

EXPERT REVIEW OF RECORDS OF DECEASED PATIENTS OF DR WATT

Ethical Advisory Group (EAG) Terms of Reference

BACKGROUND TO THE EXPERT REVIEW

1. On 01 May 2018, Belfast Health and Social Care Trust (Belfast Trust) announced a recall of 2,500 patients in the context of concerns regarding the clinical practice of Dr Watt, Consultant Neurologist. As of December 2020, there have been two cohorts of patients recalled by the Belfast Trust and the recall of a third cohort of patients was under consideration. The first cohort saw the recall of 2,358 patients who were actively under the care of Dr Watt. The second cohort saw the recall of 867 patients who were under the care of and subsequently discharged by Dr Watt between 01 April 2012 and 30 June 2017.
2. On 02 May 2018, the Permanent Secretary of the Department of Health issued a statement on the patient recall. In a system-wide response, the Regulation & Quality Improvement Authority (RQIA) was directed to undertake ‘a Review of the governance arrangements of outpatient services in the Belfast Trust, with a particular focus on Neurology and other high-volume specialties’ and ‘a Review of Governance Arrangements in Independent (Private) Hospitals in Northern Ireland’.
3. The Permanent Secretary’s statement also directed RQIA to “*commission a parallel piece of work to ensure that the records of all patients or former patients of Dr Watt who have died over the past ten years are subject to expert review*”. On 10 May 2018 RQIA received further detailed terms of reference which included a direction to “*commission an expert review of the records of all patients (current and former) of Dr Watt who have died over the last ten years to include deaths from more than ten years ago if concerns identified during this process indicating further retrospective review required*” (the Expert Review).
4. In parallel, on 10 May 2018, the Department of Health announced the establishment of an Independent Neurology Inquiry (INI) to be chaired by Mr Brett Lockhart, Queen’s Counsel (QC). Subsequently, on 11 December 2020, this Inquiry was converted to a statutory public inquiry. Terms of Reference for the latter can be viewed on the inquiries website¹.

LEGAL CONTEXT

5. The legal context under which RQIA operates is detailed in the **Legal Framework** for the Expert Review.

¹<https://neurologyinquiry.org.uk/sites/ini/files/media-files/Independent%20Neurology%20Inquiry%20Terms%20of%20Reference%2011-12-%202020.pdf>

PROPOSAL FOR CONDUCTING THE EXPERT REVIEW

6. It is estimated that in the 10-year period prior to May 2018, there may be over 3000 deceased patients who, at some point in their lives, had been under the care of Dr Watt. Reviewing the care of all these deceased patients will require significant time and resource. To derive learning as early as possible, consideration had to be given to the most efficient methodology for executing the Expert Review.
7. The Department of Health approved RQIA's proposal to adopt a multi-phased approach to the Expert Review.

PHASE ONE OF THE EXPERT REVIEW

8. Phase One, which was a preparatory phase, concluded in November 2020 with the formal adoption of a Legal Framework to ensure access to the relevant records. This Framework was agreed and signed by the Chief Executives of all required Health and Social Care (HSC) bodies:
 - Regulation and Quality Improvement Authority
 - Health and Social Care Board
 - Public Health Agency
 - Business Services Organisation
 - Belfast Health and Social Care Trust
 - South Eastern Health and Social Care Trust
 - Southern Health and Social Care Trust
 - Northern Health and Social Care Trust
 - Western Health and Social Care Trust

PHASE TWO OF THE EXPERT REVIEW

9. RQIA has established a Project Team structure to develop and implement a number of work streams during the course of Phase Two of the Expert Review, in accordance with the following objectives:
 - i. Obtain and validate a dataset of all patients who died during the 10-year period prior to May 2018 (the Defined Period).
 - ii. Identify individual deceased patients whose records will be reviewed during Phase Two of the Review, clearly setting out the rationale for this selection.
 - iii. Obtain and validate a dataset of the patients whose records have been selected for review during Phase Two.
 - iv. Take reasonable steps to contact the next-of-kin or family members of the deceased patients whose records have been selected for review during Phase Two, to provide an opportunity to share their experiences and for RQIA to make available support where needed.
 - v. Commission an external Expert Panel to review the records selected for Phase Two and to consider any information shared with RQIA by next-of-kin or family members.
 - vi. Produce a report on the findings of the expert review, including identifying learning and making any such recommendations considered necessary to the Department of Health.

FUTURE PHASES

10. The specific plans for future phases of the Expert Review will be informed by the outcomes of Phase Two and in agreement with the Department of Health.

PURPOSE OF THE ETHICAL ADVISORY GROUP TO THE EXPERT REVIEW

11. The Ethical Advisory Group will fulfil two functions. First, it will develop an ethical framework to support decision making throughout Phase Two of the Expert Review. Second, throughout Phase Two, it will offer advice on any ethical implications regarding:
 - The methodology for assessment of patient records;
 - The strategy for next-of-kin / family member engagement and involvement;
 - The communication plan;
 - The methods of sharing information and outcomes from the Expert Review; and
 - Any other relevant issues that may arise.
12. The Ethical Advisory Group's alignment within the overall structure of Phase Two is illustrated in Appendix 1.

MEMBERSHIP OF THE ETHICAL ADVISORY GROUP AND ATTENDANCE AT MEETINGS

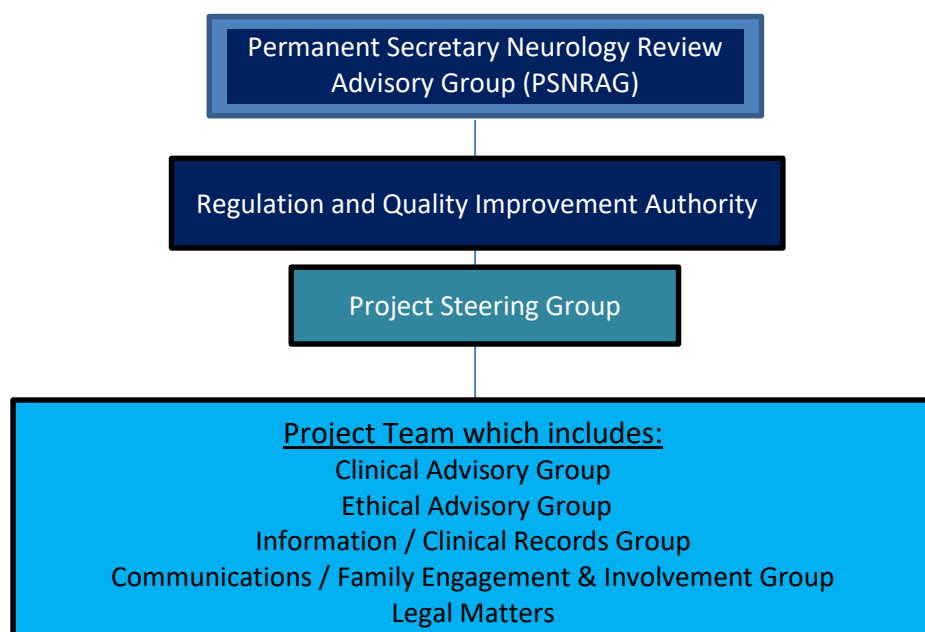
13. The Ethical Advisory Group will comprise individuals with expertise in the assessment of ethical issues. Its members are outlined in Appendix 2.
14. The Ethical Advisory Group will nominate a Chair, and in the absence of the Chair at meetings, another member will be agreed by the group as Chair of the meeting.
15. When a member of the Group cannot attend a meeting, a minimum of four members may convene a meeting, in accordance with point 14.
16. Members who are absent from a meeting will be provided with an update on matters discussed via a note of the meeting and through discussion with the Chair.
17. Members will make themselves available to attend other RQIA meetings related to the Expert Review to provide relevant information or advice.
18. If required, members of other RQIA work streams related to Phase Two will make themselves available to attend Ethical Advisory Group meetings to provide information or advice.
19. The Ethical Advisory Group will initially meet to develop an ethical framework to support decision making throughout Phase Two of the Expert Review. Thereafter, the Group will meet at least once every three months, or more often, as required during Phase Two, to provide ethical advice. Meetings may be conducted virtually or in person.

OTHER MATTERS

20. An agenda for Ethical Advisory Group meetings, save in exceptional circumstances, will be circulated to members at least five working days before each meeting and password protected supporting papers, wherever possible, will accompany the agenda.

21. Members of the Group will be asked to declare any potential conflict of interest at each meeting, or earlier if they deem it appropriate.
22. A member of the Expert Review Project Team will attend the Ethical Advisory Group meetings to make a note of the discussions. The note will be approved by the Group.
23. A summary update relating to discussions at Group meetings will be published on RQIA's Neurology Review website.
24. Members of the Group will direct all requests for information about the work of the Expert Review to the Chair, unless this information is already publicly available.
25. The Group will be kept informed of any issues raised by the public or their representatives in relation to the Expert Review by the Chair at Group meetings.
26. These Terms of Reference relate specifically to Phase Two of the Expert Review and will be reviewed and further developed at key milestones as the Expert Review progresses.

EXPERT REVIEW PHASE TWO STRUCTURE



MEMBERSHIP

PSNRAG

Richard Pengelly, Permanent Secretary for Northern Ireland (Chair) and representatives from:

- Department of Health (DoH)
- Health & Social Care Board (HSCB)
- Public Health Agency (PHA)
- Belfast Health & Social Care Trust (BHSCT)
- Regulation & Quality Improvement Authority (RQIA)

Steering Group

- Emer Hopkins, Interim Director of Improvement, RQIA (Co-Chair and SRO)
- Professor Aneez Esmail, Clinical Advisor, University of Manchester (Co-Chair)
- Lynn Long, Interim Deputy Director of Improvement, RQIA
- David Galloway, Northern Ireland Neurological Charities Alliance
- Brian O'Hagan, IHRD Duty of Candour Work Stream, Chair of the Service User and Carer Liaison Group, and Chair of the Inquiry into Hyponatraemia Related Deaths (IHRD)
- Stuart Elborn, RQIA Board Member
- Jacqueline McGarvey, RQIA Board Member

Project Team – includes representatives from each of the working groups

- Linda Rafferty, Interim Project Lead, RQIA
- Jim McIlroy, Project Manager, RQIA
- David McCann, Assistant Director of Improvement, RQIA
- Dr Leanne Morgan, Clinical Lead, RQIA
- Dr Dermot Hughes, Clinical Advisor, Associate Consultant, Health and Social Care Leadership Centre (HSCLC)
- Rachel Stewart, Information & Intelligence Manager, RQIA
- Malachy Finnegan, Communications Manager, RQIA
- Caroline Hannan, Solicitor Consultant, Directorate of Legal Services (DLS)
- Robert Mercer, Regional Clinical Auditor Facilitator, RQIA
- Richard Gamble, Research Analyst, RQIA
- Jacqui Murphy, Head of Business Support Unit, RQIA

Clinical Advisory Group

- Professor Aneez Esmail, Clinical Advisor (Chair)
- Professor Richard Baker, Clinical Advisor
- Dr Dermot Hughes, Clinical Advisor, Associate Consultant, HSCLC
- Dr Leanne Morgan, Clinical Lead, RQIA

Ethics Advisory Group

- Professor Therese Murphy, Queen's University, Belfast (QUB) Law and Ethics
- Professor Hugh McKenna, Ulster University (UU) Nursing, member of Western Health & Social Care Trust (WHST) Clinical Ethics Committee
- Dr Ciaran Mulholland, Psychiatrist, member of Northern Health & Social Care Trust (NHSCT) Clinical Ethics Committee
- Brian O'Hagan, sits on the IHRD Duty of Candour Work Stream and Chairs the Service User and Carer Liaison Group Chair Inquiry into Hyponatraemia Related Deaths (IHRD)
- Dr Charlotte Blease, Beth Israel Deaconess Medical Center, Harvard Medical School

Information / Clinical Records

- Rachel Stewart, Information & Intelligence Manager, RQIA and Lead Officer for the Expert Review's Informatics requirements
- James McIlroy, Project Manager, RQIA and Lead Officer for the Expert Review's Clinical Records requirements
- Other contributors as required

Communications / Family Engagement & Involvement Group

- Malachy Finnegan, Communications Manager, RQIA and Lead Officer for the Expert Review's Communications requirements (Co-Chair)
- Linda Rafferty, Interim Project Lead, RQIA (Co-Chair)
- Dr Dermot Hughes, Clinical Advisor, Family Liaison Team
- Dr Leanne Morgan, Clinical Lead, Family Liaison Team
- Dr Nichola Rooney, Clinical Consultant Psychologist, Professional Advisor to the Family Liaison Team
- Robert Mercer, Family Liaison Team, RQIA
- Richard Gamble, Family Liaison Team, RQIA

ETHICAL ADVISORY GROUP MEMBERS

Emer Hopkins - Chair and Senior Responsible Officer

Emer is currently Interim Director of Improvement for RQIA holding corporate responsibility for the delivery of RQIA review programmes in addition to overseeing RQIA's Assurance and Improvement roles across Health and Social Care and Independent Healthcare. Emer is a Neurological Physiotherapist by professional background and joined RQIA in February 2019.

Charlotte Blease

Charlotte is a Keane OpenNotes Scholar at the Division of General Medicine and Primary Care, Beth Israel Deaconess Medical Center, Harvard Medical School where she has been based since 2017. Charlotte has extensive experience in clinical ethics.

Hugh P. McKenna

Hugh is a general and psychiatric nurse by background and until recently was Dean of Medical School Development and Pro Vice Chancellor (Research and Innovation) at Ulster University. Hugh is a member of the Northern Ireland HSC Clinical Ethics Forum.

Ciaran Mulholland

Ciaran is a Consultant Psychiatrist with the Northern Health and Social Care Trust, a Senior Lecturer in the Centre for Medical Education at Queen's University Belfast and Visiting Professor to the Bamford Centre for Mental Health at the University of Ulster. Ciaran is a member of the Northern Ireland HSC Clinical Ethics Forum.

Thérèse Murphy

Thérèse is Professor of Law and Director of the Health & Human Rights Unit at Queen's University Belfast. Thérèse also sits on the Department of Health and Social Care's Moral and Ethical Advisory Group.

Brian O'Hagan

Brian has extensive experience working with healthcare from a service user and carer perspective. He is a member of the Minister for Health's Transformation Advisory Board (TAB), and a member of the Inquiry into the Hyponatraemia Related Deaths (IHRD), Duty of Candour Work Stream. Brian chairs the IHRD Service User and Carer Liaison Group, (SUCLG) and is a member of the Northern Ireland HSC Clinical Ethics Forum.