LIFE THREATENING ● UNPREDICATABLE ● WITHOUT WARNING ● FLUCTUATING ● DANGEROUS

Re: Complaint [redacted] – [redacted] Key [redacted] Patient [redacted] West Hampshire CCG employees [redacted] Care Agency

Although you asserted, in your letter of 21st March 2018 (March Response), that the West Hampshire CCG "local resolution process under the NHS Complaints Regulations 2009 has now concluded", this is inappropriate and therefore unacceptable. Regulation 14.2 (a) has not been met. Under point (i), it has not been made clear how the investigation was conducted. Under point (ii), you have not addressed all matters and some responses are incomplete and unsatisfactory. We have discussed these matters with the Parliamentary and Health Service Ombudsman, on 22nd March 2018, who has advised us to seek clarifications and answers to omissions.

The March Response states, "the priority of the NHS Continuing Healthcare team is to ensure that all individuals have their needs met and that care is commissioned lawfully and in line with the national framework for NHS Continuing Healthcare." This is against the backdrop of the following legislation and statutory instruments:

- The Local Authority Social Services and National Health Service Complaints (England) Regulations 2009
- The National Health Service Commissioning Board and Clinical Commissioning Groups (Responsibilities and Standing Rules) Regulations 2012
- The Data Protection Act 1998
- The NHS Constitution

You have failed to follow the correct procedures for handling complaints according to the Local Authority and National Health Service Complaints (England) Regulations 2009 [Appendix A] and the WHCCG Policy for the Management of Complaints [Appendix B]. We have raised this concern but we have not received any communication about this.

You state "that the clinical evidence provided indicates the decision support tool meeting is appropriate" but there is no paperwork that provides a rationale for this opinion. This is wholly unacceptable and contrary to the National Framework for NHS Continuing Healthcare [Appendix C]. If your priority is "to ensure that all individuals have their needs met", then you need to be transparent and deliver a person-centred approach so that we can request the appropriate clinical evidence from the consultants, GPs, specialist nurse and others who have cared [redacted] for many years. This would enable you to have the information you need to make an accurate assessment.

During our meeting on 15th February (February Meeting), you assured us that all processes will be followed correctly from that point on. Therefore, as you have failed to facilitate a meeting, we have provided a set of questions in order for us to obtain clarifications and responses to omissions from your March Response.

In accordance with your complaints procedure, we are only seeking information to significant points already raised within our complaints. Should you choose to not respond to these questions, thus failing to provide full answers to the questions within our complaint in contravention of regulations and local policy, we will immediately report the individuals involved in this case to the appropriate regulatory bodies – The Nursing and Midwifery Council [Appendix D] and the Health and Care Professions Council [Appendix E].

KEY QUESTIONS

1. Your March Response states that, after the January 2018 Review meeting (January Review), "The evidence was further reviewed." This was unlawful. It was done contrary to the Data Protection Act 1998 [Appendix F], the WHCCG Confidentiality Policy – Data Protection Act 1998 [Appendix G], the WHCCG Information Governance Policy [Appendix H], The Department of Health Confidentiality – NHS Code of Practice [Appendix I], The Calidcott Principles [Appendix J], and numerous other guides and regulations. There was no consent and no communication that information would be used for this purpose. Please explain why you believe it is appropriate to use unlawful assessments. Please refer to Question 2 for clarification as to why the escalation was not in line with "local governance procedures" (which we have not been privy to).

2. In the January Review, [redacted] stated that [redacted] "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 [redacted] agreed saying, "that two severe and a priority would indicate a Primary Health Need." Please note, whilst it was agreed that [redacted] would ask a manager about the referral to MDT due to process, this was the only purpose for escalation.

REASON FOR REVIEW

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:
    - "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." ([redacted] – November Review)
    - "That's how it came through to us, it was down to accounting." ([redacted] – January Review)
    - "In Sept/Oct 2017 [redacted] 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 [redacted] had clinically improved, stating that an NHS Continuing Healthcare review was indicated." (March Response)

    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 [redacted] Agency deny that they requested the review or that they felt that [redacted] 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.

NOVEMBER REVIEW

4. With regard to the amendments we requested for the April 2017 Review report (April Review), your March Response states that "it would not be appropriate under the Nursing and Midwifery Code of Conduct for that case review to be amended by another clinician". At no point did we or [redacted] suggest that it was [redacted]'s responsibility to make the amendments. However, he needed to be aware of inaccuracies in order to inform his judgement (unfortunately he refused to discuss the April Review with us or use it as a source of information – as accepted in the December 2017 Response [December Response]). In accordance with the NHS Care Record Guarantee [Appendix P], it is our right to "point out mistakes". Under The Data Protection Act Principle 4 [Appendix Q], if the data is not accurate "you should delete or correct it." Please confirm what amendments have been made to the April Review report.

5. You have continued to ignore the question regarding [redacted] 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 [redacted]'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 [redacted] to recommend a Multi-Disciplinary Team meeting?

6. What is your understanding of the circumstances of the discussion regarding assistive technology that took place in the November 2017 review (November Review)?

7. Your response regarding assistive technology states that this is used when there is a "requirement for an urgent response" and that "these alarms can be directly linked to emergency services, carers or representative to enable a timely response to need". This implies that there is a severe risk of harm and there is clear clinical evidence that [redacted] has multiple daily seizures due to refractory epilepsy. In light of this, please explain what expert clinical evidence there is that contradicts this.

8. The December Response states that "the views of the individual and also their representatives should be discussed and recorded within the review document." The National Framework for NHS Continuing Healthcare (CHC National Framework) states, "The evidence and the decision-making process should be accurately and fully recorded." Are you satisfied that the November review report reflects this and, if so, on what basis?

9. You have accepted that information was ignored in the November Review and "that assumptions were made which impacted on the way in which the altered state of consciousness domain was assessed". However, your March Response continues to reference the report as legitimate. Are you aware that this is a breach of The Data Protection Act [Appendix Q]?

10. Your March Response states that [redacted] "is satisfied that this [the November Review report] is reflective of [redacted]' needs as presented at the time." Considering the accepted faults in the review process, how can she reach this conclusion? Have any notes been added to the November Review to reflect our views of the report and, if so, when did this happen?

11. Your March Response states that in the November Review "assumptions were made which impacted on the way in which the altered state of consciousness domain was assessed". Please explain how the operational management team came to the conclusion "that an accurate portrayal of needs has been presented" within the review report for the altered states of consciousness domain.

12. We raised our concerns regarding the November Review report on 10th December 2017. When were these concerns first acted upon and what evidence is there to show this?

13. Your response states, "the priority… is to ensure… that care is commissioned… in line with the national framework for NHS Continuing Healthcare." The December Response states that the framework was not followed in the November Review. You accepted that previous reviews/DSTs and supporting statements were ignored, and that inappropriate assumptions about the seizure record were made. We have consistently stated that the November Review had been annulled and this statement has not been challenged by WHCCG. Why do you still consider it appropriate to refer to the findings of the November Review?

JANUARY REVIEW

14. You state in your March Response that "a change in need was evident within the psychological, communication and continence domains suggesting that a full decision support tool would be appropriate". Please explain how you justify this considering it is contrary to the statement by [redacted] at the February Meeting – "I agree, that two severe and a priority would indicate a Primary Health Need" – and your Joint Operational Policy [Appendix R].

15. Whilst stating that "a change in need was evident within the psychological, communication and continence domains", you have not answered our question regarding the communication domain. Please answer the question. We wish to point out that the mobility domain changed from low to high, and the psychological domain was put down as either low **or** moderate. Within a DST, a decision has to be made either way and if there is not agreement, the higher score is recorded with notes to explain [Appendix S]. Therefore, stating that a change in need was evident in the psychological domain is not accurate.

16. We stated within our February complaint that we advised [redacted] that we would only agree 'No Needs' for breathing if it was appropriately reflected in the Altered States of Consciousness domain. As 'Priority' was agreed, we did not feel it necessary to go back to the breathing domain. The subsequent 'review' did not provide us with the opportunity to express our views regarding breathing. Please explain how this can be considered an acceptable person-centred approach. We would like to point out that it has come to our attention that recording 'No Needs' for the breathing domain in this instance is contrary to the Decision Support Tool for NHS Continuing Healthcare [Appendix T].

17. The April Review concluded that [redacted] has a Primary Health Need. What evidence do you have that [redacted]'s health needs have improved since that review such that she may no longer meet eligibility?

18. [redacted] 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 [redacted] and the "operational management team" whom she contacted for "supervision and assurance that this recommendation was robust"?

19. Your March Response only refers to the further review amending the altered states of consciousness domain. As it is your priority to adhere to the CHC National Framework, how does [redacted]'s addendum to the cognition domain comply with the regulations and WHCCG policies? This should be considered with [redacted]'s statement, "It should be that the outcome from review that is agreed with the relatives or the patient themselves and that's the outcome that is then taken forward."

20. You March Response states, "The case coordinator advised that a new decision support tool meeting would enable a comprehensive assessment which would identify whether a primary health need is still evident. It was also highlighted within the case review that a decision support tool would support further consideration as to whether the package of care currently in place is appropriate in meeting [redacted]'s clinical needs." This is in the report but it is not true. The discussion in the review meeting questioned the need for an MDT assessment, as the only reason given for it was a minor change in the continence domain. The case coordinator felt that the MDT assessment was not justified and she would do what she could to stop it from going ahead,

agreeing that it would be an unnecessary MDT. Please acknowledge that your statement is not a true record of this aspect of the review meeting.

FURTHER REVIEW

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

22. The NMC Record Keeping – Guidance for Nurses and Midwives states that "you must not alter or destroy any records without being authorised to do so." Who gave the authorisation for the additional comments to be included on the report?

23. Your response states, "The report was not altered, but additional comments added to reflect the discussion." Are you aware that additional comments **are** an alteration, whether it reflects an unlawful discussion that took place afterwards or not?

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]?

COMPLAINTS

25. Why did [redacted] not write to us after the complaint meeting on February Meeting? She said she would write up the main points and any agreed actions. Failure to write to us is in contravention of the WHCCG Policy for Managing Complaints [Appendix W].

26. Your response refers to an email from us from 15th February 2017. We assume it meant to say 2018. The only emails we sent on 15th February 2018 were regarding our confidential letter to [redacted]. So what email are you talking about and why you have referenced social care provision as this was not part of our complaint?

27. We sent a confidential letter to [redacted] on 15th February 2018. The response of 21st March 2018 was signed on behalf of [redacted]. Did she receive our letter? How is it appropriate for [redacted] and [redacted] to draft the response to it when it was critical of their actions? Despite assurances from [redacted], we note that the issues raised in the letter were not addressed in the response letter. These actions are in contravention of the WHCCG Complaints Policy [Appendix X] and the Local Authority and NHS Complaints Regulations 2009 [Appendix Y].

28. Your reply states, "A new decision support tool will be facilitated, as agreed at your complaint local resolution meeting." We did not agree to a DST. Apart from anything else, it would be contrary to your complaints policy [Appendix Z]. We sent in a complaint on 7th February 2018 which was formally acknowledged by [redacted] on 8th February 2018. The first discussion we had regarding the content of that complaint was at the February Meeting. It would be contrary to the Local Authority Social Services and NHS Regulations 2009 [Appendix AA] to decide the outcome at that stage. As [redacted] had assured us that processes will be followed correctly, please explain how she considered herself able to determine the outcome of the complaint prior to the meeting.

29. We await your explanation as to why it took four weeks to cancel the MDT after the November Review to allow the outcome of the complaint to be established. As discussed in the February Meeting, what is being done to align the processes of the complaints team and the Continuing Healthcare team?

REVIEW PROCESS

30. We await confirmation as to whether it is standard operating procedure for WHCCG to require reassessment of DST domains at reviews, as happened in January 2018. If not, what was the standard operating procedure in place at the time of the January Review?

CARE PACKAGE FUNDING AGREEMENT

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.

CARER'S ASSESSMENT

32. Regarding the carer's assessment, your March Response states that a referral was made "on 22nd November 2017 and a social worker was allocated on 28th November 2017". Are you aware that this is not relevant as the referral was not for a carer's assessment? We are not aware of WHCCG making a referral for a carer's assessment.

In addition to the above questions and in accordance with guidelines, please could we have the names of all individuals involved in this case and, where applicable, their professional body registration details.

Please note that we received apologies on numerous occasions for poor communication. Failures to communicate effectively can be, and in this case have been, a breach of regulations and guidelines. This is particularly relevant to the data protection breaches that have occurred in our case. We do not accept poor communication as an excuse for making unlawful decisions.

Failure to answer these questions would be in contravention of the Local Authority Social Services and NHS Complaints Regulations 2009. As you stated in your response, "the priority of the NHS Continuing Healthcare team is to ensure that all individuals have their needs met and that care is commissioned lawfully and in line with the national framework for NHS Continuing Healthcare." We therefore look forward to receiving your response to the above questions.