

EXPERT REVIEW OF RECORDS OF DECEASED PATIENTS OF DR WATT

MINUTES OF PHASE THREE STEERING GROUP MEETING

Meeting 1 - Held on Wednesday 11 September 2024 at 13.30 Via MS Teams

Members:	Dr Nazia Latif Dr Ian Steele Mrs Lynn Long Mr Brian O'Hagan Mr Ray Martin Mr Stewart Finn	RQIA Authority Board RQIA Medical Lead RQIA Director / SRO Ethical Advisor / PPI Lay Representative Director of MS Society / Vice Chair of NINCA
In Attendance:	Mrs Linda Rafferty Dr Leanne Morgan Mr Malachy Finnegan Mr Sean Green	Project Lead Clinical Lead Senior Communications Manager Project Support Officer (taking minutes)
Apology:	Professor Stuart Elborn	RQIA Authority Board

1.0 Welcome, Introductions and Apologies

Mrs Long welcomed members to the meeting, noted apology for Professor Elborn and invited introductions and a brief overview of professional backgrounds.

1.1 Declaration of Interests

No conflicts of interest declared. Declaration of interests to be included as a standing item on future agendas.

Action: Members to complete Declaration of Interests form and submit via email to Mrs Rafferty for record purposes.

2.0 Background and Context

Dr Morgan provided the following overview of the background and context of Phase Three of the Expert Review:

- Work to support improvement across the HSC system, through the delivery of legacy commitments, has been ongoing since the publication of RQIA's overarching report on Phase Two in November 2022. A paper on progress to date is to be published on the RQIA website in coming weeks.
- Following publication of the Phase Two report, an independent evaluation of Phase Two families' experience of the review process was undertaken. Seventeen family members participated. Although approximately 50% of participants were content with the review process and outcome along with the support offered, a significant proportion reported that their individual case summary report did not meet their expectations. Furthermore, some family members outlined the traumatic and distressing nature of a protracted review process that involved recalling painful memories of their loved one's care, treatment and death.

- These important ethical considerations were discussed at a meeting of the Permanent Secretary Neurology Response Advisory Group (PSNRAG) in February 2023. It was decided to seek advice on options for a further phase from the Regional Ethics Committee (REC), who recommended that families actively seeking information about their loved one's care and treatment should be offered the opportunity to participate in a clinical record review process, if having been fully informed of its benefits and limitations, a record review is considered to be in their best interests.
- Following advice from the REC and subsequent direction from the Department of Health (DoH), RQIA undertook an engagement exercise with families who had contacted RQIA to express an interest in participating in a further phase of the Expert Review. The purpose of this engagement was to ascertain expectations and to provide open and honest information about the Expert Review process, its benefits and limitations, and alternative options available. A suite of information materials was provided to the 18 families who participated in the engagement. All confirmed they wished to participate in a further phase of the Expert Review.
- A written ministerial statement (WMS) released on 03 July 2024 included a direction for RQIA to commission the undertaking of a further phase of the Expert Review. The primary purpose being to provide the opportunity to impart answers, if possible, to the families in respect of the quality of care and treatment provided to their deceased relatives.
- The WMS included a deadline of 31 December 2024 for any further families of deceased patients of Dr Watt who wish to explore involvement with the deceased patients review, to contact RQIA.
- A formal project structure has been established, including the Steering Group, to take forward Phase Three of the Expert Review.

2.1 Steering Group Terms of Reference (ToR)

Members discussed the draft ToR document. Mr Martin commented that the starting point for Phase Three is different from Phase Two, given the lessons learned, and recommended this should be referenced in the ToR, particularly in terms of providing the 18 families with realistic expectations regarding the outcomes of Phase Three.

Mr O'Hagan agreed that this was a very good point. He also advised that he would provide an updated description of his professional background for the ToR.

Action: ToR to be amended to reference the lessons learned from Phase 2.

Action: Mr O'Hagan to provide an updated description of his professional background for the ToR.

3.0 Highlight Report

Mrs Rafferty asked if members found the Highlight Report beneficial, and invited views regarding additional information to include in future reports.

Mr Martin suggested sharing the Highlight Report with Phase Three families.

Mr Finnegan commented that the Highlight Report is invaluable, and could be utilised by the Communications Team when developing updates for the RQIA website.

Dr Steele requested more information regarding the Royal College of Physicians (RCP) plans to meet with Phase Three families, and whether this would be conducted virtually or in person.

Mrs Rafferty advised that the families will be given the opportunity to meet, virtually, with the Expert Review Panel, in addition to receiving a final report of the overall findings of the Expert Review, and individual case summary reports. These milestones will be facilitated by the Family Liaison Team (FLT) in accordance with the preferences of each individual family. Mrs Rafferty further advised that the individual case summary reports will be more sensitively worded, i.e. terminology such as Upheld, Partially Upheld and Not Upheld will not be used.

4.0 Family Engagement and Involvement Plan

Dr Morgan referred to the draft Family Engagement and Involvement Plan. She advised that Phase Three would mirror Phase Two, in that family wishes and preferences regarding engagement will be respected. The FLT will work to manage expectations, provide updates at significant junctures and enhance support at critical times through referrals to Inspire Wellbeing and to the Patient and Client Council (PCC) for advocacy support.

Dr Morgan advised that managing family expectations would include ensuring that families are aware of, for example, timescales for the RCP to complete quality assurance and factual accuracy checks of the Phase Three report on findings, which can take a considerable amount of time to complete. Monthly updates to families will include an estimate of each stage of the Expert Review process and its progress.

Dr Morgan confirmed that lessons learned from Phase Two, such as Dr Watt's poor record keeping, were covered during engagement with individual families, as part of the FLT pre-engagement scoping exercise November 2023 - January 2024.

5.0 Ethical Framework

Mrs Rafferty advised that the Ethical Advisory Group, established for Phase Two of the Expert Review, produced an **Ethical Framework to inform Phase Two of the Expert Review of Records of Deceased Patients of Dr Watt**. This Framework is currently on the Neurology section of RQIA's website. Mrs Rafferty proposed that the Framework equally applies to Phase Three and asked if members would be supportive of the document being amended to remove the reference to Phase Two. Members agreed to this proposal.

Dr Latif recommended the Framework should be reviewed/amended to ensure it includes the following:

- The protection of human rights and dignity, to include for the deceased patients;
- Keeping people informed and involved;
- Consider accessibility; information should be clear and any disabilities catered for;
- Individual needs i.e. fairness, treating everyone equally;
- The avoidance of jargon, i.e. medical and legal terms;
- Accountability e.g. how to make a complaint.

Dr Morgan commented that these are all valid points.

Action: Dr Morgan to engage with Dr Latif, Mr O'Hagan, who was a member of the Phase Two Ethical Advisory Group, and Mr Martin, whilst conducting a review of the Ethical Framework.

6.0 Communication & Stakeholder Engagement Plan

Mr Finnegan referred to the draft Communication & Stakeholder Engagement Plan. He advised that the plan will remain as a live document that may evolve as Phase Three progresses. He further advised that the approach to communication for Phase Three would mirror that of Phase Two, albeit in consideration of lessons learned from Phase Two.

Members discussed the issue of raising public awareness regarding the Health Minister's deadline of 31 December 2024 for families to contact RQIA. It was recognised that the Minister's statement on 03 July may have went unnoticed by families due to the time of year/eve of election.

Mr O'Hagan commented that families may approach RQIA in general, not knowing if their deceased relative was ever under Dr Watt's care. Mrs Rafferty advised that this can be managed by checking the overall deceased patient data set, NIECR and engagement with trust senior record managers, in order to advise families in a timely manner.

Mr Martin stressed the importance of considering the expectations of those families who come forward in terms of the degree to which they wish to be involved in the process. He referred to his own lived experience of participation in Phase Two of the Expert Review, advising that in his opinion there are three broad groups:

1. Those who are fearful of what the findings might uncover;
2. Those who are hopeful they will receive good news;
3. Those who want answers, regardless of whether the findings are good or bad.

Following discussion, it was agreed that the Communications Team would develop a flyer for distributing to attendees at the NICON conference on 16 October 2024. Mr O'Hagan suggested the PCC newsletter would be a good option for raising awareness, and Dr Latif suggested the creation of a short video.

Mrs Long requested the development of an options paper regarding raising awareness, for consideration by the Steering Group.

Action: Communications Team to develop a flyer for distributing at the NICON conference.

Action: Options paper to be developed for consideration by the Steering Group.

7.0 Key Risks

Mrs Rafferty advised that two risks are currently open on the Expert Review Risk Register:

1. There is a risk of damage to the reputation of the Expert Review and to RQIA, in the event of failure to meet the expectations of families who opted to engage with RQIA in relation to Phase Three of the Expert Review.
2. There is a risk of damage to the reputation of the Expert Review and to RQIA, due to the submission of a Pre-Action Proceeding Letter for Judicial Review, in respect of the Ministerial announcement on 3 July regarding DPR next steps and future approach.

Mr Finn advised that a further risk should be opened in relation to the potential of RQIA receiving a large influx of approaches from bereaved families up to the Health Minister's deadline of 31 December 2024, and the impact this may have on the DoH and Ministerial decisions regarding the future approach to the Expert Review.

Dr Morgan confirmed that the FLT have been monitoring the number of approaches from new families since the Minister's statement on 03 July 2024, and keep the DoH updated in this regard. To date, eight families have approached RQIA wishing to explore involvement in the Expert Review.

Action: Mrs Rafferty to open further risk.

8.0 Budget

Mrs Rafferty confirmed that a business case to take forward Phase Three of the Expert Review has been approved by DoH and the requested funding allocated. Monitoring of budget spend is ongoing.

9.0 Any Other Business

None

10.0 Schedule of Meetings

Date of next meeting to be arranged

11.0 Close

Mrs Rafferty thanked everyone for attending and for their valuable contribution to the meeting.