

WRITTEN OPENING SUBMISSIONS FOR HEARING COMMENCING 9 SEPTEMBER 2024 JOHN'S CAMPAIGN, THE PATIENTS ASSOCIATION AND CARE RIGHTS UK

Executive Summary

1. These Opening Submissions address the CPs' concerns about the pandemic's impact on healthcare systems from the perspective of patients and those who draw on and provide care and treatment and their loved ones. The issues raised are healthcare issues, about access to healthcare and the experience of receiving and delivering healthcare during the pandemic across a range of healthcare settings, all within the scope of Module 3. Many people received healthcare in (among other settings) residential care homes, nursing homes, mental health units and in their own homes, as well as in hospital. The provision of healthcare in all of these settings falls within the scope of Module 3. The CPs are concerned that the healthcare experience of people who also draw on social care is not overlooked simply because the impact of the pandemic on the social care sector more generally will be covered by Module 6. Many of the issues experienced by this cohort arose because they fell through the gaps during the pandemic, at least in part because of a failure by decision-makers to understand and respond to the interdependence of healthcare and social care, and the false understanding that those in social care settings (for example) are "only" receiving social care (they are not: many also receive healthcare in these settings). The CPs are anxious that the Inquiry does not make the same mistake.
2. For clarity, these submissions refer to the provision of healthcare in a person's own home as "domiciliary care"; healthcare provided in, for example, care homes, nursing homes, rehabilitation units and mental health inpatient units among others is described as healthcare in "residential healthcare settings"; references to "hospitals" should be understood to include NHS and non-NHS hospital settings. Other references, such as to care homes, are made where, for example, the statistics, guidance, or underlying evidence referred to specifically relates to care homes rather than to the wider category of residential healthcare settings.
3. The overarching points the CPs wish to underscore are that:
 - a. "Healthcare" is not just delivered by medical professionals in hospital settings. It is also delivered by staff in other settings (as described above), and by family members and loved ones in all of those settings. Decision-makers during the pandemic took too narrow a focus on healthcare as the provision of care and treatment by professionals in hospitals; and people's access to healthcare during the pandemic suffered as a result of the lack of recognition of the diversity of ways and places in which healthcare is delivered.
 - b. The failure to treat family carers as part of a healthcare team damaged the quality of and access to healthcare of individuals who rely on family carers to

advocate for them, interpret their needs, and ensure they receive the healthcare they need. One key example of this was in the visiting restrictions that prevented family carers from consistent access to their loved ones. This was true across residential healthcare settings and hospitals. There was also a significant impact on the health and wellbeing of family carers themselves.

- c. The decision to discharge patients from hospital into residential healthcare settings without testing for Covid 19 had a devastating impact on individuals who live in those settings: first because many contracted Covid and were very unwell or died; and second because the visiting restrictions that were then imposed were so draconian in response to that early failure. This impact arose in part from a failure to understand the relationship between the healthcare and social care sectors, and it had a material impact on the health, and access to healthcare, of people in care homes.
- d. Guidance and regulations across the UK were often conflicting, confusing, and lacking in clarity, or failed to address critical issues and legal obligations which could have obviated some of the harm caused to vulnerable groups. For example, guidance on visiting people in hospital, or on conveyance to hospital by ambulance, did not initially consider the needs of people with a learning disability or cognitive impairment, or accommodate the reasonable adjustments to which they had a right under the Equality Act 2010. In addition, the guidance did not consider the needs of individuals for whom English was not their first language/spoken at all. It is hard to understand how informed consent to treatment could be given in any of the above circumstances.
- e. There were serious issues with the provision of palliative and end-of-life care. These included (i) late assessment that someone was at the end of life; (ii) difficulties in carrying out assessments remotely; (iii) those delivering palliative care in hospices, charities or other care settings not being considered as frontline services and therefore not being provided with adequate PPE etc; (iii) poor communication leaving relatives with inaccurate views of a person's condition; (iv) loss of valuables in hospitals; (v) inability to connect with loved ones (as dying and bereaved people) often resulting in a deterioration of their conditions; and (vi) failure to define terminology around the end of life e.g. the definition of 'exceptional circumstances' for visiting hospital patients and care home residents.
- f. The human rights of individuals, and methods of delivering healthcare that recognise human rights (and that therefore make individualised assessments in all cases) are more, not less, important in times of crisis. Despite that, steps to respond to the pandemic incorrectly suggested that they were negotiable standards. The existence of blanket DNACPR decisions was an example of a failure to ensure respect for human rights and individualised decision making. Disabled people and older people are amongst the groups that were most acutely impacted by such undifferentiated and inappropriate decision-making. This kind of decision-making also exacerbated existing health inequalities, including in respect of disabled people's experience of healthcare.

Introduction

4. Patients and those drawing on health care find themselves in a wide range of living situations. They may live at home or in residential healthcare settings, and their healthcare needs may be met by healthcare professionals, social care professionals, or by loved ones and other unpaid carers. The impact of the pandemic on the healthcare system cannot, therefore, be understood by looking at the snapshot of the system represented by treatment given and received by professionals in NHS hospitals.
5. The healthcare needs of people who also receive social care were particularly acute during the pandemic. Nearly 40% of deaths involving Covid-19 in the first three months of the pandemic were suffered by care home residents. There were many more deaths in domiciliary care. And the care needs of those in residential healthcare settings – for example, those with dementia, learning disabilities and those with those with complex or rare conditions where their family carer is likely to have particular expertise on their condition – made them particularly vulnerable to experiencing negative impacts consequential on the Covid restrictions that were introduced.
6. The CPs’ witness statement (INQ000283957) (“CPs’ WS”) describes some of the impact of Covid-19 on patients’ experience of healthcare. For example, it describes:
 - a. A sustained pattern of difficulty in accessing services, including frequent cancellations, delays in treatment and long waiting times for patients (§47). This is further detailed in a survey by the Patients Association (INQ000273425, p3);
 - b. A reluctance to access healthcare services due to fears associated with the pandemic, the Government’s stay-at-home messaging, and a lack of information to reassure people or identify alternatives for them (§52);
 - c. A failure to understand the critical and extensive role of unpaid carers across the healthcare system and the negative impact this failure had on decision-making, with consequent adverse impacts on social care and access to healthcare throughout the pandemic (§19) (see also findings from Carers UK and the University of Sheffield: INQ000273417);
 - d. A lack of person-centred support for patients arising from the failure to recognise the importance of family carers and include them in decision-making about people’s healthcare needs (§125). This had direct negative healthcare outcomes for many patients, who suffered from the absence of loved ones advocating for them and/or providing them with essential healthcare in hospital and residential healthcare settings, as exemplified in the witness statements of Rachel Ashton (INQ000492025) and Clare Cole (INQ000421875); and
 - e. The lack of access to healthcare for people in care homes (caused in particular by GPs and other practitioners staying away to limit infection risk (§22), and latterly by isolation requirements on return to care homes that strongly disincentivised care home residents from attending external medical appointments (INQ000273453). Age UK’s evidence underscores the issues that those in residential care homes had accessing appropriate healthcare, including that: social care staff were left to perform clinical tasks they were not trained or skilled in; some were unable to administer controlled drugs for lack of suitable registered staff, such that residential healthcare setting residents were denied necessary medication (INQ000319639, §46); and some older people in residential healthcare and community settings were discouraged or prevented

from accessing healthcare services, including through non-conveyance practices, which amounted to direct discrimination against older persons (§52).

7. Strikingly, an early pandemic patient experience report (INQ000273424) conducted by the Patients Association found that (i) more than half of respondents felt their healthcare and social care needs had not been supported; (ii) 67% had had appointments cancelled; and (iii) over 48% had put off accessing healthcare services or treatments (p22). The number of people awaiting healthcare, including for serious conditions such as cancer, increased about 9-fold: INQ000300217, §2, pages 20, 22, 35-36. The impact of this was not equally felt: the Cabinet Office Equality Hub recognised that disabled people's concerns about accessing healthcare were, by October 2020, higher than among non-disabled people (INQ000436880, §8.56.2) and disabled people were twice as likely to report that their access to healthcare and treatment for non-coronavirus related issues had been affected by the pandemic (ONS data, INQ000089785, p7).
8. Relatives and carers played an essential role in provision of healthcare during the pandemic, attempting to plug gaps caused by restrictions on access to healthcare, and in the ongoing provision of healthcare for disabled loved ones. Older carers routinely provided some of the most intensive and personal levels of unpaid healthcare and social care for a loved one (Age UK, INQ000319639, §18). The enormous contribution of unpaid carers to healthcare provision during the pandemic (and beyond) has been consistently overlooked. They did not receive sufficient attention from core decision-makers and nor has the impact on them been properly appreciated (see also Age UK report [INQ000176634, pp24-25]).
9. As well as the negative impact of restricted access to healthcare, decisions made in and about the provision of healthcare during the pandemic were often inappropriate, harmful, and exacerbated existing health inequalities. For example, the CPs have serious concerns about the inappropriate application of do not resuscitate ('DNACPR') decisions on patients without their consent or even consultation, without individual assessments, or with a patient feeling pressured into agreeing. Another example is the early discharge of patients from hospitals into care homes without prior testing for Covid-19, and without ensuring that care homes were equipped and able to manage the healthcare of Covid-positive patients and minimize onward transmission to other vulnerable residents.

The failure to take account of the broad range of settings in which healthcare was received, and to view healthcare teams holistically

10. There was a failure to take account of the different means through which, and places at which, people access healthcare; and an associated failure to treat family carers as part of a core healthcare team. These failures damaged the quality of and access to healthcare of individuals who rely on family carers to advocate for them, interpret their needs, and ensure they receive the healthcare they need.
11. The CPs' witness statement details the detrimental health impacts caused by pandemic policies, in particular the isolation policies and visitor policies (which reduced and even removed the ability of family carers to be involved in healthcare decisions and delivery) (CPs' WS, §22). For people with dementia, for example, the impact of these requirements was *"devastating, leading to confusion and a deterioration in their*

condition” (§63). Indeed “carers, families and friends of people living with dementia [saw] rapid deterioration in their loved one’s cognitive function, which affected memory, sleep, mood and behaviour” and “service disruption also led to delays in dementia diagnosis, with unmanaged cognitive decline having an enormous psychological impact on both the person with dementia as well as their family and carers” (Age UK evidence, INQ000319639, §38).

12. A survey conducted by John’s Campaign showed that 80% of respondents to a November 2020 survey reported that their relative’s physical or mental health deteriorated as a result of visiting restrictions (INQ000273428). An Equality Impact Assessment on 27 August 2020 identified, in respect of those with dementia, a worsening of functional independence and cognitive symptoms during the first month of lockdown (31% of people surveyed), exacerbated agitation, apathy and depression (54%) and deterioration of health status (40%): INQ000087134. The Alzheimer’s Society Cymru stated: *“the effects of social isolation were severe”* INQ0001444934, (Dec 2020), p9. Age UK INQ000099714, noted that long periods of isolation had a profound impact on physical and mental health and caused trauma for families.
13. The exclusion of familiar carers from hospitals and residential healthcare settings had a serious adverse impact on the quality of healthcare received by many patients. Familiar carers often provided essential healthcare, and were able to give the patient an equal chance of benefitting from clinical treatment offered by virtue of “being” with their loved one to provide reassurance about what was happening to them and by acting as an advocate but, because they were not professional carers, they were not treated as a core part of a person’s healthcare team – even though unpaid carers make an invaluable contribution to the running of the healthcare sector and, in monetary terms, their contribution is estimated to equal the entire NHS budget (CPs’ WS, §19). They should have been given the status of key workers, and the Government’s failure to afford them recognition caused enormous harm to them and those for whom they cared. John’s Campaign was contacted by dementia nurses who felt that there was a conflict between, on the one hand, the obligation on them to enforce these restrictions and, on the other, their patients’ best interests. In respect of dementia, person-centred care is the only treatment known to improve people’s symptoms, and by removing family or familiar carers, this form of treatment was denied (CPs’ WS, §42).
14. In terms of the role played by familiar carers in the provision of healthcare, Age UK has explained: *“relatives or close friends often act as the eyes, ears or voice of people needing care, helping them to communicate or being a crucial confidant about health concerns or pain levels, as well as assisting with provision/facilitation of consent to medical procedures and treatment. Without this support, we heard of the impact on people’s lives, including health concerns going undiscovered until they were serious, inappropriate medications being given, and treatment being more distressing without the reassurance provided by a family carer, or not taking place.”* §61. This led to mental and physical health deterioration (§44, 101 and see also INQ000273453, and case studies at INQ000273460). These impacts were felt in residential healthcare settings, and also in hospitals: see, for example, the witness statements of Rachel Ashton (INQ000492025) and Clare Cole (INQ000421875) whose exclusion from hospital when their relatives were admitted led to serious negative healthcare consequences for their loved ones.

15. Core decision-makers failed to take into account, or decided to ignore, these harms. They knew or at least ought to have known about them. Stakeholders repeatedly warned the government about the harm, particularly in respect of those with dementia and cognitive impairment, and sought changes: e.g. Ms Herklots statement §3.6, 11.6, 11.27; and CPs' statement INQ000283957, §155-167, and exhibits INQ000273482, and INQ000273491 - INQ000273493. This occurred from an early stage in the pandemic: Nicci Gerrard, co-founder of Johns Campaign, appeared on BBC2 Politics Live as early as 13 March 2020 and warned that, for people living with dementia, separation and isolation posed a greater risk than Covid. These warnings were not heeded and appropriate amendments to the relevant policies were not made. On 16 October 2020, Jo James, a lead dementia nurse (published extensively), published an online article with John's Campaign highlighting the ongoing negative impact of visitor bans on people living with dementia. She set out not simply what was going wrong, but also provided practical examples of mitigation measures. Practical ways of adapting standards to ensure safe care was provided in the pandemic, and on 22 May 2022 a coalition of MPs signed a letter produced by Care Rights UK drawing attention to the continuing *"devastating harm"* on those in residential care, caused by the restrictions, and calling for a right for them to maintain contact with their loved ones and to have a *'care supporter'* (INQ000231923). While those with dementia were a key example of those who needed and would have benefited from such a change, they were not alone: Professor John Watkins explained more broadly that: *"I highlighted early on, that people with mental health issues may be harmed by a lack of social contact, people with early stage cancer and CVD may not get the diagnosis and treatment they needed" ... "I raised this many times and even provided the group with an evaluation matrix to track potential wider societal harms from isolation... Despite raising these issues there was no attempt to quantify, or consider, these when restrictions were being imposed"*: INQ000183846.
16. The restrictions had real, even fatal, consequences. The Cabinet Office data noted that from 6 March to 30 April 2020 there were 23,378 excess deaths from causes other than Covid-19 (similar to the number caused by Covid-19, 27,225: INQ000185073). More specifically, from 10 April to 19 June 2020, there were 3,628 excess deaths in domiciliary care in England (225% higher than the normal death rate), of which the great majority (77.4%) were from non-Covid causes. Some of the other consequences of the restrictions were that:
- a. The number of people waiting to access necessary healthcare, including for serious conditions such as cancer, increased about 9-fold: INQ000300217, §2, pages 20, 22, 35-36.
 - b. 67% of respondents to a Patients Association Survey had appointments cancelled as a result of the pandemic (INQ000273424, p22). The follow up survey recorded 66% struggled to access at least one form of care, and 56% delayed access to treatment (INQ000273425, p3).
 - c. Ms Herklots, the Older People's Commissioner for Wales, has produced evidence that many older people or people needing care were unable to access a broad range of healthcare and treatment, including GP services: INQ000232394; INQ000181725 (21 June 2020); and INQ000184990.
 - d. Surveys conducted by Inclusion Scotland reported significant disruption to essential healthcare provision, including pain clinics, neurology appointments

- and other vital services, with a resulting detrimental impact on their health (INQ000236625, §13).
- e. Age UK describes the “*widespread suspension or diversion of routine medical care*” that was needed to sustain some people’s health and wellbeing (INQ000319639, §30).
 - f. People refused necessary medical treatment or appointments outside of residential healthcare settings to avoid harmful isolation periods being imposed on their return (CPs’ WS §44).
 - g. Marie Curie’s Community Nursing Service reported that patients had limited or no interaction with other health or social care providers since the government’s call to “*protect the NHS*” (INQ000353677, §64).
17. The visiting guidance issued in respect of care homes played a material part in reducing the access of residents in those settings to the healthcare they needed. In the first instance, restrictions on visits into care homes limited (as addressed above) the access of family carers to continue delivering essential healthcare to their loved ones. It also resulted in GPs and other healthcare professionals reducing and, in some cases, stopping altogether their attendance to provide healthcare in those settings (CPs’ WS, §57), with the result that access to the healthcare they would have provided was either denied, or untrained care staff attempted to provide it. The guidance on “visits out” of care homes then strongly disincentivised residents from attending external healthcare appointments, as the purportedly obligatory 14 day isolation period on return from any period outside that setting (during which care home residents were confined to their own room with no social contact) was too much for many residents to bear (CPs’ WS, §71-73). John’s Campaign heard of some patients whose need for regular healthcare (for example, physiotherapy) outside of their care setting meant they were essentially in constant isolation between appointments (CPs’ WS, §65). This was even at a time when isolation requirements in the wider community had been reduced to 10 days, and when testing and vaccination were then widely available so that a 14 day isolation requirement was grossly disproportionate.
18. The lockdown and visitor restrictions prioritised reducing the risk of Covid-19 above all other considerations, but it is important to note that despite the care sector being so badly hit during the pandemic, Covid-19 only accounted for a small proportion (16.7%) of deaths of care home residents (see [ONS](#) table 2, Section 1, ‘Main points’). This means that non-Covid-19 causes accounted for 83.3% of those deaths, and needs relating to other health issues, including terminal illness and mental health and wellbeing, simply did not receive the attention they deserved.
19. Alongside these consequences of the restrictions, another effect was the movement of appointments to phone or virtual consultation formats. While the intention of this change was to maintain access to healthcare, in fact it reduced access for those who did not possess the technological ability to use these means of consultation, or whose healthcare needs could not properly be assessed or addressed virtually. That had the impact of widening existing health inequalities for older and disabled people (on which see further below).
20. All of these issues were obvious and foreseeable consequences of the restrictions introduced to address the pandemic, but the Government failed to take steps to mitigate

them or to communicate how patients' rights and access to essential healthcare should be protected consistent with the need for infection control.

Discharge from hospitals to care homes

21. While aspects of the decision to discharge patients from hospital into care homes without prior testing for Covid 19 may be considered by Module 6, the scope of Module 3 includes "Decisions relating to the discharge of patients from hospital to free up inpatient and critical care capacity" (Issue 2a), and the CPs therefore address it in these submissions. In particular, the policy gave little (if any) attention to (a) the well-recognised likelihood of asymptomatic transmission; (b) the extremely high rates of Covid-19 in hospitals at the time; and (c) the highly vulnerable population in care homes. In addition, it was a major contributory factor to the stringent restrictions which were subsequently reduced, as a knee jerk response to the damage that the policy had caused in care homes, and in this way it had a significant impact on the access to healthcare of those who live in care homes (as described in the section above).
22. The risk of asymptomatic transmission, and the importance of testing, were well-known by the time of this decision, and subsequent decisions to maintain the policy. Detailed evidence to demonstrate that asymptomatic transmission was well-recognised by the time of these decisions is set out in *R (Gardner) v Secretary of State for Health and Social Care, Public Health England & Another* [2022] PTSR 1338, at §34-125. The Chair is entitled to take that evidence into account, pursuant to her broad powers in s.17(1) IA 2005. There is also evidence within the disclosure provided by the Inquiry, to show asymptomatic testing was well-recognised. For example, Professor Watkins states "*it was clear, early on, that infected individuals with [covid-19] could be asymptomatic*". He wrote a widely cited editorial in the BMJ on 28 February 2020 which explained this: INQ000183846, p9 and 12-14. Then-Secretary of State for Health, Matt Hancock, also states that "*from January 2020 I was concerned about the extra risks that would be posed by asymptomatic transmission*" (INQ000421858, §43) and "*from January until 3 April 2020, I repeatedly raised my concerns about the potential for asymptomatic individuals to infect others*" (§51). This did not translate into a requirement for appropriate precautions such as pre-discharge testing until much later.
23. The importance of testing was also well-known at this time. For example, on 11 March 2020 the World Health Organisation declared Covid-19 to be a pandemic and said (*Amnesty* p16) "*We cannot say this loudly enough, or clearly enough, or often enough: ... test, treat, isolate, trace, and mobilize*". It repeatedly emphasised this, such as on 16 March 2020: "*we have not seen an urgent enough escalation in testing, isolation and contact tracing...: test, test, test*" (*ibid*). Care home providers urgently called for testing for staff and residents from at least as early as 24 March 2020 (*ibid* p17). Experts such as the Francis Crick Institute contacted the Government in March to emphasise the importance of systematic testing (*ibid* p27). Despite this, the Government's pandemic testing policy (which was determined by DHSC on advice from PHE) focused on case detection in symptomatic patients requiring critical care or hospital admission, and did not include the testing of asymptomatic patients discharged from hospital (INQ000409251, §569). It was only from 15 April 2020 when DHSC's Adult Social Care Action Plan introduced for the first time a requirement on acute hospitals to test

all patients for Covid-19 prior to their discharge to a residential healthcare setting (INQ000409251, §579).

24. The government failed to enquire into whether residential healthcare settings could effectively isolate and/or care for residents with Covid-19, and ignored the evidence that they could not do so. For example, on 13 March 2020, the Scottish Government issued clinical guidance for residential care residents which was clear that *“in the early stages... the priority is maximising hospital capacity”* (INQ000315587, p10) and stated *“if a patient being discharged from hospital is known to have had contact with other Covid-19 cases and is not displaying symptoms, secondary care staff must inform the receiving facility of the exposure and the receiving facility should ensure the exposed individual is isolated for 14 days following exposure to minimise the risk of a subsequent outbreak within the receiving facility”* (INQ000315587, p16). In fact, up to 58% of care homes did not feel able to effectively isolate suspected Covid-19 residents being discharged from hospital (Amnesty report, p19, referring to research by the Alzheimer’s Society 13 May 2020), and nor did they have sufficient staff, facilities or PPE to ensure the safe management of, and delivery of healthcare to, patients who were infected with Covid-19. But despite being ill-equipped to safely manage and care for patients being discharged to them, care homes *“were feeling pressured by hospital discharge teams to accept admissions and they felt that, without our support, they were made to feel obliged to accept admissions”* (CQC evidence, INQ000471158, §406).
25. NHS England acknowledges the importance of hospital discharges requiring a multidisciplinary assessment of the patient’s health and social care needs, including appropriate communication (INQ000409251, §530). The CQC also acknowledges that *“if patients were to be discharged [from hospitals] back into care settings, the process would need to be managed in a robust and considered manner, with checks in place to ensure that vulnerable people were kept safe and that providers were able to cope”* (INQ000471158, §384).
26. This was not, however, achieved. As Pat Cullen (former General Secretary of the Royal College of Nursing) observed, there was a *“push to get people out of hospital”* which was *“feeding the infection in care homes,”* and the singular focus *“had been on acute hospital capacity”* rather than the impact on other settings (INQ000475581, §206). This focus *“led to unsafe discharges; not allowing for the time, nor the planning and safeguards needed to safely discharge disabled people who had care needs in the community”* (Mencap witness statement, INQ000479878, §5). Mind reports that, after leaving hospital, many young people were not provided with adequate support in the community, with some leaving hospital without a care plan (INQ000479887, §70). There was no holistic consideration of how the social care sector would manage those who were discharged to it, both in terms of managing the infection risk they presented and in terms of ensuring they received proper support and/or treatment for their ongoing healthcare and social care needs. The harm caused by this was difficult to monitor in circumstances where, for example, the CQC adopted a remote-led approach to reviews from March 2020 through 2020 and 2021 (see e.g. INQ000471158, §240-244).
27. The impact of inappropriate discharges from hospitals to residential healthcare settings early in the pandemic continued to be felt years later. Of course, the most direct impact was on those whose loved ones died following infection in those settings when asymptomatic positive patients were discharged into their care home (for example). But

profound negative impacts have also been suffered by residents of those settings as a result of the over-correction that occurred once it became apparent how much damage had been done by the discharge policy, and stringent restrictions were placed on movement in and out. These restrictions meant that residents were unable to enjoy the visits from loved ones that for many were absolutely critical to their health and wellbeing, and many had their access to essential healthcare seriously curtailed by these policies, as described in the section above.

Conflicting and confusing guidance and regulations

28. Far from ensuring that the guidance and regulations in place took clear account of the harm suffered by those drawing on social care and needing healthcare, guidance and regulations across the UK were often conflicting, confusing and lacking in clarity, or failed to address critical issues and legal obligations which could have obviated some of the harm caused to vulnerable groups.
29. Mencap reports that “*guidance, such as that on visiting people in hospital, or on conveyance to hospital by ambulance... did not initially consider the needs of people with a learning disability or reasonable adjustments they had a right to under the Equality Act 2010*” (INQ000479878, §12). Repeated iterations of guidance failed to mention, describe, or ensure adherence to legal obligations such as those arising under the Equality Act 2010 and Human Rights Act 1998 requiring individualised assessments of patients’ circumstances to determine how care would be provided to them, to ensure their participation and consultation in healthcare decisions being made about them, and to decide (for example) whether their individual needs meant that visiting restrictions and isolation requirements should not be applied to them.
30. John’s Campaign felt compelled to bring repeated judicial review claims against the failure in Government guidance to communicate these important legal obligations (CP WS, §167). A survey conducted by John’s Campaign showed that a lack of clarity in government guidance resulted in care homes implementing restrictive visiting practices, with some completely banning visiting even when this was not actually required by government guidance at the time (INQ000273428).
31. In addition, the terminology used in guidance was apt to confuse, and resulted in inconsistent decisions being taken by different healthcare settings. For example, guidance variously allowed visits (despite general visiting restrictions) in “exceptional circumstances” or at the “end of life,” without defining those terms. Some healthcare settings interpreted end of life as applying to the last year of life; others to the last hours, John’s Campaign found that “*the lack of clarity as to the definition of and approach to be taken in respect of end of life has led to a wide range of approaches by care home providers and local authorities, with some maintaining blanket bans on visits on the basis that individuals are not considered to be at risk of death within a short time (days or weeks)*” (INQ000273469). In many cases, access to a loved one in hospital or a residential healthcare setting was granted too late, so that people died alone or were unconscious by the time their family was allowed to be with them. Particular distress was caused where loved ones were prevented from visiting a patient, who then died alone, when it subsequently became apparent that pursuant to the Government guidance in force at the time, they should in fact have been allowed to visit (CPs’ WS §39).

Palliative and end of life care

32. Despite the valiant efforts of many healthcare and social care workers to overcome or reduce the harm of the systemic issues within which they operated, there were substantial issues with the quality of end of life and palliative care during the pandemic. Specific issues included (i) late assessment that someone was at the end of life; (ii) difficulties in carrying out assessments remotely; (iii) those delivering palliative care in hospices, charities or other care settings not being considered as frontline services and therefore not being provided with adequate PPE etc; (iii) poor communication leaving relatives with inaccurate views of a person's condition; (iv) loss of valuables in hospitals; (v) inability to connect with loved ones (as dying and bereaved people) often resulting in a deterioration of their conditions; and (vi) as above, the failure to define terminology around the end of life e.g. the definition of 'exceptional circumstances' for visiting purposes (CPs' WS, §107). The careful consultation and communication with a patient and their loved ones which characterises good end-of-life healthcare was rarely present, and access to treatments which ensure a comfortable and dignified death were not always available.
33. The CPs' witness statement describes how much less attention was given to individuals at the end of life, including because – without loved ones being there – there was less opportunity for their needs to be identified (§109-110). Age UK describes how *“older people in care homes were left to die of Covid-19 and other illnesses without sufficient clinical support or sometimes access to palliative care teams or palliative care medicines”* (INQ000319639, §47). There were reports of *“care staff being told that their job was to provide end of life care for residents,”* despite the fact that *“prescribing and treatment expectations were beyond residential care staff training and experience ... and in some places supplies of end-of-life medication ran out”* (INQ000319639, §47).

Failure to ensure respect for equality, human rights, and individualised decision-making

34. A failure to centre individual rights and to properly communicate and respect the legal obligations that persisted despite the pandemic (for example, obligations under the Human Rights Act 1998 and Equality Act 2010 HRA) was an overarching feature of the Government guidance and regulations which introduced and described Covid restrictions. Guidance was, for example, often framed as if imposing blanket restrictions (e.g., a general suspension of visits to hospital patients and those in residential healthcare settings) without underscoring that statutory obligations continued to require individualised assessments which could override apparently blanket restrictions if the rights of the individual required it. This continuing failure by the Government formed the basis of the repeat judicial review actions which John's Campaign brought in respect of care home guidance, but it was also a feature of other decisions made in response to the pandemic (for example, the inappropriate “blanket” application of DNACPR decisions, as addressed below). These were all deeply concerning examples of the erosion by the pandemic response of person-centred care – which the CPs underscore must always be the bedrock of healthcare.

Use of do not attempt cardiopulmonary resuscitation notices (“DNACPRs”)

35. Associated with their overarching concerns about end-of-life care and the lack of consultation with patients and their loved ones which permeated healthcare during the pandemic, the CPs are concerned about the widespread use of DNACPRs. In particular, there were significant concerns raised with them about (i) decisions being made without consulting the individual or their loved ones (§111); (ii) blanket decisions being made; (iii) patients being asked to re-consider previous decisions (§116); and (iv) family members being pressured or coerced into accepting a DNACPR decision for their loved ones (CPs’ WS, §111-119). See also Dr Catherine Finnis’s evidence at INQ000409574, §116.
36. While there is no official data on the number of DNACPR notices made during the pandemic (INQ000236625, §40), there is significant evidence of callous and inappropriate communication with patients about DNACPRs, including GP practices sending letters to people with learning disabilities (INQ000475581, §198) and care home residents asking them to sign DNACPRs (INQ000280035, §94). As noted by Kamran Mallick of Disability Rights UK, this practice “*left disabled people feeling that our lives weren’t valued equally and that we would not get the healthcare we were entitled to*” (INQ000280035, §94). Dr Jim Elder-Woodward of Inclusion London describes how people were “*frightened they would be denied treatment if they became ill*” (INQ000236625, §34). Helena Herklots, the Older People’s Commissioner for Wales, states that she “*had particular concerns about the use of DNACPR*” on older people’s rights during this period (INQ000276281, §11.17).
37. The requirement to discuss a DNACPR with a patient or - where they lack capacity - those close to them is in *Tracey v Cambridge University Hospital NHS Trust & Others* [2014] EWCA Civ 822. It was underscored by practitioners at various times during the pandemic but does not seem to have been taken properly on board.
38. For example, a Joint Public Statement dated 30 March 2020 (INQ000192689) from organisations including the British Medical Association and the CQC stressed that DNACPR decisions should be individualized and that advanced care plans should be discussed directly: “*It remains essential that these decisions are made on an individual basis*”. In May 2020, the Covid-19 primary care bulletin included the reminder “*about inappropriate and unacceptable applications of DNACPR orders to people with a learning disability and autistic people. Previous communications have been clear that decisions should be made on an individual basis and in consultation with the person themselves and/or their family; blanket policies are inappropriate whether due to medical condition, disability or age*” (INQ000412890, p.266).
39. The requirement for consultation with a patient and their loved ones about important healthcare decisions (including, but not limited to, DNACPR decisions) is a crucial aspect of providing person-centred care, and it was too often overlooked during the pandemic. The exclusion of loved ones from hospitals and residential healthcare settings often meant that necessary conversations were not had, particularly where the patient themselves was too ill, spoke little or no English or were otherwise unable to manage such conversations themselves. This was a serious departure from person-centred care, at a time when the focus on individuals’ rights should have been heightened not neglected. The provision of healthcare must always be premised on the

consent, autonomy, and dignity of patients, as much in times of emergency as otherwise. The grief and harm caused by failures in this regard are perhaps some of the most significant ramifications of the pandemic.

Exacerbation of health inequalities

40. Decisions made during the pandemic exacerbated existing health inequalities, including in respect of disabled people's experience of healthcare. Pat Cullen highlighted some of these issues: *"The Covid-19 pandemic brought into sharp focus the disadvantages and inequity experienced by people with learning disabilities... concerns included outdated care plans, lack of medication reviews, and closed care and support centres. ... Reports by Mencap of people with learning disabilities being asked to consent to DNACPR notices by their GP surgery were also very concerning"* (INQ000475581, §198).
41. A report by Inclusion London highlights the shocking experiences of disabled people, many of whom felt abandoned, forgotten, and ignored (INQ000273462). People were prevented from receiving treatment and/or were denied access to hospital due to their age or disability. Additionally, terms such as 'vulnerable,' assigned without any choice or autonomy, entrenched existing stigma and prejudice against disabled people. Disabled people reported facing cuts to care packages, delays to assessments and difficulty securing PPE for their care workers (CPs' WS §77).
42. Age UK describes particular concerns around "non-conveyance practices," under which older people in care homes and the community were unable to access urgent or emergency healthcare for acute health conditions when they needed it: *"some care home residents were denied admission [to hospital] for any reason (including fractures, strokes and injuries"* (INQ000319639, §52). Similarly, Mencap reports that *"some GPs had been contacting care settings, suggesting that people with a learning disability supported in those settings would not be treated if they went to hospital with symptoms of Covid-19, and suggesting that advanced decisions should be made not to seek treatment, as well as use of DNACPR orders"* (INQ000479878, §5). NICE's guidelines that deprioritised those who needed support at home left Disabled people feeling as though they were not valued equally (INQ00028003, §94).
43. ONS data showed that during the pandemic Disabled people were twice as likely as non-Disabled people to report issues with access to healthcare and treatment (INQ000184681). Disability Rights UK describes the UK government's failure to give due consideration to two international initiatives: (i) WHO Guidance '*Disability Considerations during the Covid-19 Outbreak*' (INQ000279961), which recommended accessible healthcare information, targeted measures, and support networks; and (ii) the UN Secretary General's policy brief '*A Disability-Inclusive Response to COVID-19*' (INQ000279962), which recommended meaningful consultation with Disabled people and accountability mechanisms to ensure disability inclusion in the pandemic response (INQ00028003, §71-2).
44. Health inequalities were also exacerbated by the move to remote access to healthcare, through the use of technology. Many healthcare providers began to use, or increased the use of, technology to support remote appointments during the pandemic, in order to reduce the infection risk caused by face-to-face meetings. However, the CPs explain

that using technology as a replacement for face-to-face appointments was “*not a viable option for many people needing care,*” particularly those with communication difficulties, such as hearing loss or dementia (CPs’ WS, §59). This resulted in confusion, frustration, and an inability to participate properly in the consultation (§59).

45. Disability Rights UK report that the huge reliance on digital communication and information excluded a large number of Disabled and older people who were not digitally connected (INQ00028003, §91). Mencap also states that “*changes to the format of GP consultations, with the move to remote phone or video contact, had taken place with little equality impact assessment... in the main adjustments were not being made to this policy for those that could struggle with communication*” (INQ000479878, §5). The Health and Social Care Alliance reported that a significant proportion of people felt that virtual consultations were an inadequate replacement for face to face care (INQ000184670, p7), and this is a significant ongoing issue as healthcare providers now continue to offer services virtually. As Pat Cullen’s statement underscores “*It is easier for someone with a single healthcare need and no sensory or cognitive loss to access an effective healthcare consultation virtually then it is for an individual requiring any form of diagnostics or someone who has complex interrelated health care needs. ... the move to accessing services either over the phone or online risks further increasing health inequalities among those who find it difficult to or have no means by which to access services in that way*” (INQ000475581, §215).
46. This includes older people who may be less technologically engaged. Age UK describes how, during the pandemic, “*older people found that their GP practice had become inaccessible overnight.*” In-person consultations are indispensable for some patients, but there were places where “*there were no visits to care homes being made by the GP or any other clinically qualified person*” (INQ000319639, §25-27 and §46) – with obvious serious repercussions on patients’ access to healthcare.

Conclusion

47. A proper analysis of the impact of the pandemic on healthcare systems requires the Inquiry to have regard to the broad range of settings in which individuals receive healthcare, from their own homes, to hospitals, care homes and other residential healthcare settings. The failure to approach care homes and residential healthcare settings as an integral part of the UK’s healthcare system, and the resulting disconnect and failure to plan for transitions between them and hospital settings, were significant issues that detrimentally impacted on health and wellbeing during the pandemic, and the CPs are anxious that the Inquiry investigates this.
48. The issues identified in these submissions: (1) the failure to appreciate the wide range of healthcare settings and ways in which healthcare is delivered; (2) the failure to appreciate the importance of familiar carers in providing essential healthcare and providing the necessary and effective advocacy to ensure informed consent is given and that clinical treatment has the best chance of success and the patient has an equal chance of benefitting from the treatment offered; (3) decision to discharge patients from hospital into residential healthcare settings without testing for Covid-19, and the subsequent draconian visiting restrictions placed on these settings; (4) the confusing and conflicting Government guidance which did not set out the continuing legal obligations on healthcare providers; (5) problems with the provision of palliative and

end-of-life care, and (6) the failure to centre and prioritise the human rights of patients, all negatively affected the experience of, access to, and the quality of healthcare received during the pandemic. Each of these are critical healthcare issues which the CPs invite the Inquiry to investigate diligently.

49. While these submissions address the CPs' primary concerns, they are not exhaustive, and the CPs look forward to engaging with this Module further, through participation in the hearings and the questioning of witnesses, and through the making of oral opening submissions and closing submissions in due course.

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LEIGH DAY

X August 2024