Witness Names: Julia Jones on behalf of John's Campaign,
Helen Wildbore on behalf of Care Rights UK, and
Rachel Power on behalf of the Patients Association
Statement No: 2
Exhibits: JC2/001 - JC2/142
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UK COVID-19 INQUIRY – MODULE 6

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

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 pursuant to Rule 9 of the Inquiry Rules 2006 to provide a composite statement (and relevant associated documentation) on behalf of John's Campaign ("**JC**"), Care Rights UK and the Patients Association ("**PA**"), which we refer to as 'the Core Participant group'. 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 in further detail below, our Core Participant group had concerns prior to the pandemic regarding the structure and capacity of the adult social care sector in the UK. Unfortunately, the pandemic demonstrated that we were right to be concerned and further aggravated the existing issues in the care sector. We also have ongoing concerns about restrictions and measures in care settings which continue to be applied to those we represent.

2. 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. Further, there are some areas where the Inquiry has asked us to comment

on matters specific to one member of our Core Participant group. Where sections 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, via email and telephone, to address questions based on the Inquiry's Rule 9 requests. Parts of this statement are also based on the Witness Statement we provided to Module 3 of the Covid-19 Inquiry but have been adapted to focus on the issues relevant to Module 6.

3. 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.

Background to our organisations, and the basis for the evidence in this statement

4. Our Core Participant group has significant expertise in and understanding of the adult social care sector in the UK,[1] including how this was impacted by the pandemic. From the beginning of 2020, our organisations have supported thousands of people who were impacted by Government decision-making in the Care Sector, including those needing care, their loved ones and their carers. As will be explained in the section headed "Our experience during the pandemic" below, the evidence within this statement about the impact of the Covid-19 pandemic on and the response to it, is primarily based on information coming directly from several thousands of such people, through advicelines, numerous surveys, phone calls, emails, and social media. A number of accounts from individuals affected are exhibited as examples of what people in care experienced. This statement is also based on contact with other organisations which represent people involved in the care sector, and on our expertise built up through a combined experience of several decades of work for, and campaigning on behalf of, people who need care.

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[1] We use the terms 'adult social care sector' and 'care sector' broadly, to cover both care given and received in formal care structures such as residential care homes, and also the various types of care given and received in other settings including in assisted living structures and the domestic home (including from unpaid family carers).

5. We played a direct role both prior to and during the pandemic in supporting individuals experiencing the key issues impacting people in care, their loved ones and carers, and in bringing about alterations to policies and practices which were having a negative impact on them (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 in care homes in England, resulting in amendments to those policies).

6. 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 both prior to and during the pandemic, and (3) the individuals we represent.

Care Rights UK

7. I, Helen Wildbore, am the Director of Care Rights UK (formerly the Relatives & Residents Association), a charity focused on promoting 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. For over 30 years we have offered information, advice, and support to empower people using care services, and their relatives and friends. As a community of families and experts, we fight for better lives for people in care. We challenge poor care, highlight good practice, and demand a better care system. We are a powerful voice for those needing care and their families.

8. Through its adviceline, Care Rights UK has been in direct contact with individuals at the sharp end of the pandemic. Throughout the pandemic our adviceline supported people relying on care services in a variety of care settings, predominantly the relatives and friends of older people living in care. This has given 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-19 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. We discuss our role in the Working Group in more detail at §70 of this statement.

9. I have been in my role as Director (first of R&RA and now of Care Rights UK) since October 2019. Our small team worked tirelessly throughout the pandemic to provide support, share the voices of people seldom heard and raise their issues and concerns.

John's Campaign

10. I, Julia Jones, am the co-founder of JC and am currently on the NHS England Advisory Board for Care Partner Policy which covers both social care and health settings. 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. A November 2014 article in The Observer newspaper in which Nicci explained the impact that isolation during hospitalisation had on her father (see **Exhibit JC2/001 [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, 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.

11. 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.

12. JC supports vulnerable people and their families where a person in need of support is being accommodated in any of the institutions of the UK health and social care system. JC 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'. We now campaign for a legal right to a personal care supporter for every individual rather than in respect of any particular health and social care institution.

13. The issue of vulnerable people in health and social care settings being separated from their loved ones who provide essential care and support was something JC had been raising awareness of prior to the pandemic. Unfortunately, the pandemic response significantly exacerbated these issues and further highlighted how little decision makers understood the importance of unpaid carers. Indeed, we believe that a failure to understand the importance of the practical, economic, and emotionally supportive

role played by unpaid carers negatively impacted decision-making with adverse impacts on care and access to care throughout the pandemic.

14. We exhibit as **Exhibit JC2/002 [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." JC seeks to highlight the crucial value of care provided by unpaid carers to individuals and the health and social care system. We also consider that it is essential that the obstacles unpaid carers and individuals relying on them face are not overlooked.

15. As well as its campaign to change attitudes, JC functions via a system of pledges which are made by hospitals and other institutions (including care homes) 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. 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 JC2/003 [INQ000273421].** Shortly afterwards, the adoption of JC principles (i.e. that no one should enforce disconnection between family carers and those need who their expert knowledge and love) became part of the 'Dementia Action Plan for Wales 2018-2022' (see **Exhibit JC2/004 [INQ000273422]).** All Scottish hospital boards except one made similar pledges, though not always under the JC name. Similarly, there were pledges from individual hospitals or mental health units in all the Northern Irish Health and Social Care Trusts, though these were more fragmented.

16. As time passed the need for adoption of JC principles was also recognised in other settings such as care homes 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] I exhibit specific examples of John's Campaign pledges made by care home providers as **Exhibits JC2/005 [INQ000499300] – JC2/006 [INQ000499301].** JC's website has also become a hub of good practice for health and care settings.

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17. Whilst not the initial focus and inspiration for JC, since 2017, we have devoted significant amounts of time to working with care homes to ensure care homes enable family involvement in care, and support key relationships, including through what are often the last years of a person's life. For instance, in November 2017, in partnership with Care England, we produced the booklet *"Honoured Guests, Welcoming, Involving and Supporting the Families and Friends of People who are Living in Residential Care"*, which I exhibit to this statement as **Exhibit JC2/007 [INQ000499302].** The booklet was designed primarily for managers and professional staff in care settings, to assist them in proactively involving and supporting the families and friends of people receiving residential care by sharing examples of good practice. In February 2020, we also produced a further booklet *"Implementing John's Campaign in Care Homes"* (**Exhibit JC2/008 [INQ000499303]**), supported by the Malnutrition Task Force, to demonstrate how John's Campaign could be implemented in care homes and highlight the necessity of involving loved ones in care. As explained in the booklet, family and friends often provide essential care which improves the quality of life of care home residents, such as providing support with eating and drinking, communication, advocacy, and other personal care (brushing hair and teeth, shaving, dressing etc.). Even when direct care is not being undertaken, visits from those who matter most are an integral part of an individual's sense of identity and self-worth. Before the pandemic we were actively working with care homes to make family access more appealing and constructive, including on purely personal and emotional grounds.

18. I had direct personal experience of being the primary carer for my mother with dementia at home, in sheltered housing, in local authority 'extra care' and in the dementia nursing suite of a care home. I remained involved as a volunteer with my local care home until March 2020.

The Patients Association (PA)

19. 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, including in care settings. It is dedicated to supporting the rights and interests of all patients and their families, including family carers.

20. 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, and collaborate with families, including essential family carers. We are recognised as a national authority on patient voice; patients are our members and supporters, and we offer them assistance though our help and information services, which are also an invaluable resource for families and those who provide care and support to patients. Through our helpline we provide information to thousands of people each year about the health and social care system.

21. 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. Amongst others, we work with the Care Quality Commission ("**CQC**"), NHS commissioning teams, corporate partners, NHS England, health trusts and local authorities, local health care providers ("integrated care systems", "**ICSs**"), and charities to improve patient experiences, including in transition to care outside hospitals. We are a member of the NHS Care Partners Group which focuses on the experiences of people who require health and social care.

22. As Chief Executive at PA I ensure we investigate health and care concerns raised by patients and their families, 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 2023, Sir Robert Francis (President of PA) and I wrote to the Secretary of State for Health and Social Care ('**SSHSC**'), then Steve Barclay, about the appalling conditions so many patients were experiencing. I exhibit this letter as **Exhibit JC2/009 [INQ000273418]**. This is one example of PA continuing to strive for and speak up for change, by encouraging the Government to develop health and social care solutions in partnership with patients and carers. In 2022, we published our Theory of Change which I enclose as **Exhibit JC2/010 [INQ000273419]**. This is the road map for what PA believes needs to happen before we can say patient partnership (i.e. the involvement of patients, and their loved ones in their care and planning of that care) 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.

<u>Our experience prior to the pandemic: pre-pandemic structure and capacity of adult social care</u>

23. Whilst the majority of our statement focuses on the relevant pandemic period, it is important to recognise that long-term issues relating to the structure, funding and capacity of the social care sector made the sector less resilient to the pandemic and contributed to the problems we observed during the pandemic period. We have not provided a comprehensive statement of all our pre-pandemic concerns, however we have attempted in this section to provide an overview of the most significant concerns and those which were particularly relevant to issues arising during the pandemic. We will then turn to the pandemic itself.

Core Participant Group

24. All members of our Core Participant group agree that there are deep-rooted issues regarding funding and care provision in the UK. These include but are not limited to:

    24.1. The complexity/structure of social care;
    24.2. The (unrecognised) role of unpaid carers;
    24.3. The divide between health and social care;
    24.4. The prioritisation of health over social care;
    24.5. The absence of mechanisms for raising concerns and lack of support to use them;
    24.6. The lack of proper engagement with those drawing on care and their loved ones; and
    24.7. The lack of understanding on human rights across the sector and failure to take a truly person-centred approach to care planning and policy-making.

a) <u>The Pre-Pandemic Structure of Social Care</u>

25. The structure of adult social care in the UK is complex, confusing, and often not fully understood by those who work in the sector, let alone those who rely on it or make policy in relation to it. The social care sector includes an array of care arrangements including domiciliary care (i.e. support provided in people's own homes); reablement services (i.e. support provided to help people regain independence, often after illness of hospital discharge); day care services and residential care (such as care homes). Unlike in healthcare with the NHS, there is no single key provider of adult social care. For instance, the majority of residential care (in England) is provided by the independent care sector, ranging from small providers running a single care home, to

medium-sized and national providers. Many providers of residential care are for-profit companies, however the sector also encompasses voluntary organisations and there remain a small number of local authority owned care homes. The sector can therefore best be described as a patchwork of services in which transition between different types of services can be particularly challenging and where it is not always clear what the responsibilities of local authorities, social services, NHS funded care, independent and privately funded care are. It is also significantly different in each of the four UK nations. (The Patients Association has expertise primarily in respect of England, but Care Rights UK has expanded its focus to now being UK-wide and John's Campaign's work has always been UK-wide but with a particular focus on care homes in England during the pandemic).

26. The disparate structure of the social care sector presents specific challenges for those we represent. As acknowledged in the evidence of Mr Hancock in Module 1 (we exhibit the relevant excerpt as **Exhibit JC2/011 [PHT000000010]),** this presented specific challenges for preparing for the pandemic and also means that responsibility and accountability structures are not always clear. It is often difficult for individuals who are in need of care to identify exactly how they can access the care and support they need. Consequently, our organisations have had to expend significant time and resources assisting those we represent to navigate the sector. For instance, at PA we have an online guide to the Adult Social Care System, including a guide to care needs assessments, which helps people understand the various care options available to them depending on need. We exhibit this guide as **Exhibit JC2/012 [INQ000499307]**. At Care Rights UK, we have accessible information on the care system on our website and we provide one-to-one advice to help people understand the system via our adviceline. People often tell us they feel bemused and overwhelmed by trying to navigate through a complex system at an emotional time. They can be faced with difficult decisions whilst dealing with a mix of feelings, including guilt and fear.

27. The complex social care structure also presents challenges for those with decision-making power. In our experience, decision-makers across both Government and the social care sector itself frequently lack understanding of how social care structures work and how care is provided on the ground. Unfortunately, as set out further below, our experience has been that those with decision-making power on social care are often not prepared to listen to what they are told about the realities of care provision and the experiences of those giving and receiving care. This adversely impacts their ability to make and implement decisions and provide appropriate guidance.

b) The role of unpaid carers

28. In addition, a large percentage of social care is provided by unpaid carers. Carers UK estimated in June 2020 that an additional 4.5 million people had become unpaid carers since the pandemic began (bringing the total to 13.6 million) and the CQC's 2020/21 edition of its State of Care report outlined the increased strain on carers (see INQ000398569). Yet the importance of unpaid carers has often not been recognised in decision-making and planning for social care, including in legislation and regulation for the provision of care. There are widespread failures to provide the support and rights that unpaid carers deserve. Some examples include inadequate respite and access to equipment (including personal protective equipment), lack of financial support (e.g. Carer's Allowance is poorly paid and the system for payment is problematic and punitive), and failure to recognise them as part of the care team.

29. This systemic neglect of unpaid carers has significant impacts on those giving and drawing on care. Amongst other things, it can place an undue burden on the individual providing unpaid care, leading to adverse impacts on their health and well-being. The lack of support and status for unpaid carers can affect the quality of care received, as well as the relationship between the unpaid carer and the person they are caring for. For family carers, difficulty accessing or obtaining funding for respite care takes a physical, mental and emotional toll. As we discuss in further depth at p.12-13 of **Exhibit JC2/013 [INQ000273453]** ('The Holding Pen'), during the pandemic difficulties accessing appropriate respite care increased, either because respite was not available or because complete bans on visiting and isolation requirements during respite care (as laid out in care home admissions guidance in England – see further below) would distress an individual receiving care, meaning that carers made the choice to care without respite (often causing detriment to their own health).

30. As we outline in further detail below, visiting restrictions during the pandemic often included restrictions on the access of unpaid but essential family carers to health and social care settings. The failure of health and social care institutions to facilitate the involvement of family carers in care is an issue which was exacerbated during the pandemic, but which our organisations were aware of and campaigned on (John's Campaign and Care Rights UK in particular) prior to the pandemic. It is symptomatic of the failure to recognise the often essential contribution unpaid carers make to care and to the wellbeing of the person they care for. We have consistently stressed that the reliance during the pandemic on separation as a means of infection control has meant that husbands and wives, partners, brothers and sisters, children and parents

have been treated as 'inessential' to one another. In a blog posted on John's Campaign's website, which we exhibit as **Exhibit JC2/014 [INQ000499309]**, John Shaw explained how it felt when he was 'banned' from caring for his wife and how this impacted on John and his wife's wellbeing.

31. Our experience prior to the pandemic was also that various care homes took different approaches to the involvement of family members in the care and treatment of their loved one with some facilitating access and provision of care by loved ones, and others taking a more restrictive approach. Indeed, the reason Care Rights UK was established as a charity over 30 years ago was because our founder, Dorothy White, found herself obstructed at every attempt to become involved in key decisions about her mother's welfare in her care home. Over the past 30 years we have seen varying approaches to family carers in different care settings, from excellent practice to extremely poor practice. The pandemic was therefore not the first time we encountered issues with care homes employing vastly different policies and practices regarding family visiting and involvement in care (as set out further below). Had the importance of those in care settings maintaining contact with their loved ones been recognised universally prior to the pandemic, then people in vulnerable situations in care settings during the pandemic might not have suffered as much as they did.

c) Artificial divide between health and social care

32. Another concern shared by all members of our Core Participant group is that social care has traditionally been viewed as isolated from, and separate to, healthcare services. Whilst we do not have a unified health and social care system in the UK, often those with health needs will also be reliant on social care and vice versa. Without a functioning social care sector, the NHS would not be able to continue to provide services. It is therefore essential that, when developing and implementing health policy, decision-makers also consider the knock-on effects on the social care sector. A tendency for decision makers and the NHS is to operate in siloes, without considering the broader social care impacts of their decisions. As the then CEO of PA, Katherine Murphy, put it in oral evidence provided to The Select Committee on the Long-Term Sustainability of the NHS in 2016 (exhibited as **Exhibit JC2/015 [INQ000499310]**, page 10) "*if we continue to work in siloes, as we currently do, we will never move and we will never provide the service that is needed*". Over eight years later, our organisations continue to observe a failure by decision-makers to consider both the health *and* social care system holistically and this failure has characterised decision-making both before, during and after the pandemic. The importance of a

holistic approach has also been acknowledged by Recommendation 1 of the Covid-19 Inquiry Resilience and Preparedness (Module 1) Report which recommended a 'whole-system' approach to preparedness (see p.67).

d) Prioritisation of healthcare over social care

33. Linked to our Core Participant group's concerns regarding division between health and social care, we also have concerns regarding the prioritisation of healthcare over social care. There seems to be an (incorrect) perception that social care is secondary to health services, and this perception has been reflected in funding and policy decisions made prior to, during and after the pandemic. As recognised by the House of Commons Health and Social Care Committee, in their Report on recruitment and retention in health and social care which we enclose as **Exhibit JC2/016 [INQ000471095]**, the social care sector has been "chronically underfunded by central Government".[3] This chronic underfunding of the social care sector, which was already resulting in workforce shortages, overreliance on unsatisfactory employment conditions for care staff (including zero hours contracts, use of agency staff moving between care settings and lack of statutory sick pay), and reduced room capacity prior to the pandemic, meant the sector was more vulnerable to the impact of the pandemic.

34. Our Core Participant group made several calls prior to the pandemic for better funding and appreciation of the role of the social care sector. For example, PA has consistently warned of the dangers of failing to fund social care and the knock-on effects of this on healthcare. In 2010, PA shared concerns about the funding of the social care sector with *The Guardian* (see **Exhibit JC2/017 [INQ000499312]**), noting that *"poor services in the community lead to admissions to hospital, and a lack of services prevent discharge when it might be best for the patient".* In 2017, PA made recommendations for the 2017 Spring Budget, exhibited as **Exhibit JC2/018 [INQ000499313]**. The recommendations noted that "*social care lacks full and sustainable funding, to the extent it is widely recognised to be in crisis*" and that *"a well-functioning and properly funded social care system is essential to the smooth running of the NHS*". PA made similar pleas in its submission to HM Treasury for the March 2020 Budget (exhibited as **Exhibit JC2/019 [INQ000499314]**) for Government to address the social care funding gap and commit to fixing the social care crisis. Despite the pandemic further highlighting the importance of a robust social care system, the problem persists. Care Rights UK has consistently warned of the impact of the under-funded, under-valued

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care sector on the people relying on these vital services. Over our 30 year history we have campaigned, lobbied and pushed for reform of the care sector so that care is valued as highly as the NHS. For example, just before the pandemic in October 2019 we responded to the CQC's State of Care report (See **Exhibit JC2/020 [INQ000499315]**) and called for urgent action to reform the sector: "we shouldn't wait for the system to crack before taking action to ensure older people are treated with dignity in care".

e) The absence of mechanisms for raising concerns and lack of support to use them

35. The disparate and complex structure of the social care sector makes it difficult for those receiving care and their loved ones to find the appropriate avenue to complain about inadequate or unsafe care. This means that complaints often have to be made to the very people providing the care. The regulator for England, the CQC, too often deflect concerns by their mantra of 'we don't deal with individual complaints'. Redress via the Ombudsman or legal proceedings often takes too long and can come too late for people nearing the end of life.

36. The lack of a central/independent complaints system adds to people's feeling of vulnerability in care. The power imbalance in care means people are afraid to speak out about poor care for fear that their situation will get worse or they will face reprisals such as visiting bans or evictions. Prior to the pandemic, Care Rights UK, in particular, heard reports on a regular basis of families whose complaints about quality of care led to visiting restrictions or facing an eviction notice and we were told that many were afraid to speak out. We exhibit as **Exhibit JC2/021 [INQ000499316]** an article which highlights the pattern of excluding family members after they made complaints about provision of care. As we discuss in further depth at §240, the pandemic increased Care Rights UK's concerns in this area, as during the pandemic the suspension of routine inspections made it all the more important that there were clear avenues for people to raise concerns and complain about quality of care.

f) The lack of proper engagement with those drawing on care and their loved ones

37. Our organisations also share concerns regarding engagement with people drawing on care services and their unpaid carers, relatives and representatives. For many years, our respective organisations have emphasised the importance of including those drawing on care at the heart of decisions which affect them. Person-centred care is about focusing on individual needs and preferences, to provide care that is appropriate, respectful and dignified. All of our organisations operate by hearing and

valuing the viewpoints of people who need care, their unpaid carers, relatives and representatives. In our view, it is impossible to understand how to provide good quality care until you listen to those who need and receive care, and their chosen representatives, as well as those who provide it. This is an issue which we observed prior to the pandemic, and we believe the focus on institutions and systems, rather than on the people drawing on and giving care is an issue which continued into the pandemic and has unfortunately also continued since then.

John's Campaign (JC)

38. Whilst it became a far more significant issue during the pandemic (as set out further below), restrictions and sometimes bans on essential family carers visiting and/or providing care in health and care settings is something we observed and campaigned against consistently prior to the pandemic. We highlighted the stories of relatives being unable to visit loved ones on our website and stressed the important role they play in raising concerns about the appropriateness and quality of care being provided, including:

38.1. The experience of Brenda and her partner Donald in 2016 (**Exhibit JC2/022 [INQ000499317]**). Donald had dementia and after a stroke entered St Mary's Isle of Wight Hospital. As St Mary's Hospital had implemented John's Campaign, Brenda described a positive experience of being able to stay with Donald overnight and help him with washing and feeding. However, when Donald subsequently entered a nursing home, Brenda was told by staff that she could only stay the first night and was banned from being in Donald's room when he was having a pad changed or being washed. Brenda's visits were limited and Donald deteriorated quickly in the nursing home; no attempt was made to help stimulate his brain and he was only hoisted into a chair every other day. Donald passed away on 22 November 2016.

38.2. The experience of Shirley and her father, which was highlighted on our website in 2019 (**Exhibit JC2/023 [INQ000499318]**). Shirley and her family became worried that staff in a care home did not have the skills to properly care for her father and when Shirley and her sisters visited, the care home became increasingly hostile. The care home later banned Shirley and her family from being in her father's room during personal care. When Shirley raised a Safeguarding Alert with the local authority the care home manager responded by evicting Shirley's Dad.

38.3. The experiences of many of those living in care settings and their loved ones, who are unable to eat together due to “protected meal time” policies. The purpose of a ‘Protected Mealtime Policy’ is to protect mealtimes from unnecessary and avoidable interruptions, providing an environment conducive to eating, assisting staff to provide individuals with support and assistance with meals, and placing food first at mealtimes. However, the reality of how such policies are implemented is that they often ban family members from visiting or being present during mealtimes, even if they could play a positive role during the mealtime. In an article published on our website in December 2019 (**Exhibit JC2/024 [INQ000499319]**), I reflected on how relatives are often prevented from eating together as a result of care home policies, despite relatives often being able to help encourage their loved one to eat and prevent malnutrition and despite the fact that a care home is a person in care’s home. If care homes are homes, the people living there should have the right to invite those they love to eat with them.

39. These are just a few examples of care settings restricting the access of essential family carers and this having a negative impact on individuals receiving care prior to the pandemic.

g) <u>The lack of understanding on human rights across the sector and failure to take a truly person-centred approach to care planning and policy-making</u>

40. As above, person-centred care has always been at the heart of all of our work. Since long before the pandemic we have been concerned that too often people who draw on the care sector and particularly those who live in care settings are no longer seen as people with agency and dignity, and that policy-makers too often overlook the fact that care users are people who matter and are loved. Whilst their homes may be different (because they are in a care setting), that doesn’t mean that they are not their homes, in which they should be able to enjoy their human rights and achieve wellbeing.

41. A focus on the individual is essential to the provision of appropriate and good quality care, and is in fact a legal requirement (though unfortunately that is not understood widely enough). Whilst it may seem obvious that care should be provided in a way that focuses on the individual needing it, our experience for many years has been that far too often decisions regarding care provision are not made in an individualised way, and blanket policies and approaches are inappropriately applied. This is contrary to requirements under both the Human Rights Act and Equality Act. Unfortunately, far

too many of those making decisions within the care sector have little or no understanding of the importance of person-centered care and the legal requirements, due to a lack of training and support to meet their duties under the law, including to make individualised decisions based on assessments of individual needs. As set out further below, the application of blanket decisions and policies became a theme during the pandemic, but was a well-known issue before Covid-19 reached the UK's shores.

Our experience during the pandemic

42. Given the already precarious state of the social care sector as set out above, many of the individuals we represent were particularly vulnerable to the impact of the pandemic. Consequently, each member of our Core Participant Group worked closely with individuals needing care, their carers and representatives throughout the pandemic. We have set out below the ways in which we did this, in relation to each of our organisations.

Care Rights UK

43. Care Rights UK was in direct contact with individuals relying on care and their loved ones throughout the pandemic and heard about the issues they 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. Throughout the pandemic our adviceline supported people needing care and the families and friends who support them. Our small team (of two advisers) handled around 2,000 calls and emails a year, providing bespoke one-to-one advice and further ongoing support (such as letter writing) where necessary. This kind of support required not only expert legal knowledge but also time, empathy and compassion as we guided people through loss, anxiety, distress and often anger at the injustice of the pandemic response. Insights from our adviceline and advocacy work informed our campaigning, policy 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 care. 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, in England the CQC paused routine inspections 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, a concern we discuss in further depth at §§240-243). From September 2020, we were campaigning to End Isolation In Care, highlighting the devastating impact of pandemic restrictions on the

health and wellbeing of people living in care. More information about the campaign activities is provided below.

44. As rules and guidance for care settings 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 JC2/025 [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 successfully challenge the application of restrictions on visits in and out of care settings, examples of which are exhibited to this statement as **Exhibits JC2/026 - JC2/027 [INQ000273432 - INQ000273433]**.

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

    45.1. The testimony of one of our adviceline clients about the rollercoaster of emotions of visits to her mum in care being stopped, then permitted as end of life visits, but when her mum recuperated with the support of her family, visits being stopped again: *"I am convinced that mum decided to die. She stopped eating. She'd had enough and there wasn't enough hope that things would change. If someone had told her she could have visitors again and hold her great grandson I think she would have battled on, but there was little hope offered and her quality of life was too reduced. Whilst she had physical problems, the mental strain was too much for her in the end. I think it was a shock to the staff that mum died when she did, being one of the healthiest and most able people in the home just a month earlier."* (See **Exhibit JC2/028 [INQ000499323]**)

    45.2. The testimony of Himani, whose mother Octavia deteriorated rapidly during lockdown in her care home: *"When the receptionist let me use his phone for a video call, it was only a few days into lockdown but already mum was unable to speak. Her glow and warmth had all but disappeared. She went from being chatty and writing in her diary daily to being unable to talk and write, within days. Her deterioration was so rapid and all consuming."* (See **Exhibit JC2/029 [INQ000499324]**).

    45.3. The testimony of Helen (**Exhibit JC2/030 [INQ000499325]**), who had to wait 382 days to hold her mum's hand during the pandemic. Helen describes how not being able to visit resulted in a sharp decline in her mother's dementia and a loss of cognitive function. Whilst the care home facilitated alternatives such as Skype calls and garden visits, Helen describes how they weren't useful for her mum and didn't enable her mum to interact because her dementia affected her ability to understand what was happening.

46. 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 **Exhibits JC2/031 - JC2/037 [INQ000273437 - INQ000273443]**) and supporting the tabling parliamentary questions (see **Exhibit JC2/038 [INQ000499333]**). In addition, we wrote formally to the CQC. I discuss our correspondence with the CQC at §65 and exhibit four letters we wrote to the CQC as **Exhibits JC2/039 - JC2/041a [INQ000231915 - INQ000231918]**. Care Rights UK also submitted insights and evidence to the DHSC and provided witness evidence in support of the legal challenges by John's Campaign against the DHSC guidance (see §123 below).

47. Care Rights UK has also undertaken a survey on the healthcare experiences of those living in care home during the pandemic which we exhibit as **Exhibit JC2/042 [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 were set out in detail in our Witness Statement for Module 3 (and are referred to briefly below), illustrate what we had heard on our helpline, week in and week out, from the very beginning of the pandemic, namely that access to healthcare and appropriate care more generally was severely restricted.

48. As set out further below at §70, as a member of the DHSC working group we raised our key concerns with the DHSC directly. 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 (see **Exhibit JC2/043 [INQ000499338] and Exhibit JC2/044 [INQ000499339]**). 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, other than the emails which we

exhibit above. We also led work to challenge the Government's approach to visiting restrictions in England, drafting alternative guidance based on legal rights and securing the support from several other members of the DHSC working group. This approach was not taken up by DHSC, and we explain more about this below.

John's Campaign

49. Prior to the pandemic, JC worked with a range of health and care settings on providing dementia-friendly care for patients. With the onset of the pandemic and the impact of the isolation policies on people with dementia in particular, JC's work advocating for this cohort of people, along with other vulnerable people in health and care settings, ramped up. JC was the first organisation to warn of the effects of isolation policies on vulnerable people in health and care settings.

50. 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, email, and 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 JC2/045 [INQ000273450]**) and continually tried (but failed) to encourage the Government to listen to health and social care service users and their families. 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 JC2/046 [INQ000273416]** and **Exhibit JC2/047 [INQ000499342].**

51. We also conducted a visitor restriction survey between 17-30 November 2020, which was completed by 1049 relatives of people living in residential settings for both younger and older adults. The results of this survey are summarised on our website and exhibited as **Exhibit JC2/048 [INQ000273428]**. They 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 **Exhibit JC2/049 [INQ000273430]**), and which was 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, shared them via social media, and included them as evidence in our legal challenges regarding guidance on visiting in care homes. We also used the results from the November 2020 visitor restriction survey to inform the written evidence we produced in January 2021 for the Select Committee**.** We also shared the results with the organisations who were invited to or involved in meetings with the DHSC. We had regular meetings with organisations including Age UK and National Care Forum to discuss information to be passed on to decision-makers.

52. 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 §240 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 JC2/050 [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 we received and through the surveys) to be used as supporting evidence for those challenges.

53. 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 JC2/013 [INQ000273453]**. This is a collection of stories from individuals who experienced imposed isolation in care settings, which we published 9 June 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.

54. We also prepared and published 'Midsummer Milestones' which is exhibited as **Exhibit JC2/051 [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 Secretary of State for Health and Social Care 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 and urge the Inquiry to investigate the increase in the supply of anti-psychotics, anti-depressants and anxiolytics for people living in care homes.

55. 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.

56. Alongside lobbying for changes to DHSC guidance, we also observed and highlighted instances where individual care homes or care providers imposed harsher visitor restrictions than required by the relevant guidance at the time. On some occasions, we assisted families in their communications with these providers. In some instances, we referred them to lawyers to assist them with raising the inconsistencies.

The Patients Association (PA)

57. PA works with patients directly and runs a public helpline accessed by circa 3000 people a year. Over the course of the pandemic, 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.

58. These reports were:

    58.1. '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 JC2/052 [INQ000273424]** and will be referred to as '**The early pandemic patient experience report**'.

58.2. '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 JC2/053 [INQ000273425].** This report followed up key themes from the above-mentioned report and will be referred to as **'The follow up patient experience report'.**

58.3. '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 JC2/054 [INQ000273426]**. This report will be referred to as '**Patient experience before Omicron report'.**

59. As set out in further detail in our Module 3 Witness Statement and summarised below, across the three surveys we saw that the experience of those receiving care significantly deteriorated and trust in the health and care systems 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 CQC by writing joint publications and writing to key stakeholders and engaging in media appearances 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 §83.

Submissions made to Government bodies raising concerns

60. We have set out below further examples of submissions made directly to Government bodies raising our concerns:

Care Rights UK

61. We have already set out 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:

61.1. 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 the CQC reconsidering its approach to inspections during the pandemic and the government producing a strategy to safely unlock care homes. I exhibit the written evidence we submitted to the Committee in full as **Exhibit JC2/031 [INQ000273437]**.

61.2. the APPG on Coronavirus on the Government's response to the 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 JC2/032 [INQ000231911]**.

61.3. 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 JC2/033 [INQ000273439]**.

61.4. In June 2022 we submitted written evidence to the Adult Social Care Committee Inquiry 'Lifting the Veil: Removing the invisibility of adult social care' (See **Exhibit JC2/055 [INQ000506815]**. Our submission pointed out the devastating impact of the pandemic on people relying on social care and how the response to the pandemic had exacerbated long-standing problems in the sector such as staffing shortages.

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

62.1. 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 people living in care and their families. I exhibit a full transcript of the August APPG as **Exhibit JC2/034 [INQ000273440]**.

62.2. 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 JC2/035 [INQ000273441]**.

62.3. Joint Committee on Human Rights for their inquiry on visiting in care settings in January 2021, where we reported common concerns that our adviceline users had raised about pandemic restrictions, including the severe impact of visiting restrictions on mental and physical health. 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 JC2/036 [INQ000273442]**.

62.4. 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. Our recommendations included ensuring a better understanding of the care sector by Government and its agencies, changes to regulatory oversight to better protect rights, and closing the knowledge gap on human rights in the sector. I exhibit a transcript of the oral evidence given to the Joint Committee on Human Rights as **Exhibit JC2/037 [INQ000273443].**

63. In February 2021, we published a joint statement with Age UK, the National Care Forum, the Registered Nursing Homes Association, Rights for Residents and JC on reuniting residents of care homes with their relatives and friends which I exhibit to this statement as **Exhibit JC2/056 [INQ000273482]**.

64. Some of our other publications included:

64.1. 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 JC2/057 [INQ000231908]**) and updated throughout the pandemic;

64.2. A call for a new right to maintain contact in health and care with JC and Rights for Residents in April 2022 (see **Exhibit JC2/058 [INQ000273484]**); and

64.3. Extensive summaries and explanations of Government guidance, supporting families to understand and use legal rights to challenge restrictions, throughout pandemic, such as a FAQ factsheet about visiting care homes during outbreaks (see for example, **Exhibit JC2/025 [INQ000273431]**).

65. 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 which included an appendix of evidence from our adviceline about the harm caused (see §43 above). The CQC's approach, however, as reflected in its response dated 7 July 2022 (**Exhibit JC2/059 [INQ000499356]**), was passive and indifferent in that it merely followed the Government's generic guidance instead of making an effort to ensure services were providing individualised responses.

66. In July 2021, we wrote to the Prime Minister urging the opening of the public inquiry (**Exhibit JC2/060 [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 people living in care settings compared to the general population, and highlighting the devastating impact of continuing isolation and separation on people living in care homes and their families (**Exhibit JC2/061 [INQ000273486]**).

67. 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 JC2/062 – JC2/063 [INQ000231921 - INQ000231922]**). We enclosed an Essential Care Giver Factsheet and poster with our January 2022 letter (see **Exhibit**

JC2/064 [**INQ000273489]**) and recommended that health and care leaders referred to these resources as part of their outbreak management plan. In February 2022, we wrote (alongside Rights for Residents and JC) to the new Care Minister, Gillian Keegan, to raise our concerns and we met with her to discuss the harm of ongoing restrictions. In March 2022 we supported the tabling of Parliamentary Questions about evidence of harm of isolation in care (see §46) and organised an event in Parliament with JC and Rights for Residents 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 JC2/065 [INQ000273490]**. In April 2022 we wrote an open letter to the SSHSC (with the Care Providers Alliance and the Care Workers' Charity) on the lack of sick pay for care workers who test positive with Covid-19 which was putting people's lives at risk (**Exhibit JC2/066 [INQ000499363]**).

68. We also provided supporting evidence in legal challenges brought by JC in October 2020 and June 2021 (see for example, **Exhibit JC2/051** [**INQ000176369]**).

69. In addition, we engaged in a range of lobbying efforts. We met regularly with the CQC to raise concerns about its inaction during the pandemic, including in quarterly one-to-one meetings and in quarterly meetings of sector leaders. We continued to be disappointed with their defensive responses, consistently choosing to focus on what they couldn't do rather than focusing on what they could do. We were urging them to be proactive, to show leadership and direction to the sector, represent the voices of people relying on care services and set out expectations around respecting existing legal rights. We expressed this disappointment in correspondence and meetings but did not see a change in approach. 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.

70. As mentioned above, we were also 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. I felt a significant responsibility in these meetings and interactions with the Working Group to represent the voices of people relying on care services, who were

not represented directly. I spoke up to share the experiences of people we were supporting, trying hard to impress on DHSC and PHE/UKHSA the impact of the policies and decisions they were making. As a newer member of the group (we were only invited to join in the summer of 2021), this often meant going against the grain of discussion or thinking, and openly challenging approaches and decisions by DHSC we fundamentally disagreed with. By the time we were invited to join the group it felt like restrictive, risk-adverse approaches had become engrained and it took immense efforts to get even small changes or movement. We did this by persistently pointing out what the law said, what DHSC's (and other agencies like PHE/UKHSA) own legal duties were in relation to people's rights, and explaining how the guidance was breaching those rights. We played an active and significant role in the Working Group, including by:

70.1. Submitting evidence from our adviceline about the impact of Government guidance on visiting in August 2021 and February 2022.

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

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

70.4. We led work to challenge the Government's approach to visiting, by drafting and submitting to DHSC a suggested rewrite of the visiting guidance in February 2022 **Exhibit JC2/067 [INQ000499364]**). We secured the support of several other members of the Working Group, organisations representing people drawing on care and care providers: Care England, National Care Forum, National Care Association, Association for Real Change and the Alzheimer's Society. This suggested rewrite was submitted to DHSC on behalf of these members of the Working Group, but I received an email less than 40 minutes later from an official (the Deputy Director of the Covid-19 Strategy at DHSC) rejecting the approach (**Exhibit JC2/043 [INQ000499338]**). We wrote to express our disappointment that the approach had been rejected so swiftly, especially as it was based on legal rights the DHSC itself had a duty to uphold. We felt that 40 minutes was not long enough for the relevant team to have seriously considered and discussed our proposed approach, including with the Minister.

70.5. Requesting information sharing re clinical evidence of the impact of Covid-19 restrictions, in two meetings in February 2022, a meeting in March 2022 and twice by email (the requested information was not shared).

70.6. Requesting that the Working Group continue when DHSC decided to disband the group, pointing out that the group's work was still vital as long as the Covid-19 guidance and restrictions remained in care settings. This was rejected and the group's work was discontinued. I wrote to DHSC in August 2023 asking for the group to be reformed to discuss ongoing guidance and requesting a change to vaccine guidance to allow visitors to care settings to receive free Covid-19 boosters (**Exhibit JC2/069 [INQ000499366]**). This was not taken up.

John's Campaign (JC)

71. As set out in further detail above and below (see, for example, §165), 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), we made the decision to focus most of our campaigning attention on care home residents in England (and to a lesser extent Wales). We made contact with concerned family members in Scotland and Northern Ireland but rarely intervened directly once local organisations were informed to challenge local arrangements in devolved administrations.

72. We joined with other leading dementia organisations and charities to form a coalition called One Dementia Voice[4] seeking to speak with one voice on 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 JC2/070 [INQ000499367]**). In particular, we sought the designation of family and friend carers as "Key Workers" so that they could be subject

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[4] 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.

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.

73. The consistent refusal of the DHSC, in particular, to engage in any form of dialogue or appear to consider the impact of its 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 JC2/071 [INQ000273494]**).[5] I set out below at §240 a detailed chronology of the legal action we took.

74. 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 the report on a successful project aimed specifically at 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.

75. 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 (now called Care Rights UK) and with Rights for Residents to publicise our concerns. For instance, we published a 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 JC2/056 [INQ000273482]**). As the pandemic progressed, we increasingly found ourselves advocating for groups such as young learning disabled people and those with multiple profound disabilities, not necessarily cognitive.

76. In September 2021, we joined a protest held by Rights for Residents outside the gates of Downing Street, calling on the Government to give care home residents the legal right to an essential visitor/care supporter. During the protest members of the Rights for Residents team, including their ambassador Ruthie Henshall and the Shadow

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

Minister for Care, Liz Kendall, handed in a petition with over 270,000 signatures calling for 'Gloria's Law' - the legal right to a care supporter (See **Exhibit JC2/072 [INQ000499369]**).

77. We contributed constantly to articles and reports in national newspapers, by appearing on TV and radio ourselves, and 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 JC2/073 – JC2/075 [INQ000499370 - INQ000499372]**.

78. We felt consistently disappointed and angry at the refusal of the DHSC to engage in any dialogue with us directly but responded to requests from organisations such as the Joint Committee for Human Rights and (occasionally) the CQC.

79. I was in contact with a CQC group in March 2020 as I should have been speaking at one of their meetings. When it was cancelled, we had a conference call where I was assured that Fundamental Standard 9 (of the Health and Social Care Act 2008 (Regulated Activities) Regulations 2014, stating that care providers must ensure each person receives person-centred care**)** would always remain in operation. I was also assured that the essential elements of person-centred care (including meaningful contact with those closest to the patient) would always remain in operation and that the CQC would enforce it. I believed this for a long time but unfortunately it turned out not to be the case as we heard from people living in care and their loved ones that blanket approaches were often taken and close contact was denied for far too long.

80. At another meeting early on in the pandemic, I responded to a CQC request for the documentation we have on visiting plans, demonstrating how easy this would be to incorporate as part of individual care plans. I tried hard to interest the Deputy Chief Inspector for Adult Social Care in London and South regions, Debbie Ivanova, in unlawful restraint being imposed on young learning disabled people and I was told my messages had been passed on. Ms Ivanova had written a report *Out of Sight - who cares* about extended periods of seclusion enforced on young adults in mental health settings pre-pandemic (see **Exhibit JC2/076 [INQ000499373]**) and I therefore thought it would be a topic of interest. I pointed out that at least in mental health settings and prisons, records must be kept and length of time in isolation must be recorded. There was no such structure in care homes and the practice of imposed isolation under the guise of infection control was becoming normalised and not

monitored. I was given a meeting with the lead inspector for dementia and another senior colleague and I also engaged in some correspondence with Kate Terroni, Director of Social Services and Chief Inspector of Adult Social Care and Integrated Care at the CQC asking her to implement the Joint Committee on Human Rights' draft Statutory Instrument to facilitate face to face contact between service users and their loved ones (See **Exhibit JC2/077 [INQ000499374]**. I could not see that it made any difference.

81. We provided written evidence on 'The Government's response to Covid-19: human rights implications of long lockdown (Inquiry)' (which I exhibit as **Exhibit JC2/078 [INQ000499375])** and on 'Protecting human rights in care settings (Inquiry)' (which I exhibit as **Exhibit JC2/079 [INQ000499376])**.

82. 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 on both visits in and out of care homes published by the DHSC. I have set out the chronology of that legal battle in detail below in the section dealing with visiting restrictions 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 needing and providing care affected even when repeatedly confronted with reports of their suffering.

Patients Association

83. We sent copies of all of our reports on patient experience during the pandemic to DHSC and NHS officials as they were published. In addition to this, we wrote repeatedly to various officials such as the SSHSC to highlight key concerns. Our correspondence with the SSHSC is set out further below and exhibited to this statement as **Exhibits JC2/080 - JC2/081 [INQ000273477 - INQ000273478]**. We also raised our concerns via briefing groups and through submission of papers to Government representatives and relevant Government discussion groups for their consideration.

84. 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 and consistently highlighted the need to integrate health and social care and provide funding desperately needed by the social care system.

85. 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 JC2/082 [INQ000273479]**.

86. In September 2020, PA submitted a paper to the Treasury ahead of the Comprehensive Spending Review (see **Exhibit JC2/083 [INQ000273480]**) to make clear that major investment in healthcare and care more generally 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 care (including both health and social care) and wellbeing of the nation after Covid-19 is astonishing.

87. On 28 June 2021, we wrote to Sajid Javid, then newly appointed as SSHSC (**Exhibit JC2/080 [INQ000273477]**). We wrote to welcome him to his new role and to raise our concerns about the ever-increasing issues facing both the adult social care system and the NHS. In particular, we highlighted the scale of the injustice in adult social care

and urged the Secretary of State to develop a funding system that ensures people are able to fairly access social care. We noted that *"[r]estoring services to 2011 levels – which were themselves inadequate – will require an estimated £7-8 billion of additional baseline funding"*. We also advocated for *"strategic, cross-governmental approach to health policy"* to tackle the causes of health inequalities which often lie upstream of the NHS, including in the social care system and impact far beyond the NHS (including on care provision outside healthcare settings).

88. On 12 November 2021, we wrote again to the SSHSC (**Exhibit JC2/081 [INQ000273478]**). The letter detailed the fact that we believed the Government should (under the Civil Contingencies Act) bring in armed forces to assist services in England. We also urged the Secretary of State to *"provide immediate investment in social care".* As we had done consistently prior to the pandemic, we noted the importance of social care to the NHS, explaining in our letter that *"extra funding for social care will ensure hospitals can safely discharge medically fit patients into the community, freeing capacity in the NHS."*

Overview of our main observations and key concerns about the response to the pandemic

89. We echo the statement made by The Older People's Commissioner for Wales, Helena Herklots CBE in her 18 August 2020 report: "Many of [the] deaths [in care homes] could have been prevented had there been a better understanding of the risks faced by care home residents and the action required to ensure they had the protection and support they needed": (INQ000184908, p11).

90. The key issues we identified through our work during the pandemic, and which we discuss in turn below, are:

    90.1. The failure to protect people in care, including the lack of adequate PPE and testing; inappropriate discharge of people from hospitals to care homes; and absence of appropriate guidance on infection control, which led to significant loss of life.

    90.2. The 'closed door' policies in care settings, which resulted in response to early failures to protect people in care and had the effect of imposing severe and long-lasting restrictions on movements both in and out of care homes. Essential and family carers were prevented from visiting, and from providing critical support. The adverse effect of these restrictions cannot be overstated, and is explained in the section below headed "Impact of the 'closed door' policies". Care settings should have been recognized as homes and residents as people with individual needs.

91. There were other, longer-lasting failures to protect and respect people in care, including:

91.1. Failure to provide access to adequate care, healthcare and palliative or end of life care; lack of adequate support or resourcing, such as for sick pay; poor communication; and failure to involve people needing care and their deputies in key decision-making. For example, there were widespread reports of DNAR decisions being issued without consent being obtained;

91.2. Failure to respect private and family life and properly recognise the role in care of loved ones and to communicate with and involve them in care;

91.3. Widespread failures to carry out individualised risk assessments and cater for individuals' specific needs (with overreliance on blanket policies and decision-making) contrary to human rights and equality requirements;

91.4. Failure to provide clear and accurate guidance in relation to care settings. This often led to inconsistent interpretation and application of the guidance, with serious adverse consequences. For example, there was a failure to provide consistent and appropriate definitions of end of life care and palliative care, which resulted in end of life visiting being granted far too late or not at all. This was inhumane;

91.5. Failure to provide proper oversight and regulation to ensure appropriate care provision and safeguarding. The CQC abandoned its responsibilities;

91.6. Prioritisation of infection control over other key considerations as well as prioritisation of protection of institutions at the expense of individual rights (of individuals needing and providing care); and

91.7. Consistent failures to listen to those (like us) who were hearing what was happening on the ground and repeatedly warning of the serious detrimental impact that policies were having.

92. The final section of this statement identifies key lessons to be learnt.

93. As set out below, all of these failures impacted on the health and wellbeing of people drawing on care, their loved ones, carers and care providers. It impacted the quality and appropriateness of care received and led to significant deterioration in health, wellbeing and quality of life as well as severe trauma. All too often we heard of people losing the will to live or giving up on life. Too many people died alone in what must have been terrifying circumstances. Some who took part in our research still live with the trauma of having lost loved ones in tragic circumstances. The impact on them may last their lifetimes. Others have witnessed irreversible decline in their loved one's mental and physical health – often with a knock-on negative impact on the wellbeing and mental health of family carers.

94. It is worth underscoring at this point that, as a Core Participant group, we have been and continue to be particularly concerned about the intense and narrow focus on infection control at the expense of many other 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 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 and those who, while subject to the intense restrictions imposed on people living in care, could see no reason to carry on living. The report prepared by Amnesty entitled 'As if Expendable' (see **Exhibit JC2/084 [INQ000499381]**) draws on numerous heartbreaking personal stories, including from individuals we were in touch with who explained the profound distress experienced by people subject to onerous restrictions in care settings and their families.

95. Dementia is a particularly obvious example where people living with an untreatable, progressive, terminal illness were denied the one thing that is known to help: person-centred care[6], and were at the same time 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

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

co-morbidities). This resulted in greatly increased risk of delirium, which, as demonstrated by the Alzheimer's Society report (**Exhibit JC2/085 [INQ000499382]**) 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 profound and foreseeable impact of Covid-19 restrictions on those suffering from these conditions and their families was not properly considered.

Failure to protect people in care settings

96. The failure to protect people in care was a common thread in decision-making throughout the pandemic. It took many forms. For instance, the social care sector was not provided with adequate PPE and testing capacity, and the lack of sick pay provision meant social care staff often continued to work when infected. The rollout of testing in care settings was far slower than in healthcare, with many care homes only being able to access testing consistently from Autumn 2020 and some community care settings only being able to do so from February 2021.

97. There were often references to a 'protective ring' around care by Government officials, including by the SSHSC. It was clear to us at the time that this was nonsense, given the Government's neglect of the care sector. Giving evidence to the inquiry under Module 2, the SSHSC finally admitted that the processes he put in place around the care sector did not form a ring, or an 'unbroken circle' (**Exhibit JC2/086 [PHT000000052]**). I exhibit Care Rights UK's reaction to the SSHC's evidence and the lessons we recommended needed to be learned as **Exhibit JC2/087 [INQ000499384].**

98. In oral evidence to the JCHR on human rights in care settings in January 2022 exhibited as **Exhibit JC2/037 [INQ000273443],** Helen Wildbore said on behalf of Care Rights UK: "Right now older people in care are facing the most serious sustained attack on their human rights we've ever seen. Fundamental rights to life and wellbeing were neglected at the beginning of the pandemic. People in care are still paying for the mistakes the Government made as they swung dramatically to the other extreme, placing the most stringent far-reaching restrictions on those in care. In the name of keeping people safe from the virus, other rights are being violated and untold harm is being caused to lives and wellbeing. People in care are facing discrimination and

being left behind whilst the rest of the country gets back to normal. If this is what the Government meant by a protective ring, it is suffocating."

99. As described in detail below, the failure to protect people in care settings also included the failure to consider the impact of imposed isolation, to ensure adequate ongoing provision of care (including healthcare), and to provide adequate regulation and oversight. In our view a number of these failings resulted from a knee jerk reaction to overcompensate for the early failures to minimise the risk of exposure to Covid-19 for people living in care. Unfortunately, the substantial swing to the extreme in the other direction caused further significant harm and once again demonstrated the failure to recognise the needs of those living in care.

100. We have set out below our significant concerns around restrictions imposed in and by care settings. We were told repeatedly by those drawing on care and those providing it that access in and out of care settings could not be facilitated because care settings had been granted a different kind of insurance indemnity than the NHS at the start of the pandemic and care providers were concerned that they would face insurance liability issues if they facilitated movement in and out of their care homes. As this was often cited as a reason for obdurately refusing family access, even when guidance relaxed, we invite the Inquiry to investigate whether this was indeed the case and if so, why. It is unclear to our Core Participant group to what extent insurance liability issues were a factor in social care when they were not in healthcare (it is our understanding that NHS insurance may have been underwritten by Government funding but that the same was not true for social care settings), but if true it demonstrates a further failure to protect those living in care and therefore requires investigation.

'Closed door' policies in care homes

101. In March 2020, as the number of cases of Covid-19 grew, many care homes closed their doors – they closed their doors not only to 'visitors' but also to medical professionals, regulators, and carers, and they effectively locked in the people living within the care home. From April 2020 until June 2021, the DHSC published repeated iterations of guidance in respect of care home visits. There was no mention of visits out of care homes at all until December 2020 and DHSC correspondence with John's Campaign in December 2020 recognised that visits into and out of care homes were effectively suspended from April 2020.

102. A full chronology of the development of the guidance on visiting arrangements in care homes throughout the pandemic is set out in the 'Background to the claim: Chronology of the Department for Health and Social Care's Guidance for visiting arrangements in care homes and action taken by John's Campaign in response' document which JC prepared in support of one of its legal challenges to the guidance. We exhibit this document as **Exhibit JC2/088 [INQ000499385]**.

103. The adverse effect of care homes closing their doors cannot be overstated and was a major source of concern and work for us during the pandemic. As set out below, it impacted on a number of separate issues which we also deal with separately below, namely:

103.1. Availability and access to health(care) (by preventing access of external healthcare professionals to care settings, and preventing care home residents from attending healthcare appointments outside the care setting);

103.2. Communication with and involvement of loved ones in a care home resident's life and care;

103.3. End of life care; and

103.4. Inspection and regulation of care provision without people from outside the care home (including loved ones) to provide care, monitor care being received, safeguard people from abuse or neglect, and advocate for people living in care, the quality of care provided and received was significantly impacted.

Visits into care homes

104. The first set of guidance documents published by the DHSC in April and May 2020 prescribed a "closed door" approach in care homes (**JC2/088a [INQ000408077]** and **JC2/088b [INQ000050288]**). The May 2020 guidance provided only for short, socially distanced end-of-life visits (other types of visits were unthinkable at this point in the pandemic). Neither piece of guidance provided for visits out of care settings. Nor was any help given to people in supported living settings, though it was repeatedly promised. The guidance also imposed a 14-day isolation requirement on admission or discharge from another facility (including hospital).

105. It was immediately apparent to us from the approach taken in the Spring 2020 guidance that there was a lack of understanding in the Government of the fact that many family members and close friends are still intimately involved in the lives and care of loved ones living in care, and that many people living in care settings are heavily reliant on regular contact in and with the community. A significant number of people living in care settings were in regular contact with both (medical and other) professionals and loved ones through visits in and out of the care home prior to the pandemic, as a crucial part of their care plan or of meeting their care needs. For example, many care plans, in particular for younger care home residents (including those with cognitive and physical impairments) made provision for regular (often weekly or even daily) visits out of the care home to maintain and facilitate family contact, participate in activities in the community, and develop and maintain social and other skills.

106. Lockdown restrictions began to be eased in the community from 13 May 2020 and we, along with relatives, our campaigning partners, and care home providers, anxiously awaited updated visiting guidance from the Government for care homes, taking a more balanced approach and promising movement towards a more 'normal' life, in line with promises made to the general population. On 4 July 2020, pubs, hairdressers and gyms were allowed to reopen but the Government guidance effectively suspending visits in and out of care homes remained unchanged. By this time, John's Campaign and Care Rights UK along with many other organisations found ourselves spending an increasing amount of time supporting individual family members who were suffering from the enforced separation almost as severely (though in a different way) as the people living in care settings themselves, and were deeply worried about their loved ones confined in their care homes.

107. The guidance on visits into care homes failed until November 2020 even to clearly articulate the requirement for care homes under the law to take into account the rights and needs of individual residents when considering whether visits should be allowed. This had the effect that many were denied visits from loved ones completely until then. Substantial numbers of families had no social contact at the care home at all, while some only had garden visits, and there was no consistent approach being followed by care homes, who each followed their own interpretation of the guidance.

108. For example, in July 2020 we were made aware that even though government guidance had been published on 22 July 2020 encouraging facilitation of visits into care homes (INQ000273457), some local authorities were advising care homes not to follow the guidance and instead to wait for instructions from their Director of Public Health **(see Exhibit JC2/088c) [INQ000511435].** The divide between government guidance and local directives created frustration for people in care homes, their families and care home providers, who felt both bound and confused by the inconsistent and often stringent local requirements and the lack of cohesive messaging. In our experience, interpretations of visiting restrictions often referred to the need to take into account the circumstances within the care home and left unclear that care homes were expected to facilitate access, where possible **(see Exhibit JC2/088d [INQ000511436])**. This was frequently relied on by care homes to deny access. There was also lack of clarity on how the guidance fit with legal requirements **(see Exhibit JC2/088d [INQ000511436]).**

109. Meanwhile, there were no meaningful updates at all on visits by residents out of care settings until the first guidance on this was published in December 2020 **(JC2/088e [INQ000059150]**, and even then as set out below, blanket restrictions applied to such visits meaning that people continued to be effectively confined in their care homes until Spring 2021. We heard from care home managers who found it distressing to have to effectively detain people within their care homes due to the lack of guidance and fear of repercussions if they took the 'wrong' approach. People living in care homes were describing themselves as being in prison.

110. It was not long after the pandemic broke out before all members of our Core Participant group began to hear stories about the effect restrictions on visits in and out of care homes were having on people living in care, especially those living with dementia (who make up about 70% of the care home population in England). There were reports of people suffering increased anxiety and distress; loss of weight, speech and mobility; changes in behaviour; and rapid declines in their conditions. It was those who ordinarily received the most support from their family and who had the most significant contact with the world outside their care home, that research suggested were the most badly affected. (See blog by Marcus Stevens, British Geriatrics Society, "Loneliness – Primary and Community Care" which I exhibit as **Exhibit JC2/089 [INQ000499386]** and 'The pain of isolation - thoughts for Dementia Awareness Week' by Scottish Care, which captures the disproportionate impact of isolation on people

with dementia, and emphasises that many people were not dying from Covid-19, but from the effects of isolation, which I exhibit as **Exhibit JC2/090 [INQ000499387]**).

Visits out of care homes

111. The first time guidance dealing specifically with arrangements for visiting <u>out</u> of the care home 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" (**JC2/090a [INQ000325285]**). 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. For some people we supported this meant that they did not leave their care homes or even their rooms for months on end, which severely impacted upon their mental and their physical health. From December 2020, there were two new sets of guidance (one on visits out and one in respect of making a bubble with friends and family over Christmas) (**JC2/090b [INQ000256371]**). Both pieces of Guidance effectively imposed blanket bans on visits out of care homes (over the Christmas period and otherwise) for care home residents over working age, and both required isolation of the person on return from <u>any</u> visit out.

112. The Secretary of State then issued new guidance in respect of visits out on 12 January 2021 stating that, for the duration of the national lockdown, people living in care homes were required to follow national restrictions and that "*all movements should be minimised as far as possible and limited to exceptional circumstances only*" (**JC2/090c [INQ000325221]**). The reference to visits out only being considered in respect of individuals of working age had been removed, such that visits out (other than in "exceptional circumstances") were no longer contemplated for <u>any</u> group of people living in care homes. To the extent it had been open at all for some people, the door was now again firmly shut on any visits out of care homes.

113. Throughout the period of national restrictions in early 2021, people living in care homes remained confined in their care homes. The effects of the prolonged periods of isolation, loneliness and separation were snow-balling and we continued to hear from desperate relatives about the deterioration and suffering of their loved ones. Many considered the rapid roll-out of the Government's vaccination programme their only hope. By 27 January 2021, approximately 95% of care homes in England had been able to get all their residents vaccinated at least once, according to a poll by the

National Care Forum and, on 1 February 2021 the Government announced that a Covid-19 "milestone" had been reached as vaccines had been offered to all older people in English care homes.

114. In early March 2021, the "roadmap out of lockdown" for the general population in England was announced. A clear way forward was apparently being set out with a definitive end goal – the lifting of restrictions by 21 June 2021. Guidance was also published on 8 March 2021 in respect of visits out of care homes. But, in contrast to the road-map for the general population and to our Core Participant group's real disappointment, it remained extremely restrictive, despite the fact that almost every person living in a care home had now been given two vaccines and the Deputy Chief Medical Officer has described it as "*incredibly safe*" for two fully vaccinated people to meet indoors (**Exhibit JC2/090d [INQ000325311]**).

115. We heard from many carers and relatives later on in the pandemic, who were frustrated that restrictions continued to prevent them seeing their loved ones, at a time when the rest of the world was opening up. For instance, in an article for the John's Campaign website Sarah describes the experience of her 33 year old autistic brother who lived in a care home during the pandemic (**Exhibit JC2/091 [INQ000499388])**. Sarah describes how the Government lifting of restrictions in June 2020 gave her false hope, but that care home restrictions continued to be enforced. This meant that whilst people the same age as Sarah's brother regained their freedom if they lived in the community, he was still unable to see his family.

116. In line with the December iteration of the guidance, the guidance published on 8 March 2021:

  116.1. 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.

  116.2. 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).

117. The guidance was updated again in early May and June 2021 to allow some 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. We welcomed this as a step in the right direction – for many people living in care this was the first time they were able to go to the park in over a year. However, the updated 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 person's care plan and which for some people living in care were the only kind of visit possible consistent with their disability-related needs. It also maintained the requirement to isolate upon initial arrival in care home.

118. The imposition of the mandatory isolation requirements in the guidance had no regard for the individual's needs or circumstances, nor did it take into account the level of risk that actually arose or require a case-by-case approach in line with legal obligations. For example, an individual who had been hospitalised on a ward with no cases of Covid-19, who had been repeatedly tested and fully vaccinated was still required to isolate for 14 days upon arrival in a care home even if he or she was completely disoriented and at substantial risk due to isolation. The guidance did not provide for individual circumstances such as these to be taken into account.

Care Rights UK

119. Our adviceline heard the devastating impact on individuals of these restrictions into, out of and within care settings. They were having a significant detrimental impact on people's health, wellbeing and emotional resilience, and for some people were causing immense suffering (amounting to inhuman and degrading treatment), putting their lives at risk as they felt forgotten and abandoned. This was extremely distressing for their loved ones to witness from afar. They told us they felt powerless, helpless and frustrated that no-one was hearing or taking into account their experiences when deciding these rules. This also had an impact on our (very experienced) adviceline workers, hearing the distress and despair daily, knowing that there were legal rights designed to protect people from this kind of harm, which should have taken precedence over non-statutory guidance but didn't. As a result, our advisors shared people's pain and feelings of powerlessness. As hard as we tried to support people to use their legal rights to challenge these harmful restrictions on the ground, it was clear that there was very little understanding of these rights within the sector and the non-statutory guidance was seen as taking precedence. Some examples include:

> *"Grandma has not been able to leave her care home for over a year now. She has dementia and prior to the lockdown she was very fit and active. She just wants to go for a walk with us. Although she is not one to complain, she tells me 'they won't let me out, it's like a prison'. She asks me 'will I be stuck in here for the rest of my life?' saying she would rather end it all now.*
>
> *I can't bring myself to take Grandma out knowing she would have to endure the suffering of isolation afterwards. When the home had an outbreak, she had to quarantine in her room, which had a grave impact on her mental wellbeing. She became withdrawn and took to her bed, seeing no reason to get up. She said she longed for some wallpaper to look at, rather than the blank white walls.*
> *We try to give her hope, saying change will come soon and we will be able to go for a coffee. It is so difficult for us having to pretend this is the case."*
> Anonymous adviceline caller, April 2021.

120. Patricia (then aged 92), shared her experiences in her care home during lockdown (see **Exhibit JC2/092 [INQ000499389]**):

> *"The worst two weeks were when I had a temperature and had to be barrier nursed. Being tied to the room was horrendous. My door was kept closed and staff had to wear full PPE when they came in. I even had to use disposable crockery for my meals. I would ask the staff for news about my friends in the home. I didn't have a mobile phone so couldn't call anyone. Every day I would pray that someone would take me round the garden - we weren't allowed out of our rooms or in the garden on our own…I hated lockdown, hated the isolation. It was lonely but I did not feel frightened. I have always been independent. I had to fight mentally to survive. I noticed that my voice was weaker as I just wasn't talking so much. I made myself read poetry every day out loud. I felt the isolation was detrimental to my health."*

121. On 15 December 2020, Ruth published her article about her mother's experiences of isolation from her family (see **Exhibit JC2/093 [INQ000499390]**):

> *"Until earlier this month (when the Government changed its guidance), minimising the risk of infection seems to have been the sole concern, disregarding quality of life. My mother hasn't been able to receive a single visit inside the home for 9 months now - just a handful of 'window' or half hour outdoor visits in the summer, spilt between the*

whole family!... My mother luckily still has much clarity of mind, and can usually engage well with us by phone. She has always been remarkably independent and cheerful. However, I feel this situation has been draining her inner resource and its heart breaking when I've heard her say things like "I'm barely existing" and "I'm feeling very low". We're more hopeful now that things will change, but how soon will that be?"

122. Another example is summarised in the article about Shaikh Rehman which is enclosed as **Exhibit JC2/094 [INQ000273475]**. Shaikh's wife, Rosemary was living in a care home after suffering a stroke and also had dementia. He was told in early April 2020 that he could no longer visit her despite buying his own PPE because of restrictions aimed at cutting the risk of Covid-19 infections. Rosemary refused to eat and drink and Shaikh, who had previously spent six hours a day supporting Rosemary to eat and caring for her, was not allowed to enter the care home and carry out his usual care. Sadly, Rosemary died shortly afterwards on 23 April 2020.

John's Campaign

123. At JC, we were inundated with examples of the detrimental impact of the 'closed door' policy in the guidance and the significant distress felt by loves ones who believed it was their responsibility to love and care but who were excluded from doing so. We therefore took steps to challenge the guidance on visits in and out of care homes. Before resorting to legal action, we wrote to all the bishops of the UK and many other faith leaders seeking their support and intervention (see for example **Exhibit JC2/095 [INQ000499392]**). Eventually, as set out below, we felt we had no choice but to take legal action. Care Rights UK supported our challenges by providing supportive evidence and 'case study' examples of the way individuals it supported had been impacted:

Challenging guidance on visits into care homes

123.1. On 9 September 2020 we entered into pre action correspondence with the DHSC challenging the legality of the guidance on visits into care homes that had been published on 22 July 2020 (and updated on 31 July 2020) which I exhibit as **(Exhibit JC2/096 [INQ000273457])**. The Guidance stated that care homes could now develop a policy to allow 'limited visits' (contrary to the effective blanket ban on visits that had been in place until then) and that they should carry out dynamic risk assessment taking into account the care home and local authority's circumstances. Our key criticisms of the guidance included that (1) it failed to articulate the requirement for care homes under the law to take into account the rights and needs of individual residents and carry out individualised risk assessments, (2) made no specific reference to the need to protect rights under the Equality Act and Human Rights Act and (3) the stipulation that care providers should only allow residents to have a single person nominated as their permitted visitor was not warranted.

123.2. We wrote to the DHSC again on 23 September 2020 setting out our observations on the 'Adult social care: coronavirus (Covid-19) winter plan 2020 to 2021' which had been published on 18 September 2020 (see **Exhibit JC2/097 [INQ000499394]).** The Winter Plan required that in 'areas of intervention' care homes should not allow any visits except in 'exceptional circumstances'. We considered this to amount to what was effectively a blanket ban on visits. Exceptional circumstances were not defined but our experience was that care home would generally take this to mean end-of-life only. We informed the DHSC that we had been told by family members and our campaigning partners (Relatives and Residents Association, Rights for Residents, Age UK and Alzheimer's Society) that even those care homes who had been carefully opening their doors were now slamming them shut because of what they understood the Guidance to mandate in 'areas of intervention'.

123.3. We received a pre-action response on 30 September 2020. It did not engage with our concerns. The Government maintained that the Guidance in force at the time and the Winter Plan were lawful, even while agreeing with us about the relevant legal obligations for individualised 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.

123.4. 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 – were said only to apply in 'medium risk' areas. Care providers in 'high' and 'very high' risk areas (which then covered over half of England's population) were told 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 JC2/098 [INQ000499395].**

123.5. In addition to the updated Guidance, the Government also announced a pilot scheme on 13 October 2020 in which family carers were to be treated as key workers (see **Exhibit JC2/099 [INQ000499396])**. Whilst we welcomed the recognition that family carers are crucial care givers and necessary partners in the provision of care to individuals with dementia, we considered the announcement of the pilot to be 'too little too late' and informed the SSHSC of the same in the evidence we filed in support of our judicial review claim filed shortly afterwards. In the statement filed in support of our judicial review proceedings which I exhibit as **Exhibit JC2/100 [INQ000499397]** we stated (at §35):

> *There is no need to 'test' whether it is appropriate for family carers to be treated as key workers: the Social Care Taskforce has already recommended that approach be taken generally, and it has worked successfully for the MHA (the UK's largest charity care provider) through their Essential Family carer scheme, and in other countries. Indeed, and despite this, the Government has not even announced any details of how or when the pilot will commence, adding more unnecessary and harmful delay.*

123.6. 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. As part of this we highlighted the reasons we considered it crucial the DHSC act quickly, setting out in detail what we considered to be the 'hidden catastrophe' in care homes, and the widespread concerns that had been expressed by key organisations and experts (see **Exhibit JC2/101 [INQ000499398]** as summarised on the Leigh Day website). On 28 October 2020, Mr Justice Swift considered and granted our application for expedition.

123.7. On 5 November 2020, the SSHSC 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. Although we were relieved that our concerns in respect of visits into care homes had finally been heard, we were extremely disappointed that it had required filing a legal claim for this to happen. We also felt that it was far too little too late, bearing in mind that many care home residents had by this point faced circa 8 months of harmful isolation and many had died without having the opportunity to spend precious time with their loved ones.

Challenging guidance on visits out of care homes

123.8. 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.

123.9. We received a response to our pre-action letter on 11 December 2020. In his response, the SSHSC 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 advice) and lawful.

123.10. We wrote to the SSHSC again on 17 December 2020, specifically in relation to the requirement to isolate. 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. We also invited the SSHSC to disclose whatever medical evidence he was relying on in justifying the requirement. We drew the SSHSC's attention specifically to the fact that imposing the 14-day isolation requirement after medical appointments was causing individuals to refuse to attend appointments thereby causing a risk to health and requested clarification of whether the requirement applied regardless of the type of visit. We noted that the punitive approach taken in relation to residents stood in stark contrast with the position in respect of care home staff members who showed symptoms or tested positive for Covid-19, or had been in close contact with someone who tested positive, who were then able to return to work after 10 and not 14 days of self-isolation. We highlighted that many care home residents would not be able to face the consequences of isolation (even in exceptional circumstances) and that it was unjustifiable to impose this requirement in circumstances where less restrictive infection control measures were available.

123.11. 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.

123.12. 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 JC2/102 [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.

123.13. The SSHSC then issued new guidance in respect of visits out on 12 January 2021, which I exhibit to this statement as **Exhibit JC2/103 [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 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.

123.14. Updated guidance was then issued on 8 March 2021, which again only contemplated visits out for those of working age, in exceptional circumstances, and imposed a 14-day isolation requirement. We sent another pre-action letter to the SSHSC on 30 March 2021 highlighting that it was paramount for the guidance to make clear that individualised risk assessments in respect of visits out were always required, regardless of age. 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.

123.15. 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 JC2/104 [INQ000499401]**). 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 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 advice relied on was disclosed.

123.16. 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.

123.17. 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).

123.18. On 30 April we were advised that the guidance was once again under review and that a further announcement was to be made shortly. However, the updated Guidance published on 1 May 2021 entitled "Visits out of care homes: supplementary guidance" (see **Exhibit JC2/105 [INQ000499402]**) 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 <u>all</u> visits out.

123.19. 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 JC2/106 [INQ000499403].**

123.20. On 17 May 2021, 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. 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:

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

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

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

123.21. 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 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 fifth time refused to disclose any of the evidence purportedly relied upon. In his response, the SSHSC 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 and the worries they expressed to us and other about how deviating from it might impact their insurance liability (as set out above).

123.22. The guidance was again updated shortly after judicial review proceedings were issued. Once again, 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 social 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.

Inconsistencies in application of the guidance

124. All members of our Core Participant group were aware of examples of the guidance being inconsistently implemented, interpreted restrictively or ignored. As above, the guidance itself was often opaque and contradictory, and didn't make clear the key obligation to carry out individualised risk assessments. This meant it was difficult to interpret exactly what was required by the guidance. Even when guidance did allow visiting, some care providers enforced stricter restrictions than required by the relevant guidance at the time, including because terms such as 'end of life' which allowed for exceptional visiting weren't clearly defined.

125. As noted by the Joint Committee on Human Rights ('**JCHR**') in its report entitled 'Protecting human rights in care settings' published in July 2022 (which we exhibit as **Exhibit JC2/079 [INQ000499376]**) 'from July 2020 to March 2022, the Government's guidance to care homes on visiting arrangements was updated more than 30 times' after its original publication (see paragraph 72). It is therefore no surprise that there was confusion and inconsistent application of the guidance.

126. The JCHR noted that the guidance was not being consistently applied across different settings and reported the following:

73. The frequent updating of the guidance meant that providers were often not aware of changes or had very little time to prepare for changes to be implemented, intensifying the mismatch between care users' expectations and the reality of the service they receive. Nadra Ahmed, Chairman of the National Care Association, which represents small and medium sized providers and affiliated local associations, said: Sometimes it [visiting guidance] came out on a Friday night at 8 pm, which caused us great distress, and would be implemented on the Monday. We were trying to make sure that the right was being met rather than not met.

74. We note with concern that the CQC's own guidance at times has contradicted the Government's guidance. One such example could be found in CQC's guidance for providers about infection prevention and control in care homes, in the section "What good looks like and guidance" as updated on 20 May 2022. The CQC said that "people are supported to isolate in their own rooms where this is recommended under the current admissions guidance, for example when returning to a home from hospital due to an admission for emergency care". However, Government guidance from 3 May 2022, clearly stated that "care home residents should not be required to self-isolate *when discharged back to the care home following an admission into hospital, subject to a negative PCR or lateral flow test". Although the CQC's guidance was updated to correct this discrepancy on 23 June 2022,91 contradictions such as this can cause significant confusion and further deteriorate protections available to care users and their loved ones.*

127. The JCHR noted that evidence suggested that 'the government [had] failed people in care homes by only offering guidance and not mandating what needed to happen'. It noted the difficulties arising from the fact that the guidance was not binding and was left open to interpretation by care providers. The JCHR further referred to the fact that it had repeatedly raised concerns about visiting restrictions and the need to put requirements in relation to visiting on a statutory footing but noted that these requests had been rejected by the government which relied on the CQC to address concerns around visiting restrictions. The JCHR observed that the CQC 'did little' and that it was 'unclear what role it was expected to play', particularly given it 'did not have the power to compel care homes to report levels of visiting' (para 78).

128. The JCHR noted that '*disappointment with the CQC was expressed by many individuals who shared evidence with the Committee about the monitoring of compliance with visiting guidance.*' It referred to the following example from a respondent to its online survey:

> *I have reported the care home to the CQC anonymously months ago because of lack of access and no communication but nothing changed. I wish mum was in prison then I am sure I would have better access and not pay for the privilege of her being locked away.*

John's Campaign

129. Whilst some institutions did manage to adhere to their JC pledges throughout the pandemic, we also heard many instances in health and care settings where JC pledges to support family involvement in care were not adhered to and where vulnerable individuals and their family carers found a bewildering variety of responses across different settings and institutions, and in some cases even within the same settings depending on the member of staff. We also saw a difference between how individuals were treated in traditional healthcare settings as opposed to social care settings; some (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. Particularly later on in the pandemic, we could see a discrepancy between what the guidance actually required, and the restrictions being applied in practice by care settings, and we raised concerns with a number of care settings directly in this regard. In some cases, it was only after our intervention (or after intervention by legal representatives) that the care home accepted that the guidance required them to make individualised risk assessments.

130. We published examples of care homes enforcing stricter visiting restrictions than required, in our 'Midsummer Milestones' booklet (**Exhibit JC2/051 [INQ000176369]**). One contributor described how he was unable to visit his wife in a care home despite local public authorities and NHS bodies denying that there was any guidance in place which required a ban on visiting:

> *Currently my wife's home has a blanket ban on any sort of visits because of "guidelines re: the rise in cases locally". The Local Incident Management Team (i.e. Denbighshire CC, Public Health Wales and Betsi Cadwaladr Health Board) deny having issued such guidance. The manageress of the home has changed her phone number and does not reply to my messages. Once again they seem to be making their own rules, I have complained to Care Inspectorate Wales ('CIW') who tell me that homes can do as they wish; and that it is all to do with fear of litigation and lack of insurance against COVID related claims. CIW say they are monitoring the situation.*

131. As noted above, 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 do not know whether their concerns were justified and ask the Inquiry to investigate this issue which was so often relied upon as a basis for harmful separation and isolation requirements.

132. We also led group discussions and fed back people's experiences by submitting written evidence to Parliament on this issue in October 2021. Our comments regarding discrepancies in visiting practices in care homes included:

> *"No consistency has led to heartbreak".*

> *"Lack of consistency, even day to day within the same care home it can vary. Having to challenge refusals in visiting requests is stressful, at a time when family members are already suffering because of the health of their loved one. It is really rubbing salt into exposed wounds and harming both parties. It's such a cruel situation that no-one ever imagined would happen. One of the many during the pandemic that's been poorly handled with incalculable harm done."*
>
> *"Mums home had an unexpected visit from the cqc and went down from good to requires improvement on well led and safe. The cqc were assured of several things including that the care home were following current guidelines for visits. However there were no essential care give visits. I now have that status along with my sister but it feels wrong that relatives have not been informed of what residents are entitled to. Not everyone is able to keep up with the guidelines so they miss out. I went in to see my Mum for the first time today and as I arrived there was a lady who was visiting at the window. How is that right?"*

Care Rights UK

133. Running a national adviceline for people needing care, we heard first-hand the inconsistencies in approach across England (as the Relatives & Residents Association our remit was primarily England). Individual providers, homes or managers were interpreting the guidance in their own way. This meant two care homes next door to each other could have completely different rules on access to loved ones and carers. We were supporting people to challenge harmful restrictions which were in breach of the care home's legal duties, but people were often faced with several layers of barriers. First, the manager's rules for their individual home. Second, if the home was part of a wider provider group or chain, there were often rules imposed from the owner or 'head office.' Even if people could convince the home/provider that their legal rights took precedence over non-statutory guidance, the next barrier was often the local health protection team or local authority who could be imposing their own 'local' rules in the area. People faced a labyrinth of different rules and interpretations and had to battle many barriers to be heard. Sometimes arming them with the right information about the law and their rights meant they were able to make some headway.

134. For example, when Julie's care home locked down again in the summer of 2022 due to a Covid-19 outbreak, all visits were banned (**Exhibit JC2/107 [INQ000499404]**). Julie and the other residents were confined to their rooms. Julie

lived with dementia, was very sociable and physically active so the confinement was very difficult. Her daughter, Lorraine, was very concerned about the restrictions. After reading our guide 'Visiting and the Law' (see **Exhibit JC2/057 [INQ000231908]**), Lorraine asked the care home to see a copy of her mum's risk assessment. The home hadn't done an assessment for Julie. Lorraine quoted sections of 'Visiting and the Law' and suggested changes to the risk assessment to reflect the risk to life and other harm caused by isolation. The home changed their policy and Julie was allowed visits from her daughter.

135. However, other families were not so successful, and some care homes simply refused to listen or accept anything other than the letter of the non-statutory guidance, or their interpretation of it. Others were sympathetic but unable or unwilling to take on the local health protection teams who held significant power in their areas. We were hearing that providers were being told by local public health teams to 'close to all but essential visits' during an 'outbreak'. Providers would often interpret this to mean stopping visits from essential caregivers too, in contravention of the guidance. The rigid definition of an outbreak in the guidance often led to perpetual, rolling lockdowns in care settings which could go on for months on end. This is why we wrote to local health protection teams to explain the harmful impact of isolation and to point out their own legal duties to protect rights). For want of a better term, it was a 'postcode lottery' for people living in care and their families.

136. Many care homes introduced additional barriers or rules, well beyond those in the government guidance. Some of these additional rules or variations in interpretation of the guidance were farcical. For example, one adviceline client told us her mother's care home were requiring her to clean her car inside and out before she was permitted to take her mother out. Another home required a daughter to have the soles of her feet sprayed with a disinfectant before she could enter, but staff did not have to do this. Other additional rules included insisting visitors to a care home travel to visits in a private vehicle (unfairly excluding those without their own car), restricting visiting times to working hours (which prevented people from seeing loved ones who worked), and only permitting visitors who'd had two doses of the vaccine. We submitted these examples to DHSC as part of our evidence about the impact of its risk-averse approach to guidance.

137. Other care providers took a different approach, managing to maintain access for people's carers and relatives through the pandemic. They recognised the harm

being caused by restrictions, including the negative impact on people's health and wellbeing, and that family carers and relatives often posed less of a threat than the paid care workers – they were only seeing one resident and unlike paid carers were often self-isolating to keep themselves as safe as possible:

"We find those visiting are really understanding of the risks and recognise that to keep their loved ones safe they themselves have to be safe; in my opinion they can be relied on to follow sensible behaviours…Residents in their twilight of life care deeply about spending time with their loved ones, this is an essential part of their care and wellbeing." Richard Hawes, then Chief Executive Elizabeth Finn Homes Ltd, December 2021.

138. Many providers would be reluctant to speak publicly about taking a rights- and risk-based approach. Despite the fact that they were acting in line with their legal duties to people in their care, there was a fear in speaking out in case there were repercussions from the regulator. The country's approach to managing the pandemic created a bizarre situation where complying with legal duties became a secret, to be kept quiet in case Government agencies came knocking to ask about compliance with non-statutory guidance – guidance that we believe was encouraging providers to breach legal rights.

Impact of the 'closed door' policies

139. The restrictions on movements in and out of care homes impacted the nature and quality of care that people living in care were receiving and had severe consequences for their health, wellbeing, and quality of life. We have set out in further detail below the pandemic's more general impact on availability and access to appropriate care, including at the end of life, and this is also clearly demonstrated in the Amnesty report referred to at paragraph 94 above, but we wish to highlight some specific effects of the restrictions on movements in and out of care settings. The JCHR reports in May 2021 and July 2022 held that 'the Government and [care] providers should have done more to recognise the importance of quality of life for care home residents'. It also noted that 'it was wrong to deny essential care givers the right to see their relatives.' Similarly, Ms Herklots' report (INQ000181725, June 2020) explained that the adverse impact of a ban on visits to care home residents, and isolation, caused a serious decline in their cognition and state of mind.

140. For some people living in care homes, lockdown and restrictions on visiting had fatal consequences. We published Dorothy's story on our website (**Exhibit JC2/108 [INQ000499405]**). Dorothy sadly chose to end her life on 5 August 2020 after being subjected to a total-lockdown regime both in hospital and then in a local care-home without anyone being allowed to visit her for a total of seven weeks. Dorothy's husband Steven describes how Dorothy had been impacted by visiting restrictions and the effect her death had on the family:

> *During the day [of Dorothy's death], the GP visited and advised us that Dorothy had exercised the only free choice available to her. She was so distressed at her situation that she had taken the decision to refuse all fluids and medication. She had, in effect "had enough" and had decided to end her life in the only way available to her.*
>
> *The experience has affected all three of us profoundly. My son was prescribed anti-depressants and was medically unfit for work for four weeks. My daughter is depressed and at the age of 73 I feel that my future is bleak living a life of Covid isolation.*
>
> *I believe that had I been allowed to visit my wife she would be alive today….*

141. As Steven summarises at the end of his testimony regarding Dorothy's experience, "*[a]ny policy to counteract the Covid virus must not result in a worse outcome that that of the virus. For Dorothy, it unfortunately did.*"

142. The statements from two care home representatives included in 'Midsummer Milestones' (**Exhibit JC2/051 [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 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).

143. The exclusion of family carers and visiting restrictions, often resulted in families having to make difficult choices about care arrangements. For instance, in a blogpost for our website (**Exhibit JC2/109 [INQ000499406]**), Jill explains how she made the difficult

choice to take her disabled daughter Amy out of her care home during the pandemic, despite this putting a physical and mental strain on Jill and her husband because of Amy's complex care needs. The majority of families had no choice: either the vulnerable person was in a residential setting from which they might be completely debarred, or the person was at home with no external support for what might be dramatically increasing needs.

Care Rights UK

144. Like JC, we observed that restrictions on visits in health and care settings had a devastating impact on the physical and mental health of people needing care. The JCHR report in July 2022 quoted evidence I had given and highlighted the importance of meaningful contact with loved ones:

> *67. The availability of meaningful contact with loved ones plays a vital role in the support and care of individuals in care settings, and visiting restrictions have seriously affected this. Helen Wildbore, from the Relatives and Residents Association, told us: We are talking about meaningful contact with people who are most important to you, and maintaining relationships and lifelong bonds. Restrictions have had a hugely detrimental impact, not just on residents' mental well-being but physically (…) We know that people have stopped eating and drinking. They have lost weight, mobility and speech (…) These restrictions are isolating for family members and friends on the outside too, locked out of the usual roles that they play as a loved one, as a carer and as an advocate (…) They are feeling guilt, (…) and pain, anxiety and frustration, but they feel powerless. People tell us that they are grieving for someone who is still alive.*

145. 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 and/or care. Family carers can help practically, such as by accompanying a person during health/care appointments or discussions about their care, helping with communication, spotting health concerns/pain/deterioration that someone who does not know the person 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.

146. For people who don't have capacity to be fully involved in care discussions and decisions, the support of their chosen representative can be vital to ensuring the care staff get to know them, understand their likes and preferences, and create a care plan to meet their needs. Suddenly being cut off from this vital support had a hugely detrimental impact on people's health and the quality of their care. It also meant relatives and friends were unable to properly perform their legal roles as Power of Attorney or Relevant Person's Representative, leaving the person without the support they need during important care decisions. For example, we heard that when a woman moved into a care home, her daughter was not permitted to help her get settled. Despite having Power of Attorney for health and welfare, her daughter had not been involved in any care planning and was struggling to get essential caregiver status. The closed door policies have led to a closed culture developing in many care settings, where lack of inclusion of people's chosen representatives and relatives has continued.

147. One of our adviceline users told us: 'I have lost my relationship with mum. I can give her no comfort, no reassurance, no love. I don't know how she is coping and I worry about her physical health when it's only me she would tell if she were in pain.' Another adviceline client 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.*'[7]

148. The emotional support of family carers is also crucial for helping to reduce the stress of moving into a care setting, discussion of care plans and attending health appointments, providing familiarity and 'continuity of care.' The failure to recognise and facilitate this vital support led to wholesale interference with people's rights and unnecessary pain and suffering.

149. This support was increasingly recognised as the pandemic progressed, with guidance more clearly recognising the role of family carers, following our campaigning, and lobbying for change with JC and others. For instance, the guidance

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[7] **Exhibit JC2/042 [INQ000273449],** page 17, paragraph 5.

published on 22 March 2022 (exhibited to this statement as **Exhibit JC2/110 [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 parts of the same care setting.

150. Even when the role of essential caregiver status was written into guidance, the introduction and implementation of this caused other problems. When the role was introduced, the guidance only permitted more than one essential caregiver per person in exceptional circumstances, such as where the nominated essential caregiver was unwell. This led to immense strain and pressure on the relative or friend chosen, as an adviceline client (a daughter and essential caregiver) told us: "The pressure is so immense and distressing. It is ruining my life and relationships. I can't sleep, it overshadows everything I do. I feel permanently guilty when I am not by my mother's side. I get home after a 4 hour round trip and know I cannot continue like this. But I do. The worry is constant and there is no end in sight."

151. This also meant that people who might need support to carry out the role were unable to be nominated. One of our adviceline clients told us her dad was still unable to see his wife as he would need support for the visit. Instead, she, as daughter, was nominated as the essential caregiver but he was not permitted to accompany her. The daughter told us she felt guilty about being allowed in when her father wasn't: "My mum asks for him every time I go".

152. Implementation of the guidance on essential caregivers was patchy, with many care providers using their own interpretation of the guidance, as set out above. Many people contacting our adviceline had to battle with care providers to be granted the role. This caused a lot of frustration, pain and anxiety to people who only wanted to be with and help care for the person they loved. Many were denied this role. For example, Ann, one of our adviceline clients, shared her experience: "My request for Essential Care Giver status was denied. I was told this was only intended for situations where the presence of a relative was required to deliver essential care. When I said that this was not what the guidance stated, the care home manager insisted that I was

wrong and issued notice to leave. The manager proposed a regime of strictly monitored, time limited visits, with no opportunity to extend these unless mum was assessed as end of life. She was always upset and cried when I came, and then begged me not to leave her when the 30 minutes were over. Mum was never assessed as having reached end of life and she died a week before the notice to leave was due to expire. Sitting with my mother's body was the longest time I had been allowed to spend with her since she had entered the care home sixteen months before" (See **Exhibit JC2/111 [INQ000499409]**).

153. As the pandemic developed, care homes tried to facilitate alternatives to visits in the care home. Whilst some relatives were grateful to at least be able to communicate in some form with their loved ones, the alternatives to visits often resulted in confusion and further distress, particularly for people with dementia and other cognitive disabilities who didn't understand why a relative could only communicate with them through a window or a screen, and not hold their hand or settle them back into their room after the visit. For some people, meeting loved ones in a visiting room was confusing and distressing. An adviceline client told us his wife, who lived with dementia, would get up and walk out of the room, leaving him alone, returning distressed that he had not followed her to their usual spot in the lounge. Timed visits were particularly distressing. One adviceline client who was only permitted an hour visit with her mother told us: "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." Visits in pods were incredibly distressing for some people, especially those living with dementia, who couldn't understand why they were being put in a pod, why they couldn't reach out and touch their loved one, and many had trouble hearing each other.

154. We highlighted the impact of visiting restrictions and the inadequacies of alternatives to direct visits on our website. Examples we spotlighted included:

154.1. The story of Tony (**Exhibit JC2/112 [INQ000499410]**) and his experience visiting his wife, Rita, in a care home during the pandemic. Tony tried to visit Rita through various different visiting restrictions. He once visited Rita in full PPE, and they were able to hold hands in gloves. At a point when direct visits inside the care home were not allowed Tony "*kneeled on the ground to speak to [Rita] through a crack in the window.*" As some restrictions lifted Tony would take Rita out the care home but saying goodbye in the carpark would be very distressing for Rita, who could not understand why Tony was not allowed to come inside and would get upset and blame Tony. This experience was heart-breaking for Tony, who eventually, after sending resources we produced on the essential caregiver role to the care home manager, was allowed to spend quality time with Rita inside the care home.

154.2. The first-person testimony of Frances, who describes her experience living in a care home during the pandemic (**Exhibit JC2/113 [INQ000499411]**). Frances describes the extreme impact visiting restrictions had on her mental health and explains how frustrating alternatives to direct visiting were for someone who was deaf:

> *Lockdown was worse than living through the war. During lockdown I felt trapped, lonely, depressed and forgotten. For over a year I only saw family by appointment, through glass, at a distance. I am deaf so it was very difficult and frustrating to communicate. For 65 days I was isolated in my room; no fresh air, no exercise, no one to chat to. I felt like a caged animal, just fed and watered!*

Impact of visiting restrictions on access to (health)care

155. Lack of access to family carers exacerbated the already existing limitations on availability of and access to appropriate care. 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 failure by staff to wear appropriate PPE or adhere to appropriate infection prevention measures, 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.

156. In addition, we found it difficult to build a good understanding of whether appropriate care was being provided because loved ones were being excluded and couldn't witness the care that was being delivered. We therefore consider that many issues around inadequate care provision are likely to have been tragically underreported with the lack of monitoring of both the quality and quantity of care severely impacted during the pandemic. Without loved ones and regulators regularly accessing care settings (including unannounced) there is no way of knowing what was

actually happening behind closed doors and the level of harm and suffering is likely far greater than we can even imagine.

157. As set out above, 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. 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.

158. We heard stories of care home staff not adhering to infection prevention control measures or wearing appropriate PPE in circumstances where loved ones were excluded in the name of infection control. For example, one nurse at Eccleston Court Care Home in St Helens was struck off after multiple failures in care, including failing to provide sufficient medication, as well as vital information to paramedics and failing to wear appropriate PPE on more than one occasion (See **Exhibit JC2/114 [INQ000499412]**). The nurse admitted to not ensuring suitable infection controls were in place, despite telling the home's quality director she had been wearing the correct protective equipment.

Care Rights UK

159. Our adviceline also 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.

160. Respondents 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.'* [8]

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[8] **Exhibit JC2/042 [INQ000273449],** page 10, paragraph 4.

> *It was a huge worry, balancing Dad's need for treatment against the effect of isolation. Dad had Alzheimer's and didn't understand not being able to see family and became distressed when he felt "abandoned". Treatment had to be delayed so Dad didn't live half his life in isolation.*

161. The isolation requirement meant that those receiving care, and their loved ones often ended up making a choice between healthcare and essential social interaction:

> *It was very difficult to choose between essential healthcare for my father in law, and essential 1-2-1 interaction (e.g. personal visits, personal care) for him.*
>
> *Massive impact on my mum, 2 weeks isolation after a hospital visit. After this she even didn't go to her sister's funeral as it would have meant [sic] another 2 weeks isolation, she hated it.*

162. Our July 2023 survey entitled 'Healthcare Experiences of Care Home Residents during the Covid-19 pandemic' which focussed on the effect of the Covid-19 pandemic on recipients of care (which I explain in further detail below) found that 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. We prepared this survey specifically to collect evidence for the Covid-19 Inquiry. We have shared it with our networks, but the main purpose was to inform work on our witness statement for Module 3.

John's Campaign

163. 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.

164. Like Care Rights UK, we also found that restrictions on people coming in and going out of care settings had a significant impact on access to care. GPs, district nurses, dentists, podiatrists, physiotherapists and other professionals were unable to gain access to care settings to provide their much-needed services. Individuals

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) and individuals' health and wellbeing thus declined. 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.

165. 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 JC collated into the booklet 'The Holding Pen', which is exhibited to this statement as **Exhibit JC2/013 [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 appointments, because he was so anxious about having to isolate again after returning from them.

166. Whilst the isolation requirements would be challenging for most people, they were acutely challenging for many people living in care homes because of their medical conditions and specific needs. Approximately 70% of people in care homes have dementia or severe memory problems. A person with dementia may find it much more difficult to start an activity without prompting, and may be reliant on others suggesting and organising activities (**Exhibit JC2/115 [INQ000499413]**). Consequently, the isolation requirement had a particularly stark impact on those with dementia and other cognitive disabilities, as evidenced by the testimonies in 'The Holding Pen' **Exhibit JC2/013 [INQ000273453]**:

> *If [my daughter] had to stay in her room for 14 days it would have a detrimental impact on her health and wellbeing she would withdraw and hit herself in the nose out of frustration as she loves the banter from the staff and the social aspect of being around people, doing crafts, planting, cooking all the usual activities she knew she would be missing out on if she were in isolation.*

Another contributor told us that their loved one: '*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*'.

Mum needs the stimulation of activities that the home provides in the communal lounge and without this she sank into a deep depression.

Carers do not have time to spend 1-1 with residents so they are spending most of their time in isolation alone, with no stimulation and 4 walls for company. My mum is 100% dependent on a carer; she cannot use a phone, she does not know how to turn on her TV and radio, and she has no concept of Skype.

167. As set out above, the 'visit out guidance' effectively imposed blanket bans on visits out of care homes. 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 above, we wrote to the SSHSC repeatedly setting out our concerns about this.

168. The case studies we collected and filed in support of our legal challenge to the guidance on visits out and exhibited to this statement as **Exhibit JC2/116 [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 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'.*

169. 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 (exhibited as **Exhibit JC2/117 [INQ000499415]**) 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*'.

170. People we supported in care settings became reluctant to seek help for health problems due to fears of facing isolation 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. For example, A, who looks after her husband who has dementia told us: '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'[9].

Connecting with loved ones at the end of life

171. A significant aim of end of life care is to minimise suffering and ensure dignity. A key aspect of this is working with relatives and friends to ensure that the individual feels loved and supported, to lessen their pain. Feeling like support was given and quality time spent is also key in helping the bereaved 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 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 including because they were not considered to be dying 'actively enough'. It was a source of significant anguish, and we continue to hear of suffering from the trauma this caused.

Care Rights UK

172. 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

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[9] Person supported by John's Campaign.

Exhibit JC2/118 [INQ000273464]). The CQC guidance to providers on end of life care exhibited as **Exhibit JC2/119 [INQ000499417]** also include the following key questions:

> *Are people's preference and choices for their end of life care and where they wish to die, including in relation to their protected equality characteristics, spiritual and cultural needs, clearly recorded, communicated, kept under review and acted upon (Regulation 3.1)*
>
> *How are people, and their family, friends and other carers, involved in planning, managing and making decisions about their end life care (Regulation 3.2)*

173. Despite clear guidance from the NHS and CQC, our survey suggests that the integral role of family and friends in providing care and support at the end of someone's life was often not prioritised.

174. Despite NICE guidance defining 'end of life' as the last year of a person's life **Exhibit JC2/120 [INQ000273465]**, our helpline repeatedly heard that end of life was given a much more restrictive definition across different care settings during the pandemic. One helpline client told us in February 2022 that six months after being diagnosed by a consultant as having 3-6 months left to live, they were still being denied end of life visits with their loved one. The family was told that their relative was 'only receiving palliative care' rather than being at the end of life.

175. We heard through our adviceline that end of life visiting often wasn't granted until the final weeks and days of life, or was 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.

176. We spotlighted John and Lesley's story on our website in November 2020 (see **Exhibit JC2/121 [INQ000499419]**):

Lesley and I have been together for 45 years. We have two sons and five grandchildren. At 62 Lesley was unfortunately diagnosed with young-onset Alzheimer's. I initially looked after her at home but after two years reluctantly agreed she should go into a nursing home. It was an exceedingly difficult decision, but as her disease progressed it would not have been possible for me to look after her. For six years I visited her every day, to feed her and give her drinks as well as just being with her. This was until 9th March this year when the home closed to visitors. Now we can only meet from two metres away and wearing a mask. It makes it impossible for anyone with advanced dementia like Lesley to understand or interact in any way.

On 1st October I received a call from the care home saying that Lesley was not eating, drinking or taking her medication and thought to be nearing the end of her life. Consequently, I was allowed to go and see her in her room, which was very upsetting as I got no reaction. I had two more of these visits, and Lesley was still very weak and still not eating or drinking. On the fourth day, I rang the home and was told that she had now taken a drink and her medication and was to be given something to eat. She was also much more alert. She was not now considered end of life, which of course was good to hear, but I was told that I could not now visit in her room again.

I appreciated the opportunity to see my wife, of course I am pleased to know that she is now more responsive and eating and drinking. I could use stronger language but I am very disappointed and angry that I am not able to continue to see her other than from a socially distant visit in the porch. Although I didn't get any response when I visited, I am of the strong opinion that she would have known that I was with her and this would have contributed to her recovery. My visits for 3 days must have helped with the vast improvement. She was not able to swallow so was not drinking or taking medication at that time, so how did she improve so much?

I accept that the care home is only doing what they are told to do, and I am not questioning their care. However I feel strongly that the line taken is cruel and heartless. Visits from two metres do not work for us. As she was so unwell I didn't consider it right to expect her to be brought into the cold porch, with the front door left open.

> *This situation can't go on for ever so something has got to change. Eight months is already too long.*

177. Unfortunately, the story of John and Lesley is one of many heartbreaking stories we heard, where loved ones felt their presence would have made a real difference but who were refused the opportunity to be there.

John's Campaign

178. 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.

179. The well-intentioned practice of asking care staff to video a dying patient for their family or pass on messages was seen by many as an affront to human dignity. A carer is a person, if they could be there in suitable PPE, why not a family member? We asked managers and staff in 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. Often, we did not receive a response or were simply told something to the effect that nothing could be done in the circumstances.

180. 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 JC2/122 [INQ000273466]**). Despite this, in our experience many individuals faced significant battles with 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 misunderstandings 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).

181. One particularly stark example 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 (including not being allowed to see him for 121 days between March – July 2020 and on what she thought might be his last birthday) due to restrictions imposed by his care setting. I exhibit a report by *The Mirror* of this family's story as **Exhibit JC2/123 [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 for 'end of life', 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 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.

182. Matters were made worse by failures to define terminology around the end of life. For example, in Wales, guidance which I exhibit as **Exhibit JC2/124 [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 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 as discussed above.

183. JC wrote to Public Health Wales (PHW) setting out our concerns in this regard. In the correspondence, which I exhibit as **Exhibit JC2/125 [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.

The Patients Association (PA)

184. 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 summarised in the report, there were also clear examples of failings in services at the end of life, and people were not always able to stay in contact with their loved one at the end of life. 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.'*[10]
>
> *'Not being able to be with loved ones at the end is unforgivable.'*[11]
>
> *'Visiting restrictions due to COVID-19 made my sister's last days/weeks terrible for her and our family.'*[12]

185. Closely related to this were issues of communication (which we explore in further detail below): 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

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[10] **Exhibit JC2/052 [INQ000273424]**, ibid, page 39, paragraph 4.
[11] **Exhibit JC2/052 [INQ000273424]**, page 39, paragraph 5.
[12] **Exhibit JC2/052 [INQ000273424]**, page 39, paragraph 7.

someone's condition during their final illness, respondents to our survey provided a polarised set of responses, evenly split between good and bad.

Communication with and involvement in care of loved ones

186. Across the surveys and evidence we collected, poor communication was a common thread. All members of our Core Participant group observed that patient involvement in decisions suffered significantly – or was absent entirely. All members of our Core Participant group observed issues around lack of communication for those requiring care 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 care (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

187. Our adviceline heard that a lack of communication with people needing care was a major problem during the pandemic, particularly in the early stages. As the friends and relatives of people needing care, our adviceline 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 care their loved ones needed and relied upon. One family member told us "I've been working really hard to keep mum living well with dementia, to stimulate her. That's now fallen off a cliff. COVID has pulled up the drawbridge. I feel so shut away from her."

188. 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 adviceline client in August 2021 told us about their loved one who was living in a care home that their *'medication was changed without consultation with them and they were placed on medication they had previously had a bad reaction to.'*

189. We also heard from relatives who felt let down that they were not being consulted by care homes regarding their loved one's care. For instance, we highlighted the experience on our website, of how one relative felt completely shut out from being involved in choices regarding her mother's care:

> *I feel powerless and like I've let her down. No-one is asking us what would make this better, how families could be partners in care. There is no space for our opinions. Covid has wiped out any notion of consulting and involving families, as care homes have gone into survival mode. The mantra has become 'we are following guidance' no matter how big the holes in it.*

190. Relatives and friends also struggled to find out news and updates on the health and care 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 and wellbeing resulting from isolation from family and friends was often shocking and distressing.

John's Campaign (JC)

191. 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 than speech for many people with cognitive impairment and unconventional communication. 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 care settings. Whilst some care settings welcomed family carers for this important reason, others refused entry in the name of infection control.

192. Especially for individuals with cognitive impairment who may not communicate via speech, a loved one can be a key interpreter of their non-verbal 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.

<u>Other Infection Prevention Control Measures and their impact</u>

193. 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 such as glass/plastic screens and imposed distancing. 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

194. Our adviceline 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 care and health professionals and engage in decisions about their care.

195. It also made their interactions with their loved ones (to the extent these were allowed) more difficult, particularly where disabilities meant that the IPC measures used had a significant impact. The experience of Hazel (daughter) and Barbara (mother living in a care setting) illustrates this (**Exhibit JC2/126 [INQ000499424]**). Barbara was deaf, so she struggled to communicate via phone and Hazel was only able to Facetime Barbara when she was supported by staff, meaning they had no privacy. One week Barbara phoned Hazel unexpectedly, asking why Hazel had "abandoned her". As some restrictions eased, Hazel was allowed to see her mum through a closed window, but this was incredibly difficult given Barbara was deaf and couldn't hear what Hazel said. Eventually, Hazel secured a mere 30 minute weekly visit with Barbara in a room with a partition and a microphone. Hazel describes how these visits were unsuccessful and did not meet Barbara's needs; Barbara could still barely hear Hazel and kept trying to touch the plastic partition to reach out to Hazel. She became distressed by the fact that they were not allowed to be closer or to touch. One visit was particularly distressing for Hazel, when Barbara announced "this is silly" and walked out meaning that this was the only contact Hazel and Barbara had that week.

John's Campaign (JC)

196. We were repeatedly told that PPE was not offered to supportive family members who were being refused access to their loved one, 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.

197. Like Care Rights UK we heard that there were significant communication challenges arising due to the use of PPE 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.

198. 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, 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 JC2/096 [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.

199. We also observed that some care providers' focus on infection control measures at all costs, meant that people receiving care were sometimes denied the basic and dignified care they needed during the pandemic. We excerpt some particularly shocking testimonies from 'The Holding Pen' (**Exhibit JC2/013**):

> *[My daughter] has experienced isolation when a member of staff brought the disease into the home. She found isolation extremely difficult and was phoning us at nearly every hour of the day. It had a serious effect on her mental health. She has physical problems as well. So she went all the 14 days without a shower as staff could not help her when she had Covid.*
>
> *Contact with staff was kept to the absolute minimum, showers were offered every 3 days and there were no activities apart from a TV and radio (which we provided).*

200. Another form of infection control which we observed, was the shutting down of activities in care settings (even when a resident was not being formally isolated). People with conditions such as dementia have a greater need for stimulation, without which they may become agitated and/or their condition may deteriorate. As outlined in 'The Holding Pen' (**Exhibit JC2/013**), some care settings greatly reduced or even suspended all activities that were not considered 'essential' care, meaning that residents were left without anything to do and without stimulation they required as part of necessary care for their condition. This had a significant impact on both their cognition and mental health:

> *[Mum] has had nothing to do, is losing all ability to carry out things like turning off the TV or making a cup of tea because all this has been taken away. She has had to remove her jewellery, cannot have her nice glass vases, has been told not to have too many clothes etc. etc. I feel she is becoming institutionalised. She has lost everything she holds most dear to her. This is not a life.*
>
> *[My mother's] cognitive decline has been significant even considering her existing condition [Alzheimer's]. It has driven her literally mad. She repeats the same phrases over and over again: 'I've got nobody' 'Nobody comes' 'Where are the people?' 'There's nothing' 'Absolutely nothing"*

Availability of and access to appropriate care and resulting impact

201. As a Core Participant group we have seen and heard firsthand of the harm done as normal care practices were disrupted and neglected as the UK's care system responded to Covid-19. We have seen many cases where people in care have been denied access to the health and care that they need. 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 care system which, they believe, let them down when they most needed it.

Care Rights UK

202. As care settings went into lockdown and there was an urgent move to discharge as many people from hospital as possible, care planning and discharge planning took a back seat. We supported families where a loved one had been rapidly discharged from hospital without appropriate planning or involvement of the person or their chosen representatives. This meant many people's care needs went unrecognised or

unmet, with detrimental impacts on people's health and wellbeing. Blanket policies exacerbated these problems, such as the policy on discharge from hospitals without testing a position that remained in Wales for weeks after testing was required in England, and later discharging people who had tested positive from hospital into care. We raised our concerns about these blanket policies failing to allow for individual care planning to ensure individual needs were met but there continued to be a focus on institutions over individuals which caused harm throughout the pandemic.

203. We explained in our Module 3 Witness statement (and therefore do not repeat in detail here) that access to healthcare, therapies and personal care such as chiropody and dentist visits 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 JC2/042 [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

'*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

204. Our adviceline 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 affecting cognition, such as dementia. As a result, often neither the person needing care nor the person they were speaking to 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.

205. One caller to our adviceline described her mother's experience of video consultations and she later wrote about this on our website (see **Exhibit JC2/127 [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.*'

206. As set out above, in addition to information collected from our adviceline, we have also drawn on the survey we conducted in July 2023 entitled 'Healthcare Experiences of Care Home Residents during the Covid-19 pandemic', that focussed on the experience of the Covid-19 pandemic on recipients of care. A series of 26 questions were developed 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 for care home residents included:

206.1. 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.

206.2. 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.

206.3. 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.

206.4. 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).

206.5. Concerningly, 41 out of 291 respondents reported that, at the time of responding to this survey (Summer 2023), the person in care had not resumed normal face-to-face appointments with all health professionals that they need to see.

207. We were concerned not only by the reports we heard of inadequate provision of medical but also of personal care. In our evidence to the JCHR (See **Exhibit JC2/128 [INQ000499426]**), we noted that in some cases we were hearing of problems relating to "lack of food or fluids leading to malnutrition/dehydration", and "neglect or

lack of care leading to harm/suffering". We provided an example from an anonymous adviceline client: A son became concerned about his father's care after noticing he was not always getting his medication or appropriate diet, was becoming depressed and had a poor quality of life. We supported the son to secure a review of his father's needs and he was moved to a more appropriate setting.

208. Evidence reported by the JCHR in its July 2022 report (see p.32) shockingly included the following examples:

When he [respondent's father] became incontinent, they left him in dirty incontinence pants for 48 hours […] as he became bed bound, they left food and drink out of reach, no help with eating.

He [respondent's brother] told me about the conditions at the care home including that it was dirty and that call buttons were not responded to. He fell out of bed one night and fractured a bone. Staff did not respond to calls and he had to phone an ambulance himself.

209. These are just a few of many examples we heard of where personal care was neglected and people needing care were left with inadequate or inappropriate care, sometimes without even the most basic things to ensure their comfort and dignity.

John's Campaign

210. Like Care Rights UK, we heard that there were efforts to 'fill the gaps' with digital appointments in care homes, which often caused confusion and did not allow for proper medical examination of individuals. 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 on where to turn for help 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.

The Patients Association (PA)

211. Across the three reports we prepared referred to above at §58, we saw a sustained pattern of difficulties in accessing health and care services. Our surveys and by extension the responses to them predominantly focused on healthcare and the experience of patients, but responses included some observations about difficulties in

accessing care and the lack of proper coordination between health and care services. Cancellations, delays, and long waiting times characterised the experiences of many during the period our reports covered. This extended to all services, but GP and hospital appointments were the most starkly affected. A small, but nevertheless important, number of respondents told us they were struggling to access social care, welfare benefits and bereavement support.

212. Patients lacked confidence about a return to normal in the NHS and care services (though their responses to us focused on the former). Many were fearful about the implications of this for their care 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 in a variety of health and care settings, including care homes, that went above and beyond in supporting the people they care for.

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

The early pandemic patient experience report

214. As set out in the summary of the report (**Exhibit JC2/052 [INQ000273424]**), 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.

215. Significantly, more than half of respondents 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 that hadn't been supported emotionally when receiving 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.

216. Some responses included concerns about the provision and funding of community care, including in care homes:

> *Much more local support in the community, and allowance therapists to visit patients at home or in care homes.*
>
> *The Government needs to put more money and resources into health and social care. So both as they form part of the same care pathway to better patient outcomes…*

The follow up patient experience report

217. The second survey (**Exhibit JC2/053 [INQ000273425])** 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 made a number of key findings relevant to the scope of Module 6:

217.1. 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. Access to primary care services continued to be particularly difficult.

217.2. 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.

217.3. Disruption to care continued to be significant:
 217.3.1. 63% of our respondents had appointments cancelled or postponed.[13]
 217.3.2. 66% reported struggling to access at least one form of care.[14]
 217.3.3. 56% reported delaying accessing treatment.[15]

217.4. The concerns and anxieties felt and expressed by patients during the first survey had not abated: 70% were worried that treatment and services would be less accessible in the future. That figure had not changed at all since the first survey, and

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[13] **Exhibit JC2/053 [INQ000273425]**, page 3, paragraph 5.
[14] **Exhibit JC2/053 [INQ000273425]**, page 3, paragraph 5.
[15] **Exhibit JC2/053 [INQ000273425]**, page 3, paragraph 5.

our Executive Summary concluded that '*so far patients' concerns about ongoing difficulty accessing services have unfortunately been well justified*'.[16]

217.5. 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.

Patient experience before Omicron report

218. We carried out the third survey (**Exhibit JC2/054 [INQ000273426]**) in order to continue to monitor developments towards the end of 2021, including in relation to access to services, remote healthcare, delays and cancellations. In our report we also placed the survey in context, describing significant developments which had occurred in the six months prior the survey. 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**.*[17]

219. Although our survey and the resulting report focused on access to healthcare, we also reported on the decision that had been made to require social care staff to be vaccinated due to our specific concerns about this. We noted that:

> *[I]n adult social care all care home workers were required to be vaccinated from November 11th. Concerns that up to 8% of the workforce could be lost, arising from a National Care Forum survey, were widely reported. This followed a pattern of substantial losses of staff over the previous six months, estimated at 50 -70 000, to better-paid work in retail, hospitality and other sectors.*[18]

220. The capacity (including workforce) of social care was already overstretched prior to the pandemic, due to chronic underfunding. Consequently, the sector was particularly vulnerable when Covid-19 hit, as there were simply not the resources or

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[16] **Exhibit JC2/053 [INQ000273425]**, page 3, paragraph 6.
[17] **Exhibit JC2/054 [INQ000273426]**, page 3, paragraph 3.
[18] **Exhibit JC2/054 [INQ000273426]**, page 10.

workforce to cope with the increased demands. The introduction of vaccine requirements which was shown to further impact staffing levels was therefore of particular concern to us because we felt that the sector would simply not be able to cope with even fewer staff. Without the staff, care settings or any form would struggle to provide even their most basic services with significant detrimental impacts of those in need of care.

Provision and quality of end of life and palliative care

221. Throughout the pandemic, our Core Participant group heard of concerns about end of life care. These related both to the access given to loved ones at the end of life (as set out above), and the quality of end of life care being provided. In this section we focus on the issues we heard about relating specifically to the provision and quality of end of life and palliative care.

Care Rights UK

222. 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. Some responses commented on how there were not sufficient staff to provide individual care, meaning that dying people received very little support at the end of life, and on the adverse impact of restricted access to healthcare on end of life care. For example:

> *Devastating impacts, no support to me as the person having to face such horrific circumstances alone and no support for my mum stuck in a room dying alone. The carers don't have time for emotional support and especially when they were dealing with 22 other deaths in the rooms around them.*
>
> *The GP was very reluctant to visit and the care home made no attempt to help my Mum obtain end of life care.*

223. Respondents also spoke about how lack of appropriate end of life care impacted not just the person living in care, but also their relatives and loved ones; failure to provide appropriate palliative care caused great suffering and trauma for family members who witnessed it. One survey respondent said their relative had *"an unhappy and difficult death" which caused "[a]nguish for family. Lasting trauma"* whilst another said '*dad died without good end of life support. I experienced PTSD*'.

224. The responses to the survey also raised 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.

225. One aspect of the important role that family and friends can play in an individual's care is in assessing when their loved one needs end of life care, and, as set out above, this was disrupted by visiting restrictions during the pandemic. Some care providers used technology when someone receiving care was reaching the end of life. As is clear from responses to our May 2023 survey **(Exhibit JC2/042 [INQ000273449])**, a video or telephone call is not an adequate replacement to in person visits or assessments, and deprived many people of the opportunity to properly say goodbye to loved ones. One respondent told us about her mother's end of life experience and the fact that technology was not an appropriate means to deal with this situation:

> *Great distress to us both. 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. Video calls were very difficult as she couldn't see or hear properly.*

John's Campaign (JC)

226. 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 health and care professionals and the patient's 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.

227. 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. As explained above, 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. We also heard of concerns that medication may have been administered when it should not have been, possibly hastening death. 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, and more limited oversight. 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.

228. In end of life care and care more generally we were told of a sense that because 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).

<u>The use of DNACPR instructions</u>

229. DNRs, DNARs, and DNACPRs are all abbreviations referring to an advance decision made by medical staff not to attempt cardiopulmonary resuscitation (CPR) on a person who has stopped breathing, or whose heart has stopped. It is important for individuals and their loved ones to understand how these decisions are made so

they can have informed discussions with health and care professionals, and hopefully reach an agreed decision. These discussions should take place between the person and his/her healthcare professionals (between those needing and providing care), with relatives and carers involved if the person wishes or 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 JC2/129 [INQ000499427]**) 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'. The BBC reported on 1 April 2020 a story about a GP surgery sending a letter asking people to complete a DNAR which caused concern, anxiety and distress for the recipients, who felt "worthless" (see INQ000181737 HH/8). Commenting on how older people had felt during the pandemic in her evidence to the Inquiry in Module 2b, Ms Herklots said: "some were feeling that their lives weren't valued, that they weren't important... those feelings were compounded by things like the issuing of the letter from a GP surgery in Bridgend about DNACPR, which caused huge distress..." [2/128/3-11].

230. Although it was sadly true that the pandemic placed unprecedented demands on both the health and social care system and hence resources were a significant issue when deciding on what treatment and care an individual will receive, the applicable legal requirements did not change. As was set out in guides published during the pandemic (see **Exhibit JC2/130 [INQ000499428]**) and reinforced by the welcome statements from NHS England and others, such as the CQC, decisions about resuscitation should be taken in consultation with affected individuals, and on an individual (not a blanket/group) basis. These decisions should not be taken secretly from a person or their family. For individuals 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. Crucially (and it is therefore worth repeating this): there should be no blanket decisions.

Care Rights UK

231. 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 adviceline and our survey findings showed serious issues surrounding the process of consultation on DNACPR decisions. In November 2020, the CQC published an interim report that highlighted the pervasive problem of blanket decisions being made with regards to DNACPR decisions (see **Exhibit JC2/131 [INQ000235491]**). Evidence collected through our May 2023 survey further confirmed these concerns and brought to light specific challenges related to consultation on DNACPR decisions.

232. Our adviceline heard concerns from people living in care and their loved ones about the use of DNACPR decisions during the pandemic. Adviceline 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.

233. 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, page 14, includes various testimonies from relatives and friends 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 and relative 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.'

234. Furthermore, both our survey and adviceline revealed distressing experiences where individuals felt pressured or coerced into accepting a DNACPR decision for their loved ones. 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.

235. Poor communication between professionals, individuals in care, and their designated representatives was a key factor in instances of 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. It was felt that the lack of oversight by excluded loved ones (who would normally be more actively involved in the person's care) and regulators emboldened health and care professionals to make decisions they would not have otherwise made if appropriate oversight was in place.

Lack of proper oversight/regulation

236. All members of our Core Participant group feel strongly that monitoring and oversight are key components of safe and high quality care vital to ensuring a positive experience for those needing care, and also for those providing it. As there is no single provider of care in the UK, it is crucial that there is a system in place to ensure that minimum standards of care are met in all settings. Further, given the visiting restrictions which were in place in response to Covid-19 (and the consequent inability of family and friends to check the care being provided to their loved one) it was particularly important that there was a robust and effective system of oversight in place during the pandemic. Unfortunately, our experience is that this was not the case.

237. The regulator for health and care services in England, the CQC, had a duty to monitor care providers' compliance with the required standard, and hold providers accountable in a timely way. As explained by the JCHR in its July 2022 report (and summarised on the Leigh Day site at **Exhibit JC2/132 [INQ000273472]**):

22. The CQC has an important role in preventing abuse and neglect. As the regulator of all health and care services in England, the CQC has a duty to monitor care settings to ensure that they operate satisfactorily, and to take action when this is not being done. The CQC does not inspect providers' compliance with the HRA directly, but it applies human rights principles to inspections and other services carried out. The CQC's fundamental standards, below which care must never fall, include assurances that people will always be treated with dignity and respect, and will be safe from abuse or improper treatment. The CQC's enforcement policy outlines that it can work with providers to improve standards of service, and intervene where patients are at an unacceptable risk of harm or where providers repeatedly or seriously fail to comply with their legal obligations. The regulator must fulfil its duties, ensuring that care users *have access to adequate personal and medical care, and taking swift action where care falls below fundamental standards.*

238. The JCHR noted in its report that it had 'heard serious criticisms about how the CQC was fulfilling its monitoring and regulatory role'. Drawing on evidence provided by John's Campaign, Care Rights UK (as Relatives & Residents Association at the time) and others, the JCHR reported:

> *23….. Kari Gerstheimer, from Access Social Care, told us about a case involving a care setting rated as "good" by the CQC, which was found to suffer from serious failings in the provision of care that were not picked up by the CQC at the time of inspection. John's Campaign also shared with us an account from an individual who showed signs of distress when receiving services from a care setting rated as "good", which were only alleviated when he was moved to a different care home.*
>
> *24. Many have expressed they do not feel they can trust the CQC to adequately regulate and monitor care settings. One individual shared with John's Campaign their personal experience dealing with the CQC: I explained to her [an assistant inspector at CQC] what had happened, how anxious and upset I was and how badly I felt the care home had behaved and continued to behave. (…) I was left feeling that CQC did not care what the care home had done or how unprofessionally and callously they had acted. I totally lost faith in CQC at that point to be an effective regulator and to protect the most vulnerable people in our society.*

239. The JCHR therefore concluded that the CQC had fallen short in its duties to monitor providers' compliance with expected standards and that there were gaps in holding providers accountable in a timely way. We agree with the JCHR's assessment.

240. We have set out a brief chronology of the key changes to the regulatory inspection regime that took place during the pandemic and the steps we took to communicate our concerns regarding those changes. We understand that the CQC itself will be explaining in detail the changes that took place in its approach to regulation. We have therefore limited ourselves to noting key changes in its approach and focused on our own concerns regarding these changes:

240.1. 16 March 2020: CQC writes to all registered health and social care providers announcing the immediate cessation of routine CQC inspections (see **Exhibit JC2/133 [INQ000499431]**).

240.2. 1 May 2020: CQC launches its Emergency Support Framework (ESF) to adult social care (see **Exhibit JC2/134 [INQ000499432])** The ESF focuses on four key areas: safe care and treatment; staffing arrangements; protection from abuse; and assurance processes, monitoring, and risk management.

240.3. 22 May 2020: Care Rights UK (then Relatives & Residents Association) wrote to the CQC to express disappointment in CQC's approach to the pandemic, highlighting concerns regarding lack of scrutiny and a lack of clear policy or practice guidance to help providers ensure good communication to reassure families (see **Exhibit JC2/039 [INQ000231915]).**

240.4. 12 January 2021: CQC provides an update on its regulatory approach, stating that it will "only undertake inspection activity that either helps create capacity to respond to COVID-19 or that responds to significant risk of harm to the public".

240.5. 24 March 2021: CQC provides an update on its regulatory approach, and notes its "ambitions to regulate in a more dynamic and flexible way – moving away from using comprehensive on-site inspection as the main way of updating ratings."

240.6. 11 May 2021: Care Rights UK (then Relatives & Residents Association) writes to the CQC, urging the regulator to restart the routine inspection of care services and proactively monitor compliance with Government guidance on visiting (see **Exhibit JC2/040 [INQ000231916]**).

240.7. 20 May 2022: Care Rights UK (then Relatives & Residents Association) writes to CQC, to express disappointment with the regulator's approach and highlight concerns relating to CQC's own guidance on visiting in care homes (see **Exhibit JC2/041 [INQ000231917]**).

Care Rights UK

241. Care Rights UK's concerns regarding the approach to the regulation of the adult social care sector in England during the pandemic are set out in the letters we wrote to CQC in May 2020, May 2021 and May 2022 **(Exhibits JC2/039-040**). First, as

outlined in our May 2020 letter, we were extremely concerned at the guidance provided by Public Health England (PHE) on 25 February 2020 which said "it was very unlikely that anyone receiving care in a care home or in the community will become infected" (**Exhibit JC2/135 [INQ000499433]**) and were disappointed that the CQC failed to refute this statement and properly represent the rights of the approximately 500,000 individuals living in care homes. This led to significant harm and mismanagement of the pandemic across the sector.

242. Second, we were very concerned by the pause in routine inspections during the pandemic, and the lack of oversight of care providers and the quality of care they were providing. During the pandemic, through our adviceline, we observed that many people were concerned that care standards had dropped during lockdown, leaving people at risk. As we explained in the oral evidence we gave to the January 2021 session of the Joint Committee on Human Rights (**Exhibit JC2/036 [INQ000273442]**), the concerns regarding quality of care were "exacerbated by the Care Quality Commission ceasing routine inspections and by social workers and health practitioners staying away." The experiences we heard about through our adviceline and through our work in this area made us extremely concerned about the impact the pause in routine inspections was having on care standards and the rights of those living in care settings. As above, we were particularly concerned about this because we knew that much of the harm was likely unseen and underreported and that the glimpses of decline in care quality we were getting were likely only the 'tip of the iceberg'.

243. Unfortunately, our concerns regarding the inspection regime were not limited to the beginning of the pandemic, as routine inspections did not resume. In July 2022, four in ten care homes had not been inspected since the beginning of the pandemic. As we stated to *The Daily Express* (see **Exhibit JC2/136 [INQ000499434])**, this data is hugely concerning, and we felt urgent action was required by the CQC. We observed that: 'With one in five people living in a poor care home and almost half of homes not inspected since the start of the pandemic, people are lost in the system with no one to safeguard their rights. The regulator needs an urgent wake-up call.'

244. A third concern we raised with the CQC was its own approach to visiting restrictions and the guidance it produced. As we explain in our May 2022 letter (see **Exhibit JC2/041**), CQC's guidance seemed to encourage care providers to take action which appeared to be in breach of the CQC's own Regulations and legal rights.

For instance, the guidance encouraged people being "supported to isolate in their own rooms… when returning to a home from hospital" without any reference to Regulations 9 (person-centred care), 10 (dignity and respect) or 12 (safe care and treatment) and the requirement to undertake individual risk assessments to consider the risk to a person's health and wellbeing. This was also inconsistent with the DHSC's guidance which by this point required that isolation not be imposed. Given the lack of clarity and inconsistency around the guidance, it was of utmost importance that the regulator was clear about what was actually required under law, and explained the steps care providers should take in a consistent and clear way. Unfortunately, it did not.

John's Campaign (JC)

245. At JC we heard from many relatives who felt let down by the regulator. They felt that their complaints were not being heard and were disappointed with the CQC for failing to proactively assess quality of care. We collated feedback we had collected from relatives and summarised this in our evidence to the JCHR. Examples included:

> *I have no faith in the CQC either. I spoke to mum's previous homes CQC inspector regarding all my concerns and all she could say was to put a complaint to the home! Which I did, it went to the second stage/ It ended up affecting my mental health so mum and I decided to move her to a better care home. Best thing I ever did.*

246. The JCHR rightly noted in its July 2022 report that:

> *When something goes wrong, the users of a service should have access to an effective complaints mechanism that is capable of investigating those complaints, and putting things right, in a way that is transparent, fair, and proportionate. However, the complaints system for care users is confusing, time consuming and too often does not result in effective resolution. The system needs to become easier to navigate. Care users must not be frightened of retribution if they complain. We recommend changes to streamline the process, with the roles of the CQC, the Local Government and Social Care Ombudsman (LGSCO), and the Parliamentary and Health Service Ombudsman (PHSO) clarified and with all three organisations operating a "no wrong door policy".*

247. The JCHR observed that the evidence it had received showed that care users 'can be reluctant to pursue complaints due to fears of retaliation, and that those who wish to pursue complaints often find the available framework complex, confusing, and ineffective' (para. 94). NR, a safeguarding expert and Chair of the National Mental Capacity Forum, told the JCHR:

> *[The CQC] does not investigate complaints and (…) people are bounced from one organisation to another. I know that some complaints have gone unresolved for many, many years, and families are left feeling extraordinarily frustrated and with a sense of strong grievance. The CQC has not assisted families on this front.*

248. The JCHR concluded that there is significant confusion about the roles of the institutions involved in handling complaints and that even experienced professionals working in the care sector weren't clear on who to turn to in respect of individual complaints. Whilst some of this confusion pre-dated the pandemic (as set out above), its impacts were particularly felt during the pandemic when proactive regulation and clear complaint pathways were all the more important. Concerningly, the JCHR also raised questions about the effectiveness of the CQC's complaint handling procedures:

> *103. There is a question mark over the effectiveness of the CQC's complaint handling procedures in relation to its duties under the [Mental Health Act]. The CQC told us that in 2020/2021 they received "2,280 complaints and concerns about the MHA"... They only opened seven of these to be investigated as complaints…. We asked both the CQC and the DHSC to provide us with data to explain why so few MHA investigations (0.3%) have taken place. The CQC told us they "do not hold the granular data about the individual steps taken in the 2,280 cases". They went on to say that they employed a "robust, staged process to hold providers fully to account in how they respond to every single complaint we pass to them". However, without any data to show what has happened to the majority of complaints and concerns received, we cannot be assured that the CQC is adequately investigating such complaints.*

249. We consider this to be a telling example of the CQC's failure to take concrete steps to properly carry out its role. It was our experience throughout the pandemic that the CQC was making vague assertions about carrying out its regulatory role, without any concrete evidence of how this was being done and what specific steps were being

taken. We heard from many people who received letters from the CQC saying that they "did not investigate individual complaints" and referring them to their care home provider. As we outlined in our evidence to the JCHR, we considered this response to be completely out of touch with the experiences of those receiving care and their families, as many people were scared to complain directly to care providers given the risk of retaliation by the care home, including the common practice of evicting individuals who complain about the care received.

250. We and those we supported felt that the CQC abdicated responsibility during the pandemic and that oversight and regulation were lacking. We felt that the regulator prioritized the need of care providers to have 'minimum' interference at a time of high pressure over the safety and well-being of care users. We were disappointed at the failure to recognize that oversight and regulation were more important than ever and felt that once again those needing care were abandoned in the name of infection control (i.e. because there were some risks in carrying out inspections, they were abandoned altogether).

Discharge of patients from hospital into care homes

251. All three members of our Core Participant group heard about issues around discharge of patients from hospital into care homes. We have already provided evidence in relation to this in our Witness Statement for Module 3. However, we have summarised our key observations again here for completeness.

252. As above, one of our Core Participant group's key pre-pandemic concerns was that social care was not treated as a priority or given the same recognition as the health sector. Unfortunately this concern was reflected in the decisions that led to the inappropriate discharge of people from hospital into care homes, resulting in catastrophic and unacceptable levels of harm to some of the individuals most vulnerable to Covid-19. The PA and JC agree with the summary provided by Care Rights UK in terms of the key issues observed.

Care Rights UK

253. 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 people living in care/their families and care providers we work with that the policy led to the feeling that the lives of people living and working in care were less valued or important than the lives of others.

254. 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, as it led to discharge into care homes when the care an individual needed could not be provided to them in the care setting and under conditions of isolation.

255. For example, one adviceline client in February 2022 told us that their relative was discharged from hospital into a care home, placed in isolation, and refused access to 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 adviceline 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.

256. Our adviceline 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)

257. 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.

258. 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, without enough of a say in what care and support they needed and too often without a Covid test which put their families and those caring for them at home at risk.

Death certification and collection of data on deaths in care homes

Care Rights UK

259. We have concerns that the statistics on the number of people who died from Covid-19 is inaccurate due to problems adviceline 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 presence 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 and where this may have contributed to the lack of scrutiny of care provided in care settings.

260. Additionally, we were also told about issues around accurately recording other causes of death. As discussed in a Care Rights UK article (**Exhibit JC2/032 INQ000231911**), 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 adviceline 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.'

261. 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.

262. However, initially, the data on deaths from Covid-19 did not include older people who died in care homes. This was a stark example of the inadequacy of data collection and raised questions about how older people in care homes were valued and how the impact of the pandemic on them was being monitored. In her evidence in Module 2B, Ms Herklots said:

> "people who were dying in care homes from Covid-19, those deaths weren't even being counted, and I thought that was extraordinary... this issue of inadequate data covered a number of different areas throughout the pandemic, I would say, but was very stark at that time": [2/126/23-25].

263. This meant, as the Chair put it in response to evidence given in M2B, that the figures would be skewed and that the pandemic response would be based on inaccurate data. The reasons for this appear to include that there were few tests available for Covid-19 in care homes during March and April 2020; that staff had less experience or understanding of Covid-19; and that Covid-19 was not recorded on death certificates for other reasons: see, e.g. [3/140/14-22]. Some other reasons why deaths in care homes were underreported were explained in the Office for Statistics Regulation blog *Glimmers of Light for adult social care* (8 July 2021) **Exhibit JC2/137**

[INQ000499436] and **Exhibit JC2/138 [INQ000499437]** and [3/131/10-3/132/19] of the Module 2B hearings which highlighted a data "chasm" in social care.

264. This is reflective of a broader problem that emerged, of inadequate data about social care. Dr Cooper in his evidence in Module 2B said data in the care home sector "was a significant challenge... there wasn't a system that really could be relied on for us to help inform action or look at the reality of what was happening in any sort of systematised data way": [6/153/5-12]. Similarly, Ms Howarth noted that the Knowledge and Analytical Services only became involved in data collection analysis after the early stage of the pandemic, and that if they had been asked to advise earlier on, they could have avoided various errors and misreporting [3/121/3-12].

Key lessons to be learnt

265. A key issue which all members of our Core Participant group wish to highlight is the need to ensure parity between the NHS and social care sector, and for decision-makers to recognise that one system cannot function properly without the other. We feel that had the care sector been properly understood, recognised and valued by decision-makers, then many of the significant issues which arose during the pandemic (for instance the inappropriate discharge of people from hospital into care homes) could have been avoided. The care sector is not secondary to the health sector, and needs to be properly funded, resourced and respected in order for both the health and social care sector to be more resilient in the face of potential future pandemics.

266. Another 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 care when providing such care. Providing adequate care is simply not possible without proper engagement with an individual's 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 and in the evidence we provided in Module 3.

267. The following are additional key lessons we consider should be learned as a result of the issues we identified and explained in detail above. This is not intended to be an exhaustive list but simply highlights some of the themes we consider to be of most significance:

267.1. 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 people drawing on care in the daily count, inappropriate use of DNACPR decisions, the inappropriate discharge of people from hospital into care homes without testing for Covid-19, and the prolonged and harmful imposed separation and isolation in care homes which we have described in detail above. 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.

267.2. Systems must be in place to safeguard rights and ensure the voices of people drawing on care services are heard, including 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). Robust regulators are needed to safeguard rights and act as a voice for people relying on services. On 26 July 2024 an (interim) Independent Review into the operational effectiveness of the CQC found that it was not fit for purpose (See **Exhibit JC2/139 [INQ000499438]**). The Health Secretary, Mr Streeting was 'stunned' by the scale of the problems identified regarding the regulator and announced a set of emergency measures (see **Exhibit JC2/140 [INQ000499439]**). The report confirms many of the points we have been making for years (**Exhibit JC2/141 [INQ000499440]**): there must be better, more robust and accountable oversight of health and care services, with more frequent and effective inspections. There must also be safe routes in place for those receiving care and their loved ones to raise concerns and make complaints about the quality of care received. This is crucial to ensuring adequate standards of care are met in care settings.

267.3. In respect of regulation, including the role of the CQC, the JCHR made the following recommendations for England in its July 2022 report. We endorse these recommendations:

267.3.1. Complaints mechanisms for care service users (and those supporting them) must be clarified and streamlined.

267.3.2. In its regulatory and monitoring role, the CQC must take proper account of how complaints are being handled by providers, and how decisions made by the Ombudsman bodies are being implemented. The CQC must also routinely look at how health and care contracts between individuals and providers are being terminated and work alongside the Ombudsman bodies and providers to ensure that individuals are not suffering retaliation after lodging complaints (§245-250).

267.3.3. The Government must legislate to give the CQC the power to require care settings to inform them of any changes to their visiting status, and to report live data on levels of visiting and restrictions. The CQC must make compliance with visiting restrictions a key consideration when undertaking its regulatory and monitoring roles. (p.4) Following public consultation earlier this year, the government amended the Health and Social Care Act 2008 (Regulated Activities) Regulations 2014 to introduce on 6 April 2024 a new Regulation – Regulation 9A entitled, 'Visiting and accompanying in care homes, hospitals and hospices'. Visiting, including accompanying people to hospital diagnostic visits, receiving assistance from carers and at the end of life, is now protected as a fundamental standard across care homes, hospitals, and hospices). The Government's new Regulation makes clear that providers should support visiting. To protect this vital part of a person's care, the CQC must now act on this change and ensure adherence to the clear standard that has been set (**Exhibit JC2/142 [INQ000499441]**).

267.4. 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 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 Rights 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. Care Rights UK, John's Campaign and Rights for Residents are currently campaigning for the Care Supporters Bill, also known as Gloria's Law: a new legal right to maintain contact with an 'essential care supporter' (such as a relative or friend) in health and care settings. The role of Essential Care Supporter in Government guidance has been vital for protecting rights to wellbeing and family life for people drawing on care– it must be enshrined in law. This recommendation was echoed by the JCHR in its July 2022 report 'Protecting human rights in care settings' (p.4):

> *We have reported before on the visiting arrangements for those in care settings during the pandemic. Evidence submitted to this inquiry showed that through and beyond the pandemic problems persisted with providers following guidance. We also believe a lesson learnt from the pandemic was the harm caused by blanket bans on visiting. We have called in the past for the Government to legislate and do so again here.* ***The Government must introduce legislation to secure to care users the right to nominate one or more individuals to visit and to provide support or care in all circumstances, subject to the same infection prevention and control rules as care staff.*** (emphasis added)

267.5. Proper communication (which is not just verbal but includes all forms of communication) with loved ones is essential; it can improve the quality of care received and help ensure that a person's wishes are respected. A prominent theme in all of our communications with people throughout the pandemic was that family and friends felt let down when they were not properly communicated with. All health and care settings must ensure that family and friends are kept properly informed at all stages of care, including the end of life. We have seen that not being able to say a proper goodbye caused huge emotional distress to family members. Proper communication and appropriate involvement of family and friends can also help ensure the individual receiving care's wishes are respected and that they are able to live and die with dignity.

268. We have provided some additional recommendations from each of our respective organisations below. For the avoidance of doubt, we each support the recommendations advanced by each of our respective organisations.

The Patients Association

269. As stated above, both the health *and* social care must be adequately funded and recognised. The NHS and care sector must not work in silos; they are interdependent services. Only by ensuring the adequate funding of the social care sector, can we also ensure the survival of the NHS. 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'. A recovery plan requires sufficient staff to deliver the increased activity needed in both health and social 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.

Care Rights UK

270. 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 people from hospital into care without testing. The CQC's failure to carry out inspections and proactively regulate, stressing the desire not to put further strain on care providers also prioritised institutions over people. Responses to any crisis must identify and focus on the people most at risk and what support they need.

271. 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 not just protect people from the virus but to ensure that measures imposed to manage the virus do not breach other fundamental rights, including to liberty, autonomy and (wider) wellbeing, such as access to adequate and appropriate care. 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.

272. 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.

273. There needs to be a better understanding of the care sector and the needs of people drawing on care. The response to the pandemic demonstrates a lack of understanding about the vulnerabilities of the sector, how care services operate and the reality of living in care settings.

274. Systems to protect the human rights of people drawing on care are more important in times of crisis, not less. Legal duties to protect rights have been too easily ignored by the Government and its agencies – both the duty to protect the right to life at the beginning of the pandemic and the duty to protect rights to liberty, family life, autonomy and wellbeing throughout. We need a better system of alert and accountability when human rights breaches occur. We also need strategic action by the Government and its agencies to recognise and act upon systemic human rights risks to ensure people relying on care are not discriminated against and left behind.

John's Campaign (JC)

275. Alongside the important lessons to be learned identified by Care Rights UK, which we echo, we were also particularly shocked by the disregard of equality laws which occurred during the pandemic. 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, including during a crisis.

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 §§1-6, 23-37, 42, 60, 89-118, 124-128, 139, 155-158, 171, 193, 201, 221, 229-230, 236-240, 251-252, and 265-268, 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: §§19-22, 57-59, 83-88, 184-186, 211-220, and 269.

On behalf of the Patients Association:
Rachel Power

Signed: Personal Data
Dated: ___02/12/2024_________

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On behalf of Care Rights UK:
Helen Wildbore
Signed: PD
Dated: ___02/12/2024_________

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On behalf of John’s Campaign:
Julia Jones
Signed: PD
Dated: ___02/12/2024_________