations they share data with and why.
- Should ensure that all relevant data privacy policies and standards are observed and that data gathered during the Expert Review are used in a way that is limited to what is legally necessary³.
- Should respect and uphold requests they encounter within medical records where a patient, prior to death, has made a declaration that they wish to withhold consent from disclosure of their records to next-of-kin / family members or in general.
- Should protect deceased individuals' and next-of-kin / family members' identities by anonymising any published materials relating to this Expert Review.
- Should inform next-of-kin/ family members who are engaged with this Expert Review that they can withdraw their participation at any time without prejudice.

ii. The Right to Know and the Right Not to Know

The right to know and the right not to know is about ensuring people have the opportunity to decide the extent of information that is shared with them.

Next-of-kin / family members may wish to exercise a right to know, or a right not to know, about Expert Review findings related to relatives who are deceased patients of Dr Watt. This information may relate to their own personal health and wellbeing.

³ Legal Framework: <https://www.rqia.org.uk/RQIA/files/58/58d808ce-3c51-41a6-94d9-6edb9c0023f3.pdf>

Next-of-kin / family members will be supported in making informed decisions about the information shared with them.

To promote the right to know and right not to know, the Project Team:

- Should engage with next-of-kin / family members to understand the extent of the information they wish to receive and be open and honest about the amount of information that can legally be shared.
- Should show respect by acknowledging that next-of-kin / family members who are biological relatives may need to be informed about information that could impact their health. The Project Team will seek specific medical and ethical guidance in each individual circumstance.
- Should agree with next-of-kin / family members what information they will receive and when.
- Should inform next-of-kin / family members that there will be an option for them to receive a written summary of the assessment of the records at a later date.

Transparency and Candour

Transparency is being honest, open and visible about the decisions and actions taken and the reasons for those actions. Candour in healthcare is being actively open and honest with those involved when care has gone wrong⁴.

To promote transparency and candour, the Project Team:

- Should make publicly available as much information as possible and keep the public informed about the planning, progress and outcome of the Expert Review, so that, as required, action can be taken to enable and promote learning and improvement.
- Should be open and honest about the scope and resources available to the Expert Review, including what falls outside its remit.
- Should take into account the need to respect individuals, including their right to privacy and their right to choose not to be involved.

Fairness

Fairness is treating people equally and without prejudice or discrimination.

⁴ [Duty of Candour \(professionalstandards.org.uk\)](https://www.professionalstandards.org.uk)

Inevitably not all records are going to be included in Phase Two of the Expert Review: differences in the timeliness in which records are reviewed requires clear explanation and justification⁵.

To promote fairness, the Project Team:

- Should make clear the reasons why some records are reviewed during Phase Two of the Expert Review, while others are not.
- Should ensure when reviewing deceased patients' records that the approach undertaken is without bias or preconception.

Responsibility

Responsibility is shown by fulfilling duties and being accountable for your actions.

This Expert Review is focussed on reviewing the records of selected deceased patients to identify any lessons. The Project Team should share this framework with all relevant parties and advise and offer guidance. The Project Team will be responsible for considering all findings, including responding to and, when appropriate, sharing information with other organisations.

To promote responsibility, the Project Team:

- Should use a rigorous and systematic approach in the Expert Review to achieve its objectives.
- Should share information with other organisations in a way that is appropriate and in line with public interest, including the public inquiry.

Other Ethical Issues Not Outlined In These Principles

Additional, specific ethical issues that are not encompassed within the framework may be encountered. In the event that any such issues arise, the Project Team will seek guidance from the EAG. If required, the Project Team will, as far as possible, seek consensus with the guidance of experts.

Any comments you may have on the content of this document and how it can be improved will be considered in future versions of the framework. Please send feedback to expert.review@rqia.org.uk

⁵ <https://www.legislation.gov.uk/ukpga/1998/47/section/75>