

Appendix F

Previous Responses from WHCCG

As agreed, the response from Ellen McNicholas focused on the issue of the legal basis for the review and informed consent. As such, there are many other failings of WHCCG that have not been addressed. We will not stop until we have answers that reflect the NHS expectations of Duty of Candour.

Considering what has been written in the letter of 4 September 2019, we would like explanations for the following:

30 October 2017

"It is part of CHC funding protocol for clients to have a review every 6-12 months, this with a request for an increased package of care, has prompted our case coordinators to request me to arrange a review meeting." The first statement is disingenuous as WHCCG policy is for annual reviews. The second statement was challenged by us the following day.

31 October 2017

"We appreciate that packages need to be reviews as circumstances can change. However, this review has only been prompted due to a belief that we are requesting additional hours. This is not the case. The package was designed to be flexible. A budget, in excess of £46,000 (worth over £53,500 today if 2% interest is applied) was established based on 55hrs x 52 weeks a year. The core 55hrs x 39 weeks was supplied at a cost of approx. £30,000. The remaining budget could be used freely to top up hours in term time and any holiday periods where I was working. We do not use any hours simply for me to have an evening 'off'. We have evidence of this through emails and agency documentation."

We went on to say, *"To put things in context, a standard working week is actually 59.5 hours. I have no lates this week, unlike next week. In the last twelve months, as a headteacher I worked in school during part of the Easter holiday and 12 days during the summer holidays. It has been the other holiday periods that the hours have been 'banked' to allow the additional hours in term time. We are simply asking for this to continue."*

It should be noted that we were in Tenerife at the time of dealing with this, yet I was able to clearly articulate the truth about the package.

Later that day (31 October 2017)

Nikky Hickman forwarded our email to Roy Dube stating, *"Please can you see below email."*

"This email follows a string of emails regarding the review we have booked in for next Wednesday 8 November for a Rachael Mary Austen-Jones."

"What he is addressing has fallen a bit out of my remit to be able to answer. Are you able to communicate with Mr Austen-Jones once this has been looked into please."

8 November 2017

At the review, along with the owner of Request Nursing Agency, we questioned the reasoning for the review. Roy Dube said it was not to do with the hours. He said reviews take place every 3-6 months. He even stated it used to be the policy for annual reviews but not anymore. We have a recording of this. West Hampshire CCG has always refused to address this concern.

28 January 2018

We wrote to request a Local Resolution Meeting regarding our first complaint. It was only at this point that we realised that Roy Dube had lied to us and that the review had been called without a valid legal basis. It is within this letter that we raised what we already knew and West Hampshire has only just admitted.

"There had been a review in April 2017. The November review was only called due to a mix up between the care agency and the CCG regarding billing. Our attempts to explain this were ignored. As a result, the November review was carried in contravention of the CCG's Joint Operational Policy for CHC (paragraph 12.1)."

13 February 2018

Two days prior to the Local Resolution Meeting, notes from a pre-meeting between Ciara Rogers, Libby Thomas and Pauline Dorn state:

"PD to review DST.

"Material change would warrant an MDT."

Pauline Dorn emailed Ciara Rogers and Libby Thomas later that morning.

"having reviewed the panel notes from the original decision in 2009 and the review carried out in January I think that this is more tricky than it first seems... I think that the ASC domain may still reflect a priority level.

"...My feeling is that we should pursue MDT but this will undoubtedly leave us open to further complaints and an appeal if the outcome is not eligible."

Ciara Rogers replied, *"My view is we need to MDT where there is any doubt, we have to be fair and consistent across the population. So this would be back to MDT."*

Ellen McNicholas stated in her letter of 4 September 2019 that Pauline Dorn *"looked at the case file to respond to your complaints and to prepare for the complaint local resolution meeting."* Yet again, a fabrication of the truth. It is understandable that Pauline Dorn would look at the documentation to gain insight. However, she used it to make a clinical judgement as to whether a to take us to MDT. We had not even discussed the content of our second complaint with the CCG as per the complaints policy and regulations; we thought it would be discussed at the LRM, as this supposed to be focused on our first complaint of November 2017. The investigation into our complaint had not even started. Our complaint was about process. As such, Pauline Dorn's processing of the documentation was unlawful.

21 March 2018

Response from West Hampshire CCG to our formal complaint:

"the Continuing Healthcare team confirm that the case review was completed following correspondence from Request Nursing Agency on 25 October 2017. This highlighted that Mrs Austen-Jones had clinically improved, stating that an NHC Continuing Healthcare review was indicated." The WHCCG letter of June 2019 confirms that there is **no evidence** to support this statement. As we have repeatedly stated, Request Nursing Agency categorically deny this assertion.

27 March 2018

Following advice from the PHSO, we sent a set of questions to clarify / challenge the response we received to our second complaint on 21 March 2018. Considering the subsequent admissions, why were the following questions ignored? We have kept the focus on the content within Ellen McNicholas' letter – the failure to answer the other questions remains. The referenced appendices can be found in Appendix F.

- 2. In the January Review, Jo Craven stated that Rachael "is CHC eligible" but it has to go to MDT because of the minor change in continence as "it's literally their guidance". This is maladministration. There was no concern about the levels agreed within the domains and your response letter confirms that there is no mention of this guidance in your policies, and it is contrary to the National Framework for NHS Continuing Healthcare [Appendix K]. The WHCCG Policy for the Management of Complaints [Appendix L] states, "The underlying approach promoted by the Principles for Remedy is for the service provider to restore the complainant to the position they would have been in if the maladministration or poor service had not occurred." In light of the unlawful review that took place after the review meeting, please explain why you are treating us unfairly by not following your complaints policy in our case, especially as Pauline Dorn agreed saying, "that two severe and a priority would indicate a Primary Health Need." Please note, whilst it was agreed that Jo Craven would ask a manager about the referral to MDT due to process, this was the only purpose for escalation.*

3. We have asked for an explanation for the reason to instigate the review process considering there was a review in April 2017. The only communication we had before the November Review was that "it is part of CHC funding protocol for clients to have a review every 6-12 months, this with a request for an increased package of care, has prompted our case coordinators to request me to arrange a review meeting." It should be noted the WHCCG's Joint Operational Policy [Appendix M] is for annual reviews, not 6-12 months. We repeatedly stated we were not asking for an increased package of care. Since then, we have been told:

- "it is part of CHC funding protocol to have a review every 6-12 months, this with a request for an increased package of care, has prompted our case coordinators to request me to arrange a review meeting." [Please note that the WHCCG policy is for annual reviews unless circumstances change.]
- "In most cases, reviews are done on a three-monthly basis, on a regular basis or a six-monthly basis. We used to do them on an annual basis but they've sort of like stopped that now. That is the operational policy that is in place." (Roy Dube – November Review)
- "That's how it came through to us, it was down to accounting." (Jo Craven – January Review)
- "In Sept/Oct 2017 Request made contact with CHC in regards to invoicing queries and also requested for a review." (January Review report)
- "Correspondence from Request Nursing Agency on 25 October 2017. This highlighted that Mrs Austen-Jones had clinically improved, stating that an NHS Continuing Healthcare review was indicated." (March Response)

As we did not ask for an increase in package and the care agency deny asking for an increase, requesting a review or stating that Rachael had clinically improved, please provide the recorded information for these statements.

Your March Response is dishonest. If that were the reason, then it would have been explained on the previous four occasions. The fact that WHCCG have not been able to justify the exact purpose of the review means we have been misinformed. Are you aware that this is a breach of The Data Protection Act in respect of gaining consent?

Please note that Request Nursing Agency deny that they requested the review or that they felt that Rachael has clinically improved. They have informed me that they believe the correspondence you refer to is the care records that you asked for. Awareness of the CHC National Framework makes it clear that notes are not necessarily reliable for well managed needs [Appendix N]. As such, you have failed to comply with your Joint Operational Policy [Appendix O] as there was no clear change for the priority area of life-threatening seizures, considering the number of major seizures increased after the April Review.

5. You have continued to ignore the question regarding Roy Dube accepting that there is a Primary Health Need and then changing his mind under challenge regarding his desire to reduce the care package due to his erroneous "assumptions" on the seizure records. In your December Response, you accepted that the case coordinator recommended that care should be reduced. This is an admission that a Primary Health Need was identified. Subsequently, you have stated, "the case coordinator clinically considered the evidence relating to Mrs Austen-Jones's health care needs and recommended that a decision support tool would be best practice." What additional evidence was provided after the recommendation to reduce the package that enabled Roy Dube to recommend a Multi-Disciplinary Team meeting?

18. Jo Craven stated, "The guidance is any change goes to MDT." This is contrary to the events in the November Review and the National Framework. Who issued this guidance? Was this the guidance for just our review, all reviews from a specific date, or malpractice by Jo Craven and the "operational management team" whom she contacted for "supervision and assurance that this recommendation was robust"?

21. As discussed in the complaints meeting, when was the further review of evidence conducted?

24. *It is a requirement to record rationales for decisions [Appendix U]. Why has this not been done for the “further review by a senior member”? Please confirm who this senior member is. How can you accept the findings of this unconsented review when there is no record by the person who carried out the review, in direct contravention of WHCCG’s Records Management Policy [Appendix V]?*

31. *As discussed in the complaint meeting, has the funding arrangement for the current package been rectified? Please confirm what the understanding of the accounts department is for our package of care.*

12 April 2018

We received a response regarding our questions, signed off by Mike Fulford. The questions were not answered, we simply got the following responses.

“Please be advised that West Hampshire Clinical Commissioning Group have investigated your complaints regarding this matter and have concluded that the principles of the National Framework for NHS Continuing Healthcare have been adhered to.” This is despite the admission that there are no investigation records and informed consent was not obtained, neither was there a valid or evidenced legal basis. (Please refer to our quotes from the ICO website.)

“Having reviewed your concerns regarding the Data Protection Act 1998, we are of the opinion that the reviews undertaken complied with the National Framework and there are no indications of any breach of the Data Protection Act 1998. There is a legal basis to undertake reviews and the Continuing Healthcare process has been undertaken with the common law duty of confidence adhered to in the NHS to protect personal information. Furthermore the reviews have been undertaken with both of your prior knowledge and agreement.” Remembering that consent was misinformed, this paragraph was written on the erroneous belief that consent was not required:

“I will also run this past the AD for CHC to ensure that we are correct that the reviews do not rely on consent from the family” – Diane Bittlestone, 10 April 2018 (see Appendix F).

“All complaints follow a robust investigation in line with the NHS Complaints (England) Regulations 2009. The review and approval process for your complaint investigation responses include review and approval by Ciara Rogers, Deputy Director for Continuing Healthcare and Ellen McNicholas Director of Quality and Nursing (Board Nurse). Furthermore the complaint investigations were undertaken by the operations manager, who is unrelated to the complaint.” Except Pauline Dorn did an unconsented review and determined the outcome prior to the complaint. Furthermore, it has been confirmed by WHCCG that there are no records of investigation, contrary to the NHS Complaints (England) Regulations.

18 April 2018

We submitted a third complaint regarding the complaint process. The complaint was ignored, even though it was a separate matter to the previous complaints. The PHSO has deemed that the response to this complaint was not appropriate. Key issues, relating to the letter of Ellen McNicholas, are as follows:

***“ROY DUBE THEN LIED.** In the review meeting, he stated that the review was taking place not because of an increase in package, but because all packages are reviewed every 3 to 6 months. He even stated that it used to be the policy to have annual reviews but it was changed.”*

“A key issue raised in the complaint was that Roy Dube had identified that there was a Primary Health Need and was trying to discuss the health care package. On the basis of erroneous assumptions (as accepted in your 21 March 2018 letter), he wanted to reduce the package. We said we would appeal any reduction. He suddenly changed the outcome to MDT as there might not be a Primary Health Need. The response failed to address this and there is no evidence of an investigation into this key issue. If

it had been addressed, the outcome should have over-riden our request for a new review and reinstated the Primary Health Need outcome. This would be in accordance with the WHCCG policy for remedy and redress.”

“Following the second review, on 23 January 2018, we sent a letter questioning the decision to progress the review to an MDT, based upon failure to adhere to the WHCCG Joint Operational Policy, the National Framework for NHS Continuing Healthcare, the Decision Support Tool for NHS Continuing Healthcare and the response to our first complaint. Despite repeated requests, we did not receive an answer. As a result, in addition to issues in the January Review report, we escalated this matter to a formal complaint on 7 February 2018.”

“Now that we have a copy of the complaint file, we have identified a further breach of Data Protection. Our second complaint (7 February 2018) was regarding the **PROCESS** of the January Review. Despite this, it was agreed by Pauline Dorn, Ciara Rogers and Libby Thomas for Pauline Dorn to review the **CLINICAL** decision prior to the February Local Resolution Meeting. We were not made aware this would happen and consequently **did not consent** to it.”

“The outcome of our complaint regarding **PROCESS** was determined on the basis of a **CLINICAL** decision by Pauline Dorn, prior to any discussion with the complainant or an investigation. As a result, the ‘investigation’ into the second complaint carried out by Pauline Dorn, which followed the Local Resolution Meeting, was clearly **biased**. This is summed up by Libby Thomas’ comment in the Local Review Meeting, “It is under investigation... but we can gather from today what our recommendation will be.” (The investigation into the process had not started. Pauline Dorn didn’t even know which Senior Manager (Band 8) had carried out the un-evidenced and unconsented review.)”

“**PAULINE DORN THEN LIED** in the Local Resolution Meeting, telling us that our case has to go to MDT due to the review documentation – “I can’t question the review paperwork... The outcome from the review documentation that has been produced indicates that there may be a change in eligibility and therefore an MDT is required.” However, her email to Libby Thomas and Ciara Rogers, on 13 February 2018 (prior to the meeting on 15 February 2018), clearly demonstrates that she had reviewed the evidence and was considering changing the decision. There was a **private agreement about the outcome between Pauline Dorn and Ciara Rogers** and it was this outcome that could not be changed. This rendered us unable to challenge the real reason as she was blaming **FAKE RULES** regarding not being able to challenge the review documentation.

In the meeting, we stated, “There was no concept of what we say, you were coming to this meeting, it’s going to MDT whether you like it or not. Even though process has not been followed, you came to this meeting with it’s going to MDT.”

Pauline Dorn replied, “Unfortunately the outcome has to remain.

Pauline Dorn carried out an unconsented review, in agreement with Ciara Rogers and Libby Thomas, that determined the outcome of a complaint before it had been investigated.”

“We sent a confidential letter to Heather Hauschild following the Local Resolution Meeting. It raised serious flaws in the process, including failure to follow the National Framework for NHS Continuing Healthcare and contravening the WHCCG complaints policy. Our email, and also forwarded by our local MP, was sent to Libby Thomas. Libby Thomas then wrote to us to say that the issues raised would be addressed in the response letter due on 14 March 2018. There was **no communication** with us as to why we felt there were errors in the complaint process.”

“An email was sent by Pauline Dorn on 21 February 2018 to Libby Thomas providing her draft response to the complaint. It is clear within this email that she chose not to question Jo Craven or Meriel Chamberlain about the process of the review. **THIS IS NEGLIGENCE.**”

“The formal response that we received contained **no evidence** and **limited or highly inappropriate rationales for decisions**. These are highlighted through our questions in our letter of 27 March 2018. Despite the formal complaint being a new complaint about a different matter, we were not offered a Local Resolution Meeting. This is contrary to your complaints policy.”

20 April 2018

Response from Pauline Dorn to questions raised by Paul Davey as part of a briefing for Maggie McIsaac

"The professional undertaking the review in January felt that a decision support tool should be undertaken in order to establish continuing eligibility." That is a complete fabrication of the truth. Jo Craven disagreed with the need for an MDT but claimed it was *"simply the guidelines"*.

"...as the family were not in agreement of this following the meeting she would like to discuss it with a senior manager. When it was reviewed by a senior manager [Meriel Chamberlain] it was felt that the evidence did not support the levels indicated in the review documentation." Again, this is a complete fabrication of the truth. The only consent was to try to stop the MDT due to 1 Priority and 2 Severs. 75 minutes later it was confirmed that the MDT was go ahead due to a minor change. The later 'review' was not consented to and is contrary to guidelines, policy and law. Reading pages 22 and 23 of the review document highlights the gross incompetence of the decision or a deliberate attempt to pervert fairness and equity.

"We have apologised for the reviewer not explaining to the family that the outcome was going to be completion of a further decision support tool and that a senior manager may review the documentation." First of all, Jo Craven did explain that an MDT was going to take place, even though she disagreed with it. Secondly, failing to communicate that a senior manager may review the documentation is a failure to gain consent. Not only was it contrary to any guidelines, policies, etc, it was admitted that consent was not obtained. **Yet Ellen McNicholas still claims it was legitimate. It is only legitimate if we consent to it.**

May 2018

Response to our complaint, signed off by Mike Fulford. The response has been deemed by the PHSO as unacceptable.

"With regard to your complaint regarding the management of your complaint, West Hampshire Clinical Commissioning Group has undertaken a robust complaint process..." Where is the evidence, as required by the NHS Complaints (England) Regulations 2009?

26 March 2019

We submitted a fourth complaint, regarding Data Protection:

"With advice from a GDPR consultant, we submitted a GDPR Article 15 (Data Subject Access Request) in December 2018. This sought to obtain specific information, including the evidence your organisation holds of informed consent and the range of reasons given for the legal basis. Upon receiving the documentation, we replied (through our advisor) stating that the requested information was missing. As such, West Hampshire CCG has:

- *Not made any investigation records, as required by your own policy, the PHSO Principles of Good Complaints Handling and the NMC Code. This means you have no evidence for any of the outcomes.* This remains the case.
- *No evidence of valid consent as required by the Data Protection Act.* WHCCG has now admitted that consent was misinformed.
- *No evidence to back up any of the statements regarding the reasoning for the review.* Still claiming a reason without evidence and added a new reason which does not constitute a legal basis.
- *No guidelines that state the second review should have gone to MDT, as claimed by Jo Craven.* This matter has still been ignored.
- *No explanation as to when Meriel Chamberlain carried out her review (considering the phone call to us seventy-five minutes after the review meeting).* This matter has still been ignored.
- *No records of the funding for the package over the last three years."* WHCCG has now demonstrated maladministration on this point.

6 June 2019

Response from WHCCG to our 26 March 2019 complaint:

- *"There are no investigation records to share."*
- *"Mrs Austen-Jones had not at the time of the reviews withdrawn her consent. In addition both you and Mrs Austen-Jones participated in the review meetings and did not raise any objections at the time."* Although you have finally admitted that we were misinformed.
- *"There are no records to share on the reasoning for the review."* Ellen McNicholas is now simply relying on the recollection of the administration team of a conversation, for which a record should have been made, that took place two years ago.
- *"On 13 April 2017 Mrs Austen-Jones signed a consent form that specifically includes consent for reviews to take place. In addition both you and Mrs Austen-Jones were at the review meetings and did not raise any objections at the time. The reviews carried out in November 2017 and January 2018 were a requirement of the National Framework for NHS Continuing Healthcare. The information was limited to that purpose and the reviews dealt with information that was relevant, as such both the processing of the information and the reviews process itself were lawful."* Except there was no valid legal basis and consent was misinformed.

June 2019

We replied to Mike Fulford following his letter. We received no response despite the following points:

"Your response to our complaint is disgraceful. It contains numerous errors, lies and omissions. For example:

- *"On 13 April 2017 Mrs Austen Jones [sic] signed a consent form that specifically includes consent for reviews to take place. In addition both you and Mrs Austen Jones [sic] were at the review meetings and did not raise any objections at the time." THIS STATEMENT IS DISINGENUOUS AND A LIE. We repeatedly challenged the reasoning for the review but Roy Dube lied to us about the reasoning. Thus our 'consent' was misinformed and is therefore invalid.*
- *The reviews conducted by Meriel Chamberlain and Pauline Dorn are not part of the NHS Continuing Healthcare process, thus there was no consent.*
- *You use paragraph 184 of the National Framework for NHS Continuing Healthcare as evidence for an MDT. This is erroneous. First of all, Jo Craven stated that she felt the case did not need to go to MDT. Secondly, Pauline Dorn eventually agreed in the Local Resolution Meeting that Jo Craven should not have called an MDT. You have ignored all the evidence that demonstrates that an MDT should not have been called.*
- *You have still not answered the question as to when Meriel Chamberlain carried out her review.*
- *"I am not aware of you being considered vexatious." Yet it was within a meeting that you were part of that it was considered that I was becoming a vexatious complainant.*

"It is very disturbing that you state that, "There are no records to share on the reasoning for the review." Not only does this contradict previous responses to this, your organisation has given us five different reasons yet cannot evidence any of them. Your response, received today, states that there was a legitimate basis for the reviews, yet you cannot state nor evidence why they were legitimate. If there is no evidence for the reasoning for the reviews, how can we have given informed consent?"