AN OPEN LETTER
From: Rear Admiral Philip Mathias (Rtd)

For the personal attention of: Rebecca Hilsenrath

30 September 2019

Rebecca Hilsenrath: CEO of the Equality and Human Rights Commission

THE NHS CONTINUING HEALTHCARE (CHC) SCANDAL THAT HAS BREACHED
THE HUMAN RIGHTS OF THOUSANDS OF PEOPLE

Dear Rebecca Hilsenrath,

A recent public petition on the Continuing Healthcare (CHC) scandal, signed by over 10,000 people stated: “families have been left emotionally and financially devastated when they should be spending quality time with loved ones who, as enshrined in law, should have healthcare free at the point of delivery”.

Soon after Simon Stevens became CEO of the NHS in 2014, CHC eligibility numbers suddenly started to fall, when they had been steadily rising over the previous ten years. Widespread expert opinion considered that numbers should have continued to increase due to the demands of an ageing population.

Over the past five years, multiple independent and expert bodies have reported the failing CHC system as being dysfunctional, unjust and unlawful. These include the Parliamentary Accounts Committee (PAC), the National Audit Office (NAO), the Care Quality Commission (CQC), the Equality and Human Rights Commission (EHRC) and the CHC Alliance (17 charities). There has also been extensive coverage of this NHS scandal in numerous national press articles, on the radio and TV documentaries.

I am aware that in 2018 the EHRC threatened court action against a number of CCGs for ‘having arbitrary caps on funding’ and concerns about ‘NHS CHC policies being unlawful and breaching the human rights of patients’ - a ‘serious breach of the Human Rights Act, the public sector equality duty and the DHSC’s own NHS CHC National Framework’. Despite this EHRC action, many CCGs continue to act unlawfully. As an example, the huge and unexplained variation across CCGs in their award rates of CHC funding reported by the PAC have continued – NHS Q3 18/19 data shows a variation of between 12 to 230 people per 50,000 of population, a 19 fold difference.

Whilst the competence of CCGs to manage their budgets and comply with the law will vary significantly, the ultimate responsibility for this CHC scandal lies with the Department of Health and Social Care and the NHS. CCGs have two conflicting legal statutory duties. On one hand, if the eligibility criteria are met, entitlement to CHC funding is a matter of law and it is not discretionary or subject to funding priorities. But if CCGs lack sufficient funds to meet this need, this conflicts with another legal statutory duty that CCGs must not exceed their allocated budgets (as dictated by Sections 223G and 223H of the National Health Service Act 2006).
Wiltshire CCG demonstrates this point well. In 2015, to avoid being put under ‘special measures’, the Wiltshire CCG Chair wrote a letter to all stakeholders stating: ‘The CCG’s financial situation is dire and we need to prove to NHS England that we are impacting on all areas of expenditure.’ In 2018, the CQC reported that Wiltshire CCG ‘System leaders were unable to describe why the CHC award rate was so low but they were aware that CHC processes were not effective.’ Their CHC award rate was in the bottom 5% of the country. After an exhausting two-year battle against Wiltshire, I eventually secured CHC funding for my mother who had severe dementia. The CCG did everything possible to avoid awarding it, including ‘losing’ her initial assessment and grossly distorting the evidence. The Chair of the Independent Review reported the CCG had contravened the CHC regulations in multiple ways. But few members of the public have the time, confidence, tenacity and analytical skills to achieve a similarly successful outcome, which required over one hundred letters and three meetings (30 days work).

Members of the public who are unlawfully denied CHC funding broadly fall into two categories. Firstly, those who were assessed but were found ineligible because the CCG did not comply with the CHC National Framework and those who had never heard of CHC funding, often referred to as the ‘best kept secret in the NHS’. It is the responsibility of the NHS to screen all potential recipients. The scale of this unlawful financial deprivation is staggering. Individually, the money involved can often reach six figure sums and nationally the total figure runs in several £billion. It has also caused untold stress and anxiety to old, ill and vulnerable people and to their supporting families.

Given all the above and the detailed supporting evidence in the attached paper, I formally request that you now initiate legal action against the Department of Health and Social Care and the NHS. The leadership of these organisations is ultimately responsible for many thousands of people who have been unlawfully denied the healthcare funding to which they were entitled. The enormous scale of this scandal, both in terms of financial deprivation and emotional distress it has caused, must be one of the most serious breaches of human rights since the creation of the EHRC. It is an utterly disgraceful situation, given that the purpose of the NHS is to alleviate suffering, not to create it. Even if the current so called ‘CHC Improvement Programme’ succeeds (all previous initiatives have failed), it does not address the breach of human rights of the many thousands of people that occurred prior to this and the need for redress.

I am sure you would agree that in a democracy, it is essential that government and public bodies are held to account when they act unlawfully, as the Supreme Court has recently demonstrated. For the benefit of the 10,000 people who signed the petition, I have published this letter on social media. I have also copied it to the BBC, which recently reported on this NHS CHC scandal, and also to the Editor of the Daily Telegraph, who published a front-page article on the subject earlier this year.

I look forward to hearing from you.

Yours sincerely,

Philip Mathias

Attached: A paper on the NHS Continuing Healthcare (CHC) Scandal
A Paper by Rear Admiral Philip Mathias

THE NHS CONTINUING HEALTHCARE (CHC) SCANDAL – WHICH HAS BREACHED THE HUMAN RIGHTS OF MANY THOUSANDS OF PEOPLE

If the eligibility criteria are met, entitlement to Continuing Healthcare (CHC) funding is a matter of law and is not discretionary, or subject to policy choices, or funding priorities.

Prior to Simon Stevens becoming CEO of the NHS, CHC eligibility numbers had been steadily increasing during the previous 8 years, peaking at about 62,000 at the beginning of 2015. Within 8 months of him taking office in April 2014 (allowing for lag/inertia in the system) CHC eligibility numbers started to fall significantly, reaching about 55,000 in 2019.

CHC Eligibility Numbers (by Professor Luke Clements) – brown line using NHS snapshot data showing the number of people who were eligible for CHC funding at any one time. Other annotations added by me.

With an ageing population, widespread expert opinion considered that CHC eligibility numbers should have continued to rise. Giving evidence at the Parliamentary Accounts Committee (PAC) (7/1/2018) Norman Lamb MP (Minister for Care 2012/15) and an expert on CHC, said: "Demand is rising significantly every year across the country, yet the number of people entitled is going down.” A NHS report in January 2018 stated: ‘An ageing population and an increasing number of people living with multiple co-morbidities means that CHC is a priority for the populations that CCGs serve’. If CHC eligibility numbers had continued to rise at the rate prior to Simon Stevens taking office, they would have reached about 75,000 in 2019; statistically a differential of circa 20,000 people being unlawfully denied CHC funding in this year alone – a figure totalling about £1billion. The people who will have been denied CHC funding broadly fall into two categories. Firstly, those who were assessed but were found ineligible because the CCG did not comply with the CHC National Framework. Secondly, those who had never heard of CHC (often referred to as the 'best kept secret in the NHS'), even though it is the responsibility of the NHS to screen all potential recipients.
A CHC related policy event or decision must have occurred soon after Simon Stevens took office to cause such a significant and sudden reversal in CHC eligibility numbers. If he didn’t initiate this event himself, he would have certainly been aware of it. If the explanation by the NHS for this dramatic reversal of CHC eligibility numbers from 2015 was an attempt to improve the consistency of how CCGs apply the CHC eligibility criteria, then it failed as the significant variation in CHC award rates continues to this day.

The most plausible explanation for the significant reduction in CHC numbers is that post implementation of the government’s austerity measures, the NHS was under significant financial pressure and reducing CHC eligibility numbers saved money – if this was the case it would have been unlawful. In 2018 the Equality and Human Rights Commission threatened to take 13 CCGs to court because of ‘significant concerns about blanket NHS CHC policies having arbitrary caps on funding’. In a national press article in July 2014, about the need to better integrate NHS and Social Care funding, Simon Stevens stated: “the initiative is driven by a widespread sense that our Balkanised health and social care services are no longer fit for purpose, especially when the ageing population has created growing demands for care just when Whitehall austerity programmes have created two leaky buckets”. In 2018 Simon Stevens also made his personal views very clear in the national press stating that: “accumulated housing wealth held by older generations should be used to pay for their care.”

As the CEO of the NHS, he has been responsible for overseeing an increasingly failing CHC system that has been reported by multiple and independent expert bodies, as being dysfunctional, unjust and unlawful. These include the Parliamentary Accounts Committee (PAC), the National Audit Office (NAO), the Care Quality Commission (CQC), the Equality and Human Rights Commission (EHRC), the CHC Alliance (17 charities) and the Alzheimer’s Society. It is inconceivable that he would not have been aware of this wide-ranging and extensive criticism and the considerable high profile coverage of this NHS scandal in the national press, on the radio and TV documentaries.

**CHC Alliance:** ‘Continuing Healthcare is failing people across England. Due to flawed processes, many people who should be found eligible are being denied this much needed support.’

**The Alzheimer’s Society:** ‘the CHC system discriminates against people with dementia, despite it being a medical condition and there is weak enforcement of the National Framework that CCGs must adhere to.’

**NAO:** In July 2017 the NAO reported: ‘there is significant variation between CCGs in both the number and proportion of people assessed as eligible for CHC and there are limited assurance processes in place to ensure that eligibility decisions are consistent, both between and within CCGs’.
EHRC: In March 2018 the EHRC threatened to take 13 CCGs to court because of ‘concerns about NHS CHC policies being unlawful and significant concerns about blanket NHS CHC policies having arbitrary caps on funding’.

PAC: In January 2018, nearly 4 years after Simon Stevens became CEO of the NHS, the PAC (at which Simon Stevens gave evidence) reported: ‘The funding system is failing people with continuing healthcare needs and there is unacceptable variation between areas in the number of people assessed as eligible, ranging from 28 to 356 people per 50,000 population. NHS England recognise that the system is not working as well as it should but are not doing enough to ensure CCGs are meeting their responsibilities, or to address the variation between areas in accessing this essential funding.” At the PAC, Norman Lamb MP said: “Given that this is public money, how can we possibly justify such an extraordinary variation without any democratic legitimacy?’

CQC: In late 2017/early 2018, the CQC conducted general inspections of 30 CCGs and found many of them were not correctly applying the CHC National Framework. Here are just four examples: Wiltshire CCG: ‘System leaders were unable to describe why the CHC rate was so low but they were aware that CHC processes were not effective.’ Stockport CCG: ‘Significantly less people than comparator areas or the England average were deemed eligible for CHC funding.’ Coventry CCG: ‘Families were not given the information they needed about CHC funding.’ Birmingham CCG: CHC processes were not working and people were dying in a hospital setting who didn’t need to be there. We were told about a person with dementia and affected by multiple strokes who had their CHC funding removed following a routine review.’ There is further detail on these and other CQC reports later in the paper.

A so-called ‘CHC Strategic Improvement Programme’ initiated in April 2017 did not stop the decline in CHC eligibility numbers, or reduce the variation of CHC award rates across CCGs, reported by the PAC, of 28 to 356 (1271%). By 2019 the variation had increased from 12 to 230 (1916%). A further ‘CHC Improvement Programme’ is now underway but even in the unlikely event that this is successful, it still does not address the fact that in the last five years thousands of people have been unlawfully denied the healthcare funding to which they were entitled and the need for redress.

Furthermore, NHS England now: ‘expects delivery of £855 million worth of savings by 2020/21 from reducing administration assessment costs and the overall cost of CHC provision’. This cannot possibly be coherent or justified given the widely held view by experts that demand for CHC should be growing. As the CEO of the NHS, Simon Stevens would have initiated, or certainly approved, this significant savings target, which clearly indicates his intent and mind-set. What message does it send from the NHS senior leadership to CCGs, many of which are already operating aggressive and unlawful CHC avoidance schemes? The PAC has expressed concern about how these savings against the increased projected CHC expenditure can be achieved.
Whilst the competence of CCGs to manage their budgets will vary significantly, the root cause of this significant breach of human rights lies with the Department of Health and Social Care and the NHS. CCGs have two conflicting legal statutory duties. On one hand, entitlement to CHC funding is a matter of law and if the National Framework eligibility criteria are met, it is not discretionary, or subject to policy choices, or funding priorities. But if CCGs lack sufficient funds to meet this need, this conflicts with another legal statutory duty that CCGs must not exceed their allocated budgets (as dictated by Sections 223G and 223H of the National Health Service Act 2006).

The result of this is that many thousands of members of the public have been unlawfully denied the healthcare funding to which they were entitled (individually often six figure sums) – a total figure running into £billions. This is almost certainly the biggest financial scandal in the history of the NHS and probably any other government department, or agency, involved in awarding money to the public. It also has caused untold stress and anxiety to very ill people when they are at their most vulnerable and to their families who are often supporting their loved ones as they approach end of life.

The enormous scale of this scandal, both in terms of financial deprivation and emotional distress it has caused, must be one of the most serious breaches of human rights since the creation of the EHRC. It is an utterly disgraceful situation, given that the purpose of the NHS is to alleviate suffering, not to create it. No government department or public body, or the people leading them, should be above the law and be able to arrogantly interpret it to suit their purpose. The Supreme Court has recently demonstrated this. The CHC public petition, signed by over 10,000 members of the public stated: “families have been left emotionally and financially devastated when they should be spending quality time with loved ones who, as enshrined in law, should have healthcare free at the point of delivery”.

Further Detailed Analysis

- False and misleading claims by the DHSC/NHS on CHC eligibility numbers.
- Care Quality Commission (CQC) reports on CHC.
- My personal experience of a CCG operating an aggressive and unlawful CHC avoidance regime.
- The most recent response from the ministerial correspondence team
- Questions that the senior leadership of the DHSC and NHS need to answer.
FALSE AND MISLEADING CLAIMS BY THE DHSC AND NHS ON CHC ELIGIBILITY NUMBERS

The government’s recent response to the public petition about the unjust and unlawful CHC process, stated: “the number of individuals eligible for NHS Continuing Healthcare has increased from around 133,000 in 2012/13 to over 160,000 in 2018/19”.

Note: these figures give the impression of continuous growth over this period.

Following my response to the government’s reply to the CHC public petition, they have now clarified how these figures are derived:

‘Activity data is based on the cumulative number of cases eligible over the year. Individuals are included in this figure if they have been eligible for CHC for a portion of the financial year, rather than because they are eligible on a specific day within the year. Many individuals may only be eligible for a relatively short period, either because their needs change, or because they are nearing the end of their life. Because of this movement into and out of CHC eligibility, the cumulative number of cases is higher than the Snapshot number.’

‘Snapshot data, which breaks eligibility down into quarterly figures, is the number of individuals eligible for CHC on a specific day within the quarter, that is, the last day of the quarter.’

‘These two data sets capture different and equally important aspects of CHC provision. ‘Snapshot’ data tells us how many people CHC is likely to be supporting at any one time, but ‘Activity’ data tells us how many people CHC provision impacts over time. Both are important.’

Analysis of the above explanation:

Activity Data: The NAO audit of July 2017 stated: ‘Between 2011-12 and 2015-16, the total number of people that received, or were eligible to receive funding, increased from 125,000 to 160,000, growing by 6.4% a year on average.’ In the government’s response to the CHC petition, the figure quoted for 2018/19 (3 years later) is also 160,000. So using ‘Activity’ data, there was effectively no growth during the 3 year period after Simon Stevens became CEO - the numbers flat-lined. For the government to use wording that implies numbers had steadily increased from 2012/13 to 2018/19 is grossly misleading. The NAO graph below shows the peak of 160,000 in 2015/16.
**Snapshot Data:** Noting the DHSC state this data is *important*, it is only by examining the trend of this data (people who are actually eligible for CHC funding at any one time) that the true picture of falling CHC eligibility numbers becomes very evident. The NAO graph below shows numbers rising until about 2015 and then starting to fall.

**Figure 6**
Number of people that received, or were assessed as eligible for, CHC funding during that year, 2011-12 to 2015-16

![Graph showing trend of CHC eligibility numbers](image)

**Figure 7**
The number of people that were receiving, or assessed as eligible for, CHC funding, at 31 March, 2012 to 2016

![Graph showing trend of CHC eligibility numbers](image)
Using the same data method for the years either side of this NAO graph, the graph below shows a steady rise in eligibility numbers up to 2015 and then a sudden reversal.

Using any NHS Quarterly data points (see below statistics), or an average throughout the year, for the 6 years 2013/14 to 2018/19 shows that soon after Simon Stevens became CEO in April 2014, there was a sudden reversal in growth, followed by a continuous decline in both the numbers eligible for CHC funding and the numbers of people per 50,000 of population who received it.

**NHS Q1 data points for 2013/14 to 2018/19**

- **Q1 2013/14** = 57,000 eligible (50.7* per 50K of population) *(50.7* is a ‘weighted’ figure)*
- **Q1 2014/15** = 62,328 eligible (68.9 per 50K of population) *Stevens becomes CEO*
- **Q1 2015/16** = 61,900 eligible (68.4 per 50K of population)
- **Q1 2016/17** = 59,905 eligible (65.5 per 50K of population)
- **Q1 2017/18** = 57,216 eligible (61.5 per 50K of population)
- **Q1 2018/19** = 55,761 eligible (59.4 per 50K of population)

**Summary Data.** Between 2015 and 2019, Activity data shows eligibility numbers flat-lined and Snapshot data shows that eligibility numbers have significantly fallen. With an ageing population, widespread expert opinion believed that numbers should have been increasing. Even Simon Stevens stated that: *the ageing population has created growing demands for care.*

Using a separate metric, the DHSC also claim that CHC funding is rising, implying more people are being found eligible, but this is also misleading. Increased CHC spending does not necessarily equate to increased numbers of CHC eligibility. The NAO stated in 2017: *much of the CHC budget is spent on delivering an assessment and screening process where only 18 per cent of those assessed were found to be eligible.*
CARE QUALITY COMMISSION (CQC) REPORTS ON CHC

In late 2017/early 2018 the CQC inspected 30 CCGs (about 15% of the total). These are the CHC related extracts from 14 of these inspections. These inspections were not just focussed on CHC and it is of note that 7 of the 10 CCGs that currently have the lowest CHC award rates in England (Q3 2018/19) were not inspected (Croydon, Bath and NE Somerset, Newham, Tower Hamlets, Berkshire West, NE Essex and Luton). There also appears to be no obvious correlation in the CCGs that the CQC inspected and those the EHRC threatened to take to court.

The earliest of the reports is 3.5 years after Stevens became CEO.

**Coventry**

‘Data showed from the first quarter of 2017/18 the rate per 50,000 population who received personal health budgets (PHB) was very low compared to the national average. While we saw evidence of people and families being involved in aspects of decision-making, several providers voiced concerns that people, carers and their families were not given the information they needed about CHC funding. This led to confusion about their eligibility and the assessment process itself’.

**East Sussex**

‘Analysis of NHS England data on NHS funded continuing healthcare showed in the first quarter of 2017/18 that the number of people in receipt of continuing healthcare direct payments and personal health budgets was below the England average in each of the three CCG areas operating in East Sussex.’

**Reading**

‘The decision process for continuing healthcare (CHC) funding was not timely or widely understood by staff. Consequently, staff found the process of applying for funding lengthy and complex – decisions about funding were also having a negative impact on relationships between staff. System leaders told us that processes for CHC had been reviewed and extra training had been provided for frontline staff. Despite this frontline staff still did not feel processes were clear and consequently this was continuing to cause delays. We heard how this was impacting on people being able to die in their preferred place and were given examples of people dying in hospital before the funding was approved.’

**Hampshire**

‘Data from NHS England showed that during quarter four of 2017/18, the referral rates across Hampshire for people to receive continuing healthcare care (CHC) funding was similar to the England average of 21% with the exception of South Eastern Hampshire CCG where the rate was 47%. This had been an improvement from the quarter one figures, when most of the Hampshire CCGs had lower than England rates for assessment and referral conversion.’
Stockport

'Within recent months people in Stockport, who had been assessed for NHS Continuing Healthcare (CHC) funding, were more likely to have the funding agreed. However, significantly less people than comparator areas or the England average were deemed eligible for CHC funding. NHS England data showed that between quarter one in 2017/18 and quarter three, the assessment conversion rate from referral to receiving care had increased from 11% to 21% which was similar to the England average of 22%. This suggested that processes for accurately identifying people for CHC were improving and a lower proportion of people were entering into the CHC process to subsequently be denied funding. However, the number of people deemed eligible for CHC funding in Stockport was lower in comparison with Greater Manchester (GM) and across England. Stockport’s eligibility rate for the year to date, (excluding Fast Track), was 44.5 per 50,000 population. This was lower than GM (69.31) and across England (63.84). Fast track eligibility, a CHC pathway tool often used for people who were at the end of their life to ensure they were supported in their preferred place of care as quickly as possible, was also low. The Fast Track eligibility rate for Stockport was 34.39 per 50,000 population. This was much lower than GM (104) and across England (106).'

Birmingham

'It was widely acknowledged that CHC processes were not working as they should for people in Birmingham. We were told of delays in fast-track CHC for people at the end of their lives, which meant that people were dying in a hospital setting who didn’t need to be there. We were told about a person with dementia and affected by multiple strokes who had their CHC funding removed following a routine review. At no point was their family provided with information or guidance about the CHC process or a key point of contact; decisions were poorly communicated, and there was no support from the CCG or local authority to identify options for when the funding was withdrawn.'

Hartlepool

'NHS CHC quarterly figures for all adults (NHS England) for Q1 2017 showed that the CCG had a standard NHS CHC assessment conversion rate for all adults (% of newly eligible cases of total assessments) of 21%. This was low compared to the England average (31%) and the Cumbria & the North East region average (26%). The referral conversion rate for all adults (percentage of newly eligible cases of total referrals completed) was also lower (21% compared with 25% for the region and England respectively). This suggested that the processes for accurately identifying people for standard CHC were not working as well as they should be and a higher proportion of people were entering into the CHC process to subsequently be denied funding.'

Leeds

'We heard concerns from frontline staff about instances where CHC fast-track funding was removed and this was causing families distress when supporting their loved ones at the end of life, particularly as often it would need to be reinstated anyway.'
Northamptonshire

‘The number of people deemed eligible for both standard CHC and fast track CHC was lower than average for both CCGs. As referral conversion rates were high, the lower eligibility rate may indicate staff were not identifying enough people who needed the support of CHC funding. NHS data for Q4 2017/2018 showed the England average for the number of people eligible for standard CHC was 39.5 per 50,000 and 18.4 per 50,000 for fast track CHC. In Nene CCG it was 30.1 per 50,000 people for standard CHC and 6.5 per 50,000 for fast track and for Corby CCG it was 26.5 per 50,000 people for standard and 1.6 per 50,000 for fast track. Eligibility rates, therefore, were significantly lower than average for fast track CHC.’

Sheffield

‘Some people using services, carers, social care providers and frontline staff told us the discharge process impacted upon CHC assessments and the quality and accountability of this process with concerns about it not being person-centred. Specific issues were raised regarding reassessment and withdrawal of CHC funding for some individuals at specialist dementia nursing homes. The CHC assessment process was not always person-centred and there were issues with the quality of assessments and a lack of accountability for who would lead on this process. Some people reported concerns about not being listened to and bullying approaches with a lack of choice and control.’

Trafford

‘We received negative feedback in relation to the CHC process. Unverified data from the system’s latest submission showed there had been some significant improvements in the last quarter. However, work was required to alter this negative perception through positive engagement with staff, providers and people who use services. As of September 2017 only 42% of local resolution meetings were happening within three months of notification of an appeal compared to a target of 100%.’

Wiltshire

‘The number of people eligible for NHS CHC funding was lower for people living in Wiltshire than the England average with 18.2% eligible compared to 43% nationally. Wiltshire’s performance for CHC assessment and referral conversion rates was also lower than the England average. The assessment conversion rate for standard CHC referrals was significantly lower than the England average, with 12% of assessments being completed in comparison to 31% nationally. The referral conversion rate was also lower than the England average of 25% at 11%. System leaders were unable to describe why the rate was so low but they were aware that CHC processes were not effective.’
Plymouth

‘Significant improvements were required in relation to standard continuing healthcare (CHC) to ensure staff understood the eligibility criteria and made appropriate referrals so there was a timely use of the framework and people’s rights to care were being met. It should be noted that this data does not just describe the situation in Plymouth, but relates to the whole NHS NEW Devon CCG area. In quarter one of 2017/18 the number of people waiting longer than 28 days for their assessment was 54.3 per 50,000 compared to the England average of 10.2 per 50,000. Furthermore, the conversion rate for standard CHC was 13% compared to an England average of 25% meaning fewer people who were referred for CHC funding were deemed to meet the eligibility criteria.’

MY PERSONAL EXPERIENCE OF A CCG OPERATING AN AGGRESSIVE AND UNLAWFUL CHC AVOIDANCE REGIME

My mother had severe dementia and entered a Salisbury nursing home in 2014. Without informing my father, a CHC checklist was then conducted, which proved positive, but was not taken forward to a full assessment, as it should have been. The CCG only admitted to this when I became aware of CHC funding in 2016 and asked why a CHC assessment had not previously been conducted. The CCG stated that her positive checklist was not taken forward to a full assessment due to an ‘administrative error.’ Failing to inform my father that a CHC checklist had been conducted and then not proceeding to a full assessment, was a serious breach of Wiltshire CCG’s legal duties.

After a subsequent gruelling two-year battle with Wiltshire CCG, which required extensive analysis, over one hundred letters and three meetings (about 30 days work), I eventually recovered four years of retrospective CHC funding (£200,000) for my mother’s healthcare. The CCG did everything possible to avoid making an eligibility decision, ignoring or grossly distorting the evidence available. An Independent Review found that the regulations had been contravened in multiple ways and recommended that a CHC improvement programme be instigated. A subsequent investigation by NHS South West, initiated by me, ignored critical evidence and appeared to have all the hallmarks of a cover-up. It stated that the regulations had not been contravened and was endorsed by the Director, a previous CEO of NHS Wiltshire and supported by the MP for Salisbury - also a Treasury Minister.

Wiltshire CCG’s level of funding has been one of the lowest in the country (bottom 5%), with no credible explanation, as confirmed by the CQC. On 16 Oct 2015, the Wiltshire CCG Chair wrote a letter to all stakeholders stating: ‘The CCG’s financial situation is dire and we need to prove to NHS England that we are impacting on all areas of expenditure’. In comparison with neighbouring CCGs, Wiltshire has been under-funding CHC by up to £25 million a year. In doing so, statistically the CCG will have unlawfully denied many hundreds of old, ill and vulnerable people the healthcare funding to which they were entitled. These people will have fallen into two categories.
Firstly, those who did not even know about CHC funding (often referred to as the ‘best kept secret in the NHS’) who should have been screened by the NHS but were not - it is the responsibility of the NHS to screen all potential recipients who might be eligible. Secondly, those people who were not fortunate enough to have someone like me with the time, confidence, stamina, tenacity and analytical skills to challenge a CCG that was operating an aggressive and unlawful CHC avoidance regime.

THE MOST RECENT RESPONSE FROM THE MINISTERIAL CORRESPONDENCE TEAM

I recently sent a letter to Sir Edward Lister, the Prime Minister’s Chief of Staff, with an attached briefing package containing much of the evidence contained in this paper. This is the response I received on 17 September 2019.

Dear Rear Admiral Mathias,
Thank you for your further recent correspondence to Sir Edward Lister and ministers at the Department of Health and Social Care about NHS continuing healthcare. Your letter to 10 Downing Street has been passed to the Department and I have been asked to reply. I appreciate that this is an area of significant concern to you and many others and I would like to reassure you that the Department is committed to making a health and social care system that works for everyone.

As the Department receives around 60,000 emails and letters each year it is not possible for the Secretary of State or other ministers to see every one. However, I would like to reassure you that the relevant policy officials are aware of your correspondence and the points you raise.

The Government wants the NHS to be considered one of the best healthcare providers in the world and it is always looking for ways to improve its services. The Department would like to thank you for making it aware of your concerns, and it continues to welcome all contributions to the ongoing discussions about this complex area.

I hope this reply is helpful.

Yours sincerely,
Rosalind Hermanstein
Ministerial Correspondence

The likely reason for this almost unbelievably inadequate, insulting and disgraceful response is that the DHSC and the NHS senior leadership do not want to acknowledge an uncomfortable truth. To do so would be to accept that considerably more CHC funding is required, or that the founding principle of the NHS, that healthcare is free at the point of delivery, is being compromised even when people are at their most vulnerable. Accepting the evidence outlined in this paper would also potentially make the DHSC/NHS liable for a huge number of retrospective CHC claims.
SOME OF THE KEY QUESTIONS THAT THE SENIOR LEADERSHIP OF THE DHSC AND NHS NEED TO ANSWER

1. Do you agree that if the National Framework eligibility criteria are met, entitlement to CHC funding is a matter of law and is not discretion ary, or subject to policy choices, or funding priorities?

2. With an ageing population, do you agree with widespread expert opinion that the demand for CHC funding should have been increasing?

3. How to explain that from 2015 CHC eligibility numbers (based on Activity data) suddenly flat lined (when they had been rising) and CHC eligibility numbers (based on Snapshot data) suddenly stated to fall (when they had been rising)?

4. Since 2105 how do you explain the overwhelming criticism across the media, from the public and expert bodies reporting the CHC process as dysfunctional, unjust and unlawful? They include:

   National press articles and TV documentaries: Recent examples include Channel 4 Dispatches (CHC Postcode lottery), Daily Telegraph front page ‘Vulnerable pensioners with dementia face crippling care bills following NHS attempts to restrict funding’. BBC Victoria Derbyshire: ‘our life savings are being spent on care that should be free’.

   CQC inspections: highly critical of many CCGs that are not correctly applying the CHC National Framework. Four examples: Wiltshire CCG: ‘System leaders were unable to describe why the CHC rate was so low but they were aware that CHC processes were not effective.’ Stockport CCG: ‘Significantly less people than comparator areas or the England average were deemed eligible for CHC funding.’ Coventry CCG: ‘Families were not given the information they needed about CHC funding.’ Birmingham CCG: CHC processes were not working and people were dying in a hospital setting who didn’t need to be there. We were told about a person with dementia and affected by multiple strokes who had their CHC funding removed following a routine review.’

   CHC Alliance (17 charities): ‘Continuing Healthcare is failing people across England. Due to flawed processes, many people who should be found eligible are being denied this much needed support.’

   Alzheimer’s Society: ‘the CHC system discriminates against people with dementia, despite it being a medical condition and there is weak enforcement of the National Framework that CCGs must adhere to.’

   NAO: ‘there is significant variation between CCGs in both the number and proportion of people assessed as eligible for CHC and there are limited assurance processes in place to ensure that eligibility decisions are consistent, both between and within CCGs.’
EHRC: In March 2018 the EHRC threatened to take 13 CCGs to court because of ‘concerns about NHS CHC policies being unlawful and significant concerns about blanket NHS CHC policies having arbitrary caps on funding’.

PAC: ‘The funding system is failing people with continuing healthcare needs and there is unacceptable variation between areas in the number of people assessed as eligible, ranging from 28 to 356 people per 50,000 population. NHS England recognise that the system is not working as well as it should but are not doing enough to ensure CCGs are meeting their responsibilities, or to address the variation between areas in accessing this essential funding.” (note: the variation between CCGs has increased since this PAC report)

Public Petition: ‘families have been left emotionally and financially devastated when they should be spending quality time with loved ones who, as enshrined in law, should have healthcare free at the point of delivery.’

5. Given the above evidence, do you accept that since 2015 that many people have been unlawfully denied CHC funding to which they were entitled - either because as potential recipients they were not screened (it is the NHS responsibility to do this) or because many CCGs failed to comply with the CHC National Framework?