Witness Name: Caroline Abrahams

Statement No.: M2/AUK/01

Dated:

UK COVID-19 INQUIRY

WITNESS STATEMENT OF CAROLINE ABRAHAMS, CHARITY DIRECTOR, AGE

UK

I, Caroline Abrahams, will say as follows: Please see enclosed response 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.

Personal Data

Signed:

Dated: 27 September 2023

Module 2 of the UK Covid-19 Public Inquiry ("the Inquiry") and Impact/Inequality Evidence: a statement of Age UK's perspectives

Brief description of Age UK, including its role, aims and functions with respect to the four nations of the United Kingdom

- 1. 'Age UK' is a national charity that works in England and on matters reserved to the UK Government. We are part of a federated network of organisations across the UK working together to support older people in need and help everyone make the most of later life. I have consulted widely across the Age UK network to inform this response. I can confirm this statement is based on what I have been told and is true to the best of my knowledge and understanding.
- 2. The Age UK network as a whole comprises 130 independently registered charities that operate under a brand agreement which provides a framework for cooperation and collective endeavour. This includes 'Age UK' and 120 local Age UKs working across England and our partners in each of the nations including Age Cymru and 5 local Age Cymru partners, Age NI, Age Scotland and Age Scotland Orkney. In addition Age International works to support older people in more than 40 countries worldwide.
- 3. Across the UK, the charities reach around one million older people each year, seeking to ensure older people have enough money; are socially connected; receive high quality health and care; are comfortable, safe and secure at home; and feel valued and able to participate in society. Together we: research, advocate and campaign; provide information and advice (online, by phone, face to face and printed materials); deliver public information campaigns, direct services and support; and work to drive improvement and innovation in provision across the private and public sector. Collectively we also provide a wide range of health and social care related services, commissioned by the NHS and Local Authorities.

- 4. This statement offers the perspectives of 'Age UK' on behalf of the wider group and the overarching themes I draw on here are consistent across the nations. However, it is important to note that local jurisdictions experienced different challenges and took different approaches in relation to their specific health and care systems. Our partners in each of the nations including Age Cymru, Age NI, Age Scotland and Age International are available to provide any nation-specific or international perspectives as required.
- 5. Age UK and its partners works on behalf of the older population and advocate for long term improvement in experiences of later life. However, there is no single way to define what it means to be an 'older' person and individual aspects of our work will be context specific. Financial and legal entitlements are commonly based on chronological age either age 65 or equivalent to entitlement to the state pension. In employment 'older workers' are defined as those over the age of 50. However, 'ageing' is a physiological process with wide variation in experiences and impact on life expectancy and healthy life expectancy across different communities and parts of the country. Therefore, in other aspects of our work we take a life course approach focusing on those experiencing the challenges and forms of exclusion, disabilities, health conditions or care needs that are typically associated with older age and the ageing.
- 6. Throughout our work we also seek to ensure that the voices and experiences of minoritized older people and those experiencing social exclusion are fully represented. To quantify the scope of our work, there are nearly 25.5 million people aged over 50 in the UK representing 38% of the total population. Of which more than 12.5 million are aged over 65 (19% of the population) and 5.8 million people aged over 75 (9% of the population). For the reasons set out above, while most of our efforts are directed towards those aged 65 and over, in some areas of policy and in less advantaged communities we have reach to those in their 50s and early 60s.
- 7. Age UK plays a vital role in communicating the views and experiences of older people to the UK Government and national agencies, advocating for policies

and service provision that improve experiences of later life. Since the start of the pandemic, we have consulted with older people and their families, our community partners and professionals working with older individuals to understand how their lives have been affected. Between January 2020 and Spring 2022 we had sustained engagement with a number of relevant Government departments and representatives as they developed their response to Covid-19. Age UK has also worked alongside national Government bodies and others during this time to raise the concerns identified by our beneficiaries about the impact of key policies on older people and the adequacy of its leadership, safeguarding, decision-making and risk assessment frameworks. In this witness statement, we have provided an overview of that engagement and the challenges that emerged for older people as they sought to navigate the pandemic. We have done so in good faith and to the best of our recollection.

- 8. Unfortunately, as we set out in the following evidence to this Inquiry, the Government's overall response to the pandemic was characterised by a number of failures of decision making and implementation, reflecting an overarching failure to account for or respond to the additional risks faced by older people in an emergency, particularly underserved groups and those with the greatest unmet needs. This included a number of instances where decisions regarding policy, information, guidance and resources or lack thereof shaped or limited the capacity of local agencies, including the health and care system, to respond adequately to older people's needs, or deliver the standards of care they deserved.
- 9. We fully recognise that the Government had to make complex judgements in highly pressurised circumstances and in respect of a novel disease about which, initially, we knew very little. At the same time, the story of the pandemic is a familiar one. Despite clear indications that the virus itself and public health measures taken in response would have a disproportionate impact on older people, quite often, particularly during those early weeks and months, it seemed to Age UK that the rights and interests of older people were at best an afterthought. Government and those advising them often had no understanding

- of older people or the way in which their decisions would impact them or the services they rely on.
- 10. The decisions taken by Government bodies must be seen in the broader context of embedded age discrimination throughout our society, where older people are too often viewed as of less value. Indeed, this was a clear theme within the public discourse throughout the pandemic, where cost-benefit analysis of the measures and resources aimed at safeguarding the lives of older people was openly queried and discussed. Some aspects of poor or inadequate decision-making can be attributed to a lack of understanding or awareness. However, in other instances, the very fact that groups of older people were seen to be highly vulnerable or at risk led to their needs being deliberately deprioritised at times by decision makers or individual services or professionals operating within national structures.
- 11. Age UK operates by a clear set of values and principles that it believes should have also guided national decision-making and informed the system's response: dignity, equality, equity, inclusion and minimising human suffering. These are the guiding principles that underpin the following assessment of the failures of national decision-making during the pandemic, and the devastating impact of those decisions on older people. In the statement that follows we explore these themes in more detail, setting out a wide range of issues and challenges experienced by older people over the course of the pandemic. We hope this will aid the Inquiry to understand the unique and enduring impact this period has had on the lives of many older people and their loved ones. We have also set out our overall conclusions relating to the Government's conduct throughout the pandemic.

Lack of knowledge and understanding of the older population, including a lack of expertise in the services and support that are vital to their welfare

12. One of the most substantial barriers to effective strategic and operational decision making over this period of time was the lack of knowledge and understanding of the older population or of the essential services and support

that are vital to their welfare – most notably social care. We engage specifically with challenges relating to Government's approach to the social care sector below; however, it is important to recognise that this was part of a bigger 'blind spot' across multiple parts of Government and those advising them. The challenges facing older people were wide ranging. While some were common experiences across the population, many were either a facet of the particularly high risk posed by Covid-19 to older people or the way in which measures to combat the pandemic intersected with pre-existing vulnerabilities or underlying challenges and prejudices. However, two common themes emerge: from the start there was both (1) a lack of effective analysis of how the risk of infection and implementation of non-pharmaceuticals would impact older people; and (2) insufficient knowledge and understanding to enable Government to take decisions and design rules, guidance, services and support to mitigate against predictable and preventable harm.

- 13. At population level age is the single biggest risk factor for experiencing severe illness and dying from Covid-19. There are more than 10 million people aged 65 and older in England, almost 1 in 5 of the population. The Intensive Care National Audit and Research Centre have studied around 10,000 people critically ill in hospital with coronavirus in the UK. After accounting for people's health, sex, ethnicity and other characteristics they found that, compared to someone aged 60, the risk of dying was about doubled for someone aged 70 and almost quadrupled for someone aged 80. In April, at the height of the first wave, one in eight people over 90 died of Covid-19, compared with less than two in 50,000 aged between 20 and 24 [CA/1]NQ000221437]. The reasons for this are complex; as we age our immune system function decreases and the likelihood of living with one or more long term health conditions, complex care needs, disability or frailty significantly increases. An estimated 66% of people aged 70 and over have at least one underlying condition, placing them at increased risk of severe impact from Covid-19 [CA/2 INQ000217398]
- 14. As well as enhancing the risk severe illness from Covid-19, these factors also mean that the older population is (1) far more reliant on access to both routine and urgent health services, as well as formally or informally provided care and

- support; (2) are much more vulnerable to rapid or catastrophic changes in health and wellbeing, particularly those associated with physical deconditioning and loss of cognition; and (3) may struggle to overcome new or additional barriers in navigating everyday spaces or activities. Taken together it is unsurprising that older people were also majorly affected by indirect impacts relating to non-pharmaceutical interventions (NPI) and containment strategies.
- 15. Our evidence is clear that many older people did indeed suffer irreversible loss of health, physical function and independence as a result of the effects of long periods of isolation, inactivity and loss of access to facilities, services and support (including essential care services). Unfortunately once an older person has 'deconditioned' losing muscle mass, cardiovascular fitness or strength and balance it is very difficult to regain and can lead to increased frailty, reduced mobility, loss of independence and risk of falls. At the same time, severely reduced access to health services and treatments meant many older people saw existing health conditions deteriorate or new ones go untreated or undiagnosed leaving them living with a greater burden of ill health. In our view much of this harm could have been avoided or alleviated if decision making, policy and implementation had better understood, and been more attuned to, the needs of older people.
- 16. The impacts were felt by families and carers as well. Older carers routinely provide some of the most intensive and personal levels of unpaid care for a loved one, most likely a spouse, and take on the responsibility for accessing day to day provisions of food and other essentials. During the pandemic older carers were hit with a "triple whammy" managing the deteriorating health of their loved one, without the services and support on which they had previously relied, while attempting to manage the restrictions and disruption experienced by society as a whole.

Lack of knowledge and understanding of ageing and inequality

17. We are acutely aware that the burden of both infection risk and service disruption fell much more heavily on some groups of older people than others.

Just as there is a social gradient in health across the adult population, there is also a social gradient in healthy ageing. Health inequalities between different groups of people are often analysed across four main categories: socioeconomic factors (for example, income level and type of employment); geography (for example, region); specific characteristics (for example, age, ethnicity, sex or sexuality) and socially excluded groups (for example, people who are asylum seekers or experiencing homelessness) [CA/3 INQ000101415] The lower a person's socio-economic advantage, the more likely they are to experience age-related disability and poor health at a younger chronological age, live with poorer health throughout their later life and die sooner than people with greater advantage. For instance, those living in the most disadvantaged circumstances experience multimorbidity 10 to 15 years earlier that those in the most affluent areas [CA/4 INQ000101409]

- 18. Older people in the least advantaged circumstances faced a higher exposure risk and increased barriers to accessing services because of a combination of factors including, 1) their living and working conditions (for example, increased likelihood of working in low-paid, insecure and frontline work and being under financial pressure to continue working), 2) their housing circumstances (for example, living in multiple occupancy and/or multigenerational housing), 3) higher access barriers to information and advice (for example, many were without access to the internet or for whom English is a second language), and 4) experiences of social isolation, loneliness and exclusion. Furthermore some groups of older people have always had worse access or been less likely to be offered appropriate services than other people, and this stark fact was also reflected and amplified during the pandemic, as health and care services were reduced and adapted particularly where services shifted online. Factors that have long disadvantaged some groups in accessing suitable services also overlapped with factors that increased their risk of catching coronavirus.
- 19. As a consequences risks associated with age should also have been seen in the context of other circumstances and characteristics that accumulate or amplify risk. As ageing is a universal experience however, its interaction with other risk factors and characteristics is often poorly understood and overlooked.

This continued to be the case during the pandemic. To the extent that national decision makers sought to address and mitigate the impact of the pandemic on pre-existing inequalities, the experiences of minoritised older people and those living in the most disadvantaged circumstances did not seem to feature in those discussions. For example policy makers appeared to be unaware of the fact that significant numbers of people over state pension age work, as a matter of economic necessity, often in low paid roles outside of the home.

- 20. It has been widely reported that older people from ethnic minority communities were amongst those most at risk of being exposed to and dying from Covid-19 during the period considered in this statement. Already overrepresented in the numbers living with long-term, multiple or complex health condition at the outset of the pandemic, older people from ethnic minorities may also be more likely to catch Covid-19 for a range of reasons, including the financial need to work in high-risk frontline roles or likelihood of living in multi-generational housing [CA/5 INQ000217401]. Evidence in earlier waves of the pandemic also suggests that older people from ethnic minority backgrounds were more likely to die from it or to have poorer health outcomes. These health inequalities, exacerbated by coronavirus, are due to experiences of social, economic and racial inequalities across the life course. In November 2020 Age UK submitted a consultation response to the Commission on Race and Ethnic Disparities on this topic [CA/6 INQ000217401]
- 21. Inclusion health groups also had a very difficult time (for example when many think of older people, they do not typically consider issues such as homelessness, poverty, domestic violence, substance misuse or severe mental illness, but significant numbers are experiencing these challenges), and during the pandemic many found it much harder to access the support they needed. We have also heard extensive testimony from older people experiencing neglect, self-harm, suicidal ideation, malnutrition and substance misuse at home. As with other age groups, an indirect consequence of lockdown policy was that it further isolated those older people and posed a barrier to them seeking help. Yet many services did not initially understand or take account of the particular challenges of keeping socially vulnerable and marginalised older

- people safe and well, and strategies were not developed with socially excluded people in mind.
- 22. Another example was the heightened isolation and loneliness prevalent amongst older lesbian, gay, bisexual and trans (LGBT+) people. The pandemic has disproportionately increased psychological distress and other vulnerabilities among this group [CA/7 [INQ000217402] Further, some older members of the LGBT+ community reported the onset of the pandemic bringing back memories of the AIDS crisis and associated legacy trauma, impacting the ways they were able to engage with health services [CA/8 INQ000217403]
- 23. These kinds of challenges were compounded by the fact that many face-to-face support services were closed down, leaving people without emotional support. For example, older lesbian and gay people are also less likely to have children than their heterosexual counterparts, and cannot as readily rely on traditional support systems, placing them at heightened exposure risk during the pandemic. As each of these examples show, some older people had less of a safety net around them to protect against the risks, direct and indirect, posed by both the virus. In this way, Government decisions did not seem to factor in or take account of the differential impact on groups of older people.
- 24. The Age UK report 'Impact of Covid-19 on older people's mental and physical health: one year on' [CA/9 INQ000101408] shines a clear light on how the pandemic has impacted older people differentially, according to the degree of inequality they are experiencing. Older people living in the least advantaged circumstances, those grappling with pre-existing health conditions or disabilities and carers were all disproportionately likely to report that the pandemic had had a serious impact on their lives.

Lack of understanding or effective management of the challenges facing the social care sector

25. The lack of understanding or effective management of the challenges facing the social care sector warrants particular attention, given the seriousness of its

impact on older and disabled people. Social care is on the front line when it comes to keeping older people, younger disabled people and people with long-term health conditions safe and well, yet this did not seem to be well understood by decision-makers in Government, especially early on in the pandemic. It is important to note that the care sector is bigger than just care homes and includes supported housing, home care and live-in care agencies too. We also incorporate both local authority and self-funded care within this definition. Some 400,000 older people live in care homes in this country and the vast majority are vulnerable by any definition; a high proportion live with dementia or other forms of cognitive impairment, often in combination with frailty and long-term physical health problems such as diabetes, COPD and heart disease. There were a further 814,000 people living in England in 2020 who drew on social care services in their own homes [CA/10 - INQ000000].

- 26. Pre-pandemic the social care system was widely considered to be unfit for purpose and the Government was considering options for reform. Nonetheless, from the outset there was an overall failure to prepare the sector to manage the challenges of the pandemic or to safeguard those who relied on its services, or who deliver them too. Despite the rhetoric, promises of a 'protective ring' around care homes did not materialise in either policy or practical support measures from Government in the first stages of the pandemic. Specific challenges were also identified in home care, supported living and extra care housing, which received even less Governmental attention. The serious lack of knowledge and understanding among key Government decision-makers, and those advising them, about the needs of the social care sector (and within it the needs of older people and people living with disabilities) was evident.
- 27. At the outset it was clear that Government did not understand its own systems nor their extremely limited purchase on our highly fragmented system of social care, and the difficulties that would result from this during the pandemic emergency. Unfortunately, this critical lack of understanding was a significant flaw in advisory models and predictions as well as impeding effective decision making and resource allocation. The UK Scientific Advisory Group for Emergencies (SAGE) itself belatedly came to recognise that it lacked

- critical expertise in the care of older people and social care sector, care homes in particular.
- 28. A Director General for Social Care, Local Government and Care Partnerships at the Department of Health and Social Care was appointed in June 2020, notably the first such appointment since 2016. This appointment became vacant just one month later in July 2020, sparking fears of a leadership void and controversy over a lack of operational expertise [CA/11 INQ000000] about the social care sector. At this stage it is also important to note that the Government did not collect any routine, real time data from the care sector to guide decision making and nor did it have access to comprehensive historic data (as data collection has routinely only captured local authority commissioned services).
- 29. Age UK and other organisations with an interest in social care, including those representing care providers, repeatedly and consistently raised these emerging challenges, on behalf of service users and their families. As early as 10 March 2020 we expressed our growing concern, writing into a think piece that "the Government has to step up to advise on how the sector can plan a more coordinated and resilient response. The absence of this type of strategic planning is bound to fuel suspicions that social care is being treated as less of a priority than is necessary and appropriate". But unfortunately, the lack of grip on the challenges engulfing care services continued.
- 30. By April 2020 our sense of unease about the extent to which care homes were getting the Government help they needed turned rapidly to real alarm. On the 10th of April 2020 Age UK warned that Government must act now to avert disaster in our care homes; "In short, it's a mess and one that means care home residents, their families and staff are all being badly let down. It would not be an exaggeration to say that some are paying with their lives." [CA/12 INQ000000]. These views continued to be regularly and directly communicated to the Department of Health and Social Care, including on 11th April 2020 when Age UK were asked to provide rapid feedback on the Government's draft social care strategy. We were clear in our response that the proposed strategy was

"timid", "falls short" and "unlikely to be commensurate to the rather sizeable task" [CA/13 – INQ000000]. Sadly, this assessment proved prescient and the burden of the virus fell particularly severely on social care in the first wave, care homes especially.

- 31. The unsafe discharge of older people into care homes without testing for Covid-19 at all, or before knowing the result, was perhaps one of the plainest examples of failure of national decision makers to imagine and deliver effective care for the health of older people beyond the hospital corridor. The policies and guidance at the time (the March Discharge Policy and the April Admissions Guidance) failed to account for the operational realities of the care sector set out below. It was also too slow to respond to emerging evidence of the risk to care home residents or staff from asymptomatic transmission which was not reflected in guidance until mid-April 2020. As the NHS worked to free up hospital beds for Covid-19 patients, care home managers had the nightmarish task of managing the admission of newly discharged older people from hospitals. Some newly admitted older people were untested, others had tested positive for Covid-19 and were still admitted, and some came into the care home still awaiting test results or without those results having been communicated to the care home. They required isolation but early on in the pandemic care homes were struggling with severe shortages of Personal Protective Equipment (PPE), often lacked the staffing or facilities for effective isolation and had no access to regular testing for residents or staff.
- 32. Other serious failures stemmed from the general and pronounced lack of understanding among policy makers in Government about the social care workforce: who they were, how they lived, and how reliant large numbers were on keeping working to survive financially. We heard stories of infected or symptomatic care workers continuing to report for duty because they couldn't afford to stay off work. Likewise there was little awareness of the structure of the workforce and working practices, including the role of agency workers, routine deployment across different places of work and numbers of care workers holding multiple jobs (both in and outside of the sector). Yet as we

- set out in more detail below unfortunately these factors combined seems to have been the root cause of the virus seeding into many settings.
- 33. Yet at the same time, strict rules were swiftly implemented and upheld to prevent families and friends from visiting care home residents, without sufficient consideration or understanding of the impact on residents' and families' wider health and wellbeing of keeping them apart. The contradictions evident in policies that allowed staff to work between homes, but denied visitation rights for residents, served to underline the extent to which decision makers did not know how these settings operated in practice. It also disastrously underestimated the crucial importance to health and wellbeing of contact with loved ones for care home residents, many of them living with dementia. Age UK and other organisations spent many hours over the course of the pandemic trying over and over again to persuade officials and their public health advisers to seek an appropriate balance between the risk of infection on the one hand, and the risk of loss of hope among care home residents on the other.
- 34. The particular question of care home visiting exemplified a broader issue: the woeful inadequacy of the existing rights for residents and those in receipt of care services that meant during the pandemic emergency there was almost no framework to uphold individual rights or guide policy makers through difficult ethical decisions. Sometimes it also seemed that Government decision makers were guided by concerns about public perception and how, at times, the desire 'to be seen to act' was given greater weight in their deliberations than the wellbeing of individuals and their families while at the same time failing to provide the sector with the full practical support required.
- 35. Unfortunately, despite tremendous efforts on the part of those working in the care sector, the tragic result of so many outbreaks of the virus across care homes meant that, during the first wave of the pandemic (between March and September 2020) there were more than 19,000 deaths of care home residents attributable to Covid-19; and by the end of 2021 there were over 60,000 deaths amongst care home residents, accounting for more than 1 in 5 of all deaths. It is our view that the Government's initial response was wholly inadequate, and

- grossly ill-informed. They didn't know what they didn't know and there was no one at a sufficiently senior level within Whitehall, at a time of crisis, to help put them right. Nor, to begin with, did they reach out to others beyond Government who could have helped fill the yawning gaps of knowledge and understanding.
- 36. It is important to note that the impacts were felt in home care settings too. Data have also shown that throughout the course of the pandemic, there was a significant increase in loss of life more broadly for those receiving social care. In fact, between 7th March and 22nd May, the number of people who died in care homes was more than double (110%) the usual number of deaths in care homes and between 2nd March and 12th June, there were 6,523 deaths of recipients of care in their own homes; this was 3,628 deaths higher than the three-year average, so double the number of deaths that would usually be expected [CA/14] NQ000104086. The sector struggled with many of the same challenges as care homes such as access to PPE and pressures on care workers to continue working even when unwell. As a consequence many families felt they had no choice but to withdraw from services and manage alone, often at significant personal cost.
- 37. The challenges identified in home care, supported living and extra care housing received even less Governmental attention. Like care homes, supported housing is designed to be communal and as such implementation of infection control measures was challenging, but yet again Government was slow to understand these risks. Age UK was also aware of significant knock-on challenges in the wider care sector as surges in infections led to staff shortages and pressures on provision, including within home care. There was a general lack of business continuity planning across both health and social care, as Government decisions did not seem to anticipate the impact of Covid-19 staff sickness on essential non-Covid related core health services, social care, or the provision of other forms of support, including through the voluntary sector. For example, there was a failure to consider how these services would be delivered with significant numbers of care personnel being unavailable for work.

- 38. Government did not publish a strategy for the social care sector until April 16th 2020, by which time the virus had already taken firm hold. Unfortunately, in our view, the version of the strategy published still failed to adequately address the scale and severity of the challenge. It was not until May 2020 that the Department of Health and Social Care appointed Sir David Pearson as a senior expert advisor and established the Social Care Taskforce to oversee the Government's response to the pandemic in the care sector. The Department also introduced a capacity tracker, began soliciting routine data, and set up a process to develop a 'winter plan' in August 2020. However, overall, it is fair to say that at no stage has the care sector received the unequivocal support from Government that this essential public service required.
- 39. This patchwork of responsibility coupled with lack of knowledge and a seeming fear of opening the flood gates to demands from providers, the workforce and service users meant the Government's response to the first wave was deeply inadequate. In our view it led to avoidable suffering and harm. Subsequent waves were better managed as Government recruited new leadership and finally engaged with external sources of advice, but it remains our view that despite the best efforts of those championing the needs of the sector and those who rely on it, Government decision making failed to deliver a response fully commensurate with the scale and serious nature of the challenge at any stage. In summary, Age UK believe there were three critical factors as to why older people in receipt of social care were exposed to a major avoidable harm in ways that amounted to a failure to respect their human rights:
 - 39.1.1 Sometimes, a sense of fatalism cam through, due to an underlying assumption was that older people with care needs would be unlikely to survive and therefore there was a limited amount to be done if someone contracted the virus, or in the event of an outbreak in a care home. This attitude, we believe, sometimes led to older people being 'written off', and this contributed both to the failure to properly consider the care sector as a whole, as well as instances of care recipients being denied adequate access to clinical care (including for non-Covid related conditions).

- 39.1.2 As we set out above, at the outset Government and those advising them had little if any knowledge about the realities of the care sector. We sometimes detected similar misunderstandings among senior NHS staff too. There was 'wishful thinking' about the skills and capabilities of staff and the operational capacities and resources of providers. There was a lack of understanding of the workforce, notably its reliance on low paid staff with poor terms and conditions (including adequate or absent sick pay or protections), and the extent to which it was common for staff to work in multiple settings. Indeed, in the early days of the pandemic, Government collected no routine data about the sector and had no means of communicating with providers, relying on CQC registration lists. Unfortunately, this critical lack of understanding was a significant flaw in advisory models and predictions, as well as impeding effective decision making and resource allocation.
- 39.1.3 Especially in the early months of the pandemic but to an extent throughout, we noted some hesitation on the part of Government to intervene in or provide strategic support to services which are predominantly provided by the private or voluntary sector. This led to repeated delays. The challenges of an 'orphaned' sector delivering an essential public service were brutally exposed. Local authorities have responsibility for commissioning services, but only for those who meet strict needs and financial eligibility criteria, and for sustainable functioning of a local care market. Individual service users, carers and families must make their own arrangements under other circumstances. National bodies take responsibility for setting and registering against minimum standards of quality and safety. The NHS has responsibility for provision of healthcare services, but discharge some of this responsibility through the funding nursing contribution, with providers of residential care with nursing responsible for employing nursing staff. Ministers found they were being expected to answer for failings within services for which they had little if any actual control.

Infection control protocols in care homes and home care settings

- 40. In addition to the challenges posed to care homes from the unsafe discharge of hospital patients, infection control was challenged on a further two fronts. Care homes struggled to rota enough of their own staff to fill shifts. There were already pre-existing recruitment issues, exacerbated by sickness and self-isolation. This necessitated regular staff moving between homes in the same group and a high use of agency staff, many of whom worked across multiple care establishments. This practice was slow to be identified as a key factor in the rapid spread between care homes, as was the lack of adequate or appropriate PPE. By the same token little attention was paid to the risk of home care workers moving between older people's own homes.
- 41. Hands on personal care unavoidably exposes vulnerable older people to the risk of infection and many care providers had a continual struggle to source enough PPE. The reality here was that staff frequently had no real protection in the early months of the pandemic. PPE was also an issue of deep concern for families some of whom were asked to source PPE for their loved ones, with the situation even more dire for those receiving care at home. Distribution of PPE via local resilience forums and councils was erratic and unreliable as those bodies themselves experienced issues with supply. Care providers had to rapidly establish new supply chains and often paid hugely inflated prices. The consequence of this lack of PPE was to put many older people's lives at risk, along with those frontline workers across health, social care and voluntary sector services who were caring for them.
- 42. Alongside health and care workers, there were other groups of people who were providing support to older people and those living with health conditions or disabilities, and we need to recognise the impact on them as well. For example, many people working in the voluntary, community and social enterprise sector, including local Age UKs, provide a lot of frontline and health-related support services and are relied upon by huge numbers of older people to manage at home. These services were greatly impacted by many of the same challenges as those that hit statutory services, such as access to PPE, managing the

staffing gaps and the risk of infection. For some Age UK services this lack of PPE impacted formal, CQC registered, care services, as well as our wider health-related support services, which had even less access to protection.

Interdependencies between health and social care

- 43. At some point in their lives, most often towards the end, many older people can come to rely on hands-on care to meet their daily needs. This includes activities that are an essential part of managing health conditions such as taking medication, maintaining mobility and skin health, managing incontinence, and maintaining adequate nutrition and hydration. More typically, it falls to informal carers, including spouses and partners, to help, but some will receive support from care workers. Therefore, it must be understood that health and care systems are complex and adaptive structures and include healthcare interactions outside of the hospital or GP setting.
- 44. Consequently, the availability and quality of residential care home and home-based or domiciliary care, has a direct impact on the NHS, with interdependencies in operation across every aspect of the system. In the case of older people as well as other vulnerable groups, social care is a critical component of healthcare provision without which many older people are simply unable to manage their health and independence. Despite this, national decision making around health and care systems did not seem to account for older people when undertaking impact assessments about the most equitable way to manage constraints on services and reductions in planned care.

Non-conveyance policies and lack of access to urgent services, including essential clinical care

45. Age UK was particularly concerned by non-conveyance practices and, nationally, were made aware of protracted arguments about these with responsible organisations. At worst, these meant a lack of access to urgent services in hospital for people with significant needs living in the community or in care homes, simply on the basis of their age or where they lived. In some

places these policies or informal practices amounted to effective bans on older people being admitted to hospital, whether they had Covid-19 or not. Some care home residents were denied admission for any reason (including fractures, strokes and injuries) as a result. We are also aware of examples of older people and their families being directly discouraged from accessing acute care, or being directly told that they would not be given access to those services in the event of a health emergency. In one example, we were told by a senior clinician overseeing a community hub through the pandemic that an older individual with respiratory symptoms was assumed to have contracted Covid-19 and would not be considered for further care. He described intervening personally on behalf of the patient who he in fact judged to have a case of treatable pneumonia.

- 46. It is important to remember that policies and practices that resulted in withholding access to urgent and emergency care were taking place in the context of older people's usual access to health services being severely curtailed or suspended. Older people living in the community, including those living with complex health needs and at the end of life, were frequently left struggling to access primary care services, medications, community services (such as district nursing) and specialist or outpatient care. As a result many older people simply went without the help they need. For some, this resulted left them living with significant and irreversible deterioration in their health.
 Others, as we explain in more detail below, died in harrowing circumstances.
- 47. These problems were particularly apparent in care homes. We are aware of places where health services largely withdrew from care homes, with no visits to being made by the GP, palliative care teams or any other clinically qualified person. This was very difficult even in care homes with nursing staff in place, but even more problematic in residential care where there were no qualified nurses and NHS community teams were relied upon to provide all clinical care. In some cases, residential care home staff were left to perform clinical tasks and provide clinical care that they weren't trained or skilled to undertake, including with respect to strokes, fractures, cuts and wounds and end of life care. Age UK heard of care homes with nursing being short of medications for

providing pain relief and symptom control for end-of-life care. Residential care homes were not able to administer controlled drugs because there were no suitable registered staff and it took time for these rules to change.

End of life care

- 48. Perhaps one of the most distressing examples of this failure was in end-of-life care. Age UK heard reports that older people left to die of Covid-19 and other illnesses without sufficient clinical support or sometimes without access to palliative care teams or palliative medicines. In care homes Age UK heard reports of staff being told that their job was to provide end of life care for residents who were sadly dying, without enough back up support from GP and community based palliative care services, and without the possibility of these older people being admitted to hospital. Residential care services were not able to give symptom- control medications (as these are controlled drugs) and in some places supplies of end-of- life medication ran out. As we set out earlier in this statement, such prescribing and treatment expectations were beyond residential care staff training and experience. These older people were not afforded the dignified, comfortable, pain-free death that they should have been, in the company of their loved ones.
- 49. Alongside concerns about the availability of clinical care in residential and care home settings were concerns about care in the community and for those living in their own homes. With palliative care challenges similar to those described in care home settings people died in unprecedented numbers behind closed doors. And again, because of shielding restrictions, many people died without the company of their loved ones. Age UK worked with others across the care sector to raise these concerns and drive changes in policy to allow better access to palliative care medicines; however, we know change came too late for many older people who died in the first wave of the pandemic.
- 50. The combined impact of disruption to end-of-life care services and more people dying at home has raised significant questions about the level of service provision and the quality of end-of-life care since the start of the pandemic.

Since the start of the Covid-19 pandemic, a third more people have died at home in England. In normal times, this would represent progress as many people express a preference for dying in their own home. However in the context of the pandemic, and related factors such as high vacancies in home care and slower relative growth in the community health workforce, it raises significant questions about the volume and quality of care they were receiving [CA/15 INQ000217388] How well the healthcare system is able to provide high quality, compassionate care for the dying, alongside their loved ones and carers, is a true test of whether the core values of that health and care system are operative in practice. Very sadly, healthcare systems failed that test many times over the course of the pandemic across all settings. These are serious breaches of accepted practice.

Access to routine health and care

- 51. There was also widespread suspension or diversion of routine medical care: this meant restricted access to help in primary, secondary and community care that many people, and particularly older people, need to sustain their health and wellbeing. Numbers of outpatient visits, GP appointments and medication reviews were all lower than would usually have been the case to manage multiple or complex conditions. Many health and care services stopped altogether, particularly those that operated face-to-face. In some instances, community health staff stopped visiting and important services were withdrawn or greatly reduced. Services highlighted as particularly difficult to access included blood tests, rehabilitation and physiotherapy, speech and language therapy, mental health services, drug and alcohol services, rheumatology and orthopaedics.
- 52. Patients managing long-term conditions often had no access to specialist support and no idea when it could be reinstated, although a few were redirected to other clinics. Poor communication included an inability to reach existing consultants, being handed across to new healthcare professionals with no knowledge of past history and minimal information supplied about cancelled or moved appointments.

- 53. Across all groups there is a recognition that Covid-19 has exacerbated already existing problems with the length of NHS waiting lists for elective care. Our research with Thinks Insight (previously Britain Thinks) [CA/16 INQ000217385] showed that people felt that they had to be very proactive, and even pushy, to get the care they needed. This was highlighted as a significant concern, particularly among those who care for older parents with health needs, as many felt that some older people would be less able to navigate the system, follow up on referrals and advocate strongly for the care that they needed.
- 54. A patient cited in Age UK's recent 'Fixing the Foundations' report [CA/17 INQ000217378] comes to mind. Marie started to experience severe back pain at the beginning of the pandemic. She tried to access support from her regular GP who she felt knew her family well but struggled to navigate the new triage system. She eventually saw a doctor who examined her in her garden and diagnosed a chest infection, but the pain intensified and an ambulance was called. In hospital an X-ray showed her spine was fractured in four places. There was no in-person follow up once she returned home. She explained: "The doctor phoned me up once a month to check me because of this morphine. I didn't see anybody. So, got through best way I could." [CA/18 INQ000217378] This is just one of many such experiences older people have shared with us.
- 55. Some older people and families also cancelled their existing care packages in order to protect themselves or their loved ones from infection particularly at a time when it was clear to service users that care providers did not have access to PPE. Others worried about breaking the law and non-resident family and friends stepped back from providing essential support, unclear about what was allowed. The confusion and lack of clarity over social distancing rules also caused many services and forms of support to close down or withdraw over this period, including day centres, support groups and other home visitors.
- 56. Another common example was confusion as to whether older people were permitted to have cleaners enter their homes. The lack of clear guidance on

this subject overlooked the extent to which many older people rely on cleaners to complete essential tasks they cannot manage themselves (changing bed linen, cleaning the bathroom, doing laundry, running errands) and to provide low-level care that many older people rely on. As a result, this confusion led to people getting less support than was allowed within the rules and that they badly needed.

57. The consequences were that many older people were unable to take care of their own well-being. This increased the burden on resident family members who saw their own health and well-being deteriorate alongside that of the person they cared for. Others, who developed new care needs during the pandemic, struggled to access any support. Insight came from local Age UK services and national Age UK advice lines and the pandemic resulted in a huge increase in the volume of calls to the advice line – reaching an 88% increase at the height of concern – with many calls from family very worried about how to provide care for their loved ones they believed they were unable to visit.

Impact of decision making on access to intensive and critical care

58. In the same theme, the Department of Health and Social Care came perilously close to adopting a national blanket policy on admissions to critical and intensive care units which would have denied access to intensive and critical care to the older population at large, on the basis of their age. In March 2020 the Department's Moral and Ethical Advisory Group was tasked with drawing up national guidance for critical and intensive care. The proposed criteria that were developing, and we saw, gave huge weighting to a person's chronological age. At the same time, we were aware that parts of the country were close to breaching bed capacity in the acute sector, with clinicians preparing to make deeply difficult decisions about resource allocation. The Guidance and resource allocation tool associated with it were not formally endorsed or published by the Department but we became aware that it was nevertheless used in some acute settings.

59. Age UK made clear to the Group our outrage about age ever being used as a good proxy for health status and prospects of survival on an individual level. We were fully aware of the evidence that the risk of severe infection and fatality rises with age, but we contended that in a system with significant pre-existing evidence of age discrimination there were huge and unacceptable risks that it would be misused to deny acute care to older people, whether this was warranted or not. We were also acutely aware of the panic such an approach would instil in older people and their families, were its existence to become publicly known. We have set out our concerns about the process in detail in our witness statement to Module 3 of this Inquiry [CA/19 INQ00000000]

Age based restrictions including do not attempt cardiopulmonary resuscitation (DNACPR) orders

- 60. There was evidence of other 'blanket' policies being applied to older people. Unfortunately, in some cases individuals told us they felt under pressure to agree to do not attempt cardiopulmonary resuscitation (DNACPR) notices and/or to record that in an advanced care plan that they did not wish to be admitted to hospital in an emergency. In some cases, relatives were sent DNACPR letters to sign on a relative's behalf, with no assessment of an individual's capacity to make their own decisions.
- 61. We also heard accounts of people receiving phone calls in their own homes from unknown callers to persuade them to compete DNACPR instructions and care home managers under pressure to sign wholesale DNACPR instructions on behalf of all residents within a home. Advanced care planning, including DNACPR, is an important tool to support people to discuss and record decisions about their care; however, this crisis has revealed a deeply concerning lack of systematic training and awareness of how these tools should be appropriately used and the crucial importance of informed consent. In one such example, we heard from a woman caring for her husband with COPD, cognitive impairment and epilepsy who told us she had been contacted 'out of the blue' by his GP in late March 2020 and told 'bluntly' that if he became ill he wouldn't be taken into hospital or receive any treatment. She was told that a

DNACPR notice had been placed on his file. As you would expect, she described this experience as having 'frightened and upset her a great deal' and felt it left her not knowing what to do if her husband experienced breathing difficulties.

62. Following pressure from Age UK and others, policies relating to conveyance, DNACPR and others were largely withdrawn, with Government and NHS England making it clear that such approaches are unacceptable. However Age UK is aware that, even then, there was evidence that such practices continued. Furthermore, it is our view that some of the measures highlighted above, including those considered by Government, amounted to direct and indirect discrimination towards older people. In May 2020 Age UK submitted a response to the Joint Committee on Human Rights COVID-19: human rights implications for older people setting out these apparent failures to meet the Government's public sector equality duty under the Equality Act and Breaches under European Convention on Human Rights [CA/20 - INQ000217389]

Impact of non-pharmaceutical interventions on older people

63. Non-pharmaceutical interventions deployed during the pandemic have had a profound and disproportionate long-term impact on many older people. As we set out at the beginning of this statement, and in other evidence to this Inquiry [CA/21] INQ000106031 the reasons for and consequences of increased vulnerability and risk of adverse outcomes amongst the older population were predictable and many preventable with the right support and mitigations. However I must once again return to a familiar theme: in our experience of engaging with Government and those advising them throughout the pandemic, decision makers regularly displayed a profound lack of understanding of or interest in older people or the way in which their decisions would impact them or the services they rely on. At the same time the central machinery of Government, working across Departments and in collaboration with national and local bodies, was too often unable or unwilling to respond to with requisite speed and agility to events. We routinely expended considerable effort in simply identifying relevant decision makers and persuading them of the

challenges we saw or could foresee emerging, at which point it would take more time still to achieve tangible progress on those issues.

Shielding, social distancing and self-isolation guidance

- 64. There were 1.4 million older people who were told to shield during the peak of the virus, while everyone over the age of 70 was advised to take extra precautions, including staying inside as much as possible and limiting social interactions. Much like lockdown measures, shielding and social distancing measures aimed at preventing the spread of coronavirus and protecting the most vulnerable groups had a profound impact on older people. Unsurprisingly, and as detailed above, people who were managing a condition that made them more clinically vulnerable were particularly likely to have become severely socially isolated.
- At the same time, confusion over the 'Support for Shielding guidance' and associated terminology led to many older people struggling in other ways too. Guidance was often not well explained, with communications often arriving after the fact. The result of such last-minute changes was that many older people lost access to important support at short notice (e.g. priority shopping slots). People were often expected to resume in person interactions and go back to managing tasks such as shopping, going to work or attending appointments with no warning, whilst feeling highly anxious about the health risks and not psychologically prepared. There were also constant on going, non-specific, messages about the need to take "additional precautions". People who had been identified as needing to shield could not easily switch gears as guidance was relaxed. It seemed that Government did not comprehend the profound psychological impact on older people of being identified as vulnerable in this way.
- 66. Later, the re-classification of the language to describe shielded groups ('clinically vulnerable' or 'extremely clinically vulnerable' individuals) added to the confusion. Many older people did not understand the distinction between the two categories, and both classifications caused people to adopt a

'shielding-lite' strategy, whether they had been advised to or not. As we have set out in our evidence to Module 3 of this Inquiry, we drew these concerns to the Government's attention, but no action resulted [CA/22 INQ000000000] In this way, Age UK saw little evidence that decisions taken on shielding guidance were informed by the lived experience of those who were shielding, or the organisations supporting them. As the roadmaps in and out of lockdown or shielding instructions were designed, there was often delayed, chaotic or very last-minute engagement with Age UK and other members of the voluntary sector. For example, on one occasion changes to national Shielding guidance were published over a weekend, via a tweet from the former Health Minister, for implementation the following Monday.

67. Again, we saw policies adopted based on chronological age. As we entered October 2020, Age UK argued against the use of age-based definitions of 'vulnerability' for older people. It was clear that not all older people were equally at risk of becoming severely ill with coronavirus, even if the precise reasons were yet to be fully understood. Encouraging millions of people to severely restrict their freedoms purely because of their age was disproportionate and risked preventable harm. We argued that age-based recommendations posed a risk to older people's health and would mean that many would become increasingly frail – a situation that would be difficult if not impossible to reverse once the epidemic receded. Sadly, in the years since 2020 we have seen that for many older people this has proven to be true.

Impact of lockdown on loneliness and isolation of care home residents

68. Care homes residents were essentially required to 'shield' from the outside world by default whether they wished to or not. Visiting was repeatedly halted or restricted in an effort to prevent the virus from spreading. Even during periods when restrictions were eased, visiting was often slow or to restart or simply failed to do so. Interruption to family visits had a particular impact on people living with dementia who did not understand why their relatives were no longer coming to see them.

69. At times these bans seemed disproportionate to the actual degree of infection risk and did not consider the huge variation across the care sector in terms of size of facility and safeguarding ability. The result was that many care home residents were isolated from those they loved for long periods of time, causing them enormous distress and, in some cases, leading them to give up all hope or reason for living. Local public health officials were given considerable say over the safety or otherwise of visiting in specific care homes but were swamped with other responsibilities and often seemed to know relatively little about social care generally or care homes in particular.

Older people's mental and physical deconditioning

- 70. Unfortunately the combined effects of a lack of access to services and support, alongside prolonged periods of inactivity and isolation at home meant many older people have experiences irreversible decline in their physical and cognitive function.
- 71. Appointments and many planned procedures were cancelled or postponed far into the future. Waiting lists for treatment rose rapidly and, for many older people, that meant living with symptoms including chronic pain that are impossible to ignore and had a devastating impact on their quality of life, psychological wellbeing, ability to move, work or keep active. For example, our research showed how increased pain impacted on some older people's appetite and diet. We heard from friends and family of older people who were concerned that their loved ones had stopped eating or drinking and were losing weight [CA/23 INQ000217377 The same survey results showed that 43% of people with a long-term health condition are unable to walk as far as before, compared to 13% of people without a long-term health condition. One respondent explained; "Although I have a husband and family I am so alone. I sit and cry for no reason. My mood is so low as I feel so isolated. I am now taking pills for pain & low mood.". These problems were exacerbated by difficulties in communicating with specialist teams and feeling that there was no one to turn to for support.

- 72. Consequently, a significant number of older people have seen a decline in their health and wellbeing alongside a rise in anxiety/depression, muscle deconditioning, memory loss and increased frailty. Lagging rates of referrals, and lower volumes of diagnostic and screening tests and medication reviews risked patients presenting later with more advanced illness and may explain some of the picture as it relates to excess and avoidable deaths. As previously stated, older people are much more likely to rely on access to both routine and urgent health services, as well as formally or informally provided care and support to prevent physical deconditioning and loss of cognition, both major risks to the older population. Once an older person has lost muscle mass, cardiovascular fitness or strength and balance, it is very difficult to recover.
- Even as we moved out of the first wave of Covid-19 and restrictions began to 73. be lifted, many older people continued to be extremely cautious and did not leave their home, and for some that caution continues to this day. Months, and for some years, of staying inside, with limited social interactions, reduced opportunities for physical activity, and limited access to health and social care, has led to deconditioning for large numbers of older people and taken a huge toll on their physical and mental health. For example, Age UK research has highlighted [CA/24]NQ000101408 that one in four older people are unable to walk as far as they could before the start of the pandemic, one in five feel less steady on their feet, and one in three has less energy. It seems that this kind of impact was given little if any meaningful consideration in risk modelling lockdown and other similar measures. As a result opportunities to minimise, mitigate or compensate for the impact of NPI on older people were consistently overlooked by decision makers, and once again exemplified the Government's lack of interest in the reality of older people's lives.
- 74. The impact of the pandemic and NPI has been more profoundly felt by some groups than others. Older people told us that their personal circumstances, such as not having a garden or experiencing financial worries on top of the pandemic, made their experience of lockdown much more challenging. Our research consistently demonstrated that older people living on very low incomes and in areas of multiple deprivation have been more severely affected,

- both mentally and physically, as were older people with pre-existing health conditions and disabilities or providing care for a loved one.
- 75. Unfortunately, a consequence of this was to lower general resilience so that older people were left in worse shape to recover from Covid-19 or other adverse health events. At population level, the task of managing overall demand on the health and care system was made more difficult.

Older people's mental health

- 76. When assessing these factors in combination, it is worth returning to the damage done to older people's mental health and restate that the risk to older people's mental health was not sufficiently recognised. Prior to the pandemic, one in four older people were already living with a mental health condition, while 1.4 million were chronically lonely [CA/25] INQ000217377 Covid-19 and the political response to the pandemic has exacerbated this situation. Many older people have seen their mental health plummet. Rates of depression among over 70s have doubled since the start of the pandemic.
- 77. We heard from older people who had lost pleasure in their lives and were experiencing low mood, anxiety and depression, and in Age UK polling 36% of older people told us they had lost motivation to do the things which they used to enjoy. Sadly, a minority of older people have also told us that they were unable to cope with the situation and were considering suicide, and we saw an increase in behaviours symptomatic of self-harm, eating disorders and self-neglect (which often manifest differently compared to commonly understood symptoms which are more typical of younger age groups). We have had consistent reports of older people not washing, taking care of their appearance, eating, taking medication or managing health conditions, going outside, or cleaning their house. For many of these older people their families and loved ones felt this was completely out of character.
- 78. Severe anxiety was found to be twice as common among those who had been shielding than those who had not, [CA/26] INQ000217381 with older people telling

us that continuous messages of increased vulnerability meant they were living in constant fear of contracting Covid-19. Unfortunately, the studies that Government have relied on to understand the impact of pandemic on the mental health of the population have significant design flaws with regard to older people, who were either under-represented or excluded. This has led to their needs being overlooked and has fuelled a myth that older people have been less seriously affected than other age groups, which is untrue.

79. Age UK has previously documented examples of older people having less access to (or been less likely to be offered) services than others, and this too was reflected and heightened during the pandemic. For example, NHS Talking Therapies (previously IAPT) has never achieved its access objectives for older people, and sadly the evidence is that access declined significantly during the pandemic, and has not recovered (unlike other age groups).

Impact of lockdown on dementia patients

- 80. We heard particularly distressing stories from carers and family members of older people with dementia. Amongst those living in care homes, many families and care staff reported a marked rapid deterioration in their symptoms, accelerated by a lack of routine, isolation, loss of frequent contact with loved ones and reduced physical contact from staff. Some very challenging behaviour and symptoms emerged as dementia patients became disorientated, upset and aggressive. Families and carers supporting people with dementia living at home reported similar experiences as they struggled to cope without access to their usual routines, services and support.
- 81. Families, carers and care staff also found themselves with no where to turn for support. With memory clinics no longer functioning and scant access to mental health community services, sadly the only treatment on offer was often an increase or new prescribing of psychotropic medications, leading to overmedication of these patients (running counter to lots of work that has gone before to prevent it). These medications can bring side effects of dizziness,

- drowsiness and fatigue and changes in appetite, leading to an increased risk of trips and falls, and malnutrition.
- 82. For older people living with dementia at home, restrictions imposed by social distancing and NPI were often very difficult to safely navigate. We were also aware that the complexity of rules and unclear advice meant that many older people were scared not only of Covid-19, but also of getting into trouble for falling foul of regulations. As a result of this concern, many limited their lives or put themselves in unsafe situations. For instance we heard stories of people living with dementia getting lost, their carers scared to go out to find them in case they breached lockdown rules.

Impact on health and care staff morale (paid and unpaid carers)

- 83. There was, and remains, huge frustration about the enduring lack of recognition of the skills of care workers, across both health and social care settings, and very significant concerns about the impact of these experiences on an already incredibly stretched workforce (within which EU nationals and others from across the world have played an important part). Staff working in homes where there have been large numbers of deaths had to cope with repeated loss, grief and bereavement, on a scale they were unprepared for and had no experience. They also had to care for people at end of life over and over again, often within a short time period when the virus was sweeping through the resident population.
- 84. The workforce crisis cannot fail to have an impact on the quality and quantity of care older people receive. Day in, day out, the people working in health and care services make a huge difference to people's lives. Since the start of the pandemic, they have been under incredible strain to keep services going. A legacy commitment must be to prioritise the health and wellbeing of carers, both paid and unpaid, across the health and social care workforce.
- 85. Similar challenges faced unpaid carers, many of whom are themselves older people, with many reporting high levels of burn-out and exhaustion. As we set

out elsewhere in this statement, throughout our research tracking the impact of the pandemic, informal carers have repeatedly emerged as a group who have seen a disproportionate deterioration in their health and mental wellbeing. Not only did the pandemic dramatically increase the numbers of carers, it made a challenging role that much harder. As with other services, much of the support carers relied on suddenly disappeared. Many carers – often caring for people who were shielding or clinically vulnerable – felt they had no choice but to stop receiving help at home, particularly in the early days of the pandemic when PPE was hard to buy.

- 86. At the same time, carers were trying to manage deteriorating health and escalating needs of the person they cared for with limited, if any, access to health services. Communications from Government were confusing for those caring for older people, particularly if they did not live with the person they were caring for. Carers often found it difficult to cope with such intensive responsibilities over such an extended period and received very little support or recognition of their role. Furthermore, many continue to report that little has changed for them or their loved one and that they feel forgotten and left behind as others have returned to 'normal' life.
- 87. On workforce more broadly, Age UK observed an assumption that older people didn't go out to work when in fact there were around 1.3 million people aged over 65 in the labour market heading into the pandemic. With regards to healthcare services specifically, large numbers of older people were working in public administration, hospital cleaning services and frontline delivery roles. Similarly, those returning to health & care work (including retirees) at the height of the pandemic skewed towards the older end of the workforce and it is not clear whether these risk factors (age in combination with other protected characteristics) were taken into consideration in terms of decisions for deployment and the necessary processes to protect vulnerable older staff at greater risk of infection.

Impact on older people's experiences in the community and ability to access essential goods and services

- 88. Navigating the daily realities of NPI (including lockdowns and sustained periods of social distancing) was often much harder for older people living with mobility challenges, frailty and disability. Tasks that were inconvenient for the general population (for example, supermarket shopping according to one-way systems, mask-wearing, waiting in long queues) were totally impossible for some older people to manage, particularly if they experienced additional physical or cognitive challenges, such as sensory impairment, physical disability, incontinence or dementia. For those same reasons older people were also more likely to struggle with a lack of access to essential public infrastructure, and social distancing measures in public spaces (for example, closure of public toilets, reports of people fined for sitting on benches or seating taped off). The fact that many social distancing measures were on-going made it very difficult for many older people to independently navigate the outside world, leaving them feeling effectively trapped at home long after formal orders to stay at home were lifted.
- 89. As a result, and when combined with the fact that many older people had been advised to stay largely or exclusively indoors, access to food, medicines and other essential products quickly emerged as one of the most pressing issues for older people in March 2020. It is worth noting the risk of preventable malnutrition is significant for older people. Pre-pandemic, 1 in 10 people aged over 65 were malnourished or at risk of malnutrition, rising to 1 in 3 amongst those admitted to hospital or a care home. Malnutrition significantly increases the risk of infection, illness and injury and reduces capacity for effective recovery. Practical difficulties accessing and preparing food, lack of motivation (associated with poor mental health, loneliness and isolation) and issues such as poor dentition or medication side effects (i.e. nausea) are all common causes. The pandemic severely exacerbated these challenges for many older people and Age UK, working with partners in the Malnutrition Task Force, are aware of a rise in malnutrition over this period. We heard directly from older people and families detailing the impact as they struggled to secure sufficient appropriate food, including instances of older people found to have become severely malnourished at home.

- 90. Even though to access to food, banking and essential products and services for people who were shielding or otherwise vulnerable was a predictable issue, the Government's response was initially confused and continued to be desperately slow and confused. For example, Age UK received many calls from older people expressing concern about how to access cash, on which they were heavily or totally reliant to pay for food and essentials delivered by others. Organisations such as Age UK pressed the Department for Environment, Food and Rural Affairs to join up services and coordinate efforts to ensure support reached those who needed it most, especially those who were isolated and not online. We spent many hours in meetings with DEFRA officials but ultimately the outcomes were disappointing. Age UK also contacted the financial regulators, the banks and the Post Office to seek solutions to the problems accessing cash facing older people.
- 91. Sadly criminals also lost no time at the start of the pandemic targeting older people with scams. The majority of coronavirus linked fraud reports related to online shopping for items such as face masks and hand sanitiser, which never arrived. Criminals were also sending phishing emails and text messages claiming to be from the Government, HMRC and health bodies to convince people to open links or attachments and reveal personal or financial information. All of the above were a huge source of difficulty and anxiety for many older people in both the 'shielded group', and for those older people who have a health condition that increased their vulnerability.

Older people's access to medications in the community

92. For some older people, pharmacies have played a more prominent, and positive, role in their healthcare during the pandemic. Many patients and members of the public utilised the electronic prescription service for the first time during the lockdown. Some patients also report having repeat prescriptions arranged due to mobility decreasing or shielding. However, access to pharmacy services, prescriptions and over the counter items became difficult for many older people, particularly those in self-isolation or shielding

- and/or with additional needs. Digital and physical barriers to access, supply issues, and delays with getting scripts renewed were all cited as common problems.
- Risks around medicines management also increased during this time. For 93. instance, the more health conditions someone has, the more medications they are likely to take. However, taking multiple medications - known as polypharmacy - increases the risk of a range of problems including adverse side effects, drug interactions and mismanagement. This occurs more frequently as we age with a third of all people over 80 on eight medicines or more [CA/27] INQ000217383 Prescriptions for people over 60 represent the majority of all prescribed items, yet many older people had to forgo medicines reviews or had new medications prescribed. Mental health medications were a particular concern, with a notable rise in prescribing for antidepressants, antipsychotics, hypnotics and sedatives, and corresponding concerns that GPs were overprescribing because it was the only therapeutic intervention available to them at the time. The DHSC National Overprescribing Review published its report in September 2021 outlining the extent of the problem, suggesting that at least 10% of prescribed items need not have been issued [CA/28] INQ000217383 The report further included warnings about remote practices brought in during the pandemic and subsequently embedded, saying that these will need to be monitored into the future to ensure they are safe and effective.

Universal services supporting wellbeing

94. One hugely underestimated consequence of NPI has been the adverse impact of shutting down universal services, which many older people reported as sometimes equal to or greater than the lack of access to healthcare. Closures of clubs, classes, facilities, churches, leisure centres (many of which either haven't reopened or have reopened in ways accessible to those communities) have had a massive impact on older people's wellbeing and social relationships. Age UK research suggests that some older people who previously did not need care and support to maintain their independence are now requiring it for the first time, much earlier than would have otherwise been

the case. Our research has also found that those who were already struggling to carry out activities of daily living, such as walking, eating, showering, and getting dressed are now finding things harder. Many older people have told us that this is largely due to extended periods isolated at home coupled with the loss of the facilities and services that enabled them to maintain their health and wellbeing.

Digital exclusion

- 95. Another example of a lack of understanding of the patterns of need and common barriers to access in the older population is well illustrated by the unequal impact of digitization on older people. Digital exclusion is linked to age, as well as disability and socioeconomic factors. While internet use amongst older age groups has increased substantially over the past decade, many are still non-users. At the start of 2020, 3.4 million people aged over 65 in the UK were not recent internet users (most of whom had never used the internet). The likelihood of being offline also rises with age. 14% of people aged 65-74 are without access to the internet, increasing to 46% of those aged 75 and over [CA/29 INQ000000000]
- 96. It quickly emerged as a major barrier to older people accessing support and services during the pandemic. Many more older people may have had access to the internet but lacked the skills or confidence to engage in a broad range of digital services. Others lacked the funds for or access to digital technology at home and may have been relying on places such as public libraries. Yet many decisions were premised on an assumption that everyone had access to a smart phone, email address and internet access, but this was by no means the case for every older person. Measures to provide alternative 'offline' routes were often inadequate, ad hoc or slow, if they materialised at all. As a result, many older people were unprepared and unable to manage the wholesale shift to digital services and engagement in March 2020.
- 97. Age UK has heard repeatedly from older people who found themselves cut off overnight. For example, the rapid digitization of primary care services at the

start of the pandemic meant that older people offline found that their GP practice had become inaccessible overnight. People struggled to understand how to reach their GP if not in person, not helped by the fact that most signposting information and advice was available online, overlooking the fact that large numbers of older people are not digitally enabled. If you couldn't access the information telling you when it was possible to phone up, or indeed find the correct number to call, there was no way for many of those older people who did not have access to the internet to get in contact with their GP: the doors to the surgery had literally shut.

- 98. Nor was the shift to digital access and services simply a question of 'being online'. Even for those who did, for instance, have the ability to access online GP services, many struggled to navigate the online booking system and triage processes (e.g., requests made for photos when many didn't own or didn't know how to use a digital camera). While many older people live with additional needs, (e.g., hearing impairment or cognitive dysfunction), making effective communication by telephone appointment or video consultation challenging. Particularly disadvantaged by the digital mode shift were underserved groups of older people, including people living with disabilities, people living with cognitive impairment and those for whom English is not their first language. For older people, whether because of this lack of digital access or because of physical impairment, medical condition or safeguarding concerns, telephone access always needs to be available as an option, and face to face too.
- 99. The impacts went beyond access to healthcare as many services switched to online only access (e.g. booking vaccines, banking and online shopping). Many services were also premised on people having access to a smartphone specifically, yet nearly half (47%) of people aged 65 and over in Great Britain did not use a smartphone for private use [CA/30 INQ00000]. As service providers and businesses rapidly shifted to digital provision, older people unable to use QR codes, display digital passes, pay online at point of service or follow links embedded into messages found and continue to find themselves locked out of day-to-day life. This was a point we had to raise repeatedly with Government over key challenges such as access Covid-19

testing and during discussions about potential 'Covid passports' for domestic use.

100. While there are many more older people who could benefit from being digitally engaged, they need support to do so, which was lacking both before and during the pandemic, and that continues to this day. As detailed in Age UK's submission to the House of Lords COVID- 19 Committee Inquiry - Living online: the long-term impact on wellbeing in December 2020 [CA/31 - INQ00000], we cautioned against an over-reliance on digital access (whether from a lack of skills, unaffordable equipment, poor broadband and mobile coverage, or inability to pay for digital connectivity).

National communication failures

101. The lack of consistency and clarity around Government's communications and public health information was another recurring issue throughout the pandemic period. From the outset we heard repeatedly from older people and families who were struggling to make sense of what they were being asked to do or who the 'stay at home' orders applied to and in what circumstances. For some individuals this was a practical challenge, detailed advice and guidance, in so far as it was available, was routinely only available online leaving many older people unsure about what was allowed, what was safe and how to manage their own needs in that context. There was some uncertainty over who the initial stay at home order applied to, and disquiet over the Government's decision not to provide a British Sign Language (BSL) interpreter on-set at the televised briefings. Similar briefings in Scotland and Wales did include an interpreter, socially distanced from Ministers. As we have set out earlier in this statement, this cause some older people to take steps that were harmful to their health and wellbeing. We also quickly became aware of significant gaps in the advice, particularly for older people in need of care and support. We regularly raised these challenges with Government, but more often than not we were left to fill the void.

- 102. There was also confusion over the classification of, and communications with, high risk groups. Many older people were confused by the distinction between 'extremely clinically vulnerable' individuals and guidance that all people over the age of 70 should consider themselves 'clinically vulnerable' and take additional precautions. As a result, many adopted far more restricted approaches to the guidance than was set out in communications. This reflected in part deficiencies in the establishing and communicating with 'shielding' groups in the first instance (for example some people did not receive texts advising them to shield leading to a view that the system could not be trusted) and in part a degree of confusion caused by earlier messaging from Government sources about the risks for the older population.
- 103. Age UK has extensive experiences of public-facing guidance to support older people at risk in emergencies across a range of topics and the advice identified in these publications is highly relevant to the Covid-19 scenario and coping with NPI's. Throughout this time, we published regular and comprehensive guidance for older people, seeking to help them make sense of complex, localised and often unclear rules by developing and refining advice and information and ensuring it was available to older people in accessible formats and via our free advice services. However, these communications failures reduced public trust and resulted in some degree of communications breakdown with older audiences, in turn directly impacting on older people's ability to access healthcare services safely and effectively, and for some creating a gap into which misinformation was able to spread (the 'infodemic'). The low rates of vaccine uptake amongst some groups of older people demonstrate one particularly negative example of this type of communications failure. This was another area where we had done a lot of work pre-pandemic on vaccination uptake amongst older people and could have shared the learning and insight into preparations to roll out the vaccination programme.
- 104. Organisations like ours have significant communications expertise for older audiences and Age UK offered extensive advice to Government bodies over this period on how best to communicate with older people and made regular offers to use its own communications channels in support. However, we

received a mixed response. In some instances, and with some bodies, our advice was heeded and support offers well received; in other instances, there was a lack of engagement. For example, Age UK supported NHS England extensively in some of their communications, when our advice was sought. Other branches of Government either did not seek or were resistant to taking on board our expertise. Nor, to the best of our knowledge, did Government proactively seek expert advice on messaging and communications to older people specifically from any source. As we have set out in our evidence to Module 3 of this Inquiry, shielding was another area where our advice was largely rejected [CA/32 - INQ00000]. We would also observe that this was a widespread challenge impacting on many groups where meaningful collaboration with relevant voluntary and community sector organisations (with expertise and experience in communicating with their populations as well as real time understanding of their attitudes) could have significantly strengthened public communication efforts.

105. In an unfortunate bookend, the Government's approach to withdrawal of most public health protections in February 2022 ended restrictions in much the same way they began: without due consideration of the impact on older people. The decision to remove free testing for all but a few clinically extremely vulnerable, the withdrawal of masking policies in shops and on public transport, and the end to general social distancing measures has led to many older people feeling unsafe and abandoned. Some older people continue to report that the lack of protections means they do not feel confident to resume their previous activities or social contact.

Lack of accurate data to guide decision-making across key services

106. National decision makers failed to operate with an understanding of needs likely to arise in various communities of older people at times of emergency. One key indicator of this was the inadequate data held about the older population, highlighting the relative invisibility of older people in key datasets and analysis. Too often, data on older people is presented in the category 'over 65/65+' with no further breakdowns beyond that age cut-off. Data

disaggregated by age, but also sex and other relevant social characteristics, are essential to effective and equitable public policy making that is inclusive of older people.

- 107. However, this meant at the outset of the pandemic Government and other public bodies lacked access to granular data charting the lives and experiences of older people even if they had sought it out. This largely continued over the course of the pandemic. As a result, decisions remained hampered by a lack of accurate, timely data and had negative consequences for older people. There were also significant gaps in data collection across key services for older people. As we have set out elsewhere in this statement, there were large gaps in social care data; there was no central database that identified the care homes that had the capacity to isolate infected residents and the ones that did not. The Care Quality Commission (CQC) was the only national body with a record of the names and addresses of all care providers. The UK and devolved Governments were aware of such data deficiencies before the pandemic. In early 2020 alone for example, the Office for Statistical Regulation (OSR) published two reports on the state of adult social care statistics in England and Scotland [CA/33 INQ00000].
- 108. Age UK has long argued that improvements must be made to data collection and analytical methods in order to fully understand diverse experiences across the older population, particularly those of minoritised groups. Other analysis relies on self-selecting samples that are not representative of all older people or otherwise flawed by language and design. Age UK has called for the enactment of the socio-economic duty of the Equality Act 2010 which would require public bodies to take steps to combat and reduce inequalities that result from differences in social class, occupation and education. We have also called for the enactment of the dual discrimination duty under Section 14 of the Equality Act 2010, in recognition of the fact that discrimination can take place based on more than one characteristic at a time.

Low or inconsistent consideration given to external sources of information or expertise

- 109. We would like to draw out one particular aspect of the engagement and collaboration challenges set out above. We noted a resistance on the part of Government to engage with data or insight generated outside of academic bodies or official collections. It was also often apparent that much greater weight was given to information or expert input derived from a relatively small number of channels, while lesser weight or consideration was given to other sources. It meant data and advice was drawn from a comparatively narrow perspective and often biased against those bringing information or insight grounded in real-time experience and data collection. As a result, Government was often slow to recognise or respond to emerging problems and challenges or made less effective decisions. It is clear that better knowledge of and engagement with the care sector from the outset, acknowledging and responding to its strategic importance in protecting lives and delivering an effective pandemic response would have made a significant difference. It could have saved many lives and safeguarded service users, families and staff from deeply traumatic experience.
- 110. Again, we recognise that establishing engagement can be operationally challenging in a crisis. However future planning should consider approaches to gathering and interpreting evidence and insight which recognise the value of a broader range of sources, including those from outside Government or academic sources. This is of particular importance in fast evolving and novel situation where traditional models of evidence gathering may be too slow or fail to capture relevant data and insight.

Concluding statements

111. It should have been apparent from the very beginning that older people would be at the eye of the storm. Age was identified early on as a major population risk factor for critical illness and mortality; the risk of living with a pre-existing health conditions, disability or care need rises directly in line with age, including the majority of people advised they were clinical or extremely clinically vulnerable; older people have greater likelihood of social isolation and digital

exclusion; older carers are more likely to be providing intensive informal care; and there was a predictably high risk of losing (and not regaining) mobility, cognitive function, strength and balance or cardiovascular fitness amongst older people. In addition, the experiences of other countries that were ahead of us during the pandemic, such as Italy, demonstrated the vulnerability of older people, especially those living in residential settings.

- 112. Time and again decisions were made with little understanding or consideration of the impact they would have on lives of older people and the entirely predictable, harm they would cause. An overriding fatalism about their chances of survival, coupled with lower value placed on safeguarding older people's lives and health, led to an inappropriate reliance on chronological age in policymaking, as well as blanket application of policies to older people. Lastly, when there were difficult trade-offs to be made or a balance to be struck between different aspects of managing the pandemic, we saw little evidence that the rights of older people influenced the decision-making process. While only some of this critique can be directly attributed to Government actions and decisions, we would like to point out that national bodies and their leaders also have an important platform and responsibility to set the tone and influence implementation and practice. Government largely failed to do this, although we would like to note and commend some important exceptions to that observation.
- 113. It is clear that decisions taken by Government and across public services has had, and will continue to have, a profound impact on almost all aspects of older people's lives. Government must recognise that millions of older people are now living in a poorer state of mental and physical health than would otherwise be the case. Ageing should be better considered in all decision making, guidance and policy development, and system leaders should maintain an up to date understanding of those populations and invest in specialist expertise and advice. It is vital that older people are given appropriate consideration in current and future plans, and that we take particular care to balance the desire to safeguard the health of those at greatest risk, the impact of wider risk reduction or containment strategies on older population and their human rights.

- In getting that balance right we must guard against unwarranted age-based policy approaches and direct or indirect age discrimination.
- 114. The Government faced many extremely difficult decisions where there were few 'good' options, but we would argue that it is therefore all the more important to make equality and protection of people's rights with particular reference to protected characteristics an explicit and visible part of decision making. Older people felt marginalised and devalued, which eroded the trust of many in Government and national institutions at a critical time. In future we recommend that the Government explicitly considers equalities and human rights in plans and preparations, as well as establishing a clear rights-based framework to guide decision making for officials and national bodies.
- 115. Underlying challenges across the NHS and social care, including the degree to which they are interdependent in ways unrecognised by formal policy delineations, has been manifest during the pandemic. In addition, the moral case for Government, on behalf of us all, to act to make good the deficits that have been laid bare is even stronger than it was before. Older people in receipt of care, in care homes especially, have been catastrophically let down. Many have died before their time as a result and in a manner that was inhumane. That similar tragedies have unfolded in other countries too is no consolation and no excuse.
- 116. Age UK hopes this statement will aid the Inquiry to understand the impact these leadership failures across the healthcare system have had on the lives of many older people and their loved ones, and learn the necessary lessons, so that the nightmare scenarios we have seen play out for older people through the Covid-19 pandemic are never repeated.