



The **Regulation** and
Quality Improvement
Authority

Report on the Expert Review of Records of Deceased Patients (Neurology)

November 2022

PREFACE

At the direction of the Department of Health, in August 2021, RQIA commissioned the Royal College of Physicians to undertake an expert review of the clinical records of certain deceased patients who had been under the care of Dr Watt, with the intention to understand his clinical practice, to ensure learning for others and to help make care better and safer in the future. Much has been learned through the record review alone, but this has been greatly enriched by the direct involvement by families of the deceased patients with RQIA.

As citizens, we all place our trust in our health and social care system and expect it to deliver the best possible outcomes for us. When this goes wrong, we rightly expect open and honest explanations to why and how that situation occurred. No review process, no matter how rigorous, can make up for the impact that poor care and a lack of openness can have on individual patients and family members involved. RQIA commends the courage and openness of all those families who came forward to engage in this review. RQIA acknowledges that this process has been difficult and may not have produced the outcome sought by some of the families involved. RQIA has used the very honest feedback given during this review to help shape its work, with a particular focus on how and when RQIA will engage with individuals and families in any similar processes in the future. Family accounts starkly illustrate how failings by the individual practitioner, and by the system, led to deep human impacts and resulting harm, both to the deceased patients and to their bereaved families.

Failings in health and social care services are often reported first by patients and families. It has often been patients and families who have identified the issues and “raised the red flag”. Unfortunately systems are sometimes slow to respond. As a result of family engagement, RQIA will ensure that during its future inspection and review work it will test how well patients, families, and staff are being listened to, particularly when raising concerns.

RQIA hopes that the families involved feel they have been able to be open and direct in this review process and can draw comfort from the knowledge that their engagement has helped shape how RQIA will approach inspections and reviews in the future. Family engagement with RQIA has underlined that the voice of the patient and family needs to be listened to and respected, their concerns captured, and that they have the same standing as any professional contributing information to an inspection or review process.

RQIA understands that for many of the families this has been a distressing and painful experience. This has been an exceptionally difficult process, and although some families have been disappointed with aspects of the review, RQIA sincerely thanks every family for their patience, their personal commitment and the invaluable contribution they have made on behalf of their loved ones.

The RQIA has reflected on the expert panel's findings from their review of the clinical records, and their assessment of the clinical harm that may have resulted from the care and treatment received. The RQIA has also reflected on the testimony of the families, both in their written statements to the expert panel and in their engagement with the RQIA's Family Liaison Team.

The importance of a genuine focus on "Patient Centred Care" is crystal clear. Good communication, hearing the patient, respecting what they say, analysing information that along with clinical observations and working in partnerships with others across a multi-disciplinary team is key to timely and accurate diagnosis, and to establishing a robust care plan. It is well understood that this is the gateway to far more than a clinical treatment pathway or even the appropriate involvement of multidisciplinary support in daily life.

It is widely understood and accepted that accurate and timely diagnosis enables connection with appropriate support networks. It helps remove stigma; and allows patients and their families to work in an informed way, planning for their future, recognising whatever that future may hold.

Without good communication, timely and accurate diagnosis and co-ordinated multidisciplinary patient/family centred care, harm can readily be caused to the patient and to their family. Communication, both within and between clinical circles, and with patients and families must be improved. Genuine, multidisciplinary "Patient and Family Centred Care" must be made a reality to protect the dignity and human rights of patients and their families, and promote the best outcomes possible in difficult circumstances.

RQIA will work in partnership with patients and families, and with service providers, to achieve this.



Christine Collins MBE

Chair

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1. Introduction and Context

On 2 May 2018 the Permanent Secretary of the Department of Health, in announcing an RQIA review of the governance arrangements of outpatient services in the Belfast Trust¹, also announced that RQIA would commission an expert review of the records of all patients of Dr Watt who had died in the preceding ten years (2008–2018).

On 10 May 2018 the Department announced the establishment of a separate Independent Inquiry (converted to a Public Inquiry in December 2020) under the Chairmanship of Brett Lockhart QC² (*since published on 21 June 2022*).

Separate to this Public Inquiry, and underpinning the Permanent Secretary's 2 May 2018 announcement, the Chief Medical Officer, Dr Michael McBride issued a formal direction to the RQIA 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*".

At the request of the Department of Health RQIA commenced a phased approach to the review of records of deceased patients. RQIA had first to undertake significant planning and preparatory work. This included the development of a legal framework to enable RQIA to gain access to the tightly controlled clinical records of deceased patients, the development of operational protocols to ensure the safe management of those clinical records, the establishment of a staff team and the negotiation of a contract with the Royal College of Physicians

In August 2021, RQIA commissioned the Royal College of Physicians (RCP) to undertake the expert review of the deceased patients records.

The clinical records of deceased patients were reviewed twice: firstly without the accompanying family information; and a second time with the family information provided, where it was available. Where family information was available, the expert panel was asked to make a judgement on whether family concerns were evidenced or 'upheld' by the clinical records.

The final reports of this work were received by RQIA in June 2022. These reports covered the review of two groups of patients' records (45 patients in total). The first group consisted of 29 deceased patients whose families contacted the RQIA with concerns about their care and treatment; the second group consisted of 16 patients who died during the course of the live patient recall, undertaken by the Belfast HSC Trust, before their reassessment could be undertaken. These two groups are referred to as Cohort 1 and Cohort 2.

[One patient in the original 45 patients was excluded by RCP as no evidence could be found in their records of Dr Watt's involvement in their care. As a result 44 records were finally included in the review.]

Throughout this, a personalised programme of family engagement was undertaken by a dedicated Family Liaison Team established by RQIA. Team members included RQIA's Clinical Lead; a highly experienced external clinical advisor; a clinical psychologist who provides sessional support to RQIA; and the project lead supported by a family liaison support officer.

The Review's Ethical Advisory Group developed an ethical framework, and RQIA developed an Involvement Framework, to help guide this family engagement work.

2. The Expert Review: Methodology, Strengths and Limitations of a Clinical Record Review

The expert panel were tasked to review the clinical records and to produce an overarching report for each Cohort, as well as individual summaries for each patient. They have told RQIA that they regarded it as both a privilege and a challenge to have undertaken this work.

They developed a robust process ("Structured Judgement Review") to undertake the review of the clinical records provided to them.

This used a reliable, well validated tool which is widely used by independent experts to assess the quality of care and treatment, according to the clinical standards at the time the treatment was provided. The approach requires expert reviewers to make safety and quality judgements on particulars of care, to make explicit written comments, and to make a judgement on the quality of care at each phase of the patient journey. This produces a rich set of information about each case in a form that can be brought together to produce valuable learning.

Although the review of clinical records was robustly and diligently undertaken, it is by its nature limited because:

- The expert panel had access only to the clinical records of the deceased patients; they did not have direct contact with other records or with people/staff who had knowledge of the particular record/patient.
- Many of the records were found by the expert panel to be very limited and may have contained significant omissions.

In some (but not all) cases the record review was supplemented by accounts volunteered by some families. Although the expert panel did not have the privilege of direct contact with families that RQIA had, they reported being deeply saddened by the accounts provided by families and the care outlined in the clinical records.

Some families will be disappointed that the individual case summary does not cover every detail of the engagement by Dr Watt with their family member. By its nature, the expert panel, which could only examine the clinical records, and take account of family input, could not answer all questions families had, or reach a definitive finding in each individual case. It was not within the remit of the expert panel to interview other staff or conduct any deeper investigation into specific events. Nonetheless, the evidence it has collated, and the overall professional judgements it has reached, are powerful and compelling. The findings provide a rich analysis of the contributors to the failure of care and deliver recommendations to prevent such events happening again.

These findings enable actions to be identified to improve the safety and quality of services. RQIA is committed to doing all it can to make sure this happens, and trust that this will offer some support to families who have contributed so much to this process.

3. The Findings and Impact

The expert panel have studied the clinical records available to them, and where available, family accounts. Their findings and recommendations point to specific actions that are needed to address individual cases and conditions, as well as systemic issues. The findings highlight the need for effective communication between clinicians and their patients, and for clinicians and their practice to be subject to and supported by multidisciplinary and team working.

RQIA has also had direct access to many of the families involved and been privileged to hear direct accounts of the experience of their loved one, and of the family and of the impact on them.

These accounts starkly illustrate how failings by the individual practitioner and by the system led to deep human impacts and resulting harm, both to the deceased patients and to their bereaved families.

RQIA recognises that families have endured significant additional distress through involvement in this review process, not least because they have had to recall, re-tell and re-live their loved one's treatment and death. This distress has been exacerbated by the additional worry and anxiety caused by the necessarily protracted process for the individual reports to be made available and for the publication of the overall Report. RQIA deeply regrets this.

Now that this Report is completed, it is the responsibility of all involved in the planning, commissioning and delivery of health services to ensure that shortcomings are identified, and remedial action is taken.

4. Making Care Safer

Patients and families expect care to be safe, and expect to be treated with dignity. They must be respected and have their experience and views captured, and action taken when they raise concerns. The expert panel has provided RQIA with the two separate Cohort reports which outline the findings of their clinical review of the records, and identify key points regarding the clinical management of these patients.

These reports identify:

- Poor practice including a lack of proper clinical investigation;
- Inaccurate diagnosis;
- Poor prescribing practices;
- Poor record keeping;
- Lack of openness and effective communication;
- Inappropriate treatment;
- The risks of clinicians working in isolation.

The expert panel has made specific recommendations for RQIA including:

- Ensuring that patients have direct access to doctors' letters;
- Ensuring proper multidisciplinary team working;
- Tackling isolation in clinicians working alone

These important recommendations are at the heart of addressing the failings of the care and treatment provided. Clinicians must be supported to adopt good practice, especially in using up to date best practice routes to diagnosis and treatments. They should be encouraged and facilitated to seek the support of peers and others to challenge and review their analysis and thinking.

These are issues, not only for neurology services, but throughout the health and social care system.

As Northern Ireland's independent health and social care regulator, RQIA will use its role and powers to ensure the effective delivery of these recommendations.

RQIA will:

- Monitor and evaluate the Belfast Health and Social Care Trust's implementation of this work through its continued programme of service inspections and reviews;
- Respond appropriately to the findings of individual complaint investigations notified to it by patients, families, or victims.

As these recommendations are not limited to the Belfast HSC Trust, or to neurology as a speciality, through its inspection and review programme **RQIA will:**

- consider and evaluate evidence that each of the Health and Social Care Trusts
 - Takes account of the recommendations from this Review, and
 - Can evidence actions taken to act on them.

RQIA believes that it is important that all health service providers, policy makers, service commissioners, clinicians, managers, and healthcare staff are aware of the types of poor practices identified in these reports and in the accounts of families; and understand how these poor practices can have devastating consequences.

So, in addition to taking the actions set out above, RQIA intends to take forward further work to address the strategic issues identified in the findings of the Review, and have lasting impact.

RQIA will:

- Share these finding with current practising clinicians, through identifying existing networks, through Trusts and professional bodies, and encourage collaboration, reflection, peer support and collective actions to ensure poor practices are recognised and addressed.
- Influence the training and development of health care professionals; so that as part of that training and development, the importance of compliance with clinical standards and guidelines, and of effective communication with patients, openness and active listening to capture their concerns is made obvious.
- Strengthen how it reviews and inspects services to ensure that the level of scrutiny of clinical practice, and of adherence to clinical standards, is evaluated.
- Strengthen the assessment of a safety culture, particularly around evidence of listening to patients and families, and evidence that staff feel safe to challenge each other and raise concerns.
- Require improvements if there is evidence of substandard systems, or poor culture or care.
- Use its position as independent regulator to support the adoption of openness and candour across all services, especially when reporting that care has gone wrong.

RQIA will monitor and report on progress against these commitments, both in individual reports on services and in its annual report. RQIA hopes this may provide a legacy for families, both those who have been directly involved in the review process and those who have not, and ultimately to make services safer for all.

5. References

1. RQIA Review of The Governance Arrangements of Outpatients Services in the Belfast HSC Trust with a Focus on Neurology Services and Other High Volume Specialities, RQIA, February 2020. Available at: https://www.rqia.org.uk/RQIA/media/RQIA/Neurology/Review_of_BHSCT_Outpatients_Service_February_2020.pdf (Accessed 20 November 2022)
2. Report of the Independent Neurology Inquiry, June 2021, Available at <https://www.neurologyinquiry.org.uk>, (Accessed 20 November 2022)



Invited Reviews

Report of the clinical
record review for

Regulation and Quality
Improvement Authority
(RQIA)

Cohort 1

This report is the property of the healthcare
organisation responsible for the commission
of this invited review

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This report has been prepared by the Royal College of Physicians (RCP), with the support of the Association of British Neurologists, under the RCP Invited Reviews (IRs) mechanism for submission to the healthcare organisation that commissioned the invited review. It is an advisory document, and it is for the healthcare organisation concerned to consider any conclusions and recommendations reached and to determine subsequent action.

It is the responsibility of the healthcare organisation to review the content of this report and take any action that is considered appropriate to protect patient safety. The healthcare organisation should ensure that patients have received communication in line with the responsibilities set out in the Health and Social Care Act 2008 (Regulated activities) Regulations 2014, Regulation 20.¹

The Regulation and Quality Improvement Authority (RQIA) has anonymised the case numbers in this report to protect the identity of individual patients.

1 Executive summary

This is the first of two linked reviews commissioned by the Regulation and Quality Improvement Authority (RQIA), which is the independent body responsible for monitoring and inspecting the availability and quality of health and social care services in Northern Ireland, and encouraging improvements in the quality of those services. The review arises from a recall, in 2018, of 2,500 outpatients patients who had been under the care of a specific consultant neurologist, referred to throughout this report as Dr Y. The recall was instigated by the Belfast Health and Social Care Trust ('the Trust'), where Dr Y had worked until mid-2017, following the Trust's internal review process and subsequent request to the RCP to review a series of patients who had been under his care. Patients who had consulted Dr Y privately were also included in the recall.

In May 2018, the Permanent Secretary in Northern Ireland requested that the RQIA should conduct an expert review of clinical records of all patients or former patients of Dr Y in the preceding 10 years. The RQIA planned to undertake this review in a staged process to maximise learning. The first stage, which is documented in this report, was to review the clinical records of 29 deceased patients identified by the RQIA following concerns raised by relatives of the deceased patients about the care provided by Dr Y. The second stage, covered by a separate review report, involved reviewing the clinical records of 16 deceased patients, who were selected for review as they were due to be seen as part of the outpatient recall (2018) but sadly died before this could happen. The RCP and the Association of British Neurologists agreed to conduct the clinical record review under the auspices of the invited review service.

This first stage review was challenging. The review team comprised three specialist reviewers, all experienced neurologists of good standing, as well as the medical director and immediate past medical director of RCP invited reviews. The review manager was an experienced lay reviewer. This experienced team found some of the patient stories that emerged from review of the clinical records and in the accounts of family members who raised concerns, deeply upsetting. Many of the patients in this cohort of 29 cases had degenerative neurological conditions, including multiple sclerosis (MS), motor neurone disease (MND) and Parkinson's Disease. Several patients had died from conditions for which there was no treatment, and the prognosis was poor. This patient cohort and their family members had an acute need for supportive care, to help them to manage difficult symptoms, to accept a life limiting diagnosis and to plan how they wished to use the time available to them. A holistic approach was important to ensure that such patients and their families had access to a wide range of support, including but extending beyond prescribed medication to manage symptoms, to sharing information about the illness and its prognosis. Too often these needs were undermined by Dr Y's poor interactions with patients and family members, which sometimes exacerbated the anxiety and distress they experienced as the patient's condition deteriorated. The review team concluded that, at times, Dr Y demonstrated a lack of empathy and often a failure to consider patients' needs holistically.

This review raised concerns with Dr Y's approach to assessment and initial management of patients; aspects of his clinical decision-making, diagnostic approach and prescribing; the way he communicated and engaged with other clinicians; and his interactions with patients. Across the 29 cases, not one case was considered to have represented good practice in terms of the overall quality of neurology care provided. The majority of the 29 cases were graded either unsatisfactory (14 cases) or room for improvement for clinical reasons (12 cases). The remaining three cases were graded as room for improvement for clinical and organisational reasons, or just organisational reasons. Therefore, the

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quality of care provided to this cohort of patients mostly was below the standard expected. The RQIA will need to consider the implications of this for other cases included in the recall.

The review team concluded that Dr Y's diagnosis was secure in just over half of cases (55%); the remaining cases were associated with concerns regarding the diagnosis. Four of 13 cases where the diagnosis was thought not to be secure related to diagnoses of seizures (epilepsy)², which is a finding that is echoed in the second review. The RQIA will need to consider whether these findings warrant further attention to cohorts of patients diagnosed with epilepsy by Dr Y.

Another area of concern related to Dr Y's diagnosis of neuropathies, specifically chronic inflammatory demyelinating polyneuropathy (CIDP)*. The RQIA will need to consider whether the two cases included in this review, and a further case in the second review, warrant further attention to cohorts of patients who were diagnosed by Dr Y with CIDP or similar neuropathies.

The review team identified concerns or omissions that the RQIA may wish to consider further for their potential to lead to harm in 13 of the 29 cases, including that some of the treatments prescribed were unnecessary and invasive. In several instances, the review team believed Dr Y's approach had denied the patient holistic, supportive care that may have made their condition and ultimately end of life care easier to manage.

The RQIA requested that case summaries were created for each case with a view to these being shared with the families of the deceased patients. Appendix 1 (separate document) contains these case summaries. The review team tried to explain medical terminology or signpost websites that family members could use to find out more about a particular condition. Nevertheless, the RQIA is advised to arrange for medically qualified staff to go through the case summary with the family members.

For this review, 23 of 29 cases were associated with concerns raised with the RQIA in the context of this review by family members of the deceased patients. In 21 of 23 cases where concerns were raised, the review team concluded that these concerns were upheld in full (11 cases) or partially upheld (10 cases). A summary of the main concerns, together with the review team's response is contained within the relevant case summary in Appendix 1. The RQIA will need to consider how best to share the outcome of this review with these family members. Some relatives had unresolved questions over their loved one's diagnosis and the potential genetic impact for their children and grandchildren. Dr Y's neurology practice has had ramifications that extend beyond the patients who were under his care.

* Chronic inflammatory demyelinating polyneuropathy (CIDP) is a rare type of autoimmune disorder where the body attacks the myelin sheaths that insulate and protect the nerves.

2 Conclusions

The review team was asked to consider in each case whether the diagnosis made by Dr Y was secure. In over half of cases (55%, 16 cases), the review team believed the diagnosis was secure. In the remaining 13 cases (45%) the review team did not consider the diagnosis to have been secure. Four of these 13 cases related to diagnoses of seizures (epilepsy), and the review team observed that Dr Y's documentation lacked the clinical details necessary to support this diagnosis, such as examination, a description of the episodes the patient was said to be having, or investigations (such as Electroencephalography (EEG)[†] or telemetry[‡]). A recurring theme across these and some other cases where the diagnosis was not secure was that Dr Y did not demonstrate consideration of other possible diagnoses, such as cardiovascular explanations for blackouts³ in two patients.

In two cases the lack of diagnostic certainty did not reflect on Dr Y's abilities as a diagnostician and instead were indicative of the complexity of the patients' conditions. The remaining cases where the diagnosis was not secure related in two cases to a diagnosis of MS; in another two cases to Dr Y's diagnosis or treatment of patients as if they had CIDP; in two cases to the management of patients with blackouts (one of whom was diagnosed with focal seizures and included with the four epilepsy cases described above); and in two cases, incomplete diagnoses due to a lack of clinical information.

In 13 cases, 45%, the review team identified concerns or omissions that the RQIA may wish to consider further for their potential to lead to harm. For nine of the 13 cases, concerns regarding potential harm arose from a diagnosis that was not thought to be secure and therefore raised issues of potentially unnecessary exposure to treatments and medicines, often in high doses, and associated side effects. In the remaining four cases, concerns over potential harm arose from Dr Y's approach to prescribing corticosteroids; an apparent failure to communicate effectively with the patient regarding the risk of sudden unexpected death; and his failure to refer the patient and family members to sources of support and allied health professionals.

The review team considered the certified cause of death in light of the stated diagnosis and any concerns raised during review of the clinical records. For most cases, 83% (24 cases), the review team did not identify any concerns with the recorded cause of death. However, in five instances, the review team believed the RQIA should consider review of death certification or referral to a medical examiner or coroner, as set out in [section 5.1.9](#).

The review team concluded that more than half of cases (52%, 15 cases) were graded poor care or very poor care in terms of Dr Y's initial management of the patient. A theme arising from the review of this phase of care was that Dr Y often failed to document an examination of the patient, including in a patient who presented with balance problems and slurred speech and was suspected by a general practitioner (GP) of having a cerebellar problem. Another theme under this heading was that Dr Y often failed to demonstrate sufficient rigour in assessing the patient's presenting condition and requesting investigations to establish the diagnosis. In several cases, Dr Y was quick to arrive at a diagnosis without first establishing that the clinical criteria underpinning this diagnosis had been met. This was a recurring theme in cases where Dr Y diagnosed epilepsy or started a patient on antiepileptic medicines before confirming the diagnosis of epileptic seizures was secure. The review team was critical that he did not

[†] Recording of brain activity www.nhs.uk/conditions/electroencephalogram

[‡] Monitoring the electrical activity of the heart for an extended time

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request such investigations as telemetry, an EEG or an magnetic resonance imaging (MRI) scan of the brain.

Diagnostic ambiguity was also a recurring finding. In several cases, there was an apparent failure by Dr Y to share his suspicions regarding diagnosis with the patient and family members. This issue also impacted how other clinicians understood the patient's diagnosis. On occasion, the diagnoses suggested by Dr Y were not ones that the review team, comprised of three specialist neurology reviewers, could comprehend (see [section 5.1.2](#) for details).

The review team concluded that Dr Y's clinical decision making was poor care or very poor care in 17 of the 29 cases (59%). The review team considered Dr Y's reasoning for reaching some diagnoses hard to follow and in some cases to have led to inaccurate diagnoses. Concern was raised over two cases in which Dr Y diagnosed CIDP, which the review team considered to have been incorrect in both cases and which raised questions over Dr Y's ability to correctly diagnose CIDP. Several cases raised issues over Dr Y's prescribing, particularly with respect to immunoglobulins and steroids (his prescribing of steroids in two patients was considered excessive by the review team). The review team was also critical of Dr Y's prescribing of anti-epileptic drugs in one case when the clinical diagnosis was of functional seizures. A coroner's inquest confirmed that the patient died from drug intoxication, reflecting the combination of medications he was taking. Whilst Dr Y did not prescribe all the medicines this patient took, it was not clear who was taking oversight of the combination of drugs prescribed and their cumulative impact.

There was little evidence that Dr Y sought multidisciplinary team input into complex cases or involved other neurologists with subspecialty expertise to confirm a diagnosis of CIDP, for example. In one complex case, Dr Y's neurology notes were very sparse and there was no evidence of multidisciplinary working or collaboration with colleagues to pinpoint a diagnosis. Other specialties reached out to Dr Y but there was no evidence of engagement from him. In a clearly difficult case, he did not seek help from colleagues when he should have.

The review team's gradings of Dr Y's follow up arrangements were generally more positive, with 59% (17 cases) graded adequate care and almost a quarter of cases (24%, seven cases) graded good care. These gradings reflected that Dr Y tended to conduct regular and sometimes frequent follow up with patients, which on one level suggested a commitment to patient care. However, frequent follow up did not always translate to effective or considered care.

The review team concluded that more than half of cases (55%) were graded poor care (13 cases) or very poor care (three cases) in terms of Dr Y's communication with colleagues. There were several cases in which the documentation indicated a failure by Dr Y to engage with other physicians involved in a patient's care, such as for one patient who was also under the care of rheumatology and haematology. These other specialties reached out to Dr Y but there was little evidence of engagement from him. Another example was Dr Y's failure to respond to requests for information from occupational health physicians who were assessing the capacity of one patient to continue employment. For one case, Dr Y's failure to work effectively with colleagues only properly came to light via the concerns raised by the patient's family that Dr Y advised the patient he had a recurrence of cancer and that he should refer himself back to oncology.

The review team concluded that across most of the 29 cases – 83% (24 cases) – the records indicated that Dr Y’s interactions with patients and their family members was unsatisfactory, with 14 cases graded poor care and 10 cases graded very poor care under this heading. The review team observed that Dr Y sometimes appeared very reluctant to have difficult conversations with patients that involved conveying an upsetting diagnosis or prognosis. On several occasions, when faced with an untreatable condition, Dr Y appeared to suggest it was treatable and prescribed multiple courses of immune therapies. One family expressed concern that Dr Y caused harm by offering a treatable diagnosis in the face of a deteriorating neurological disease and therefore offering the patient hope that was without foundation. The review team emphasised the importance of an accurate diagnosis in providing patients and their families with realistic expectations for the future. Many of the patients in this sample had untreatable neurodegenerative conditions, and it was incumbent on Dr Y to have honest discussions with patients and family members to enable them to come to terms with the diagnosis and its prognosis, and so to allow them to plan future care around the wishes of the patient. There were examples of patients referred to Dr Y who expressed anxiety when they were first referred to him that they might have a neurological condition (usually MS or MND) that a relative had succumbed to. In the long-term, it was not in the patient’s best interests to be vague over a diagnosis, especially if there were treatment implications.

The review team was often critical of Dr Y for failing to signpost sources of support or information to patients diagnosed with long-term degenerative neurological conditions. In failing to do this, he denied his patients useful information and undermined their agency in their own care.

Some cases gave rise to concern that some of Dr Y’s interactions with patients or family members were inappropriate. This included one case where Dr Y may have given incorrect telephone advice to the family to stop thyroxine (the patient was found to be extremely hypothyroid in 2018 just prior to death). Another example concerned a request made by the daughter of a patient for a letter from him that would allow her to assume power of attorney (POA) over her father’s affairs. She stated that Dr Y asked her to draft this letter herself and forward to him for signature.

More than half of cases, 55% (16 cases), were graded adequate care in terms of clinical record keeping, although 38% were graded poor care (nine cases) or very poor care (two cases). The overriding theme was that Dr Y’s clinical records tended to be brief. His letters were observed to be more detailed following consultations held in his private clinic. For one case, Dr Y’s initial assessment of the patient comprised of three lines. The review team noted that some family concerns related to record-keeping and perceptions that Dr Y did not refer to previous notes. More than one family concern referred to a tendency for Dr Y to write clinical details on ‘scraps’ of paper. The review team could not establish the facts underpinning these concerns, however it noted that it gave rise in some patients and their families to the impression that Dr Y was disorganised and was not taking their case seriously.

Of the 23 cases where concerns were raised with the RQIA by relatives or carers, 11 were upheld in full, 10 were partially upheld, and two were not upheld. With one exception, the review team accepted the accounts provided as an accurate description of the family’s experience. The review team was profoundly moved by the accounts provided by families of the care provided to their loved one, which at times fell below the standards expected of a doctor as defined in *Good Medical Practice*.⁴ Several raised issues that extended beyond the care provided by Dr Y, to highlight issues relating to inpatient and ward care, and the information and support provided to patients with a neurodegenerative condition.

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The most upsetting aspect of the families' concerns related to Dr Y's interactions with patients and family members. A lack of openness regarding the diagnosis has already been highlighted. The family concerns often described a doctor who was unhelpful and at times rude in his interactions. Failures by Dr Y to effectively communicate with patients and family members were most evident where family members had unresolved questions over their loved one's diagnosis and the potential genetic impact. There were eight cases where the review team concluded that further follow up is required by the RQIA and/or the Trust (highlighted in the recommendations below and in [section 5.2.1](#)).

3 Recommendations

Key for timelines for implementing recommendations:

- > **Short term (0-6 months)** - action should be completed within 6 months of receipt of the invited review report
- > **Medium term (6-12 months)** – action should be completed within 12 months of receipt of the invited review report. Planning for actions resulting from these recommendations should start as soon as possible.
- > **Long term (12-24 months)** - action should be completed within 24 months receipt of the invited review report. Planning for actions resulting from these recommendations should start as soon as possible.

Recommendation	Timelines
a. The RQIA will need to consider the implications of the finding of this review that 14 of the 29 cases (48%) were found to be unsatisfactory, for its wider consideration of the cases included in the recall of patients who died.	Short term (0-6 months)
b. The RQIA should consider the potential for harm arising from concerns identified by the review teams with respect to the following cases: RCPXXXX, RCPXXXX, RCPXXXX, RCPXXXX, RCPXXXX, RCPXXXX, RCPXXXX, RCPXXXX, RCPXXXX, RCPXXXX, RCPXXXX, RCPXXXX, RCPXXXX.	Short term (0-6 months)
c. The RQIA should consider how to respond to the concerns identified by the review team with respect to the recorded cause of death in cases RCPXXXX, RCPXXXX, RCPXXXX, RCPXXXX.	Short term (0-6 months)
d. The RQIA should liaise with the Belfast Health and Social Care Trust to follow up on the concerns raised by family members with respect to the following cases: RCPXXXX, RCPXXXX, RCPXXXX, RCPXXXX, RCPXXXX, RCPXXXX, RCPXXXX, RCPXXXX. The RQIA should seek assurance that the Belfast Trust has taken steps to protect patients, e.g. how single-handed unsupervised practice can be prevented in the future.	Short term (0-6 months)
e. The RQIA should consider making it mandatory for clinicians in Northern Ireland to copy most outpatient clinic letters to patients. The Academy of Medical Royal Colleges goes further and encourages doctors to write most of their outpatient letters directly to patients and send a copy of the letter to the patient's general practitioner. See: www.aomrc.org.uk/reports-guidance/please-write-to-me-writing-outpatient-clinic-letters-to-patients-guidance/	Long term (12-24 months)
f. The RQIA should consider the wider implications of this review for clinicians working in an isolated way. Whilst the findings here are specific to neurological services, the RQIA should consider whether health services in Northern Ireland are able to demonstrate the type of multidisciplinary team working and culture of open and constructive challenge expected from contemporary health services.	Long term (12-24 months)

4 Introduction and background

On 1 May 2018, the Belfast Health and Social Care Trust ('the Trust') announced a recall of approximately 2,500 patients who had been under the care of consultant neurologist Dr Y following concerns regarding his clinical management. The recall was instigated following the Trust's internal review process and subsequent request to the RCP to review a series of patients who had been under the care of Dr Y. The Trust's review culminated in Dr Y ceasing all patient care and treatment in the summer of 2017. It is noted that patients who had seen Dr Y privately were also included as part of the recall.

In May 2018, the Permanent Secretary in Northern Ireland requested that the RQIA should conduct an expert review of clinical records of all patients or former patients of Dr Y in the preceding 10 years. A formal direction of this was also issued by the Chief Medical Officer on 10 May 2018. The RQIA was directed to commission a review of the above by the Department of Health (DOH) and planned to do so in a staged process to maximise learning.

The first stage was to review the clinical records of 29 deceased patients identified by the RQIA. These 29 patients were selected for review following concerns raised by relatives of the deceased patients about the care provided by Dr Y.

The RQIA discussed this matter with the RCP on several occasions. The RCP and the Association of British Neurologists agreed a review under the auspices of the invited review service would be appropriate.

4.1 Terms of reference for this clinical record review

1. The RCP will provide an independent and expert review of 29 former patients of Dr Y using a structured judgement review (SJR) tool and assess the overall quality of neurology care provided to those patients by Dr Y.

Consideration will be given to:

- The initial investigations and choice of treatment options
- Whether the diagnosis was secure?
- Whether the ongoing management and treatment of the patient was appropriate?
- Whether the prescribing was appropriate?
- Follow up arrangements in place
- Communication with colleagues and MDT working
- Communication with the patient and/or their family/carers
- Clinical record keeping
- Whether there are any concerns about the impact of the care and treatment provided by Dr Y and which may have resulted in potential patient harm?
- Where the clinical records indicate the likely cause of death, the RCP reviewers will also provide their considered view. If there is a significant difference of opinion, this information may subsequently signpost the RQIA to refer to a medical examiner or coroner to reconsider the case.

In reviewing the overall care, the review team will take into account whether this is in line with national good practice and guidelines.

2. Whilst the clinical record review is progressing, the RQIA will liaise with the families and carers of patients to complete a form requesting details of the key areas of concern (provided separately). Following completion of the record review, the RCP review team will then consider whether, based on the information available, the key areas of concerns for each case are upheld[§], partially upheld** or not upheld^{††}.

The review team will highlight any lessons to be learned and recommend appropriate actions (where relevant) and provide an individual case summary for each patient reviewed.

The RCP will recommend that the final report is shared with the Department of Health and other relevant external stakeholders.

4.2 Approach to this review

The RCP consulted with the Association of British Neurologists, which nominated specialist reviewers. The RCP convened a review team, as set out in [Section 4.3](#).

The RCP was provided with clinical records for 29 patients, as detailed in the terms of reference ([Section 4.1](#)). Each of the 29 cases was considered independently by a specialist clinical reviewer see [Section 4.3](#) for details of the review team. Each reviewer used a structured form adapted from the [RCP National Mortality Case Record Review \(NMCRR\) programme](#)⁵ to independently examine phases of care that the patient received. These were graded by the reviewers as **1 = very poor care; 2 = poor care; 3 = adequate care; 4 = good care, or 5 = excellent care**. The reviewers also utilised a [grading system](#)⁶ developed by the [National Confidential Enquiry into Patient Outcome and Death \(NCEPOD\)](#)⁷ to give an overall perspective on the quality of care provided. This considers both clinical and organisational care. The overall gradings were as follows: **good practice, room for improvement – clinical, room for improvement – organisational, room for improvement – clinical and organisational, unsatisfactory, insufficient information**.

Having independently reviewed the cases, the reviewers presented them at virtual meetings held on **9 and 10 September 2021**. The meetings were chaired by the immediate past medical director for invited reviews, supported by the current medical director for invited reviews and by the RCP review manager, who has extensive experience as a lay reviewer and health analyst. Each case was considered in turn, the specialist reviewers presented their views, followed by a 'confirm and challenge' discussion to agree the grading of phases of care and the overall care. In making judgements about the overall care provided to the patient, the review team considered national good practice and guidelines.

[§] Upheld – the concern is supported by the information provided.

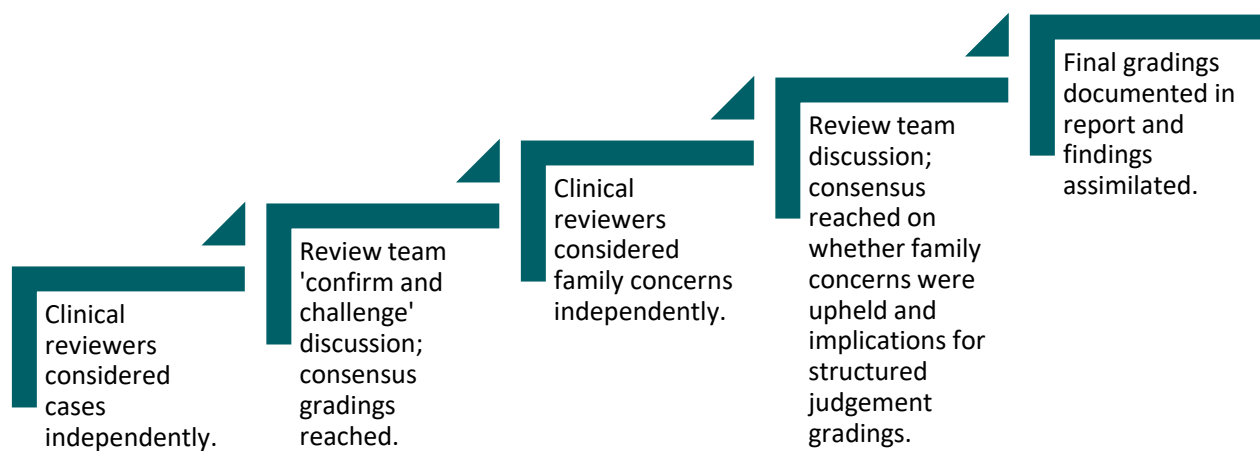
^{**} Partially upheld – some aspects of the complaint were supported by the information provided, but not all the issues that were complained about or the mistakes made did not have a negative impact on the patient.

^{††} Not upheld – either the information provided does not support the concern raised or there is insufficient information available to make a judgement.

Clinical record review report

The review team considered the case records in the absence of any information relating to the family concerns regarding each case. After the clinical case record review was completed, the RQIA shared **family concerns relating to 23 cases** – no concerns were raised by family members with respect to the remaining six cases. Having independently reviewed the concerns associated with the cases, the reviewers presented these at virtual meetings held on **13 and 27 October 2021**, which followed the same format used at the September meetings. The concerns raised by family members were considered in turn, the specialist reviewers presented their views, and the review team agreed whether the complaint was upheld, partially upheld or not upheld. The review team then revisited the case in light of the concerns raised by family members and decided whether the original gradings should stand or should be altered to reflect the new information (in particular, the family concerns shed light on Dr Y's reported interactions with patients and family members, which was often hard to judge based on the clinical record review alone).

Figure 1: Review process



4.3 Invited review team

	Role
	Past Medical Director
	Medical Director
Expert Reviewer 1	Consultant neurologist, independent expert, external to N Ireland
Expert Reviewer 2	Consultant neurologist, independent expert, external to N Ireland
Expert Reviewer 3	Consultant neurologist, independent expert, external to N Ireland
	Lay reviewer and review manager

Quality assurance of this report was provided by clinical representatives of the RCP and the Association of British Neurologists, and two independent lay people.

5 Findings

5.1 Terms of reference 1

1. The RCP will provide an independent and expert review of 29 former patients of Dr Y using a structured judgement review (SJR) tool and assess the overall quality of neurology care provided to those patients by Dr Y.

Consideration will be given to:

- The initial investigations and choice of treatment options
- Whether the diagnosis was secure?
- Whether the ongoing management and treatment of the patient was appropriate?
- Whether the prescribing was appropriate?
- Follow up arrangements in place
- Communication with colleagues and MDT working
- Communication with the patient and/or their family/carers
- Clinical record keeping
- Whether there are any concerns about the impact of the care and treatment provided by Dr Y and which may have resulted in potential patient harm?
- Where the clinical records indicate the likely cause of death, the RCP reviewers will also provide their considered view. If there is a significant difference of opinion, this information may subsequently signpost the RQIA to refer to a medical examiner or coroner to reconsider the case.

In reviewing the overall care, the review team will take into account whether this is in line with national good practice and guidelines.

5.1.1 Overall rating for quality of care

5.1.1.1 Record review

The RQIA provided the RCP review team with access to the clinical records for 29 deceased patients. The records were accessed via secure RQIA server. These access arrangements, whilst secure and rightly protecting patient confidentiality, were complex and required the clinical reviewers to use particular types of computers. This created delay in the review of the 29 cases and a learning point for future reviews using this server for additional technical support, including loan computers, to be provided to clinical reviewers.

The clinical records associated with some cases were extremely extensive in size; for example, one case was associated with 90 separate documents. This created challenges for the clinical reviewers in reviewing the care provided by Dr Y, which for some patients spanned many years.

This was also a challenging review in respect to the patient stories that were uncovered. All the patients in this case selection were deceased and several had died of degenerative neurological conditions for which there was no treatment, and the prognosis was poor. The specialist clinical reviewers said that neurologists tend to place emphasis on supporting patients with degenerative neurological conditions to accept a life limiting diagnosis and to plan how they wish to use the time available to them. A holistic

approach was important to ensuring that such patients and their families had access to a wide range of support, including but extending beyond prescribed medication to manage symptoms.

This approach to neurological care for patients with a life-limiting illness was often lacking across the cases reviewed, which seems to serve only to exacerbate anxiety and distress experienced by patients and their family members as the patient's condition deteriorated. Overall, there was little evidence to demonstrate that Dr Y took a holistic approach and provided patients with information to enable them to seek support with their condition. In several cases, Dr Y seemed unwilling to share his diagnostic suspicions with patients and family members, and instead communicated an overly optimistic prognosis. This denied these patients and their families the opportunity to engage in advance care planning – which offers people the opportunity to plan their future care and support, including medical treatment, while they have the capacity to do so.^{8,9}

The review team observed some examples of excellent care, particularly end of life care and care provided by motor neurone disease specialist services. Dr Y was not involved in the provision of end-of-life care for the great majority of the 29 patients.

In 12 cases, the patient had at least one consultation with Dr Y in the private sector^{††}. Two patients were first seen in a TIA (minor stroke) clinic (RCPXXXX, RCPXXXX).

In six cases, according to the clinical records, Dr Y had somewhat limited involvement in the patient's care. In five of the six cases, Dr Y's involvement whilst limited was very important to the management plan for the patient and the care pathway that was followed. In the sixth case (RCPXXXX), it was not evident from the file provided to the review team that Dr Y ever reviewed the patient or took responsibility for their care, although the deceased patient's family raised concern regarding Dr Y's interactions with the patient at a consultation. Dr Y's involvement in these six cases is detailed as follows:

- **RCPXXXX**– Dr Y's involvement with the patient's care appeared limited to a single private outpatient appointment at which he assessed the patient and ordered tests, which showed metastases in the patient's lumbar spine were the cause of the patient's symptoms. The records shared with the review team contained a clinic letter written by Dr Y setting out his assessment. There was no other correspondence from Dr Y or documentation to evidence that Dr Y discussed the findings of the scan with the patient or referred the patient back to oncology or wrote to the patient's GP with the results of the tests. The family's concerns provided additional information and indicated that, on receiving the scan report, Dr Y telephoned the patient to tell him that he had a recurrence of cancer and that he should refer himself back to oncology.
- **RCPXXXX**– the review team could not identify any involvement by Dr Y in the patient's care, other than to write to the patient regarding a missed appointment. There was a discrepancy between the complaint raised by the patient's family regarding brain scans conducted in XXXXX and evidence that scans were conducted in Belfast. The review team was not provided with documentary evidence to show that Dr Y saw the patient although there was no reason to disbelieve the patient's son's account that a consultation took place. There were documented scans in Northern Ireland. However, the review team could not comment further in the absence of any documentation relating to a consultation.

^{††} RCPXXXX, RCPXXXX, RCPXXXX, RCPXXXX, RCPXXXX, RCOXXXX, RCPXXXX, RCPXXXX, RCPXXXX, RCPXXXX, RCPXXXX, RCPXXXX

- **RCPXXXX**– Dr Y’s involvement was limited to providing a third opinion on a neurological diagnosis. The review team could identify only one letter written by Dr Y following his review of the patient in a private clinic. Dr Y wrote to other doctors who had been involved in the patient’s care. There were no plans for Dr Y to manage or treat the patient.
- **RCPXXXX**– Dr Y appeared to have one private outpatient appointment with the patient in 2009; the records indicated that the patient died in 2014. He documented the presenting complaint (blackouts), took a medical and family history, examined the patient, diagnosed vertebrobasilar migraine (migraines with predominantly brainstem aura symptoms^{§§}) and prescribed medication. The review team was critical of Dr Y’s decision making not to investigate the blackouts further and considered that this may have been relevant to the patient’s sudden death five years later.
- **RCPXXXX**– The patient consulted Dr Y as an outpatient, however most of their care was as an inpatient and whilst the patient was under Dr Y’s care, there was little evidence of involvement by Dr Y whilst the patient was an inpatient. Most of the patient’s management was intensive care related. Dr Y offered follow up for the patient when an outpatient. The concerns raised by the patient’s family indicated that there was little, if any, interaction between Dr Y and family members and instead one of his team was the main provider of care to this patient. The review team was critical that there appeared to be a lack of consultant neurologist ownership in this case; as the named consultant, Dr Y should have demonstrated greater involvement and leadership in decisions over this patient’s care.
- **RCPXXXX**– the patient died within two months of having been assessed in Dr Y’s clinic by a neurology registrar, who discussed the assessment with Dr Y. The ear, nose, and throat (ENT) department had referred the patient to neurology in June 2016. It was five months before she was seen by a neurology registrar in Dr Y’s clinic in November 2016. The registrar’s assessment was reviewed by Dr Y, who suggested an anti-epileptic medication. The review team did not support this prescribing decision, and instead believed an MRI brain scan should have been conducted given the symptoms identified on examination by the registrar. A previous MRI scan had happened 10 months before. It appeared that Dr Y’s assumption was that the patient had a cerebellar syndrome secondary to a previous head injury in 2010. There were no indications to prescribe an anti-epileptic drug. The patient died before the planned three month follow up.

In terms of the overall quality of neurology care provided to those 29 patients by Dr Y, not one case was considered to have represented good practice. A majority of the 29 cases were graded either unsatisfactory (14 cases) or room for improvement for clinical reasons (12 cases). The remaining three cases were graded room for improvement for clinical and organisational reasons, or just organisational reasons.

^{§§} <https://migrainetrust.org/understand-migraine/types-of-migraine/migraine-with-brainstem-aura/>

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The review team's overall gradings for the quality of care provided across the 29 cases were as follows:

Clinical reviewer's overall perspective on quality of care	
Good practice: a standard you would accept from yourself, your trainees and your institution.	None
Room for improvement: aspects of <u>clinical care</u> that could have been better.	RCPXXXX, RCPXXXX RCPXXXX, RCPXXXX, RCPXXXX, RCPXXXX, RCPXXXX, RCPXXXX, RCPXXXX
Room for improvement: aspects of <u>organisational care</u> that could have been better.	RCPXXXX
Room for improvement: aspects of both <u>clinical and organisational care</u> that could have been better.	RCPXXXX, RCPXXXX
Unsatisfactory: Several aspects of clinical and/or organisational care that were well below that you would accept from yourself, your trainees and your institution.	RCPXXXX, RCPXXXX, RCPXXXX, RCPXXXX, RCPXXXX, RCPXXXX, RCPXXXX, RCPXXXX, RCPXXXX, RCPXXXX, RCPXXXX, RCPXXXX
Insufficient information available to make an assessment of quality of care.	

In addition to grading the overall quality of neurology care provided to the 29 patients, the review team graded the distinct phases or aspects of care. This provided an understanding of areas of strength or weakness in terms of Dr Y's clinical care. As the table below shows, the evidence indicated that Dr Y's interactions with patients and their family members was generally poor, with no cases graded good care and 23 examples of poor care (14 cases) or very poor care (10 cases) under this heading. Clinical decision making was also graded as poor care or very poor care in 17 out of the 29 cases, with only two cases graded good care, although one case was graded excellent care.

Dr Y's follow up of patients was the phase of care graded most positively, with 17 cases graded as adequate care and seven cases graded good care. Only four cases were graded poor care (three cases) or very poor care (one case).

	Very poor care	Poor care	Adequate care	Good care	Excellent care	Insufficient evidence
Admission and initial management	RCPXXXX RCPXXXX RCPXXXX RCPXXXX RCPXXXX	RCPXXXX RCPXXXX RCPXXXX RCPXXXX RCPXXXX RCPXXXX RCPXXXX RCPXXXX RCPXXXX RCPXXXX	RCPXXXX RCPXXXX RCPXXXX RCPXXXX RCPXXXX RCPXXXX	RCPXXXX RCPXXXX RCPXXXX RCPXXXX	RCPXXXX	RCPXXXX

	Very poor care	Poor care	Adequate care	Good care	Excellent care	Insufficient evidence
Clinical decision making	RCPXXXX RCPXXXX RCPXXXX RCPXXXX RCPXXXX RCPXXXX RCPXXXX	RCPXXXX RCPXXXX RCPXXXX RCPXXXX RCPXXXX RCPXXXX RCPXXXX RCPXXXX	RCPXXXX RCPXXXX RCPXXXX RCPXXXX RCPXXXX RCPXXXX RCPXXXX	RCPXXXX RCPXXXX	RCPXXXX	RCPXXXX
Follow up arrangements	RCPXXXX	RCPXXXX RCPXXXX RCPXXXX	RCPXXXX RCPXXXX RCPXXXX RCPXXXX RCPXXXX RCPXXXX RCPXXXX RCPXXXX RCPXXXX RCPXXXX RCPXXXX RCPXXXX RCPXXXX RCPXXXX RCPXXXX RCPXXXX RCPXXXX RCPXXXX RCPXXXX	RCPXXXX RCPXXXX RCPXXXX RCPXXXX RCPXXXX RCPXXXX		RCPXXXX
Communication with colleagues	RCPXXXX RCPXXXX RCPXXXX	RCPXXXX RCPXXXX RCPXXXX RCPXXXX RCPXXXX RCPXXXX RCPXXXX RCPXXXX RCPXXXX RCPXXXX RCPXXXX RCPXXXX RCPXXXX	RCPXXXX RCPXXXX RCPXXXX RCPXXXX RCPXXXX RCPXXXX	RCPXXXX RCPXXXX RCPXXXX	RCPXXXX	RCPXXXX RCPXXXX RCPXXXX
Interactions with patients and their family	RCPXXXX RCPXXXX RCPXXXX RCPXXXX RCPXXXX RCPXXXX	RCPXXXX RCPXXXX RCPXXXX RCPXXXX RCPXXXX	RCPXXXX RCPXXXX RCPXXXX			RCPXXXX RCPXXXX

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	Very poor care	Poor care	Adequate care	Good care	Excellent care	Insufficient evidence
	RCPXXXX RCPXXXX RCPXXXX	RCPXXXX RCPXXXX RCPXXXX RCPXXXX RCPXXXX RCPXXXX RCPXXXX RCPXXXX				
Clinical record keeping	RCPXXXX RCPXXXX	RCPXXXX RCPXXXX RCPXXXX RCPXXXX RCPXXXX RCPXXXX RCPXXXX RCPXXXX RCPXXXX	RCPXXXX RCPXXXX RCPXXXX RCPXXXX RCPXXXX RCPXXXX RCPXXXX RCPXXXX RCPXXXX RCPXXXX RCPXXXX RCPXXXX RCPXXXX RCPXXXX RCPXXXX RCPXXXX	RCPXXXX		RCPXXXX

Having graded each case, the review team was asked to consider whether the diagnosis reached by Dr Y was secure – i.e., likely to be accurate, based on the available clinical information. In 16 out of 29 cases (55%), the review team believed that the diagnosis was secure. For 13 cases (45%), the diagnosis was not secure. This does not necessarily indicate that it was a misdiagnosis, but that Dr Y did not undertake sufficient steps (such as investigations or witness accounts of a seizure) to make the diagnosis secure. Further insights can be found at [section 5.1.9](#).

The review team also considered whether any concerns identified during the course of reviewing the case could have resulted in potential patient harm. In 16 out of 29 cases (55%), the review team did not have any concern regarding harm. In 13 of the 29 cases (45%), the potential for harm was identified. Harm was considered broadly – including where a patient may have suffered anxiety due to unnecessary uncertainty over their diagnosis or failed to benefit from holistic or supportive care. Further details are provided at [section 5.1.9](#).

Finally, the review team was asked to consider whether the RQIA should refer any cases to a medical examiner or coroner. The review team identified five cases where it believed the RQIA should do this. The reasons underpinning these decisions are outlined at [section 5.1.9](#).

	Yes	No
Was the diagnosis secure?	RCPXXXX, RCPXXXX, RCPXXXX, RCPXXXX, RCPXXXX, RCPXXXX, RCPXXXX, RCPXXXX, RCPXXXX, RCPXXXX, RCPXXXX, RCPXXXX, RCPXXXX, RCPXXXX, RCPXXXX	RCPXXXX, RCPXXXX, RCPXXXX, RCPXXXX, RCPXXXX, RCPXXXX, RCPXXXX, RCPXXXX, RCPXXXX, RCPXXXX, RCPXXXX, RCPXXXX, RCPXXXX, RCPXXXX, RCPXXXX
Could any concerns have resulted in potential patient harm?	RCPXXXX, RCPXXXX, RCPXXXX, RCPXXXX, RCPXXXX, RCPXXXX, RCPXXXX, RCPXXXX, RCPXXXX, RCPXXXX, RCPXXXX, RCPXXXX, RCPXXXX, RCPXXXX, RCPXXXX	RCPXXXX, RCPXXXX, RCPXXXX, RCPXXXX, RCPXXXX, RCPXXXX, RCPXXXX, RCPXXXX, RCPXXXX, RCPXXXX, RCPXXXX, RCPXXXX, RCPXXXX, RCPXXXX, RCPXXXX
Should the RQIA refer the case to a medical examiner or coroner?	RCPXXXX, RCPXXXX, RCPXXXX, RCPXXXX, RCPXXXX, RCPXXXX, RCPXXXX, RCPXXXX, RCPXXXX, RCPXXXX, RCPXXXX, RCPXXXX, RCPXXXX, RCPXXXX, RCPXXXX	RCPXXXX, RCPXXXX, RCPXXXX, RCPXXXX, RCPXXXX, RCPXXXX, RCPXXXX, RCPXXXX, RCPXXXX, RCPXXXX, RCPXXXX, RCPXXXX, RCPXXXX, RCPXXXX, RCPXXXX

- i. Good care
None of the 29 cases were graded good care in terms of the overall quality of neurology care. This meant the review team did not identify any cases that met of a standard they would expect from themselves, their trainees and their institution.
- ii. Room for improvement
Of the 29 cases, 15 were graded room for improvement. Of these 15, 12 cases were graded room for improvement for clinical reasons (i.e., aspects of clinical care could have been better); two were graded room for improvement for clinical and organisational reasons (i.e., aspects of both clinical and organisational care could have been better), and one was graded room for improvement for organisational reasons (i.e., aspects of organisational care could have been better).
- iii. Unsatisfactory
Of the 29 cases, 14 were graded unsatisfactory in terms of the overall quality of neurology care. This meant the review team identified several aspects of clinical and/or organisational care that were well below the standard they would expect from themselves, trainees and institution.

5.1.2 Admission and initial management (including history taking, investigations and assessment)

5.1.2.1 Record review

- 52% of cases were graded poor care (10 cases) or very poor care (five cases) under this heading.
- 24% (seven cases) were graded adequate care.
- 21% of cases were graded good care (five cases) or excellent care (one case).
- For one case there was insufficient evidence to reach a judgement.

i. Examination

A theme arising from the review of this phase of care was that Dr Y often failed to document an examination of the patient. For example, in case **RCPXXXX** the review team were critical that Dr Y did not record any examination findings in a patient who presented with balance problems and slurred speech and was suspected by the GP of having a cerebellar problem. In case **RCPXXXX** Dr Y was asked to provide a third opinion in a patient who was experiencing stress because of uncertainty regarding a diagnosis of multiple sclerosis (MS). Dr Y diagnosed MS, which was in keeping with a 'possible' diagnosis made by another neurologist. However, the review team concluded that the diagnosis was based on incomplete information and was not in keeping with diagnostic guidelines at the time. Dr Y should have examined the patient – even though a neurological examination had previously been undertaken by another neurologist, examining the patient himself would have been advisable considering the uncertain diagnosis and that this was a request for a third opinion. His diagnosis could also have been made more secure by demonstrating awareness of the diagnostic criteria needed for multiple sclerosis and undertaking a lumbar puncture.

ii. Diagnostic criteria

Another theme under this heading was that Dr Y often failed to demonstrate sufficient rigour in assessing the patient's presenting condition and requesting investigations to establish the diagnosis. In several cases, Dr Y was quick to arrive at a diagnosis without first establishing that the clinical criteria underpinning this diagnosis had been met.

This was a recurring theme in cases where Dr Y diagnosed epilepsy or started a patient on antiepileptic medicines before confirming the diagnosis of epileptic seizures was secure. The review team were critical that he did not request such investigations as telemetry, an EEG (recording of brain activity) or an MRI scan of the brain. For example, case **RCPXXXX** concerned a patient with a lengthy history of seizures. Dr Y prescribed an anti-epileptic medicine, but it was not evident that he investigated this patient's epilepsy to enable accurate classification of the seizures. There was no good description of a witnessed seizure and the review team concluded that Dr Y should have taken steps to confirm the diagnosis of generalised onset epilepsy. There was no record of an EEG (a recording of brain activity^{***}) report or an MRI scan of the brain. It was quite likely that the diagnosis of primary generalised epilepsy (which would now be called generalised onset tonic clonic seizures⁺⁺⁺) was correct but it should have been proven. Efforts should always be made, particularly in young patients, to classify their seizures. This cause of death for this patient was Sudden Unexpected Death in Epilepsy (SUDEP).

Similarly, for case **RCPXXXX** the review team was concerned that in a case of brief blackouts, basic test results, such as an ECG, were not documented and Dr Y labelled the blackouts as seizures. Dr Y's clinic letter was very brief – just three lines stating that the patient had partial epilepsy and starting her on treatment, when the problem was one of blackouts.

iii. Diagnostic ambiguity

A recurring theme in several cases was a failure by Dr Y to share his suspicions regarding diagnosis with the patient and family members. This is returned to at [section 5.1.7](#), which examines Dr Y's interactions with patients and family members. This issue also impacted how other clinicians understood the patient's diagnosis. On occasion, the diagnoses suggested by Dr Y were not ones that the review team, comprised of three specialist neurology reviewers, could comprehend. In case

^{***} www.nhs.uk/conditions/electroencephalogram/

⁺⁺⁺ www.epilepsy.org.uk/info/seizures/tonic-clonic

RCPXXXX Dr Y arranged appropriate investigations for the presenting complaint but reached a surprising formulation by stating: *‘the diagnosis lies between TIAs, partial seizures or a combination of the two’*. He invoked diagnoses that the review team considered made no sense, like *‘coeliac disease and anti-Rho’* or *‘coeliac neuropathy/bulbar weakness’*. His suggestion of MS as a diagnosis, in a patient over the age of 50 and against the express indications of the radiologist reporting the patient’s MRI scans, was also vulnerable to criticism. This lack of clarity in the diagnosis was to have ramifications throughout the case and meant that the patient’s management plan was haphazard.

5.1.3 Clinical decision making (including case selection, evidence-based treatment, multidisciplinary team discussion, prescribing)

5.1.3.1 Record review

- Most cases (59%) were graded poor care (nine cases) or very poor care (eight cases) under this heading; 28% (eight cases) were graded adequate care. Two cases were graded good care and one case was graded excellent care for clinical decision making. For one case there was insufficient evidence to reach a judgement.

Several themes emerged under this heading.

i. Diagnostic decisions

The review team considered Dr Y’s reasoning for reaching some diagnosis hard to follow and in some cases to have led to inaccurate diagnoses. For example, particular concern was raised over two cases in which Dr Y diagnosed CIDP (inflammation of the nerves), which the review team considered to have been incorrect in both cases, as demonstrated by the lack of demyelination⁺⁺⁺ on neurophysiology (demyelination being the ‘D’ aspect of CIDP). This finding raised questions over Dr Y’s ability to correctly diagnose CIDP. For case **RCPXXXX** Dr Y diagnosed Parkinson’s disease. The patient went on to develop a sensory neuropathy which Dr Y attributed to CIDP and/or B12 deficiency. He proceeded to treat the patient with IV immunoglobulins (IVIg)^{§§§} even though the diagnosis of CIDP was incorrect. The cause of the patient’s neuropathy was not determined and may have related to a rare disease. There was no documentation to indicate that Dr Y examined the patient in assessing his condition. The review team considered the diagnosis of CIDP to have been unlikely given the neurophysiology test results (no sign of demyelination) and the lumbar puncture results (which failed to show a significantly raised protein).

Similarly, for case **RCPXXXX** the review team concluded that Dr Y committed to diagnoses that were based on questionable reasoning. The patient’s presentation in the initial phase was complex diagnostically, however appropriate confirmatory diagnostic tests were not undertaken. Dr Y initially diagnosed and treated CIDP, without arranging a lumbar puncture to confirm the diagnosis or using accepted diagnostic criteria. The justification for Dr Y’s decision to treat the patient with IVIg was unclear. This can be an effective treatment, but it is expensive and usually prescribed with care and only when CIDP has been confirmed.

⁺⁺⁺ Demyelination is damage to the myelin sheath around nerves

^{§§§} IVIg involves giving immunoglobulin straight into the blood via a cannula in a vein. Each treatment can take several hours.

ii. Prescribing

Several cases raised issues over Dr Y's prescribing, particularly with respect to immunoglobulins and steroids. For example, Dr Y's use of steroids in case **RCPXXXX** (a patient diagnosed with MS) was considered excessive by the review team. Steroids are useful only in treatment for relapse and have no long-term effect on the course of MS. Yet, Dr Y prescribed steroids without first diagnosing that there had been a relapse. The review team was also critical of Dr Y's decision to prescribe B12 for fatigue in this patient, which was specifically prohibited in NICE guidance published in 2014, *Multiple sclerosis: management of multiple sclerosis in primary and secondary care*, which stated: 'Do not use vitamin B12 injections to treat fatigue in people with MS.'¹⁰

There is evidence that the persistent use of corticosteroids caused one patient harm (case **RCPXXXX**), as demonstrated by medical observations that she became Cushingoid****. Dr Y's notes did not acknowledge this, nor show any awareness for the possibility of other well-known side effects from long-term steroid use, such as hypertension and diabetes. The review team concluded that this patient suffered unnecessarily from the long-term complications of steroids.

The review team was critical of Dr Y's prescribing of anti-epileptic drugs in case **RCPXXXX** when the clinical diagnosis was of functional seizures. A coroner's inquest confirmed that the patient died from drug intoxication, reflecting the combination of medications he was taking. Whilst Dr Y did not prescribe all the medicines the patient was taking, it was not clear who was taking oversight of the combination of drugs prescribed and their cumulative impact.

In case **RCPXXXX**, Dr Y demonstrated good prescribing skills in suggesting a treatment and documenting the potential for risks and the specific need for monitoring blood tests. He utilised medications appropriately and in line with standard care. He also appeared to respond reasonably to side effects to medications, making appropriate suggestions to amend doses where appropriate (e.g., when the patient suffered hallucinations). The review team graded his clinical decision making as good care in this case, which showed that Dr Y was able to demonstrate good prescribing practice. This was one of only two cases graded good care under this heading. **RCPXXXX** was graded excellent care, for whilst Dr Y's decision to offer a particular treatment (mitoxantrone) was considered high-risk and outside the strict letter of the guidance, Dr Y sought another neurology opinion on this, and the review team could understand the rationale for offering this treatment. The patient was counselled (by a second neurologist) on the risks of therapy.

iii. MDT decision-making

There was little evidence that Dr Y sought multidisciplinary team input into complex cases. For example, in case **RCPXXXX**, Dr Y diagnosed Parkinson's Disease and went on to attribute a sensory neuropathy to inflammation of the nerves (CIDP) and/or B12 deficiency. The cause of the patient's nerve disease (neuropathy) was not determined and may have related to a rare disease. This could be a difficult diagnosis for a neurologist without specialist expertise in (peripheral) nerve disorders. In such situations, it would be common to involve a neurologist with subspecialty expertise, especially when IVIg is used, and the diagnosis is uncertain (the diagnosis was described as 'possible'). It was not evident that Dr Y involved other neurologists with subspecialty expertise to confirm the diagnosis of CIDP, or that he referred the patient for discussion at a multidisciplinary team meeting, which would have been helpful to diagnose an unusual neuropathy. It was not evident that there was any communication between Dr Y and the second neurologist who became involved in the patient's care when he transferred to another hospital.

**** www.nhs.uk/conditions/cushings-syndrome/

Similarly, case **RCPXXXX**, was a complex case that required extensive multidisciplinary working. Dr Y's neurology notes were very sparse and there was no evidence of multidisciplinary working or collaboration with colleagues to pinpoint a diagnosis. Other specialties reached out to Dr Y but there was no evidence of engagement from him. In a clearly difficult case, he did not seek help from colleagues when he should have.

Another example was case **RCPXXXX**, where it was not evident from the records that Dr Y considered what type of MS the patient may have had (the review team believed that, based on the information contained in the records, it seemed likely that the patient had primary progressive MS). There was no reference in the patient notes to multidisciplinary team discussion, referral to colleagues, or an evidence-based treatment plan.

5.1.4 Follow up arrangements

5.1.4.1 Record review

- The gradings under this heading were generally more positive than for other phases of care, with 59% (17 cases) graded adequate care and almost a quarter of cases (24%, seven cases) graded good care in terms of follow up arrangements. None were graded excellent care and for one case there was insufficient evidence to reach a judgement.
- Three cases were graded poor care and one was graded very poor care.

These gradings reflected that Dr Y tended to conduct regular and sometimes frequent follow up with patients, which on one level suggested a commitment to patient care. However, frequent follow up did not always translate to effective or considered care.

Case **RCPXXXX** was graded very poor care under this heading because the review team found Dr Y's approach to the patient's care to have been cursory. The patient was first seen by Dr Y in February 2013 in a private clinic and diagnosed '*some form of chorea*' (a movement disorder that causes unpredictable muscle movements). Her care was then transferred to the NHS and a doctor in training requested investigations that took place in June 2013. In November 2013 the patient's GP wrote to Dr Y expressing concern that the patient's condition had deteriorated, and she had not had a follow up appointment. The patient's husband had been informed that the GP would need to re-refer the patient. A detailed letter from another neurologist summarising this patient's case reported that she had multiple problems that had not been documented by Dr Y and that she had not had any neurological reviews for some time prior to her final admission into hospital in June 2018. The records indicated that her last neurology appointment with Dr Y was in 2016, although Dr Y had been in email correspondence with her haematologist in 2017.

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5.1.5 End of life care

5.1.5.1 Record review

The review team did not grade this aspect of care, as in most cases, it was not evident that Dr Y had any involvement in the patient's end of life care. Across the cases, end of life care for patients who died in hospital was to a very high standard and reflected the input of multidisciplinary teams of staff who evidently worked hard to make patients as comfortable as possible. These staff also frequently demonstrated good practice in sharing information with patients and family members on the prognosis and with respect to advance planning.

5.1.6 Communication with colleagues (including delegation, referrals and multidisciplinary team working)

5.1.6.1 Record review

- Under this heading, 55% of cases were graded poor care (13 cases) or very poor care (three cases); 21% (six cases) were graded adequate care.
- Three cases were graded good care and one case was graded excellent care.
- In three cases there was insufficient evidence to reach a judgement.

RCPXXXX, was the case graded excellent care under this heading. It reflected that a second neurologist provided an opinion on this patient's diagnosis and Dr Y later asked this second neurologist for advice regarding use of a medicine for which the patient did not fit the usual criteria for its use. In the patient's last hospital admission, the clinical records indicated that multidisciplinary discussion took place with the patient and family members regarding how to optimise the patient's care.

i. Referral to other physicians

There were several cases in which the documentation indicated a failure by Dr Y to engage with other physicians involved in a patient's care. For example, case **RCPXXXX** was graded very poor care under this heading. This was a complex case in a patient in whom Dr Y described as suffering from chorea but never made a complete diagnosis. This patient was also under the care of rheumatology and haematology. Yet, there was no evidence of multidisciplinary working or collaboration between Dr Y and other physicians to pinpoint a diagnosis. Other specialties attempted to engage with Dr Y but there was little evidence of reciprocation from him.

Case **RCPXXXX** was also graded very poor care under this heading. This was a patient with a family history of MS and who was fearful of this diagnosis. The review team concluded that the most straightforward diagnosis was secondary progressive MS and yet there was no evidence to show that this diagnosis was considered. The review team was critical that Dr Y allowed vagueness over the diagnosis from another neurologist and a rheumatologist to continue. The lack of clarity and honesty over the diagnosis meant that the patient was exposed to powerful immunotherapies that would not have helped her, and instead exposed her to significant risk. If the correct diagnosis had been made earlier, the patient could have planned for a dignified death, under the auspices of palliative care, and free from invasive therapies and investigations. Whilst there was evidence of multidisciplinary communication in this case, there appeared to be agreement between clinicians over the wrong diagnosis, perhaps out of misconceived kindness to the patient given her family history.

For case **RCPXXXX** Dr Y's failure to work effectively with colleagues only properly came to light via the concerns raised by the patient's family. Dr Y's involvement with this patient's care appeared limited to the diagnosis of the cause of their neurological symptoms. He ordered a scan which was reported to show metastases in the lumbar spine. There was no correspondence in the clinical records from Dr Y or documentation to evidence that he discussed the findings of the scan with the patient or referred the patient back to oncology or wrote to the patient's GP with the results of the tests. The family's concerns provided additional information and indicated that Dr Y did not refer the patient to oncology, which should have been the appropriate pathway. Instead, the family's account was that, on receiving the scan report, Dr Y telephoned the patient to tell him that he had a recurrence of cancer and that he should refer himself back to oncology. The review team considered it to have been very unprofessional to expect a patient to arrange their own referral when given a life-limiting diagnosis.

For example, case **RCPXXXX** was graded poor care under this heading. The review team concluded that Dr Y demonstrated good clinical acumen in maintaining a diagnosis of motor neurone disease, even when investigations pointed in other directions and the other doctors attributed the patient's symptoms to cerebrovascular disease. Due to this positive aspect of Dr Y's care, the patient was put on the appropriate care pathway early on; he arranged two admissions to manage the patient's symptoms and provide access to the MND team, who provided excellent care. However, it appeared that Dr Y did not communicate effectively with the stroke physicians and geriatrician also involved in the patient's care that he suspected the diagnosis of MND, and so they continued to investigate and treat alternative conditions.

ii. Seeking subspecialty expertise

In some cases, the review team was critical that Dr Y did not seek specialist subspecialty expertise. Case **RCPXXXX** and Dr Y's diagnosis of CIDP has already been highlighted ([section 5.1.3.1](#)). In case **RCPXXXX**, the review team was surprised that Dr Y did not refer a patient diagnosed with moyamoya syndrome (a rare progressive cerebrovascular disorder) to a specialist vascular neurologist. The review team graded this phase of care as good care, however this reflected on the input of the hospital neurology team, as distinct to Dr Y's involvement.

iii. Referral to therapy staff

A theme arising from many of the cases was that Dr Y did not demonstrate a holistic approach towards patients with long-term neurological conditions, in that he failed to signpost sources of support and information to patients. Linked to this was an apparent failure to refer patients in many cases to allied health professionals, such as physiotherapists, occupational therapists or continence advisers.

For example, for case **RCPXXXX**, Dr Y referred the patient for physiotherapy two years after diagnosing the patient with Parkinson's Disease. For case **RCPXXXX**, again relating to a patient diagnosed with Parkinson's Disease, the review team considered Dr Y's care to have been responsive when a GP twice raised concerns over the patient's deterioration, but he did not demonstrate multidisciplinary working or a holistic approach to the management of this patient's condition. Referral to early physiotherapy or neurophysiotherapy might have reduced the risk of the patient's significant fall and injury, which resulted in an admission towards the end of the patient's life. There was evidence that a Parkinson's nurse was involved in December 2015 and referral to other therapy services was mentioned in the records in October 2015, but it was not apparent that Dr Y had instigated these referrals.

Similarly, for case **RCPXXXX** the review team observed that timely onward referral of this patient with motor neurone disease to allied health professionals, such as neurophysiotherapy for falls prevention or to speech and language therapy for early management of dysphagia (swallowing problems), could have helped the patient to manage their symptoms. For case **RCPXXXX** concerning a patient with parkinsonism, the family reported that it was the patient's GP who made onward referrals to a Parkinson's nurse specialist and for speech and language therapy.

In some cases, there was evidence that Dr Y did refer patients for physiotherapy review (cases **RCPXXXX** and **RCPXXXX**, both relating to patients with Parkinson's Disease), and in case **RCPXXXX** Dr Y referred this patient, with cerebellar degeneration, for both physiotherapy and occupational therapy review. The reasons why he made these referrals for some patients and not others were not clear. Sometimes therapists were involved in the care of patients, not at Dr Y's instigation, but due to the involvement of other clinicians.

iv. Failure to respond to requests from other clinicians

Case **RCPXXXX** concerned a patient in whom Dr Y diagnosed MS. Positively, MS nurses were involved throughout the patient's care and there was evidence of communication between the nurses and Dr Y. However, the clinical records contained several letters from occupational health physicians who were assessing the patient's capacity to continue his employment and had approached Dr Y for a report on the patient's condition. Concerns raised by this patient's family to RQIA indicated that Dr Y resisted answering reasonable requests for information. The concerns articulate the enormous stress that Dr Y's failure to engage with occupational health physicians caused; the patient had a cognitively demanding job and there were significant financial implications for the family from his withdrawal from work. The review team considered this to have been very poor care; Dr Y should have engaged more fully with the occupational health physicians as the questions of his patient's capacity to continue work was clearly an important issue.

5.1.7 Interactions with patients and family (including information sharing, duty of candour)

5.1.7.1 Record review

- Most cases – 83% (24 cases) – were graded poor care (14 cases) or very poor care (10 cases) under this heading. Three cases were graded as adequate care and none were graded good or excellent.
- There was insufficient evidence in two cases to reach a judgement. This reflected a tendency for Dr Y's letters and notes to contain little detail about his discussions with patients or the information he had shared with them.

i. Communicating the diagnosis

The review team observed that Dr Y sometimes appeared very reluctant to have difficult conversations with patients that involved conveying an upsetting diagnosis. On several occasions, when faced with an untreatable condition, Dr Y appeared to suggest it was treatable and prescribed multiple courses of immune therapies. For example, in case **RCPXXXX**, highlighted previously, Dr Y diagnosed Parkinson's Disease and went on to attribute a sensory neuropathy to inflammation of the nerves (CIDP) and/or B12 deficiency. Dr Y treated the patient with weekly B12 injections even when the B12 levels were replete. Dr Y treated the patient with IV immunoglobulins even though the diagnosis of CIDP was incorrect. It also offered the possibility of a treatable condition and the expectation that the patient may get better, when the review team believed this patient was most

likely to have had an untreatable condition. The family's concern indicated that Dr Y caused harm by offering a treatable diagnosis in the face of a deteriorating neurological disease and therefore offering the patient hope that was without foundation.

The review team emphasised the importance of an accurate diagnosis in providing patients and their families with realistic expectations for the future. Many of the patients in this sample had untreatable neurodegenerative conditions, and it was incumbent on Dr Y to have honest discussions with patients and family members to enable them to come to terms with the diagnosis and allow them to plan future care around the wishes of the patient. There were examples of patients referred to Dr Y who were anxious when they were referred to him that they might have a neurological condition (usually MS or motor neurone disease) that a relative had succumbed to. In the long-term, it was not in the patient's best interests to be vague over a diagnosis, especially if there were treatment implications.

For example, case **RCPXXXX** was graded very poor care under this heading. This was a case in which Dr Y made an early diagnosis of motor neurone disease, even when investigations pointed in other directions and other doctors attributed the patient's symptoms to cerebrovascular disease. However, there was no evidence in the records to demonstrate that Dr Y communicated his diagnostic suspicions with the patient's family until a definitive diagnosis was made. Concerns raised by the family confirmed that he did not share his diagnosis with the family, who continued to believe that the patient was being treated for TIAs (mini strokes) and were confused by the patient's deterioration when they expected improvement with strokes. Dr Y's follow up with the patient was very frequent (there were 10 appointments with the patient), which provided ample opportunity to share information with the patient and her family.

Case **RCPXXXX** was another example where Dr Y was clearly suspicious from the outset that the patient might have motor neurone disease and arranged the appropriate tests but did not share these suspicions with the patient despite her expressed concerns that she might have this disease. The diagnosis emerged only when the patient was admitted under the respiratory team and a referral was made to another neurologist. Family members reported that, during one appointment, Dr Y mentioned '*Progressive Bulbar Palsy*', which is a specialist term for a form of MND, which most non-neurologists – and members of the public – would not understand. This provided further evidence that Dr Y believed the patient had MND, but was avoiding making this clear to the patient and her family.

Case **RCPXXXX** related to a patient who had primary progressive MS. The review team could not identify evidence to demonstrate that Dr Y communicated effectively with the patient and his family, and concerns expressed by the family indicated that Dr Y *failed to communicate the diagnosis and management plan clearly to the patient and his family. The family stated: "Dr [Y] didn't tell us what it was"*. This uncertainty over the diagnosis persisted after the patient's death and his wife expressed concern that the diagnosis could be hereditary and impact their children and grandchildren.

ii. Sign-posting further information and sources of support

The review team was often critical of Dr Y for failing to signpost sources of support or information to patients diagnosed with degenerative neurological conditions. In failing to do this, he did not demonstrate a holistic approach and consider the range of support these patients needed, beyond prescribing medicines.

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For example, this approach was seen in case **RCPXXXX** concerning a patient with parkinsonism. Dr Y identified early morning slowness (akinesia) and planned to treat this with night-time slow-release levodopa (dopamine tablets). It was not evident that the patient was provided with any supportive information or signposting to other services.

iii. Inappropriate interactions

Some cases gave rise to concern that some of Dr Y's interactions with patients or family members were inappropriate.

For example, in case **RCPXXXX**, mentioned previously, the review team raised concern that Dr Y may have given incorrect telephone advice to the family to stop thyroxine. The patient was found to be extremely hypothyroid in 2018 just prior to death. The records indicated that family members stated they were told by neurology previously to stop the thyroxine treatment. At this stage the patient was bedbound and unable to communicate. Any changes to treatments made during telephone conversations should have been documented in the medical records. If Dr Y had given this advice, this was a serious error.

Another example arose from the concerns expressed by the patient's family relating to case **RCPXXXX**. This concerned a patient diagnosed with a progressive neurological condition. The patient's daughter approached Dr Y to request a letter from him which would allow her to assume power of attorney (POA) over her father's affairs. She stated that Dr Y asked her to draft this letter herself and forward to him for signature. The review team concluded that whilst it is common for doctors to involve family members in providing details for such letters, there are potential serious conflicts of interest, and such a letter should never be signed without first confirming with the patient that it reflects their wishes. The review team observed the relative's frustration over how difficult it was to achieve a POA and had no reason to doubt that she was acting in the patient's interests. However, Dr Y did not fulfil his responsibility to the patient in this instance. Good Medical Practice has the following expectation of doctors: *'You must work in partnership with patients, sharing with them the information they will need to make decisions about their care'*.¹¹

5.1.8 Clinical record keeping (including level of details in letters, notes of conversations)

The General Medical Council states that clinical records should include: *'relevant clinical findings, the decisions made and actions agreed, and who is making the decisions and agreeing the actions the information given to patients, any drugs prescribed or other investigation or treatment, who is making the record and when.'*¹²

5.1.8.1 Record review

- 55% (16 cases), were graded adequate care under this heading; 38% were graded poor care (nine cases) or very poor care (two cases). One case was graded good care. In one case there was insufficient evidence to reach a judgement.

The overriding theme was that Dr Y's clinical records tended to be brief. His letters were observed to be more detailed following consultations held in his private clinic. His NHS outpatient records tended to be

particularly brief. For example, for case **RCPXXXX**, Dr Y's assessment of the patient comprised of three lines, stating that the patient had partial epilepsy and he had started her on treatment, when the problem she had presented with was blackouts.

The review team noted that some family concerns related to record-keeping and perceptions that Dr Y did not refer to previous notes. More than one family concern referred to a tendency for Dr Y to write clinical details on 'scraps' of paper (for example, **RCPXXXX**). The review team could not establish the facts underpinning these concerns, however noted that it gave rise in some patients and their families to the impression that Dr Y was disorganised and was not taking their case seriously.

5.1.9 Diagnostic accuracy and potential patient harm

5.1.9.1 Record review

i. Diagnostic accuracy

The review team was asked to consider in each case whether the diagnosis made by Dr Y was secure. In over half of cases (55%, 16 cases), the review team believed the diagnosis was secure. In 45% (13 cases), the review team did not consider the diagnosis to have been secure.

In two cases the lack of diagnostic certainty did not reflect on Dr Y's abilities as a diagnostician. For case **RCPXXXX** there was no clear diagnosis, even after exhaustive investigations and consultations arranged at the National Hospital for Neurology and Neurosurgery (NHNN). For case **RCPXXXX**, Dr Y's approach to arriving at a diagnosis was appropriate, however the working diagnosis was complex and may have included some very rare conditions.

Four cases related to a diagnosis of seizures (**RCPXXXX,RCPXXXX,RCPXXXX,RCPXXXX**), which in each case were thought by the review team not to have been secure, suggesting that Dr Y's diagnosis of epilepsy may warrant further attention. Cases **RCPXXXX** and **RCPXXXX** both concerned blackouts that Dr Y managed, respectively, as vertebrobasilar migraine and seizures, without evidence that other possible causes had been excluded (particularly cardiovascular causes).

Two cases related to diagnosis of MS that were not secure: for **RCPXXXX** the diagnosis was not in keeping with diagnostic guidelines at that time; for case **RCPXXXX** the review team believed that the patient had secondary progressive MS and yet Dr Y used imprecise terminology to allude to a diagnosis of MS and lupus.

In two cases, Dr Y diagnosed or treated patients as if they had CIDP: **RCPXXXX** and **RCPXXXX**. In both instances, this diagnosis was incorrect by all diagnostic criteria.

For cases **RCPXXXX** and **RCPXXXX**, the diagnoses were not secure due to a lack of clinical information.

Case No.	Concerns that the diagnosis made by Dr Y was not secure
RCPXXXX	Dr Y made a diagnosis of focal seizures. There were potentially better alternative diagnoses and yet there was no evidence that Dr Y properly considered these or took sufficient steps to ensure that the diagnosis was as accurate as possible (e.g., arrange for an EEG). NICE guidelines for epilepsy in 2004 (the earliest date relevant guidance could be identified) – <i>The epilepsies: The diagnosis and management of the epilepsies in adults and children in primary and secondary care Clinical guideline [CG20]</i> – recommended that neuroimaging (preferably an MRI scan) should take place in suspected epilepsy. MRI scanning appeared to be available at that time as it was considered for use in this patient in 2002. The MRI may have shown the presence of a tumour, which was later identified. The patient did well on the treatment Dr Y prescribed for epilepsy and so his diagnosis was not revisited. Had Dr Y considered alternative diagnoses, then onward referral to a cardiologist may have been helpful. It is notable that a year after consulting Dr Y, the patient was found to have a heart rhythm disorder (atrial fibrillation).
RCPXXXX	Dr Y advised surgery to remove a cyst and prescribed anti-epileptic medication and yet the evidence suggested the patient was suffering from functional seizures (non-epileptic seizures). It was not evident that efforts were made to investigate his seizures when there was clear doubt as to the nature of his attacks. The patient was having very frequent events; it would have been very easy to record these events to confirm a diagnosis but this was not done.
RCPXXXX	There was no clear diagnosis, even after exhaustive investigations and consultations arranged at the NHNN.
RCPXXXX	The diagnosis was not secure; however, the working diagnosis was complex and may have included some very rare conditions. Dr Y's approach to arriving at a diagnosis was appropriate.
RCPXXXX	Dr Y was asked to provide a third opinion on a 'working/probable diagnosis' of MS. His diagnosis (of MS) was based on incomplete information and was not in keeping with diagnostic guidelines at the time. A subsequent, fourth opinion, did not believe the patient had MS.
RCPXXXX	Dr Y diagnosed vertebrobasilar migraine in a young patient, without evidence to demonstrate that other causes of the patient's blackouts had been excluded (such as referring the patient for specialist cardiovascular assessment).
RCPXXXX	Dr Y labelled the patient's blackouts as seizures and other causes still needed to be considered, particularly a cardiac cause.
RCPXXXX	The patient died within two months of having been assessed in Dr Y's clinic in November 2016 by a neurology registrar. The registrar's assessment was reviewed by Dr Y, who suggested an anti-epileptic medication. It appeared that Dr Y's assumption was that the patient had a cerebellar syndrome secondary to the previous head injury and he diagnosed minor seizures. The question should have been explored as to why the patient was getting worse (the head injury was in 2010) and why she should be having minor seizures (Dr Y's diagnosis). There were focal neurological signs and the notes indicated that these were new. There were no indications to prescribe an anti-epileptic drug.

Case No.	Concerns that the diagnosis made by Dr Y was not secure
RCPXXXX	Dr Y's Parkinson's diagnosis was secure, however his 'possible' diagnosis of CIDP (inflammation of nerves) was inaccurate.
RCPXXXX	There was evidence to support a diagnosis of parkinsonism. However, the nature of the exact underlying aetiology (i.e., cause of disease) was not clear due to the limited clinical information. The diagnostic uncertainty may have been improved with more detailed clinical information and investigation.
RCPXXXX	Dr Y diagnosed 'inflammatory neurological disease' and gave the indications for prescription as 'Lupus and MS', however the evidence was that the patient had secondary progressive MS.
RCPXXXX	Dr Y did not make a complete diagnosis other than to describe the patient as suffering from chorea, although he did mention the problem might be related to anti-phospholipid syndrome years later.
RCPXXXX	Dr Y initially diagnosed CIDP despite test findings and without arranging a lumbar puncture to confirm the diagnosis. He later considered MND to be most likely diagnosis, despite a lack of evidence to support this diagnosis and the signs of Parkinson's already identified. The diagnosis of multiple system atrophy made by another neurologist was supported by the clinical picture.

i. Potential patient harm

The review team was asked to consider for each case whether any concerns identified from the review gave rise to the opinion that, potentially, they could lead to some level of harm. In this context, harm was considered in the broadest sense, including any omissions in care that may have been to the detriment of the patient, such as failing to demonstrate holistic, supportive care that may have made the patient's condition and demise easier to manage.

In 16 cases, 55%, there was no concern regarding potential patient harm. However, in 13 cases, 45%, the review team identified concerns or omissions that the RQIA may wish to consider further for their potential to lead to harm.

For nine of the 13 cases⁺⁺⁺⁺, concerns regarding potential harm arose from a diagnosis that was not thought to be secure and therefore raised issues of potentially unnecessary exposure to treatments and medicines, often in high doses, and associated side effects. In the remaining four cases (RCPXXXX, RCPXXXX, RCPXXXX, RCPXXXX), concerns over potential harm arose from, respectively, Dr Y's approach to prescribing corticosteroids; an apparent failure to communicate effectively with the patient regarding the risk of sudden unexpected death; and his failure to refer the patient and family members to sources of support and allied health professionals.

++++ RCPXXXX, RCPXXXX, RCPXXXX, RCPXXXX, RCPXXXX, RCPXXXX, RCPXXXX, RCPXXXX, RCPXXXX

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The table below sets out details of the concerns or omissions relevant to these 13 cases.

Case No.	Potential patient harm
RCPXXXX	The RQIA should consider the potential for harm arising from what appeared to be an unnecessary neurosurgical procedure (to remove an arachnoid cyst, without first confirming that a diagnosis of epileptic seizures due to the cyst was secure), together with an apparent failure to refer the patient to appropriate services to help manage his problems. The review team could not understand why this patient was prescribed high doses of benzodiazepines and narcotics, in addition to high dose medications for epilepsy, when this diagnosis was not secure.
RCPXXXX	The RQIA should consider the potential for harm arising from the persistent use of corticosteroids in this patient, who developed weight gain and a Cushingoid appearance, with the associated risks of skin thinning, high blood pressure and osteoporosis.
RCPXXXX	The RQIA should consider the potential for harm arising from Dr Y's failure to provide a robust diagnosis, which led to unnecessary treatments and investigations for the patient towards the end of life when potentially he could have benefited from palliative care.
RCPXXXX	The RQIA should consider the potential for harm arising from the absence of evidence that the patient was involved in decisions about her care or was provided with information about issues specific to women with epilepsy or support resources, or the risks associated with seizures including Sudden Unexpected Death in Epilepsy.
RCPXXXX	The RQIA should consider the potential for harm arising from an insecure diagnosis of vertebrobasilar migraine. It was possible that a potentially treatable cause was missed, and this may have had harmful consequences for this young patient. The symptom of sudden blackout is not a symptom of vertebrobasilar migraine.
RCPXXXX	The RQIA should consider the potential for harm arising from Dr Y's labelling of this patient's blackouts as seizures. Cardiac investigations needed to be documented and reviewed. Dr Y should have captured events (e.g., no record of EEG); instead, he stuck to a diagnosis and never confirmed that they were seizures.
RCPXXXX	The RQIA should consider the potential for harm arising from the apparent absence of referral by Dr Y to allied health professionals, who could have provided the patient with more supportive care during their trajectory of decline. The patient had an increased risk of falls and aspiration pneumonia, and involvement of allied health professionals could have helped in managing these risks.
RCPXXXX	The RQIA should consider the potential for harm arising from the delay in the patient receiving the correct diagnosis, in terms of denying the patient and her family the opportunity to come to terms with the diagnosis, make appropriate plans and receive palliative care.
RCPXXXX	The RQIA should consider the potential for harm arising from Dr Y's treatment of the patient with weekly B12 injections even when the B12 levels were replete and his treatment of the patient with IV immunoglobulins even though the diagnosis of CIDP was incorrect. The RQIA may also wish to consider the family's concern indicated that Dr Y caused harm by offering a treatable diagnosis in the face of a deteriorating

Case No.	Potential patient harm
	neurological disease and therefore offering the patient hope that was without foundation.
RCPXXXX	The RQIA should consider the potential for harm arising from a lack of information and support, together with the unnecessarily delayed diagnosis of MS, which caused the patient anxiety. The family's concerns articulated the impact on the patient's daughters.
RCPXXXX	The RQIA should consider the potential for harm arising from the lack of timely onward referral of the patient to allied health professionals, such as neurophysiotherapy, for falls prevention or to speech and language therapy for early management of dysphagia (swallowing problems), which could have helped the patient to manage their symptoms.
RCPXXXX	The RQIA should consider the potential for harm arising from an inaccurate diagnosis made by several clinicians, including Dr Y, which led to the patient being exposed to unnecessary and potentially dangerous treatments.
RCPXXXX	The RQIA should consider the potential for harm arising from Dr Y's apparent failure to: pinpoint the diagnosis and establish whether there was a treatable cause; organise ongoing care; communicate honestly with the patient and her family; and signpost what to do if her condition deteriorated. The review team was particularly concerned as to the impact stopping the thyroxine may have had on the patient's health.

ii. Referral to a medical examiner or coroner

The review team considered the certified cause of death in the records in light of the stated diagnosis and any concerns raised during review of the clinical records. For most cases, 83% (24 cases), the review team did not consider that the RQIA should refer the case to a medical examiner or coroner. However, in five instances, the review team believed the RQIA should consider review of death certification or referral to a medical examiner or coroner.

Case No.	Referral to a medical examiner or coroner
RCPXXXX	The death certificate specifically stated CIDP, which the review team concluded was an incorrect diagnosis.
RCPXXXX	The review team considered the certified causes of death to have been incorrect. The review team concluded that the phrase ' <i>inflammatory demyelination</i> ' (as on the death certificate) was used as a way of avoiding stating a diagnosis of MS. There was evidence that several clinicians, including Dr Y, made an inaccurate diagnosis that led to the patient being exposed to unnecessary treatments.
RCPXXXX	The family raised concerns over the death certificate, which was not as precise or complete as it could be and did not mention parkinsonism.
RCPXXXX	The death certificate needed to document the patient's neurological condition as the antecedent cause of her death.

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RCPXXXX	The neurological condition (moyamoya disease ^{***}) should have been recorded on the death certificate.
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*** Moyamoya disease is a progressive cerebrovascular disorder caused by blocked arteries at the base of the brain, which can cause strokes.

5.2 Terms of reference 2

Whilst the clinical record review is progressing, the RQIA will liaise with the families and carers of patients to complete a form requesting details of the key areas of concern (provided separately). Following completion of the record review, the RCP review team will then consider whether, based on the information available, the key areas of concerns for each case are upheld, partially upheld or not upheld.

The review team will highlight any lessons to be learned and recommend appropriate actions (where relevant) and provide an individual case summary for each patient reviewed.

5.2.1 Overall decisions on complaints

Review team’s decisions on concerns raised by family/relatives/carers	
Upheld: the concern is supported by the information provided	RCPXXXX, RCPXXXX, RCPXXXX, RCPXXXX, RCPXXXX, RCPXXXX, RCPXXXX, RCPXXXX, RCPXXXX, RCPXXXX
Partially upheld: some aspects of the complaint were supported by the information provided, but not all the issues that were complained about or the mistakes made did not have a negative impact on the patient	RCPXXXX, RCPXXXX, RCPXXXX, RCPXXXX, RCPXXXX, RCPXXXX, RCPXXXX, RCPXXXX
Not upheld: either the information provided does not support the concern raised or there is insufficient information available to make a judgement	RCPXXXX, RCPXXXX
No concerns raised with RQIA by family/relatives/carers	RCPXXXX, RCPXXXX, RCPXXXX, RCPXXXX, RCPXXXX, RCPXXXX

5.2.1.1 Record review

- Of the 23 cases where concerns were raised by relatives or carers, 11 were upheld in full, 10 were partially upheld, and two were not upheld.

The review team was profoundly moved by the accounts provided by families of the care provided to their loved one.

The review team accepted the accounts provided as an accurate description of the family’s experience. The exception was **RCPXXXX** where there was a discrepancy between the complaint and evidence that scans were carried out in Belfast. In deciding whether concerns were upheld or not, the intention was never to appear dismissive of a family concern, but instead to provide a structure to identify problems. In the instances where the complaint, or aspects of it, were not upheld, this often reflected that the concerns expressed by relatives that the patient might have had a different outcome had they been diagnosed sooner or received different treatment, were not shared by the review team. In such situations, it is hoped that the decision not to uphold the complaint (or aspects of it), will provide some reassurance to family members.

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The most upsetting aspect of the family concerns related to Dr Y's interactions with patients and family members. A lack of openness regarding the diagnosis has already been highlighted. The family concerns often described a doctor who was unhelpful and at times rude in his interactions.

For example, **RCPXXXX** the concerns raised by the family indicated that Dr Y used language that failed to convey empathy for the patient and his situation. The experience detailed in the family concerns was a stark departure from the neurological care that the review team would expect from their own hospitals or for any neurology patient.

Family concerns raised in relation to **RCPXXXX** included that whilst the patient was in the high dependency unit Dr Y made no attempt to visit her and failed to have any face-to-face contact with her family. The family spoke of *'a sense of abandonment and distinct lack of compassion'*.

Failures by Dr Y to effectively communicate with patients and family members were most evident where family members had unresolved questions over their loved one's diagnosis and the potential genetic impact.

There were several cases where the review team concluded that further follow up is required by the RQIA and/or the Trust.

Case No.	Follow up required
RCPXXXX	The suggestions made by the parents for oversight of consultants' caseloads and prescribing were constructively made and the Trust should revisit this case to identify learning to ensure high quality care for future patients and their families.
RCPXXXX	The patient's wife articulated an unresolved concern regarding her husband's diagnosis and any potential hereditary impact on their children and grandchildren. The review team believed the diagnosis was probably primary progressive MS, which is not thought to have a significant genetic component and therefore poses little increased risk to the children. The review team concluded that the family should be given an opportunity to discuss this further with an experienced neurologist.
RCPXXXX	The review team concluded that the findings of the post-mortem should be shared with the family and their questions regarding inherited risk should be answered by an experienced neurologist, as part of a two-way discussion.
RCPXXXX	The patient's wife described the sort of service she would like to see offered to people with MS. The review team was in full agreement with the nine points made, most of which are reflected in the NICE guidelines on MS. The RQIA should consider how best to share these suggestions with neurologists in Belfast.
RCPXXXX	There can be a genetic component to the neurological disorder that the patient had, which the family should be made aware of. The review team recommended that the RQIA should arrange for the family to discuss the patient's neurodegenerative condition with an experienced neurologist, who can provide them with further explanation about the diagnosis.
RCPXXXX	The family concerns raised questions over why the Trust allowed Dr Y to practise unsupervised whilst he was under investigation, and also whether the patient had a blood patch procedure, or a spinal tap performed. The RQIA will need to approach the Trust regarding these questions.

Case No.	Follow up required
RCPXXXX	A post-mortem carried out in 2017 clearly established that the patient had both MS and MND. The review team was concerned that this information had not been communicated adequately to the family. The risks to the daughters are very low and should be discussed with them by an experienced neurologist as part of a two-way discussion.
RCPXXXX	The family concerns raised questions over why Dr Y was still treating patients during 2016/2017 when his practice had been restricted. The patient's daughter believed that information regarding Dr Y's restricted practice should have been shared with patients and their families as this would have enabled them to seek alternative care and may have meant that any problems could have been prevented or at least better-informed decisions could have been made. The review team could not answer this question and recommended that the RQIA approached the Trust for a response.

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Invited Reviews

Report of the clinical
record review for

Regulation and Quality
Improvement Authority
(RQIA)

Cohort 2

This report is the property of the healthcare
organisation responsible for the commission
of this invited review

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This report has been prepared by the Royal College of Physicians (RCP), with the support of the Association of British Neurologists, under the RCP Invited Reviews (IRs) mechanism for submission to the healthcare organisation that commissioned the invited review. It is an advisory document, and it is for the healthcare organisation concerned to consider any conclusions and recommendations reached and to determine subsequent action.

It is the responsibility of the healthcare organisation to review the content of this report and take any action that is considered appropriate to protect patient safety. The healthcare organisation should ensure that patients have received communication in line with the responsibilities set out in the Health and Social Care Act 2008 (Regulated activities) Regulations 2014, Regulation 20.¹

The Regulation and Quality Improvement Authority (RQIA) has anonymised the case numbers in this report to protect the identity of individual patients.

1 Executive summary

This is the second of two linked reviews commissioned by the Regulation and Quality Improvement Authority (RQIA), which is the independent body responsible for monitoring and inspecting the availability and quality of health and social care services in Northern Ireland, and encouraging improvements in the quality of those services. The review arises from a recall in 2018, of 2,500 patients who had been under the care of a specific consultant neurologist, referred to throughout this report as Dr Y. The recall was instigated by the Belfast Health and Social Care Trust at which Dr Y had worked until mid-2017, following the Trust's internal review process and subsequent request to the RCP to review a series of patients who had been under his care. Patients who had consulted Dr Y privately were also included in the recall.

In May 2018, the Permanent Secretary in Northern Ireland requested that the RQIA should conduct an expert review of clinical records of all patients or former patients of Dr Y in the preceding 10 years. The RQIA planned to undertake this review in a staged process to maximise learning. The first stage was to review the clinical records of 29 deceased patients identified by the RQIA following concerns raised by the patients' relatives about the care provided by Dr Y. The second stage was to review the clinical records of 16 deceased patients, who were selected for review as they were due to be seen as part of the recall but sadly died before this could happen. The clinical records covered entries made in the patients' notes, as well as clinical letters written after an outpatient consultation. The RCP and the Association of British Neurologists agreed to conduct the clinical record review under the auspices of the invited review service.

This second review reinforced concerns identified in the previous review, with respect to Dr Y's clinical decision-making, diagnostic approach and prescribing; his communication with clinical colleagues; and his interactions with patients and their families. As for the first review, all the patients in this case selection were deceased and some had died of degenerative neurological conditions such as Parkinson's disease, however none of the patients in this sample were diagnosed with motor neurone disease. Fewer patients in this sample appeared to have seen Dr Y privately. Another feature that was different in this review was that concerns were raised by relatives of patients for only two cases.

The review team could not identify that Dr Y had any involvement in one case, so the review team's ratings related to the remaining 15 cases. Across these 15 cases, two were considered to have represented good practice in terms of the overall quality of neurology care provided. The rest were graded either unsatisfactory (eight cases) or room for improvement for clinical reasons (five cases). The review team's conclusions provide further details of the reasons underpinning these gradings.

The particular significance of these findings was that the sample was considered because the patients in this cohort had died before they could be recalled and were not generally associated with concerns. Yet, more than half of the 15 cases – 53% (eight cases) – were found to be unsatisfactory, which meant the review team identified several aspects of care that were well below expected standards. Almost as many were room for improvement, which meant that aspects of the clinical care provided could have been better. Therefore, the quality of care provided to this group of patients was for the majority below the standard expected. The RQIA will need to consider the implications of this for other patients who died while under follow up by Dr Y.

This cohort of cases also gave rise to greater concern than the other (RQIA 1) review regarding Dr Y's diagnosis of epilepsy. The specialist neurology reviewers were mindful that epilepsy clinics were known

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to have some patients who may not actually have a diagnosis of epilepsy. Given this, investigations were important to confirm diagnosis. Dr Y's diagnosis and management of epilepsy fell well short of expectations in this respect. He demonstrated a tendency to diagnose epilepsy quickly, at the first consultation, and without arranging investigation to confirm his suspicions. The RQIA will need to consider whether these findings warrant further attention to cohorts of patients who were diagnosed by Dr Y with epilepsy.

Another area of concern – which was seen in the first review – related to Dr Y's diagnosis of neuropathies, specifically chronic inflammatory demyelinating polyneuropathy (CIDP)*. For the single case contained in this sample, the review team considered Dr Y's reasoning for reaching this diagnosis hard to follow; other clinicians clearly had differing opinions and yet Dr Y arranged for ten admissions for the patient to receive an expensive treatment that the reviewers believed was unnecessary. This mirrored the findings of the first review, in which concern was raised over two cases in which Dr Y diagnosed CIDP and which the review team considered to have been incorrect in both cases. The RQIA will need to consider whether these findings warrant further attention to cohorts of patients who were diagnosed by Dr Y with CIDP or similar neuropathies.

The review team was asked to consider for each case whether any concerns identified gave rise to the opinion that, potentially, they could lead to some level of harm. In this context, harm was considered in the broadest sense, including any omissions in care that may have been to the detriment of the patient, such as failing to demonstrate holistic, supportive care that may have made the patient's condition and demise easier to manage. In nine cases, 60%, the review team identified concerns or omissions that the RQIA may wish to consider further for their potential to lead to harm. In several cases, concerns regarding potential harm arose from a diagnosis that was not thought to be secure and therefore raised issues of potentially unnecessary exposure to medicines, often in high doses, and associated side effects. The review team was particularly concerned about one case, concerning a patient who had repeated falls and died from a traumatic brain injury due to a fall. The review team questioned whether the sedative effect of the anti-epileptic medication Dr Y prescribed for this patient may have been a contributory factor. This was compounded by the review team's conclusion that the diagnosis of epilepsy was not secure.

* CIDP is a rare type of autoimmune disorder where the body attacks the myelin sheaths that insulate and protect the nerves.

2 Conclusions

The review team was asked to consider in each case whether or not the diagnosis made by Dr Y was secure. In over half of cases (60%, nine cases), the review team believed the diagnosis was secure. In the remaining six cases the review team did not consider the diagnosis to have been secure. Five of these six cases related to diagnoses of epilepsy, and the review team observed that Dr Y's documentation lacked detail to support this diagnosis, such as examination or a description of the episodes the patient was said to be having. A theme across these cases was a failure by Dr Y to document having arranged investigations (such as electroencephalogram (EEG)[†] or telemetry[‡]) to confirm the diagnosis of epilepsy, or to demonstrate consideration of other diagnoses, particularly when the patient's condition did not respond to anti-epileptic medications.

In nine cases, 60%, the review team identified concerns or omissions that the RQIA may wish to consider further for their potential to lead to harm. For six of the nine cases, concerns regarding potential harm arose from a diagnosis that was not thought to be secure and therefore raised issues of potentially unnecessary exposure to medicines, often in high doses, and associated side effects. The review team was particularly concerned about one case, concerning a patient who had repeated falls and died from a traumatic brain injury due to a fall. The review team questioned whether the sedative effect of the anti-epileptic medication Dr Y prescribed for this patient may have been a contributory factor. This was compounded by the review team's conclusion that the diagnosis of epilepsy was not secure. In the remaining three cases, concerns over potential harm arose from, respectively, Dr Y's apparent failure to communicate effectively with the patient and family members; his decision not to pursue advanced therapy options; and his failure to refer the patient to sources of support and allied health professionals.

The review team considered the certified cause of death in the records in light of the stated diagnosis and any concerns raised during review of the clinical records. For most cases, 80% (12 cases), the review team did not identify any concerns with the recorded cause of death. However, in three instances, the review team identified concerns with the death certificate, as set out at [section 5.1.7](#). Consideration should be given specifically to case RCP2039.

The review team concluded that for nine of the 15 cases (60%) Dr Y's ongoing management and treatment of the patient was not appropriate. A recurring theme was that Dr Y did not arrange for investigations to confirm his diagnosis, often in cases of suspected epilepsy, and did not demonstrate consideration of other possible diagnoses despite the patient's poor response to medications. Dr Y often reviewed patients frequently and yet sometimes his approach to the management of the patient's condition was cursory and overly focused on changing prescribed medicines. In some cases, failures in management of the patient related to the absence of evidence that Dr Y referred the patient to other sources of support, such as a Parkinson's disease nurse, physiotherapy, or speech and language therapy.

The review team concluded that Dr Y's prescribing decisions had been appropriate in nine of the 15 cases (60%). Concerns were raised with the appropriateness of prescribing in six cases (40%). In all six cases these concerns aligned with the review team's finding that the diagnosis was not secure and therefore it followed that the prescribing was problematic. Five of these six cases related to diagnoses of epilepsy and issues were highlighted with Dr Y's approach to prescribing epilepsy medication,

[†] A recording of brain activity www.nhs.uk/conditions/electroencephalogram

[‡] Telemetry is a test that looks at the function of the brain.

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including omissions in terms of documenting potential side effects or having counselled patients about these. Dr Y sometimes did not allow prescribed anticonvulsant drugs to take effect, before switching to another medication prematurely, and to repeatedly change a patient's anti-epileptic medication without reviewing the diagnosis. The last case where the review team concluded Dr Y's prescribing had not been appropriate related to a suspected diagnosis of CIDP. The patient had at least ten admissions for intravenous immunoglobulin (IVIg)[§] that the review team believed were unnecessary, would not have benefitted the patient and were associated with significant costs both to the patient and the system.

The review team concluded that Dr Y's communication with colleagues was generally poor care (five cases, 33%) or very poor care (five cases, 33%). Four cases were graded adequate care. One case was graded excellent care, but this reflected excellent communication between the neurosurgical and neuro-oncology service and there was little evidence of Dr Y's communication with colleagues. In several cases, a very poor grading reflected a lack of communication with colleagues involved in the patient's care. In one instance, there was a suggestion that Dr Y had demonstrated a wilful failure to communicate with a Parkinson's disease specialist nurse whom he was said to dislike. Other clinicians (for example, an immunologist) highlighted a lack of response from Dr Y. There were also instances where Dr Y demonstrated disregard for the differing opinions of his neurology colleagues at the Trust and at the National Hospital for Neurology and Neurosurgery (NHNN) in London. Such cases created an impression that, at times, Dr Y acted deliberately not to communicate with colleagues. A poor or very poor care grading sometimes reflected an absence of evidence to demonstrate that the patient had been referred to any support services or to other health professionals.

The review team concluded that, across the 15 cases, the records indicated that Dr Y's interactions with patients and their family members was overwhelmingly poor, with most cases graded poor care (six cases, 40%) or very poor care (five cases, 33%) under this heading. No cases were graded adequate or good care. In four cases there was insufficient evidence to reach a judgement. The two cases where concerns were raised by family members gave rise in the first case to the impression of an overly casual and unprofessional approach to some of his interactions. In the second case, there was a lack of documentation to demonstrate that Dr Y advised the patient about possible treatment plans or discussed treatment options, and he was reported to be unresponsive to the patient's requests to review her medications given the side effects she was experiencing.

In several cases, the grading of poor or very poor care reflected the absence of evidence that Dr Y explained the diagnosis and prognosis to the patient or documented the patient's wishes, or the potential side effects of medicines he prescribed. Such cases suggested that Dr Y failed to communicate effectively with the patient or share information to enable the patient to participate in decisions about treatment or to enable advanced care planning.

Eight cases were graded adequate care in terms of clinical record keeping. Six cases were graded very poor care and one case was poor care. Across the cases, Dr Y's approach to clinical record keeping tended to be brief. Where cases were graded poor or very poor care under this heading it largely reflected that the review team could not identify that important information was documented. In several instances the grading reflected that Dr Y did not document the findings of an examination, even following a first consultation with the patient. Sometimes his clinical records were so brief that they contained no explanation of his clinical decisions, which made the rationale for his treatment decisions hard to follow. The review team also identified omissions in Dr Y's record keeping with respect to documenting the potential side effects of medicines.

[§] IVIg involves giving immunoglobulin straight into the blood via a cannula in a vein. Each treatment can take several hours.

There were only two cases in this cohort where concerns were raised with the RQIA by relatives or carers of the patient. In both instances, the families provided credible and troubling accounts of care that fell below the standards expected of a doctor as defined in *Good Medical Practice*².

3 Recommendations

Key for timelines for implementing recommendations:

- > **Short term (0-6 months)** - action should be completed within 6 months of receipt of the invited review report
- > **Medium term (6-12 months)** – action should be completed within 12 months of receipt of the invited review report. Planning for actions resulting from these recommendations should start as soon as possible.
- > **Long term (12-24 months)** - action should be completed within 24 months receipt of the invited review report. Planning for actions resulting from these recommendations should start as soon as possible.

Recommendation	Timelines
a. The RQIA will need to consider the implications of the finding of this review that more than half of the 15 cases – 53% (eight cases) – were found to be unsatisfactory, for its wider consideration of the cases included in the recall of patients who died.	Short term (0-6 months)
b. The RQIA should consider the potential for harm arising from concerns identified by the review teams with respect to the following cases: RCPXXXX, RCPXXXX, RCPXXXX, RCPXXXX, RCPXXXX, RCPXXXX, RCPXXXX, RCPXXXX, RCPXXXX.	Short term (0-6 months)
c. The RQIA should consider how to respond to the concerns identified by the review team with respect to the recorded cause of death in cases RCPXXXX, RCPXXXX and RCPXXXX.	Short term (0-6 months)
d. The RQIA should share the review team’s concerns regarding the management of case RCPXXXX with this patient’s family members. This case concerned a patient who committed suicide. The review team graded this case unsatisfactory and believed its findings should be shared with the family.	Short term (0-6 months)
e. The RQIA will need to consider whether these findings warrant further attention to cohorts of deceased patients who were diagnosed by Dr Y with epilepsy.	Medium term (6-12 months)
f. The RQIA will need to consider whether the findings in this review relating to a single case of neuropathy (CIDP), when combined with two cases of concern in the previous review, warrant further attention to cohorts of deceased patients who were diagnosed by Dr Y with CIDP or similar neuropathies.	Medium term (6-12 months)
g. The RQIA should consider making it mandatory for clinicians in Northern Ireland to copy most outpatient clinics letters to patients. The Academy of Medical Royal Colleges goes further and encourages doctors to write most of their outpatient letters directly to patients and send a copy of the letter to the patient’s general practitioner (GP). See: www.aomrc.org.uk/reports-guidance/please-write-to-me-writing-outpatient-clinic-letters-to-patients-guidance/	Long term (12-24 months)

<p>h. The RQIA should consider the wider implications of this review for clinicians working in an isolated way. Whilst the findings here are specific to neurological services, the RQIA should consider whether health services in Northern Ireland are able to demonstrate the type of multidisciplinary team working and culture of open and constructive challenge expected from contemporary health services.</p>	<p>Long term (12-24 months)</p>
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4 Introduction and background

On 1 May 2018, the Belfast Health and Social Care Trust ('the Trust') announced a recall of approximately 2,500 patients who had been under the care of consultant neurologist Dr Y following concerns regarding his clinical management. The recall was instigated following the Trust's internal review process and subsequent request to the RCP to review a series of patients who had been under the care of Dr Y. The Trust's review culminated in Dr Y ceasing all patient care and treatment in the summer of 2017. It is noted that patients who had seen Dr Y privately were also included as part of the recall.

In May 2018, the Permanent Secretary in Northern Ireland requested that the RQIA should conduct an expert review of clinical records of all patients or former patients of Dr Y in the preceding 10 years. A formal direction of this was also issued by the Chief Medical Officer on 10 May 2018. The RQIA was directed to commission a review of the above by the Department of Health (DOH) and planned to do so in a staged process to maximise learning.

The first stage was to review the clinical records of 29 deceased patients identified by the RQIA. The focus of this review was to consider the clinical records (including clinical letters following consultations) of 16 deceased patients identified by the RQIA. These 16 patients were selected for review as they were due to be seen as part of the recall but died before this could happen.

The RQIA discussed this matter with the RCP on several occasions. The RCP and the Association of British Neurologists agreed a review under the auspices of the invited review service would be appropriate.

4.1 Terms of reference for this clinical record review

This review will take place in two stages: an independent review of the clinical records followed by consideration of the concerns raised about the care received by patients.

1. The RCP will provide an independent and expert review of 16 patients and former patients of Dr Y using a structured judgement review (SJR) tool and assess the overall quality of neurology care provided to those patients by Dr Y.

Consideration will be given to:

- The initial investigations and choice of treatment options
- Whether the diagnosis was secure?
- Whether the ongoing management and treatment of the patient was appropriate?
- Whether the prescribing was appropriate?
- Follow up arrangements in place
- Communication with colleagues and MDT working
- Communication with the patient and/or their family/carers
- Clinical record keeping
- Whether there are any concerns about the impact of the care and treatment provided by Dr Y and which may have resulted in potential patient harm?

- Where the clinical records indicate the likely cause of death, the RCP reviewers will also provide their considered view. If there is a significant difference of opinion, this information may subsequently signpost the RQIA to refer to a medical examiner or coroner to reconsider the case.

In reviewing the overall care, the review team will take into account whether this is in line with national good practice and guidelines.

2. The RQIA will liaise with the families and carers of patients in this group to discuss whether they wish to share any concerns with the RCP review team. Those that do will be asked to complete a form requesting details of the key areas of concern (provided separately). The RCP review team will then consider whether, based on the information available, the key areas of concerns for each case are upheld**, partially upheld** or not upheld**.

The review team will highlight any lessons to be learned and recommend appropriate actions (where relevant) and provide an individual case summary for each patient reviewed.

The RCP will recommend that the final report is shared with the Department of Health and other relevant external stakeholders.

4.2 Approach to this review

The RCP consulted with the Association of British Neurologists, which nominated specialist reviewers. The RCP convened a review team, as set out in [Section 4.3](#).

The RCP was provided with clinical records for 16 patients, as detailed in the terms of reference ([Section 4.1](#)). Each of the 16 cases was considered independently by a specialist clinical reviewer (see [Section 4.3](#) for details of the review team). Each reviewer used a structured form adapted from the [RCP National Mortality Case Record Review \(NMCRR\) programme](#)³ to independently examine phases of care that the patients received. These were graded by the reviewers as **1 = very poor care; 2 = poor care; 3 = adequate care; 4 = good care, or 5 = excellent care**. The reviewers also utilised a [grading system](#)⁴ developed by the [National Confidential Enquiry into Patient Outcome and Death \(NCEPOD\)](#)⁵ to give an overall perspective on the quality of care provided. This considers both clinical and organisational care. The overall gradings were as follows: **good practice, room for improvement – clinical, room for improvement – organisational, room for improvement – clinical and organisational, unsatisfactory, insufficient information**.

The terms of reference were to consider the clinical case records in the absence of any information relating to the family concerns, and then once this stage had been completed, to consider the family concerns. However, the RQIA shared **family concerns relating to only two cases** – no concerns were raised by family members with respect to the remaining 14 cases. Therefore, the clinical records were reviewed at the same time as the family concerns for these two cases.

** Upheld – the concern is supported by the information provided

** Partially upheld – some aspects of the complaint were supported by the information provided, but not all the issues that were complained about or the mistakes made did not have a negative impact on the patient.

** Not upheld – either the information provided does not support the concern raised or there is insufficient information available to make a judgement.

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Having independently reviewed the cases, the reviewers presented them at virtual meetings held on **27 and 29 October 2021**. The meetings were chaired by the immediate past medical director for invited reviews, supported by the current medical director for invited reviews and by the RCP review manager, who has extensive experience as a lay reviewer and health analyst. Each case was considered in turn, the specialist reviewers presented their views, followed by a ‘confirm and challenge’ discussion to agree the grading of phases of care and the overall care. In making judgements about the overall care provided to the patient, the review team considered national good practice and guidelines.

4.3 Invited review team

	Role
	Past Medical Director
	Medical Director
Expert Reviewer 1	Consultant neurologist, independent expert, external to N Ireland
Expert Reviewer 2	Consultant neurologist, independent expert, external to N Ireland
Expert Reviewer 3	Consultant neurologist, independent expert, external to N Ireland
	Lay reviewer and review manager

Quality assurance of this report was provided by clinical representatives of the RCP the Association of British Neurologists and two independent lay people.

5 Findings

5.1 Terms of reference 1

1. The RCP will provide an independent and expert review of 16 patients and former patients of Dr Y using a structured judgement review (SJR) tool and assess the overall quality of neurology care provided to those patients by Dr Y.

Consideration will be given to:

- The initial investigations and choice of treatment options
- Whether the diagnosis was secure?
- Whether the ongoing management and treatment of the patient was appropriate?
- Whether the prescribing was appropriate?
- Follow up arrangements in place
- Communication with colleagues and MDT working
- Communication with the patient and/or their family/carers
- Clinical record keeping
- Whether there are any concerns about the impact of the care and treatment provided by Dr Y and which may have resulted in potential patient harm?
- Where the clinical records indicate the likely cause of death, the RCP reviewers will also provide their considered view. If there is a significant difference of opinion, this information may subsequently signpost the RQIA to refer to a medical examiner or coroner to reconsider the case.

In reviewing the overall care, the review team will take into account whether this is in line with national good practice and guidelines.

5.1.1 Overall rating for quality of care

5.1.1.1 Record review

The RQIA provided the RCP review team with access to the clinical records for 16 deceased patients. The records were accessed via a secure RQIA server. The review team experienced several challenges with these access arrangements, which required considerable additional IT support. The review team could not identify that Dr Y had any involvement in case RCPXXXX, leaving 15 cases the focus of this review.

As for the first linked review, all the patients in this case selection were deceased and some had died of degenerative neurological conditions such as Parkinson's disease. In contrast to the previous review, none of the patients in this sample were diagnosed with motor neurone disease. Fewer patients in this sample appeared to have seen Dr Y privately. In two cases, the patient had at least one consultation with Dr Y in the private sector^{§§}. It was possible that other patients had consultations in the private sector, but this was not identified from the records. Another feature that was different in this review was that concerns were raised by relatives of patients for only two cases (RCPXXXX and RCPXXXX). In terms of the overall quality of neurology care provided to the 15 patients by Dr Y, two cases were considered to have represented good practice. The rest were graded either unsatisfactory (eight cases) or room for improvement for clinical reasons (five cases).

^{§§} RCPXXXX, RCPXXXX

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The review team's overall gradings for the quality of care provided across the 15 cases were as follows:

Clinical reviewer's overall perspective on quality of care	
Good practice: a standard you would accept from yourself, your trainees and your institution.	RCPXXXX, RCPXXXX
Room for improvement: aspects of <u>clinical care</u> that could have been better.	RCPXXXX, RCPXXXX, RCPXXXX, RCPXXXX, RCPXXXX
Room for improvement: aspects of <u>organisational care</u> that could have been better.	
Room for improvement: aspects of both <u>clinical and organisational care</u> that could have been better.	
Unsatisfactory: Several aspects of clinical and/or organisational care that were well below that you would accept from yourself, your trainees and your institution.	RCPXXXX, RCPXXXX, RCPXXXX, RCPXXXX, RCPXXXX, RCPXXXX, RCPXXXX, RCPXXXX
Insufficient information available to make an assessment of quality of care.	

In addition to grading the overall quality of neurology care provided to the 15 patients, the review team graded the distinct aspects of care. This provided an understanding of areas of strength or weakness in terms of Dr Y's clinical care. As the table below shows, the evidence indicated that Dr Y's interactions with patients and their family members was overwhelmingly poor, with no cases graded adequate or good care. His clinical record keeping was either very poor or adequate, with one case in-between these two gradings. Dr Y's communication with colleagues was generally poor care (five cases) or very poor care (five cases), although four cases were graded adequate care, and one was excellent care. Clinical record keeping was either adequate (eight cases) or very poor care (six cases).

	Very poor care (1)	Poor care (2)	Adequate care (3)	Good care (4)	Excellent care (5)	Insufficient evidence
Communication with colleagues	RCPXXXX RCPXXXX RCPXXXX RCPXXXX RCPXXXX	RCPXXXX RCPXXXX RCPXXXX RCPXXXX RCPXXXX	RCPXXXX RCPXXXX RCPXXXX RCPXXXX		RCPXXXX	
Interactions with patients and their family	RCPXXXX RCPXXXX RCPXXXX RCPXXXX RCPXXXX	RCPXXXX RCPXXXX RCPXXXX RCPXXXX RCPXXXX				RCPXXXX RCPXXXX RCPXXXX RCPXXXX
Clinical record keeping	RCP2037 RCP2038 RCP2039 RCP2044 RCP2045 RCP2046	RCP2032	RCPXXXX RCPXXXX RCPXXXX RCPXXXX RCPXXXX			

	Very poor care (1)	Poor care (2)	Adequate care (3)	Good care (4)	Excellent care (5)	Insufficient evidence
			RCPXXXX RCPXXXX			

Having graded each case, the review team was asked to consider whether the diagnosis reached by Dr Y was secure – i.e., likely to be accurate, based on the available clinical information. In nine of the 15 cases (60%), the review team believed that the diagnosis was secure. For six cases (40%), the diagnosis was not secure. This does not necessarily indicate that it was a misdiagnosis, but that Dr Y did not undertake sufficient steps (such as investigations or witness accounts of a seizure) to make the diagnosis secure. The review team also considered whether any concerns or omissions identified by the review team could have resulted in potential patient harm. In nine of the 15 cases (60%), the review team identified concerns or omissions that the RQIA should consider further to assess the potential for harm. Concerns with the recorded cause of death were identified in three cases. The reasons underpinning these decisions are outlined at [section 5.1.7](#).

	Yes	No
Was the diagnosis secure?	RCPXXXX, RCPXXXX, RCPXXXX, RCPXXXX, RCPXXXX, RCPXXXX, RCPXXXX, RCPXXXX, RCPXXXX	RCPXXXX, RCPXXXX, RCPXXXX, RCPXXXX, RCPXXXX, RCPXXXX
Was the ongoing management and treatment appropriate?	RCPXXXX, RCPXXXX, RCPXXXX, RCPXXXX, RCPXXXX, RCPXXXX	RCPXXXX, RCPXXXX, RCPXXXX, RCPXXXX, RCPXXXX, RCPXXXX, RCPXXXX, RCPXXXX, RCPXXXX
Was the prescribing appropriate?	RCPXXXX, RCPXXXX, RCPXXXX, RCPXXXX, RCPXXXX, RCPXXXX, RCPXXXX, RCPXXXX, RCPXXXX	RCPXXXX, RCPXXXX, RCPXXXX, RCPXXXX, RCPXXXX, RCPXXXX
Could any concerns have resulted in potential patient harm?	RCPXXXX, RCPXXXX, RCPXXXX, RCPXXXX, RCPXXXX, RCPXXXX, RCPXXXX, RCPXXXX, RCPXXXX	RCPXXXX, RCPXXXX, RCPXXXX, RCPXXXX, RCPXXXX, RCPXXXX
Any concerns with the recorded cause of death?	RCPXXXX, RCPXXXX, RCPXXXX	RCPXXXX, RCPXXXX, RCPXXXX, RCPXXXX, RCPXXXX, RCPXXXX, RCPXXXX, RCPXXXX, RCPXXXX, RCPXXXX, RCPXXXX, RCPXXXX

i. Good care

Two of the 15 cases were graded good care in terms of the overall quality of neurology care. For case RCPXXXX, Dr Y’s involvement was largely focused on prescribing medication for the patient’s Parkinson’s disease. The review team concluded that Dr Y’s management and treatment of the patient was appropriate, and the patient received good care from the geriatric team and the Parkinson’s disease specialist nurses. For case RCPXXXX, Dr Y’s involvement in the case was limited and only after the diagnosis had been made. The management and treatment of the patient was appropriate. He provided appropriate and timely advice on the patient’s anticonvulsant treatment and his prescribing suggestions were reasonable. The neurosurgical and neuro-oncology service was excellent, and these colleagues communicated very well with each other. There was little evidence of Dr Y’s communication with colleagues.

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ii. Room for improvement

Of the 15 cases, five cases were graded room for improvement for clinical reasons in terms of the overall quality of neurology care. Two examples are given below.

- RCPXXXX was graded room for improvement because Dr Y was observed to have documented little detail in terms of examination of the patient, and because he did not demonstrate a holistic approach to care (for example, by referring the patient to sources of support and allied health professionals, such as physiotherapy). There was no documented evidence of communication with colleagues except for the patient's GP and his interactions with the patient and family members was graded poor care because there was no documentation to indicate that Dr Y discussed the risks of treatment or prognosis with the patient, to enable them to undertake advanced care planning. Clinical record keeping was also graded as poor care.
- RCPXXXX was graded room for improvement because once Dr Y became involved in this case (after a diagnosis of superficial siderosis had been made), he appeared to have encouraged the patient to pursue lumbar surgery, although other clinicians advised against this. Dr Y demonstrated multidisciplinary working in referring the patient to a neurosurgeon, physiotherapists and dermatologist. However, his letter reporting that he had advised the patient to have lumbar surgery was not copied to the neurologist at the National Hospital for Neurology and Neurosurgery (NHNN), under whose care the patient had also been.

iii. Unsatisfactory

Of the 15 cases, eight cases were graded unsatisfactory in terms of the overall quality of neurology care. This meant the review team had identified several aspects of clinical and/or organisational care that were well below the standard they would expect from themselves, trainees and institution. For these cases, the grading reflected that the review team identified deficiencies in care across several domains. All eight cases were ones in which the review team had concerns with the potential to lead to patient harm – see [section 5.1.7](#) for details. For example:

- RCPXXXX concerned a patient who died from a traumatic brain injury due to a fall. The review team concluded that the RQIA should consider the potential for harm arising from Dr Y's continued treatment of the patient with anti-epileptic medication despite the diagnosis not being secure and the medications not helping the patient's symptoms. It was likely the patient was having significant side effects due to these medications, which may have contributed to the deterioration that led to her falls, including the fall that ended her life.

5.1.2 Management (including history taking, investigations and assessment) and treatment

5.1.2.1 Record review

- The review team concluded that for nine of the 15 cases (60%) Dr Y's ongoing management and treatment of the patient was not appropriate.

A recurring theme was that Dr Y did not arrange for investigations to confirm his diagnosis, often in cases of suspected epilepsy, and did not demonstrate consideration of other possible diagnoses despite the patient's poor response to medications (for example, case RCPXXXX).

Dr Y often reviewed patients frequently (for example, cases RCPXXXX, RCPXXXX and RCPXXXX) and yet sometimes his approach to the management of the patient's condition was cursory and overly focused on changing prescribed medicines. For example, in case RCPXXXX, the review team was concerned that there was a missed opportunity for use of advanced treatment options – namely deep brain stimulation – despite the initial appropriate consideration of this group of treatments. The patient never went on to have advanced treatment options (following Dr Y's advice) and the window of opportunity was missed. In case RCP2038, despite reviewing the patient regularly, Dr Y did not fully investigate the underlying cause of the patient's ongoing frequent blackouts, and his management of the patient was largely limited to altering medications. Similarly, in case RCPXXXX, Dr Y did not arrange investigations to confirm his diagnosis and ignored the red flag of a lack of response of the patient's attacks to five anticonvulsants. Given the frequency of the patient's events, it would not have been difficult to have captured these. Dr Y should have considered referring the patient to a specialist at a tertiary centre.

In some cases, failures in management of the patient related to the absence of evidence that Dr Y referred the patient to support services. For example, this was observed in case RCPXXXX, where there was no documented referral to a Parkinson's disease nurse or to show that Dr Y informed the patient and his family of resources such as Parkinson's UK (the Parkinson's Disease Society), or referral of the patient to allied health care professionals such as physiotherapy or sources of support regarding the patient's cognitive issues.

5.1.3 Appropriateness of prescribing

5.1.3.1 Record review

- The review team concluded that Dr Y's prescribing decisions had been appropriate in nine of the 15 cases (60%). Concerns were raised with the appropriateness of prescribing in six cases (40%).

In all six cases these concerns aligned with the review team's finding that the diagnosis was not secure and therefore it followed that the prescribing was problematic. Five of these six cases related to diagnoses of epilepsy (see [section 5.1.7](#)) and issues were highlighted with Dr Y's approach to prescribing epilepsy medication.

For example, in case RCPXXXX, the review team concluded that Dr Y did not demonstrate efforts to secure the epilepsy diagnosis and did not document potential side effects when he prescribed medications. Similarly, in case RCPXXXX, Dr Y continued over many years to change anti-epileptic medicines, which made no difference clinically to the patient, and he continued to treat the events as seizures even when, in 2009, he believed the patient's symptoms might not be seizure related. It was clear the patient was having problems with medication and at times she was on many different prescribed drugs. Dr Y did not document any advice he provided to the patient regarding the side effects of the medicines he prescribed. A psychiatrist seeing the patient recorded that the patient had asked Dr Y to change her medication and that he had refused.

In case RCPXXXX, Dr Y prescribed anticonvulsant drugs but he did not always allow them to take effect, before switching to another medication prematurely (for example, starting and stopping topiramate from June to October 2014). In another case (RCPXXXX), Dr Y kept changing the patient's anti-epileptic medication without reviewing the patient's diagnosis. This was another example where Dr Y did not document having discussed the side effects of these medicines with the patient. A similar pattern was observed in case RCPXXXX, where Dr Y prescribed multiple anti-epileptic medications, with no evidence

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that they were helping, and were causing side effects. This patient was at times on very high doses of some medications and yet Dr Y did not document having counselled the patient about side effects.

The last case where the review team concluded Dr Y's prescribing had not been appropriate did not relate to a diagnosis of epilepsy. Dr Y never made a definite diagnosis in case RCPXXXX, however his treatment of the patient with multiple courses of intravenous immunoglobulin (IVIg) implied he thought the diagnosis was CIDP. The patient had at least ten admissions for IVIg that the review team believed were unnecessary, would not have benefitted her and were associated with significant costs in terms of inconvenience to the patient (each treatment required an admission of several days at a time when she was also receiving treatment for colon cancer) and to the system.

5.1.4 Communication with colleagues (including delegation, referrals and multidisciplinary team working)

5.1.4.1 Record review

- The review team concluded that Dr Y's communication with colleagues was generally poor care (five cases) or very poor care (five cases).
- Four cases were graded adequate care.
- One case, RCPXXXX, was graded excellent care. This reflected excellent communication between the neurosurgical and neuro-oncology service; there was little evidence of Dr Y's communication with colleagues.

In several cases, a very poor grading reflected a lack of communication with colleagues involved in the patient's care. In case RCPXXXX, Dr Y mentioned a Parkinson's disease nurse specialist in his clinical records. It was reported by family members that he made comments about this nurse that indicated a wilful failure to communicate with this colleague. When challenged by family members about why he had not communicated with the Parkinson's disease nurse specialist he was said to have disclosed that he had not communicated with this nurse because he was not 'fond' of her. Similarly, in case RCPXXXX, an immunologist who was reviewing the patient regularly commented in a letter that he had not received any correspondence from Dr Y despite the immunologist having written to Dr Y about the patient's symptoms. In case RCPXXXX, Dr Y failed to revisit his working diagnosis (of CIDP) despite another neurologist and two doctors in training expressing differing opinions.

Such cases created an impression that, at times, Dr Y acted in isolation and communicated poorly with colleagues. Another example was case RCPXXXX, where Dr Y demonstrated multidisciplinary working in referring the patient to a neurosurgeon, physiotherapists and dermatologist. However, his letter advising the patient to have lumbar surgery was not copied to a neurologist at the National Hospital for Neurology and Neurosurgery (NHNN), who had been providing care to the patient prior to Dr Y's involvement. There was evidence in the records to indicate that Dr Y was aware that the neurologist at NHNN did not support lumbar surgery for this patient and indeed considered the small disc identified via scanning as not relevant to the patient's problems. Therefore, in recommending lumbar surgery to the patient and not copying his letter to the NHNN neurologist, Dr Y appeared to be deliberately excluding this neurologist from this decision-making.

It was not evident in case RCPXXXX that Dr Y acted upon a letter from the patient's GP, expressing concern regarding the patient's medication and asking Dr Y to review these. The patient was not improving and yet Dr Y did not seek a second opinion with the diagnosis.

A poor or very poor care grading sometimes reflected an absence of evidence to demonstrate that the patient had been referred to any support services or to other health professionals, such as physiotherapy (case RCPXXXX), speech and language therapy (case RCPXXXX) or specialist epilepsy nurses (case RCPXXXX).

5.1.5 Interactions with patients and family (including information sharing, duty of candour)

5.1.5.1 Record review

- The review team concluded that, across the 15 cases, the records indicated that Dr Y's interactions with patients and their family members were overwhelmingly poor, with most cases graded poor care (six cases, 40%) or very poor care (five cases, 33%) under this heading.
- No cases were graded adequate or good care.
- In four cases there was insufficient evidence to reach a judgement.

Cases RCPXXXX and RCPXXXX were two where concerns were raised by family members. These concerns were raised with the RQIA after issues regarding Dr Y's conduct had come to light. The family's account in case RCPXXXX of Dr Y's interactions with the patient and family members represented very poor care, with comments he was reported to have made creating the impression of an overly casual and unprofessional approach to his interactions. The review team graded Dr Y's interactions with the patient and family members for case RCPXXXX as very poor care as there was no documentation to demonstrate that he advised the patient about possible treatment plans or discussed treatment options and the review team upheld the concerns raised by the patient's daughter that Dr Y should have responded to the patient's request to review her medications and considered both the side effects of specific medicines and the cumulative impact of all the medication she was prescribed.

In several cases, the grading of poor or very poor care reflected the absence of evidence that Dr Y explained the diagnosis to the patient or documented the patient's wishes or the potential side effects of medicines he prescribed (cases RCPXXXX and RCPXXXX). Case RCPXXXX was graded very poor care because there was no evidence from Dr Y's clinical records that he communicated effectively with the patient or shared information to enable the patient to participate in decisions about his treatment. For cases RCPXXXX, RCPXXXX, RCPXXXX, the grading reflected the absence of documented discussions with the patient regarding their prognosis or to enable advanced care planning.

In some instances, shortfalls in Dr Y's documentation regarding his interactions with patients were adequately compensated by other health professionals. For example, in case RCPXXXX, a Parkinson's disease specialist nurse's carefully documented discussion with the patient and his family, about arranging a multidisciplinary assessment and the possibility of moving to a nursing home. In contrast, there was nothing in Dr Y's clinical records to indicate what discussion he had with the patient or family members at any point.

5.1.6 Clinical record keeping (including level of details in letters, notes of conversations)

The General Medical Council states that clinical records should include: *'relevant clinical findings, the decisions made and actions agreed, and who is making the decisions and agreeing the actions the information given to patients, any drugs prescribed or other investigation or treatment, who is making the record and when'*.⁶

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5.1.6.1 Record review

- Eight cases were graded adequate care under this heading.
- Six cases were graded very poor care and one case was poor care.

Across the cases, Dr Y's approach to clinical record keeping tended to be brief. Where cases were graded poor or very poor care under this heading it largely reflected that the review team could not identify that important information was documented. In several instances the grading reflected that Dr Y did not document the findings of an examination, even following a first consultation with the patient (cases RCPXXXX, RCPXXXX, RCPXXXX, RCPXXXX, RCPXXXX). Sometimes his clinical records were so brief that they contained no explanation of his clinical decisions, which made the rationale for his treatment decisions hard to follow (for example, case RCPXXXX). The review team identified omissions in Dr Y's record keeping with respect to documenting the potential side effects of medicines (for example, case RCPXXXX).

The concerns raised by the family members of one patient (RCPXXXX) included that Dr Y sometimes wrote clinical details on 'scraps' of paper and seldom referred to previous records, which gave rise to a sense that he was not professional in his manner.

5.1.7 Diagnostic accuracy and potential patient harm

5.1.7.1 Record review

i. Diagnostic accuracy

The review team was asked to consider in each case whether or not the diagnosis made by Dr Y was secure. In over half of cases (60%, nine cases), the review team believed the diagnosis was secure. In the remaining six cases the review team did not consider the diagnosis to have been secure. Five of these six cases related to diagnoses of epilepsy, and the review team observed that Dr Y's documentation lacked detail to support this diagnosis, such as examination or a description of the episodes the patient was said to be having. A theme across these cases was a failure by Dr Y to document having arranged investigations (such as EEG or telemetry) to confirm the diagnosis of epilepsy, or to demonstrate consideration of other diagnoses, particularly when the patient's condition did not respond to anti-epileptic medications.

The table below provides an overview of cases the review team concluded did not have a secure diagnosis.

Case No.	Concerns that the diagnosis made by Dr Y was not secure
RCPXXXX	The diagnosis of epilepsy was not secure. The patient was having falls (not blackouts) initially, which Dr Y chose to treat with anti-epileptic medication. He later said this was to treat nerve root irritation but did not document a scan to establish this or consider other treatment options. The patient then went on to have very frequent blackouts that were not fully investigated.
RCPXXXX	The diagnosis of epilepsy was not secure. The events described in the clinical records did not fit with a diagnosis of epileptic seizures. The events were too long (lasting several days), there was a long prodrome (early signs or symptoms before the event), and there were brainstem symptoms (vertigo and slurred speech).

Case No.	Concerns that the diagnosis made by Dr Y was not secure
RCPXXXX	The diagnosis of epilepsy was not secure. Dr Y's description of the patient's attacks was different in laterality and content to other doctors' descriptions. Dr Y made no attempt to confirm the diagnosis with EEG. In addition, the fact that the patient's seizures did not respond to five anticonvulsants was a red flag to suggest that epilepsy may not be the correct diagnosis. Good care would be to retake this history and investigate with EEG and, if needed, telemetry.
RCPXXXX	Dr Y's diagnosis of focal seizures (epilepsies are either generalised or focal; the type is relevant as it determines the best treatment. A focal seizure starts in an area of the brain and can spread ^{***, +}) was not secure. The patient was at risk of seizures due to her previous diagnosis and treatment for aneurysms, however Dr Y diagnosed seizures without arranging investigations before diagnosing focal seizures (a type of epilepsy). Dr Y never questioned the diagnosis once made even though the patient's symptoms were not typical for seizures and even when another neurologist thought the patient should be reinvestigated as to the cause of the symptoms.
RCPXXXX	Dr Y's diagnosis of focal seizures (a type of epilepsy) was not secure. There was very little description by Dr Y as to the type of problem he was treating beyond dysphasia (difficulty with speaking). Epilepsy can be a difficult diagnosis to get right, however in this case Dr Y seemed to be treating events that were not typical of focal seizures. The patient's symptoms would have been very atypical for focal seizures and efforts were not made to investigate the symptoms more thoroughly to prove or disprove the diagnosis.
RCPXXXX	Dr Y never made a definite diagnosis, but his management plan implied he thought the diagnosis was CIDP, without meeting the diagnostic criteria for CIDP. Other doctors did not agree with this diagnosis, something Dr Y appeared to have ignored. The review team supported the diagnosis of axonal neuropathy proposed by another neurologist (Dr H).

ii. Potential for patient harm

The review team was asked to consider for each case whether any concerns identified from the review gave rise to the opinion that, potentially, they could lead to some level of harm. In this context, harm was considered in the broadest sense, including any omissions in care that may have been to the detriment of the patient, such as failing to demonstrate holistic, supportive care that may have made the patient's condition and demise easier to manage.

In nine cases, 60%, the review team identified concerns or omissions that the RQIA may wish to consider further for their potential to lead to harm. For six of the nine cases, concerns regarding potential harm arose from a diagnosis that was not thought to be secure and therefore raised issues of potentially unnecessary exposure to medicines, often in high doses, and associated side effects. In case RCPXXXX, Dr Y's prescribing of anti-epileptic medication may have been a contributory factor in the falls suffered by the patient. In the remaining three cases (RCPXXXX, RCPXXXX, RCPXXXX), concerns over potential harm arose from, respectively, Dr Y's apparent failure to communicate

^{***} www.epilepsy.org.uk/info/seizures/focal-seizures

⁺⁺⁺ Epilepsies are either generalised or focal. The type is relevant as it determines the best treatment. A focal seizure starts in an area of the brain and can spread. Neurologists look for structural lesions that can cause these types of seizures. In generalised seizures there are no structural abnormalities. Seizures can present in many different ways: from a generalised tonic clonic seizure to just focal twitching or loss of awareness.

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effectively with the patient and family members; his decision not to pursue advanced therapy options; and his failure to refer the patient to sources of support and allied health professionals.

The table below sets out details of the concerns or omissions relevant to these nine cases.

Case No.	Potential for patient harm
RCPXXXX	Whilst it was very unlikely that the patient's condition would have taken a different course, the RQIA should consider the potential for harm arising from Dr Y's failure to communicate effectively with the patient and family members, including their belief that the patient was not cared for appropriately and that the medications prescribed by Dr Y were causing side effects that were not understood.
RCPXXXX	The RQIA should consider the potential for harm arising from Dr Y's decision not to pursue advanced therapy options for this patient, having made an appropriate onward referral to Frenchay Hospital, Bristol, for consideration of deep brain stimulation, only eight months later to advise against it.
RCPXXXX	The RQIA should consider the potential for harm arising from an apparent failure by Dr Y to refer the patient and his family to sources of support and allied health professionals, particularly considering the patient's cognitive decline.
RCPXXXX	The RQIA should consider the potential for harm arising from Dr Y's diagnosis of epilepsy, which was not secure, and the associated treatment. The patient was severely disabled by his very frequent blackouts, which had a profound effect on his life (he was unable to work and was dependent on others). Sadly, the patient died from suicide.
RCPXXXX	The RQIA should consider the potential for harm arising from Dr Y's continued treatment of the patient with anti-epileptic medication despite the diagnosis not being secure and the medications not helping the patient's symptoms. It was likely the patient was having significant side effects due to these medications, which may have contributed to the deterioration that led to her falls, including the fall that ended her life.
RCPXXXX	The RQIA should consider the potential for harm arising from Dr Y's management of this patient, whose diagnosis of epilepsy was not secure and who may not have needed any of the five anticonvulsants he was prescribed. The patient experienced side effects from these medicines: drowsiness with one anticonvulsant, memory issues with another, and did not tolerate a third drug.
RCPXXXX	The RQIA should consider the potential for harm arising from Dr Y's management of this patient, which exposed her to potentially unnecessary medicines and their associated side effects.
RCPXXXX	The RQIA should consider the potential for harm arising from a diagnosis of epilepsy that was not secure, which meant that the patient may have received unnecessary medications and exposure to the associated side-effects.
RCPXXXX	The RQIA should consider the potential for harm arising from a diagnosis that was not secure, which led to at least ten admissions that were unnecessary for a treatment (intravenous immunoglobulin (IVIg)) that would not benefit the patient, although there was no evidence to suggest that the patient experienced side effects from the IVIg.

iii. Concerns with the recorded cause of death

The review team considered the certified cause of death in the records in light of the stated diagnosis and any concerns raised during review of the clinical records. For 12 cases, the review team did not identify any concerns with the recorded cause of death. However, in three instances, the review team identified concerns, as set out in the table below.

Case No.	Concerns with the recorded cause of death
RCPXXXX	The certified cause of death appeared accurate. However, there was no mention of the potential for treatment side effects from the epilepsy medication prescribed to have contributed to the patient’s final fall.
RCPXXXX	The clinical records from Ulster hospital clearly described the patient’s myocardial infarction and this was the immediate cause of death, however no other conditions were listed, and the review team believed that superficial siderosis should appear as Part II on the death certificate (i.e., to indicate an underlying condition), given that it caused significant and progressive disability.
RCPXXXX	The death certificate gave the cause of death as 1a <i>‘debility of old age’</i> 2 colon cancer. The review team did not consider debility to be an adequate description for a cause of death. Further, much of the patient’s poor mobility was due to her axonal neuropathy, which was not listed.

5.2 Terms of reference 2

5.2.1 Family concerns

RQIA had no legal way of identifying the next-of-kin or family members of the 16 deceased patients within this cohort. RQIA reported that it had made best efforts by contacting the GP for each deceased patient and asking them to forward a letter to any known next-of-kin or family member. Two families contacted RQIA in response and provided their concerns for submitting to the review team for consideration: **RCPXXXX** and **RCPXXXX**. The next-of-kin for **RCPXXXX** also made contact, but to advise that they were content with the care and treatment provided to their deceased relative and they did not wish to become further involved in the review.

RQIA received no response from next-of-kin or family members for the following cases: RCPXXXX, RCPXXXX, RCPXXXX, RCPXXXX, RCPXXXX, RCPXXXX, RCPXXXX, RCPXXXX^{†††}, RCPXXXX, RCPXXXX, RCPXXXX and RCPXXXX.

Review team's decisions on concerns raised by family/relatives/carers

Upheld: the concern is supported by the information provided	RCPXXXX, RCPXXXX
Partially upheld: some aspects of the complaint were supported by the information provided, but not all the issues that were complained about or the mistakes made did not have a negative impact on the patient	
Not upheld: either the information provided does not support the concern raised or there is insufficient information available to make a judgement	

i. RCPXXXX

Case RCPXXXX was graded unsatisfactory by the review team, which reflected the family's credible and troubling account of care that fell below standards expected of a doctor as defined in *Good Medical Practice*². The review team did not identify any concerns with the clinical diagnosis of Parkinson's disease and did not share the family's concerns that Dr Y reached this diagnosis without consulting others and considered the diagnosis to have been reasonable based on the patient's clinical history and examination. However, the review team concluded that Dr Y's ongoing management and treatment of the patient was not appropriate, and the concerns raised by family members provided a credible account of poor communication with the patient and her family in terms of explaining the prescribed medications and associated side effects.

It was not evident from the clinical records that a Parkinson's disease nurse specialist was involved in the patient's care. The patient's family reported that Dr Y made comments about this nurse specialist that indicated a wilful failure to communicate with this colleague.

The family reported that Dr Y sometimes wrote clinical details on scraps of paper and seldom referred to previous records, which reinforced a sense that he was not professional in his manner.

The family's account of Dr Y's interactions with the patient and family members represented very poor care. Dr Y was said to have stated: '*Oh, Oh, what have I done now?*' when seeing the patient

^{†††} The review team could not identify that Dr Y had any involvement in case RCPXXXX.

and family members, which the review team agreed was unprofessional. The patient was said to have been very happy with the care provided by Dr Y and did not wish to seek a second opinion, however, the family concerns were that the patient was misled by Dr Y and given false hope.

ii. RCPXXXX

Case RCPXXXX was also graded unsatisfactory. The review team graded Dr Y's interactions with the patient and family members as very poor care and upheld the concerns raised by the patient's daughter that Dr Y should have responded to the patient's request to review her medications and considered both the side effects of specific medicines and the cumulative impact of all the medication she was prescribed. Not to do this indicated a very poor standard of care, especially as the medication may have contributed to the falls the patient went on to experience.

6 References

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