Witness Name:
Statement No.:
Exhibits:
Dated:

UK COVID-19 INQUIRY

WITNESS STATEMENT OF THE PATIENTS ASSOCIATION, CARE RIGHTS UK AND JOHN'S CAMPAIGN

We, Julia Jones of John's Campaign (Sokens, Green Street, Pleshey, Chemsford, Essex CM3 1HT), Helen Wildbore of Care Rights UK (Unit 6 Aztec Row, 1 Berners Road, London N1 0PW) and Rachel Power of The Patients Association (PO Box 935, Harrow, Middlesex, HA1 3Y), will say as follows: -

1. We have been asked to provide a composite statement (and relevant associated documentation) on behalf of John's Campaign ("**JC**"), Care Rights UK and the Patients Association ("**PA**"), 'the Core Participant group', pursuant to Rule 9 of the Inquiry Rules 2006. This statement incorporates responses from all members of our Core Participant group and, as requested, focuses on the period of time between 1 March 2020 and 28 June 2022. As set out further below, we also have ongoing concerns about restrictions and measures which continue to be applied to those we represent.

2. We understand that a later module will examine the impact of the COVID-19 pandemic specifically on the care sector and have made plain our views on the importance of this analysis occurring as soon as possible. In light of the narrower focus of Module 3 on 'healthcare systems', we have accordingly only included information about settings (including in the care sector) which, strictly speaking, fall beyond the settings which the Inquiry considers to be the subject of Module 3 where we consider it is necessary to answer a specific question asked. We note, however, that there is significant overlap between the issues faced by different

institutional settings which may fall into 'health' and 'care' categories respectively. To analyse 'healthcare systems' in isolation without regard to the broad range of settings in which individuals may or may not have received healthcare would in our view undermine the efficacy of the Inquiry's review. The failure to understand care homes as an integral part of the UK healthcare system, and the resulting disconnect and failure to plan for transitions between different health and care settings were themselves significant issues that impacted on healthcare and welfare during the pandemic.

3. There are areas covered by this statement which some members of our Core Participant group are better placed to comment on than others and indeed some areas where only one of us feels able to comment based on our respective knowledge and experience. Where aspects of the statement are provided by one member of our Core Participant group this has been made clear by using a sub-heading referring to the specific member. We have prepared this statement in liaison with our solicitors at Leigh Day who asked us to address questions based on the Inquiry's Rule 9 requests via telephone and email.

4. Except where we indicate to the contrary, we make this witness statement on the basis of facts and matters within our knowledge. Where these facts and matters are within our knowledge, they are true. Where the facts and matters in this witness statement are not within our knowledge, they are true to the best of our information and belief.

Introduction: Background to our organisations and work

5. Our Core Participant group has significant expertise in the patient experience of healthcare provision during the pandemic. We have set out below our roles, particular areas of expertise and the work we did throughout the pandemic before discussing substantively the observations we made about the response to COVID-19's impact on healthcare in the course of that work. We have provided an overview of our main observations and key concerns regarding healthcare during the pandemic for the individuals we represent before setting these out in further detail. We then go on to outline key lessons to be learned from what we

observed. Our combined organisational experience developed through, amongst other things, our contemporaneous work with patients receiving healthcare in a range of settings before, during and after the pandemic. This has given us insight in particular into the following topics which we address in further detail below:

5.1. The impact of COVID-19 on people's experience of and access to healthcare.

5.2. Health inequalities

5.3. NHS 111 services

5.4. Discharge of patients from hospital into care homes

5.5. End of life and palliative care

5.6. The use of DNACPR instructions

5.7. The measures taken to prevent the spread of COVID-19 and their impact

5.8. Communication with patients and their loved ones

5.9. Shielding and designation as clinically vulnerable.

6. We played a direct role during the pandemic in supporting individuals experiencing the above issues, and in bringing about alterations to policies and practices which were having a negative impact on individuals receiving or in need of healthcare (for example, in the case of John's Campaign, by challenging the lawfulness of the Government's policies on measures taken to reduce the spread of COVID-19, resulting in amendments to those policies).

7. We have set out below brief backgrounds regarding each of our organisations, including information about (1) the role of each of the co-signatories to the statement, (2) the formation and operation of our organisations and (3) the individuals we represent.

The Patients Association (PA)

8. I, Rachel Power, am the Chief Executive at PA. I have had this role since July 2017. The purpose of PA is to ensure patient partnership in the design and delivery of all health services. It is dedicated to supporting the rights and the interests of all patients and their families.

9. PA was founded in 1963. It is an independent patient charity campaigning for improvements in health and social care for patients. Its guiding purpose is to ensure that everybody can access and benefit from the health and care they need to live well, by ensuring that services are designed and delivered through equal partnership with patients. Uniquely for a charity with a remit covering all health and care issues, we work with patients directly. We are recognised as a national authority on patient voice; patients are our members and supporters, and we offer them assistance through our help and information services. Through our helpline we provide information to thousands of people each year about the health and social care system.

10. Patient experience is at the heart of everything we do. Patients place their trust in us to reflect their experiences honestly and accurately, and to draw on them to make the case for change wherever it is needed in the health and social care system. We work with patients on our own projects and in partnership with other organisations, at both a local and national level. Among others, we work with the Care Quality Commission, NHS commissioning teams, corporate partners, NHS England, health trusts and local authorities, and local health care providers ("integrated care systems", "ICSs"), and charities to improve patient experiences.

11. As Chief Executive at PA I ensure we investigate health and care concerns raised by patients, monitor trends in patient satisfaction, and support health and care providers to deliver services in ways that meet every person's health and social care needs. It is part of my role to ensure that the patient voice is heard. At the start of this year, 2023, Sir Robert Francis (President of PA) and I wrote to the Secretary of State for Health and Social Care, Steve Barclay about the appalling conditions so many patients were experiencing which I exhibit to this statement as **Exhibit 001/ INQ000273418**. This is one example of PA continuing to strive for and speak up for change. In 2022, we published our Theory of Change which I enclose as **Exhibit 002/ INQ000273419**. This is the road map for what PA believes needs to happen before we can say patient partnership is embedded across health and social care. As set out further below, patient partnership was

particularly impacted during the relevant period of the pandemic with effects continuing to impact the patient experience now.

Care Rights UK

12. I, Helen Wildbore, am the Director of Care Rights UK (formerly the Relatives & Residents Association), a charity focused on defending the rights of people in care. Our vision is for the best quality of life for older people needing care. We want people to know their rights and how to use them. We offer information, advice and support to empower people using care services, and their relatives and friends. As a community of families and experts, we have joined forces to fight for better lives for people in care. We challenge poor care, highlight good practice and demand a better system.

13. Care Rights UK brings together the charity the Relatives & Residents Association (R&RA) and campaign group Rights for Residents. For thirty years R&RA supported older people needing care and their relatives and friends. Rights for Residents was set up as a campaign group in the summer of 2020 in response to the impact of lockdown on people living in care and brought together families across the country to successfully lobby for changes to visiting restrictions. Together as Care Rights UK we are a powerful voice for those needing care and their families. The activities outlined in this statement were carried out by the two organisations both separately and collectively before our formal merger in 2023.

14. Through its helpline, Care Rights UK has been in direct contact with individuals in healthcare settings and their loved ones throughout the pandemic and heard about the issues they have faced. Throughout the pandemic, our helpline has been supporting older people and their families at the sharp end of the pandemic, giving us a unique insight into the experiences of families dealing with COVID-19 and measures taken to manage it. We were a member of the Department of Health and Social Care's ('**DHSC**') Covid Adult Social Care Working Group of Stakeholders ('**the Working Group'**) and as such have played a direct role in reviewing and analysing Government policy on health and social care during the relevant period.

15. I have been in my role as Director (first of R&RA and now of Care Rights UK) since October 2019 and worked hard with my team throughout the pandemic to monitor and raise the issues we heard about from those we support.

John's Campaign (JC)

16. I, Julia Jones, am the co-founder of JC and am on the NHS England Advisory Board for Care Partner Policy. I founded JC together with Nicci Gerrard in 2014 as a direct result of the observed deterioration and death of Dr John Gerrard, a man living with dementia, when he was separated from his family support due to infection control measures taken in hospital. An article in *The Observer* newspaper in which Nicci explained the impact that isolation during hospitalisation had on her father (see **Exhibit 003/ INQ000273420**) triggered one of their biggest reader responses with support from readers whose loved ones had suffered similarly. Many of those who responded had not experienced complete separation from their loved one due to infection control but the daily structural separations enforced by restricted hospital visiting times had proved hugely detrimental to the wellbeing of many people living with dementia. Damage was usually irreversible.

17. The initial focus of the campaign was to change this system of restricted access to individuals receiving healthcare and ensure that the family carers of people with dementia in hospital were always welcome to support them – at any time of day or night – if they were willing and able to do so. It was not long before the movement extended from England to Wales, Scotland and Northern Ireland where all four Chief Nursing Officers and several of the Royal Colleges spoke out in support of our campaign.[1]

18. John's Campaign supports vulnerable people and their families where a person in need of support is being accommodated in any of the institutions of the UK

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[1] In 2017 Julia was commissioned by Care England to write Honoured Guests a guide for managers of health and care settings on how to involve family carers and in 2019 she began working with an informal care home steering group, which shared good practice welcoming and involving family carers in care home communities to provide person-centred care. The booklet 'Implementing John's Campaign in Residential Care' was published with Age UK's support in February 2020. Between June 2016-December 2018 Julia spent a minimum of 4-5 hours per day, seven days per week supporting her mother in both practical and emotional ways through her final years in a care home. This gave her essential insight into the role of the family in (health)care settings.

health and social care system. It began with a particular focus on people living with dementia but has learned the truth of the saying 'get it right for dementia and you get it right for everyone'. People living with dementia have an undeniable need for their regular carer (who has expert person-centred knowledge), just as a physically disabled person would have undeniable need of a wheelchair or a non-English speaker an interpreter. In fact we now campaign for a legal right to a personal care supporter which should arise in respect of each individual rather than in respect of any particular health and social care institution.

19. As explained further at §§128-129 we believe that a failure to understand the importance of the practical, economic and emotionally supportive role played by unpaid carers across the healthcare system negatively impacted decision-making with adverse impacts on health and access to healthcare throughout the pandemic. We exhibit as **Exhibit 003A/ INQ000273417** findings from Carers UK and the University of Sheffield which show that unpaid carers in England and Wales '*contribute a staggering £445 million to the economy in England and Wales every day – that's £162 billion per year. The value of unpaid care is equivalent to a second NHS in England and Wales, which in 2020/21 received an estimated £164 billion in funding.*' It is therefore crucial that the value of healthcare provided by unpaid carers to both individuals and the healthcare system and the obstacles unpaid carers and individuals relying on them face are not overlooked.

20. As well as its campaign to change attitudes, JC functions via a system of pledges which are made by hospitals and other institutions throughout the health and care system to welcome carers whenever the patient (or resident or service user) needs them. These pledges are recorded on our own website and on a list held by *The Observer* newspaper. By June 2018 all 152 acute hospital trusts in England had made pledges to welcome family carers at any time the patient needs them. John's Campaign collated these pledges in a book of pledges which I exhibit to this statement as **Exhibit 004/ INQ000273421**. Shortly afterwards, the adoption of JC principles became part of the 'Dementia Action Plan for Wales 2018-2022' (see **Exhibit 005/ INQ000273422**). All Scottish hospital boards except one made similar pledges, though not always under the JC name. As time passed the need for adoption of JC principles was also recognised in other settings such as care homes, mental health units and other institutions where a vulnerable individual

risks being denied the support of the person who knows them best and whose expertise should be used for their benefit.[2] Our website has become a hub of good practice for health and care settings.

21. Some institutions managed to adhere to their JC pledges through the pandemic and there was some support from both NHS England and Scotland for them to do so. For example, the NHS England guidance entitled 'Visiting healthcare inpatient settings while COVID-19 is in general circulation: principles' **(Exhibit 006 INQ000409940** emphasised the contribution visiting makes to patients' wellbeing and recommended that '*[v]isiting should be accommodated for at least one hour per day and ideally for longer*'. Despite this, many health and care settings did not adhere to their JC pledges throughout the pandemic and vulnerable individuals and their family carers found a bewildering variety of responses across different settings and institutions. Many (though by no means all) were welcomed when the person they supported was in a hospital setting, only to have the gates clang shut when the person moved back into the care setting that was allegedly their home.

Our experience during the pandemic

22. As a Core Participant group our expertise and interest in the subjects falling within the scope of Module 3 is derived in particular from the following experience:

    22.1. As explained above, **PA** works with patients directly. This includes running a public helpline accessed by circa 3000 people a year. Over the course of the pandemic, PA conducted three major patient experience reports (**Exhibits 007-009/ INQ000273424 - INQ000273426**). The reports, which we refer to in more detail below, cover patient experience of health care from May 2020 to August 2020, from February 2021 to April 2021 and from November to December 2021 (as the Omicron wave hit). These significant pieces of work (comprising responses from more than 2500 patients) covered a number of areas central to Module 3 of the Inquiry's work: the experience of patients being treated for COVID-19 and the care received by patients with non-Covid illnesses, delays in treatment and difficulties accessing treatment, problems

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[2] The response from mental health trusts has been far more varied and their degree of openness and welcome to family carers generally (but invariably) less.

with shielding, the NHS 111 helpline, and communication with patients and their families.

22.2. Through its helpline, **Care Rights UK** has been in direct contact with individuals in healthcare settings and their loved ones throughout the pandemic and heard about the issues they have faced. As a member of the DHSC Working Group, we also reviewed, discussed and provided feedback on Government policy on health and social care from July 2021. For example, we requested that the DHSC circulate to the Working Group clinical evidence of the health impact of restrictions on visiting. This request was made in meetings on 17 and 24 February 2022 and 10 March 2022, and via email on 7 February 2022 and 4 March 2022. It led to a member of the SAGE Group attending a Working Group meeting on 24 March 2022 who admitted that there was an 'evidential black hole' around the impact of isolation, but that the harm was 'overwhelming'. We do not hold any documents relating to these discussions. Of particular relevance to the areas of focus identified in the Module 3 provisional scope, we were engaged with and raising concerns via our lobbying and campaigning about issues such as the imposition of DNACPR decisions on patients, the lack of access to medical care for people in residential care settings (caused by GPs and other practitioners staying away to limit infection risk), inappropriate provision of care due to failure to adequately monitor and involve family carers, and the detrimental health impacts caused by pandemic policies, in particular isolation policies, misplaced attempts to avoid hospitalisation where individuals needed hospital care, and visitor policies (which reduced and even removed the ability of family carers, those with Power of Attorney, and Relevant Person's Representatives from being involved in healthcare decisions).

22.3. As set out above, prior to the pandemic, **JC** worked with a range of healthcare settings on providing dementia-friendly care for patients. With the onset of the pandemic and the impact of the isolation policies on dementia patients in particular, JC's work advocating for this cohort of patients, along with other vulnerable patients in health and care settings, ramped up. JC was the first organisation to warn of the effects of isolation policies on vulnerable inpatients and residents in health and care settings, and brought judicial review challenges to the DHSC's approach to patients in these care settings, which resulted in material changes to the applicable Government guidance, as discussed in the *BBC News* article exhibited to this statement as **Exhibit 010/ INQ000273427**.

22.4. JC also provided support and advice to families and carers affected by COVID-19 restrictions, conducted a visitor restriction survey in November 2020 and published the results of the May 2021 Rights for Residents visitor restriction survey on our website. We discuss the results of these surveys in further detail below at §32 and exhibit summaries of the surveys to this statement as **Exhibits 011 - 013/ INQ000273428 - INQ000273430**. JC has particular expertise and interest in the impact of non-pharmaceutical interventions on the experience and health outcomes of patients, including people with a progressive terminal illness (such as dementia) and those at the end of life (including the significant majority of people living in care homes).

Our work during the pandemic

The Patients Association (PA)

23. PA conducted three major pieces of research, based on the findings of three online surveys. In total the surveys were completed by more than 2500 people. They resulted in the publication of three separate reports between September 2020 and January 2022.

24. These reports were:

24.1. 'Pandemic patient experience: UK patient experience of health, care and other support during the COVID-19 pandemic', published in September 2020, based on a survey that ran from May to August 2020, which is exhibited to this statement as **Exhibit 007/ INQ000273424** and will be referred to as '**The early pandemic patient experience report**'.

24.2. 'Pandemic patient experience II: From lockdown to vaccine roll-out', published in April 2021, based on survey that ran from February to April 2021, which is exhibited to this statement as **Exhibit 008/ INQ000273425**. This report followed up key themes from the above-mentioned report and will be referred to as '**The follow up patient experience report'**.

24.3. 'Patient experience before the Omicron wave: the storm before the storm', published in January 2022, based on a survey that ran from November to December 2021, which is exhibited to this statement as **Exhibit 009/ INQ000273426**. This report will be referred to as '**Patient experience before Omicron report'**.

25. As set out in further detail below, across the three surveys we saw a sustained pattern of difficulty in accessing healthcare services. The patient experience significantly deteriorated and trust in the healthcare system decreased. We provided support wherever we could through our helpline (by providing practical advice and advocacy). We also publicised our findings and drew attention the issues we were seeing, including by partnering with the Care Quality Commission to report patient concerns directly and by sending copies of our reports to the DHSC and NHS. Other efforts made by PA to engage with government bodies to raise our concerns are set out further below at §§145-150.

Care Rights UK

26. As stated above, throughout the pandemic our helpline supported people living in care who were using, or needed access to, health services. Insights from our helpline and advocacy work informed our campaign and lobbying work. Like our fellow core participants, we were a vital source of support for people facing the most desperate of situations due to Government policy and decisions on healthcare. They had very few other sources of support as key agencies and professionals who had legal duties to protect their rights stepped back (for example, the Care Quality Commission paused routine inspections, appointments with health professionals moved to phone/video contact, and the Local Government and Social Care Ombudsman suspended casework that required action by local authorities or care providers which effectively halted the complaints process). The Rights for Residents Facebook group was a key source of peer-to-peer support. Thousands of families came together from across the country to

share experiences and good practice, hear from others how they had challenged harmful restrictions and take solace and support through a collective, shared trauma. The campaign attracted thousands of supporters, motivated by their own personal experiences as relatives and friends of those in care, to successfully lobby, individually and collectively, against harmful restrictions.

27. As rules and guidance changed regularly, we provided summaries of the guidance to assist people to understand and interpret what it meant for them and their families. I exhibit an example of these summaries to this statement as **Exhibit 014/ INQ000273431.** We also included relevant legal requirements to explain where (non-statutory) guidance was incompatible with statutory duties and rights. We provided template letters to help people challenge the application of restrictions on visits in and out of care settings, examples of which are exhibited to this statement as **Exhibits 015-016/ INQ000273432 - INQ000273433**.

28. We published stories and testimonials on our website to highlight the harmful impact of restrictions, including:

    28.1. The testimony of Susan (**Exhibit 017/ INQ000273434**), whose 27 year old daughter Sarah has epilepsy and severe learning disabilities and lives in a specialist care home with 1:1 care: Susan recounted how mask-wearing resulted in a dramatic deterioration in Sarah's speech during Covid-19 and caused great distress for Sarah, who '*cried to [her parents] about what hard work it is to understand the staff*'. Susan further described how Sarah's behaviour worsened, explaining her daughter wouldn't '*come out of her bedroom most of the time and refuse[d] to eat half her meals*', which triggered seizures.

    28.2. The testimony of Wendy (**Exhibit 018/ INQ000273435**), who lives with dementia, and recounted her experience of going to hospital after breaking and dislocating her wrist: Wendy highlighted the importance of family members and carers being able to stay with patients whilst they receive medical treatment. She explained how she would forget which allergies she had when doctors asked, but that fortunately her daughter was able to correct her and ensure doctors were provided with the correct information, meaning potentially serious consequences were avoided by her daughter's presence.

28.3. The testimony of Kate (**Exhibit 019/ INQ000273436**), who described the 'horrific' impact restrictions had on her parents, who were both in care homes: Kate explained that for a long period of time she was only allowed to stand outside the glass doors of the care home to see her mother, who lives with Alzheimer's disease, which caused her mother so much distress that the visits had to be stopped. When Kate was finally allowed a 30 minute supervised visit, 365 days after she had last seen her mother properly, her mother '*burst out laughing and crying at the same time*' because, in Kate's words, '*it was all she wanted – to see me*'.

29. We worked with the media to highlight our concerns about Government policy and shine a spotlight on the harm being caused by measures taken to manage the pandemic. We made hundreds of media appearances during this period across national TV, radio and print. We raised our concerns in Parliament, through giving evidence to parliamentary committees (see §§151-152 and **Exhibit 21 INQ000231911** **Exhibit 20 INQ000273437, Exhibit 22 INQ000273439 to Exhibit 26 INQ000273443** and tabling parliamentary questions (see §156 and **Exhibit 027/ INQ000273444**). In addition, we wrote formally to the Care Quality Commission (CQC). I discuss our correspondence with the CQC in further depth at §154 and exhibit three letters we wrote to the CQC as Exhibits **028-030/ INQ000231915 - INQ000231917** Care Rights UK also submitted insights and evidence to the DHSC (see §159) and supported the legal challenges by John's Campaign against the DHSC guidance (see for example, **Exhibit 031/ INQ000176369**).

30. Care Rights UK has also undertaken a survey on patient experience during the pandemic (**Exhibit 032/ INQ000273449**). Although this was undertaken after the pandemic, in May 2023, it was carried out with the aim of collecting information on the healthcare experiences of people in care settings during the COVID-19 pandemic with the benefit of hindsight. The findings of this survey, which are set out in further detail below, illustrate what we had heard on our helpline, week in and week out, from the very beginning of the pandemic.

John's Campaign (JC)

31. At JC, we listened, considered, communicated, advocated, lobbied, and challenged throughout the pandemic. We received enquiries and complaints from individuals and their loved ones by phone, by email, by social media. We tried to help by communicating with health and care settings, local leaders and government via phone, email, social media and mainstream media. We gave evidence to Parliament about the devastating impact of enforced isolation on care home residents (see **Exhibit 033/ INQ000273450**) and continually tried (but failed) to reach the government on behalf of health and social care service users and their families (see further §161 below). We issued a series of 'How to guides' as guides to the Guidance which many individuals told us they found very helpful as they fought their own battles to facilitate their loved ones' access to the outside world, examples of which I exhibit to this statement as **Exhibit 033A/ INQ000273416** and **Exhibit 034/ INQ000273451**.

32. We also conducted a visitor restriction survey between 17-30 November 2020, the results of which are summarised on our website and exhibited as **Exhibit 011/ INQ000273428**. This demonstrated how a lack of clarity in government guidance resulted in care homes implementing very restrictive visiting practices, with 41% of respondents reporting care homes having completely banned visiting (despite this not actually being required by government guidance at the time). Further, 80% of respondents to our November survey reported that their relative's physical or mental health had deteriorated as a result of visiting restrictions. The results of the Rights for Residents survey which we summarised on our website (see **Exhibits 012-013/ INQ000273429 - INQ000273430**) conducted between 10-21 May 2021 were similarly bleak. Despite the rest of society opening up in this time period, 41.5% of respondents to our survey stated they were only allowed to visit their loved ones in care homes once per week. In addition, 40.7% of respondents reported that care homes restricted visiting times to 30 minutes per visit. We published the results of the survey on our website and included them as evidence in our legal challenges regarding guidance on visiting in care homes (explained in further detail in §§33-36 and §§70-74).

33. A key focus of our work became legal challenges to the DHSC guidance on visits in and out of care homes. We have set out in further detail below at §167 a

chronology which shows the protracted back and forth we engaged in with the DHSC through legal correspondence and the judicial review challenges that we brought, which were widely covered in the media and summarised on the Leigh Day website (see **Exhibit 035/ INQ000273452**). This work involved instructing our lawyers to repeatedly write to the SSHSC, prepare to file judicial review proceedings, and collate evidence (including from enquiries and through the surveys discussed at §32) to be used as supporting evidence for those challenges.

34. Our main source of information were the voices of people – we heard stories of the experiences of individuals and their loved ones daily and we worked to collate and publicise this information in an effort to ensure the stories were heard. For example, we produced and published a booklet entitled 'The Holding Pen' which is exhibited as **Exhibit 036/ INQ000273453**. This is a collection of stories from individuals who experienced imposed isolation, including in their transition between hospitals and care homes. This booklet is based mainly on testimonies sent directly to John's Campaign or via the Rights for Residents group during the bank holiday weekend 29-31 May 2021. Many of these case studies were included as evidence in our judicial review challenge to the DHSC's guidance on visits out of care homes and the requirement to isolate for 14 days after visits out and were also sent to the DHSC directly.

35. We also prepared and published 'Midsummer Milestones' which is exhibited as **Exhibit 031/ INQ000176369** This included the stories of people affected by ongoing restrictions, excerpts from the 'Statement of Facts and Grounds' in our judicial review challenge on visits out, along with evidence offered by two care home representatives and Care Rights UK which were filed in support of our legal case. This was also sent to the DHSC directly. Far too often the desperation felt by people living with dementia, whose pleas for their loved one(s) were denied, was expressed through distressing behaviour. We heard that this led to sedation, isolation and transfer into mental health units under sedation.

36. As set out further below, the legal action we took did lead to changes to the Government's guidance but this was often only after lengthy pre-action correspondence or after judicial review proceedings were filed (which then had to

be withdrawn due to the guidance being amended). Unfortunately, changes were 'too little too late' and we ended up having to spend much of our time and resources during the pandemic on legal challenges that could have been avoided if there had been proper engagement from the DHSC.

37. Alongside lobbying for changes to DHSC guidance, we also highlighted instances where individual NHS Trusts imposed harsher visitor restrictions than required by NHS England and other guidance at the time. We could see the discrepancy between approaches being taken from guidance published on different websites and what we were told by those we were supporting. For instance, we published a list on our website, which I exhibit to this statement as **Exhibit 037/ INQ000273454**, demonstrating the significant variance in the publicly available guidance on visiting published online by individual NHS England Mental Health Trusts. For instance, whilst Surrey and Borders Partnership NHS Foundation trust stated '*In line with a change in national guidance, we are relaxing our guidance on visits*', Worcestershire Health and Care NHS Trust stated '*all our community hospitals and mental health units will be closed to visitors until further notice*'.

38. Visiting restrictions had a particularly negative impact on patients receiving hospital treatment for mental health conditions. We raised awareness of this through our website, by publishing the testimonies of patients and their relatives. For instance, we shared Rachel's story (see **Exhibit 037A/ INQ000273413**), who described how her brother Chris suffered from depression and was taken to hospital after an overdose. In her testimony, Rachel explains how visiting restrictions during the pandemic prevented her from supporting her brother in hospital:

> *'When in Accident and Emergency, Chris was still saying he wanted to die. We asked if one of us could stay with him to be his voice but this was dismissed due to COVID.'*

As discussed in Rachel's testimony, Chris was later reviewed by a psychiatric liaison, and despite requesting admission to a psychiatric hospital, was sent home with no follow up care. Chris died by suicide on 13 February 2021.

39. The divergent approaches of hospitals towards visiting also resulted in particular distress for relatives of those in hospital, who were barred from visiting by individual NHS trusts, but later learned after their loved one passed away that they would have been eligible to visit under relevant applicable guidance. We heard heartbreaking stories, including from one son whose father passed away, who later learned that on the NHS trusts' own guidance he should have been allowed to visit and say his final goodbye.

Overview of our main observations and key concerns regarding healthcare during the pandemic for the individuals we represent

40. We have set out in more detail below the issues we observed both as a group and as individual organisations throughout the pandemic. The key themes from the May 2023 survey (**Exhibit 032/ INQ000273449**) conducted by Care Rights UK (on which we provide further details below) are reflective of some of our key concerns as a group:

    40.1. Theme 1: Access to healthcare during the pandemic was restricted and that had a significant impact on people's physical and mental health.

    40.2. Theme 2: there were widespread problems with (remote) communications in healthcare and communications more generally, which impacted access to healthcare and also impacted the ability of individuals and families to provide informed consent to treatment or decisions to cease or alter treatment plans (a key aspect of medical intervention).

    40.3. Theme 3: The role of family and friends in healthcare was not well understood and was severely disrupted with discernably adverse effect and irreversible damage.

    40.4. Theme 4: Staff didn't always have training to take on healthcare tasks (for example, staff in care settings were having to fill the gaps left by restricted access to healthcare).

41. As a Core Participant group, we have been and continue to be particularly concerned about the intense focus on infection control at the expense of many other (healthcare) issues faced by individuals we represent. The exclusive focus on COVID-19 as a potential cause of ill-health and death had a huge impact on the quality of the overall experience of care, including healthcare, for those who required it. It also significantly impacted the quality of the end of life period and death, including for thousands of people dying from causes unrelated to COVID-19.

42. Dementia is a particularly obvious example where people living with an untreatable, progressive, terminal illness were not only denied the one thing that is known to help: person-centred care[3], but were also subjected to measures that were likely to worsen their condition – separation, isolation, disruption of routine, and reduced quality of care (including: nutrition, hydration, mobilisation, attention to basic medical needs and co-morbidities). This resulted in greatly increased risk of delirium, which, as demonstrated by the Alzheimer's Society report (**Exhibit 038/ INQ000273455**) entitled 'Lockdown isolation causes shocking levels of decline for people with dementia, who are rapidly losing memory, speech, and ability to dress and feed themselves', is known to irreversibly worsen an individual's condition and precipitate decline. The impact of restrictions on those suffering from these conditions and their families was not properly considered.

43. Across the surveys and evidence we collected, poor communication was a common thread. PA observed that many patients were either passed between services when trying to access healthcare, or received no communication at all from services, often having tried to proactively contact them themselves, frequently to no avail. Care Rights UK and JC observed poor communication by care providers in relation to healthcare (including availability and access) and a general lack of understanding of how holistic care, including healthcare, could and should be facilitated despite restrictions in place. All members of our core participant group observed that patient involvement in decisions suffered significantly – or was absent entirely.

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[3] Developed by Professor Thomas Kitwood during 1980s and 1990s and adopted as standard best practice.

44. Key concerns identified by the Care Rights UK helpline are reflective of many of the concerns our Core Participant group observed in interactions with those we support, with key themes including restricted access to healthcare and inadequate quality of (health)care. The key concerns identified included:

   a. People living in care not being sent to hospital for health treatment despite needing hospital treatment
   b. People being asked to agree end of life plans that excluded hospitalization
   c. People being asked to consider or re-consider DNACPR decisions
   d. Lack of access to healthcare as GPs and other health practitioners stayed away from care settings
   e. Inadequate medical and palliative care as care staff lacked the necessary expertise or equipment and where expert healthcare providers were not attending
   f. Inaccurate reporting on death certificates of cause of death, including inappropriate terminology like ‘frailty’
   g. Inappropriate healthcare or medication being given due to lack of support and input from family carers who knew and understood individual needs
   h. Physical health deteriorating due to lack of in-person support from family carers to spot issues and ensure action was taken
   i. Adverse effects of prolonged confinement and withdrawal of activities
   j. Mental health deteriorating due to lack of cognitive and emotional support by family carers and lack of alternative support within health/care settings
   k. People refusing necessary medical appointments outside of care settings to avoid harmful isolation periods being imposed on return
   l. A focus on institutions, rather than people, putting lives at risk – particularly hospital discharge into care without testing to ‘protect the NHS’.

45. We expand on these in further detail below. As the patient testimonies we have included show, in many cases these issues came with extremely serious consequences for patients. Some who took part in our research lost loves ones in tragic circumstances. Others have witnessed irreversible decline in their loved one’s health.

The Impact of COVID-19 on the experience of and access to healthcare

46. As a Core Participant group, we have supported people needing (health)care and their loved ones throughout the COVID-19 pandemic. We have seen and heard firsthand of the harm done as normal healthcare practices were disrupted and neglected as the UKs health and care system responded to COVID-19. We have seen many cases where people in care have been denied access to the healthcare that they need, their rights infringed as their physical and mental health suffered. We have spoken to family members in despair as they try to secure basic comfort and dignity for their loved ones and heard that many people have lost trust in a healthcare system which, they believe, has let them down when they most needed it.

The Patients Association (PA)

47. Across the three reports we prepared referred to above at §§23-24, we saw a sustained pattern of difficulty in accessing NHS services. Cancellations, delays, and long waiting times characterised the experiences of many patients during the period our reports covered. This extended to all services, but GP and hospital appointments were the most starkly affected.

48. Patients lacked confidence about a return to normal in the NHS. Many were fearful about the implications of this for treatment in the longer term. Despite these difficulties, patients acknowledged the circumstances during the pandemic were unprecedented. There were also several touching examples of staff and services that went above and beyond in supporting the people they care for.

49. The observations and concerns we set out below draw on the finding of our surveys and resulting reports which focused largely on what patients experienced in their own words.

The early pandemic patient experience report (**Exhibit 007/ INQ000273424**)

50. As set out in the summary of the report, we conducted the first survey because we wanted to get a better understanding of how patients and others were experiencing the COVID-19 pandemic. The survey had four sections: (1)

Managing and accessing care for existing health condition(s); (2) Experience of treatment and care for COVID-19; (3) Experience of end of life care and bereavement support; and (4) Experience of services under lockdown overall. It ran from May until August 2020, and around 953 people responded to at least one section of the survey.

51. The key findings, which are stark and we think are therefore worth including in full, can be found at pages 3-4 of the report and are excerpted below:

> *'Overall, we heard about major disruptions to the relationships between the patients and the health and care services they rely on. People told us of their frustrations in being cut off from the support that had previously been essential to their daily lives. Many have had treatments and other support postponed or cancelled; in some cases this may be understandable, but a lack of information about how services will restart has left people in the dark. Regular support that is essential for quality of life has also disappeared for some. There is a risk during crisis situations that the voice and experience of patients, including their relationship with staff, gets lost in the need to get things done; there is some evidence from this survey that this has happened. Disabled people and people who are chronically ill have told us they have been left behind. While priority lists have helped some, those with conditions other than those on the government's 'clinically most vulnerable' list have been left with little access or support, despite the necessity of this to daily life. People have told us that services for mental ill health have become even more difficult to access under lockdown, and that they do not feel mental wellbeing has been a priority for government services. Many have been cut off from friends and family members, and some are extremely isolated as a result of the pandemic, without anyone checking in on their health and wellbeing.'*

52. Other key findings included:

52.1. Overall, more than half of respondees felt that their **health and care needs had not been supported** during this phase of the pandemic. More than half of the patients that took our survey felt they hadn't been supported emotionally when receiving health and care services. A similar proportion felt they had to wait too long for health and care services, did not receive the help they needed to feel safe or to address their fears, and that their care was not well coordinated.

52.2. 67% of respondents (of a total of 721) told us they had had appointments cancelled as a result of the COVID-19 pandemic.[4]

52.3. 48%+ told us they had chosen to put off accessing services or treatments as a result of the crisis.[5]

52.4. Some comments suggested a reluctance to access healthcare services, especially primary care, to avoid either exposure to the virus or adding to health professionals' workloads. Others stated that while they had nominally chosen to postpone appointments, in reality there was no choice involved, as services had shut down.[6]

52.5. Others expressed concern about how or whether they will be able to access services in the future, and a lack of information about when and how healthcare services might restart.[7]

52.6. Diagnostic services, GP appointments, dentistry and support for mental health were particularly hard to access.[8]

52.7. Opinions on the impact of **virtual consultations** were mixed. Some felt continuity of care became more difficult, whilst others benefited because they didn't live close to their surgery or could access services faster over the phone.[9]

52.8. Responses on the **ability to access healthcare** included the following:

> *'Most medical services have worked round the clock to provide the usual level of care but my surgery tell me they have difficulty contacting specialists in hospital and obtaining pathology reports. Certainly my ongoing conditions have been less well monitored and*

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[4] **Exhibit 007/ INQ000273424**, page 22.
[5] **Exhibit 007/ INQ000273424**, page 22.
[6] **Exhibit 007/ INQ000273424**, page 22.
[7] **Exhibit 007/ INQ000273424**, page 22.
[8] **Exhibit 007/ INQ000273424**, page 23.
[9] **Exhibit 007/ INQ000273424**, page 29-31.

> *we still cannot get advice about one condition from which I became and remain acutely ill'.*[10]
>
> *'For many weeks we have had a 'COVID-19 Care Service' and Emergency Care Service; we haven't had a National Health Service because it was basically stopped. My partner, who luckily had their heart surgery the day before lockdown, has had very little follow-up care and no rehabilitation. It has affected their mood and no doubt the delay will affect their recovery'.*[11]
>
> *'All my long term care has been cancelled and not re-arranged. I feel unsupported and not able to access the care I need'.*[12]
>
> *'The NHS has let ordinary people down'.*[13]

52.9. On what could or should have been done to improve access and communication, respondents said:

> *'When 'routine' appointments are cancelled, a later date could have been arranged recognising that the revised date might have to cancelled also. With no date, one is left in limbo'.*[14]
>
> *'Have plans for a return to usual services and communicate these to patients. A time frame need not be included but to know that monitoring will return eventually and that there is a plan for this would help. Annual diabetes checks is what I am considering'.*[15]
>
> *'Provide telephone consultations for everyone and by all hospitals, GPs, etc, so all patients have access to a consultation still but via telephone no matter where they live, condition, hospital they are with or consultant they are under'.*[16]
>
> *'Far better follow up for people with multi-morbidities is desperately needed. If telephone checks are going to be the way forward then they must be completed: it is no good making a call, getting no reply and then not following up'.*[17]

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[10] **Exhibit 007/ INQ000273424**, page 28, paragraph 2.
[11] **Exhibit 007/ INQ000273424**, page 28, paragraph 6.
[12] **Exhibit 007/ INQ000273424**, page 47, paragraph 11.
[13] **Exhibit 007/ INQ000273424**, page 48, paragraph 5.
[14] **Exhibit 007/ INQ000273424**, page 28. paragraph 8.
[15] **Exhibit 007/ INQ000273424**, page 29, paragraph 2.
[16] **Exhibit 007/ INQ000273424**, page 30, paragraph 2.
[17] **Exhibit 007/ INQ000273424**, page 30, paragraph 4.

The follow up patient experience report (**Exhibit 008/ INQ000273425**)

53. The second survey was intended to follow up on the work of the initial survey to gain an understanding of how matters were developing and whether there were any improvements or changes. As summarised in its Executive Summary, the survey found that:

    53.1. The **struggle to access services** for non-Covid care that many patients experienced in the spring and summer of 2020 had become less severe, but continued to some extent.[18]

    53.2. Access to primary care still proved particularly difficult, with patients finding it hard to access it. One respondent to the survey said '*it has become impossible to access GP assistance. I have put any health issues on hold'*.[19]

    53.3. Digital appointments and provision of care had still not become mainstream, and instead remote consultations were mainly by telephone. Patients often found these a poor substitute for face-to-face contact. For example, one survey respondent said: '*I had major surgery for adenocarcinoma, March 2020. I have not seen a medically qualified person since leaving the hospital on 3rd April 2020. All telephone consultations, and numerous nurses taking blood'*.[20] Another called telephone consultations 'pointless',[21] whilst another respondent told us: '*I have been denied referrals to specialists based on mobile phone photos rather than proper visual / specialist machine inspections. I feel I have been fobbed off*'.[22] We therefore concluded: '*The NHS must restore face-to-face contact as the default form for GP appointments, and we also support Healthwatch England's call for a review of GP access as part of the NHS's recovery from the pandemic'*.[23]

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[18] **Exhibit 008/ INQ000273425**, page 3, paragraph 2.
[19] Survey Respondent, PA Survey April 2021
[20] **Exhibit 008/ INQ000273425**, page 9, paragraph 5.
[21] Survey Respondent, PA Survey April 2021.
[22] Survey Respondent, PA Survey April 2021.
[23] **Exhibit 008/ INQ000273425**, page 3, paragraph 3.

53.4. The **disruption of patient care** was significant:

53.4.1. only one in four respondents who had appointments arranged in the period of 2020-2021 saw them go ahead without being postponed or cancelled at least once.[24]

53.4.2. Another one in four saw the same appointment re-arranged on successive occasions before it eventually took place.[25]

53.4.3. It became more common for patients to seek care and struggle to access it than for them to voluntarily stay away from the NHS.[26]

53.4.3.1. 63% of our respondents had appointments cancelled or postponed.[27]

53.4.3.2. 66% reported struggling to access at least one form of care.[28]

53.4.3.3. 56% reported delaying accessing treatment.[29]

53.5. One survey respondent reported cardiac outpatient services being cancelled repeatedly, and another stated there was no treatment plan for their new diagnosis. Another respondent said: '*I spent 5 nights in the local hospital. I was sent home still bleeding and with no follow up appointment plus was not told that a CT scan had shown a nodule in my lung. Disgusted at what I had to go through and just feel I was treated like an elderly nuisance*'.[30]

53.6. The concerns and anxieties felt and expressed by patients during the first survey had not abated: 55% were worried about how their conditions might

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[24] **Exhibit 008/ INQ000273425**, page 3, paragraph 4.
[25] **Exhibit 008/ INQ000273425**, page 3, paragraph 4.
[26] **Exhibit 008/ INQ000273425**, page 3, paragraph 5.
[27] **Exhibit 008/ INQ000273425**, page 3, paragraph 5.
[28] **Exhibit 008/ INQ000273425**, page 3, paragraph 5.
[29] **Exhibit 008/ INQ000273425**, page 3, paragraph 5.
[30] Survey Respondent, PA Survey April 2021.

change as a result of the pandemic, while 70% were worried that treatment and services would be less accessible in the future. The latter figure had not changed at all since the first survey, and our Executive Summary concluded that '*so far patients' concerns about ongoing difficulty accessing services have unfortunately been well justified*'.[31]

53.7. Asked about the **quality of the care and support** they had enjoyed, patients overall reported mostly negative answers, including on being able to access the services they needed, not having to wait too long, and having the right support to feel safe. Survey respondents told us: '*My rehabilitation physiotherapy was cancelled and has never been re scheduled*'[32] and '*I had to wait a year for cataract operation that was cancelled at the start of lockdown. I have been waiting for a long time on treatment for my right eye and have gone blind in it whilst still waiting for treatment*'.[33] Another respondent said: '... *My GP diagnosed me with a heart murmur over a month ago, after I had waited four months to be offered an in-person appointment. I am still waiting for further assessment, even though my cardiac issues have been classified as urgent*'.[34]

53.8. There were also significant concerns around lack of communication around available care and support. One survey respondent said: '*No communication from the hospital or the consultant as when or if [my knee replacement] surgery will resume, and I have been left in severe pain with only painkillers that will either turn me into a zombie or have no effect on a lower dose'*.[35] Another respondent said: '*No one rings you back to rearrange appointments. It's a shambles'*.[36]

53.9. Patients' views on the **overall handling of the pandemic** were somewhat mixed. Very few rated it as very good, but across the other response options there was a range of opinion, trending overall to the negative. Vaccinated

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[31] **Exhibit 008/ INQ000273425**, page 3, paragraph 6.
[32] Survey Respondent, PA Survey April 2021.
[33] Survey Respondent, PA Survey April 2021.
[34] Survey Respondent, PA Survey April 2021.
[35] **Exhibit 008/ INQ000273425**, page 9, paragraph 2.
[36] Survey Respondent, PA Survey April 2021.

respondents were clearly likely to rate it more positively than unvaccinated respondents, but we concluded that this may reflect a well-documented trend in views across age groups rather than people's views being specifically influenced by whether or not they have had a vaccination.[37]

Patient experience before Omicron report (**Exhibit 009/ INQ000273426**)

54. We carried out the third survey in order to continue to monitor developments towards the end of 2021. The conclusions in the Executive Summary of the report on the survey state (emphasis added):

> *The findings show not only* ***how difficult patients found it to access care****, and how pressures affecting the NHS compromised their care: they also show that* ***patients whose illness or care needs seriously affect their day-to-day lives have been affected more than other people****. We have warned previously of how the health emergency has* ***disrupted the relationship between patients and the NHS****; our latest survey appears to show that* ***things have worsened for some patients****, and we worry about the long-term consequences.*[38]

55. Other findings included:

    55.1. Three out of four respondents said they have been treated with respect and listened to but most said there were problems with waiting times and access.

    55.2. Concerningly, one in four respondents disagreed or strongly disagreed that they had been treated with respect and listened to.[39]

    55.3. Our results showed that patients whose conditions and care needs affected their day-to-day life more significantly were impacted the most.[40]

    55.4. Respondents still reported encountering barriers, particularly long waits, to getting appointments and accessing services (especially follow-up care). Examples given by respondents to the survey included:

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[37] **Exhibit 008/ INQ000273425**, page 4, paragraph 4.
[38] **Exhibit 009/ INQ000273426**, page 3, paragraph 3.
[39] **Exhibit 009/ INQ000273426**, page 4, paragraph 2.
[40] **Exhibit 009/ INQ000273426**, page 3, paragraph 3.

> *"Did not see any professional from the day I had a total knee replacement and had to dress and do my own sutures'.*[41]
>
> *'My regular hospital treatment has been delayed from every 3 months to every 5 to 6 months'.*[42]
>
> *'Spent 6 hours in ambulance parked outside emergency department, then 11 hours in majors before being admitted to a ward at 0415 the following day after admission'.*[43]
>
> *'Waiting 18 months for assessment to damaged eye after fall'.*[44]

55.5. Long waits, delays and cancellations were most commonly associated with care and treatment delivered in hospitals. 27% of respondents had a hospital appointment cancelled in the six months prior to taking the survey, and a further 22% had one or more appointment cancelled.[45]

55.6. 69% of people who took our survey had had a face-to-face appointment in the last 6 months, compared to 66% who took part in a remote one. In person appointments were most common in all services apart from GPs, where remote appointments were more common.[46]

55.7. Respondents also said that a face-to-face appointment would have been better than the remote appointment they actually had. Telephone consultations remained by far the most common type of remote appointment. Where digital consultations took place, they were more likely to be used by younger people.[47]

55.8. Confidence about recovery from the pandemic was extremely low, with two thirds of respondents indicating they are not very or not at all confident that

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[41] **Exhibit 009/ INQ000273426**, page 15, paragraph 4.
[42] **Exhibit 009/ INQ000273426**, page 15, paragraph 4.
[43] **Exhibit 009/ INQ000273426**, page 15, paragraph 4
[44] **Exhibit 009/ INQ000273426,** page 15, paragraph 4.
[45] **Exhibit 009/ INQ000273426**, page 5, paragraph 2.
[46] **Exhibit 009/ INQ000273426**, page 4, paragraph 6.
[47] **Exhibit 009/ INQ000273426**, page 5, paragraph 1.

the health and care system will be able to recover to deliver high quality care and treatment. Among people whose daily lives are affected entirely or to a great extent by their health or care needs, that proportion rose to over three quarters.[48]

55.9. This report showed a continuing poor outlook for patients, with many reporting their needs being met badly or not at all. 42% felt that overall their needs had been supported, compared to 45% who did not (13% did not respond to this question).[49]

Care Rights UK

56. Our helpline heard about significant problems faced by people living in care settings in accessing healthcare services, both for COVID-19 and non COVID-19 conditions. This had a devastating impact on people's health and wellbeing. This ranged from people being denied access to hospital for serious conditions such as COVID-19 or cancer, to difficulties accessing routine healthcare appointments with GPs, dentists, chiropodists, optometrists etc.

57. Access to healthcare in care homes was significantly impacted by restrictions, and by healthcare professionals staying away, to prevent transmission of COVID-19. This is reflected in responses to our survey conducted in May 2023 (**Exhibit 032/ INQ000273449**):

> '*I was told no [GPs] would be visiting, no resident would be admitted to hospital, no respiratory assistance would be given*.' Survey respondent, May 2023[50]
>
> *'GPs had over the phone consultation, instructed care workers on how to do a GPs job, frustrating at best, dangerous at worst.'* Survey respondent, May 2023[51]

58. We heard that the results of this included risks to life, being left in pain, reductions in speech, mobility and oral health. Often this led to further impact on health such

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[48] **Exhibit 009/ INQ000273426**, page 4, paragraph 4.
[49] **Exhibit 009/ INQ000273426**, page 3, paragraph 7.
[50] **Exhibit 032/ INQ000273449**, page 6, paragraph 2.
[51] **Exhibit 032/ INQ000273449**, page 8, paragraph 3.

as weight loss and increase in falls, as well as a reduction in wellbeing and quality of life.

59. Our helpline heard that use of technology as a replacement for face-to-face contact with healthcare professionals was simply not a viable option for many people needing care. This was the case particularly for older people who had communication difficulties, such as hearing loss, or conditions such as dementia. As a result, often neither the person nor their representative were able to participate properly in the consultation. We heard telephone or video appointments led to confusion or frustration at being unable to communicate effectively or have symptoms assessed properly.

60. One caller to our helpline described her mother's experience of video consultations and she later wrote about this on our website (see **Exhibit 039/ INQ000273456**). I set out a key excerpt from this testimony below:

> '*The doctor told me [mum] had a UTI, but they were only seeing her over video. During the same phone call, I queried her rapid breathing and the doctor said he would look at the possibility of a chest infection. I was then told to prepare for end of life.*'

61. Lack of access to family carers exacerbated these issues – 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.

62. The need to isolate in a care setting after visits out for health appointments had a chilling impact on people's ability to access healthcare. Our helpline heard of the damage caused by isolation periods on the mental and physical health of people living in care. This included distress, anxiety, depression, and deterioration in mobility and speech. One son who contacted our helpline fought to get his father back into rehabilitation after a stroke, but he then faced rolling quarantine periods

in isolation after each appointment. Another helpline client told us about a care home resident who after becoming withdrawn when isolating in her room, took to her bed, seeing no reason to get up. She described it as being like a prison and said she longed for some wallpaper to look at, rather than the blank white walls (see **Exhibit 029/ INQ000231916**

63. For people with dementia the impact of isolation requirements imposed after medical appointments was devastating, leading to confusion and a deterioration in their condition. The serious impact on health led to impossible decisions about whether to attend medical appointments and a terrible balancing of the risk to health of another isolation period or the risk to health of missing out on vital healthcare. One respondent to our Survey in May 2023 told us:

> *'Mum delayed going for X-ray until after Xmas as she would have been isolated over Xmas 2021 for 14 days. She was in considerable pain and her mobility was affected.'* [52]

64. As set out above, in addition to information collected from our helpline, we have also drawn on the survey we recently conducted. A series of 26 questions were developed, drawing on the provisional scope for module 3 of the COVID-19 Inquiry and we received almost 300 responses. These questions focused on 5 key dimensions of healthcare: access to hospitals; face-to-face appointments with healthcare practitioners; visits out of care settings for healthcare appointments; palliative and end of life care; and "do not resuscitate" decisions. Key findings on access to and quality of healthcare included:

    64.1. More than 1 in 5 respondents to our survey reported that the person in care was prevented from receiving treatment in hospital during the pandemic, for reasons including a cancelled routine appointment or being denied an ambulance.[53]

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[52] **Exhibit 032/ INQ000273449,** page 10, paragraph 4.

[53] **Exhibit 032/ INQ000273449**, page 5, paragraph 1.

64.2. 55% of respondents whose loved one was denied access to hospital felt that they were prevented from receiving treatment in a hospital because of their age or a disability.[54]

64.3. 69% of respondents to our survey reported that the person in care was unable to arrange face-to-face appointments with healthcare professionals including GPs, dentists, opticians, district nurses, physiotherapists, and chiropodists.[55]

64.4. 177 respondents felt that the healthcare their loved ones received was made worse by restricted access to healthcare professionals during the pandemic (88% of respondents to that question).[56]

64.5. Concerningly, 41 out of 291 respondents reported that, at the time of responding to this survey, the person in care has not resumed normal face-to-face appointments with all health professionals that they need to see.[57]

64.6. The requirement that care home residents isolate on return from "high-risk" visits out, including a hospital stay, had a significant impact on many people's decision making when it came to their or their loved ones' healthcare. 89 of 291 respondents reported that it affected decisions to access healthcare services outside of the care home and resulted in decisions not to access healthcare for fear of isolation requirements on return.[58]

John's Campaign (JC)

65. As set out above, JC was particularly concerned with the impact of 'closed door' policies adopted by or imposed on health and care settings during the pandemic. Like Care Rights UK, we found that restrictions on people coming in and going out of care settings had a significant impact on health and access to healthcare. GPs, district nurses, dentists, podiatrists, physiotherapists and other professionals were unable to gain access to provide their much-needed services. Individuals

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[54] **Exhibit 032/ INQ000273449**, page 5, paragraph 1.
[55] **Exhibit 032/ INQ000273449**, page 7, paragraph 1.
[56] **Exhibit 032/ INQ000273449**, page 7, paragraph 1.
[57] **Exhibit 032/ INQ000273449**, page 22, table 8.
[58] **Exhibit 032/ INQ000273449**, page 22, table 10.

resident in care settings were unable to leave in order to attend appointments with the same professionals. The result was often that necessary healthcare was simply not provided for extended periods (often for months not weeks) and individuals' health and wellbeing thus declined. Like Care Rights UK, we were told stories about care staff ill-equipped to provide medical care attempting to fill the gap left by medical practitioners' absence. We heard of people in pain unable to see a range of medical professionals. We were told about decline in mobility made worse by the absence of regular physiotherapy. Like Care Rights UK, we heard that there were efforts to 'fill the gaps' with digital appointments, which often caused confusion and did not allow for proper medical examination of individuals.

66. The initial blanket ban on visits out of care settings and then the imposition of isolation requirements on return from any visit out had a particularly stark effect on individuals who needed to leave care settings to attend medical appointments, as evidenced in the testimonies John' Campaign collated into the booklet 'The Holding Pen', which is exhibited to this statement as **Exhibit 036/ INQ000273453**. Many testimonies demonstrated how disabled people and people requiring medical care were particularly harmed by repeated applications of the 14-day isolation rule. For example, one contributor to the booklet explained that her 99 year old grandma was currently isolating for 14 days for the 5th time, after repeated trips to hospital, resulting in a significant decline in her grandma's mental health and wellbeing. Another contributor described how her father, who is blind and has terminal cancer and emphysema, would beg her not to remind care home staff about his hospital admissions, because he was so anxious about having to isolate again after returning from them.

67. It is worth remembering that the first guidance dealing specifically with arrangements for visiting <u>out</u> of the care home (i.e. permitting residents to make trips out of their residential setting) was published was on 1 December 2020 – 10 months after the outbreak of the pandemic and 5 months after the DHSC first promised that an update regarding visits out would be published "shortly" (see **Exhibit 040/ INQ000273457**). The effect of this was that many care settings assumed that visits out, including to attend medical appointments and treatment,

were simply not permitted (unless circumstances were exceptional/urgent emergency care was required) and kept their doors firmly shut.

68. The Guidance introduced in December 2020 (exhibited to this statement as **Exhibit 041/ INQ000273458**) effectively imposed blanket bans on visits out of care homes (over the Christmas period and otherwise) for care home residents over working age and required isolation of the resident on return from <u>any</u> visit out, including any visit to a medical professional or hospital. We knew and were hearing from individuals and their families that this rendered visits out impossible in practice because the impact of the subsequent isolation period would be too hard. As set out further below, we wrote to the SSHSC setting out our concerns about this.

69. Updated Guidance published on 8 March 2021 (exhibited to this statement as **Exhibit 042/ INQ000273459**) stated that visits out were only to be considered for care home residents of working age and only in exceptional circumstances (interpreted as end of life) for older residents and imposed a requirement to isolate for 14 days upon return from any visits out, regardless of the type of visit (including if a resident attended an outpatient medical appointment).

70. As set out further below, we raised concerns about this guidance repeatedly, including via legal correspondence, and changes were subsequently made allowing visits to medical appointments during the day. However, the May 2021 guidance still required isolation for 14 days after any overnight stay (including in hospital).

71. The case studies we collected, filed in support of our legal challenge to the guidance on visits out and exhibited to this statement as **Exhibit 043/ INQ000273460** tell of the suffering of both residents and their family members during the periods of enforced isolation imposed after visits out. They tell of the serious and significant decline of residents during the 14 day forced isolation period and provide shocking images of individuals of all ages being constrained and sometimes even physically restrained to achieve that. The final case study discussed in **Exhibit 043/ INQ000273460** notes that for 43 year old 'R', who lacks mental capacity, the requirement of 14 days isolation after a hospital admission

meant '*being strapped in his chair with a chest restraint, lap restraint and his legs secured for 14 days*'.

72. The isolation requirements had particularly stark impacts for those in need of regular medical support. As John's Campaign co-founder Nicci Gerrard discussed in an article for *The Observer* (exhibited as **Exhibit 044/ INQ000273461**) the requirement of a 14-day quarantine following visits out from care homes was '*so grotesque and absurd it beggared belief*'. For example, Nicci recounted how the wife of a 57-year-old care home resident with multiple sclerosis, cognitive issues and epilepsy told John's Campaign that because her husband '*has to go to hospital every two-to-three weeks to have throat procedures, he is now in more or less constant quarantine in his room*'. His wife described this as '*inhumane*'.

73. People we supported in care settings became reluctant to seek help for health problems due to fears of facing isolation[59] and carers who desperately required the support of respite care (including in circumstances where their care responsibilities were impacting on their own health) found it impossible to access this resource because of the effects of the isolation requirements[60]. On top of this, we observed that concerns around contracting COVID-19 in healthcare settings also had a chilling effect on willingness to encourage, facilitate and attend medical appointments.

74. The witness statements from two care home representatives included in 'Midsummer Milestones' (**Exhibit 031/ INQ000176369**) explain the difficult position care providers were in due to the Guidance which offended their sense of right but which they felt obliged to follow. We highlighted the fact that there was no legal basis for the isolation requirement in our legal case as well as the advice booklet we produced and stressed that many care settings were therefore

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[59] See for example **Exhibit 043/ INQ000273460**, page 11 which explains how J's son R '*cannot verbalise his distress so he bites his arm until it is red and sore. R needs dental treatment at the moment but this would involve a hospital admission and 14 days' isolation*'.

[60] See for example **Exhibit 043/ INQ000273460**, page 1 where A, who looks after her husband who has dementia states: '*I have had no respite for 16 months now. I'm so, so, tired and exhausted and I really need a break. I was told my husband could go into respite care but would have to have a PCR test 72 hours before and would have to isolate in his room for 14 days. I understand the reason for having the PCR test before going into respite, but if you test negative surely there is no need to keep these vulnerable people away from others. I'm therefore reluctant to send my husband to respite because I do not want him stuck in a room on his own*'.

unwittingly in danger of acting unlawfully if they confined residents without consent and in a manner so obviously detrimental to their well-being (including because it affected their access to medical care).

75. We also heard that access to (health)care and support was particularly impacted for those without internet skills. We were saddened by the bewilderment and exclusion felt by those who called us having received our number from someone else. It was very difficult to give them tangible help when so much guidance was internet based. During the pandemic it was very difficult indeed for individuals and family members to know where to call and who to ask for help, to make a complaint or object.

Health Inequalities

The Patients Association (PA)

76. 'The early pandemic patient experience report' referred to above (**Exhibit 007/ INQ000273424**) makes clear that the COVID-19 pandemic exacerbated existing health inequalities and drew fresh attention to the extensive challenges and barriers already faced by marginalised groups. This topic is extensive and of such importance that it warrants a public inquiry in its own right. There are other Core Participants better placed to comment on it in detail. I will therefore limit myself to 'headline points' that we think are crucial for the Inquiry to have in mind in order to carry out an effective review of healthcare during the pandemic. I set out key excerpts from 'The early pandemic patient experience report' below, but would encourage a full review of the report and underlying documents:

> *'2020 marked ten years since the publication of the Marmot Review, which highlighted unjust and unnecessary health inequalities.*
>
> *'Reports and campaigns by the Race Equality Foundation, the Ubele Initiative, the Royal College of Midwives, the British Medical Association (BMA), government health bodies and others have already noted the impact of COVID-19 on bringing to light existing health and other inequalities in the UK relating to race. The virus, like other health conditions, has had a disproportionately negative effect on those who already face discrimination within health services. The King's Fund points out some people from Black, Asian and other minority ethnic (BAME)*

> *backgrounds, including African Caribbean and South Asian people, may tend to have higher incidences of cardiovascular disorders and diabetes, which might complicate cases of COVID-19. The Race Equality Foundation also highlights certain groups with disproportionately older populations than White British people, including people from Irish and Jewish communities. Some of these groups also include a disproportionately high number of low-paid, frontline workers, live in poorer areas and in more crowded households, and the impact of this on health risks, outcomes and incidences of ill health should not be ignored.*
>
> *Even if not directly affected by COVID-19, some communities will face additional – or compounded – challenges accessing healthcare as a result of the pandemic. As the NHS Confederation highlights, some key services, such as translation and interpretation, are at risk of being withdrawn, or stretched further, during the pandemic. Where professional services are not available, this risks the ability of some patients to articulate their needs, priorities and preferences. It also risks placing extra pressure on patients to have friends or family members take on this role, where this may not be appropriate or safe. Groups and individuals working on issues affecting Black, South Asian and other ethnic minority groups recently told Public Health England (PHE) that racism within health and care systems, and a related lack of trust, also prevented some people from seeking diagnosis, treatment and further support.*
>
> [Stakeholders] stated clearly that *'racism is a root cause of poor health, risk of exposure and risk of worse health outcomes'.*

Core Participant Group

77. The report also commented on the experience of people with disabilities. Again, there are other core participants well placed to provide detailed insight, however the following excerpts from the report summarise the impression our Core Participant group got from those we supported during the pandemic, namely that there was a widespread feeling that the lives of disabled people were valued less and that they were impacted disproportionately in healthcare (and more generally). PA's 'early pandemic patient experience report' discussed research from DPPO Inclusion London. We have exhibited Inclusion London's report to this statement as **Exhibit 045/ INQ000182684**. We further set out an excerpt containing a summary of Inclusion London's notable and shocking findings below:

> *'Inclusion London, a Deaf and Disabled people's organisation (DDPO), found that D/deaf and disabled people feel 'abandoned, forgotten and ignored' as a result of the COVID-19 pandemic …'*
>
> *'The interim report, based on survey results from over 300 people, found that 60% of disabled people had struggled to access food, medicine and other necessities, 35% reported increased levels of psychological distress, and almost half described inaccessible information, confusing guidance and a lack of advice. Disabled people reported facing cuts to care packages, delays to assessments and difficulty securing PPE for their care workers. Respondents had the impression that their lives were valued less as a result of requests to sign Do Not Resuscitate (DNR) notices, or fears that they would be denied emergency treatment because they are disabled or scored highly against official measures of frailty. Terms such as 'vulnerable', assigned without any choice, entrenched existing stigma and prejudice against disabled people, and employers, retailers and government services have failed to provide reasonable adjustments or accessible information, according to respondents.'*

NHS111 services

The Patients Association (PA)

78. We collected information about NHS111 services during the pandemic as part of our surveys referred to above (introduced §§23-24). In our 'follow up patient experience' survey (first referred to at §24.2), we found that although a majority of respondents were very or somewhat satisfied with their experience of using NHS 111, the proportion who were only slightly or not at all satisfied was high for a service on which the NHS was placing increasing reliance. The picture was worse in our third survey ('patient experience before Omicron'). There was a shift towards lower satisfaction levels, with more than one in four respondents saying they were not at all satisfied by November 2021. We stated in the conclusion of our third report that '*the apparent variability in NHS 111's quality of delivery is increasingly concerning to us*'.

79. The responses we collected showed that the NHS111 service that was provided during the pandemic was at times not fit for purpose. But at the other end of the spectrum there are reports of an excellent service. Comments on NHS111 given as part of our surveys included:

> *'Contacted 111 - no help. Advised to access a test 46 miles away when too ill to drive. Told to take paracetamol'.*[61]
>
> *'We needed to use it as a last resort on a Sunday. After an initial call we had a two hour wait for a doctor to call back. That was good, she diagnosed the problem and sent a prescription to a relatively nearby pharmacy (in a branch of Tesco). We have a car so could collect. Not sure how anyone without a car would have managed'.*[62]
>
> *'It took over 40 minutes to get a human who then said to dial 999. I was calling on behalf of a neighbour'.*[63]
>
> *'They were disorganised, patronising and repetitive, and followed a script'.*[64]

80. Whilst I know this statement should focus on the relevant period, PA is still hearing of significant variation in the quality of NHS111 services. It has been widely reported that since 2015 Coroners have issued 11 Prevention of Future Death reports to NHS111 (see for example, a report in *The Telegraph* which I exhibit to this statement as **Exhibit 046/ INQ000273463**). Consideration must be given to what caused and is continuing to cause variation in quality. Until the reasons for such a variation are known, steps cannot be taken to address the concerns to ensure that the quality of service provided is consistent and to the level required for such an important service. I believe the Inquiry is well placed to look into this and provide recommendations about how to improve the NHS111 service and ensure consistency in the quality of the service.

Discharge of patients from hospital into care homes

81. All three members of our Core Participant group heard about issues around discharge of patients from hospital into care homes. The PA and JC agree with the summary provided by Care Rights UK in terms of the key issues observed.

Care Rights UK

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[61] Survey Respondent, PA Survey September 2020.
[62] **INQ000273425**, page 24, paragraph 1.
[63] **INQ000273425**, page 25, paragraph 3.
[64] **INQ000273425**, page 25, paragraph 10.

82. Policies to 'protect the NHS' and discharge people from hospital into care settings without testing them for COVID-19 put lives at risk. It resulted in the transfer of a life-threatening health issue from the NHS into care homes. The Government knew – or should have known – that the sector did not have the equipment (PPE, testing etc) or skills (training) to manage this health crisis. The resulting loss of life and detrimental impact on wellbeing (for those who caught COVID-19 but didn't die) has caused anger, resentment, anxiety and distress. We know from both residents/families and care providers we work with that the policy led to the feeling that the lives of people living and working in the care sector were less valued or important than the lives of others.

83. Throughout the pandemic there remained concerns about the discharge of people from hospital into care settings and the isolation requirements later imposed in the name of infection control upon discharge. We and JC set out above the issues around enforced isolation (including after outpatient appointments and hospital visits), but it is important to reiterate the concerns around this in the context of discussing discharge from hospital into care homes.

84. One helpline client in February 2022 told us that their relative was discharged from hospital into a care home, placed in isolation, and refused an essential caregiver. Access to a physiotherapist was denied and he was rarely assisted out of bed during this two week period. As a result, he lost the mobility he had regained prior to the move into care. Another helpline client in September 2020 told us about their relative who was discharged from hospital into a care home and isolated for 14 days on the top floor. With care staff only dropping off and picking up trays of food, he became seriously dehydrated within a few days but this went unnoticed. Fearing for his life, his family moved him out of the care home.

85. Our helpline heard and continues to hear that when people and their families/representatives are not involved in the discharge process this leads to poor care planning. The hurried nature of many discharges during the pandemic made it far more likely that care planning was not carried out properly and that family members were not consulted properly in the process. This can lead to people feeling forced into a care home without proper planning or involvement

before or after discharge, leaving them in unsafe or inappropriate care. This can hamper recovery, lead to ongoing health issues and have a significant detrimental impact on people's rights, autonomy and quality of life.

John's Campaign (JC)

86. It was our experience that early discharges with no testing wreaked havoc on transmission levels in care homes and then caused the over-cautious guidance on visits in and out that followed to try to prevent repeats of that uncontrolled transmission. This meant that care home residents were hit with a double whammy flowing from the poorly thought out early discharges from hospital. We heard repeatedly from individuals who were denied access to their loved ones and told that this was to prevent dangerous outbreaks like the ones that had been seen early on in the pandemic after discharges from hospitals into care homes.

87. This reason was often cited in particular in relation to denials of 'visits out' including to attend medical appointments or hospital. We refer you to the case studies set out in **Exhibit 036/ INQ000273453** and **Exhibit 043/ INQ000273460**, which (as set out above) show the devastating impact of 14 day imposed isolation including after hospital admissions. They also contrast the 14-day imposed isolation period with the inexplicably different approaches taken in respect of other imposed isolation periods: e.g. 10 day isolation on return from travel or COVID-19 infection. It was our strong belief that this was at least in part due to a 'knee jerk' reaction to what was recognised as an early mistake (discharging people with COVID-19 into care homes) but it had a devastating impact and continued long after testing and other infection control measures made it far less likely that uncontrolled infection transmission would occur.

88. People, especially those without much confidence, articulacy, or system knowledge had a very hard time resisting unwanted discharge or care home placement. For example, not only did we hear of individuals inappropriately discharged into care homes without being tested, we also heard of individuals being discharged into care homes when they did not want to be in a care home at all or had been sent to a care home that was too far away from their family to allow any in-person contact. On top of issues around testing, we heard that the rush to

discharge from hospital led to poor decisions being made around appropriate care after discharge. Individuals were rushed home without appropriate care packages for care at home in place, without support for follow up and without enough of a say in what (health)care and support they needed.

End of life and palliative care

89. Throughout the pandemic, Care Rights UK and JC have heard many concerns about end of life care. These related both to the access given to loved ones at the end of life, and the quality of end of life care being provided. A significant aim of end of life care is to minimize suffering and ensure dignity. A key aspect of this is working with relatives and friends to ensure that the patient feels loved and supported, to lessen their pain. Feeling like support was given and quality time spent is also key in helping bereaved loved ones process the trauma of a death. Feeling that matters were left unresolved / unsaid / undone can be a huge source of trauma in bereavement. As set out in further detail below, all members of our Core Participant group witnessed the horrors that many individuals and families went through as their loved ones came to the end of life and they were denied the right to properly support them. It was a source of significant anguish and we continue to hear of suffering from the trauma this caused.

The Patients Association (PA)

90. In our 'early pandemic patient experience' survey, which was available online from 6 May 2020 to 17 August 2020, some of those who had experienced a bereavement during lockdown told us about good experiences of compassionate care and support. As summarized in the report[65], there were some clear examples of failings in services, and people were not always able to stay in contact with their loved one at the end of life. Some people also raised long-standing issues with end-of-life care, including poor communication leaving relatives with inaccurate views of a person's condition, the loss of valuables in hospital or problems associated with the discharge process, which may have been exacerbated due to the pandemic. We therefore included the following recommendation in our report: '*Maintain compassionate end-of-life and bereavement support services, with clear*

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[65] **Exhibit 007/ INQ000273424,** pages 38-41.

communication between staff, patients and others, and the opportunity to be with friends and family members at the end of life unless totally impossible'.[66]

91. Overall, respondents to our survey offered mixed views on the end of life experiences of their loved ones, tending slightly towards the positive.[67] Some respondents reported very high quality, highly compassionate care at end of life but notably 24% of respondents reported what they felt was a poor or very poor experience. However, it is clear that restrictions associated with COVID-19 exacted a heavy toll, in some cases, on the dying person, bereaved people, or both.

92. Not all of the feedback from respondents was novel: problems such as poor communication leaving relatives with inaccurate views of a person's condition, the loss of valuables in hospital or problems associated with the discharge process were all among the sorts of problems that could mark a bad end of life experience before the coronavirus period but there was a clear increase in experiences of dying alone and in a way that was perceived to be without dignity.

Connecting with loved ones at the end of life

The Patients Association (PA)

93. Relatives being unable to visit to say final goodbyes was a prominent theme in the responses to our survey; many people expressed horror at the thought of their loved one dying alone, deep sadness at being unable to be with them, or both. Some of the observations on end of life from the respondents to our survey included:

> *'Two relatives in care homes contracted the illness and died alone. Their main focus during life was to care for their families, and they were denied the opportunity to say goodbye. The relatives, because they were in care homes, could not access hospital care or specialist care. This is inhumane.'*[68]

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[66] **Exhibit 007/ INQ000273424**, page 50, paragraph 3.
[67] **Exhibit 007/ INQ000273424**, ibid, page 38, paragraph 3.
[68] **Exhibit 007/ INQ000273424**, ibid, page 39, paragraph 4.

> *'Not being able to be with loved ones at the end is unforgivable.'*[69]
>
> *'It was my friend's mother that died in hospital. She was tested twice for COVID and each time showed negative. However she was left on a ward on her own for a week, terrified and lonely, and she died alone. The ward did not tell the daughter until a few hours after she had died. I could not believe they were so inhumane. The woman that died was in her mid-80s – it was so tragic that all the work about dignity of dying has gone out the window for COVID-19.'*[70]
>
> *'Visiting restrictions due to COVID-19 made my sister's last days/weeks terrible for her and our family.'*[71]

94. Closely related to this were issues of communication: some people appeared to be unsure, even after the event, of the circumstances in which their loved one had died – particularly, whether they were alone or not. When asked whether they felt they had been kept informed about someone's condition during their final illness, respondents provided a polarised set of responses, evenly split between good and bad.

Care Rights UK

95. With visiting restrictions in place, family and friends had to rely on the care providers' assessment that their loved one was at the end of life before they were able to visit. It's clear that there were issues with this, with some family members denied the chance to be with their loved ones in their final moments. The NHS emphasises that palliative and end of life care should enable someone to die with dignity (see **Exhibit 047/ INQ000273464**), however our survey suggests that the integral role of family and friends in providing care and support at the end of someone's life was not always prioritised.

96. Despite NICE guidance defining 'end of life' as the last year of a person's life (see **Exhibit 048/ INQ000273465**), our helpline repeatedly heard that end of life was given a much more restrictive definition across different settings during the pandemic. One helpline client told us in February 2022 that six months after being

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[69] **Exhibit 047/ INQ000273424**, page 39, paragraph 5.
[70] **Exhibit 047/ INQ000273424**, page 39, paragraph 6.
[71] **Exhibit 047/ INQ000273424**, page 39, paragraph 7.

diagnosed by a consultant as having 3-6 months left to live, they were still being denied end of life visits to their loved one. The family was told that their relative was 'only receiving palliative care' rather than being at the end of life.

97. We heard through our helpline that end of life visiting often wasn't granted until the final weeks and days of life, or even granted too late or not at all. This meant people were denied the right to a dignified death and too many died alone or fell unconscious before their relatives and friends were granted access, robbing them of the opportunity to say goodbye. For the relatives and friends of people who died in these circumstances, this caused immense distress, anger, and feelings of guilt and trauma they may never recover from. For many, they are unable to remember their loved one without reliving this trauma and many tell us they suffered from mental health issues as a result.

98. The following testimony from one respondent to our May 2023 survey about the difficulties remembering their mother's end of life period is one of many we have heard throughout and since the pandemic:

> *'Still upset by the memories of those difficult last months of her life. Not even allowed an end of life visit. The manager told me, 'she's close to the end of her life, but not quite there yet.' On a video call my mum pleaded with me to visit.'* Survey respondent, May 2023[72]

John's Campaign (JC)

99. End of life should be understood as a period (like infancy) rather than as an event (like birth). Like Care Rights UK we witnessed huge and damaging disparities in understanding around this during the pandemic which led to significant deterioration in mental health and wellbeing of individuals at the end of life and their families. We were told repeatedly of deeply shocking instances where families were prevented from seeing their loved ones because they weren't dying 'actively' enough.

100. The well-intentioned practice of getting a nurse or healthcare assistant to video a dying patient for their family or pass messages was seen by many as an affront to human dignity. A nurse is a person, if they could be there in suitable

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[72] **Exhibit 032/ INQ000273449**, page 12, paragraph 1.

PPE, why not a family member? We asked care settings repeatedly why strangers were given priority over loved ones with no regard being given as to whether they posed a greater infection risk.

101. Failures of communication in this crucial area are one of the most enduring negative legacies of the pandemic for many individuals we support. The guidance in England specified 'visits in exceptional circumstances such as end of life should always be supported and enabled' and that 'end of life means early identification of those who are in their last year of life and offering them the support to live as well as possible and then die with dignity' (**Exhibit 049/ INQ000273466**) Despite this, in our experience many individuals faced significant battles with health and care settings to be given access to their loved one at the end of life due to fears of not meeting the threshold of 'exceptional circumstances' or due to misunderstanding which led to settings believing that they could shut their doors entirely if they were experiencing an 'outbreak' of COVID-19 (which was often defined as 2 positive tests and led to many health and care settings being in a constant state of outbreak throughout the pandemic).

102. One particularly stark example (amongst many examples we were seeing on a daily basis) is a mother we supported who was not allowed to see her 34-year old son (Sam) who was at the end of life due to Huntington's Disease for long periods of time (including for 121 days between March – July 2020 and on what she thought might be his last birthday). I exhibit a report by *The Mirror* of this family's story as **Exhibit 050/ INQ000273467**. The family had been told by Sam's GP that he was in the final year of his life, but Sam's care home claimed that as the majority of the residents within the care home were considered to meet the relevant definition, they would not facilitate access to him for his family on this basis. It was only after we referred this mother to Leigh Day who engaged in pre-action correspondence with the care provider setting out the relevant guidance and legal requirements as well as the stark impact of this separation on Sam's health (which was deteriorating significantly) and wellbeing, that the family were finally able to visit their son and individualised assessments based on his needs (including his health needs) were carried out. When visits resumed the family observed that Sam's speech had deteriorated as they had not been able to

continue mouth muscle exercises with him due to the long period in which they had not seen him.

103. Matters were made worse by failures to define terminology around the end of life. For example, in Wales, guidance which I exhibit as **Exhibit 051/ INQ000273468** stated that 'visits by close relatives at the end of life or for other compassionate reasons in exceptional circumstances should be supported' but the guidance offered no clarification as to the definition of 'end of life' nor did it make clear what could be considered 'exceptional circumstances' and what might give rise to 'other compassionate reasons for visits'. UK Government Guidance similarly stated that visitor restrictions should have regard to exceptional circumstances such as end of life', but left unclear how 'end of life' was defined leaving many to battle with health and care settings about the relevant meaning and when was 'late enough' to be with their relative at the end of life. Advice on how to advocate on the existence of 'exceptional circumstances' and 'end of life' became a key feature of multiple iterations of our 'how-to' guides of which we enclose a sample as **Exhibit 033A/ INQ000273416** and **Exhibit 034/ INQ000273451**.

104. JC wrote to Public Health Wales (PHW) setting out our concerns in this regard. In the correspondence, which I exhibit as **Exhibit 052/ INQ000273469**, we stated: '*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)'*. We requested clarification of the position. Unfortunately, we faced an obstructive approach by PHW which treated our correspondence as a Freedom of Information request and failed to engage with the underlying concerns despite our multiple efforts to stress our concerns about the impact on health and wellbeing of patients/residents and their families which the lack of clarity in this area was causing. I exhibit PHW's response to our correspondence as **Exhibit 053/ INQ000273470**.

105. We were also aware from reports we were receiving from loved ones through calls, social media or via email that of hospitals taking very restrictive

approaches, including limiting 'end of life' visits to set time periods (e.g. no more than 30 minutes) and only to a set, limited number of relatives (e.g. no more than 3 designated people being allowed to visit). One example we were told of involved a mother who had been in a coma from COVID-19 infection whose life support was due to be switched off within days. Initially her family were told only 2 family members could visit for no more than 30 minutes per day to say goodbye. It was only after intervention by lawyers that her husband and adult children were allowed to spend quality time with her to offer her a dignified death and her family some closure.

Provision and quality of palliative care

Care Rights UK

106. The responses to our survey paint a disturbing picture of the traumatic deaths that took place during the pandemic. Nearly 1 in 5 respondents to our 2023 May survey reported that the person in care had difficulty accessing palliative care professionals or end of life support during the pandemic. Respondents spoke of the lack of adequate end of life care and the suffering and trauma this caused for family members who witnessed it. One survey respondent said: '*the GP was very reluctant to visit and the care home made no attempt to help my Mum obtain end of life care*' whilst another said '*dad died without good end of life support. I experienced PTSD*'.

107. The survey also raises clear concerns around whether appropriate end of life care was taking place in instances where care providers were late in their assessment that someone was at the end of life. Assessing and making decisions around end of life care can be difficult, and our survey suggests that some care home staff and medical professionals struggled during the pandemic, sometimes due to having to carry out assessments remotely. A number of responses to our survey reported that people in care received inadequate pain relief and monitoring towards the end of their life, contributing to unnecessary distress and suffering. Family and friends often play an important and under-recognised role in care, including assessing when their loved one needs end of life care, and, as set out above, this was disrupted by visiting restrictions during the pandemic.

John's Campaign (JC)

108. Palliative care is symptom management for those who have a terminal illness. It is often thought of as easing the pathway to death. It can be positive (for example, the giving of morphine to ease pain, reduce the distress of end of life secretions, or muscle spasms) or it can be negative (for example, withholding food and water, precipitating unconsciousness). From working with a range of people at the end of life and those supporting them (including both health and care professionals and their loved ones) we know that it matters so much that the patient's wishes are ascertained and adhered to as far as possible when making decisions around palliative care. Consent matters. Family communication matters. We were already aware of issues around this, but this situation became much worse during the pandemic. We heard of communication with family about care breaking down (including because of conflicts around end of life visits). We heard of consent not being sought or being ignored.

109. Hospices may have a good understanding of the impact of this on those they supported, and we therefore recommend seeking evidence from them in this regard. We found it difficult to build a holistic understanding of whether end of life and palliative care was being provided appropriately because families were often excluded from this during the pandemic and there were therefore fewer witnesses to the care that was provided. Monitoring the quality and impact of care is difficult if no one is there to see what is happening and in circumstances where consultation and communication with family decreased. We heard of a range of experiences with some reporting good end of life care and others speaking of their loved one being in pain and in undignified circumstances. Some of this reflected the 'postcode lottery' of available end of life/palliative care prior to the pandemic but during the pandemic the overall picture became worse with more limited resources and staff. This meant less attention was given to individuals at the end of life and the overall quality of care and support for wellbeing was diminished.

110. In end of life care and care more generally we were told of a sense that because (health)care providers were much less 'watched' by family members, less needed to be done for individuals. Family members are often the ones who identify gaps in care or issues with the care being provided. This can range from

spotting that medication is making an individual disoriented to noticing that they have been left in a bed with soiled sheets. Without the presence of family members to identify these gaps, many of them tragically remained unaddressed leading to effects on both health and wellbeing (for example, an individual left in soiled sheets is of course exposed to a terribly undignified situation but may also face health risks such as rashes and infections as a result).

The use of DNACPR instructions

111. DNRs, DNARs, and DNACPRs are all abbreviations referring to an advance decision made by medical staff not to attempt cardiopulmonary resuscitation (CPR) on a patient who has stopped breathing, or whose heart has stopped. It is important for patients and their loved ones to understand how these decisions are made so they can have informed discussions with their healthcare professionals, and hopefully reach an agreed decision. These discussions should take place between the patient and his/her healthcare professionals, with relatives and carers involved if the patient wishes or the patient lacks the capacity to have the discussion. Despite this, there were concerning reports that such decisions were being made without consultation during the pandemic, in part as a way to address substantial pressures on healthcare resources. For example, the *BBC* reported in March 2021 (see **Exhibit 054/ INQ000273471**) that '*some 508 'do not attempt resuscitation' (DNAR) decisions [had been] made since March 2020*' that '*were not agreed in discussion with the person or their family*'.

112. Although it was sadly true that the pandemic placed unprecedented demands on the NHS and hence resources were a significant issue when deciding on what treatment a patient will receive, the law in terms of patients' rights did not change. As was set out in guides published during the pandemic (see **Exhibit 055/ INQ000273472**) and was reinforced by the welcome statements from NHS England and others, decisions about resuscitation should be taken in consultation with patients, and on an individual basis. These decisions should not be taken secretly from a patient or their family, but it is important to remember there is no legal requirement for a patient or their family to consent to a DNACPR decision.

113. Where an advance decision not to receive CPR is made by a healthcare professional rather than a request by a patient, their decision should be based on an understanding of the individual patient's health and wishes. Any DNACPR decision about an individual should be discussed with the individual. The individual has a right to know of any decision made. For patients lacking the required mental capacity to make their own advance decision about resuscitation or to express their own wishes about receiving CPR, there is a legal requirement to involve families in the decision-making process and for them to be informed. There may well be emergency situations where this is not possible, however with families likely to be available by telephone or video call, exceptions should be rare.

114. There should be no blanket decisions. Decisions about resuscitation need to be individual and made with the individual. There is no doubt these discussions and decisions are hard for everyone involved and were made more so by the extreme pressure brought by the pandemic but in our view good communication around these decisions was key and unfortunately too often absent.

Care Rights UK

115. Do-Not-Resuscitate (DNACPR) decisions serve as an important mechanism to honor the wishes of individuals in care and provide reassurance regarding their preferred end-of-life care. However, both our helpline and our survey findings showed serious issues surrounding the process of consultation on DNACPR decisions. In November 2020, the Care Quality Commission (CQC) published an interim report that highlighted the pervasive problem of blanket decisions being made with regards to DNACPR decisions (see **Exhibit 056/ INQ000235491**). This was clearly a pervasive issue during the pandemic, as has already been highlighted by Mencap (see **Exhibit 057/ INQ000273474**). Evidence collected through our May 2023 survey further confirmed these concerns and brought to light specific challenges related to consultation on DNACPR decisions.[73]

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[73] **Exhibit 032/ INQ000273449,** page 13.

116. Our helpline heard serious concerns about the use of DNACPR decisions during the pandemic. Helpline clients contacted us after discovering that a DNACPR decision had been made about their loved one, without their involvement in the decision-making process. Others told us they were asked to reconsider previously made DNACPR decisions, or pressured into accepting end of life plans that excluded hospitalisation. This led to concerns that the lives of older and disabled people were less valued.

117. Our May 2023 survey revealed dozens of instances where people reported problems with DNACPR decisions, including lack of consultation with the individuals in care or their nominated relatives or friends holding lasting power of attorney for health and welfare. By way of example, **Exhibit 032/ INQ000273449**, page 14 includes various testimonies from relatives and friends and patients who had no knowledge of DNACPR decisions being implemented. One testimony of a daughter whose mother lacked capacity on this decision states '*…DNR put in place without my knowledge or permission – I am daughter'*. One survey respondent who was the relative of a patient said: *'It was explained to me that the NHS was too busy to cope during the pandemic so decisions were made to not actively keep someone alive if their age and condition meant the outcome would not be in the NHS's interests.'*[74]

118. Furthermore, both our survey and helpline revealed distressing experiences where individuals felt pressured or coerced into accepting a DNACPR decision for their loved ones.[75] This coercion often stemmed from healthcare professionals or institutions, leaving family members and friends feeling marginalized and powerless in the decision-making process. The survey respondents expressed a profound sense of frustration and disappointment, as their wishes and the wishes of the individuals in care were disregarded.[76]

119. Poor communication between healthcare professionals, individuals in care, and their designated representatives was a key factor in such instances of

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[74] **Exhibit 032/ INQ000273449**, page 14, paragraph 1.
[75] **Exhibit 032/ INQ000273449**, page 13, paragraph 3.
[76] **Exhibit 032/ INQ000273449**, page 13, paragraph 3.

unauthorized or pressured implementation of DNACPRs. Respecting individual autonomy, facilitating open and honest communication, and involving designated representatives in the decision-making process are essential to prevent inappropriate or coerced implementation of DNACPR decisions. This lack of involvement and discussion in the decision-making process raised significant ethical and legal concerns. Respondents to our survey reported that in some cases, it was discovered after the fact that DNACPRs had been put in place without proper consultation, necessitating the challenge of these decisions.

Death certification

Care Rights UK

120. We have concerns that the statistics on the number of people who died from COVID-19 is inaccurate due to problems helpline clients have told us about concerning death certificates. There are concerns that COVID-19 deaths were underreported, including because testing was not available in care homes during the early stages of the pandemic. There are also concerns that people had coronavirus listed as their cause of death inappropriately in circumstances where they in fact died of other causes but due to lack of testing and the prevalence of certain symptoms COVID-19 was recorded as the cause of death. This was particularly problematic in circumstances where this meant there was no referral to a Coroner to consider the cause of death.

121. Additionally, we were also told about issues around accurately recording other causes of death. As discussed in a Care Rights UK article (**Exhibit 058/ INQ000273475**), which examined the various issues with how causes of death were recorded during the pandemic, we saw the return of phrases like 'frailty' being used on death certificates, often as a 'catch-all' for (both mental and physical) deterioration frequently linked to isolation and lack of support. For example, one helpline client told us about his wife whose mental health deteriorated so significantly that she stopped eating and drinking:

> *'[My wife] starved herself to death. Her death was due to the pandemic – but she didn't die from the virus itself. It wasn't coronavirus, or the 'frailty of old age' [as listed on her death certificate]. It was death due to a refusal to eat.'*

This means that death certificates were often not an accurate reflection of what was really happening during the pandemic. Figures on excess deaths may be the only reliable count of the true impact of COVID-19 in care settings.

The measures taken to prevent the spread of COVID-19 and their impact

122. A key measure taken to prevent the spread of COVID-19 in health and care settings was imposing restrictions on visits in and out. We have already discussed some of these restrictions and their substantial negative impact on access to healthcare and health at §§56 to 64.6 above and will therefore not repeat them here. However, it is important to reiterate and highlight in this context our concerns around the exclusion of and the failure to recognise the importance of family carers as partners in healthcare. We also observed the communication challenges, particularly for those with cognitive impairment and unconventional communications, resulting from the use of PPE and other similar measures. The impact of such restrictions could have been reduced if the importance of family carers (who could have helped address or mitigate some of those challenges) had been recognised.

Care Rights UK

123. As set out in detail above at §56 to 64.6 restrictions on visits in health and care settings had a devastating impact on the physical and mental health of people needing care. For people living in care who can have multiple health issues, conditions such as dementia or are nearing the end of their life, the support of a relative or friend can be crucial when they need to access health services. Family carers can help practically, such as by accompanying a person to hospital/other health settings, helping with communication, spotting health concerns/pain/deterioration that someone who does not know the patient wouldn't spot (particularly where the individual doesn't communicate in conventional ways), assisting with eating/drinking, encouraging to take medication etc. This is particularly important in circumstances where staff are overworked and stressed and may miss details about individuals that those who know and love them are more likely to notice.

124. One of our helpline users told us: '*A care user was found by a relative to have missing teeth and others in a bad state of repair which staff had not noticed*'. A respondent to our May 2023 survey told us: '*The lack of contact with family from March 2020-March 2021 had a huge detrimental impact on Dad's physical health. We used to monitor his health closely and knew when he needed medical advice/attention: the care home staff were often not on the ball enough / too busy with the lockdown to know when to escalate Dad's care to the GP and this led to a few serious incidents*'.[77]

125. Emotional support of family carers is also crucial for helping to reduce the stress of health appointments, and providing familiarity and 'continuity of care' between health and care settings. The failure to recognise and facilitate this vital support led to wholesale interference with people rights and unnecessary pain and suffering. This support was increasingly recognised as the pandemic progressed, with guidance more clearly recognising the role of family carers. For instance, the guidance published on 22 March 2022 (exhibited to this statement as **Exhibit 059/ INQ000273476**) noted that [t]he essential care giver role is vitally important to supporting residents' health and wellbeing' and recognised that family and friends are able to 'contribute to [a resident's] support and care' and that this should be encouraged and facilitated. Nonetheless, the improvements in later stages of the pandemic were too late for too many people, and the facilitation and implementation remained patchy. People faced different rules regarding when family carers were allowed to be present in different settings, sometimes even within different wards of the same hospital.

126. Our helpline also heard of the immense challenges older people faced communicating with people wearing PPE. For people affected by dementia, face coverings could cause confusion and distress. For people with hearing loss, face coverings made it extremely difficult to hear and understand, especially for people who needed to lip-read. This hampered their ability to communicate with health professionals and engage in decisions about their healthcare.

John's Campaign (JC)

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[77] **Exhibit 032/ INQ000273449,** page 17, paragraph 5.

127. We have already set out above in detail some of our key concerns around the adverse impact of visiting restrictions on the delivery of (health)care and more generally on wellbeing. We highlighted above the fact that this was a major focus of our work. We do not repeat some of the details covered at §§65-75 but instead focus specifically on infection control measures other than restrictions on visits in and out of settings to build on what we have already set out above.

128. Like Care Rights UK, we heard from individuals who called and/or emailed, or commented on social media posts of significant problems resulting from the exclusion of family carers, including failure to spot and monitor health issues and facilitate communication and informed consent. We were also repeatedly told that PPE was not offered to supportive family members, often for reasons we considered poor including ‘because they might not know how to put it on correctly’. We are not aware of any reasons why one could not have explained the use of PPE to family carers and were particularly perplexed by these suggestions in circumstances where the population at large was required to wear masks.

129. We repeatedly heard from individuals, their families and some care providers that there was a general lack of commitment to finding effective ways to manage the involvement in care of volunteers. In light of the substantial impact of this (set out immediately above and at §§65-75 above), we think it is crucial for the Inquiry to look at the underlying reasons that family members were being excluded from (health)care. Care providers told us they were worried about allowing family carers into their settings to support provision of essential care because of concerns that this might somehow result in insurance liability (e.g. if infection was brought into the setting by the individual). We therefore feel that concerns around insurance liability ought to be investigated.

130. Like Care Rights UK we heard that there were significant communication challenges for individuals across a range of settings. We heard from those we supported via calls, emails or social media of the adverse effects of 'one-size-fits-all' PPE on people with communication difficulties. We were told that little effort was made to adjust existing PPE (e.g. to use transparent masks to facilitate lipreading). In some cases the substantial impact on communication was

irreversible. For example, one family reported that their learning disabled daughter had lost her ability to speak. In Autumn 2022 one care home manager told me that some residents had not seen the faces of those caring for them for 2.5 years, impacting the relationship and leading to mistrust in circumstances where trust is required to facilitate safe and appropriate care.

131. We were also told by those we supported via calls, emails and social media that the focus on PPE and other physical barriers (such a plastic screens) was prioritised over basic hygiene such as hand washing. We published information on infection prevention measures which would still enable visiting by relatives and loved ones (see for example **Exhibit 059A/ INQ000273414**), but despite this in many care homes there was little or no consideration of what was appropriate to an individual's circumstances. Although individual risk assessments were required by law and guidance (see for instance, the guidance published on 22 July 2020 (**Exhibit 040/ INQ000273457**), which stated there should be 'a dynamic risk assessment' and set out factors which care providers should take into account when assessing individual risk) we saw in the various individual cases we supported an overall unwillingness to use individual risk assessments to assess what infection control measures might be appropriate in individual circumstances. This also translated to failures to carry out individual risk assessments regarding family carers.

Communication with patients with COVID-19 and their loved ones

132. As foreshadowed above, all members of our Core Participant group observed issues around lack of communication for those requiring healthcare in the pandemic and their families. We were told of a range of communication issues, including (1) poor or no communication on how to access healthcare (from home or in different settings), (2) failures to communicate (effectively) with individuals and their families about the status of an individual's health and their care and (3) failures to obtain consent from individuals and their deputies in the context of medical/care decision-making.

Care Rights UK

133. Our helpline heard that a lack of communication with people needing to access health services was a major problem during the pandemic, particularly in the early stages. As the friends and relatives of people needing care, our helpline clients found themselves cut out of conversations and decisions about their loved one's health and care. As lockdown restrictions kept them physically away, they struggled to provide the kind of support around health and wellbeing their loved ones needed and relied upon. One family member who was only permitted to visit for up to an hour at a time told us via our helpline: '*sometimes my mother would just open up about a serious issue – impending death or fear for the future – and a carer would come to tell me my time was up.*'[78]

134. This led to negative consequences for the people needing care, including pain or health concerns going unnoticed, inappropriate medication being given, or health appointments/treatment being missed without the family carers pushing for them. One helpline client in August 2021 told us that their relative*'s 'medication was changed without consultation with them and they were placed on medication they had previously had a bad reaction to.*'[79]

135. Relatives and friends also struggled to find out news and updates on the health of their loved one. This led to unnecessary anxiety, worry and stress during what was already an extremely challenging time. When communication lines did open up, the visible deterioration in health resulting from isolation from family and friends was often shocking and distressing.

John's Campaign (JC)

136. It is important to remember that communication by speech is only a part of communication. There is also communication by touch and body language. These non-verbal aspects of communication are much more important for many people with cognitive impairment and unconventional communication than speech. Touch can also be crucial for those in a state of semi-consciousness or those suddenly rendered vulnerable, for example by a stroke. We heard that the approaches to this varied hugely across different settings. Whilst a stroke ward in

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[78] Care Rights UK helpline user.

[79] Care Rights UK helpline user, August 2021.

one area welcomed family carers for this important reason, other stroke wards refused entry in the name of infection control.

137. As explained by Care Rights UK, familiarity can mean expert interpretation of small signs by a loved one. Especially for individuals with cognitive impairment who may not communicate via speech, a loved one can be a key interpreter of their signals and can provide key insight into whether they are experiencing pain or discomfort. Their absence can cause crucial information to be lost and is akin to leaving an individual who does not speak English without any interpretation/translation facilities, which also happened too frequently.

Shielding and designation as clinically vulnerable

The Patients Association (PA)

138. Our 'follow up patient experience' survey found that many people shielded during the pandemic, but most shielding was not done in line with official advice.[80] It found that:

138.1. Two thirds of our respondents who shielded had not actually been advised to do so by the NHS.[81]

138.2. Most people who shielded did so when they judged it best, not when officially advised to.[82]

138.3. Among respondents who shielded, 30% had done so continuously from March 2020 onwards.[83]

139. We concluded in our report that '*the impact of shielding, and the numbers of people who will find it hard to return to participating fully in society, may therefore be widely underestimated*'.[84]

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[80] **Exhibit 008/ INQ000273425**, page 3, paragraph 8.
[81] **Exhibit 008/ INQ000273425**, page 3, paragraph 8.
[82] **Exhibit 008/ INQ000273425**, page 3, paragraph 8.
[83] **Exhibit 008/ INQ000273425**, page 3, paragraph 8.
[84] **Exhibit 008/ INQ000273425**, page 3, paragraph 8.

140. In our initial survey on the early pandemic patient experience, we had found out that more than a third (38%) of those that were deemed 'clinically extremely vulnerable' or in the shielding group were unhappy with the process of finding out they were in these groups, and/or the support they received.[85] Some felt that it had taken too long to find out and that mistakes had been made (either because they were asked to shield or because they expected to be asked to shield but were not).[86] Government food parcels were helpful in some instances, but others struggled to make use of them (e.g. because of dietary requirements), or faced severe delays (e.g. because they struggled to access delivery slots).[87] Many disabled, chronically ill, or older people felt left behind as a result.[88]

141. Some reported receiving information regarding the need to 'shield' very quickly. For example, one respondent said: *'Within the first week I had a letter from my consultant telling me to self-isolate. This letter allowed my husband to work from home'*.[89] Others complained of belated notification and lack of clarity on what support was available: '*Government letter didn't arrive for eight weeks and so I didn't know what help was available or who to contact'*.[90] Another respondent said: '*My consultant said I would receive a letter at the start of lockdown. Nothing came. I filled in the government online form to apply – three weeks later the response was to contact my GP. I did this and two weeks later I received the letter'*.[91] For some the notification came too late – one respondent told us: '*I am a nurse and by the time I had received my letter, I had already nursed COVID patients'*[92] and another said '*It took seven weeks before I received any letter or any help and by then I'd had the virus'*.[93] Some respondents said they received confusing 'mixed messages' with government letters saying they were in a shielding group whilst their GP was saying they were not.

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[85] **Exhibit 007/ INQ000273424**, page 3, paragraph 5.
[86] **Exhibit 007/ INQ000273424**, page 3, paragraph 5.
[87] **Exhibit 007/ INQ000273424**, page 3, paragraph 5.
[88] **Exhibit 007/ INQ000273424**, page 3, paragraph 5.
[89] **Exhibit 007/ INQ000273424**, page 13, paragraph 8.
[90] **Exhibit 007/ INQ000273424**, page 14, paragraph 2.
[91] **Exhibit 007/ INQ000273424**, page 14, paragraph 11.
[92] **Exhibit 007/ INQ000273424**, page 15, paragraph 5.
[93] **Exhibit 007/ INQ000273424**, page 15, paragraph 7.

142. Our respondents also highlighted a failure to have regard to those with 'invisible disabilities' such as those with mental health difficulties who were not included and may have found it difficult to 'fend for themselves' in a crisis situation.[94] Concerns were also raised about failures to adjust communications to the needs of those with disabilities (despite specifically targeting them). One profoundly deaf woman we support received no information in her first language – British Sign Language ("BSL"). All information was sent in written format she struggled to understand.[95] No information was produced in BSL and it was left to charities to fill the void.

John's Campaign (JC)

143. Like PA, we heard from individuals who called and emailed or contacted us via social media of issues around blanket approaches re 'shielding' which wrongly included or excluded some. People were not assessed on an individual basis and categorisation often appeared to occur on the basis of the setting the individual was living in, rather than their health needs. In our experience, this meant that a significant number of people in supported living, rehabilitation or with mental health issues (living in institutionalized settings) who we were in contact with or whose loved ones contacted us were wrongly required to shield. Conversely, many who were cared for at home were excluded, despite their individual needs indicating that shielding would be appropriate.

Submissions made to Government bodies raising concerns

144. We have already set out above at §§22-39 the key work we carried out during the pandemic and how this was brought to the attention of Government bodies. We have set out below further examples of submissions made directly to Government bodies raising our concerns.

Patients Association

145. As set out above, we sent copies of all of our reports to DHSC and NHS officials as they were published. In addition to this, we wrote repeatedly to various

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[94] **Exhibit 007/ INQ000273424**, page 19, paragraph 10.
[95] **Exhibit 007/ INQ000273424**, page 15, paragraph 2.

officials such as the Secretary of State for Health and Social Care (SSHSC) to highlight key concerns. Our correspondence with the SSHSC is discussed in depth at §149 and §150 and Exhibited to this statement as **Exhibits 060-061/ INQ000273477 - INQ000273478**. We also raised our concerns via briefing groups and through submission of papers.

146. PA was part of the voluntary sector COVID-19 briefing group with the DHSC, which meant that we could raise concerns from patients directly with the briefing group. The COVID-19 briefing group met (and continues to meet) regularly (approximately once per month, and more frequently at the start of the pandemic). We fed back concerns raised in the surveys we conducted. For example, we raised concerns around shielding and those who felt they had been inappropriately included or excluded from the list.

147. We also fed into the Elective Care Recovery and Communications Group run by NHS England. We worked with the group on how to prioritise and validate the elective list i.e. those on the list for elective procedures. This meant identifying those in most need of support and checking that those on the list were still appropriately included (e.g. the list still contained names of individuals who had died). We also provided guidance and assistance on how to communicate with patients. Our recommendations were incorporated into NHS England guidance entitled, 'Good communications with patients waiting for care', which I exhibit to this statement as **Exhibit 062/ INQ000273479**.

148. In September 2020, PA submitted a paper to the Treasury ahead of the Comprehensive Spending Review (see **Exhibit 063/ INQ000273480**) to make clear that major investment would be needed both to cope with the aftermath of COVID-19 on multiple fronts, and to tackle the structural problems that were already apparent before it. We explained that new funding would be needed to: 'cover added costs from COVID-19 itself; pay for clearing the backlog of planned treatment and restoring normal services; bring baseline NHS funding, excluding COVID costs, back in line with historical trend growth; pay for service transformation under the Long Term Plan, fund the Government's stated plans for

hospital building; reverse cuts in health budgets and top up social care budgets as a stop-gap while the new settlement was devised and implemented. The analysis continued to apply the following year and the paper was therefore re-submitted in 2021 without amendment with the request to the Chancellor to consider the paper when making fiscal decisions. Apart from a claim of £3 billion 'extra' to help with COVID-19 recovery in healthcare, the March 2021 budget did not do any of the things we had requested. It remains our view that the lack of vision for the health and wellbeing of the nation after COVID-19 is astonishing.

149. On 28 June 2021, we wrote to Sajid Javid, then newly appointed as Secretary of State for Health and Social Care ('**SSHSC**') (**Exhibit 060/ INQ000273477**). We wrote to welcome him to his new role and to raise our concerns about the ever-increasing issues facing the NHS, existing issues made more extreme as a result of the pandemic. We invited him '*to consider the absence of a role for patients in the current proposals*'. We stressed that although the new legislation to put ICS's onto a legal footing that had been proposed would '*undoubtedly help the system work in a smoother and more integrated way*', they would '*do nothing to remedy the NHS's culture of not listening to or valuing what patients*'. We explained that services '*often meet patients' needs partially and clumsily, and a failure to listen to patients is a constant feature of NHS safety scandals*'. *The 'most pressing request'* highlighted in the letter was therefore for the SSHSC to mandate '*re-examination of the question of patient involvement and ensure a meaningful role for patients in the NHS*'. To date no response has been received.

150. On 12 November 2021, we wrote again to the SSHSC (**Exhibit 061/ INQ000273478**). The letter detailed the fact that we believed the government should (under the Civil Contingencies Act) bring in armed forces to assist frontline NHS staff because the NHS frontline was in an acute crisis. NHS Scotland had, at that time, already called in miliary personnel to support it. We explained that this was required because the government should not, and organisations such as PA could not, stand by while people are dying. I exhibit the coverage by *The Independent* of our calls for military support to this statement as **Exhibit 064/ INQ000273481**. To date no response has been received from the SSHSC.

Care Rights UK

151. We have already set out at §§26-30 some of the steps we took to not only support individuals but raise our concerns publicly during the pandemic. In addition to the work outlined above, we submitted written evidence to a number of parliamentary committees, including:

151.1. the Joint Committee on Human Rights inquiry on human rights implications of the Government's response to COVID-19 in July 2020, where we highlighted how the pandemic response had restricted rights, including to life, dignity, wellbeing and family life. Recommended actions included additional NHS support for care users. I exhibit the written evidence we submitted to the Committee in full as **Exhibit 020/ INQ000273437**.

151.2. the APPG on Coronavirus on the Government's response to pandemic in August 2020, where we outlined issues in PPE supply and highlighted a lack of any reliable system of central government oversight or safeguarding of older people using care services. I exhibit the written evidence we submitted to the APPG in full as **Exhibit 021 INQ000231911**

151.3. the November 2021 Joint Committee on Human Rights inquiry on human rights in care settings, where we outlined the systemic infringements on the rights of older people needing care during the pandemic, including access to health practitioners not being facilitated and decisions regarding care and treatment being made without their or their chosen representative's consent. Our recommendations included the need for a robust regulator which is able to monitor compliance with Covid-19 visiting guidance. I exhibit the written evidence we submitted to the Committee in full as **Exhibit 022/ INQ000273439**.

152. We also gave oral evidence to parliamentary committees, including the:

152.1. APPG on Coronavirus in August 2020, where we discussed the government's apparent lack of understanding of the shape and structure of the care sector in their Covid-19 response and highlighted the severe mental health impacts of care home visiting restrictions on residents and their families. I exhibit a full transcript of the August APPG as **Exhibit 023/ INQ000273440**.

152.2. APPG on Coronavirus in October 2020, where we explained the impact that lack of access to Covid-19 tests was having on care home staff, residents, and their families. I exhibit a full transcript of the October APPG as **Exhibit 024/ INQ000273441**.

152.3. Joint Committee on Human Rights for their inquiry on visiting in care settings in January 2021, where we reported common concerns that our helpline users had raised about pandemic restrictions, including the severe impact on mental and physical health of visiting restrictions. We recommended greater training for staff and a human rights-informed approach to decisions about visiting, based on individualised risk assessments. I exhibit a transcript of the oral evidence given to the Joint Committee on Human Rights as **Exhibit 025/ INQ000273442**.

152.4. Joint Committee on Human Rights for their inquiry on human rights in care settings during the pandemic and beyond in January 2022, where we discussed how longstanding issues in the care sector including neglect and a disregard of a person's autonomy had been exacerbated by restrictions implemented in care homes in response to the pandemic. I exhibit a transcript of the oral evidence given to the Joint Committee on Human Rights as **Exhibit 026/ INQ000273443.**

153. We published a joint statement on reuniting residents of care homes with their relatives and friends with Age UK, the National Care Forum, the Registered Nursing Homes Association, Rights for Residents (prior to our merger) and JC in February 2021 which I exhibit to this statement as **Exhibit 065/ INQ000273482**. Some of our other publications included:

153.1. Visiting and the Law, a guide for care providers to ensure their use of Government guidance was compliant with their legal duties, first published in June 2021 (see **Exhibit 066/ INQ000231908** and updated throughout the pandemic;

153.2. A call for a new right to maintain contact in health and care with JC and Rights for Residents (prior to our merger) in April 2022 (see **Exhibit 067/ INQ000273484**); and

153.3. Extensive summaries and explanations of Government guidance, supporting families to understand and use legal rights to challenge restrictions, throughout pandemic (see for example, **Exhibit 014/ INQ000273431**).

154. We also repeatedly engaged in correspondence with key organisations and Government agencies. For example, we engaged in correspondence with the CQC in May 2020, May 2021, May 2022 and August 2022 expressing disappointment with their role during the pandemic and calling for them to take a proactive role in ending the harm caused by COVID-19 restrictions (see for example **Exhibits 028-30/ INQ000231915 - INQ000231917**. We included an appendix of evidence from our helpline about the harm caused, which we exhibit to this statement as **Exhibit 029/ INQ000231916**

155. In July 2021 we wrote to the Prime Minister urging the opening of the public inquiry (**Exhibit 068/ INQ000273485**). We also wrote a letter in October 2021 to the Prime Minister and the Department for Health and Social Care, summarising our concerns around the disparate treatment of care home residents compared to the general population, and highlighting the devastating impact of continuing isolation and separation on care home residents and their families (**Exhibit 069/ INQ000273486**).

156. In January and September 2022, we wrote Joint letters (in collaboration with leading care organisations) to local health and care leaders on the harm

caused by COVID-19 restrictions and calling for an end to isolation and for legal duties to be met (see **Exhibits 070-071/ I INQ000231921 - INQ000231922**. We enclosed an Essential Care Giver Factsheet and poster with our January 2022 letter (see **Exhibit 072/ INQ000273489**) and recommended that health and care leaders referred to these resources as part of their outbreak management plan. In February 2022 we met with the Care Minister to discuss the harm of ongoing restrictions. In March 2022 we tabled Parliamentary Questions about evidence of harm of isolation in care (see for example **Exhibit 027/ INQ000273444**) and organised an event in Parliament with JC and Rights for Residents (prior to our merger) calling for an end to the harm of COVID-19 restrictions and a new legal right to maintain contact with at least one essential carer supporter across health and care settings. We also supported a joint letter to the SSHSC from over 60 MPs calling for a new legal right to maintain contact across health and care settings in May 2022. I exhibit the letter and accompanying press release to this statement as **Exhibit 073/ INQ000273490**.

157. As set out above, we also provided supporting evidence in legal challenges brought by JC in October 2020 and June 2021 (see for example, **Exhibit 031/ INQ000176369**.

158. In addition, we also engaged in a range of lobbying efforts. We met regularly with the CQC to raise concerns about their inaction during the pandemic, including in quarterly one-to-one meetings and in quarterly meetings of sector leaders. We highlighted concerns raised via our helpline, including the severe harm to mental and physical health being caused by visiting restrictions in health and care settings, standards of care dropping and safeguarding risks of lack of access for family carers.

159. As mentioned above, we also were part of the DHSC's Working Group from July 2021. This meant attending regular meetings with DHSC civil servants and other agencies (such as PHE/UKHSA), being consulted on policy changes and updates to the guidance. We played an active and significant role during these meetings, including by:

159.1. Submitting evidence from our helpline about the impact of Government guidance on visiting in August 2021 and February 2022;

159.2. Participating in one-to-one meetings with DHSC civil servants on the guidance and its impact in July 2021, September 2021 and November 2021;

159.3. Making suggested amendments to guidance on visiting which resulted in improvements to the guidance in November 2021, March 2022 and July 2022;

159.4. Drafting and submitting to DHSC a suggested rewrite of the visiting guidance in February 2022. This was supported by Care England, National Care Forum, National Care Association, Association for Real Change and the Alzheimer's Society, but it was not taken up by DHSC.

159.5. Requesting information sharing re clinical evidence of the impact of COVID restrictions, in two meetings in February 2022, a meeting in March 2022 and twice by email (the requested information was not shared).

John's Campaign (JC)

160. As set out in further detail above and below (see for example §161 and §§164-165, **Exhibit 065/ INQ000273482** and **Exhibits 074-076/ INQ000273491 - INQ000273493**), from March 2020 we warned as consistently and publicly as we could about the real dangers of imposed separation particularly for people with dementia or other cognitive impairment.. Because of our extreme structural limitations (two volunteers and a website manager) events led us to focus most of our campaigning attention on care home residents in England (and to a lesser extent Wales) though we did not lose touch with the healthcare/hospital sector in England and did our best to respond to pleas for help wherever we received them.

161. We joined with other leading dementia organisations and charities to form a coalition called One Dementia Voice[96] seeking to speak with one voice on

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[96] The coalition consists of the following organisations: Innovations in Dementia, Dementia UK, TIDE (Together in Dementia Everyday), Young Dementia UK, Alzheimer's Society and Alzheimer's Research UK.

behalf of those adversely affected and campaigning for care settings to be opened up. In July 2020, One Dementia Voice sent a letter to the SSHSC calling on him to act urgently and describing what was happening in care homes due to visiting restrictions as a "hidden catastrophe" (see Exhibit **076A/ INQ000273415**). In particular, we sought the designation of family and friend carers as "Key Workers" so that they could be subject to the same testing regime as care home staff and could resume their roles fulfilling the essential care needs of residents. To date we have not received a response to that letter.

162. The consistent refusal of the DHSC, in particular, to engage in any form of dialogue or appear to consider the impact of their actions on the most vulnerable people eventually persuaded us to crowdfund and take legal action against Government guidance on visiting in and out of English care homes (see **Exhibit 077/ INQ000273494**).[97] I set out below at §167 a detailed chronology of the legal action we took.

163. We used our personal links with providers and charities to share our concerns and offer consensus approaches whenever possible. JC has an informal network of NHS Ambassadors and also a Care Home Providers group who had worked together to co-produce a booklet on family carer involvement in February 2020 – which included work on balancing infection prevention and the maintenance of individual wellbeing. Quite often we were able to speak for both NHS and social care providers who were not able to voice their concerns publicly.

164. We also undertook some surveys and worked together with other concerned organisations, including One Dementia Voice, Five Nations Care home forum and increasingly closely with the Relatives and Residents association and with Rights for Residents (as set out above by Care Rights UK) to publicise our concerns. For instance, we published a the joint statement on 9 February 2021 in collaboration with Rights for Residents, Relatives and Residents Association, Age UK, the Registered National Care Forum and the National Care forum, appealing for government to allow essential caregivers visiting rights in care homes (see **Exhibit 065/ INQ000273482**). As the pandemic progressed we increasingly found

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[97] Our crowdfunder raised a total of £72,787

ourselves advocating for groups such as young learning disabled people and those with multiple profound disabilities, not necessarily cognitive.

165. We contributed constantly to articles and reports in national newspapers, on TV and radio both in our own persons and also by putting programme makers in touch with people directly impacted by official guidance. I exhibit examples of media coverage of John's Campaign's work during the pandemic to this statement as Exhibits **074-076/ INQ000273491 - INQ000273493**. We felt consistently disappointed and angry at the refusal of the DHSC to engage in any dialogue with us directly but have always responded to requests from organisations such as the Joint Committee for Human Rights and (occasionally) the CQC.

166. As set out above, we consistently offered case studies as evidence (including as part of our judicial review challenges) and have worked closely with other relevant organisations and also with experts. Our website has continually featured the eloquent testimony of the individuals who have suffered and we have done our best to share this with those who have the power to make change.

167. We eventually approached lawyers to see whether there was any way of bringing a legal challenge to the Government's guidance on visiting arrangements. We instructed Leigh Day following which we waged a long running legal battle seeking to challenge and improve the various iterations of the guidance published by the DHSC. I have set out the chronology in detail below because it is of clear relevance to this module in the Inquiry and it is illustrative of the failure of the Government during the pandemic to listen to the voices of those affected even when repeatedly confronted with reports of their suffering:

167.1. On 9 September 2020 we entered into pre action correspondence with the DHSC challenging the legality of the guidance on visits into care homes.

167.2. We received a pre-action response in respect of the guidance on visits into care homes on 30 September 2020. It did not engage with our concerns. The Government maintained that the Guidance and Winter Plan were lawful, even while agreeing with us about the relevant legal obligations for individualized risk assessments which the Guidance did not reflect. We then received further correspondence telling us that the Guidance was under review and would be updated shortly and asking us to await this guidance before moving forward with any legal challenge. We did so.

167.3. We reviewed the amended Guidance published on 15 October 2020 with great anticipation, but were disappointed to discover that, although there were some positive developments, our key concerns remained. The Guidance was still badly drafted and confusing but, worse than that, the positive amendments - to require providers to take into account their Human Rights Act and Equality Act duties, and to conduct individualised risk assessments when determining visiting policies - only applied in 'medium risk' areas. Care providers in 'high' and 'very high' risk areas (which then covered over half of England's population) were told just as they had been in Spring that '*visiting should be limited to exceptional circumstances only such as end of life*'. I exhibit the Guidance published on 15 October 2020 to this statement as **Exhibit 051/ INQ000273468**.

167.4. On 27 October 2020 we filed an urgent application for permission to proceed with a judicial review of the October iteration of the guidance on visits into care homes. On 28 October Mr Justice Swift considered and granted our application for expedition.

167.5. On 5 November 2020, the Secretary of State amended his guidance to address the concerns we had raised in our claim and, as a result, we were able to withdraw our proceedings by consent on 24 November 2020.

167.6. As set out above, we also wrote to the SSHSC repeatedly raising our concerns about the guidance on 'visits out' of care homes, including for care home residents to attend medical appointments. We sent a pre-action letter to the SSHSC on 4 December 2020 setting out our concerns regarding the guidance and, in particular, why we considered the imposition of the blanket ban on visits for those over working age to be unlawful. We also requested clarification of the requirement to isolate for 14 days on return from a visit out noting its imposition on a vulnerable group on whom the impact of isolation is particularly severe and the increased availability of testing to enable infection control.

167.7. We received a response to our pre-action letter on 11 December 2020. In his response, the Secretary of State asserted that, in issuing the guidance, he was seeking '*to strike a balance between the increased risk of infection to residents…and the risk that not having visits poses to their mental and physical health and wellbeing*.' However, he maintained the position that the approach taken in respect of individuals who were not of working age and in respect of isolation on return from any visit was supported by expert advice (though he did not disclose any evidence of this) and lawful.

167.8. We wrote to the Secretary of State again on 17 December 2020 specifically in relation to the requirement to isolate. In that letter:

167.8.1. We reiterated our concerns about the imposition of the requirement on a vulnerable group, highlighting the fact that the impact of isolation on this group had been proven to be particularly severe.

167.8.2. We invited the Secretary of State to disclose whatever medical evidence he was relying on in justifying the requirement.

167.8.3. We drew the Secretary of State's attention specifically to the fact that imposing the 14-day isolation requirement after medical appointments was having the effect of causing individuals to refuse to attend appointments thereby causing a risk to health and requested clarification if the requirement applied regardless of the type of visit.

167.8.4. We noted that the punitive approach taken in relation to residents stood in stark contrast with the position that care home staff members who showed symptoms or tested positive for COVID-19, or had been in close contact with someone who tested positive, are able to return to work after 10 and not 14 days of self-isolation.

167.8.5. We noted that the requirement effectively undermined the guidance on visits out in that many would not be able to face the consequences of isolation (even in exceptional consequences) and that it was unjustifiable in circumstances where less restrictive infection control measures were available.

167.8.6. The SSHSC responded substantively on 6 January 2021, after the announcement of a new national lockdown on 4 January 2021. At the outset of his response, the SSHSC stated that the guidance on both visits in and out of care homes was under urgent review as a result of the new lockdown. The remainder of the letter again referred to the "*medical advice and reasoning*" behind the 14-day isolation period as justification for the approach. Again, the evidence on which the SSHSC's assertions were based were not disclosed to us.

167.8.7. In respect of isolation after medical appointments, the SSHC stated that "*medical appointments in a clinical setting outside the home do not fall within the visits out guidance, which is directed at visits to a setting in the community such as a family home*" and directed us to the Guidance entitled 'Admission and Care of Residents in a Care Home during COVID-19', which I exhibit to this statement as **Exhibit 078/ INQ000273495**. Notably, that guidance only expressly provided for 14 days isolation in relation to discharge from hospital or other clinical settings, but was not clear on isolation requirements after other external medical appointments. It merely noted that, where possible, medical appointments should be arranged within the care home.

167.9. The SSHSC then issued new guidance in respect of visits out on 12 January 2020, which I exhibit to this statement as **Exhibit 079/ INQ000273496**. The 12 January Guidance stated that, for the duration of the national lockdown, care home residents were required to follow national restrictions and that '*all movements should be minimised as far as possible and limited to exceptional circumstances only*'. The reference to visits out only being considered in respect of individuals of working age had been removed, such that visits out were no longer contemplated for <u>any</u> group of residents. Throughout the period of national restrictions, residents remained confined in their care homes.

167.10. In late February 2021 the "roadmap out of lockdown" for the general population in England was announced. Guidance was published on 8 March 2021 in respect of visits out of care homes (see **Exhibit 042/ INQ000273459**). In line with the December iteration of the guidance, the guidance published on 8 March 2021:

167.10.1. stated that visits out should only be considered for care home residents of working age and only in exceptional circumstances (interpreted as end of life) for older residents.

167.10.2. imposed a requirement to isolate for 14 days upon return from any visits out, regardless of the type of visit (including, therefore, if a resident went on a walk with a member of care home staff in a neighboring park, or if a resident attended an outpatient doctor's or dental appointment).

167.11. We sent another pre-action letter to the SSHSC on 30 March 2021. Again, we set out in detail the reasons we considered the guidance that visits out of care homes be unlawful and why it was paramount for the guidance to make clear that individualised risk assessments in respect of visits out were always required, regardless of age.

167.12. Once again, we asked the SSHC to amend the requirement in the Guidance on visits out that any resident who takes a visit out of a care home must isolate on return for 14 days. We pointed out that the continued application of the requirement was at odds with broader developments, including widespread vaccination and availability of testing.

167.13. The SSHSC responded on 13 April 2021 after having published revised guidance on 7 April 2021 that applied from 12 April 2021 (which I exhibit as **Exhibit 080/ INQ000273497**). The guidance that visits out should only be considered for those of working age had been dropped but unfortunately the requirement to isolate for 14 days remained. In his response, the SSHSC referred to his letters of 11 December 2020 and 6 January 2021 and the reasons given in those letters for the imposition of the isolation requirement. He stated that although the isolation period had been kept under review since January 2021, the position remained that it would be required and that this was in line with advice from Public Health England. For the third time, no evidence of any scientific advice relied on was disclosed.

167.14. We wrote to the SSHSC again on 14 April 2021 setting out the reasons we considered the isolation requirement to be unlawful and enquiring about the legal basis of the rule, which remained unclear to us.

167.15. In his response on 23 April 2021 the SSHSC clarified that there was no legal basis for the isolation requirement. He stated that the Guidance "*is non-statutory*" and as such "*it does not impose a legal requirement that residents isolate following a visit out*". The SSHSC's response further stated that the Guidance did not "*displace care home providers' existing legal obligations towards residents in their care, such as under the Care Act 2014, the Equality Act 2020, the Human Rights Act 1998 and the Mental Capacity Act 2005*". He also made clear that he did not agree that the Guidance was unlawful or propose to amend the current Guidance but made reference to ongoing review of the guidance and that "*any change to Guidance is likely to be published as part of the move to step 3 of the roadmap which is due to take place <u>no earlier than</u> 17 May 2021*" (emphasis added).

167.16. In light of the SSHSC's indication that he was not prepared to amend the guidance applicable from 12 April 2021 in line with the requests in our pre-action letter of 14 April, we instructed our legal team to prepare to issue proceedings.

167.17. On 30 April we were advised that the guidance was once again under review and that a further announcement was to be made shortly. We welcomed the long-overdue changes subsequently made to the guidance to allow <u>some</u> visits out of care homes, including for walks in the park, to meet with family outdoors and to attend medical appointments without the need for isolation for 14 days on return as a step in the right direction. However, the updated Guidance published on 1 May 2021 entitled "Visits out of care homes: supplementary guidance" (see **Exhibit 081/ INQ000273498**) still contained blanket isolation requirements in respect of certain types of visits out (including overnight stays in hospital). We wrote to the Secretary of State again on 4 May 2021 making clear that we maintained that the isolation requirement was unlawful on the basis of the arguments set out in our pre-action letter of 14 April. We invited the SSHSC to lift the blanket forced isolation requirement in respect of all visits out.

167.18. On 10 May 2021, the Secretary of State published a press release announcing further changes to the guidance on visits out of care homes due to apply from 17 May. I exhibit that press release to this statement as **Exhibit 082/ INQ000273499**.

167.19. On 17 May 2021, we received notification that the guidance on visiting arrangements in care homes and arrangements for visiting out of care homes had been updated. Unfortunately, we and those affected were again let down because the new guidance failed to lift the isolation requirement for **all** visits out and, in particular, maintained the isolation requirement in respect of **all** overnight visits, which may form an important part of a resident's care plan and which for some residents may be the only kind of visit consistent with their disability-related needs.

167.20. In a final effort to effect much needed change and avoid legal action, we therefore instructed our solicitors to write to the SSHSC again on 19 May requesting that the Secretary of State:

167.20.1. remove the blanket 14 day forced isolation requirement in respect of overnight visits out and admission into care homes;

167.20.2. make clear in further amended guidance that individualised risk assessment should inform all decisions on visits out and admission, and whether isolation (including the length of any isolation) is necessary and appropriate on return admission;

167.20.3. In line with his duty of candour, disclose any clinical advice or scientific data relied upon in maintaining the blanket requirement to compulsorily isolate for 14 days (both at all and rather than a reduced length of time).

167.21. We received a disappointing and dismissive response on 28 May 2021 in which the SSHSC maintained that the approach taken in his guidance on visits out and admissions into care homes was based on "*expert advice*" and "*advice from PHE*". Once again, the SSHC paid lip service to the need to "*balance the need to protect residents from infection whilst protecting their health and wellbeing in other respects*" whilst imposing a 14-day isolation requirement which effectively displaces individualised risk assessments in respect of visits overnight, hospital stays and admissions into care homes. After justifying his stance as being based on expert advice and scientific evidence since December 2020 and despite multiple requests for disclosure of this evidence, the SSHC for the <u>fifth</u> time refused to disclose any of the evidence purportedly relied upon.

167.22. In his response, the SSHC also stated that he "*did not accept [our] characterisation of the Visits Out Guidance as imposing a "blanket" requirement with respect to isolation following a visit out. The Visits Out Guidance remains just that: guidance. It is headed and described as such. Ultimately, it remains for providers to determine how best to protect and comply with their statutory and common law duties towards the residents in their care.*" But that simply did not accord with the evidence of how care providers understood and applied the guidance.

167.23. The guidance was again updated shortly after judicial review proceedings were issued, but the SSHSC's approach to the guidance and to our proposed litigation was indicative of (i) repeated misunderstandings and lack of clarity in the way in which the Government communicated with the health and care sector, and expressed their legal obligations, over the course of the pandemic, with seriously detrimental effects on residents and (ii) the Government's uncooperative and obstructive engagement with stakeholders and those with insight and expertise to offer to improve system functions.

Key lessons to be learned

168. A key concern for all members of our Core Participant group throughout the pandemic and now is the need to focus on the individual in need of (health)care when providing such (health)care. Providing adequate (health)care is simply not possible without proper engagement with an individuals' specific needs. In our view, it is the disconnect between the individual and the health and care system that has been the root cause of many of the problems we have explained above. Although we have each set out our key recommendations below, it will be noted that there is overlap between these with the need to focus on individual needs at the heart of the lessons we say need to be learned.

The Patients Association

169. The NHS must ensure that patients receive the comprehensive service they are entitled to, even in times of crisis. Specific recommendations put forward by PA include:

169.1. The NHS must recognise the extent of patient difficulties in accessing care, long waits for care and treatment, delays and cancellations, and the impact these have on patients. The NHS must develop a thorough understanding of these difficulties, through a concerted effort to find out patients' concerns.

169.2. The NHS needs to reconnect with patients as we come out of the pandemic. This means working in partnership with the patients to rebuild their relationship with the NHS and, together, redesign services, which will improve outcomes for care and treatment.

169.3. The finding in our survey that a quarter of patients didn't feel respected or listened to by healthcare professionals is unacceptable. This must change.

We believe shared decision making is a way to bring about this change and promote partnership with patients. Health leaders must remove the barriers in the health system that stand in the way of health professionals and patients working in partnership. This should include leaders championing a culture change that fosters patient partnership and shared decision making, as well as leading by example.

169.4. Given the significant increase in the length of time patients were and are now having to wait for treatment it is vital that the NHS puts in place arrangements to communicate with patients about their wait, and where they can get support while they wait. All NHS organisations should be using communications guidelines on how to keep patients up to date with what is happening with their care.

169.5. The highly variable performance of NHS 111 is a significant concern. If the NHS expects people to use NHS 111, then it must look into this variation rigorously and take firm steps to remedy the problems. This may mean investing in the infrastructure of NHS 111 or its workforce, so that the service can meet the current demand and offer a high quality service.

170. We expect a lot from the NHS but it cannot recover and prepare for any future crises without support from the Government. We echo the House of Commons Health and Social Care Committee calls for the government and NHS England to 'produce a broader national health and care recovery plan that goes beyond the elective backlog to emergency care, mental health, primary care, community care and social care'. However, a recovery plan will do nothing without sufficient staff to deliver the increased activity needed to bring down the waiting lists and improve access to primary care. To this end, we also support the Committee's call that an annual independently-audited report on workforce projections in the NHS and social care that covers the next five, ten and twenty years, is published every year.

171. The road ahead will be a long one. We should aim to return to a position where waiting lists are not counted in the millions and patients can access the

care they need before their health has deteriorated so much that their chance of recovery, or a good outcome, are reduced. We must also plan for any future crises with a view to preventing a situation such as the one we are now in. We recognise that this is challenging. Nevertheless, this is something to strive for although we must all recognise the extent of the task ahead and work in partnership if there is to be any prospect of success. In order to facilitate this, there must be significant and sustained long term investment in the NHS.

172. As stated above, the pandemic shone a light on the significant health inequalities that characterise the health system. There should be a full and thorough investigation into these health inequalities; a public inquiry in its own right.

Care Rights UK

173. As above, one of our key concerns is to highlight the need to focus on people, not institutions. Policies should focus on the people most at risk and in need, not on protecting institutions. Government policies to 'protect the NHS' put the lives of older people needing care, and those caring for them, at far greater risk, particularly the discharge of patients from hospital without testing. Responses to any crisis must identify and focus on the people most at risk and what support they need.

174. This would have helped to avoid people needing care being an afterthought and care staff not receiving the support they needed to protect people most at risk from the virus. The Government response to COVID-19 demonstrates a lack of understanding about the legal responsibilities on the Government and its agencies (including PHE/UKHSA and CQC) to protect not just wellbeing from the virus but to ensure that measures imposed to manage the virus do not breach other fundamental rights, including to (wider) wellbeing, such as access to healthcare. Policies must recognise that people needing care have the same legal rights as everyone else and they should not be discriminated against or left behind during a crisis or the recovery from it.

175. Lives must not be devalued in times of crisis (or otherwise). The response to the pandemic has at times been discriminatory and devalued the lives of older

and disabled people. This includes the Government's initial failure to include known mortality figures of care users in the daily count, inappropriate use of DNACPR decisions, inaccurate death certification, and decisions about access to healthcare raising fears that the process of prioritising health services was being based on non-clinical factors such as age or disability. Leadership from Government is needed to ensure all lives are valued, and health and care services are adequately supported and financed to protect the rights of all people.

176. Systems must be in place to safeguard rights and ensure the voices of people using services are heard, this includes by ensuring oversight of services being delivered (for example, by ensuring the CQC and other regulators seek and maintain access to exercise their role even in times of crisis). A robust regulator is needed to safeguard rights and act as a voice for people relying on services. As explained above, our letter exchange with the Care Quality Commission outlined how they had let down older people needing care during the pandemic. There must be better, more robust and accountable oversight of health and care services, with more frequent inspections by the CQC. This is crucial to ensuring adequate standards of (health)care are met in care settings.

177. The vital role relatives and friends play must be recognised and respected – not only in terms of love, companionship and emotional support but also the many other roles they might provide for a person relying on services, including carer, advocate, voice, confidant, advisor, mediator, protector of rights. The right to family life must be respected, protected and fulfilled by all those with duties under the Human Right Act in all settings. This must include a recognition of the importance of maintaining contact with relatives and friends for the emotional, mental and physical health, and quality of life, of people relying on services. This must also include promoting cultures where relatives and friends are seen as partners in care, not a 'problem' or 'barrier' for services. The role of Essential Care Supporter has been vital for protecting (health) care user's rights to wellbeing and family life – it must be enshrined in law.

178. Health and care practitioners, Commissioners and inspectors need accessible, practical tools to help them understand their human rights duties and

how to meet them. Such tools would help to ensure human rights and other laws are not overlooked in favour of non-statutory, advisory guidance. Health and care staff must undergo mandatory training on the Human Rights Act and other laws protecting rights – not just on understanding the rights and their legal duties to avoid breaches, but also on how to use those laws in practice to improve services and ensure individual needs are met.

John's Campaign (JC)

179. We echo the key lessons to be learned outlined by Care Rights UK, including in particular the recognition of the importance of essential care givers who must be treated as key workers and not visitors in any health and care settings in recognition of the crucial role they play in (health)care. We also echo Care Rights UK's calls for ensuring fundamental rights and laws are respected, especially in times of crisis.

180. We were particularly shocked by the disregard of equality laws and it is crucial that these inform all decision-making, including in times of crisis. Laws such as the Equality Act, the Care Act, the Mental Capacity Act and Human Rights legislation are there for a good purpose and public authorities should be obliged to consider and respect them at all times. We were shocked by Equality Impact Assessments (EIAs) we received alongside responses to pre-action correspondence sent to the SSHSC that showed clearly the disproportionate damage that would be inflicted by enforced separations but which were ignored. We are unable to provide copies of these EIAs disclosed in the course of legal proceedings at this time. .

181. Like Care Rights UK we were very concerned by the disregard of the needs of people with protected characteristics and those approaching the end of life. It is important to ensure protection and adequate quality of life for all and consent is and must remain a key aspect of provision of healthcare at any time. We believe that respect for individual dignity and responsibility should always be maintained and that infection control should not be allowed to override personal consent. Family responsibilities such as guidance and power of attorney should be respected, especially when decisions are being taken which affect both quality and quantity of life.

182. Attention should be paid to consulting with people who speak for those who will be most directly affected by interventions such as compulsory separation, distancing, mask-wearing, enforced isolation and confinement, deprivation of liberty and who cannot easily speak for themselves. It is not good enough only to consult provider organisations whose priorities are necessarily different in important respects.

Statement of Truth

I believe that the facts stated in this witness statement are true. I understand that proceedings may be brought against anyone who makes, or causes to be made, a false statement in a document verified by a statement of truth without an honest belief of its truth. In particular, I confirm this in respect of §§1-7, 40-46, 77, 81, 89, 11-114, 122, 132, 144 and 168, which are paragraphs relating to our Core Participant group as a whole. I also confirm this in relation to the following paragraphs which are specific to PA: §§8-11, 22.1, 23-25, 47-55.9, 76, 78-80, 90-94, 138-142, 145-150, 169-172.

On behalf of the Patients Association:
Rachel Power
Signed: **Personal Data**

Dated: 15/09/2023

Statement of Truth

I believe that the facts stated in this witness statement are true. I understand that proceedings may be brought against anyone who makes, or causes to be made, a false statement in a document verified by a statement of truth without an honest belief of its truth. In particular, I confirm this in respect of §§1-7, 40-46, 77, 81, 89, 11-114, 122, 132, 144 and 168, which are paragraphs relating to our Core Participant group as a whole. I also confirm this in relation to the following paragraphs which are specific to Care Rights

UK: §§12-15, 22.2, 26-30, 56-64.6, 82-85, 95-98, 106-107, 115-121, 123-126, 133-135, 151-159.5, 173-178.

On behalf of Care Rights UK:
Helen Wildbore

Signed: Personal Data

Dated: 15/09/2023

Statement of Truth

I believe that the facts stated in this witness statement are true. I understand that proceedings may be brought against anyone who makes, or causes to be made, a false statement in a document verified by a statement of truth without an honest belief of its truth. In particular, I confirm this in respect of §§1-7, 40-46, 77, 81, 89, 11-114, 122, 132, 144 and 168, which are paragraphs relating to our Core Participant group as a whole. I also confirm this in relation to the following paragraphs which are specific to JC: §§16-21, 22.3-22.4, 31-39, 65-75, 86-88, 99-105, 108-110, 127-131, 136-137, 143, 160-167.23, 179-182.

On behalf of John's Campaign:
Julia Jones

Signed: Personal Data

Dated: 20/09/2023