The NHS Continuing Healthcare (CHC) Scandal

Many of thousands of old, ill and vulnerable people have been unlawfully denied healthcare funding to which they were entitled - totalling circa £5billion.

'The NHS may become open to judicial review and severe reputational damage.'
(2019 NHS report endorsed by Trish O'Gorman Head of CHC Policy)

Rear Admiral Philip Mathias
August 2020

In our advanced democracy, it is unacceptable that a Department of State (the DHSC) and our biggest public body (the NHS) can be allowed to systematically break the law, with almost total impunity, whilst causing emotional distress and financial devastation to many of thousands of old, ill and vulnerable people.

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What is Continuing Healthcare?

The dysfunctional relationship between Social Care and Continuing Healthcare (CHC) is not widely understood. Social Care for the frail and elderly is means-tested and either provided by the Local Authority or is privately funded. CHC is not means-tested, as healthcare is free at the point of use. Outside of hospital, it is the legal responsibility of the NHS, via Clinical Commissioning Groups (CCGs), to fully fund an individual's care, in any setting, if their care needs are primarily health related. This in theory is what should happen but the reality is often very different.

The failing and unlawful CHC system

'The law requires CCGs within England to allocate the CHC funding to individuals based on a set of fixed objective criteria' (Met Police specialist crime unit 2019)

There are two key elements of the NHS CHC scandal. First, the significant decline in the overall numbers of old and ill people found eligible for funding, when due to an ageing population the numbers should have been increasing. Second, the huge variations in the award rate of CHC funding across the country, caused many CCGs failing to correctly apply the complex eligibility criteria. These huge variations are often referred to as the 'postcode lottery' and result in people in one part of the country receiving funding (often 6 figure sums) and others living in a different area, who have the same healthcare needs, getting no funding at all.

Over the last three years, multiple independent and expert bodies, the media and the public have been highly critical of the failing and unlawful CHC system. The Public Accounts Committee (PAC), National Audit Office (NAO), Care Quality Commission (CQC), CHC Alliance (17 Charities), national press and TV documentaries and a Public Petition, have described the CHC system as dysfunctional, complex, discriminatory, lacking the necessary assurance processes and **unlawful.**

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 is not adequately carrying out its responsibility to ensure CCGs are complying with the legal requirement to provide CHC to those who are eligible'* Giving evidence, Norman Lamb MP, a previous minister for care and an expert on CHC, said: *'Demand is rising significantly every year across the country, yet the number of people entitled is going down. Given that this is public money, how can we possibly justify such an extraordinary variation without any democratic legitimacy?'*

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.'*

CQC: *Examples of 2017/18 inspections:* **Wiltshire:** *'System leaders were unable to describe why the CHC rate was so low but they were aware that CHC processes were not effective.'* **Stockport:** *'Significantly less people than comparator areas or the national average were deemed eligible for CHC funding.'* **Coventry:** *'the CHC award rate was very low compared to the national average and families were not given the information they needed about CHC funding.'* **Birmingham:** *'CHC processes were not working and people were dying in hospital who didn't need to be there. A person with dementia and multiple strokes had their CHC funding removed following a review.'* **Hartlepool:** *'the processes for identifying people for CHC were not working well and a high proportion of people were entering the CHC process to subsequently be denied funding.'* **Northamptonshire:** *'The number of people eligible was lower than average for both CCGs and staff were not identifying enough people who needed CHC funding.'* **Reading:** *'The decision process for CHC funding was not timely or widely understood by staff and people were dying in hospital before funding was approved.'* **East Sussex:** *'CHC award rates were below average in each of the three CCGs.'* **Plymouth:** *'Significant improvements were required to ensure staff understood the CHC eligibility criteria. The eligibility rate was half the national average.'*

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 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.'*

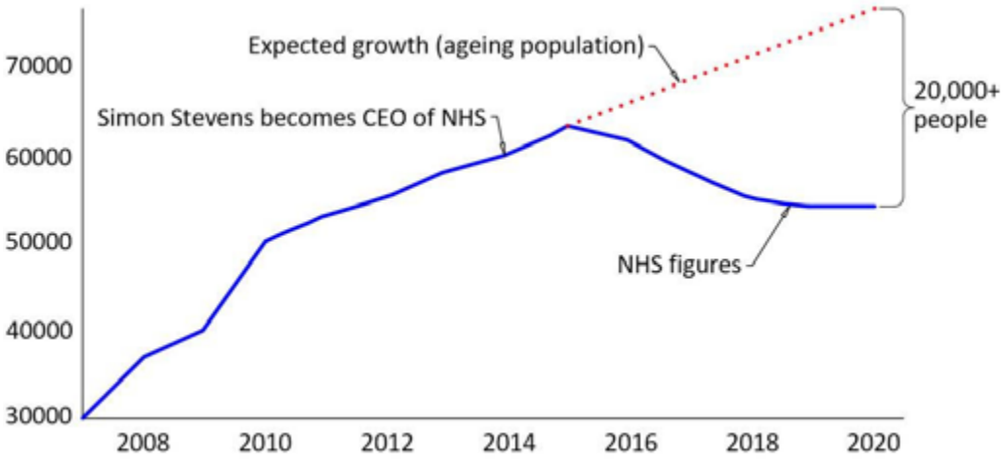
Media: Over the last few years virtually every national newspaper has covered the CHC scandal, the most comprehensive being a front page article in the Daily Telegraph (Feb 2019), which discovered NHS England documents submitted to the NAO in 2017 saying *'reducing the number of people eligible for continuing healthcare and reducing the average cost of the CHC package is key'.* A Channel 4 Dispatches documentary in 2017 exposed the tactics deployed by many CCGs to avoid making funding eligibility decisions.

Public Petition: signed by 10,000 people calling for a Public Inquiry into the CHC scandal, 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."* Despite the widespread and damning criticism, the response from the Minister for Care (then Caroline Dinenage) was: *"The Government does not believe that CHC is being mismanaged by CCGs."*

Those who are unlawfully denied CHC funding fall into two categories. First, those who have 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. Second, those who are found ineligible because the CCG contravened the regulations, resulting in many thousands of people paying significant sums for their own healthcare, with some being unlawfully forced to sell their homes.

Declining CHC eligibility numbers

The graph below uses open source NHS quarterly 'snapshot' data and shows the number of people eligible for CHC funding at any one time. This metric has historically been the recognised method of monitoring CHC eligibility numbers. In 2017 additional metrics were introduced, which appears to be a smoke screen in an attempt to conceal the truth about declining eligibility numbers.



Unsurprisingly, expert opinion considered that due to an ageing population, CHC eligibility numbers should have continued to increase, when in fact the opposite occurred and numbers significantly declined. In addition to Norman Lamb's expert comment at the PAC, an NHS report in 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.'*

Analysis of the graph shows that between 2015 and 2020 the number of people who were unlawfully denied CHC funding could be as high as 50,000. A reasonable assumption is that the average level of funding unlawfully denied to each individual was about £100,000 (my mother received £200,000), which equates to a staggering total figure of about £5billion of unlawful financial deprivation.

Allowing for inertia, the graph clearly shows that the significant and sudden reversal in CHC eligibility numbers coincided with Simon Stevens becoming CEO. If he didn't initiate this himself, he would have certainly been aware of it. Whilst he would have had some discretion in determining NHS spending priorities, in the case of CHC funding he appears to have arrogantly disregarded the law and in doing so compromised the founding principle of the NHS - that healthcare is free at the point of use.

If the NHS and the government considered that CHC was unaffordable, the law should have been changed – not broken. If the stringent eligibility criteria are met, the provision of CHC funding is a statutory legal requirement and is not discretionary. Reducing CHC entitlement, without changing the law, would be like the Department for Education deciding arbitrarily that it could no longer afford to offer a school place to every child.

In terms of the sheer scale of this scandal, measured by the significant numbers of old, ill and vulnerable people adversely affected and the huge level of unlawful financial deprivation, this is very possibly one of the biggest government scandals of modern times. So in our 'advanced' democracy, here we have a Department of State and our largest public body disregarding the law on a massive scale and with almost total impunity - a situation normally associated with corrupt and failed states. The DHSC and NHS have also grossly violated the human rights of some of the most vulnerable people in our society, discrimination based on age and disability, with many being unlawfully forced to sell their homes when their care should be funded by the NHS.

Failure of CHC Improvement Programmes

In the last few years there have been several attempts at CHC 'Improvement Programmes', which NHS England claim have been successful but its own data does not support this assertion. Whilst the significant inconsistency in CCG level of compliance with the regulations has been slightly dampened, huge variations in their award rates of CHC funding continue.

In 2019, the NHS CHC policy lead (Trish O'Gorman) endorsed a report stating: *'There could be potential for far reaching legal and financial implications if CCGs do not apply the National Framework consistently and accurately to ensure the NHS does not become the subject of maladministration and the associated costs that come with it.'* Analysis of NHS 2019/20 Q2 data (released 8 months ago) shows that an individual in Salford was 17 times more likely to be awarded CHC funding than someone in Luton – a variation of between 211 and 12 people per 50,000 of population who were found eligible. In Airedale someone was 13 times more likely to be awarded funding than if they lived in West Berkshire. Many more examples are listed at the end of this document. The NHS simply refers to CCGs with low CHC award rates as 'outliers' but in the real world this means that statistically thousands of old, ill and vulnerable people have been and continue to be unlawfully denied significant sums of CHC funding. If the NHS wishes to contest this, it should provide detailed and credible socio-economic and health demographic reasons to explain and justify these huge variations.

Even if these CHC improvements programmes had resolved the huge variations of award rates across CCGs, it still does not address the fundamental point that in the last five years overall CHC eligibility numbers have significantly declined, when with an ageing population they should have been rising.

The NHS and DHSC also claim the CHC budget has never been higher but fail to add that this does not relate directly to eligibility numbers. In 2017, the NAO reported that *'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.'* It is far more cost effective for CCGs operating aggressive and unlawful CHC avoidance regimes to employ large numbers of CHC assessors, including an increasing use of private consultants, than to fully fund CHC. There are also some highly questionable practices being conducted by NHS employees and CHC private consultants.

At the end of last year, Matt Hancock launched an immediate investigation into *'an extremely concerning apparent conflict of interest'* after the Telegraph exposed NHS officials charging families up to £400 a day for advice on how to secure CHC funding. Conversely, there have been cases where consultants have held NHS CCG executive appointments. For example, someone was appointed as the Interim Head of CHC for Wiltshire CCG, whilst simultaneously being a director of two CHC related consultancy companies. Given that commissioning and decision-making are key elements of this CCG role, there is a clear potential for conflict of interest.

The challenge of holding the NHS and DHSC to account

This CHC scandal certainly has all the hallmarks of a government cover-up and ministers know the potentially significant political implications of it detonating and being held to account. Extracts from the previously mentioned 2019 NHS report endorsed by the CHC policy lead include: *'CHC is of significant interest to Ministers who receive considerable correspondence on the matter; there is particular concern regarding lack of compliance with the National Framework, a lack of data in this area and very poor patient experiences; NHS England may be open to judicial review as well as severe reputational damage.'* I am also sure that it was no coincidence that after I wrote an open letter to Sir Edward Lister (PM's Chief of Staff), the Prime Minister's personal secretary and special advisers were then included on the distribution list for NHS quarterly CHC data.

Given the significant implications, of this scandal being exposed, both financial and political, the least bad strategy for the government has been to 'hold the line' and brush off the barrage of damning criticism from numerous expert public bodies, the media and the public, with disingenuous, inaccurate or meaningless statements, none of which answer the questions, or stand the test of even the most basic level of scrutiny. So far this strategy of denial has worked - so why change it? The response I got to my letter to Sir Edward Lister is typical: *'Thank you for your 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. I hope this reply is helpful.'*

The NHS and government also know that the whole process of CHC funding is hugely complex and they exploit this to the full. Very few people understand the dysfunctional relationship between social care funding which is means-tested and NHS CHC funding, which should be free at the point of delivery. Open source NHS CHC data is also difficult to access and analyse and its format has often changed. The government has demonstrated during the Covid-19 crisis its ability to manipulate complex data sets to suit its purpose and it has most certainly attempted to do this to conceal the truth about declining CHC eligibility numbers.

The CHC assessment process itself is also hugely complex (140 page National Framework) and is beyond most members of the public to comprehend. Leaving aside those who are not even aware of CHC funding, most people do not know if the eligibility criteria are being applied correctly - certainly not those who are old, frail and ill. Those who are fortunate enough to have a family member, who is sufficiently capable and willing to challenge a CCG's ineligibility decision, statistically stand little chance of success at the multiple levels of appeal, which can take several years. As a former director of nuclear policy in MOD (Whitehall), I am comfortable with complex analysis and it took me two years, over one hundred letters and three appeal meetings to win my mother's case. A summary is at the end of this document, as it is a typical example of a CCG operating an aggressive and unlawful CHC avoidance regime.

Investigations by the Metropolitan Police and Equality and Human Rights Commission

The government will know that the only real threat of being held to account is a legal challenge. Last year I wrote an open letter to Cressida Dick, the Commissioner of the Metropolitan Police, making an allegation of Misconduct in Public Office against Simon Stevens. She personally read my letter and took the allegation sufficiently seriously to direct that her specialist crime unit review the evidence. I worked closely with the lead investigating officer for three months. Whilst he confirmed: *'the law requires CCGs within England to allocate CHC funding to individuals based on a set of fixed objective criteria'*, given the very high bar for a criminal charge associated with this offence, he eventually concluded, for a number of complex and technical legal reasons, that it was not appropriate to proceed to a criminal investigation. That said, he was very aware and sympathetic to the significant scale of injustice and implied (carefully) that a case under civil law could well be feasible.

I subsequently made a formal submission to the CEO of the Equality and Human Rights Commission (Rebecca Hilsenrath), providing extensive and irrefutable evidence that many thousands of old, ill and vulnerable people had been discriminated against, based on age and disability and this was a gross violation of their human rights. Her initial response was very positive when she stated this issue was of *'immense and growing significance'* but after six months she eventually concluded: *'the DHSC and NHS already have obligations to prevent unlawful discrimination; this issue is not covered in the EHRC's strategic plan; EHRC legal action would not achieve better compliance by CCGs.'*

By any standards this was a woeful failure of the EHRC, bringing into question its credibility, not least given one of its three strategic goals is *'to protect the rights of people in the most vulnerable situations.'* How much more vulnerable can someone be if they are old, ill and suffering from significant health related disabilities, particularly those with severe cognitive impairment due to dementia? During the EHRC's investigation, Rebecca Hilsenrath repeatedly ignored my requests that NHS England and the DHSC should be required to provide detailed and credible answers to the following questions, the answers to which would fully expose this scandal:

- How do they explain the significant decline in CHC eligibility numbers over the last 5 years, when numbers should have been increasing due to an ageing population?
- Post CHC improvement programmes, how do they explain the continuing huge variations (up to 17 fold) in CHC funding award rates across CCGs?
- Why are so many CCGs failing to follow CHC Case Law (Coughlan 99, Grogan 06) to ensure an 'objective' test is conducted?
- Given the extensive criticism and evidence of the failing and unlawful CHC system by the PAC, NAO, CQC, CHC Alliance (17 charities) and the media, how can a Minister of State justify the following statement? *'The Government does not believe that CHC is being mismanaged by CCGs.'*

My subsequent appeal to the EHRC Chair (David Isaac) and Commissioners was unsuccessful noting: *'prior to his appointment as chair of the Commission, two parliamentary committees warned that there was a potential conflict of interest because his legal firm (Pinsent Masons) carries out significant work for the government. In*

May 2019, Suzanne Baxter, another EHRC board member, joined Pinsent Masons.' It also of note that over the last few years government funding for the EHRC has reduced significantly and ministers approve key appointments.

In terms of other legal options, the vast majority of people cannot afford the time or financial risk of taking the NHS to court once the appeal process is exhausted and a 'class' type action would be legally highly problematic, as every CHC case is different. Given the significant scale of this unlawful conduct by a government department and a public body, there are clear grounds for a Judicial Review, noting that even NHS England believes that it is at risk from one.

Conclusion

This CHC scandal is very topical when set against the backdrop of the related issues of the repeated failure of successive governments to reform the funding of social care and more recently, the failure to safeguard highly vulnerable people in care homes during the early stages of the Covid-19 pandemic. This resulted in many thousands of avoidable deaths and in the most harrowing of circumstances.

The significant difference though is that these were woeful failures of policy, whereas the CHC scandal concerns the NHS and DHSC knowingly and systematically breaking the law on a significant scale by denying many thousands of old, ill and vulnerable people the healthcare funding they are legally entitled to. It is also unforgivable the emotional distress this has caused to so many people, who often do not have long to live, including the worry and distraction it creates for their loved ones during a sad period of their lives. The NHS was established to alleviate suffering – not to create it.

I appeal to all those in positions of power and influence to hold those responsible for this disgraceful Continuing Healthcare scandal to account, not least to provide redress to those so adversely affected by it and to stop further unlawful conduct, which continues to this day. If the government considers that CHC funding is unaffordable, then it should change the law - not break it. At the highest levels of leadership, those responsible for either creating this scandal, or concealing the truth and failing to take corrective action when they became aware of it, include the CEO of NHS England (Sir Simon Stevens), the Secretary of State for Health and Social Care (Matt Hancock) and his Permanent Secretary (Sir Chris Wormald).

Finally, if any of the eminent QCs who have read this paper are prepared to make the case for a Judicial Review, I am confident that costs could be covered by crowd-funding.

An example of a CCG operating an unlawful CHC avoidance regime

My mother had severe dementia, including regular episodes of violent behaviour and numerous other health related care needs. She entered a Salisbury nursing home in 2014, initially funded by my 90-year-old father (£48,000 a year). Without informing him, a CHC initial 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. I discovered a letter written in October 2015 by the Wiltshire CCG Chair, which stated: *'The CCG's financial situation is dire and we need to prove to NHS England that we are impacting on all areas of expenditure.'* The CHC National Framework states: *'the final eligibility decision should be independent of budgetary constraints.'*

After a subsequent gruelling two-year battle with Wiltshire CCG, (CEO Linda Prosser), I eventually recovered four years of retrospective CHC funding (£200,000) to pay for my mother's care. To achieve this required a huge amount of complex analysis, over one hundred letters and three meetings - about 30 days work. The CCG did everything possible to avoid making an eligibility decision, ignoring and grossly distorting the evidence available. An Independent Review Panel found that the regulations had been contravened in multiple ways. A subsequent investigation by NHS South, 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 financial director and CEO of Wiltshire CCG (Jennifer Howells).

Wiltshire CCG's level of funding had been one of the lowest in the country (bottom 5%), with no credible explanation, as confirmed by a CQC inspection. In comparison with neighbouring CCGs, Wiltshire had been significantly under-funding CHC and in doing so statistically will have unlawfully denied many hundreds of old, ill and vulnerable people the healthcare funding to which they were entitled.

Throughout this whole process, I had extensive and often heated discussions with the MP for Salisbury and Treasury Minister (John Glen), including exchanging open letters in the local press. Despite the overwhelming evidence above, he refused to accept that many of his constituents had been unlawfully denied CHC funding.

There is extensive evidence to indicate that this disgraceful and unlawful conduct by Wiltshire is replicated by many CCGs but few members of the public have the time, analytical skills, tenacity and confidence to successfully challenge a CCG which is acting unlawfully.

The CHC Postcode Lottery

CCGs with the highest and lowest CHC funding rates per 50,000 of population (NHS 2019/20 Q2 data)

Salford **211**
Airedale, Wharfedale & Craven **172**
Blackpool **156**
Heywood, Middleton & Rochdale **151**
Bury **145**
Richmond **139**
Cannock Chase **133**
Stafford & Surrounds **128**
North Staffordshire **127**
Wigan Borough **123**
South Tyneside **117**
Bradford Districts **117**
South Tees **116**
Stoke on Trent **114**

Luton **12**
Berkshire West **13**
Tower Hamlets **23**
Bath & NE Somerset **23**
NE Essex **24**
Newham **24**
Hastings & Rother **25**
Croydon **27**
High Weald Lewes Haven **28**
Eastbourne, Hailsham & Seaford **30**
City & Hackney **30**
Guildford & Waverly **30**
Wolverhampton **32**
Southampton **34**