Case reference: GRO-C Complaint about: University Hospitals Coventry and Warwickshire NHS Trust Complaint made by Mr Jason Evans Decision Date: 26 February 2021

### Our decision

- 1. We find there was maladministration by the Trust. When Mr Evans requested his late father's records, he was wrongly told several times that the Trust did not have them. It was over a year later and with the involvement of a television producer that Mr Evans discovered the Trust did have them. He was eventually able to obtain copies, but we consider the delay and the incorrect information, which was relayed on several occasions, caused him distress, annoyance and frustration.
- 2. In its response the Trust acknowledged it had wrongly told Mr Evans that it did not have his father's records and apologised. However, we do not consider it did enough to put things right. Therefore, we uphold the complaint.
- 3. We recommend the Trust take action to prevent a recurrence of a similar situation.

### The complaint

- 4. Mr Evans complained about University Hospitals Coventry and Warwickshire NHS Trust's handling of his request for copies of his late father's medical records.
- 5. He said that for over a year after his initial request in February 2016, the Trust denied that the records existed despite him contacting the Access to Health Records (A2HR) team several times during this period. When a BBC producer contacted the Trust in May 2017 in relation to a television programme, the Trust found the records within two days.
- 6. Mr Evans said that although the Trust apologised for not locating the records sooner, it did not give him an adequate explanation of why it insisted for so long that they did not exist. He said this was compounded by its continued failure to provide an adequate explanation when he followed the matter up after the records were found. The events caused him stress and inconvenience in pursuing the matter and added to his grief and anger about what happened to his father.
- 7. Mr Evans wanted a full explanation of what happened, for the Trust to acknowledge the full extent of it errors and to take action to ensure that it does not happen again.





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## Background

- In the 1970s and 1980s over 4,500 people with haemophilia and other bleeding disorders were infected with HIV, Hepatitis B and C and other blood-borne viruses due to contaminated clotting factor products (Factor VIII and Factor IX). The Haemophilia Society says that over 2,000 people have since died. (<u>https://haemophilia.org.uk/support/day-day-living/patient-support/contaminatedblood/history-contaminated-blood/</u>)
- There is currently an Inquiry underway that 'will examine why men, women and children in the UK were given infected blood and/or infected blood products'. (<u>https://www.infectedbloodinquiry.org.uk/</u>)
- 10. In 1993, Mr Evans' father, **GRO-A** died as a result of such blood product contamination. Mr Evans is the founder, spokesperson, and investigator of *Factor 8 The Independent Haemophilia Group*, an organisation which advocates on behalf of those affected by these events. Its website describes Mr Evans as a core participant in the Inquiry.

# Chronology

- 11. The following is a chronology of events based on the evidence we have seen so far. The Trust has not provided us with records of phone calls or personal visits it received from Mr Evans. Given the passage of time since the events, we understand that such records had they been made would no longer exist. We have considered email correspondence and the Trust's response letter alongside the evidence Mr Evans has provided.
- 12. On 22 February 2016 Mr Evans applied to the A2HR team for a copy of his father's records. On 16 March 2016, he spoke to the team's senior administration officer, who told him they were having difficulties locating them. In a follow up email, he gave her extra details and on 30 June he emailed again as he had obtained some records from another trust and could now provide his father's NHS number. The following day, the A2HR officer emailed Mr Evans to say she had tried that number but it still did not bring up a match. She advised him to try another hospital (at a different trust).
- 13. Around March 2017, a BBC producer contacted the Trust (with Mr Evans' consent) asking it to comment on the fact **GRO-A** records appeared to have been lost. Within two days, the Trust told her it had located the records. The producer told Mr Evans about this.

- 14. On 11 April, Mr Evans emailed the Trust asking for the records again saying 'I asked for this information multiple times over the last year and was advised that nothing existed. However, following enquiries by BBC Panorama, it appears they have been advised that this is not the case and the records do exist.'
- 15. Mr Evans emailed the A2HR team on 28 May as he was still unclear about what had happened and believed he was entitled to an explanation. He pointed out that after he first applied for the records in February 2016, he had visited the office in person and over the next four months he made further requests to the Trust. He was told 'numerous times' there was no trace on their system, that his father had never been a patient there and that no records existed. He said that despite his extensive attempts via email, phone and visits, he was repeatedly told the Trust held nothing about his father.
- 16. He emphasised that even when the records were found, it was the BBC producer who told him, not the Trust. He also had to contact the Trust himself to raise the matter as the Trust had not contacted him when the error became evident. He said he had had no explanation. He recalled that after finding out about the records' existence, he had spoken to the A2HR senior administration officer who mentioned a haematologist had 'suddenly remembered something', which Mr Evans did not think was an acceptable explanation. He asked for a substantial response to his e-mail.
- 17. The A2HR team manager replied by email two days later and said 'I don't know why your father's records were not available when you first requested them. I understand that a thorough check was made throughout the organisation and the records were finally obtained by our department. The records were then disclosed to you by our department.'
- 18. Mr Evans responded by saying he had asked for a written account of the exact events so he could provide it for the Infected Blood Inquiry. He said that the account had now changed three times. After the records had been found, the administration officer told him a haematologist had remembered where they were. When he had previously spoken to the A2HR team manager herself two months previously, she told him this was not true and they were found in storage (although without an explanation of why this was not part of the original search). Now her email said that she did not know.
- 19. Following email correspondence in early 2019, the A2HR manager told Mr Evans she did not know why the records were not available when he first requested them. In June 2019, the Trust's complaints team contacted Mr Evans and told him the A2HR team had referred the matter to them and on 15 October 2019, the Trust sent a complaint response to Mr Evans.

20. In the response, the Trust said when Mr Evans first requested his father's records its Patient Management System showed no records for his father. When the Trust was made aware of the involvement of the BBC, the A2HR team advised the Trust's communications team, who investigated further and found the records had been archived. The Trust explained that any records that do not meet the criteria for destruction (which included those that are to be retained for 30 years but are no longer active) are stored separately. It said that at the time, the A2HR team were not aware that this was the case. The Trust apologised for what had happened.

### Evidence

- 21. To help us form a view, we considered correspondence between Mr Evans and the Trust and our phone discussions with Mr Evans. We considered comments the Trust gave us after we issued our Provisional Views report. We use related or relevant law, policy, guidance and standards to inform our thinking. This allows us to consider what should have happened. In this case we referred to the following standards:
  - The Trust's Health Records Operational Management Policy
  - Information Governance Alliance (IGA), Records Management Code of Practice for Health and Social Care, 2016
  - The Ombudsman's Principles of Good Complaint Handling and Principles for Remedy, 2009

### Findings

- 22. The Trust's policy states 'The Trust's Health Records Management Policy has been updated to reflect *Records Management: NHS Code of Practice Part 2*, which extends the retention period for certain types of records (eg blood transfusions administered since 2005 where paperwork is required to be retained for 30 years). Due to difficulties in easily identifying records which will have to be retained for 30 years, it has been agreed to retain all health records for this period.'
- 23. The national guidance it cites was in place from January 2009 to August 2016, although the current guidance Records Management Code of Practice for Health and Social Care 2016 is similar to its predecessor in this regard. We note the Trust's complaint response refers to the 30-year period.
- 24. We recognise it may be unusual for the A2HR team to receive requests for the records of a patient who died over two decades previously. We also realise that whatever national or local guidance has been in place since 2009, it does not necessarily mean that records for a person who died 1993, would have been kept that long. But we have

seen no indication in the correspondence that the A2HR team consulted and considered the Trust's own guidance.

- 25. Mr Evans was clear that his father was treated at the Trust and had died 23 years previously. The Trust's guidance says records will be kept for at least 30 years after the patient's death. From the Trust's comments on our Provisional View report, we understand the A2HR team contacted an external provider which holds some of the Trust's records and were told they did not exist.
- 26. While we appreciate the A2HR team relied on that information, the Trust's own guidance said that records had a retention period of 30 years. This should have prompted the A2HR team to explore the possibility that the records still existed and to consider further action to locate them. When the BBC producer contacted the Trust, the records were found quickly. It appears this time, the storage provider located the records soon after. The Trust has not provided further information as to why this happened. There appears to be a failure in communication within the Trust and with the storage provider.
- 27. Our Principles for Good Complaint Handling say that appropriate responses to a complaint include 'remedial action, which may include... revising procedures, policies or guidance to prevent the same thing happening again; training or supervising staff; or any combination of these'. While we recognise the apology the Trust gave in its complaint response was sincere, we do not consider the response provides reassurance to Mr Evans that the Trust had undertaken robust action to stop something similar happening again. We also recognise that Mr Evans says the Trust gave him different explanations for what happened. Furthermore, the Trust gave us information about the external provider's role after we issued our Provisional Views, which Mr Evans had not been previously aware of.
- 28. We do not think the Trust has taken enough action to put things right. The A2HR team is the Trust's point of contact for people who want copies of their health records or those of deceased relatives. As Investigator and Founder of Factor 8, Mr Evans is particularly keen that the Trust learns from its mistakes. He is concerned that other people who may be told their relatives' records do not exist may encounter similar problems.
- 29. Mr Evans wants a full explanation of why he was told repeatedly that his father's records did not exist. We understand why he was frustrated with the complaint response. It did not address why the team responsible for dealing with record requests were unaware of the existence and location of old records when a different team did, or why the A2HR team did not escalate or look further into the matter. The Trust has since told us about the information the external storage provider gave the teams.

Given the passage of time and lack of contemporaneous evidence other than emails, we recognise it might not be possible to provide a complete explanation now (for example regarding the potential role of a haematologist) other than the A2HR team was not aware how long records are kept, did not refer to the Trust's policy and were unaware that colleagues elsewhere in the Trust could have helped.

- 30. The Trust acknowledges that GRO-A clinical records existed, were held by the Trust and Mr Evans was wrongly told a number of times between February 2016 and March 2017 that they did not exist. From the evidence we saw, we find this amounts to maladministration.
- 31. Mr Evans is understandably angry that his father died as the result of receiving contaminated blood. He is dedicated to obtaining the truth about and justice for what happened. When he approached the Trust for evidence that he wanted for the Inquiry, it took over a year for the Trust to find them. During that time he was wrongly told the records did not exist. When he did obtain copies, he appears to have received different explanations of why it happened. We consider the events caused him inconvenience and annoyance and added to his distress and grief.

### Recommendations

- 32. In considering our recommendations, we have referred to our Principles for Remedy. These state that where poor service or maladministration has led to injustice or hardship, the organisation responsible should take steps to put things right.
- 33. In considering our recommendations, we have referred to our *Principles for Remedy*. These state that where poor service or maladministration has led to injustice or hardship, the organisation responsible should take steps to put things right.
- 34. Our Principles say that public organisations should seek continuous improvement and should use the lessons learnt from complaints to ensure they do not repeat maladministration or poor service. In line with this, we recommend that within two months of the date of the final report the Trust prepare an action plan, including timescales, setting out what steps it will take to minimise the risk of the situation happening again.
- 35. The actions should ensure all relevant staff and teams will be aware of the issue and the impact it can have on people if they cannot access relatives' records and are repeatedly given incorrect information. In particular, the Trust should ensure the A2HR team is aware of its Records Policy, particularly how long records are kept, and how to obtain them. Given the information we received from the Trust since we issued our Provisional Views, the role of its external provider should be included its consideration.

- 36. The Trust should send a copy of the plan to us, Mr Evans, the Care Quality Commission and NHS Improvement.
- 37. It should also send an anonymised copy of our final report and the action plan to NHS Improvement and the CQC.

Andrew Nield Senior Caseworker